

Inequity in Health Equity: Expanding Data Collection to Advance Health Equity for Transgender and Nonbinary Individuals



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Opinion editorial
Published December 2022

Abstract

The push for health equity is leaving transgender (trans) and nonbinary people behind; research continues to find drastic inequities across health and mental health for trans and nonbinary people compared to cisgender individuals. This could be linked to the stark lack of national, population-based surveys that include explicit questions around gender identity. Without this data, it is harder for advocates and policymakers to target interventions and improve the material conditions of trans and nonbinary people. Clear, robust research among marginalized populations is necessary to achieve health equity; increased research and data better positions policymakers, advocates and practitioners to address health disparities. For this reason, it is necessary for gender identity to be enumerated on data collection policies and initiatives.

The push for health equity is leaving transgender (trans) and nonbinary people behind. While several federal offices and departments, such as the federal Department of Health and Human Services, have indicated that health equity is a priority, little has been done to address the health disparities the trans and nonbinary community face. For example, The California Health Interview Survey found that trans adults are more than three times more likely to have suicidal thoughts and nearly 6 times as likely to have ever attempted suicide when compared to cisgender adults. Additionally, trans adults are more than four times as likely to have ever experienced serious psychological distress. (1,2) Not only are there mental health disparities, but physical health disparities exist, as well. Trans and nonbinary adults are more likely to report poor health, more likely to report having a disability, and more likely to have HIV than their cisgender counterparts, including those that identify as LGBTQ. (2,3) Failing to address these disparities affects millions, including the 1.6 million adults who identify as transgender in the United States. Notably, youth ages 13 to 17 are significantly more likely to identify as transgender (1.4%) than adults ages 65 or older (0.3%) and estimates of youth who identify as trans or nonbinary are growing rapidly each year. (2) This finding could suggest that, if health disparities among trans and nonbinary people continue to be understudied and thus unaddressed, the problem will grow as the population of trans and nonbinary people grows. It is also important to keep in mind that, since gender has not been included in

national health surveys and because identification is highly stigmatized, the prevalence of trans and nonbinary people has likely been underestimated; therefore, these health disparities likely impact even more people.

The gap in addressing these disparities corresponds with the gap in the research literature surrounding this population. With the exception of the recent COVID-19 Household Pulse Survey, there have been no national, population-based surveys that have included explicit questions surrounding gender identity, making trans and nonbinary people statistically invisible on a national level. Clear, robust research among marginalized populations is necessary to achieve health equity; increased research and data better positions policymakers, advocates and practitioners to address health disparities. For this reason, it is necessary for gender identity to be enumerated on data collection policies and initiatives.

This territory is not uncharted, as advocates seeking to address racial health disparities demonstrate. More specifically, Section 4302 of the Affordable Care Act (ACA) could be amended to mandate inclusion in research for trans and nonbinary people. Section 4302 is a policy initiative to understand and eliminate health disparities in the United States. The law established data collection standards and required them to be used in all national population health surveys. The current demographics included in Section 4302 are race, ethnicity, sex, primary

language and disability status. (4) Gender is not among them.

An expansion of Section 4302 to explicitly include gender provides one avenue to address the disparity issue. Alternatively, passing a bill that is currently under review could yield results, too. In June, the LGBTQI+ Data Inclusion Act was passed in the House. This bill addresses federal data collection of SOGI (sexual orientation and gender identity) information. In July, it was received in the Senate, read twice and referred to the Committee on Homeland Security and Governmental Affairs. No updates on the bill's progress have been made public since then. (5) This most recent attempt to mandate SOGI data collection follows President Joe Biden's Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (Executive Order 13985). (6) Executive Order No. 13985 established an Interagency Working Group on Equitable Data. Among the tasks assigned to said group was "identifying inadequacies in existing Federal data collection programs," and creating strategies for addressing any deficiencies identified." (6) The goal of the order was to "expand and refine the data available to the Federal Government to measure equity," as it pertains to marginalized communities, including trans and nonbinary people. (6) While this is a step in the right direction, Executive Order No. 13985 failed in mandating the implementation of collecting gender identity information on national population health surveys. Once again, trans and nonbinary people have been left behind.

This call to action does not stand alone. One of the most prominent and impactful research projects on LGBTQ+ health, the report by the Institute of Medicine, "The Health of Lesbian, Gay, Bisexual, and Transgender People," assessed the state of research on the health status of LGBTQ+ populations and concluded that we need more data about these communities. The report also called for improved methods for collecting sexual orientation and gender identity (SOGI) data and widespread adoption of said methods when developed. (7) While methods have improved, both across academic and nonprofit research, these methods have yet to be adopted by the federal government on national surveys. The need to progress now regarding this issue is critical; trans and nonbinary people continue to experience transphobia and violence, both on interpersonal and systemic levels. (8,9) It is imperative that we continue to urge HHS to include gender in the demographics deemed necessary in all national population health surveys, by explicitly enumerating gender in

Section 4302 of the Affordable Care Act (ACA). Alternatively, we must urge the House and Senate to work together to pass H.R.4176.

While passage of such a law would not immediately eliminate such disparities, it would be the first step in such a process; to ensure the elimination of health disparities, we must first know what the disparities truly are. As highlighted by Scheim and colleagues, "measurement is fundamental to public health research, evaluation, surveillance and policy".

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