

NCQA

Public Comment on Proposed Standards for a new accreditation program, Health Equity Accreditation Plus

Submitted December 24, 2021 to:

<https://my.ncqa.org/>

Dear NCQA colleagues,

The Fenway Institute at Fenway Health submits the following comment regarding NCQA's Proposed Standards for a new accreditation program, Health Equity Accreditation Plus. The Fenway Institute is the research, education and training, and policy arm of Fenway Health, a federally qualified health center in Boston, Massachusetts. We provide care to about 35,000 patients annually. Half of our patients are LGBTQIA+, and about 4500 are transgender and gender diverse. About 2,300 of our patients are people living with HIV. We are a Ryan White Part C clinic. Currently we have nearly 3,000 patients receiving pre-exposure prophylaxis for HIV prevention, and have prescribed PrEP to about 5,000 patients since it became available nearly 10 years ago. Fenway Health's Public Health Program/AIDS Action Committee provides support services to people living with HIV, HIV/STI prevention and screening services, and services for youth experiencing unstable housing.

In spite of advancements in LGBTQIA+ acceptance and policy, many LGBTQIA+ people remain largely invisible to their primary care providers and may delay access to care. LGBTQIA+ people experience challenges in accessing appropriate health care. For example, lesbian women and transgender men have lower cervical cancer screening rates compared to heterosexual and cisgender women,¹²³ and transgender people report delaying medically necessary care due to discrimination.⁴ The comprehensive framework in the accreditation program can positively impact health equity among many underserved populations.

The Fenway Institute has answered some but not all of the many questions asked in the request for public comment.

Global Questions

5. Will proposed updates help your organization meet its objectives? If so, how? If not, why not?

The proposed updates will assist us in better understanding the social determinants of health affecting Fenway Health's patient population, especially LGBTQIA+ and/or BIPOC patients. They will also assist health care providers across the U.S. better care for underserved and invisible populations that experience intersectional discrimination and stigma, as well as lack of economic opportunity and social support.

HE Plus 1: Program to Improve Social Risks and Address Social Needs

¹ Cochran SD, Mays VM, Bowen D, et al. Cancer-related risk indicators and preventive screening behaviors among lesbians and bisexual women. *Am J Public Health.* 2001;91(4):591-597.

² Potter J, Peitzmeier SM, Bernstein I, et al. Cervical cancer screening for patients on the female-to-male spectrum: A narrative review and guide for clinicians. *J Gen Intern Med.* 2015;30(12):1857-1864.

³ Charkhchi P, Schabath MB, Carlos RC. Modifiers of cancer screening prevention among sexual and gender minorities in the Behavioral Risk Factor Surveillance System. *J Am Coll Radiol.* 2019;16(4 Pt B):607-620.

⁴ Grant JM ML, Tanis J, Harrison J, Herman JL, Keisling M. Injustice at every turn: A Report of the National Transgender Discrimination Survey. Washington, DC 2011.

Factor 2: Process to identify social risks The organization describes its process for identifying the social risks of the community where it operates (service area) in order to better understand the social needs of the individuals it serves. The description includes: • The location of the community where it operates. • The organization’s methodology for integrating data about social risks at the community level. • Data types and sources used (e.g., community health assessments, claims, population health registries, census, socioeconomic data, demographics).

We recommend analysis of surveys done at the national and state/regional level, such as by the Centers for American Progress, the National Center for Transgender Equality, the Fenway Institute, and other entities, that gather data on LGBTQIA+ people’s experiences with discrimination based on real or perceived sexual orientation and gender identity (SOGI). Most national and state population-based surveys, such as BRFSS, do not ask questions about experiences of anti-LGBTQIA+ discrimination, and how this intersects with racial/ethnic discrimination, sex discrimination, access to care, culturally competent care and other forms of discrimination. Some federally funded surveys, including state-level BRFSS and YRBS surveys, offer SOGI questions.

We encourage NCQA to require that health care organizations use surveys that have SOGI data, and look at SOGI data at least at the state level to understand health disparities such as rates of tobacco use, behavioral health indicators, BMI, diabetes, cardiovascular disease, and other factors. State health departments can pool multiple years of data from these surveys and identify LGBTQIA+ health disparities as well as differences by age cohort, sex, race/ethnicity, and other demographic factors. Increasingly health care providers are incorporating social determinants of health into their Electronic Health Records (EHRs).

We recommend developing and adopting SOGI discrimination measures into EHRs, as well as of course asking SOGI questions of all patients. We recommend requiring SOGI questions and stratifying these data with social determinants of health to understand the impact on their patient population. The goal is to provide care teams with timely data so that they are able to provide individualized treatment with an aim toward achieving better outcomes.

The ACA requires all non-profit hospitals to conduct a community needs assessment every three years. NCQA should explicitly require all hospitals to collect data and report on the needs of the LGBTQIA+ community in their geographic catchment area.

Targeted Questions for HE Plus 1 • Do you support adding new element HE Plus 1A: Program Description?

Yes, social determinants of health are a huge factor in LGBTQIA+ health disparities and health inequities, especially for LGBTQIA+ BIPOC individuals, transgender individuals, older adults, immigrants, people with disabilities, and/or low-income LGBTQIA+ individuals.

• *Should the processes described in HE Plus 1A, factors 4–10 be performed annually?*

Yes.

• *What are good ways to demonstrate that the program’s objectives support diversity, equity, inclusion and cultural humility for HE Plus 1A, factor 11?*

We only see 10 factors. Where is factor 11?

