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SHARING VISIT NOTES: GETTING PATIENTS AND PHYSICIANS ON THE SAME PAGE

Inviting patients to review your visit notes is a promising change in practice. Here's how to get started.

Health care benefits from productive patient engagement, and patient engagement benefits from fully transparent health care. However, patients have long lacked ready access to their health information. Twenty years ago, HIPAA granted virtually all patients the right to review their medical records, but logistical barriers keep most patients from regularly doing so.¹⁻²

With the widespread adoption of electronic health records (EHRs) and the advent of secure patient portals, patients are now increasingly able to exchange emails with their physicians and review laboratory and radiographic results and medication lists online. But visit notes, which tell the patient's story and weave together disparate issues, have remained largely hidden from patients.

OpenNotes is a national initiative whereby physicians invite patients to review their visit notes. It is not a product or service for sale; it is a movement to allow patients greater access to their health information. In what follows, we outline early experiences, explain how to implement shared

notes, point out challenges and unanswered questions, and attempt to demonstrate that this practice holds considerable potential for improving the value and safety of care.

Early experiences

The initial OpenNotes demonstration and evaluation effort in 2010 involved 20,000 patients and more than 100 primary care physicians at three diverse institutions: Beth Israel Deaconess Medical Center in Boston, Geisinger Health System in rural Pennsylvania, and Harborview Medical Center in inner-city Seattle. The findings after a year of intervention were striking. (See "What the research shows," page 12.) Eight of 10 patients chose to read at least one of their visit notes, and three of four reported clinically important benefits, including recalling visit details more completely, understanding their medical conditions better, taking better care of themselves, and feeling more in control of their care.³ Few patients were confused, frightened, or offended after reading their

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notes, and many shared their notes with family members and caregivers. Whether or not they chose to read their notes, 99 percent of patients wanted the practice to continue after the year-long study, and almost 90 percent reported that the availability of shared notes would affect their future choice of a practice or clinician.³

Clinicians reported that patients who received shared notes seemed to feel more in control of their care, coming to their visits better prepared and asking well-informed questions. Moreover, shared notes enhanced trust and the doctor-patient relationship. More than one third of patients who read at least one note during the OpenNotes trial reported feeling better about their doctor, and shared visit notes had overall positive effects on physician perceptions of patient trust and satisfaction.⁴

Clinicians also reported that shared notes reinforced their discussions in the office, helping patients remember next steps and adhere to treatment plans. A separate study reinforced this, finding that patients who viewed shared notes are more likely to refill their blood pressure medication than those without access to their visit notes.⁵

Shared notes also benefitted patient safety and quality of care by offering patients and caregivers opportunities to correct errors or clarify misunderstandings. Among the 7 percent of patients in the OpenNotes trial who reported contacting their doctor's office about their note, about one third found an error in their note, and 85 percent of these patients were satisfied with the resolution.⁴ In addition, caregivers expressed that shared access to visit notes helped them to participate more actively in patient care, including interpreting health information, advocating for quality care, and managing the patient's health behaviors and medical care.⁶

Contrary to primary care physicians' expectations prior

to the study, the process of sharing visit notes required little change in their workflow. Eight percent reported taking more time to address patients' questions outside of visits, and 21 percent reported taking more time to write notes.

Although roughly a quarter of the doctors who participated said they would prefer not to continue the practice at the end of the voluntary year-long intervention, each decided to continue. Today, each of the three sites is deploying shared notes widely in their primary care and specialty practices, about 10 million Americans are being invited to review their visit notes, and we know of fewer than 10 doctors who have discontinued the practice.

How to implement shared notes

Although sharing visit notes is a radical change in practice, it can be relatively easy to adopt. Physicians should consider the following issues.

Documentation. Most providers participating in the OpenNotes pilot project reported they did not need to change the way they wrote their notes. However, a minority of doctors reported modifying the way they documented potentially sensitive topics, such as mental health, obesity, substance abuse, sexual history, or elder, child, or spousal abuse. We recommend physicians take simple steps to improve their notes such as avoiding patient labels (e.g., "non-compliant"), medical jargon, and confusing abbreviations. (See "Tips for writing transparent notes," page 13.)

The practice of sharing notes may gradually influence some of the language, tone, and terms clinicians use in documenting patient care,⁷ but this could be a positive development as medicine becomes more collaborative. ►

EIGHT OF 10 PATIENTS CHOSE TO READ AT LEAST ONE OF THEIR VISIT NOTES, AND THREE OF FOUR REPORTED CLINICALLY IMPORTANT BENEFITS.

■ In a study of patients' experiences with shared notes, 99 percent of patients said they wanted the practice to continue.

■ Sharing visit notes requires little change in a physician's workflow.

