



Online Access to Medical Records Helps Engage Patients, Improve Outcomes

Synopsis

The OpenNotes program was launched in 2010 to give patients real-time, unfettered access to their medical records. Early evaluations were positive, both from patients' and providers' perspectives. This study, conducted five years later, found the program helps to deepen trust between primary care providers and patients while increasing patients' understanding of their health and improving their ability to take care of themselves. Concerns about privacy appear to be relatively minor. The program is now being extended to specialists, mental health providers, and physical therapists.

The Issue

Historically, patients have had little or no access to their own medical records. Technical issues and security and privacy concerns have been roadblocks, as has providers' apprehension that such information might "scare" patients. Launched in 2010 in Boston, rural Pennsylvania, and Seattle, the rapidly expanding OpenNotes movement is allowing more and more patients real-time, online access to their clinical notes. Findings after one year were striking: four of five patients had read their notes, and two-thirds reported clinically important benefits, like improved understanding of their medical condition. And, despite some initial resistance, all participating physicians agreed to continue with the program.

Since then, OpenNotes has been replicated in other settings with similar success. Writing in *BMJ Open*, former Commonwealth Fund Harkness Fellow Tobias Esch and colleagues at Harvard University reported on their study of the original adopters of OpenNotes five years later. Focusing on patients with chronic illness, the authors used survey data and face-to-face interviews to examine the relationship between using fully transparent electronic medical records and quality. They looked specifically at the doctor-patient relationship, patient engagement, self-care, self-management skills, and clinical outcomes.

Key Findings

- Many patients reported that having access to their clinical notes helped enhance trust in their doctors and in the care they were receiving. One study participant commented, "I think it's important to know that I'm trusted as part of this relationship. And it helps me trust the doctor as well."
- Nearly all interviewed patients reported that reading their notes led them to correct their therapeutic regimen in some way, typically by correcting wrong dosages or the timing of medication. "I discovered that

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Patients pointed to increased trust, improved management of medications, and a stronger sense of control, and they hoped that easy access to doctors' notes would become more widespread.

the doctor [had] misunderstood something I said,” one participant said. Another noted that having access to their record “sometimes clarifies my need and use of medications.”

- Study participants reported an increased sense of control and reduced feelings of helplessness. They also felt encouraged to take care of themselves and ask questions. As one individual said, “It made me feel...proactive...and not just reacting.”
- While the majority of study participants read and reviewed notes on their own, some also shared the contents with family members or other physicians. Some said they might actively withhold information because of the possibility that other people might read their notes, especially information about spouses or family. While some participants desired an option to approve notes, few were interested in coauthoring notes with their providers.

The Big Picture

The OpenNotes movement is spreading to health care organizations across the country and has extended beyond primary care physicians to include medical and surgical specialists, mental health providers, and physical therapists. “As the use of fully open and transparent medical records spreads, it is important to gain a deeper understanding of the possible benefits or harms, and to characterize target populations that may require varying modes of delivery,” the authors conclude.

About the Study

Researchers analyzed survey data from several thousand patients in the Boston area who had participated in a pilot OpenNotes program. They focused on about 500 “heavy users,” defined as patients who had viewed at least seven notes in the past year. Researchers also conducted interviews with a subset of heavy users.

The Bottom Line

The evidence thus far indicates that giving patients immediate, unfettered electronic access to their medical records has the potential to improve care and possibly outcomes as well.

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This summary was prepared by Brian Schilling.