

Evaluation of the Role of the Informatician after Changes in the Legislative Landscape of Women's Reproductive Health

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Abstract: In the United States, on June 24, 2022, the Supreme Court removed constitutional rights for abortion in the *Dobbs v. Jackson Women's Health Organization* decision, which had been precedent for almost 50 years. Given these legal changes, how do health informaticists continue to use data and information to improve health and healthcare, when that data may, quite plausibly, diminish the quality of care for girls and women. This position paper discusses three strategies for health informaticians to improve health and healthcare in light of these recent legislation changes: 1) education and training of patients and stakeholders on limitations of HIPAA and on the importance of maintaining privacy and personal health information; 2) strengthening the protection of personal health information for women's reproductive care by re-categorizing it as 'sensitive' information, similar to behavioral and mental health data; and 3) clarify medical conditions by evaluating medical vocabularies and coding structures that accurately reflect the clinical realities of reproductive care.

1 INTRODUCTION

Legal and regulatory changes can create a necessity for alignment of the health informatics profession. In the United States, on June 24, 2022, the Supreme Court removed constitutional rights for abortion in the *Dobbs v. Jackson Women's Health Organization* (2022) decision, which had been precedent for almost 50 years. Given these legal changes, how do health informaticists adjust to do their job successfully? In response to the *Dobbs* legal decision, Arvisais-Anhalt, et al (2023) present a call to action among clinical informaticists (there are over 80 co-authors on Arvisais-Anhalt, et al) to "actively leverage our expertise, codify ethical and professional obligations in healthcare and support patient care." They identify 8 specific areas for health informaticists to address. (Arvisais-Anhalt, et al, 2023). The health informatics profession adjusts with these changes but stays aligned with its primary focus of "using data, information, and knowledge to improve health and the delivery of health care services" (AMIA, 2023). The data and information the health informaticist helps to collect, analyze and share may no longer meet the challenge of improving health and healthcare, but quite plausibly, it may diminish the quality of care for girls and women, and may, in some circumstances, be harmful.

2 BACKGROUND

These policy changes have significant implications for clinicians and patients (Huff, 2022; Simmons-Duffin, 2022). Amidst the impact to primary healthcare stakeholders, we need to consider the health informatics profession, and their role in facilitating the access, storage and sharing of health information to improve health and healthcare. Improving secured access and sharing health data with permissions has demonstrated benefits and frames many informatics initiatives in healthcare (Menachemi, et al, 2018; Kalkman, et al, 2019). The importance of sharing data has also been demonstrated through policy changes in the HITECH Act (2010) and 21st Century Cures Act (2016), as well as a recent federal rule to remove information blocking efforts (DHHS, 2023) (Khanna, et al 2023). This creates the context for the everyday work of a health informaticist.

Informaticists integrate health IT into their work, like the electronic health record (EHR) which is designed not to be used in a silo, but instead to be widely accessed by other approved health care stakeholders in the care team, across many locations. The need to protect personal health information has always been important, but potential health implications for women and girls from this legal

change reaffirm this need. Shared or viewable health information in the wrong place could cause harmful outcomes for patients. Khanna and colleagues (2023) identify areas of risk where reproductive health information may be compromised including: EHR, health information exchange (HIE), billing records, lab imaging and pathology records, medications, and server locations. Health informaticists need to evaluate each of these access points that might compromise a patient's personal health information around reproductive health care.

The health informatics profession has an opportunity to reframe a strategy on how best to use data, information, and knowledge to improve health and healthcare. Health informaticians need to work with their health care stakeholders among patients, administrative, clinical and technical teams to review processes for how and when to leverage health IT, access, store and share data in the context of women's reproductive care. For example, some applications may include:

- The EHR may not be needed in all circumstances or consider modification of documentation strategies during pregnancy (Khanna, et al, 2023).
- Always ask the patient if they permit the use of AI tools to listen during a patient encounter, instead of just allowing the clinician to take notes. Make it easy for the clinician to disable a listening/ note taking tool.
- For patients using a consumer mobile device to gather information related to reproduction (e.g. to monitor menstrual cycle), there should be consumer information and reminders to patients that this information may not be protected under HIPAA, and instead only the Federal Trade Commission (FTC) which does not have protections for personal health information.
- Patients can opt out of sharing data on an HIE and should be reminded of opportunities to share or not share their information.

These are just a few examples of the strategies and day to day processes of working with clinicians, patients, and health IT tools to maintain privacy of personal health information. Whether you agree or disagree with the legislation change, it has a ripple effect across health care professions and requires health informaticians to examine the impact on their profession.

