VIEWPOINT

Interoperability in a Post-*Roe* Era
Sustaining Progress While Protecting Reproductive Health Information

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The Supreme Court recently eliminated the constitutional protection that *Roe v Wade* provided for abortion access in 1973. Many states already have restricted or are poised to restrict access to abortions and are ready to prosecute individuals who provide or attempt to provide these procedures. It is possible that some states will expand these restrictions to in vitro fertilization and access to contraceptives.[1]

These changes are emerging while health policy continues to progress toward timely and secure access, integration, and use of electronic health information to optimize health outcomes for individuals and populations, often referred to as *interoperability*. With interoperability, health systems are able to share patient health information and use that information once it is received. Current guidance under the Health Information Technology for Economic and Clinical Health Act (HITECH) and then through the 21st Century Cures Act now must consider how to adapt to the new limits on reproductive rights; specifically, how to ensure privacy protections for patients while still ensuring data sharing to support care coordination, patient engagement, and population health.[2]

> [S]trengthening 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 of complete records.

This Viewpoint focuses on health information exchange (HIE) networks. These networks are critical to sustaining progress toward robust interoperability but simultaneously are targets in the post-*Roe* era because they can furnish more complete patient records. A technology solution is proposed that could be developed to better safeguard reproductive health information as HIE networks continue to expand interoperability support.

Current Interoperability Policies and the Role of HIE Networks

The Cures Act mandates that health care organizations and payers make certain patient record data elements available for sharing, defines exceptions for data access (information blocking), and promotes application programming interfaces to technically ease HIE. Collectively, these policy efforts increase the number of health care organizations and payers engaging in HIE and specifically facilitate connecting to 1 or more HIE networks.[3] HIE networks are heterogeneous; some are operated by electronic health record vendors (eg, Epic's Care Everywhere, eClinicalWorks' Electronic Health eXchange, Cerner's Clinical Exchange Platform), others are operated by third-party nonprofit organizations, and yet others are operated by states. They can facilitate exchange between different subsets of health care stakeholders, such as ambulatory practices, pharmacies, laboratories, and public health departments. Two recent national surveys, one of 10 302 office-based physicians (with 1524 respondents) and another of all acute-care hospitals (with 2614 of 4352 responding), reported that 65%[4] of office-based physicians and 69%[5] of acute care hospitals participate in at least 1 of the approximately 90 HIE networks across the US.[6] Within the Cures Act, a key policy vehicle to expand the breadth of data available for exchange via HIE networks and other exchange approaches is the United States Core Data for Interoperability standards. The Office of the National Coordinator for Health Information Technology (ONC) recently included pregnancy status as a data element in version 3 of these standards, which will result in HIE networks' having substantially more complete data on pregnancy status.

Post-*Roe* Interoperability Challenges for HIE Networks

Because HIEs are entities that facilitate information sharing and therefore have access to more complete patient records (including the names of clinicians who delivered care), law enforcement could pursue HIE network records for information on reproductive health services. HIE networks are covered entities under the HIPAA (Health Insurance Portability and Accountability Act) Privacy Rule. However, the HIPAA Privacy Rule does not protect health information from disclosure to law enforcement authorities who have court orders, court-ordered warrants, or subpoenas. With enhanced interoperability, law enforcement authorities may not need to identify and query a particular facility or clinician and instead could submit broad requests to HIE networks. The Department of Health and Human Services recently released guidance on the HIPAA Privacy Rule and disclosure of reproductive health information.[7] The guidance addressed disclosures that are required by law or made by law enforcement authorities and emphasized that disclosures that exceed or are inconsistent with legal requirements are not permissible. However, the guidance does not change the fact that HIEs would have to disclose reproductive health information to law enforcement authorities that have used proper legal processes such as subpoenas.

New state abortion bans have thus far focused on clinicians rather than individuals who seek or obtain abortions. If this approach were to change, the more comprehensive records included in HIE networks could facilitate investigation and prosecution of individuals who obtained abortion services. Furthermore, HIE networks enable data access across state borders and could be used by law enforcement authorities to identify individuals who cross state lines to obtain legal abortion care if states were to prohibit interstate travel.

A Potential Solution

In the post-*Roe* era it is vital to better safeguard reproductive health data in the context of HIE networks. To that end, a promising policy option to promote greater confidentiality protection of reproductive information is to prohibit its disclosure to HIE networks without explicit patient consent. This restriction could be accomplished through a modification to the HIPAA Privacy Rule or the Cures Act. A model for this approach is Pennsylvania's Confidentiality of HIV-Related Information Act, which prohibits disclosure of HIV status without consent except in limited, specified circumstances. Likewise, the Substance Abuse Confidentiality Regulations prohibit disclosure of information about an individual's drug or alcohol treatment without consent (unless an exception applies). Implementing distinct consent for reproductive health information is likely more difficult than for information regarding HIV and substance abuse, given that reproductive health information is found in many places within the patient's medical record (eg, laboratory results, clinical notes, procedure reports) and across different settings (eg, primary care, specialists, hospitals).

As part of such a change to HIPAA or pursued separately (under other policy vehicles or by HIE networks), technology can help facilitate protection of sensitive portions of the medical record. The Data Segmentation for Privacy (DS4P) standards enable health care organizations to parse parts of a patient's medical record for which additional consent is required before data sharing. These standards were released by ONC in 2017. In theory, DS4P allows patients to select data from predefined categories (eg, sexuality, reproductive health) that will remain inaccessible if records are shared through HIE networks.[8] Other clinicians would be aware that the patient's record is incomplete but would not know the excluded category of data. Today, adoption of DS4P standards is voluntary and remains low, and their testing suggests low accuracy and the need for additional validation.

Implementing the data exclusion solution requires addressing at least 4 complex issues. First, data exclusion will clearly hinder the creation of comprehensive patient records, which could result in patient safety risks. Second, unlike substance abuse services, reproductive health services are often provided in the same settings as other primary and acute care and thus could be inferred or directly reflected in many parts of the record. For instance, pregnancy testing is recommended for teratogenic medications (eg, antibiotics, statins, anxiolytics, anticonvulsants, isotretinoin) commonly prescribed by primary and specialty care clinicians.[9,10] The scope of data to be partitioned is not obvious and would need to be clearly defined. For example, should data regarding care for an individual who experienced a miscarriage (eg, dilation and curettage) be segmented?

Third, important questions remain about segmented data, such as what requirements should exist to bypass technical safeguards and access segmented data and whether these data can or should be available for clinical decision support algorithms. Fourth, no national standards for consent for data sharing in HIE networks exist, resulting in a patchwork of complicated state- and network-specific policies. Particularly problematic are the questions of how patients can revoke consent for data sharing once their records are shared with an HIE network and how to technically "pull back" data that have already been shared (potentially across multiple networks).

Conclusions

Given the urgency of protecting reproductive health information, close coordination with policy makers around further development of data segmentation standards is warranted as a near-term solution. However, the DS4P-associated challenges create uncertainty about how health care organizations may respond (eg, withdrawing from HIE network participation) and could detract from HIE progress. Thus, in the longer term, 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 of complete records. Achieving this balance would have benefits beyond reproductive health and could solve current challenges related to substance abuse data segmentation and future sensitive data related to potential bans on gender-affirming care and other matters of bodily autonomy.

ARTICLE INFORMATION

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