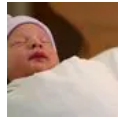




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HEALTH

At Northwestern Medicine, nonbinary patients can now record their legal sex as 'X'

By Ilana Arougheti

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Dr. Sumanas Jordan, assistant professor of plastic surgery, and Dr. Lauren Beach, assistant professor of medical social sciences at Northwestern University's Feinberg School of Medicine, were both part of the workgroup on the legal X at Northwestern Medicine. (Eileen T. Meslar/Chicago Tribune)

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As a plastic surgeon at Northwestern Medicine, Dr. Sumanas Jordan knows transgender and nonbinary patients can have unique needs. About half of her patients come in for gender-affirming surgeries, and their tests and treatments often lead to deep conversations about gender identity.

Now, conversations about gender at Northwestern Medicine are expanding to include patients' medical records.

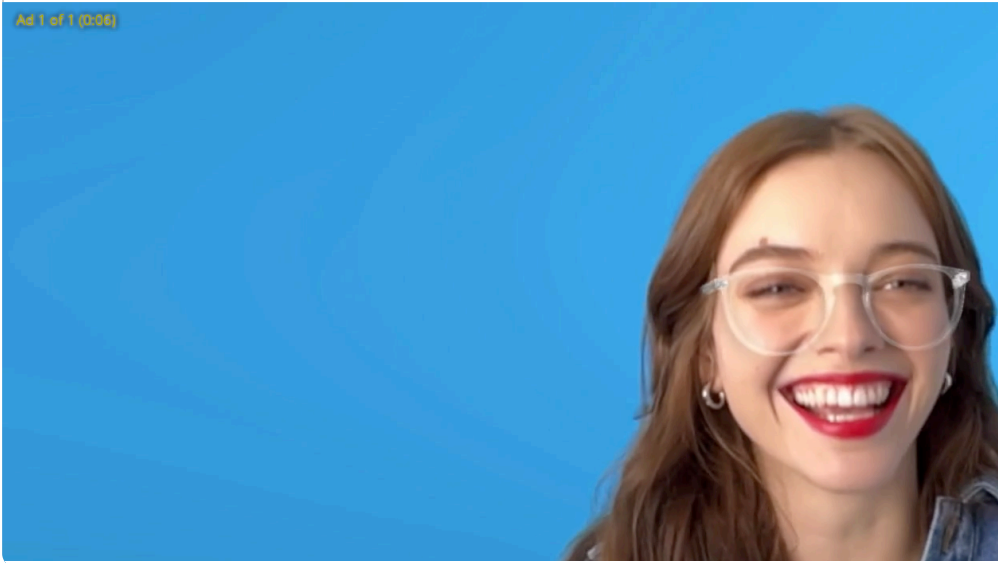
As of Dec. 18, Northwestern Medicine patients can record their legal sex as "X" in electronic medical records.

"X" is an alternate gender marker for those who do not identify as male or female. On legal records, it's commonly used by transgender, nonbinary and intersex people.

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The change comes just ahead of a state bill allowing the gender category of “X” on driver’s licenses and other forms of state identification. Gov. J.B. Pritzker first introduced the bill in 2019. The Illinois secretary of state’s office determined that X would become available on driver’s licenses in 2024.

“Over the last year, since we knew this law was going to be put into place, we’ve been working really hard to make sure our system was ready for that,” Jordan said. “It doesn’t seem like a huge task ... but that little letter actually affects a number of downstream events.”

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Multiple health systems in the Chicago area, including Rush, Advocate and NorthShore, allow patients to identify their gender as “unknown” when signing up for an appointment. However, their legal medical records still list the gender associated with their legal documents. This typically is whatever is written on their driver’s license.

Dr. Jordan said she doesn’t know of another Illinois health system that has updated their system to include X in electronic medical records.

[[*State struggles to implement 2019 law that allows ‘X’ gender on IDs for nonbinary residents*](#)]

On the technology side, Northwestern looked to a playbook from Epic Systems to physically create an X option on digital charts. The Wisconsin-based software company, which holds more than 305 million medical records, offers a tool kit for hospital systems looking to do so.

Putting an X on one’s state ID is now possible in 22 states, plus Washington, D.C. In Illinois, it means submitting [a form](#), plus a \$5-

\$10 fee.

Reading a medical chart with X on it is more complicated.

Patients who elect to have X on their legal documents hold a wide variety of gender identities, each with unique implications for medical care. Some patients are nonbinary, meaning they identify as something other than male or female. Others are intersex or transgender.