2.1 Different State Laws

While the federal law change was immediate, state laws are emerging. Thus, there are 50 possible sets of

rules and regulations (Felix, et al, 2023), creating confusion for clinical care teams, informaticists and patients on how to seek, offer, communicate, and code reproductive care issues accurately, securely and in a way that provides the best health outcomes for patients. In 2023, many states have enacted laws, some providing reproductive freedom (California State Law, 2022) and others banning abortions outright, with consequences for family or friends who help someone seek an abortion and the health professionals who perform an abortion (SB8, Texas State Law, 2021; Felix, et al, 2023; Spitzer & Buchanan, 2022). Some laws result in felony charges and the loss of medical licenses to practice (SB8, Texas State Law, 2021). Because of the relative newness of the change in federal law, there continue to be court challenges and ballot measures to update and change state laws. It is likely these laws will continue to shift in the years to come. Because of the ambiguity of laws, the newness and immediate time frame, and a large divide on this political issue, there may be unintended consequences, having a broad impact on women's healthcare in general.

2.2 Potential Health Consequences

Both a decrease in the number of obstetrician and gynecologist (OB-GYN) physicians available and the standard of care maintained are at risk. The Kaiser Family Foundation funded a national survey of OB-GYN experiences after the federal law change, where researchers found that "...over a third of OBGYNs nationally (36%), and half practicing in states where abortion is banned (55%) or where there are gestational limits (47%), say their ability to practice within the standard of care has become worse." (Frederiksen, et al 2023). Recent data demonstrate that a growing number of OB-GYNs and maternal-fetal medicine specialists (MFMs) are likely to leave states with abortion bans (Tobin-Tyler, et al, 2023). These trends are also starting to be seen among medical student seniors who are applying for OB-GYN residencies. "The Association of American Medical Colleges (AAMC) found that states with near-total abortion bans saw a 10.5% decrease in OB-GYN applicants who were M.D. seniors this year." (Dreher & Gonzalez, 2023).

2.2.1 Miscarriage

While these legislative changes limit access to abortion, an unintended consequence is the impact on care for women experiencing a miscarriage. There is misleading and confusing language about the legality

and legal consequences of caring for women experiencing a miscarriage, or those seeking birth control or going through fertility treatments. Simmons-Duffin (2022) described the case of a woman and her husband traveling to Ohio for a family wedding, who then presented to an emergency room in Ohio with signs of a miscarriage, but was monitored and sent home stable, although in continued distress, indicating they would not be able to treat her. Simmons-Duffin (2022) outlined that because health care providers use the same clinical tools to manage a miscarriage as they do to perform an abortion, a pharmacist or doctor who suspects a patient is seeking an abortion might delay or deny care because of potential prosecution and revoking of a professional license. In another case, a group of women affected by these changing laws in Texas are suing their state for denying necessary and potentially life-saving obstetrical care because medical professionals throughout the state fear liability under Texas's abortion bans (Zurawski vs. State of Texas, March 6, 2023). While many state laws have exceptions for the life of the mother, there remains confusion over what constitutes an emergency. This Texas case seeks to clarify the extent of the state's "medical emergency" exception under its state abortion bans. (Zurawski vs. State of Texas, March 6, 2023).

There are ripple effects beyond the confines of the clinician's office between the doctor and patients. These changes also impact consumer healthcare through limitations on related medications (e.g. Misoprostol) for treating miscarriage that pharmacies can choose to sell to consumers or not (Kaiser Family Foundation, 2023; Pinatado, 2022); freedom to travel to other states for reproductive health care (Bendix, 2023); and the potential for community citizens to bring a civil case against people suspected of performing an abortion or helping someone in this effort (SB8 Texas State Law, 2021). These many legal changes for women's reproductive health in the United States, present challenges for the health informatics profession. How do we, as health informaticians, continue to use data and information to improve health and healthcare for both patients and their clinical care teams?

3 MITIGATION STRATEGIES

This position paper proposes three strategies for health informaticians to improve health and healthcare considering recent legislation changes. They include: 1) education and training of patients

and medical staff on the importance of maintaining privacy and personal health information in the context of new law changes in reproductive health; 2) strengthening the protection strengthen protection of personal health information for women's reproductive care by re-categorizing it as 'sensitive' information, similar to behavioral and mental health data; and 3) assessing standard medical terminologies and the potential risks associated with the interoperability they support.

3.1 Education and Training

The first strategy involves educating patients about the limitations of The Health Insurance Portability and Accountability Act (HIPAA) and the lack of protection of personal health information when using many consumer health apps. Moreover, it is important to have continued re-training among medical staff and informaticians related to the importance of maintaining privacy of personal health information in the context of women's reproductive health. To address this, it is important to review the HIPAA Privacy Rule, and revisit the ethical standards of the health informatics profession.

