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Updating Gender in Electronic Medical Records – A Commentary

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ABSTRACT

It is argued in this commentary that many patient intake and permanent medical record forms make archaic assumptions about use of the word "gender." A further argument is made for change that accounts for the needs of persons who do not readily identify as "male" or "female." Several suggestions for making such accommodations available are offered.

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When most people seek medical care, they are given the option of selecting either "male" or "female" on intake forms, and this binary option carries through to electronic medical records (EMRs). Trans and non-binary people have no choice but to select one of two sexes, and in many cases, neither accurately reflects their actual identity. (Some people may not identify with the word "trans," but for the sake of brevity I will subsequently use "trans" in the broader sense, meaning anyone who identifies as a gender different than the sex they were assigned at birth.) Faced with incomplete choices, trans people know immediately that they will have to either come out to their provider—a conversation which may or may not go well—or risk experiencing sub-optimal care because of concealing necessary information. On the other hand, if a trans patient's first experience with a new provider is that they ask respectfully about preferred name, gender identity, and pronouns, that person is more likely to give accurate information because they feel safe and affirmed.

Despite the importance of updating gender practices in EMRs, there are many factors to consider before implementing updates. There is the most obvious consideration of what default choices should be provided and named, whether and what additional fields should be added, and whether write-in options should be available. If sex assigned at birth, legal sex, and gender identity are all tracked, for instance, which of those fields need to be shown, and to whom and in what contexts, and how are patients' identities respected as well as their confidentiality? What happens when the normal ranges of a particular test differ based on sex, as in CBC results? Sex assigned at birth will provide the appropriate parameters for some tests, whereas others could be additionally affected by hormones or other factors. It is imperative that institutions consider these and other questions before implementing updates to records to avoid causing further harm to a population, some of whose members already may be distrustful of medical health professionals.

Having a positive experience increases the likelihood that trans people will seek subsequent medical care. Even things as basic as accessing care need improvement in trans populations; a 2015 study found that 23% of trans people had delayed getting needed care within the last year because of fear of discrimination by providers as a result of trans status (James et al., 2016). This fear is not unwarranted; 33% of respondents in the same study reported at least one negative experience due to their gender identity while visiting a healthcare provider in the last year (James et al., 2016). Comprehensive training on various aspects of healthcare as it relates to trans people is required; further discussion of training content is beyond the scope of this paper. However, one way to indicate that providers are educated about trans people is to ask appropriate questions about gender identity and to store that information accurately in the operational EMR.

The most frequent initial reaction I have encountered in discussion around what forms should ask in place of "male or female" is the inclination to add a third category labeled "transgender," "non-binary," or simply "other." Although well-intentioned, on closer examination, this is problematic for several reasons. First, calling the additional choice "transgender" creates a dilemma for many people, as approximately two-thirds of trans

people fall into the category called "binary," (James et al., 2016) meaning that they transition from the sex assigned at birth to the so-called opposite gender. Someone who is binary and transitions from male to female, for example, would identify as female, but likely would still identify as transgender. Second, some people who have non-binary gender identities may not identify as transgender. "Non-binary" is an umbrella term used to encompass those whose gender identity is outside the binary of male and female, including people who identify as both male and female, neither male nor female, or have a more fluid gender identity. Although many non-binary people do identify as trans, there are increasing numbers who do not; therefore, calling a third option "transgender" is not inclusive of these people. "Other" is not an acceptable solution because it feels dehumanizing and clearly delineates people who do not identify as male or female to some presumed "lower status." For many non-medical forms, naming the third option "non-binary" would be the least problematic of the three possibilities, but it would still exclude intersex people who do not identify as male, female, or non-binary. I do not have another linguistic solution that would be all-inclusive; however, I would argue that asking about sex/gender on many of the forms that do is irrelevant and unnecessary; societal institutions could take a step forward by moving away from that practice. However, in medical situations, this is reasonable and necessary information to request.

Lumping all trans and non-binary people into one "other" category, regardless of what it is called, creates other complications. Using a single category for all people who are not "male" or "female" would encompass a group so diverse that any such designation on someone's record could become meaningless. As a result, providers would need to ask questions that could be avoided with more effective documentation practices. Additionally, in EMRs, the sex field can be linked to hundreds of other fields, such as patient headers and graph images (Landman, 2017). An "other" category would be unable to provide guidance for fields that had different acceptable values associated with sex, such as lab results, leading to potential complications and negative health outcomes.

Epic Systems Corporation, a software company that develops EMRs, created fields for sex assigned at birth, legal sex, and gender identity to replace the previous single field for sex (Landman, 2017). As there are ramifications for patient trust and safety if detailed information about gender is sought before providers are professionally prepared to handle it appropriately, this functionality has the capability to be turned on or left off as users see fit (Landman, 2017). Making sure the updated gender fields are used properly is a substantial undertaking, as every field that extracts data from the field that was previously "sex" must be found, and then evaluated to determine whether it should extract from sex assigned at birth, legal sex, or gender identity.

Another relevant concern is tracking which body parts a person has to determine the appropriate care. No combination of sex and gender identity fields can answer this question, as people could have the same values for all three fields but warrant different care based on hormonal and surgical interventions. For example, people who were assigned male at birth and identify as trans women, may need a prostate exam and a breast exam, one or the other, or neither one. Ideally (and legally), legal sex would be irrelevant in this example, but in practice, many insurance companies, including plans bought through the Affordable Care Act (ACA) Marketplace, look at legal sex to determine which claims they will allow; if a procedure is filed that is deemed "gender-specific" and does not match the sex on file, it is likely to be flagged (Ford, 2015). Thus, it is crucial for EMRs to provide a way to track body parts that previously would have been linked to the sex field in some other way so that providers are able to reference this information readily, if needed, to advocate for their patients to insurance companies.

EMR users also must consider which information appears in which fields and who is able to view it. For example, is it appropriate for receptionists to see sex assigned at birth, legal sex, or gender identity? None of these three, as far as I am aware, impacts the work receptionists do, except as it impacts possible disclosure of trans status to others, another topic whose consequences are beyond the scope of this paper. Similarly, some people have no complaint about disclosing trans status to anyone actively involved in treatment during a healthcare visit, whereas others prefer to disclose strictly on a need-to-know basis, even during situations like visits to the ER. These judgments are formed based on people's prior experiences and whether they feel safe having other people know they are trans when they are in a potentially vulnerable position.

I have discussed some of the reasons why the current way the binary sex field is used is not inclusive and why merely adding a third option, regardless of what it is called, is not an acceptable solution. I also touched briefly on a few of the reasons updating fields around gender may improve trans people's health. I went into more depth about a few factors that must be considered prior to updating gender fields in EMRs. There are often not easy or "right" answers to the questions posed in this paper; however, it is vital that discussions are started if providers hope to provide quality care for their trans patients.

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