TRANS INCLUSIVE ELECTRONIC HEALTH RECORDS

Electronic health records are a vital tool in providing trans-affirming care and reducing health disparities. In the last decade, Electronic Health Records (EHRs) have become ubiquitous in US healthcare environments, but developers haven't kept up with parallel develop-ment of trans-aware policy, creating barriers to affirming care.

In December 2019, the American Medical Association emphasized the need for EHR companies to voluntarily update their functionality to support trans-affirming care. This brief synthesizes up to date recommendations for EHRs and their customers to adopt standards supporting up-to-date requirements with room to grow as needs evolve. This level of policy allows care providers to respond to the needs and cultures of local communities with greater agility and specificity than state or federal legislators.
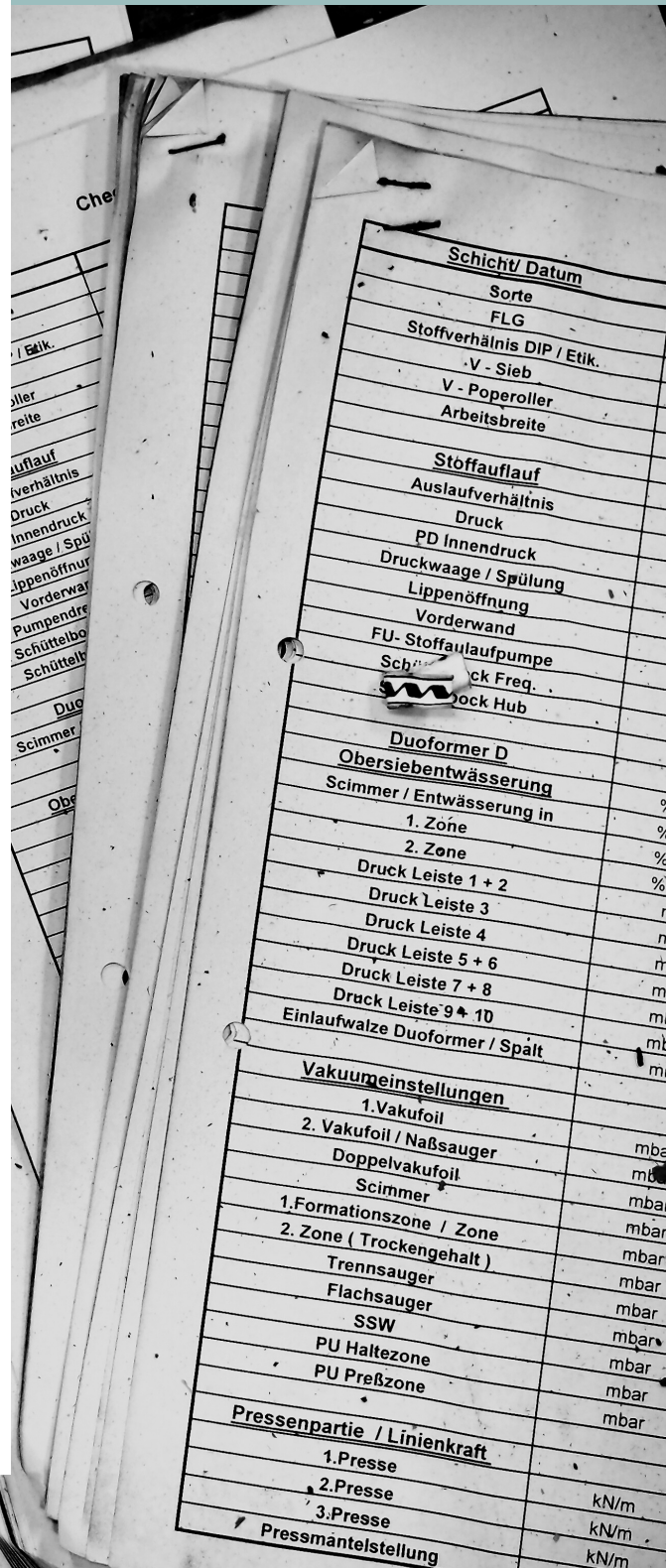
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HOW DOES EHR DESIGN IMPACT OUTCOMES & SERVICE UTILIZATION?

