

Evolving Sex and Gender in Electronic Health Records

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Development, training, and documentation for the implementation of a self-identified gender identity field in the electronic health record system may improve patient-centered care for transgender and gender nonconforming patients.

Providing consistent and high-quality services to gender diverse patients is a top priority for health care systems, including the Veterans Health Administration (VHA).¹ Over the past decade, awareness of transgender and gender nonconforming (TGNC) people in the US has increased. Gender identity refers to a person's inner sense of where that person belongs on a continuum of masculine to androgynous to feminine traits. This identity range can additionally include nonbinary identifications, such as "gender fluid" or "genderqueer." A goal of patient-centered care is for health care providers (HCPs) to refer to TGNC individuals, like their cisgender counterparts, according to their gender identity. Gender identity for TGNC individuals may be different from their birth sex. Birth sex, commonly referred to as "sex assigned at birth," is the biologic and physiologic characteristics that are reflected on a person's original birth certificate and described as male or female.

BACKGROUND

In the electronic health record (EHR), birth sex is an important, structured variable that is used to facilitate effective patient care that is efficient, equitable, and patient-centered. Birth sex in an EHR often is used to cue automatic timely generation of health screens (eg, pap smears, prostate exams) and calculation of medication dosages and laboratory test ranges by adjusting for a person's typical hormonal history and anatomy.

Gender identity fields are independently helpful to include in the EHR, because clinicians can use this information to ensure proper pronoun use and avoid misgendering a patient. Additionally, the gen-

der identity field informs HCPs who may conduct more frequent or different health screenings to evaluate specific health risks that are more prevalent in gender minority (ie, lesbian, gay, bisexual) patients.^{2,3}

EHRs rely on structured data elements to standardize data about patients for clinical care, quality improvement, data sharing, and patient safety.^{4,5} However, health care organizations are grappling with how to incorporate gender identity and birth sex information into EHRs.³ A 2011 Veterans Health Administration (VHA) directive required staff and providers to address and provide care to veterans based on their gender identity. Like other health systems, VHA had 1 demographic data field in the EHR to indicate birth sex, with no field for gender identity. A HCP could enter gender identity information into a progress note, but this addition might not be noticed by other HCPs. Consequently, staff and providers had no effective way of knowing a veteran's gender identity from the EHR, which contributed to misgendering TGNC veterans.

With the singular demographic field of sex representing both birth sex and gender identity, some TGNC veterans chose to change their birth sex information to align with their gender identity. This change assured TGNC veterans that staff and providers would not misgender them because the birth sex field is easily observed and would allow providers to use respectful, gender-consistent pronouns when speaking with them. However, changing the birth sex field can misalign natal sex-based clinical reminders, medication dosages, and laboratory test values, which created potential patient safety risks. Thus, birth sex

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FIGURE 1 Veteran Fact Sheet

Get the Facts...

TRANSGENDER VETERAN HEALTH CARE
Birth Sex and Self-Identified Gender Identity

Your Birth Sex and Self-Identified Gender Identity are important parts of who you are that should be shared with your health care provider. By sharing this information with your provider, you are helping to ensure that you receive the highest quality care. VA understands that Veterans with transgender and related gender identities face increased health risks and unique challenges in health care, and is committed to promoting a welcoming environment that is inclusive of all Veterans.

Previously, your medical record had only one place for your sex and gender. Now, you can have both your Birth Sex and your Self-Identified Gender Identity in your medical record. If you wish to change your Birth Sex information after talking with your health care team, this is your right in the VA system. However, it is important that you understand the safety risks of changing your Birth Sex field in your medical record.

What are the Self-Identified Gender Identity and Birth Sex fields?
Self-Identified Gender Identity is a new field in VA records. It is how you think about yourself. Options are male, female, transman, transwoman, other, or choose not to answer. This field will be blank until you update it and can be changed as needed.
Birth Sex is the box that was checked on your original birth certificate. Options are male or female. If you were born intersex, this field indicates the sex assigned to you at birth.

How is Self-Identified Gender Identity used?
Self-Identified Gender Identity helps VA staff and providers know your identity and use respectful terms during interactions when delivering personalized care.

