Genspect

Toolkit for Parents Interacting with Gender Related Medical Data

Carrie Mendoza, M.D.

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INTRODUCTION

Navigating medical data can feel overwhelming, especially when it comes to your child's health. In recent years, gender-related activism has had a significant impact on medical practices, and many parents may not realize just how deeply it has influenced care and management.

These changes raise important concerns about safety and quality for all patients, and they also present potential legal challenges for healthcare providers. Gender activism has reshaped medical forms, electronic health records, lab tests, and even medication protocols, affecting the entire healthcare system.

Because these shifts have occurred gradually and often align with broader changes like the adoption of electronic health records and the merging of medical practices, their full impact can be difficult to see. This toolkit is designed to give parents the information they need to navigate these changes and ensure their child receives safe, high-quality care.

Problems:

1. “Patient Portals” block parental access
2. Electronic Health Records support gender confusion
3. Hormone use is unregulated and the polypharmacy is an underreported safety risk

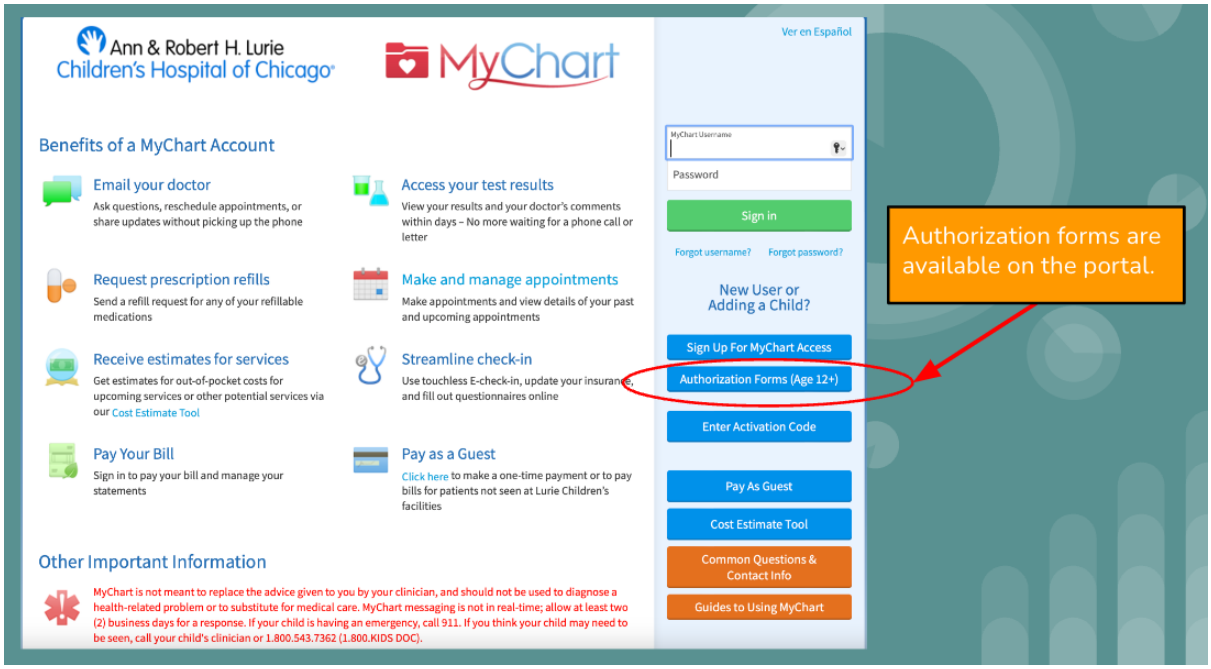
Solutions:

1. Be proactive about consent to access your minor’s records
2. Be proactive about sex and gender fields on electronic forms
3. Be proactive about medication interactions

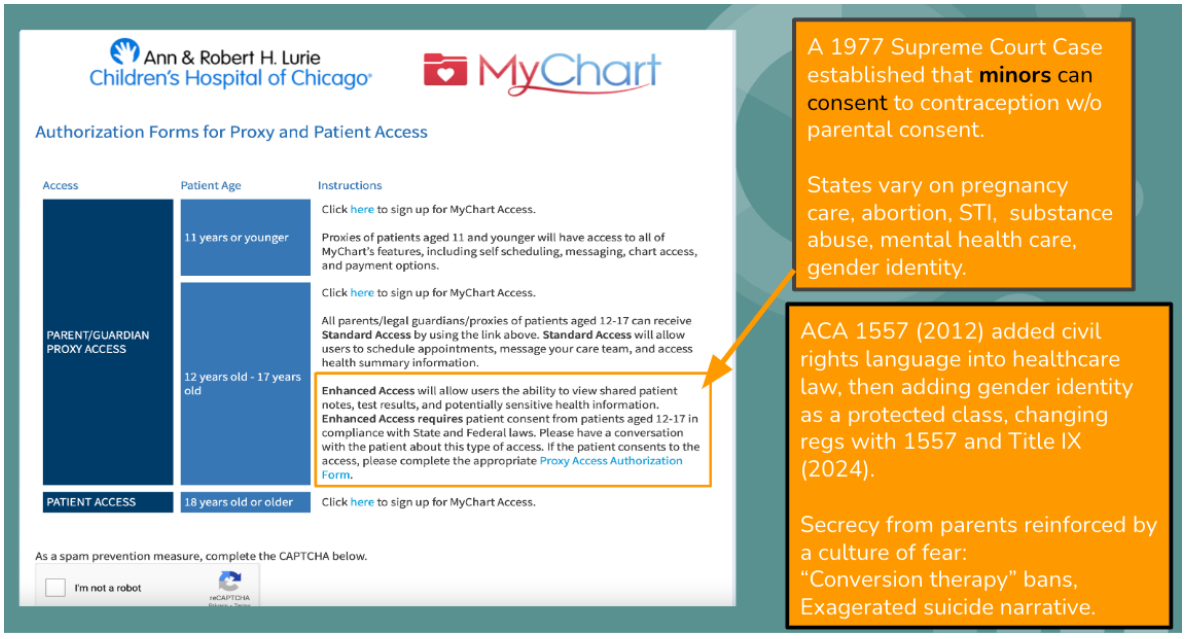
"PATIENT PORTALS" BLOCK PARENTAL ACCESS

Patient Portals reveal how some of your minor's records are concealed from your view.

Portal access for patients to view their records is mandated by State and Federal Government. But parents require authorization forms FROM minors aged 12-17 to access certain records.