3.1.1 Personal Health Information

The Privacy Rule of HIPAA provides the first comprehensive federal protection for the privacy of health information. However, this does not mean that health data, including reproductive health care data, cannot be shared. The Privacy Rule created a national standard to protect individuals' medical records and other personal health information. While the rule gives patients more control over their health information and sets boundaries on the use and release of health records, it does not stop law enforcement functions from continuing. The Rule allows covered entities (e.g., health insurance companies, HMOs, etc.) to disclose protected health information (PHI) to law enforcement officials, without the individual's written authorization, under specific circumstances (e.g., to comply with a court-ordered warrant, subpoena, or summons). Shachar (2022) cuts to the chase by noting "HIPAA will not protect patients' privacy in the face of virtually any legal proceeding (civil or criminal), especially if warrants, discovery requests, subpoenas, and law enforcement are involved." Thus, patients need to expect that their health care records around reproductive health will be accessible through court order. Moreover, patients should be educated on the "very real risk that digital data mining could be used

to support abortion-related prosecutions and civil actions.” (Shachar, 2022). Thus, as Walker and colleagues (2022) note, “...strengthening privacy protections in HIPAA, such as limiting law enforcement’s access to sensitive data in health records, should be a key goal to minimize the trade-offs between protection and sharing incomplete records.” As patients are more engaged as consumers of health information, there is a growing use of health mobile apps for any number of health management issues, including monitoring of menstrual cycles for women. It is important to inform consumers that personal health information shared on these apps is not protected by HIPAA. While this notification may be issued in the “fine print” for some apps, it is worthwhile to examine the clarity of the information, to allow informed consumer choice.

3.2 Re-Categorize as Sensitive Information

The second strategy, also suggested for consideration by other informaticians (Walker, et al, 2022; Khanna, et al, 2023; Clayton, et al, 2023), involves strengthening existing mechanisms for protecting health information, by re-categorizing data and information about women’s reproductive health care as ‘sensitive’ information, and have it follow the precedent of protecting behavioral, addiction or mental health information. Health language sensitivity codes were developed based on the federal regulations outlined in 42 CFR Part 2 (Confidentiality of Substance Use Disorder Patient Records) in order to limit the use and disclosure of sensitive health information that may have unexpected or unanticipated negative consequences to a person’s wellbeing in terms of social and work life (Adams and Sutton, 2021). Using this strategy, health organizations would need to filter information around women’s reproductive health to follow workflow patterns of segmentation. Beyond the overall federal mandate (42 CFR Part 2) individual state mandates on how to treat segmented sensitive information can vary, so there will be inconsistencies.

Currently, there is no additional mandate in the state of Ohio to provide additional segmentation, and many provider offices (e.g., behavioral or mental health providers) choose to create separate electronic health records (EHR) for segmented information and could choose to obscure and protect the information in this way. However, this data may no longer be obscured when it is integrated into a wider health record in the health system. There is not one prescribed way to accomplish this, and it is applied

differently across all states. Although there were other health categories that used to be obscured (e.g. HIV status), these regulations have fallen away over time. Moreover, covered entities like payers or health insurance companies are able to see this data without it being obscured, following a typical workflow for health data. That is, when it is reviewed for payment or reimbursement, payers follow a typical workflow for protecting all personal health information, including sensitive information.

Often a patient’s data needs to be shared using a health information exchange (HIE). Each of the 50 states in the US has its own policy on opt-in vs. opt-out, vs. how to treat “sensitive information” (see State HIE Opt-In vs Opt-Out Policy Research_09-30-16_Final PDF at www.healthit.gov). At the state level, the HIE may receive segmented data with some data obscured, depending on the policies of the individual health systems sending the file. Walker and colleagues (2022) suggest that pregnancy status should be prohibited to disclose to HIE networks without explicit patient consent. This would be complicated as many elements of a pregnancy diagnosis can be viewed across the EHR (e.g. images, lab results, etc.). One extra protection for patients who want to maintain privacy, is actively choosing to “opt out” of sharing information in the HIE. On a practical level, many patients may have given permission to exchange information earlier in their health journey but may not realize that they can change their mind and opt out at any point. Efforts should be made to educate patients that they have the choice to opt-out of sharing health information on the HIE at any time. It does not mean that the data will not reside in the original file, but that it will not be shared with other sites without their permission. It is a communication point that is too often overlooked.

