Federal mandate aims to improve how gender identity is recorded in EHR

by Patrick J. Brown M.D., FAAP

The topic of gender identity recently has focused national attention on the tension between federal nondiscrimination policies and state laws that restrict transgender individuals to the sex identified on their birth certificate.

Some states have argued that federal polices do not apply to these laws because federal language does not explicitly differentiate between "sex" and "gender." For example, Title IX of the Education Amendments of 1972 states "No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance."

In response to any perceived ambiguity, the U.S. Departments of Justice and Education released joint guidance on May 13 to clarify that both agencies treat a student's gender identity as the student's sex for the purposes of enforcing Title IX. While this guidance does not have the effect of law, it defines and distinguishes "gender identity" from "sex assigned at birth" and emphasizes the importance of using names and pronouns that correspond to a student's gender identity.

In the clinical setting, it is no less important for health care professionals to record patients' sex and gender identity accurately. Transgender patients are known to face health disparities, and lack of adherence to preferred names and pronouns can lead to embarrassment and even discrimination in health care.

In 2013, the World Professional Association for Transgender Health Electronic Medical Record Working Group published recommendations for how gender should be recorded in the electronic record. The recommendations specify that "Preferred name, gender identity, and pronoun preference, as identified by patients, should be included as demographic variables."

Many electronic health records (EHRs), however, may only have fields for "sex," and within this category, they may only allow the binary options of "male" or "female." A recent survey of providers found that even when sex
and gender identity are recorded in the EHR, they are stored in a variety of ways. For example, some sites record this information in the demographics section while others use social history, a banner bar or a note somewhere else in the chart. The lack of consistency makes it difficult to establish policies or procedures to ensure that the EHR truly reflects the patient's identity.

Fortunately, changes are on the horizon to improve how gender identity is recorded in the EHR. In October 2015, the Centers for Medicare & Medicaid Services published its final rule for meaningful use (MU), which mandated that health IT modules enable a user to record, change and access sexual orientation/gender identity to be certified to the 2015 edition "demographics" certification criterion. This requirement will become effective in MU Stage 3 and places the onus on vendors to have vocabulary standards for birth sex (male, female and unknown), sexual orientation and gender identity.

Of note, the certification rule does not require providers to collect this information or patients to disclose it. In that light, improving technology alone will not be sufficient to meet the needs of transgender patients. Closing that gap will require workflows to ensure that collecting this information balances clerical efficiency, patient privacy and clinical accuracy.

As a guide for best practice in data capture, an expert panel has recommended a two-step method to record both "birth sex" and "current gender identity" rather than gender identity or sex. This process accounts for the fact that some transgender individuals may identify only as male or female and not transgender as well as the fact that a person's sex may be legally changed from the sex assigned at birth. By capturing both birth sex and current gender identity, it is more likely that transgender patients will be correctly identified and not miss necessary screening tests (e.g., cervical cancer screening for a transgender male). The expert panel also recommended collecting information such as preferred name and pronouns in the EHR to ensure that patients are addressed according to their preferences.

Since transgender patients - especially adolescents - may face rejection or emotional abuse, it also is recommended that patients have a confidential means to provide this information. This may include having the patient enter the information online through an EHR portal or having an electronic registration kiosk in the health care setting. Alternatively, providers may enter the information into the EHR after discussing the questions with the patient. Training staff to ask questions in a culturally sensitive nature also can alleviate potential barriers to information exchange.

In summary, transgender patients are at risk for health disparities due in part to the fact that most EHRs do not enable birth sex and gender identity to be recorded as discrete fields. New federal mandates for Certified Electronic Health Record Technology will require the capacity to record birth sex, sexual orientation and gender identity as demographic information for MU Stage 3. Establishing consistent policies about what information to record and effective workflows for patients to disclose the information confidentially also will be needed to improve care for transgender patients.

Dr. Brown is a member of the AAP Council on Clinical Information Technology.

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