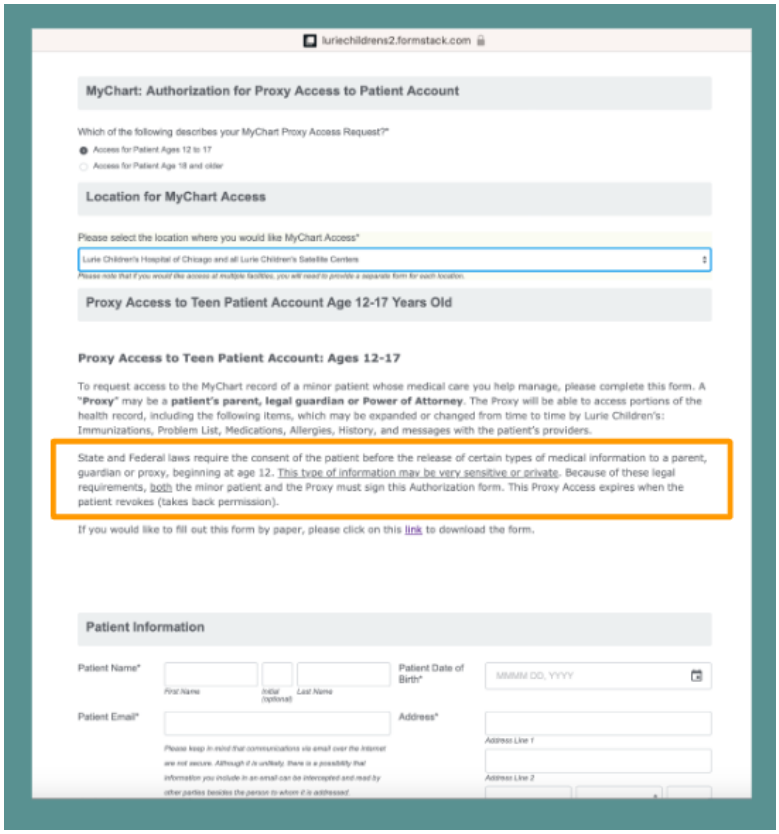


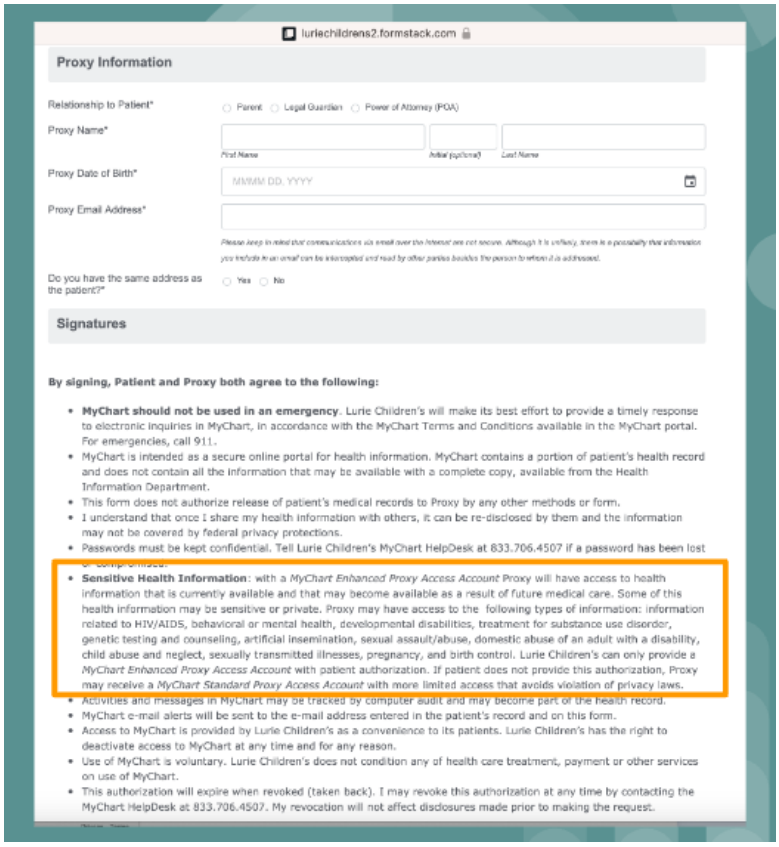
The variable access is mandated by the government. This started with the sexual revolution and a minor's right to obtain contraception without a parent's consent. The list has expanded over time, and now may include gender identity issues.



Consent form for your minor to sign to give parental access:

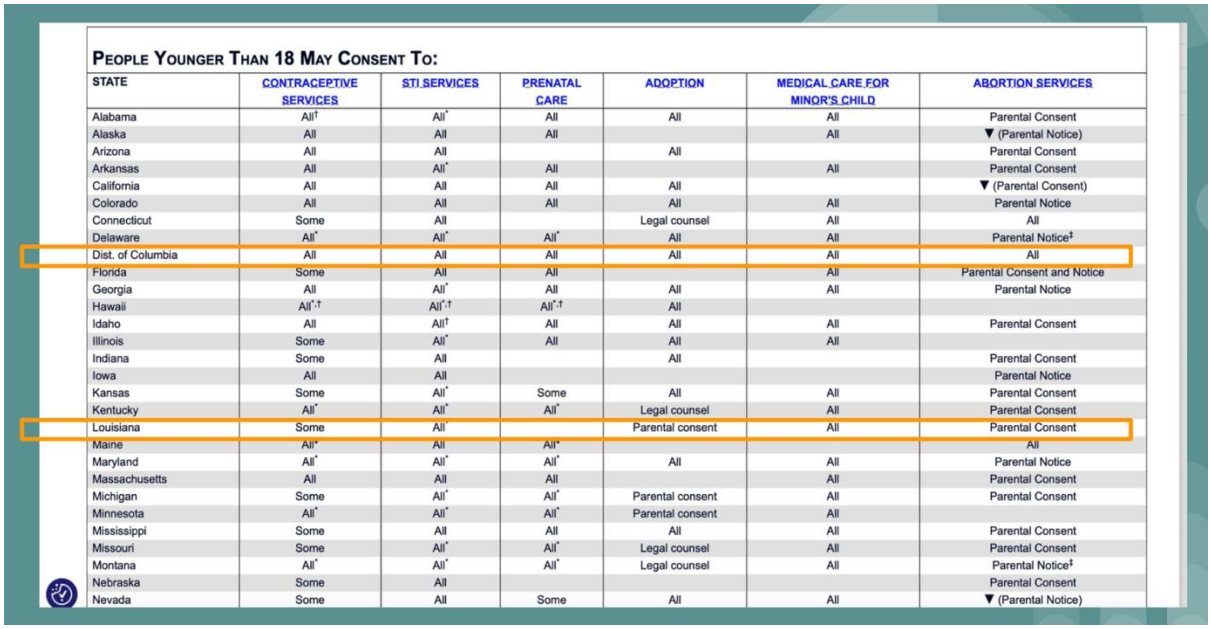
Your minor, starting at age 12, has to grant you, the parent, access to their full records.





Parental Consent Variation: "sexual health"

A minor's access to services varies by state. Gender related services have been grafted onto the liberal consent rules for sexual related issues.



People Younger Than 18 May Consent To:

STATE	CONTRACEPTIVE SERVICES	STI SERVICES	PRENATAL CARE	ADOPTION	MEDICAL CARE FOR MINOR'S CHILD	ABORTION SERVICES
Alabama	All†	All*	All	All	All	Parental Consent
Alaska	All	All	All		All	▼ (Parental Notice)
Arizona	All	All		All		Parental Consent
Arkansas	All	All*	All		All	Parental Consent
California	All	All	All	All		▼ (Parental Consent)
Colorado	All	All	All	All	All	Parental Notice
Connecticut	Some	All		Legal counsel	All	All
Delaware	All*	All*	All*	All	All	Parental Notice‡
Dist. of Columbia	All	All	All	All	All	All
Florida	Some	All	All		All	Parental Consent and Notice
Georgia	All	All*	All	All	All	Parental Notice
Hawaii	All*,†	All*,†	All*,†	All		
Idaho	All	All†	All	All	All	Parental Consent
Illinois	Some	All*	All	All	All	
Indiana	Some	All		All		Parental Consent
Iowa	All	All				Parental Notice
Kansas	Some	All*	Some	All	All	Parental Consent
Kentucky	All*	All*	All*	Legal counsel	All	Parental Consent
Louisiana	Some	All*		Parental consent	All	Parental Consent
Maine	All*	All	All*			All
Maryland	All*	All*	All*	All	All	Parental Notice
Massachusetts	All	All	All		All	Parental Consent
Michigan	Some	All*	All*	Parental consent	All	Parental Consent
Minnesota	All*	All*	All*	Parental consent	All	
Mississippi	Some	All	All	All	All	Parental Consent
Missouri	Some	All*	All*	Legal counsel	All	Parental Consent
Montana	All*	All*	All*	Legal counsel	All	Parental Notice‡
Nebraska	Some	All				Parental Consent
Nevada	Some	All	Some	All	All	▼ (Parental Notice)