Currently, most EHRs treat the legal name as the default name, meaning that whatever a patient actually goes by, they will be addressed by their legal name. Providers may update personal names and pronouns through digital sticky notes, alerts, or other manual record-keeping; or administrators may redirect functionalities such as "alias" to record and display name and pronoun alongside the legal name. Such workarounds are vulnerable to errors and disclosures that lead to **misgendering**, a type of identity miscategorization in which a person is addressed using inappropriate gender labels such as the wrong name or pronoun.
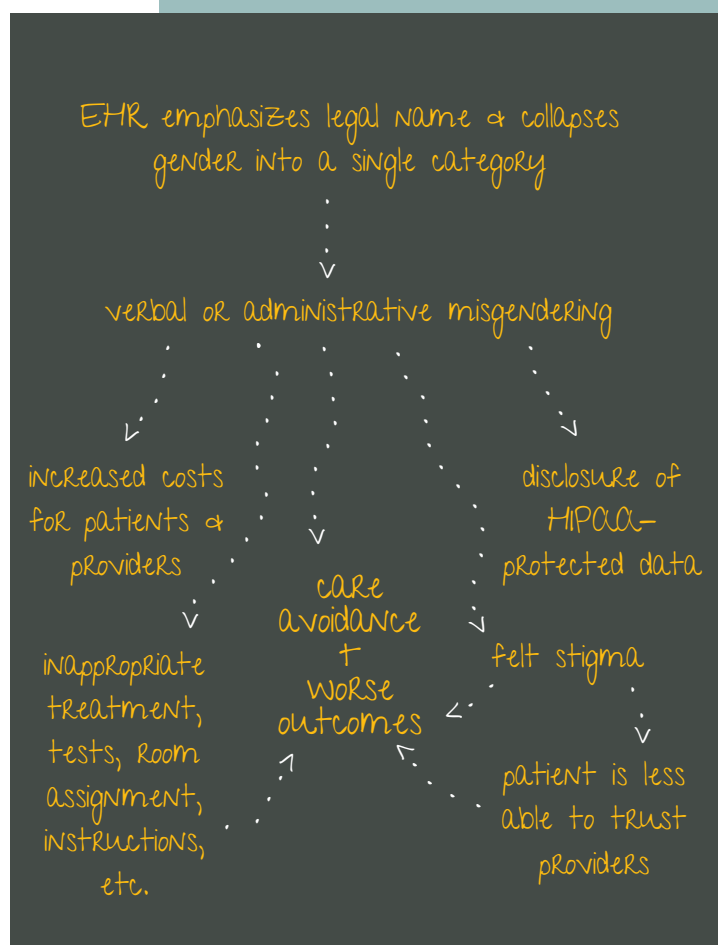
Misgendering is an important cultural index of **safety, acceptance, and cultural competency** for trans patients. Misgendering is associated with significant psychosocial disruption, including felt stigma. [1] Within healthcare contexts, felt stigma contributes to **delays and avoidance of care**, **concealment** of the stigmatized identity, **self-administered transition medications** and procedures, and **overall worse outcomes** for health and wellness. [2-4]

