

Medical News & Perspectives

Patient Access to Physician Notes Is Gaining Momentum

Julie A. Jacob, MA

Family physician Richard Martin, MD, sees many patients with chronic conditions. Among them is a man in his 80s who arrives prepped by Martin's notes from his last visit. Martin was one of the first physicians at Geisinger Health System, headquartered in Danville, Pennsylvania, to volunteer in 2010 for an OpenNotes pilot program making physician notes readily available through a secure online portal. Sharing medical notes, he said, appears to engage his patients and refreshes their memory of office conversations.

Sharing medical notes with patients is a trend more health institutions are adopting as they foster transparency in medical records. OpenNotes is an initiative to promote medical note sharing that was launched in 2010 by clinicians and researchers at Beth Israel Deaconess Medical Center in Boston (<http://bit.ly/1T7xNIR>, <http://rwjf.ws/1VxXgYR>). Funded by the Robert Wood Johnson Foundation and other charitable groups, OpenNotes has developed copyrighted materials that it shares for free with health systems to introduce simple patient access to medical notes.

"[My patient] contends to this day that [reading his medical notes] motivated him to maintain his health," said Martin, who practices at Geisinger's Scranton, Pennsylvania, location.

The feedback from Martin's elderly patient illustrates why health systems across the country are making physician notes easily available to patients. According to a recent study, patients who frequently read their physician's notes reported they better understood their health condition, took better care of their health, and had a better relationship with their physician (Esch T et al. *BMJ Open*. 2016;6:e010034).

Easy and Quick Online Access

For decades, patients could legally access their medical notes as part of the Health Insurance Portability and Accountability Act of 1996. But fees or long wait times to receive the records sometimes hampered



the process (<http://1.usa.gov/1TDgl4q>). What sets OpenNotes apart is the ease and speed with which patients can access notes.

The OpenNotes initiative was the brainchild of Tom Delbanco, MD, a professor of general medicine and primary care at Harvard Medical School, and Jan Walker, RN, an assistant professor of medicine, also at Harvard. Throughout his 40 years of practice, Delbanco freely shared his notes with patients. When patient portals were introduced, Delbanco realized that patients could email their physicians and schedule appointments, but physician notes were hidden. He and Walker decided to investigate the consequences of inviting patients to view physician notes via online patient portals by setting up a 1-year research and demonstration project, funded by the Robert Wood Johnson Foundation and 2 other organizations.

The project involved 105 primary care physicians and 13 564 patients at 3 sites: Beth Israel, Geisinger, and Harborview Medical Center in Seattle. Both participating patients and participating and nonparticipating physicians completed an online survey at the beginning of the study assessing their attitudes toward medical note sharing. Initially, most patients (92%-97%) at the 3 sites thought patient access to

notes was a good idea, although fewer participating physicians thought so (69%-81% at the 3 sites) (Walker J et al. *Ann Intern Med*. 2011;155[12]:811-819).

At the study's conclusion, after a year of access to physician notes, participating patients and physicians completed a follow-up online survey, which asked the same questions as the baseline survey, but with the verb tense changed to reflect that patient access to medical notes had been established. The results showed that 99% of responding patients supported continued access to medical notes online, and the majority of responding physicians at each of the 3 sites, ranging from 85% at Beth Israel to 91% at Geisinger, agreed that access was a good idea (Delbanco T et al. *Ann Intern Med*. 2012; 157[7]:461-470).

Some physicians were skeptical at first, expressing concerns that giving patients access to medical notes might add to their workload if patients called and emailed with questions based on what they read, Delbanco said. For the most part, those fears were unfounded, he noted. Less than 10% of participating physicians reported increased length of visits or time responding to patient queries.

Since the pilot study, other health systems have adopted the OpenNotes concept. Delbanco estimates that about 100 health care institutions are at some stage, from planning to implementation, of sharing medical notes with patients. Some have used the OpenNotes resources, and others have not, Delbanco said.

The medical notes that the patients read are the physician's notes—the patient's story—Delbanco emphasized, and not simply the after-visit laundry list of medications and instructions that patients customarily receive.

Mayo Clinic in Rochester, Minnesota, is one health system that has implemented medical note sharing. Mayo had launched its own patient portal in 2009, so providing patients access to physician notes in 2012, which it did independently of the OpenNotes initiative, seemed like the logi-

cal next step, said nephrologist Dawn Milliner, MD, Mayo Clinic's chief medical information officer. Although individual physicians can't opt out of notes sharing, she said, certain types of notes, such as confidential psychiatric notes, may be withheld.

MD Anderson Cancer Center in Houston has been another pioneer in medical note sharing. The cancer center has provided patients access to their medical notes online since 2009, said Thomas W. Feeley, MD, a professor of anesthesiology and head of MD Anderson's Institute for Cancer Care Innovation.

Physicians at MD Anderson had fewer concerns about patients reading medical notes because the organization already had a culture of sharing information with patients, Feeley noted.

Questions of Access and Fairness

Despite OpenNotes' benefits, some concerns remain. One is that patients might find the information they read upsetting. To cushion a potential blow, MD Anderson Cancer Center holds laboratory, radiology,

and pathology results for 7 days and Mayo Clinic delays patient access to radiology and pathology results for 3 days so physicians can first speak with patients.

In addition, OpenNotes raises issues of access and fairness for patients who don't have a computer or have a limited knowledge of English, noted Nancy Berlinger, PhD, a Hastings Center research scholar.

Furthermore, physicians may be inclined to censor themselves because patients can electronically peer over their shoulder. The OpenNotes pilot study found that 28% of participating physicians at Beth Israel, 9% at Geisinger, and 11% at Harborview reported in the poststudy survey that they were less candid in their notes knowing patients could read them, suggesting the concern may be valid.

Steven Malkin, MD, an internist who practices in Arlington Heights, Illinois, is concerned that if his patients routinely read his notes, he would be less forthcoming. Malkin practices with Amita Health Medical Care Group, which is not part of the OpenNotes initiative.

"My notes are for me," Malkin said. "If I knew a patient was going to read them, I would write them differently."

For instance, he said, he may write that he suspects a patient has dementia or cancer before subsequent tests determine otherwise. In this case, his concern is that a patient who reads his preliminary notes before a firm diagnosis is made would needlessly worry.

"Until you have more information, what value is there in scaring [the patient]?" Malkin said.

Although Geisinger's Martin said he has not changed the way he writes notes, he has learned that patients may interpret a word differently than anticipated, citing a patient who took offense to being described as obese. Nonetheless, that description motivated the patient to lose weight, he said.

Despite lingering apprehension, Milliner thinks sharing notes with patients is a good tool for improving communication between patients and physicians.

"It is one more way they become part of decision making," Milliner said. "I view that as a very positive thing." ■