

March 22, 2023

Donna Pickett, MPH, RHIA
Co-Chair
ICD-10 Coordination and Maintenance Committee
National Center for Health Statistics
Centers for Disease Control and Prevention
6525 Belcrest Road, Room 1100
Hyattsville, MD 20782

Dear Ms. Pickett:

On behalf of the physician and medical student members of the American Medical Association (AMA), I am writing to request the ICD-10 Coordination and Maintenance Committee make revisions to the current International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) to remove derogatory language and adopt destigmatizing terminology. We also ask that you advocate for the World Health Organization to do the same in its current work on ICD-10 and International Classification of Diseases, Eleventh Revision (ICD-11) classification systems.

Physicians today are taking significant actions to ensure underrepresented and marginalized populations receive equitable care. In order to gain the trust of patients, the language and terminology used to describe patients and their health conditions must be inclusive and lack stigmatization. Concerns about being inappropriately labeled may prevent patients from seeking the care they need.

Specifically, LGBTQ+ individuals, particularly transgender patients, face high levels of stigma, violence, and discrimination. Much of this is reflected in the increased introduction and adoption of anti-LGBTQ+ legislation, particularly surrounding transgender health and gender-affirming services. As a result, transgender individuals continue to experience many challenges in accessing appropriate health care and encounter difficulties with insurance coverage, despite the AMA, GLMA (formerly known as the Gay & Lesbian Medical Association) and other major medical associations supporting gender-affirming care as effective, safe, and lifesaving. Using a diagnosis code with derogatory language may further restrict and harm LGBTQ+ patients attempting to access inclusive health care, such as gender-affirming hormonal therapy and surgery, or preexposure prophylaxis, to lower the risk of acquiring HIV. The current applicable ICD-10-CM diagnosis codes containing derogatory language risks undermining insurance companies' coverage of these relevant services.

The World Health Organization has made strides in ICD-11 in addressing current understanding of sexual health and gender identity. The concepts of "transsexualism" and "gender identity disorder" have been replaced with "gender incongruence" and the classification has been moved from the mental health chapter to the sexual health chapter. These terms are associated with a deficit-based approach and biased framing regarding gender and gender identity, which perpetuate harmful narratives about transgender and other gender identities. Efforts to move from the mental health chapter to a sexual health chapter affirm evidence that gender incongruence can lead to mental health challenges, due to social stigma, not that it is a mental health disorder to be addressed. Unfortunately, these concepts remain current in category F64 in

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ICD-10-CM. We urge the ICD-10 Coordination and Maintenance Committee to take similar action to modify the language in ICD-10-CM to help destigmatize these conditions and increase patient access to gender-affirming health care.

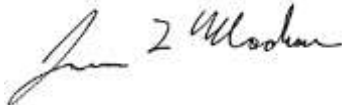
Additionally, the ICD-10 Coordination and Maintenance Committee should review the language used throughout ICD-10-CM and modify any other derogatory or stigmatizing language. Language that supports ableism, ageism, racism, cultural insensitivity, and genderism should not be perpetuated in health care diagnosis coding. Examples include “abuse” in the context of alcohol, opioid, cannabis, cocaine, etc., “abuser” in the context of drug, “elderly” and “young” in the context of pregnancy, “alcoholic,” “man-made,” “nonadherence,” and “retardation.” Some of our concerns echo the recently published guidance from the Centers for Disease Control and Prevention (CDC) in its “Health Equity Guiding Principles for Inclusive Communication,” which lays out five key principles:

1. Avoid use of adjectives such as “vulnerable,” “marginalized,” and “high-risk.”
2. Avoid dehumanizing language. Use person-first language instead.
3. Remember that there are many types of subpopulations.
4. Avoid saying “target,” “tackle,” “combat,” or other terms with violent connotation when referring to people, groups, or communities.
5. Avoid unintentional blaming.

We recommend the ICD-10 Coordination and Maintenance Committee work with health equity and medical specialty experts to correct derogatory language in ICD-10-CM to improve inclusivity and access to health care for all patients.

We welcome the opportunity to discuss our request with you further. Please feel free to contact Nancy Spector, Coding and HIT Advocacy Director, at nancy.spector@ama-assn.org or 202-789-7489 for more information.

Sincerely,

A handwritten signature in black ink, appearing to read "James L. Madara". The signature is written in a cursive style with a large initial "J" and "M".

James L. Madara, MD