3.2.1 Unintended Consequences

This strategy of re-categorizing reproductive care as sensitive data may have potential unintended consequences. Throughout routine obstetric care of a pregnant person, it is crucial for the care team to have insight and information about the person’s health without being precluded from seeing pertinent information. For example, clinicians need to know about allergies, family history, diabetes or hypertension. Any barrier to this information that a ‘sensitive data’ classification may create could lead to complications at the point of care.

3.3 Clarify Standard Medical Terminologies

The third strategy is about adding clarity to describe someone's health condition using standard medical terminologies. It is important to have a critical assessment of standard medical terminologies, areas to improve clarity and the potential risks associated with the interoperability they support. The healthcare landscape comprising a spectrum of stakeholders – including clinicians, patients, medical and laboratory technicians, pharmacists, insurance providers, administrators, government agencies, and researchers – relies heavily on the constant and multifaceted exchange of data exchange. Clinical standard terminologies, such as the International Classification of Diseases (ICD), Current Procedural Terminology (CPT), Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT), and Logical Observation Identifiers Names and Codes (LOINC), RX Norm, and other classification schemes have been mandated for use in healthcare to represent complex medical conditions, ensuring standardization across various healthcare systems and contexts. These terminologies, as types of knowledge organization systems (KOS), are key in eliminating ambiguity, controlling synonyms, establishing hierarchical and associative relationships, representing the underlying semantic structure of medical domains (Zeng, 2008). Health KOS are categorized into administrative terminologies which support billing, reimbursement, classification and data aggregations, clinical terminologies developed for clinical data exchange and aggregation, reference terminologies which act as a reference point in health information systems and interface terminologies which ensure interoperability (Zeng et al, 2020).

The classification and nomenclature of women's reproductive health conditions within these schemes bear significant consequences. The way conditions are classified impacts insurance coverage, reimbursement, and treatment appropriateness. Misclassifications or vague definitions can hinder access to necessary treatment and lead to suboptimal care, and choice of terms can influence patient perception and societal attitudes, or willingness to seek care. Furthermore, the classification of conditions like abortion holds legal and ethical implications, particularly in regions with contested reproductive health services. Within clinical settings, practices such as categorizing abortions into elective and non-elective procedures e.g., spontaneous, septic, and induced abortions can carry stigma that influence quality of care and access to care (Smith et al, 2018).

In addition, terms like 'miscarriage' and 'ectopic pregnancy' are classified under specific codes in ICD-10. For example, the term 'spontaneous abortion' (003.0 in ICD-10) encompasses miscarriages due to various causes, ranging from infections to genetic abnormalities. Ectopic pregnancies are classified under 'pregnancy with abortive outcome' (000-008). Similarly, the Current Procedural Terminology (CPT) system, which standardizes medical procedures for billing, classifies abortions into various categories. These include missed abortions (59820, 59821), procedural abortions (59840, 59841, 58941-22), medical abortions (59850-59852, 59855-59857, S0199-,S0190, E/M code, E/M Code + 59414, Delivery Code), and both complete and incomplete spontaneous abortions, each with their respective codes (ACOG, 2023). However, these medical terms often diverge from everyday language, creating potential misunderstandings, especially under heightened legal scrutiny.

Given these complexities, the role of clinicians and informaticians becomes increasingly crucial. They must navigate the medico-legal landscape, ensuring that legal and social terms do not conflate with medical terminology. Informaticians have a role to play with maintaining clarity in documentation and coding, particularly for non-elective procedures, to prevent stigmatization and legal risks to patients seeking care, particularly in the wake of heightened legal scrutiny following changes to reproductive rights legislation. Although some states have established exceptions – such as not criminalizing care for procedures preventing substantial impairment to a major bodily function – the use of ambiguous language and conflicting regulations creates uncertainty among clinicians about which clinical conditions fall under these exceptions (Felix, et al, 2023; Goodwin et al. 2023).

Policymakers often seem to presume a universal understanding of the concept of abortion, yet there is a noticeable lack of alignment between legal and policy contexts and the medical community. Heuser et al (2023) illustrates this disparity by highlighting how routine medical procedures like labor induction or caesarean delivery could potentially fall under the legal definition of abortion – e.g. [Utah] the intentional or attempted termination of a human pregnancy through a medical procedure carried out by a physician or through a substance used under the direction of a physician – as defined by States. This legal definition can encompass both an abortion and procedures like induction of labor and underscores the importance of ensuring that critical nuances are captured, and that legal and social terms are not

conflated with medical terminology, nor enshrined in policies that stigmatize or negatively impact patient care.