How is Birth Sex used?
Birth Sex is used to guide medical care. Ways this field is used include:

- The medical record system uses Birth Sex to automatically determine your lab ranges, for example hormone levels and kidney function.
- Birth Sex is used to automatically remind your provider what health screenings are due, such as prostate screening and pap smears.
- Birth Sex along with height, weight, and age are used to determine doses for your medication(s).

For the reasons above, medical advice is that your Birth Sex should be the same as what appears on your original birth certificate.

How can I be sure the information about my Self-Identified Gender Identity and Birth Sex is correct?
The new Self-Identified Gender Identity field will be blank until you provide the information and it can be updated at any time. New enrollees can provide that during their enrollment process, and previously enrolled Veterans can add it at their local VA facility by checking with clerical staff in a clinic or eligibility office.

What if I already changed my Birth Sex field information?
Complete and accurate information is necessary to care for you. When you changed your Birth Sex field it changed the information that your providers receive to guide your care including computer-generated lab values on blood work and reminders for health screenings. Talk to your provider to understand how this affects your care.

What if I previously changed my Birth Sex field and now want my VA records to show the sex listed on my original birth certificate?
If you previously changed your Birth Sex field and now want your records to show the sex listed on your original birth certificate, you need to complete a form with your facility VA Privacy Officer. You do not need any supporting documentation.

What if I want to change my Birth Sex field in the VA records for the first time?
To change your Birth Sex field from what was listed on your original birth certificate, you will need to complete a form with your facility VA Privacy Officer. In addition, you will need two types of supporting documents, one of which can be a letter from your provider. You may contact your local LGBT Veteran Care Coordinator or local Patient Advocate to assist you with the process.

Does Self-Identified Gender Identity affect my VA benefits?
No, Self-Identified Gender Identity will not change service connection or benefits eligibility.

Is information about Self-Identified Gender Identity shared with the Department of Defense?
No, Self-Identified Gender Identity is not shared with the Department of Defense.

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created potential hazards to quality and safety when used as a marker even with other variables—such as current anatomy, height, and weight—for health screenings, medication dosing, and other medical decisions.

In this article, we: (1) outline several patient safety issues that can arise with the birth sex field serving as an indicator for both birth sex and gender identity; (2) present case examples that illustrate the benefits of self-identified gender identity (SIGI) in an EHR; (3) describe the process of work-group development of patient-provider communication tools to improve patient safety; and (4) provide a brief overview of resources rolled out as a part of SIGI. This report serves as a guide for other federal organizations that wish to increase affirmative care and safe practices for transgender consumers. We will provide an overview of the tasks leading up to SIGI im-

plementation, deliverables from the project, and lessons learned.

VETERANS AFFAIRS SIGI EHR FIELD

In 2016, the US Department of Veterans Affairs (VA) began implementing a SIGI demographic field across all EHRs, requiring administrative staff to ask enrolled and new veterans their gender identity (full implementation of SIGI has not yet occurred and will occur when a later EHR upgrade displays SIGI in the EHR). The initiation of SIGI did not change any information in the birth sex field, meaning that some veterans continue to have birth sex field information that results in problematic automatic medical reminders and dosing values. Consequently, the National Center for Patient Safety (NCPS) noted that this discrepancy may be a pertinent patient safety issue. The NCPS and Lesbian, Gay Bisexual, and Transgender (LGBT) Health national program offices worked to provide documentation to TGNC veterans to inform them of the clinical health care implications of having their birth sex demographic field reflect gender identity that is inconsistent with their natal sex (ie, original birth certificate record of sex).

Patient Safety Issues

Conversations between transgender patients and their HCPs about transition goals, necessary medical tests, and laboratory ranges based on their current anatomy and physiology can improve patient safety and satisfaction with medical care. Prior to the availability of the SIGI field, VA facilities varied in their documentation of gender identity in the patient chart. LGBT veteran care coordinators discussed diverse suggestions that ranged from informally documenting SIGI in each progress note to using flags to draw attention to use certain sections of local EHRs. These suggestions, though well intentioned, were not adequate for documenting gender identity at the national level because of regional variations in EHR customization options. Furthermore, the use of flags for drawing clinical attention to gender identity posed a potential for stigma toward patients, given that flags are typically reserved for behavioral or other risk concerns.