“Patients with X will have many different needs, but one need they’re all going to have is to have been treated with dignity and respect across the board,” said Dr. Lauren Beach, director of the ADVOCATE program at Northwestern Medicine, who uses the pronouns they/them. The program works to improve public health research by incorporating the needs and concerns of LGBTQ+ patients.

Nonbinary patients still have medical needs related to their anatomy. For example, a nonbinary patient might menstruate, become pregnant or need to be screened for prostate cancer.

Seeing an X on a patient’s legal medical record will prompt doctors to ask for a patient’s name and pronouns, and to ask about their anatomy separately from their gender identity, Beach said.

Northwestern Medicine providers will also be prompted to directly ask patients questions about their anatomy, when it’s relevant to their illness or injury. Questions about hormones, menstrual cycle and medical history might follow.

Avoiding assumptions about a patient’s identity is important no matter who you’re treating, Beach said.

“What you can do if you see an X on their driver’s license,” Beach said, “is just start a conversation with the health care team about

what is their anatomy, what's their gender identity, what are the things they're looking for out of their health care."

When doctors aren't so used to asking about people's pronouns and gender identity, it opens the door for patients to feel discomfort or face discrimination, Jordan said.

Nonbinary, intersex and transgender residents have long been challenged by legal documents limited to two gender categories. Along with health care, a state ID system without an X category can complicate [end-of-life care](#), higher education and interactions with the criminal justice system.

Medical billing records also typically include legal gender markers, Jordan said.

"We live in a very binary world, but we can come up with a number of experiences where a binary perception is not accurate," Jordan said.

"A lot of folks have never heard of (nonbinary people) before, and that can lead to quizzical looks and divergence from the matter at hand. So you kind of get discriminated against in that regard."

For health care providers, designing a new approach to patient intake takes time. Scaling it up through all of Northwestern Medicine took a year.

To design new procedures for X patients, a task force of five spent time with each department inside Northwestern Medicine to learn what it might look like when a patient marked X came through.

The group was led by Dr. Cynthia Barnard, vice president for quality at Northwestern Memorial Healthcare. More than 200 employees across 50 departments weighed in.

For departments that needed to decide on clinical changes, like what

baseline hormone or cholesterol levels to compare nonbinary patients with, the task force turned to the Gender Pathways Program. The program, which Jordan leads, includes more than 30 doctors with experience in trans-affirming health care.

Program members and others had already tackled the questions now consuming all of Northwestern Medicine, Beach said. The task force designed more than 20 training modules to keep everyone on staff in the discussions.

A lot of medical tests historically involve gender markers, Beach said. For example, gender usually dictates guidelines about when to get screened for different cancers, and whether your blood has the right amount of glucose.

Figuring out what reference values to look for when a patient undergoes blood tests was a big part of redesigning for X, Jordan said. Understanding a patient's goals for their own health care can help doctors decide what to look for, no matter what letter is on their records.

“Even things like cholesterol risks and heart screening can be dependent on that little letter,” Jordan said. “Now we’re looking at, does the logic break down when the X is in place? And what do we do with that? We can’t just have an entire electronic medical record blow up because it doesn’t receive a (male or female) designation.”

The task force also consulted with the Gender Pathways Program community advisory board, which includes faculty, patients and advocates in the LGBTQ+ community.

“The biggest concern that people had is, ‘I want to make sure I get the right health care for me,’” Beach said. “There’s this double desire — ‘I want to be recognized for who I am’ and ‘I want to get the best health

care for me.”

But as patients schedule their first appointments with X on their medical records, medical students are taking notice.

Students in their third or fourth year of training, who perform clinical rotations at Northwestern hospitals, have seen that X is now an option on charts, Beach said. Those who have ideas or experience working with nonbinary patients have organized peer training sessions.

“There are existing medical students who are actually providing trainings independently,” Beach said, “to educate each other about X.”

For Beach themselves, preparing for X created an environment at Northwestern with more opportunities to talk about gender identity. As the reckoning continues, they hope providers also spend more time discussing social determinants of health.

LGBTQ+ patients experience higher levels of poverty, intimate partner violence, mental health conditions and substance abuse, Beach said. For medical providers, there’s always more to know about a patient’s bigger picture.

“By scaling up the questions to not just understand who people are, but to ask those social determinant questions to understand their lives ... the promise for addressing health inequity is scaling up across the board,” Beach said.

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