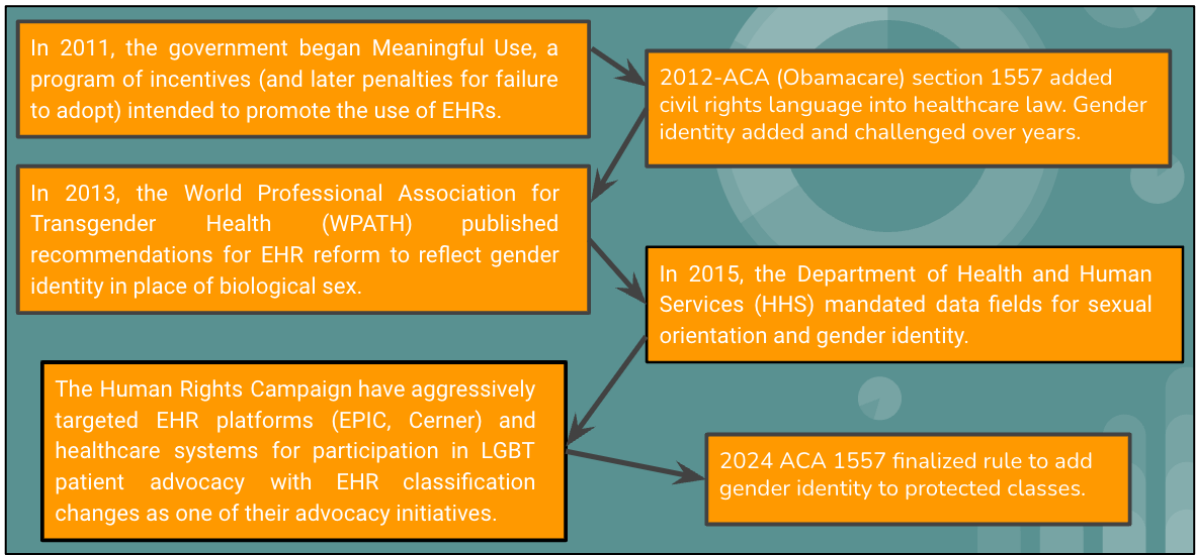
source: https://www.guttmacher.org/state-policy/explore/overview-minors-consent-law

TAKEAWAYS

- "Patient Portals" block parental access for "sexual health" or "sensitive information" including gender confusion and an expanding list of issues
- Regulations are state by state
- Be proactive about consent to access your minor's records
- Start at age 12 or as soon as you can
- Inform your pediatrician you are in control of the information

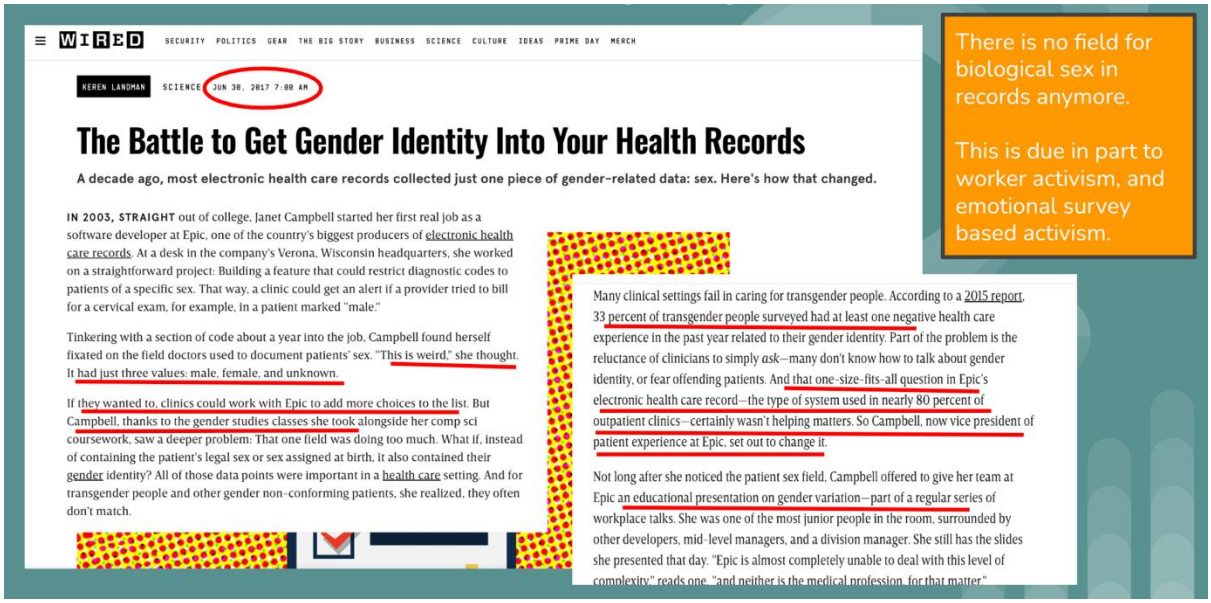
ELECTRONIC HEALTH RECORDS: GENDER FIELDS

The evolution of electronic health records has allowed gender related language to be scaled across the country. How did this happen?



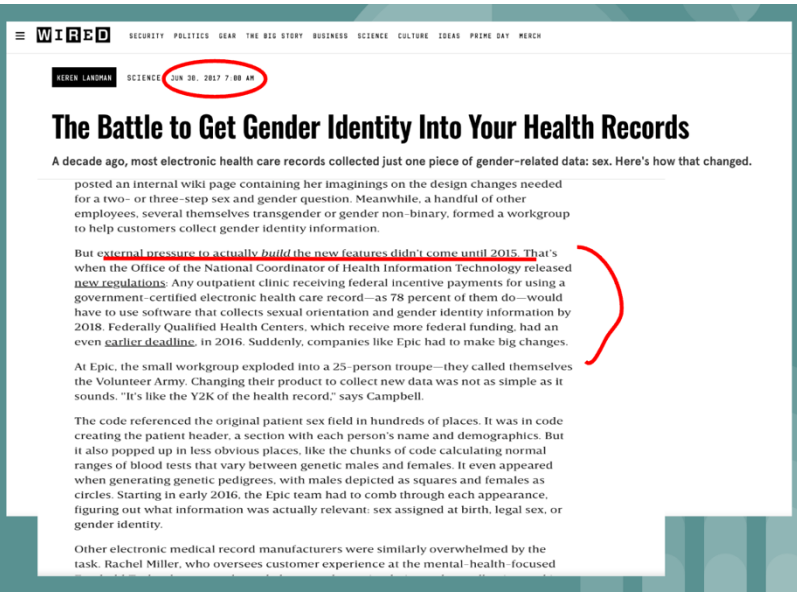
Gender Fields Evolve

Cultural activists pressured Electronic Health Record (EHR) companies to expand sex and gender fields.



