

# Transparency through open notes: The risks and rewards of inviting patients to review their medical records

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Technology has placed vast amounts of medical information literally a mouse click away. Yet what often may be central - a doctor's notes about a patient visit - has traditionally not been part of the discussion. In effect, such records have long been out of bounds.

In "Open Notes: [Doctors](#) and [Patients](#) Signing On," published in the July 20 issue of the [Annals of Internal Medicine](#), researchers speculate about the risks and rewards of making clinicians' notes transparent to patients.

"Opening documents that are often both highly personal and highly technical is anything but simple," write 10 investigators, led by Tom Delbanco MD and Jan Walker RN, MBA of Beth Israel Deaconess Medical Center. They document what they have learned from preparing their 'OpenNotes' study, in which more than 100 primary care doctors are inviting about 25,000 patients to read their notes. The 12-month trial involves doctors and patients associated with Beth Israel Deaconess Medical Center, Geisinger Health System in Pennsylvania, and Harborview Medical Center in Seattle.

After patient encounters, doctors have long written notes ranging, "from cryptic abbreviations on an index card to lyrical essays." Yet despite a patient's legal right to read their doctor's note, few do. In a world where 57 percent of respondents to a 2009 Pew Internet Project and the California HealthCare Foundation survey said they got medical

information on the Internet, the doctor's note is uncharted territory.

Although literature suggests that promoting active patient involvement in care may improve doctor-patient communication and [clinical outcomes](#), both patients and doctors express everything from enthusiasm to dismay when it comes to sharing the visit note.

Some primary care doctors interviewed as part of a pre-study assessment "...anticipated both clinical benefits and efficiencies from incorporating laboratory findings and recommendations into the note, thereby obviating the need for a follow-up letter." They hoped for improved patient education and more active involvement by patients in their care.

On the other hand, some doctors "worry first and foremost about the effect on their time, including calls, letters and e-mails as patients seek clarifications, disagree with statements, or correct what the doctors consider trivial errors of fact." Others were concerned they would have to leave out important information, omit frightening diagnostic or therapeutic considerations, or that patients would not understand that 'SOB' stood for 'shortness of breath.' And some were simply embarrassed about how they write.

From the patient perspective, the investigators note that views are also somewhat mixed. For some of the patients, the dialogue inherent in the process was appealing. "As more patients e-mail their doctors and use other online services, some saw open communications through electronic notes as a logical next step, enabling patients to play a more active role in their care," they write.

On the other hand, "Some clearly did not want to read what their doctors wrote because they were worried about discovering something they would rather not know, finding potential diagnoses that might make them anxious, or reading what their doctors really thought of them."

The study will use secure Internet portals and only include notes written during the trial period. The centers involved represent a broad array of settings, from urban and suburban practices in Boston to a rural Pennsylvania health system and a county hospital in Washington state that serves many indigent patients.

While they are gathering considerable data from the patient and doctors' experiences during the study period, Delbanco and Walker say their ultimate question is whether the participants will want to "leave the OpenNotes switch on" after 12 months.

"Open notes pose many questions and probably represents the Model-T stage of the future. Can a single note serve many different audiences, and can the push toward structure and template preserve the unique attributes of each person?" And, in the future, will doctors and patients generate and sign notes together that reflect their perspectives on the individual patient's circumstance and plans for the future?

Provided by Beth Israel Deaconess Medical Center

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