Protecting Transgender and Gender-Diverse Patients With Cancer in a Shifting Political Landscape

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An estimated 1.4 million adults and 150,000 youths in the United States identify as transgender and gender diverse (TGD),¹ and disproportionately experience negative health outcomes and discrimination in health care settings. These disparities extend to, and are amplified within, cancer care. In May 2019, the US Department of Health and Human Services (HHS) first proposed a regulatory reform to eliminate federal protections against health care discrimination on the basis of gender identity in Section 1557 of the Patient Protection and Affordable Care Act. This reform purportedly seeks to promote religious freedom and help reduce unnecessary costs to the American public. However, if implemented, the changes will substantially limit the rights of all patients while eliminating prohibitions against discrimination by insurers, hospitals, and individual providers. The burden of these changes will undoubtedly be felt by the LGBT community as a whole and represent especially imminent threats to the safety and health of our country's TGD people, including those with cancer. Within this context, we urge the oncology community to commit collectively to protecting and promoting the rights of our TGD patients to receive high-quality and inclusive cancer care.

The landscape of legal protections against discrimination in the health care context for TGD people has evolved rapidly over the past decade. When the Affordable Care Act became law in March 2010, Section 1557 went into effect immediately, preventing discrimination on the basis of ethnicity, color, national origin, sex, age, and disability in any health program receiving federal financial assistance.² However, 6 years passed before the US HHS Office for Civil Rights issued regulations clarifying that sex nondiscrimination protections under the Affordable Care Act included protections against discrimination based on sex stereotyping and gender identity. The legal response to this regulation was swift. In 2016, a federal district court judge in the Northern District of Texas issued a nation-wide injunction that precluded the Office for Civil Rights from enforcing the gender identity protections clarified in the regulation. This judge, however, waited until the current administration proposed its reform to the public and then issued

his own ruling, in which he formally vacated the parts of the rule including gender identity. The decision can still be appealed, and other courts have reached different conclusions; however, it portends the possibility that the current administration may move to finalize the Section 1557 regulatory proposal with similarly noninclusive protections.

The HHS proposal and concomitant legal arguments are perhaps most striking given the clear recognition that people who identify as TGD face pervasive discrimination in the general population.³ The impact of this discrimination based on gender identity and expression leads to sociopolitical and economic inequalities, which are magnified in populations with multiple oppressed social identities. The experience of discrimination and mistreatment is especially remarkable within the health care system.⁴⁻⁶ Of over six thousand TGD participants in the seminal National Transgender Discrimination Survey in 2015, nearly one third of respondents reported postponing or avoiding medical treatment when they were sick or injured, and one third delayed or did not seek preventive health care because of the fear of discrimination against their gender identity.³ Similarly one third of respondents reported having at least one negative experience in health care related to being transgender, including harassment and assault.⁷ In the context of cancer, delayed, lack of, or suboptimal care is particularly concerning because timely and regular interaction with health care providers may significantly alter patients' quality of life and outcomes, including survival.

In 2017, ASCO published a formative position statement addressing these very disparities in cancer care for sexual and gender minority individuals and proposed systemic policy change to both prohibit discrimination on the basis of sexual orientation and gender identity and foster a more accepting medical culture to better serve these vulnerable patients. This statement has provided a critical framework for the examination of existing policies, as well as for policy expansion in a political climate that requires us to direct our attention to the needs of TGD individuals in particular, with the knowledge that members of

Author affiliations and support information (if applicable) appear at the end of this article.

Accepted on January 20, 2020 and published at ascopubs.org/journal/op on March 2, 2020; DOI <https://doi.org/10.1200/JCOOP.20.00011>

these communities bear unique burdens within the oncology arena.

