

4 reasons physicians should share their notes with patients

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Legally, patients have had a right to see their medical records since the adoption of HIPAA in 1996. Practically, most patients have only had electronic access to all their information—including their physicians' notes—since a new federal rule took effect in April.

The information-blocking rule brings health care into the modern era in terms of data and interoperability, said Catherine DesRoches, DrPH, during a recent AMA STEPS Forward™ webinar on best practices for sharing clinical notes with patients.

“It will create health care data that is searchable and indexable so that when patients want something in their record, they don't have to get the PDF of everything in their record like they used to,” she said.

DesRoches is associate professor of medicine at Harvard Medical School and executive director of OpenNotes, a Beth Israel Deaconess Medical Center-based organization that promotes transparent communication in health care. Prior to April, there were 260 health organizations were sharing notes with more than 55 million patients.

The information-blocking rule is an outgrowth of the 21st Century Cures Act. While the law mandates that physician notes be available to patients upon request, there is no law compelling patients to read them. That's why DesRoches argues that physicians and health organizations should actively encourage patients to read their notes. She outlined four reasons to engage patients in their own care through the physician note.

Reducing the “big amnesia”

Regardless of educational attainment, research shows patients only retain about half of what is said in a clinical visit. “As the stress of that visit increases, the amount that they remember decreases,” DesRoches said. “And a fairly significant proportion of what they think they remember is actually

wrong.”

Improving understanding and adherence

When patients read their notes and understand why a medication is prescribed, they are more likely to take that medication as prescribed, DesRoches said.

Increasing trust

“Even when patients don’t read their notes, just knowing that the note is available, increases their trust in their provider and in the organization where they’re getting the care,” DesRoches said.

Improving safety

Research has shown that patients are not only good at finding mistakes in their record, they can discern between typographical errors that don’t matter and issues that need to be resolved right away.

“No one, I would argue, cares more about making sure the information in their record is correct than a patient,” DesRoches said.

When OpenNotes was launched in 2009, participating health care organizations initially were concerned that they would be inundated with phone calls and messages from confused or upset patients, but that did not come to pass.

“They found it had very little effect on their workflow,” DesRoches said.

According to a 2017 follow-up survey, 20% of patients detected errors that could have affected the safety and diagnostic accuracy of their care. About one-quarter of physicians reported that there was a time when a patient found an error that could be considered “clinically important.”

Don’t be an information blocker

“Information blocking” is defined as any activity designed to interfere with access, exchange, or use of electronic health information. The new federal rule defines the failure to share these eight types of notes with patients as a form of information blocking:

- | Consultation notes.
- | Discharge summary notes.
- | History and physical.
- | Imaging narratives.
- | Laboratory report narratives.
- | Pathology report narratives.
- | Procedure notes.
- | Progress notes.

There are a few exceptions to the rule. Psychotherapy notes and “information compiled in reasonable anticipation of, or use in a civil, criminal or administrative action or proceeding,” are exempted. Other exceptions include concerns with patient privacy or harm.

Yet, a striking difference between OpenNotes and information-blocking regulations is that, under OpenNotes, physicians ultimately can—based on their professional judgement—withhold notes or lab results if they feel it’s in the best interest of the patient. The new regulations are more restrictive. The AMA is advocating for more flexibility—particularly around information that may cause mental or emotional distress for the patient or caregiver.

To help ensure compliance and to incorporate the regulations into practice, an AMA continuing medical education module explains what physicians need to know about these rules going forward.

The CME module, “Information Blocking Regulations: What to know and how to comply,” is accessible through the AMA Ed Hub™ online learning platform. It builds on two essential resources made available by the AMA last year.