Several problems can emerge when HCPs are not equipped with accurate information

about patient birth sex and SIGI. For instance, TGNC patients lack a way of being known from clinic to clinic by proper pronouns or self-labels. Providers may misgender veterans, which is a negative experience for TGNC veterans linked with increased barriers to care and decreased frequency of health care visits.⁴ Moreover, the quality and personalization of care across clinic locations in the facility's system is variable without a consistent method of documenting birth sex and SIGI. For example, in clinics where the veteran is well known (eg, primary care), staff may be more affirming of the veteran's gender identity than those in specialty care clinics that lack prior patient contact.

Furthermore, depending on hormone and surgical interventions, some health screenings may be irrelevant for TGNC patients. To determine appropriate health screens and assess potential risks associated with hormone therapy, providers must have access to current information regarding a patient's physiologic anatomy.⁶ Health screenings and laboratory results in sophisticated EHRs (ie, EHRs that might autodetermine normative values) may populate incorrect treatment recommendations, such as sex-based medication dosages. Furthermore, laboratory test results could be incorrectly paired with a different assumed hormonal history, potentially putting the patient at risk.

CASE EXAMPLES

An important element of EHRs facilitating the goal of patient-centered care is that patients have their EHR validate their sense of self, and their providers can use names and pronouns that correspond to the patient's SIGI. Some patients have spent a great amount of effort altering their name and sex in legal records and may want their birth sex field to conform to their gender identity. To that end, patients may seek to alter their birth sex information so that it is congruent with how they see themselves to affirm their identity, despite patient safety risks. Several scenarios below demonstrate the potential costs and benefits to patients altering birth sex and SIGI in the EHR.

Case 1 Presentation

A young transman is working with his therapist on engaging in self-validating behaviors.

This veteran has met with his PCP and informed the provider of his decision to alter the birth sex field in his EHR from female to male.

Ideally, the patient would begin to have regular conversations with his HCPs about his birth sex and gender identity, so that medical professionals can provide relevant screenings and affirm the patient's gender identity while acknowledging his right to list his birth sex as he chooses. However, particular attention will need to be paid to assuring that natal sex-based health screenings (eg, pap smears, mammograms) are conducted on an appropriate schedule and that the veteran continues to discuss his current anatomy with providers.

Case 2 Presentation

A veteran has a male birth sex, identifies as a transwoman, and uses nongendered plural pronouns "they/them/theirs." The word "they," used as a singular pronoun may feel uncomfortable to some providers, but it validates the veteran's sense of self and helps them feel welcome in the treatment environment. This patient communicated proactively with their HCPs about their transition goals and current hormone use.

They opted to have their birth sex field continue to indicate "male" because they, after a discussion with their PCP, are aware of the health implications of receiving an incorrect dose for their diabetes medication. They understand that having open communication and receiving input from their HCPs is part of good health care.

Case 3 Presentation

A patient with a sexual development disorder (intersex condition) identifies as a man (indicated as "male" in the SIGI field) and had his birth sex field changed to match his gender identity. He now seeks to change his birth sex field back to female, as he has complicated health considerations due to breast cancer.

The veteran thinks it is important that providers know about his intersex condition so that his breast cancer care is as seamless as possible. In particular, although this veteran is comfortable talking about his intersex condition and his identity with his PCP and

FIGURE 2 Provider Fact Sheet

Provider Factsheet on Birth-Sex and Self-Identified Gender Identity

This factsheet is a companion document to the Transgender Veteran Health Care "Get the Facts" Birth Sex and Self-Identified Gender Identity factsheet.¹ Together, these two documents are intended to facilitate a conversation between providers and Veterans regarding patient safety issues and documentation of birth sex and gender identity.

1. How are the terms "Birth Sex" and "Self-Identified Gender Identity" used in the medical record system?

The term "birth sex" is used as the demographic identifier for automated generation of clinical reminders, lab ranges, and other values (e.g., prostate screening, pap smears, medication doses). Although Veterans have the right to change their "birth sex" demographic field in their VA medical record, current medical advice is that reported "birth sex" in the medical record should match the sex listed on a Veteran's original birth certificate.^{2,3} This document can assist the Veteran's decision-making process by helping explain the impact of changing the "birth sex" field in the medical record. The "Self-Identified Gender Identity (SIGI)" field is where the Veteran describes their gender identity. "SIGI" is a new, separate field within the medical record. SIGI does not need to be the same as the Veteran's sex assigned at birth. Since the Veteran's gender identity may differ from the birth sex, the "SIGI" demographic field helps VA staff respect transgender and gender non-conforming Veterans by using the appropriate pronouns and terms to deliver personalized care.