Misgendering is extremely common. At UCSB, **only 37% of trans spectrum students who access university clinics said they are always called by the correct name and pronoun** by clinic staff.[5] Students expressed frustration that entering their name in the alias field didn't stop staff from using their legal names, while staff worry that confusing record systems lead to frequent errors and distrust from students.
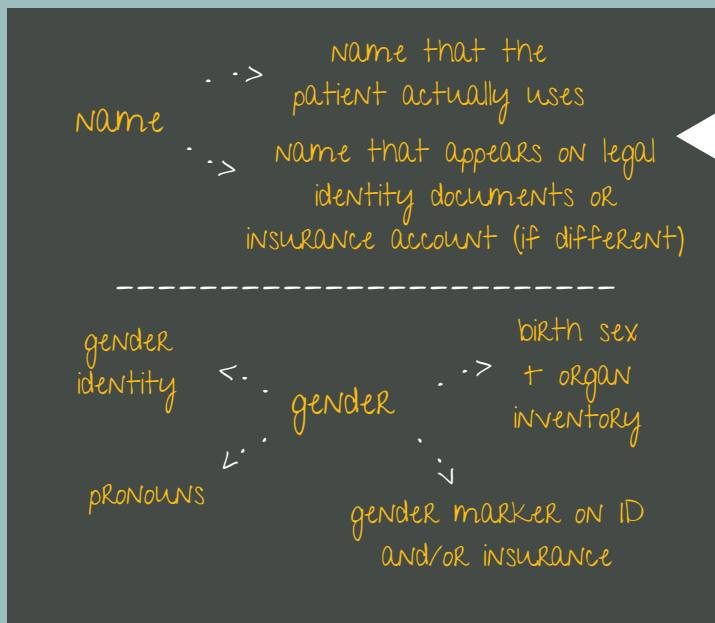
EHR designs that collapse legal gender, sex organs, and identity into one category can also cause **administrative errors** such as assigning a person to an inappropriate room, prompting funding denials (and additional administrative inefficiencies) by billing procedures with the wrong marker, assigning unnecessary testing or procedures, or even skipping needed ones. For instance, transgender women with F markers may report being asked to take a pregnancy test before x-rays, despite being unable to become pregnant; these facilities are likely not asking transgender men, who CAN become pregnant, to take pregnancy tests. This creates validity challenges with countless diagnostic and treatment tasks, all of which can also bear the risk of both stigma and medical risk when we get things wrong.

For most trans people in the US, updating identity documents can be difficult (or in many states, impossible) without first going through the gauntlet of accessing and receiving gender-affirming surgical care. The National Transgender Discrimination Survey found that only 21% of trans people who had fully completed their desired medical transition AND had binary genders (i.e. trans men and trans women) had been able to update all their documents [6]. The same survey found that a minority of trans people have had any gender-affirming surgeries, and the rates of document updates without surgery were even lower.

In other words, most trans patients who present for medical care of any kind will not have identity documents that reflect their name and gender. Our EHRs are either an indespensible tool for providing gender-affirming care, or a major barrier. [7]

EHR emphasizes legal name & collapses gender into a single category

↓

verbal or administrative misgendering

increased costs for patients & providers

disclosure of HIPAA-protected data

care avoidance + worse outcomes

inappropriate treatment, tests, room assignment, instructions, etc.

felt stigma

patient is less able to trust providers

DESIGN REQUIREMENTS

Name

- -> name that the patient actually uses
- -> name that appears on legal identity documents or insurance account (if different)

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gender identity <- gender -> birth sex + organ inventory

pronouns

gender marker on ID and/or insurance

IDENTITY ELEMENTS

Currently most EHRs collect and display legal name and a single field for gender, which is assumed to align with gender identity, current and past reproductive organs, and current and past legal gender marker. Some systems have an additional field for alias which adds a nickname to the (primary) legal name. Recommended elements break down as follows:

Name: Current name (the name a patient goes by) and legal name (if different)

Gender: Gender identity (e.g. man, woman, nonbinary); pronouns (e.g. he, she, they); sex assigned at birth (male, female, intersex); organ inventory (e.g. has prostate); and legal gender marker (M, F, X)

DISPLAY

The banner display should show the current name, the pronouns, and the gender identity, with asterisks to denote that the legal name or gender is different. This minimizes visibility (and therefore disclosure) of data that might be stigmatizing, while preserving availability for billing, identity verification, and other tasks where legal information is required.[6]

The record itself should indicate current and lifetime reproductive organs and other sex-specific organs; these records should inform screening, diagnosis, and treatment rather than the gender identity.[6]

Current name should be used in patient-facing communications, such as in patient portals, emails, phone calls, and face-to-face interactions. Where legal name must be used, add current name and use current name in procedurally generated greetings.[7]

Name: Jay* Sample (he/him)   Gender: M*

Asterisks next to Jay's name and gender marker indicate that his legal gender differs. In the history section of Jay's chart, staff will be able to learn Jay's legal first name, his legal gender (F), and his assigned sex (F), and his organ inventory.