As federal protections evolve, state and local regulations become increasingly important. At a minimum, hospitals and other health care facilities should aim to have non-discrimination statements and a Patient Bill of Rights that explicitly protect gender identity and expression. Importantly, these statements are only as powerful as the practices that they codify on the ground. With that in mind, we call on oncology providers and cancer center administrators to

support ASCO's position statement and to collaborate with TGD community stakeholders as equitable partners to assess the accessibility of oncologic care at their institutions. Such collaborations will lead to the development of ethical and just policies that both prohibit gender identity and expression discrimination and foster more inclusive and affirming experiences in cancer care to increase access and improve outcomes. This crucial collaboration could ensure that a vulnerable population is protected in the current political climate and beyond.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

Disclosures provided by the authors and data availability statement (if applicable) are available with this article at DOI <https://doi.org/10.1200/JCOOP.20.00011>.

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REFERENCES

- Flores AR, Herman JL, Gates GJ, et al: How Many Adults Identify as Transgender in the United States? Los Angeles, CA, The Williams Institute, 2016
- Federal Register: The Daily Journal of the United States Government: Nondiscrimination in Health and Health Education Programs or Activities. <https://www.federalregister.gov/documents/2019/06/14/2019-11512/nondiscrimination-in-health-and-health-education-programs-or-activities>
- Grant JM, Mottet LA, Tanis J, et al: Injustice At Every Turn: A Report of the National Transgender Discrimination Survey. Washington, DC, National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011
- Safer JD, Coleman E, Feldman J, et al: Barriers to healthcare for transgender individuals. *Curr Opin Endocrinol Diabetes Obes* 23:168-171, 2016
- Poteat T, German D, Kerrigan D: Managing uncertainty: A grounded theory of stigma in transgender health care encounters. *Soc Sci Med* 84:22-29, 2013
- Adams N, Pearce R, Veale J, et al: Guidance and ethical considerations for undertaking transgender health research and institutional review boards adjudicating this research. *Transgend Health* 2:165-175, 2017
- James SE, Herman JL, Rankin S, et al: The Report of the 2015 U.S. Transgender Survey. Washington, DC, National Center for Transgender Equality, 2016
- Kamen CS, Alpert A, Margolies L, et al: "Treat us with dignity": A qualitative study of the experiences and recommendations of lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients with cancer. *Support Care Cancer* 27:2525-2532, 2019
- Braun H, Nash R, Tangpricha V, et al: Cancer in transgender people: Evidence and methodological considerations. *Epidemiol Rev* 39:93-107, 2017
- de Blok CJM, Wiepjes CM, Nota NM, et al: Breast cancer risk in transgender people receiving hormone treatment: Nationwide cohort study in the Netherlands. *BMJ* 365:l1652, 2019
- Brown GR, Jones KT: Incidence of breast cancer in a cohort of 5,135 transgender veterans. *Breast Cancer Res Treat* 149:191-198, 2015
- Blosnich JR, Brown GR, Wojcio S, et al: Mortality among veterans with transgender-related diagnoses in the Veterans Health Administration, FY2000-2009. *LGBT Health* 1:269-276, 2014
- Wierckx K, Elaut E, Declercq E, et al: Prevalence of cardiovascular disease and cancer during cross-sex hormone therapy in a large cohort of trans persons: A case-control study. *Eur J Endocrinol* 169:471-478, 2013
- The Joint Commission: Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals. Oakbrook Terrace, IL, The Joint Commission, 2010
- Campaign HR. Healthcare Equality Index 2018: Rising to the New Standard. 2018
- Griggs J, Maingi S, Blinder V, et al: American Society of Clinical Oncology position statement: Strategies for reducing cancer health disparities among sexual and gender minority populations. *J Clin Oncol* 35:2203-2208, 2017
- Aysola J, Barg FK, Martinez AB, et al: Perceptions of factors associated with inclusive work and learning environments in health care organizations: A qualitative narrative analysis. *JAMA Netw Open* 1:e181003, 2018
- Cahill SR: Legal and policy issues for LGBT patients with cancer or at elevated risk of cancer. *Semin Oncol Nurs* 34:90-98, 2018
- Herman JL (ed): Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys. Los Angeles, CA, The Williams Institute, 2014

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Honoraria: FLO Health

Research Funding: Boehringer Ingelheim (Inst)

No other potential conflicts of interest were reported.