2. How does Birth Sex relate to screenings and diagnostic testing?

Within the VA system, clinical reminders for screenings, ranges for lab results, and medication dosing are auto-calculated based on birth sex. Approaches to care that vary by birth sex include but are not limited to:

- **Health Screens** for breast cancer, cervical cancer, prostate cancer, cardiovascular risk including cholesterol and triglycerides, pregnancy testing, STI/HIV, alcohol use, and obesity/overweight nomograms.
- **Drug Dosing** for chemotherapy dosing by body surface area (BSA), antibiotics, and other medications affected by creatinine clearance calculation.
- **Diagnostic Testing** for creatinine clearance, hemoglobin/hematocrit, liver function tests, pulmonary function tests, and DEXA scans.

Providers should always take an individualized approach to Veteran medical care. Transgender patients have health factors that uniquely influence health care. These factors include **existing anatomy** (e.g., penis, testes, prostate, breasts, vagina, cervix, uterus, ovaries), **medical history**, and **gender transition goals**. Veterans should undergo health screens that are consistent with their present anatomy (e.g., patients with a cervix should have recommended cervical cancer screenings; patients with a prostate should have recommended prostate cancer screenings). Their health screenings should be performed even when the automatic clinical reminders do not appear.

In situations in which the clinical implications of birth sex are unclear, you should use your clinical judgement, available resources (see resource list at end of document), and consult with more experienced providers when clinically indicated, such as the transgender e-consult program.⁴ Research on relationships of sex and gender to different domains of clinical care are available.⁵

3. What if Birth Sex is changed in the medical record?

Patients may be considering changing, or have previously changed, the birth sex field in their medical record to be consistent with their self-identified gender identity. It is important to have a conversation with your patient about the potential clinical and safety implications of this decision. It is the Veteran's right to have their birth sex listed in a way that affirms their gender identity. However, it is also important that Veterans make this decision with a full understanding of the health and safety impact of this choice.

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Additional Resources:

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It is important that all Veterans are treated with respect and dignity.




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oncologist, he wants to ensure that all people involved in his care (eg, pharmacists, radiologists) use the correct values in interpreting his medical data. Providers will need to use the female birth sex field for interpreting his medical data but use male pronouns when interacting with the veteran and documenting his care.

These case examples illustrate the need for HCPs to have patient-affirming education and appropriate clinical tools available when speaking to patients about birth sex, SIGI, and the implications of changing birth sex in the EHR. Moreover, these cases highlight that patient health needs may vary over time, due to factors such as perceived costs/benefits of a change in the sex field of the EHR as well as patient comfort with providers.

CURRENT STATUS OF SIGI AND EHR

Although having separate fields for birth sex and SIGI in the EHR is ideal, the VHA does not yet have a fully functional SIGI field, and several TGNC veterans have changed their birth sex field to align with their gender identity. Roughly 9,700 patients have diagnostic codes related to transgender care in the VHA, meaning thousands of current patients would potentially benefit from SIGI implementation (John Blosnich, written communication, March 2018). A possible action that the VHA could take with the goal of enhancing patient safety would be to revert the birth sex field of patients who had previously changed the field back to the patient's original birth sex. However, if this alteration to the EHR were done without the patient's consent, numerous additional problems would result—including invalidating a veteran's wishes—potentially driving patients away from receiving health care.

Moreover, in the absence of updated SIGI information (which only the veteran can provide), making a change in the EHR would perpetuate the misgendering of TGNC veterans who have already sought an administrative fix for this problem. Thus, the agency decided to engage patients in a discussion about their decision to keep the birth sex field consistent with their original birth certificate. In cases in which the field had been changed previously, the recommendation is for HCPs to gain patient consent to change the birth sex field back to what was on their original birth certificate. Thus, decisions about what should be listed in the EHR are made by the veteran using an informed decision-making model.