Name: Jill* Sample (they/them)   Gender: F

An asterisk next to Jill's name indicates that their legal name is different. However, there is no asterisk next to Jill's gender marker. This may mean that they were assigned female at birth, but it could also mean that they were assigned male at birth but legally changed their gender marker to F. Jill's providers could learn about their sex assignment and organ inventory from their history section.
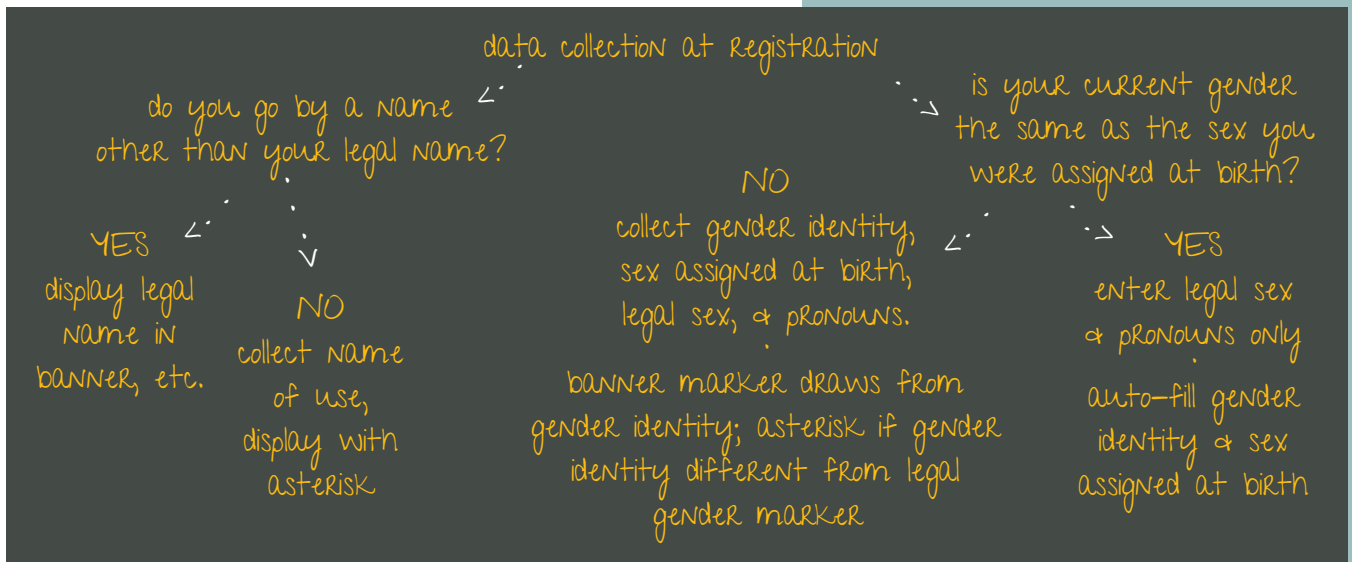
Some current recommendations treat pronoun as equivalent to gender identity, such that someone who identifies as a man should be called "he" and someone who identifies as nonbinary should be called "they."[6] However, this is not always the case, and the most important reason to collect gender identity is to gender patients correctly. These options are a great place to start. [8]

he/him/his
she/her/hers
they/them/theirs
ze/hir/hirs
"I do not use a pronoun"
"Please ask me"

DATA FLOW

While recording complexities in identity data is crucial for patients who need it, most patients do not, and asking them three different times about the same information would be unnecessary and annoying. Therefore, data collection logics can help identify whether this information needs to be collected separately at all.

data collection at registration

do you go by a name other than your legal name?

is your current gender the same as the sex you were assigned at birth?

YES
display legal name in banner, etc.

NO
collect name of use, display with asterisk

NO
collect gender identity, sex assigned at birth, legal sex, & pronouns.

banner marker draws from gender identity; asterisk if gender identity different from legal gender marker

YES
enter legal sex & pronouns only

auto-fill gender identity & sex assigned at birth

Once collected, application of name and gender data will depend on the particular functions (current and future) of EHRs. One application is data-to-text functionality. Developers may prefer to use gender-neutral language for all patients (e.g. "the patient reported no pain" versus "he reported no pain") or using language reflecting the selected pronoun.

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