Informaticians also need to consider the implications of standard terminologies in promoting data exchange and semantic interoperability in women's reproductive health. Semantic interoperability in healthcare refers to the ability of different information systems, applications, and devices to not only exchange data but also interpret and use this data effectively across various platforms and technologies. It involves using knowledge organization systems to ensure that health data retains its intended meaning consistently when shared among diverse stakeholders (de Mello, 2022; Arvantis, 2014). However, it also raises concerns about privacy and security, particularly considering legislation like the 21st Century CURES Act which mandates sharing and promoting the deployment of interfaces to support health information exchange networks run by a variety of entities such as electronic health record vendors, third party non-profits, or by the states themselves. The Cures Act uses the United States Core Data for Interoperability standard which includes pregnancy status as a shareable data element (Walker et al, 2022). Since HIPAA does not protect health information disclosures when court-ordered or subpoenaed despite recently released guidance for reproductive health, this data may still be at risk as these entities are not required to but are permitted to disclose (Shachar, 2022).

Electronic Health Records (EHRs) and patient portals further complicate this landscape by expanding access to health data, including to third-party applications, thereby necessitating stringent measures to protect sensitive patient information (Charles, 2023; Carter et al., 2023). An example of this is the use of integrated pharmacy information systems, which, by feeding medication information into the EHR, could inadvertently and inaccurately indicate procedures like abortion or suggest potential harm to a fetus. Additionally, the growing reliance on cloud infrastructure presents another layer of complexity. Data stored on servers in restrictive states could potentially expose patients to legal risks if those states opt to access data within their jurisdiction (Khanna et al., 2023). This situation is further aggravated by the increasing interconnectedness of health systems. One specific scenario involves services provided in non-restricted states potentially becoming a part of the legal medical record in a state with restrictive laws. If a provider either documents out-of-state care or incorporates diagnosis codes for elective procedures into the record, it could lead to

legal complications (Khanna et al., 2023; Zubrzycki, 2022). Such scenarios highlight the growing need for careful and considered approaches to managing health data across different legal jurisdictions.

In addressing these challenges, informaticians have a critical role to play in leveraging data and information to enhance health and healthcare. One key area of focus is the review and update of medical terminology standards. By aligning these with current legal standards and societal understanding, informaticians may be able to bridge the gap between medical practice and legal considerations. They should consider whether alignment or allowances in terminology could make any tangible differences. Another critical area is the development and implementation of stringent data privacy protocols. This is especially important for sensitive health data stored in cloud infrastructures or shared through integrated systems. Furthermore, informaticians should perhaps take the opportunity to educate stakeholders about the disagreement between terms used in new reproductive health policies and laws and the subtleties of medical terminologies and the resulting implications. Advocating for standardized terminologies that are consistent across states and institutions might be an option for mitigating legal and ethical conflicts. Finally continual monitoring of legislative changes and their impact on health information is vital. Informaticians can contribute to shaping best practices and informing policy decisions as it relates to proactively addressing challenges at the intersection of medical terminology, legal considerations, and patient care.

4 CONCLUSIONS

This position paper addresses the need to re-examine the role of the health informaticist in the context of changing laws around women's reproductive care. We discuss three informatics-based strategies for improving health and health care, affecting the individual patient and the clinical provider. Some of these strategies align with other research groups, lending to the potential for creating a solution. However, all these strategies need to be evaluated for advantages and disadvantages for patient health outcomes. Specific initiatives will need evaluation with considerations of strengths and unintended consequences of implementing the approach. First, it is important to educate patients about the importance and methods of protecting personal health information in general, limitations of HIPAA, policies around sharing information in a HIE, and

risks of sharing health information in consumer-based health apps and mobile devices. Second, it may be helpful to reclassify reproductive health care as “sensitive information,” providing additional protection of personal health information and heightened scrutiny of data sharing among healthcare stakeholders. Third, emphasize the need to clarify health conditions using medical vocabularies and coding structures that accurately reflect the clinical realities of reproductive care. This entails a systematic approach to enhancing the representation, categorization, and utilization of medical terms and concepts related to women’s health. Consideration should also be given to the risks of semantic interoperability, particularly in how data is shared and interpreted across diverse healthcare systems. It is important to prevent misinterpretations or inappropriate usage of sensitive health information when handling data that is impacted by varying regional and national legal frameworks.

While changes to federal laws may have an immediate effect, implications for professional roles, organizations, workflow, and interpersonal communication are dynamic and evolve over time. Therefore, a continuous review and revision of professional roles in health care, including health informaticists, is necessary to consider changes and how they impact clinical care. It is important to reassess and refine strategies for using data, and information to support improvement in health and healthcare, in a landscape marked by rapid change and complex challenges.

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