Patient Safety Education Workgroup

To begin the process of disentangling birth sex and SIGI fields in the EHR, 2 work groups were created: a technical work group (coding the patches for SIGI implementation) and a SIGI patient safety education work group. The patient safety education work group was committed to promoting affirmative VA policies that require validation of the gender identity of all veterans and pursuing best practices through clinical guidelines to promote effective, efficient, equitable, and safe veteran care. The patient safety education work

group included representatives from all 3 branches of the VA (VHA, Veterans Benefits Administration, and National Cemetery Administration), including clinical media, patient safety, information technology, and education specialists. The group developed trainings for administrative staff about the appropriate ways to ask birth sex and SIGI questions, and how to record veteran-driven responses.

SIGI Fact Sheet

The patient safety education work group examined clinical literature and developed tools for staff and veterans to facilitate effective discussions about the importance and utility of documenting both birth sex and SIGI in the EHR. The patient safety education work group along with media and educational experts created basic key term definition documents to address the importance, purpose, and use of the SIGI field. The patient safety education work group developed 2 documents to facilitate communication between patients and providers.

A 1-page veteran-facing fact sheet was developed that described the differences between birth sex and SIGI fields and how these fields are used in the VA EHR system (Figure 1). In addition, a 1-page HCP-facing fact sheet was designed to inform HCPs that patients may have changed their birth sex in their EHR or might still wish to change their birth sex field, and to inform HCPs of the importance of patient-centered, gender-affirmative care (Figure 2). An additional goal of both documents was to educate veterans and HCPs on how the EHR automatically calculates laboratory results and screening notifications based on birth sex.

Review Process

As part of reviewing and finalizing the SIGI patient fact sheet, the patient safety education work group previewed the document's content with veterans who provided feedback on drafts to improve comprehension, patient-centered care, and clinical accuracy. For instance, several patients commented that the document should address many gender identities, including intersex identities. As noted in one of the case presentations earlier, individuals who identify as intersex may have changed their birth sex to be consistent with

their gender and might benefit from being informed about the EHR's autocalculation feature. The patient safety education work group adjusted the SIGI patient fact sheet to include individuals who identify as intersex and instructed them to have a conversation with their HCP regarding potential birth sex changes in the EHR.

Much of the veteran feedback to the patient safety education work group reflected veteran concerns, more broadly, about implementation of SIGI. Many veterans were interested in how federal policy changes might affect their benefits package or clinical care within the VA. The SIGI patient fact sheet was a tool for communicating that Department of Defense (DoD) policies, specifically, do not have a bearing on VA care for LGBT veterans. Therefore, SIGI information does not affect service connection or benefits eligibility and is not shared with the DoD. Veterans found this information helpful to see reflected in the SIGI patient fact sheet.

The patient safety education work group also shared the SIGI provider fact sheet with VHA providers before finalizing the content. PCPs gave feedback to improve the specification of patient safety concerns and appropriate readership language. The patient safety education work group adjusted the SIGI provider fact sheet to be inclusive of relevant literature and an e-consultation link for assisting HCPs who are unsure how to proceed with a patient.

Implementation

The patient safety education work group also developed several materials to provide information about the birth sex and SIGI fields in the EHR. Because the SIGI demographic field is new and collected by clerical staff, training was necessary to explain the difference between birth sex and SIGI before implementation in the EHR. The training sessions educated staff about the difference between birth sex and SIGI, how to ask and respond to questions respectfully, and how to update these fields in the EHR. These trainings included a 20-minute video demonstrating best practices for asking about SIGI, a frequently asked questions document responding to 7 common questions about the new fields, and a quick reference guide for

administrative staff to have handy at their desks.

Dissemination of the SIGI patient and provider fact sheets is planned to occur, ideally, several weeks before implementation of the new patches updating the EHR fields in spring 2020. Building on existing resources, the patient safety education work group plans to disseminate the patient fact sheets via e-mail lists for the national mental health facility leaders as well as through e-mail lists for VA PCPs, nursing and clerical staff, privacy officers, facility LGBT veteran care coordinators, VISN leads, transgender e-consultation, the Office of Connected Care, the LGBT external homepage for the VA, and the training website for VA employees. The goal is to target potential points of contact for veterans who may have already changed their birth sex and might benefit medically from altering birth sex to be consistent with their original birth certificate.

