



## Perspective

### The Road toward Fully Transparent Medical Records

Jan Walker, R.N., M.B.A., Jonathan D. Darer, M.D., M.P.H., Joann G. Elmore, M.D., M.P.H., and Tom Delbanco, M.D.

Forty years ago, Shenkin and Warner argued that giving patients their medical records “would lead to more appropriate utilization of physicians and a greater ability of patients to participate in their own

care.”<sup>1</sup> At that time, patients in most states could obtain their records only through litigation, but the rules gradually changed, and in 1996 the Health Insurance Portability and Accountability Act entitled virtually all patients to obtain their records on request. Today, we’re on the verge of eliminating such requests by simply providing patients online access. Thanks in part to federal financial incentives,<sup>2</sup> electronic medical records are becoming the rule, accompanied increasingly by password-protected portals that offer patients laboratory, radiology, and pathology results and secure communication with their clinicians by e-mail.

One central component of the records, the notes composed by clinicians, remains largely hidden from patients. But now OpenNotes, an initiative fueled primarily by the Robert Wood Johnson Foundation, is exploring the effects of providing access to these notes.<sup>3</sup> Beginning in 2010, at Beth Israel Deaconess Medical Center (which serves urban and suburban Boston), Geisinger Health System (in rural Pennsylvania), and Harborview Medical Center (Seattle’s safety-net hospital), more than 100 primary care doctors volunteered to invite 20,000 of their patients to read their notes securely online.<sup>4</sup>

Although only a small minor-

ity of these doctors’ patients used the portals, the initial findings were striking. At the end of a year, four of five patients had read the notes, and among those who responded to a survey, large majorities reported having better recall and understanding of their care plans and feeling more in control of their health care. Moreover, two thirds of patients who were taking medications reported improved adherence. Doctors reported little effect on their work lives and were surprised by how few patients appeared troubled by what they read. Although the notes were not formally evaluated, the majority of doctors reported not modifying their tone or content. A minority, however, reported changing the way they addressed four potentially charged topics: cancer, mental health, substance abuse, and obesity. After the first year, 99% of the pa-

tients surveyed wanted “open notes” to continue, and 85% indicated that ready access would be important for their future choice of a provider or system; no doctors chose to discontinue the practice.

Despite limitations in the sample, the findings persuaded the three institutions to implement open notes broadly. Leading health care organizations, including MD Anderson Cancer Center, Mayo Clinic, and the Veterans Health Administration, are doing so also, many others are in the planning stages, and clinicians are experimenting within their practices.<sup>5</sup>

Early adopters are learning that such a practice means more than simply mailing notes or visit summaries or having patients log on to a portal. For starters, the knowledge that patients (and often their families) will have access to records affects the intent and sometimes the content of clinical documentation. Language related to cancer, obesity, substance abuse, mental illness, and lifestyle demands particular attention. Writing accurately about a suspicion of cancer, for instance, can be difficult for clinicians who don't want to worry patients unnecessarily, and addressing character disorders or cognitive dysfunction in ways that are useful to patients, consulting providers, and others who use such records requires carefully considered words. These challenges are compounded by today's electronic records, in which the story weaving together social, familial, cultural, and medical contributors to the patient's health and illness often disappears, obscured by templates. A boon to billers, quality assessors, and researchers, such records can become formu-

laic and susceptible to data-entry errors. Moreover, they're often filled with copied-and-pasted information that buries the essential narrative under voluminous repetitive text.

As open notes spread at our institutions, clinicians are expressing widely varied preferences. Some want the option to hide notes, or portions of notes, from patients or families, and some want ways to communicate with colleagues privately. Some worry that “watered-down” notes will obscure important medical details, and mental health professionals appear to be divided about the effects of sharing their notes with patients. Overall, our experience suggests that doctors initially feel safest when they can choose which patients can see what, but as they evaluate feedback from patients and colleagues and learn to discuss choices with their patients, their preconceived limits tend to fade away. Ideally, both patients and providers should be able to set preferences about sharing information, but current health information systems can't handle such nuance.

As patients become familiar with medical records and clinical notes, they consider new opportunities and risks. Some say they have become more careful about what information they share with clinicians, and some ask for more control over access to their information. Providers are experimenting with strategies that help patients protect their privacy with regard to mental health, sexual function, suspected abuse, or other sensitive topics. And though family caregivers may find that reading notes improves their understanding of care plans and reduces stress, it's a complex task to establish separate proxy access

based on patients' preferences about who gets to see what.

As transparent practice evolves, it's impossible to predict how much patients may stray from long-standing conventions. Portals afford patients secure access to their information, and doctor-patient confidentiality remains undisturbed. But patients' attitudes toward privacy may change as online access allows them to share documents, including notes. A third of patients in the Open-Notes study expressed concern about privacy, but more than one in five shared a note with others who could clarify meanings, offer clinical insights or second opinions, or — for those participating in the patient's care — improve their own knowledge. Indeed, some patients may choose to post their providers' progress notes on Facebook, Twitter, medical forums, and other social media, potentially exposing clinicians to public scrutiny and crowd-fueled praise or criticism.

Among the institutional adopters we've encountered, most have opened access to notes written primarily by ambulatory care doctors. We expect that patients and families will find other notes useful, too, including those from nurse practitioners, physician assistants, case managers, social workers, pharmacists, rehabilitation specialists, and others. And health care systems will probably expand open notes to inpatient hospital services, recuperative and rehabilitation centers, long-term care facilities, home care, and other settings. Although nearly 90% of the patients we surveyed indicated that they would want notes to be accessible during a hospitalization, implementing this practice in acute care hospitals will be particularly complex, since

a patient's status may fluctuate, multiple clinicians may offer opinions, and plans may change frequently.

Regardless of the setting, open notes can help improve patient safety by allowing contributions from patients and families who may catch questionable statements or clinically important mistakes in notes or find lapses in follow-up that need to be rectified. Indeed, the very existence of an environment in which patients are encouraged to identify potential errors may increase patients' trust. But policies and processes for amending records remain in flux and vary widely among record systems and practice settings.

Despite the challenges, we anticipate that open electronic records will become the standard of care, accompanied by electronic tools that explain medical terminology and abbreviations, translate notes into different languages, and adjust for health-literacy

levels. Given that more than half the patients we surveyed wanted to add comments to their doctors' notes and approximately a third wanted to approve what was written, we expect that patients will soon share in generating content such as family and social histories and descriptions of their subjective experiences with illness. Indeed, we believe that ultimately notes will be signed by both patients and providers, as they become the foundations for planning care, monitoring the course of health and illness, and evaluating care processes and outcomes.

Shenkin and Warner predicted that increasing patient engagement through transparent medical records would contribute to improvements in health, care, and costs. As open notes spread, and strategies and safeguards evolve, we expect that both patients and providers will benefit from the wisdom of their proposal.

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From the Division of General Medicine and Primary Care, Beth Israel Deaconess Medical Center and Harvard Medical School, Boston (J.W., T.D.); Geisinger Health System, Danville, PA (J.D.D.); and Harborview Medical Center, University of Washington School of Medicine, Seattle (J.G.E.).

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