Gender Diversity in Electronic

Health Records:

The Silicon Sword of Damocles

2023 TransPride YOUniting Health & Wellness Conference October 6

The Silicon Sword of Damocles

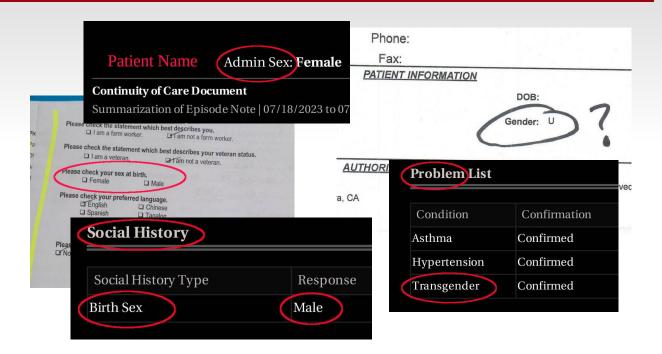
- Nick Eliot, Patient Advocate
- Quinnehtukqut McLamore, University of Missouri at Columbia
- Rebecca Niederlander, GRO Gifted
- Alicyn Simpson, University of Pittsburgh School of Medicine
- Kelley Winters, International Transgender Health Forum

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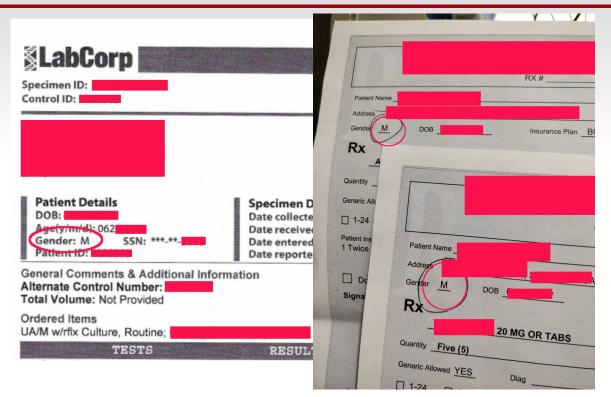


"Since this life delights you," an annoyed Dionysius replied, "do you wish to taste it yourself and make a trial of my good fortune?"

EHR Misrepresentation and Nonconsensual Recording of Presumed Status



Nonconsensual, Inappropriate, & Misgendered 3rd-party Disclosure of Trans/Nonbinary Status



"UMMC Exchanges One Million Patient Records..."



This...

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NEWS (USA)

Republican AGs demand Biden administration allow them to keep access to out-of-state medical records

The Republicans say that they need out-of-state medical records to enforce state bans on abortion and gender-affirming care.

By John Russell Tuesday, July 18, 2023

LGBT NATION



Some EHR/Intake Policy Issues (1)

- Explicit release consent for SOGI disclosures.
- SOGI information not disclosed by patients at intake, should not be presumed and recorded by staff without consent
- SOGI information that is disclosed by patients, should not be deliberately misgendered/mis-recorded by staff

Some EHR/Intake Policy Issues (2)

- Nonbinary and intersex inclusion in all relevant data fields
- Segregation of SOGI information in database with appropriately restricted access and thirdparty disclosure. (Cures Act discussion)
- Voluntary SOGI disclosures, with "Choose not to disclose" options for all data fields.

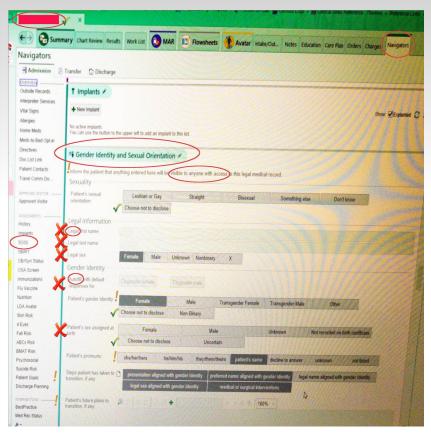
Some EHR/Intake Policy Issues (3)

- Default, generic "Name" data field that reflects affirming name
- References to "legal name" replaced by "Name for Billing Purposes."
- Default, generic "Sex" data field that reflects affirming status
- References to "birth sex" replaced by respectful organ inventory practices

Some EHR/Intake Policy Issues (4)

- References to "legal sex" replaced by "Sex for Billing Purposes"
- Expedited and transparent process for correcting SOGI errors in EHR and thirdparty disclosures
- Accommodation for extraordinary privacy and safety concerns with SOGI data for TGD patients and families

The Kahuna: EPIC EHR SOGI Page



CURES ACT Info Blocking Exceptions

The Office of the National Coordinator for Health Information Technology

() INFORMATION BLOCKING

CURES ACT FINAL RULE Information Blocking Exceptions

Section 4004 of the 21st Century Cures Act (Cures Act) defines practices that constitute information blocking *and* authorizes the Secretary of Health and Human Services (HHS) to identify reasonable and necessary activities that do <u>not</u> constitute information blocking (referred to as "exceptions").

On behalf of HHS, ONC has defined **eight** exceptions that offer actors (i.e., health care providers, health IT developers, health information networks (HINs) and health information exchanges (HIEs)) *certainty* that, when their practices with respect to accessing, exchanging, or using electronic health information (EHI) meet the conditions of one or more exceptions, such practices will not be considered information blocking.

An actor's practice that does <u>not</u> meet the conditions of an exception will <u>not</u> automatically constitute information blocking. Instead such practices will be evaluated on a case-by-case basis to determine whether information blocking has occurred.

We have finalized **eight** exceptions that are divided into two categories:

- Exceptions that involve not fulfilling requests to access, exchange, or use EHI; and
- Exceptions that involve procedures for fulfilling requests to access, exchange, or use EHI.

Exceptions that involve not fulfilling requests to access, exchange, or use EHI

Preventing Harm Exception

Privacy Exception

Security Exception

Infeasibility Exception

Health IT Performance Exception

Exceptions that involve procedures for fulfilling requests to access, exchange, or use EHI

Content and Manner Exception

Fees Exception

Licensing Exception

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