The SIGI provider fact sheet will be disseminated using internal e-mails, announcements on routine LGBT veteran care coordinator calls, weekly Ask LGBT Health teleconferences, and announcements at LGBT health training events both internally and externally. Several dissemination tools have already ensured that VA employees are aware of the SIGI field in the EHR. Leadership throughout the VA will be encouraged to share SIGI trainings with clerical staff. Additionally, broad-based e-mails summarizing changes to the EHR will be provided concurrent to the SIGI patch implementation to VA staff as well as links to the resources and training materials.

Challenges

One difficulty in the development process for both SIGI fact sheets was addressing the issue of patient safety for veterans who may be at different points in their gender transition process. It was challenging for the patient safety education work group to not sound alarmist in discussing the safety implications of birth sex changes in the EHR, as this is just one factor in clinical decision making. The goal was to educate veterans from a patient safety perspective about the implications of having a state-of-the-art, automated EHR. However, text can be perceived differently by different people, which is why the patient

safety education work group asked veterans to preview the patient document and clinical providers to preview the provider document.

Both work groups encountered technologic challenges, including a delay in the implementation of the SIGI field due to a systemwide delay of EHR updates. Although it released training and educational materials to the VHA, the patient safety education work group understood that at some point in the future, VA programmers will update the EHR to change the information clerks and HCPs can see in the EHR. Coordination of the fact sheet release alongside information technology has been an important part of the SIGI rollout process.

CONCLUSION

HCPs have a complex role in providing treatment to TGNC patients in the VHA: They must affirm a patient's gender identity through how they address them, while openly communicating the health risks inherent in having their birth sex field be incongruent with the sex recorded on their original birth certificate. Accomplishing these tasks simultaneously is difficult without invalidating the veteran's identity or right to choose their EHR demographic birth sex label. Furthermore, patients may ask HCPs to write letters of support for either medical or surgical intervention or other documentation changes (eg, changes to a patient's legal name, passport changes, or a safe passage letter for TGNC patients). Navigating the dialectic of safety and validation requires strong rapport, trust, and effective communication in the patient-provider relationship and great empathy by the provider.

A future task for the SIGI patient safety education work group is to continue to communicate with the technical work group and providers in the field about how demographic fields in the EHR are utilized to enable future EHR changes. This hurdle is not easy because EHR updates change the infrastructure through which demographic content is delivered and incorporated into a patient's treatment. The VA HCPs are tasked with thoroughly examining the results that automated systems produce to ensure safe and accurate medical services are always provided to all patients. An integral part of patient-centered care is balancing any

computer-guided recommendations with an understanding that actual patient needs may differ due to presence/absence of anatomy and other factors (eg, weight, current medications).

From a systems perspective, a benefit of adding the SIGI demographic field is systemic improvement in calculating the number of transgender veterans under VA care and evaluating health outcomes for this population. SIGI is particularly important for signaling gender pronouns for veterans, regardless of whether they are receiving care for a gender-related diagnosis. In terms of scope, the SIGI project potentially will apply to > 9 million enrolled veterans and nearly 400,000 VA employees.

Improvements could be made in the SIGI field of the new EHR, such as expanding the options for self-labels. Additionally, a text field could be used to enhance the quality of personalization provided to veterans self-identifying in the EHR, including pronoun specification. Moreover, adding new fields such as “preferred name” could improve the health care experience of not only TGNC veterans but all veterans who use something other than their full legal name (eg, a nickname). It will be good practice to notify providers and staff of a veteran’s requested name and pronouns when the patient checks in at an electronic kiosk so that all staff immediately know how to address the patient. The VHA can continue to adjust the options for the SIGI field once the new EHR system is operational. Ideally, this new EHR will display birth sex and SIGI to clinicians or clerks engaged in patient interactions.

Technology will continue to automate medical care, meaning that HCPs must be vigilant about how computer programming and the accuracy of prepopulated information affect patient care. The concerns discussed in this report relating to patient safety are relatively absent in the medical literature, even though substantial health risks exist to patients who have birth sex listed incorrectly for any reason.^{6,7} Additionally, administrative burden can be reduced if patients who do not need certain screenings based on their current anatomy are not contacted for unnecessary screenings. Future EHR systems might

incorporate anatomical considerations from an inventory to assist in automating patient care in safe and accessible ways.

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Author disclosures

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