2012-ACA (Obamacare) section 1557 added civil rights language into healthcare law, then adding gender identity as a protected class, changing regs with 1557 and Title IX (2024)

2015 Regulatory mandate to include gender identity fields



WIRED SECURITY POLITICS GEAR THE BIG STORY BUSINESS SCIENCE CULTURE IDEAS PRIME DAY MERCH

KEREN LANDMAN SCIENCE JUN 30, 2017 7:00 AM

The Battle to Get Gender Identity Into Your Health Records

A decade ago, most electronic health care records collected just one piece of gender-related data: sex. Here's how that changed.

posted an internal wiki page containing her imaginings on the design changes needed for a two- or three-step sex and gender question. Meanwhile, a handful of other employees, several themselves transgender or gender non-binary, formed a workgroup to help customers collect gender identity information.

But external pressure to actually *build* the new features didn't come until 2015. That's when the Office of the National Coordinator of Health Information Technology released new regulations: Any outpatient clinic receiving federal incentive payments for using a government-certified electronic health care record—as 78 percent of them do—would have to use software that collects sexual orientation and gender identity information by 2018. Federally Qualified Health Centers, which receive more federal funding, had an even earlier deadline, in 2016. Suddenly, companies like Epic had to make big changes.

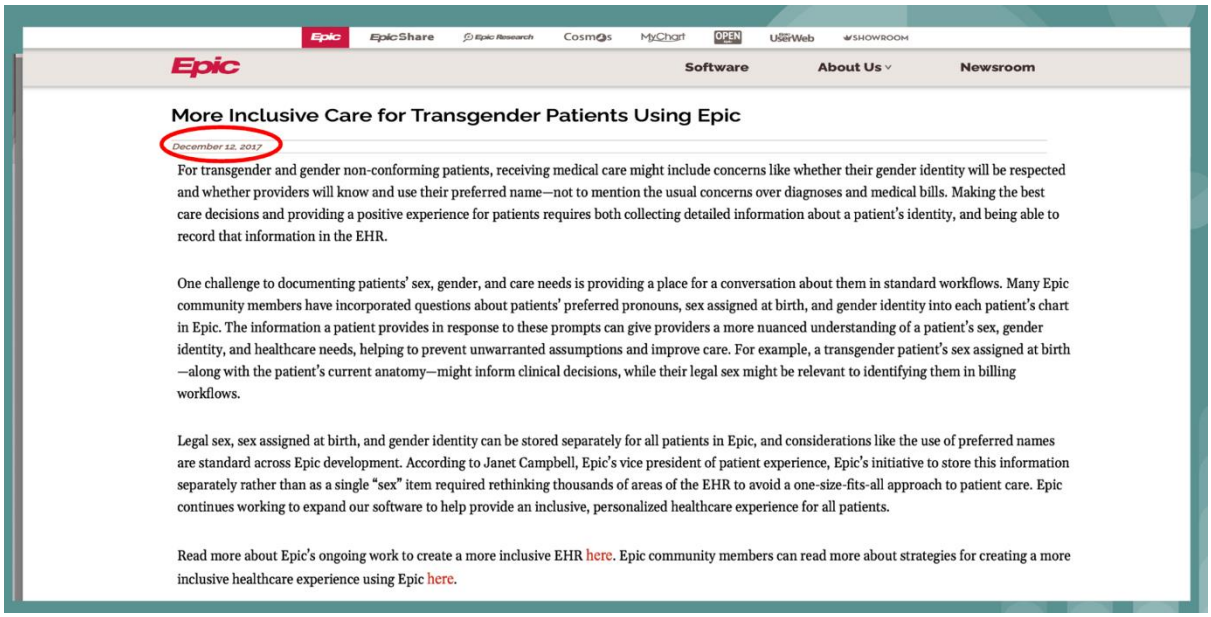
At Epic, the small workgroup exploded into a 25-person troupe—they called themselves the Volunteer Army. Changing their product to collect new data was not as simple as it sounds. "It's like the Y2K of the health record," says Campbell.

The code referenced the original patient sex field in hundreds of places. It was in code creating the patient header, a section with each person's name and demographics. But it also popped up in less obvious places, like the chunks of code calculating normal ranges of blood tests that vary between genetic males and females. It even appeared when generating genetic pedigrees, with males depicted as squares and females as circles. Starting in early 2016, the Epic team had to comb through each appearance, figuring out what information was actually relevant: sex assigned at birth, legal sex, or gender identity.

Other electronic medical record manufacturers were similarly overwhelmed by the task. Rachel Miller, who oversees customer experience at the mental-health-focused

EHR Regulations: Culture Activists

The EHR company EPIC highlighted their commitment to "inclusive" records by creating expanded fields for gender.



Epic EpicShare Epic Research Cosmos MyChart OPEN UserWeb SHOWROOM

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More Inclusive Care for Transgender Patients Using Epic

December 12, 2017

For transgender and gender non-conforming patients, receiving medical care might include concerns like whether their gender identity will be respected and whether providers will know and use their preferred name—not to mention the usual concerns over diagnoses and medical bills. Making the best care decisions and providing a positive experience for patients requires both collecting detailed information about a patient's identity, and being able to record that information in the EHR.

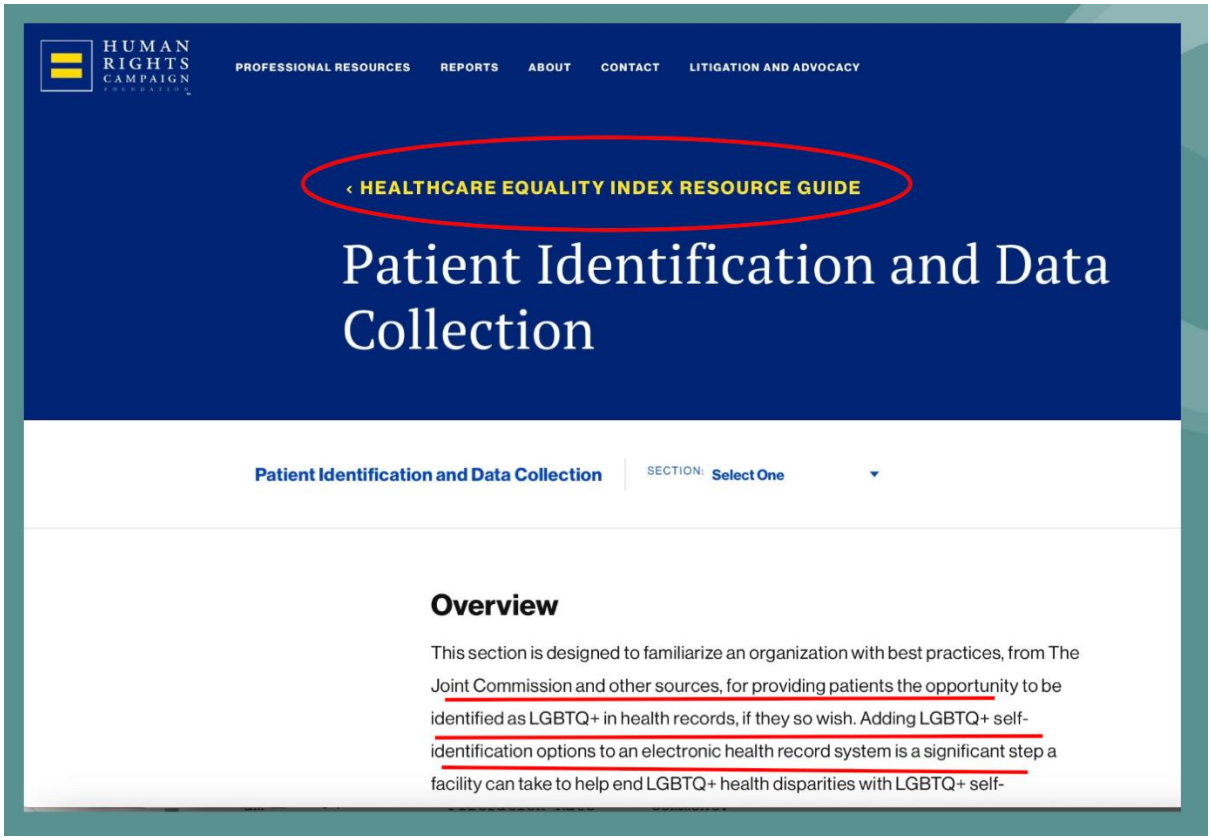
One challenge to documenting patients' sex, gender, and care needs is providing a place for a conversation about them in standard workflows. Many Epic community members have incorporated questions about patients' preferred pronouns, sex assigned at birth, and gender identity into each patient's chart in Epic. The information a patient provides in response to these prompts can give providers a more nuanced understanding of a patient's sex, gender identity, and healthcare needs, helping to prevent unwarranted assumptions and improve care. For example, a transgender patient's sex assigned at birth —along with the patient's current anatomy—might inform clinical decisions, while their legal sex might be relevant to identifying them in billing workflows.