Technology. OpenNotes is *not* a software program or technology product. It is simply an initiative to encourage physicians to share their notes. It does not depend on health information technology. For example, physicians can share their visit notes manually by printing a copy and handing it to the patient at the end of the visit, although EHRs and patient portals facilitate the practice markedly. Not all EHR vendors offer patient portals, and among those that do, clinical notes have generally remained hidden by default, although we do know of one major vendor that is now offering full transparency by default on their new installations. As the call for full transparency spreads, we expect more vendors to follow suit.

Early OpenNotes implementers have learned the importance of setting up automatic electronic alerts to notify patients via email that a new note is available for viewing in the patient portal. Patients are much more likely to look at visit notes when reminded electronically. In the year following the OpenNotes trial, one institution discontinued electronic alerts, while another institution

continued to use them. Patients who received reminders continued to view their notes consistently, while the reading rates at the site without reminders dropped nearly 50 percent.⁸

Implementation. As more institutions begin to offer shared notes, we are seeing many different approaches to implementation. Some institutions and health care systems begin by making clinical notes open throughout all practices, while others begin with pilot programs in a few departments. Some institutions allow clinicians to opt in, but most take an opt-out approach, making shared notes the default. Nearly all institutions allow clinicians to “hide” selected notes from patients, and patients are usually not offered access to notes written before the adoption of shared notes. Regardless of how a group chooses to implement shared notes, the change should be communicated in a timely and clear way to clinicians, staff, and patients so that everyone feels prepared. This may include compiling a set of frequently asked questions and answers that address common concerns among clinicians, equipping staff with materials that describe the change for patients, and sharing the research with clinicians and staff to show that shared notes benefit patients with minimal impact on clinician work life. (For more information and resources for getting started, visit <http://www.opennotes.org/toolkit>.)

Physician buy-in. Practice change is difficult and often requires a vocal “champion” – a respected leader with strong commitment to the change. Many physicians already feel overworked and stressed by changes in health care and view their EHR as onerous, perhaps rightly so. They may assume that shared notes will add to their daily workload, worry about potential harm to patients,⁹ or fear that patients will question the accuracy of their medical histories or become more aware of errors or instances of suboptimal quality of care. Having a champion who can serve as a

WHAT THE RESEARCH SHOWS

Patients report that by reading visit notes, they:

- Remember better what was discussed during visits,
- Feel more in control of their care,
- Are more likely to take medications as prescribed,
- Can share notes with their caregivers and better equip them.

Doctors and other clinicians report that by sharing visit notes, they:

- Promote patient communication and education,
- Can help patients be better prepared for visits,
- Can help patients' family and caregivers optimize care,
- Can meet patients' desire for access to their notes.

Source: Delbanco T, Walker J, Bell SK, et al. Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead [published correction appears in *Ann Intern Med*. 2015;162(7):532]. *Ann Intern Med*. 2012;157(7):461-470.

resource for these physicians, addressing their questions and concerns, is invaluable.

Cautions. We have seen few negative consequences of shared notes, but we encourage groups to consider potential pitfalls and challenges, including these:

- As doctors direct their notes increasingly toward patients and families, will some oversimplify notes in a way that interferes with communication with their fellow clinicians?
- As patients become more familiar with the content of medical records, will some withhold important information from their clinicians?
- How should situations of suspected abuse of a patient be documented?
- How can adolescents gain access to their records in a way that fosters their engagement without interfering with the rights of parents?
- How can records be meaningful and accessible to diverse populations, including those who speak another language or have limited health literacy?

These important questions need continued attention and research as we move forward.

Small change, big results

Shared notes enhance communication and engagement among patients, clinicians, and family members and can be an important facilitator of shared decision making. Patients report valuable clinical benefits, including improved adherence to their medications and treatment plans. Patients want transparency, and those who have experienced shared notes believe the practice should continue. Most providers who share notes want to continue the practice as well and do not report an increase in time spent writing notes.

With greater transparency, quality of care and patient safety may increase, along with health care value. Much remains to be learned about the best way to make patients' health information meaningful and accessible to them. But overall, we believe that this inter-

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TIPS FOR WRITING TRANSPARENT NOTES

Be transparent. Your communication in the office should reflect what you plan to put in the note.

Minimize jargon and abbreviations, especially any that patients might easily misinterpret.

Briefly define or simplify medical terms, such as short of breath, rather than SOB or dyspneic.

Highlight the patient's strengths and achievements in addition to his or her symptoms.

Describe behaviors rather than labeling the patient or making judgments. For example, consider these alternatives:

- "Patient could not recall" instead of "Poor historian,"
- "Patient is not doing X" instead of "Non-compliant,"
- "Patient prefers not to" or "Patient declines" instead of "Patient refuses."

vention, which is simple to execute yet quite complex in its ramifications, will bring many transformative benefits to health care. **FPM**

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Shared notes do not depend on health information technology, but EHRs and patient portals facilitate the process.

Greater transparency can lead to increases in quality and safety.