- *What are the parameters of a “community” for organizations like health plans with broad service areas as large as a state or geographical region? (e.g., provider network, county, neighborhood)*

One important thing to note is that organizations that provide affirming and culturally relevant care for LGBTQIA+ patients often have a broad catchment area, especially for transgender and gender diverse patients and people living with HIV. LGBTQIA+ patients and those seeking HIV and STI prevention and care services will often travel many hundreds of miles to access care due to stigma, fear of disclosure in rural areas, and lack of affirming and culturally relevant care providers in large swaths of the country. With widespread use of telehealth, the geographic area has increase for organizations that specialize in caring for underserved populations.

Targeted Questions for HE Plus 2

- *Do you support adding new element HE Plus 2A: Community-Level Social Risk Data Integration?*

Yes.

- *Do you support adding new element HE Plus 2B: Collection of Individual-Level Social Needs Data?*

Yes.

- *Should the minimum list of social needs in HE Plus 2B, factors 1–7, include Adverse Childhood Experiences (ACEs)?*

Yes, ACEs affect health and well-being over the life trajectory. Many populations experiencing health disparities experience higher rates of ACEs. ACEs are an upstream factor in health inequity.

- *Do you support adding new element HE Plus 2C: Identification of Individual Social Needs Resources?*

Yes.

- *Should the process described in HE Plus 2C require organizations to outline appropriate timeframes for referring individuals to resources or interventions?*

Yes. Individuals should be referred to resources and interventions as soon as possible to help them meet their needs and improve health outcomes.

- *Do you support adding new element HE Plus 2D: Population Segmentation or Risk Stratification?*

Yes, so long as the risk stratification model does not perpetuate bias. An alternative option would be to require stratifying by multiple demographic fields such as sexual orientation, gender identity, race, and ethnicity which will provide insight into the communities being underserved or that have poorer health outcomes.

- *Should the activity described in HE Plus 2D be performed annually?*

Yes.

- *Do you support adding new element HE Plus 2E: Analysis of Community-Level and Individual Level Data?*

Yes.

- *Should the activity described in HE Plus 2E be performed annually?*

Yes.

HE Plus 3: Cross-Sector Partnerships and Engagement

General comment: NCQA should require health care organizations to work with local LGBTQIA+ social service and community-based organizations, including statewide equality organizations, LGBTQIA+ community centers, and LGBTQIA+ focused health centers and HIV care organizations. Health care organizations should provide funding from their community benefit programs to LGBTQIA+ organizations to support their efforts to develop better health care services that are affirming and culturally relevant for LGBTQIA+ patients and meet their unique needs.

HE Plus 4: Data Management and Interoperability

C: Notification of Privacy, Security and Sharing Policies.

The organization communicates information to the individuals it serves about its controls for physical and electronic access to data, privacy and security protocols for sharing data, permissible and impermissible use of data and how the organization communicates to individuals how they may opt out of sharing data.

SOGI data fields align with the new standards set forth in the United States Core Data for Interoperability (USCDI).⁵ NCQA should require that health care providers be *required to allow patients to opt in when agreeing to share sensitive data, including sexual orientation and gender identity data*. An opt out policy is not appropriate when LGBTQIA+ people are not explicitly protected against SOGI discrimination in public accommodations in health care settings by state law in 29 states. A voluntary national interest group, the Protecting Privacy to Promote Interoperability (PP2PI) Workgroup, was formed in 2020 to develop recommendations for protecting patient privacy in interoperability and EHRs.

Evaluating Bias in Algorithms

In addition to the standards proposed for public comment, NCQA is exploring requirements for evaluating whether algorithms that support processes (e.g., stratification/segmentation, prior authorization, utilization management, clinical decision making and social needs resource allocation) create or perpetuate bias.

We appreciate the opportunity to comment on this important point. Many of these requirements (e.g., prior authorization) inherently create undue burden on underserved populations. Many clinical recommendations are based solely on the recorded sex for a patient and consequently, clinicians may receive incorrect recommendations for quality measures and clinical decisions support tools.⁶ Health care providers should collect SOGI data and anatomical inventory data, and integrate this with clinical decision support to inform preventive screenings. A transgender male patient with a cervix should be offered cervical cancer screening, but a transgender patient whose cervix has been removed does not need this screening. Also, providers should not have to spend an inordinate amount of time seeking prior approval for hormone therapy and other forms of gender-affirming care. According to the American

⁵ (“United States Core Data for Interoperability (USCDI)” 2021) <https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi#uscdi-v2>

⁶ Chris Grasso, Hilary Goldhammer, Julie Thompson, Alex S Keuroghlian, Optimizing gender-affirming medical care through anatomical inventories, clinical decision support, and population health management in electronic health record systems, Journal of the American Medical Informatics Association, 2021;, ocab080, <https://doi.org/10.1093/jamia/ocab080>

Medical Association, the Endocrine Society of America, and the World Professional Association of Transgender Health, gender-affirming care for transgender and gender diverse patients is medically necessary. Unrealistic hurdles should not be put in the way of providers' ability to provide this care.

Thank you for the opportunity to comment on Proposed Standards for a new accreditation program, Health Equity Accreditation Plus. Should you have any questions, please contact Sean Cahill, PhD, Director of Health Policy Research at the Fenway Institute, at scahill@fenwayhealth.org or 617-927-6016.

Sincerely,

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