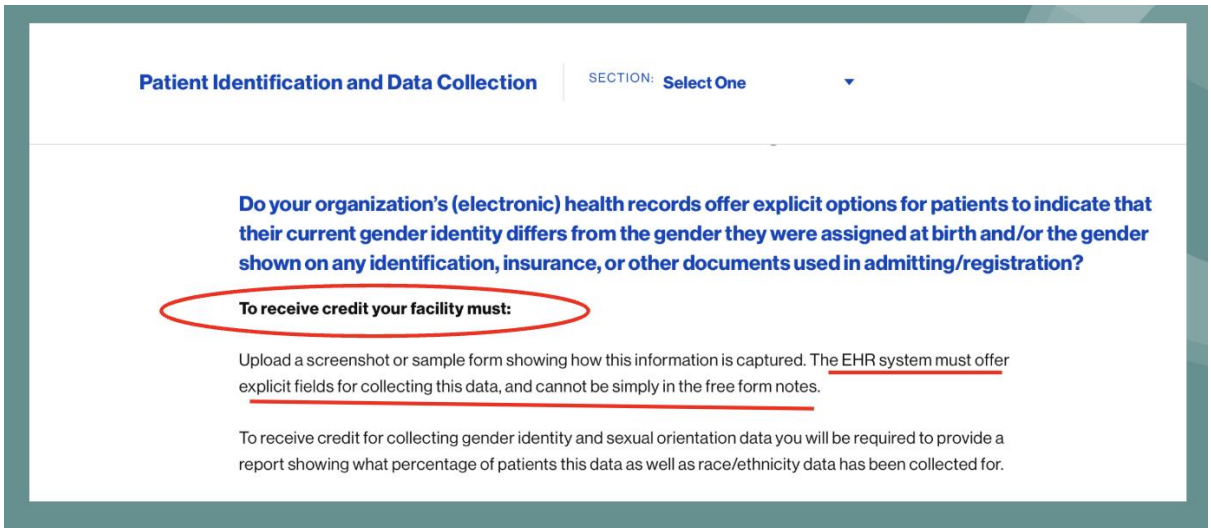
Legal sex, sex assigned at birth, and gender identity can be stored separately for all patients in Epic, and considerations like the use of preferred names are standard across Epic development. According to Janet Campbell, Epic's vice president of patient experience, Epic's initiative to store this information separately rather than as a single "sex" item required rethinking thousands of areas of the EHR to avoid a one-size-fits-all approach to patient care. Epic continues working to expand our software to help provide an inclusive, personalized healthcare experience for all patients.

Read more about Epic's ongoing work to create a more inclusive EHR here. Epic community members can read more about strategies for creating a more inclusive healthcare experience using Epic here.

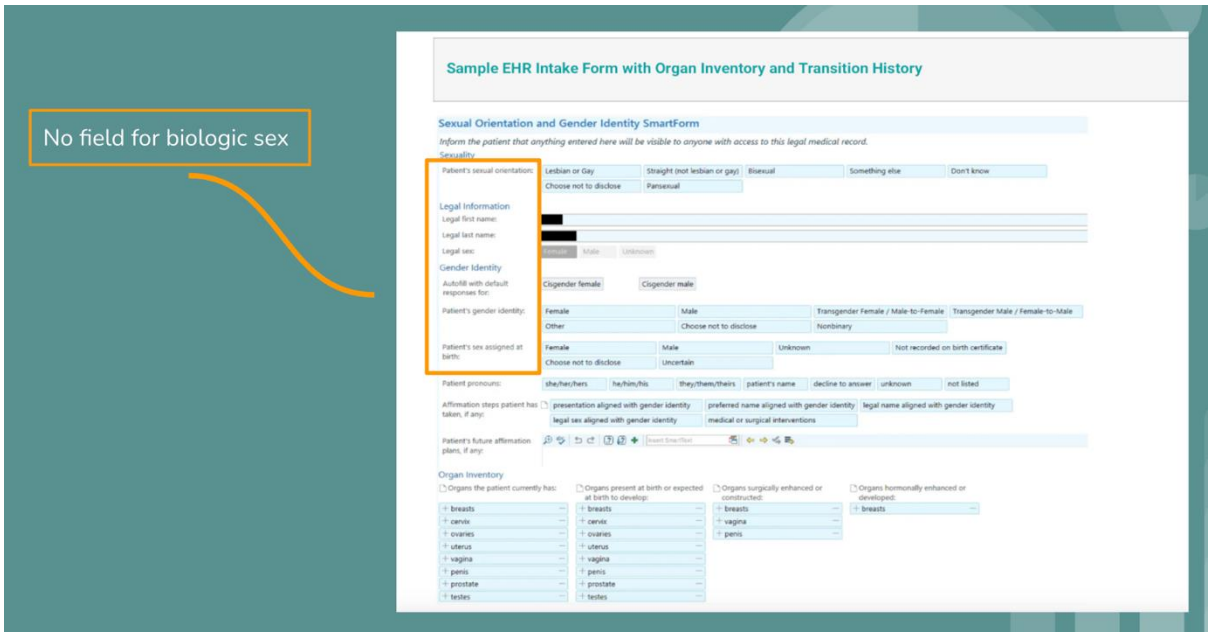
Advocacy group influence on Electronic Health Records

The activist group HRC applied pressure by adding EHR changes to their corporate "rankings". Organizations felt pressure to comply in the name of compassion and inclusivity.

