New U.S. Law Mandates Access to Clinical Notes: Implications for Patients and Clinicians

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On 2 November 2020, new federal rules will implement the bipartisan 21st Century Cures Act that, in part, ". . . promotes patient access to their electronic health information, supports provider needs, advances innovation, and addresses industry-wide information blocking practices" (1). The rules forbid health care organizations, information technology vendors, and others from restricting patients' access to their electronic health care data, or "information blocking" (Table). Although the Health Insurance Portability and Accountability Act gave patients the legal right to review their medical records, the new ruling goes further by giving them the right to access their electronic health records rapidly and conveniently via secure online portals. Providers must share not only test results, medication lists, and referral information but also the notes written by clinicians. Over the past decade, this practice innovation—known as "open notes"—has spread widely, and today more than 50 million patients in the United States are offered access to their clinical notes. As the rest of U.S. clinicians prepare for change, we ask: What has been learned about this practice, and what remains uncharted territory?

A growing body of data suggests that many patients highly value accessing the notes written by their physicians and other clinicians. We recently published findings from large internet surveys with patients and practitioners from 3 diverse health systems. More than 22 000 patients (response rate, 22%) who accessed open notes for as many as 7 years reported on their experiences with clinicians in virtually all specialties (2). Two thirds reported that reading their clinicians' notes was very important for taking care of their health and for remembering their care plans, and 64% reported better understanding why a medication was prescribed, with 14% indicating that reading their notes made them more likely to take their medications (2, 3).

In addition, more than one third of the respondents reported showing their notes to others. Older and chronically ill patients, in particular, expressed desire to share access with their care partners. Participants also reported that reading their clinical notes strengthens collaboration and teamwork with their doctors. These benefits appear to be reported most often by patients who are older, are less educated, are a person of color or Hispanic, or do not speak English at home (2). Open notes may function as a novel workaround that helps address poor recall among all populations and which may be exacerbated by stereotype threat among disadvantaged populations and enhances understanding among those with limited language proficiency (4).

Table. New Federal Rules Mandating Open Notes

What notes must be made available electronically to patients?	
Consultation notes	Laboratory report narratives
Discharge and summary notes	Pathology report narratives
History and physical	Procedure notes
Imaging narratives	Progress notes
Clinical notes that are exempt from mandate:	
Psychotherapy notes	
Information compiled in anticipation of or for use in civil, criminal, or administrative actions or proceedings	
Exceptions to the rules:	
The ruling does permit information blocking in exceptional situations. For example, physicians can withhold information if doing so ". . . will substantially reduce the risk of harm" to a patient or to another person (§ 171.201(a) p. 704). Permitted exceptions include domestic abuse situations where a patient or a named party might be at increased risk for harm as a result of a disclosure in the notes.	
When will the rules go into effect?	
2 November 2020: Clinical notes must be shared by health systems.	
Late fall 2022: Clinical notes must be shared with a patient's third-party application (e.g., downloadable via smartphone).	

Clinicians worry that patient access to notes may increase anxiety, but only 3% of patients surveyed reported feeling very confused, and 5% felt more worried about what they read. Overall, 98% of patients considered web-based access a good idea, and almost 2 in 3 described the practice as extremely important for choosing future clinicians (2). Response biases in internet survey data, however, do leave some uncertainty.

Although initially hesitant, the majority of the 1628 clinicians (response rate, 27%) surveyed after at least 1 year of experience with open notes in the same 3 health systems were positive about the practice (5). Most (71%) considered the innovation a good idea, with a similar proportion of advanced practice nurses and physician assistants agreeing it is useful for engaging patients in their care. Most clinicians (84%) reported that patients never contacted them with questions about their notes or did so less than once a month. However, one third reported spending more time writing their notes and being more mindful of the language they use. Primary care physicians in particular described adjusting their language to avoid being perceived as critical of patients; omitting certain terms, such as "noncompliant" and "patient denies"; and modifying how they document sensitive information.

Changes in documentation aimed at appeasing patients may interfere with reliable clinician communication or prompt the use of coded language, and 22% of clinicians believed their notes were less valuable as a result of open notes. In addition, a long-standing purpose of clinical recordkeeping is to serve as an aide-mémoire for diagnostic thinking, and in a survey, almost a quarter of clinicians reported changing how

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they listed differential diagnoses (5). Whether such changes influence diagnostic thinking is not yet understood. On the other hand, access to clinical notes may improve patient safety. Medical records inevitably contain human errors, and patients and their caregivers can, and do, identify nontrivial inaccuracies, omissions, and oversights in their records. In response to the survey, 1 in 5 patients reported having ever found an error, and 42% of them perceived it to be "serious" (6).

Education in how to write more empathic and patient-friendly notes, while also preserving the detail necessary for clinical decision making, will be important and may help mitigate potential workplace burdens related to open notes (7). Today, disease-specific questionnaires and physiologic data can be uploaded into the electronic medical record by patients, and pilot studies are examining the feasibility of having patients contribute to the clinical notes themselves (8). Ideally, the notes should be much more than repositories of information, or even transcripts of an encounter. They should outline both the patient's story and the clinician's impressions, while reflecting the unique individual's values and preferences (7, 9).

As a result of the dramatic increase in telemedicine visits due to coronavirus disease 2019, patient access to notes may be especially important for conveying information effectively (10). However, already disadvantaged patients, such as those with no broadband access, limited digital skills, or low literacy levels, risk being left behind. To improve diversity in patient engagement, health systems should make portals available in multiple languages and encourage connections with family members and other health care proxies dedicated to supporting disadvantaged patients. Patient-informed design will be imperative to ensure that different patient populations can understand content readily (4).

Offering online access to clinical notes will now be mandatory. In the era of fully transparent health care, it will be the patients' prerogative—and not practitioners'—about when, where, or whether to read their personal health information. As U.S. health care prepares for a new era of openness, the upcoming rules may help better mobilize its most underused resources: patients and their care partners. And with more transparent communication, clinicians too may find themselves empowered.

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