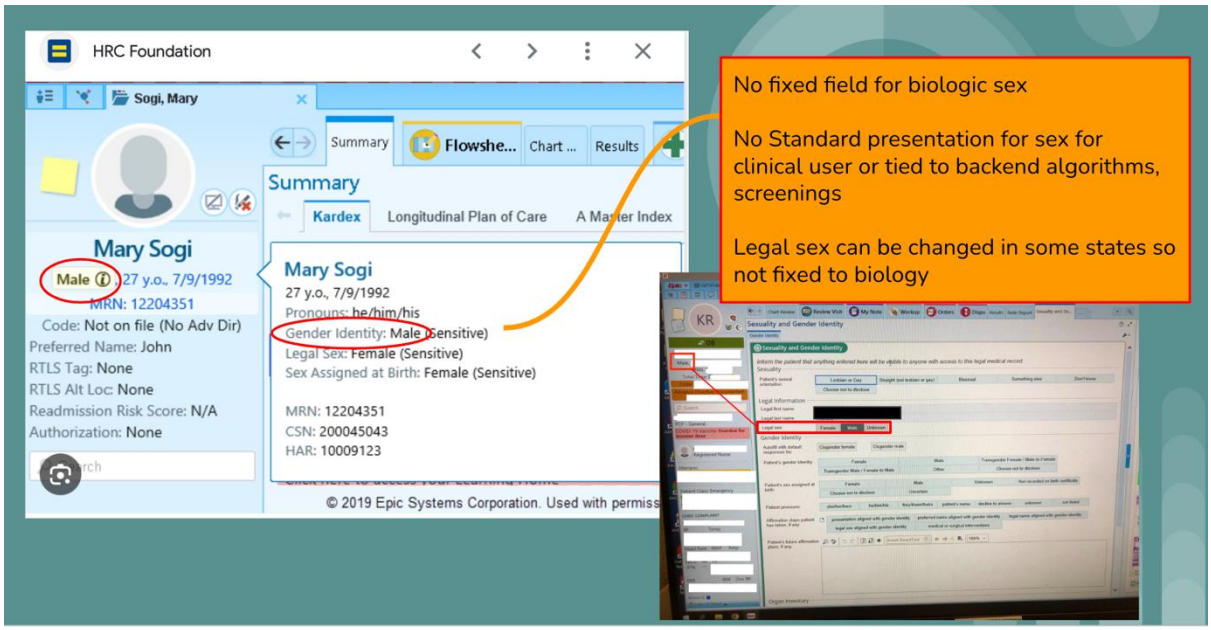




The activist vision has resulted in the field for biologic sex being removed. A grouping of variable terms — legal sex, gender identity, sex assigned at birth — has replaced one fixed field for biologic sex.

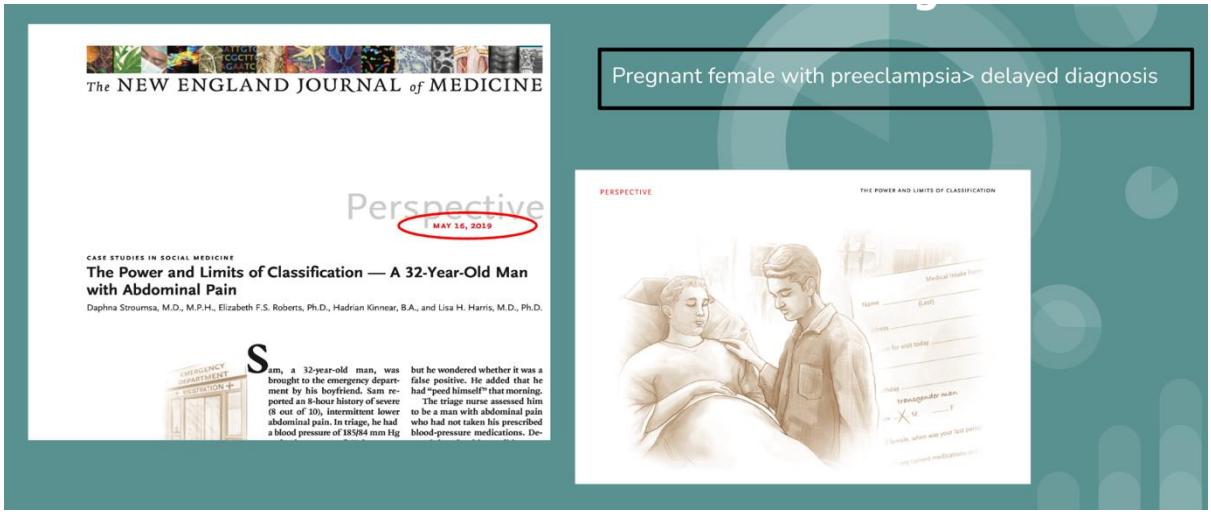


The clinical user will see a “sex” designation but that may not be the patient’s biologic sex. Which field is tied to backend algorithms is unclear, since legal sex can be changed in certain states. This can lead to patient harm by missing important alerts for such things as a pregnancy test, lab value differences, or certain screenings such as cervical or prostate cancer.

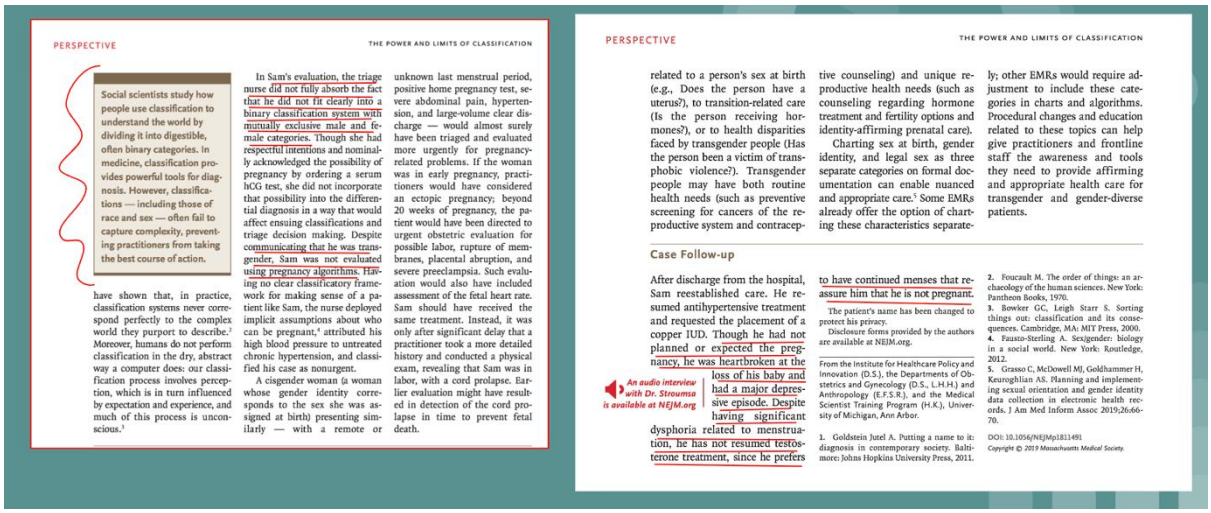


Medical Errors Due to Unclear Charting

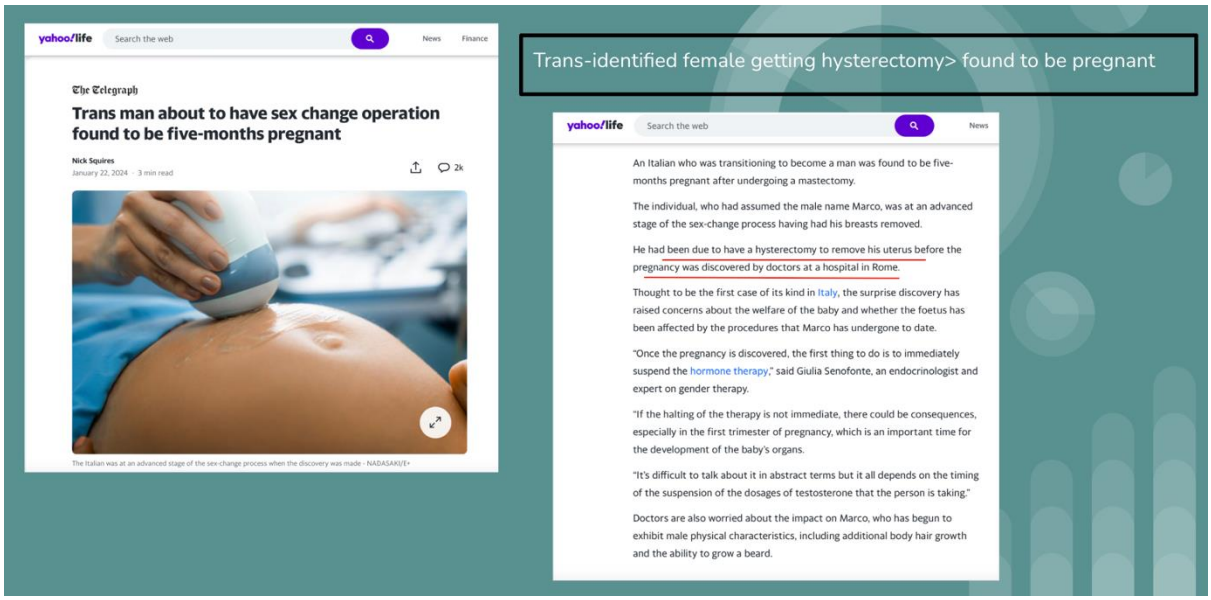
Here is an example from 2019 of a pregnant female who had a delayed diagnosis of preeclampsia because of her masculine appearance and confusing EHR documentation. She had a miscarriage.



The article highlights how the classification confusion leads to human error yet this philosophy places the burden on busy clinical staff and the promise of EHR changes. This is dangerous.



Medical errors are being reported due to medical record changes that no longer have a fixed field for biologic sex regardless of a patient's gender identity or appearance.

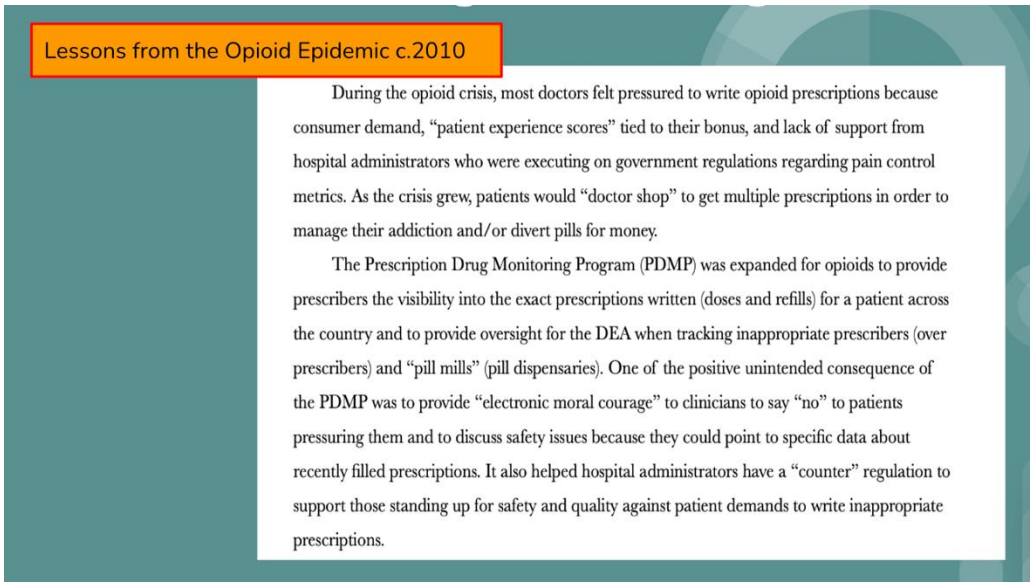


TAKEAWAYS

- Be aware of gender fields and lack of fixed field for biologic sex
- Safeguard against clinical errors by making sure all fields are consistent with biologic sex
- Write the CMO (Chief Medical Officer), Patient Experience Officer, Chief Technology Officer of hospital about your concerns with data fields

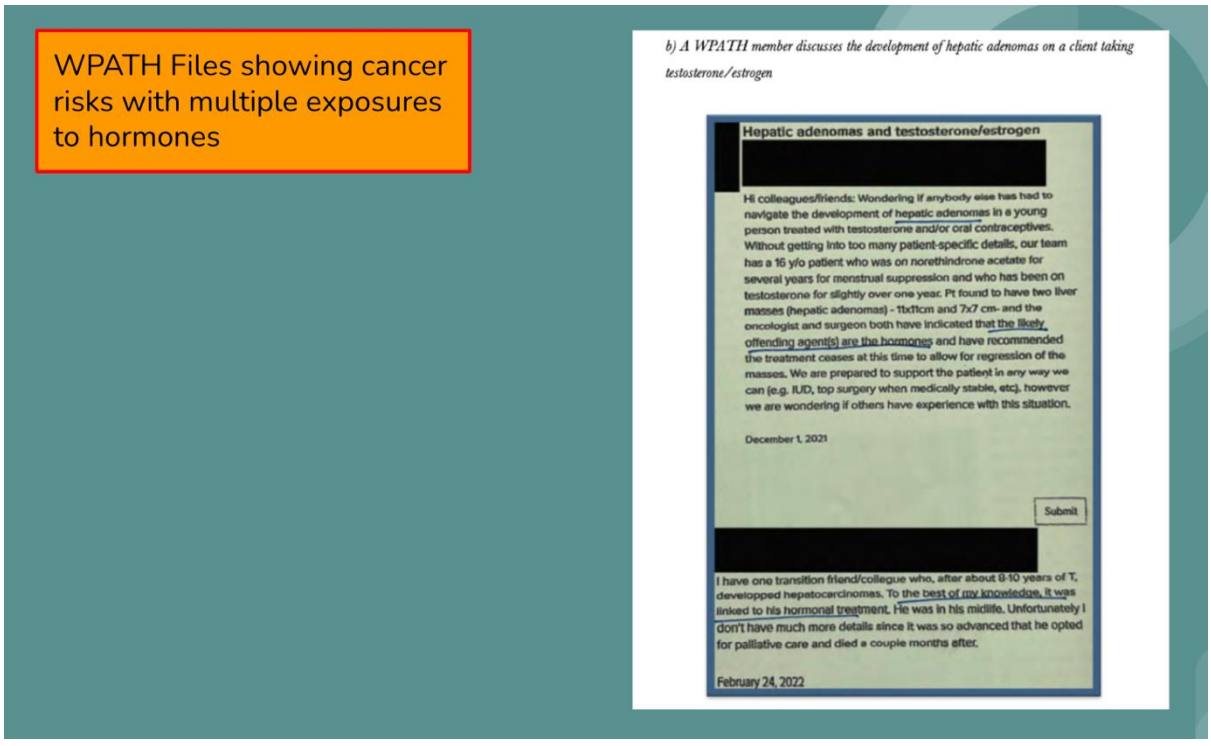
PRESCRIPTION DRUG MONITORING: IMPROVING SAFETY

The opioid crisis lead to the expansion of the Prescription Drug Monitoring System to track opioid prescriptions. This helped decrease the amount of prescriptions written, helped pharmacies stop filling inappropriate prescriptions, and highlighted cross reactivity between classes of medications.



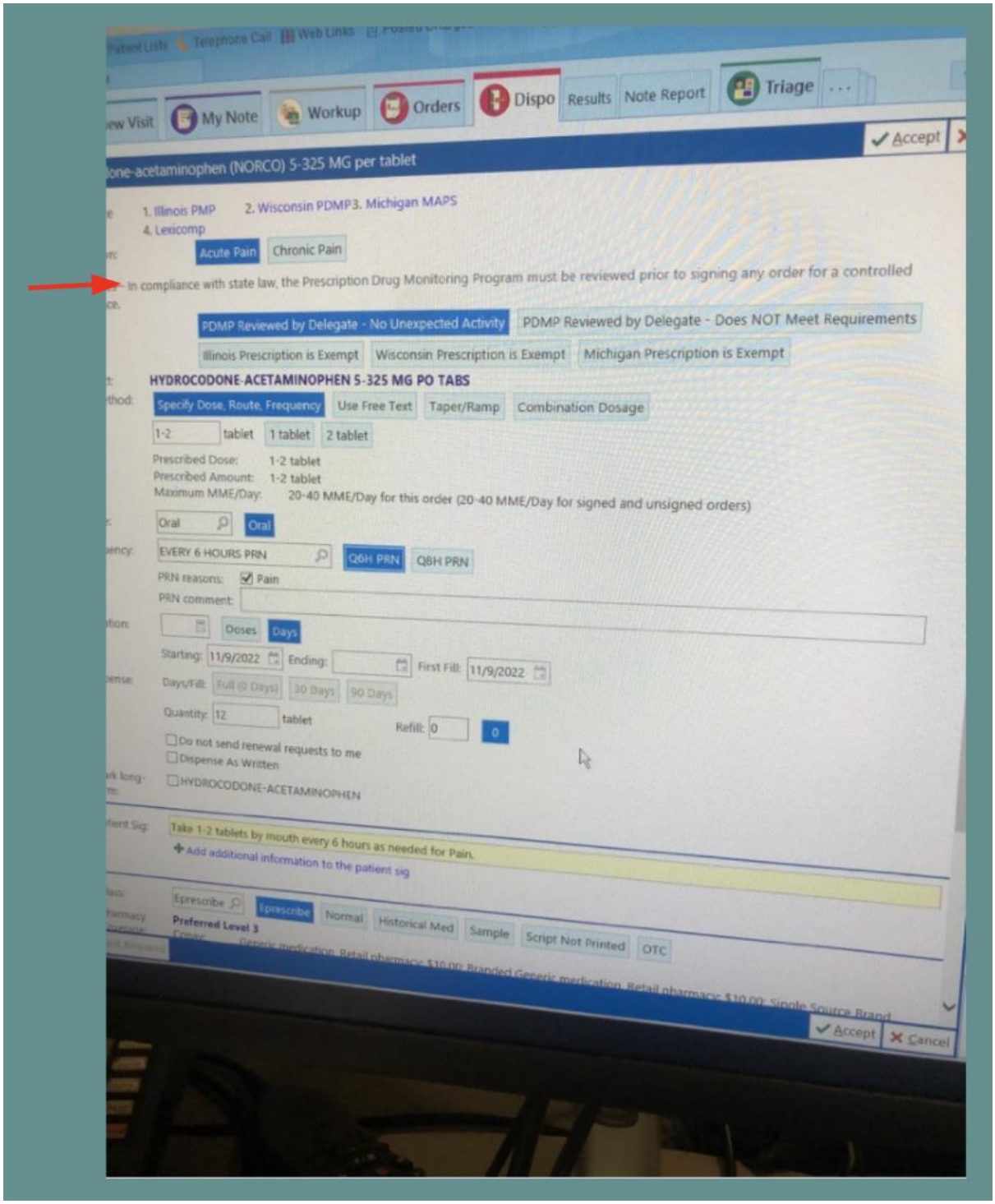
Hormone Risks Underappreciated

The WPATH Files highlight the danger of large scale hormone exposure to minors, such as possible carcinogenesis. The large amount of hormones written to minors on multiple medications and with variable dosing is a true medical emergency.



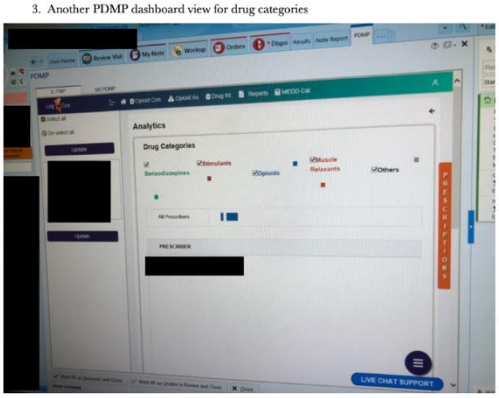
Monitoring System: How It Works

The Prescription Drug Monitoring system highlights classification of medications, doses, and adverse effects when a clinician is writing a prescription.

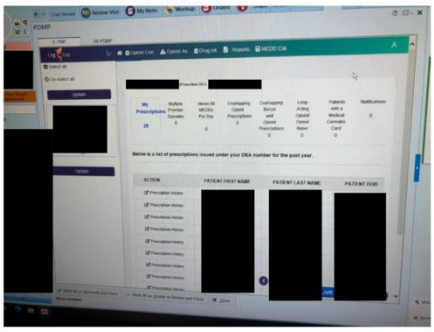


Drug categories are highlighted as well as prescription history.

3. Another PDMP dashboard view for drug categories

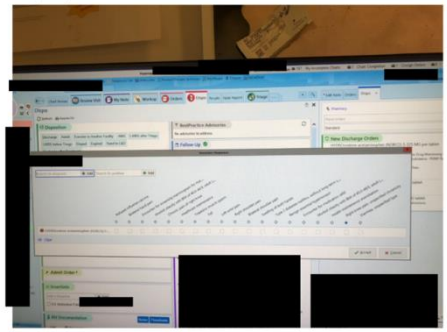


4. The PDMP dashboard for the prescriber



The prescription has to be matched to a diagnosis. Hormones for minors for gender related diagnoses could be added to the PMPD system to track doses, highlight potential adverse effects, and improve safety. Clinicians and parents of minors need to understand the safety issues.

5. After checking the PDMP, the prescriber finishes the prescription writing process in the EHR. The next screen asks the prescriber to select the diagnostic reason for the controlled substance prescription.



With this step, prescribers of exogenous hormones would be required to document their reason for prescribing the hormones (birth control, precocious puberty, menopause, gender dysphoria).

Adding hormones would help ensure dose monitoring dose and safety

PDMP changes are done at the state level and would require legislative changes

Patient and clinicians should be aware of underappreciated drug-drug interactions and confusion about changing gender designation

TAKEAWAYS

- Multiple hormone exposures not properly monitored, leading to overexposure that may be carcinogenic
- Drug-drug interactions and adverse effects underappreciated
- Ask your pharmacist detailed questions
- Adding hormone monitoring to PMPD portals is a commonsense state level policy to consider for future legislation