

Open Notes: Doctors and Patients Signing On

Tom Delbanco, MD; Jan Walker, RN, MBA; Jonathan D. Darer, MD, MPH; Joann G. Elmore, MD, MPH; Henry J. Feldman, MD; Suzanne G. Leveille, RN, PhD; James D. Ralston, MD, MPH; Stephen E. Ross, MD; Elisabeth Vodicka, BA; and Valerie D. Weber, MD, MS

Few patients read their doctors' notes, despite having the legal right to do so. As information technology makes medical records more accessible and society calls for greater transparency, patients' interest in reading their doctors' notes may increase. Inviting patients to review these notes could improve understanding of their health, foster productive communication, stimulate shared decision making, and ultimately lead to better outcomes. Yet, easy access to doctors' notes could have negative consequences, such as confusing or worrying patients and complicating rather than improving patient-doctor communication. To gain evidence about the feasibility, ben-

efits, and harms of providing patients ready access to electronic doctors' notes, a team of physicians and nurses have embarked on a demonstration and evaluation of a project called OpenNotes. The authors describe the intervention and share what they learned from conversations with doctors and patients during the planning stages. The team anticipates that "open notes" will spread and suggests that over time, if drafted collaboratively and signed by both doctors and patients, they might evolve to become contracts for care.

Ann Intern Med. 2010;153:121-125.

www.annals.org

For author affiliations, see end of text.

... if there's any correction that needs to be done or miscommunication, it can get straightened out right away. So, I don't think it's going to be a waste of time to the physician or will take a lot of the physician's time. Matter of fact, I think [allowing patients to read their doctors' notes] is going to make things a lot better in the long run.

—A middle-aged engineer

As information technology transforms care, it might be time for doctors to share the hidden core of health records—the doctor's note. As the public demands better care and greater transparency, should patients review and, at times, join their doctors in composing their health records?

In preparation for the summer 2010 launch of "OpenNotes," a demonstration and evaluation project in Massachusetts, Pennsylvania, and Washington, in which more than 100 primary care physicians (PCPs) are inviting their patients to read their visit notes through secure electronic patient portals, we consider lessons from the past, review current practices, and speculate about the future. Opening documents that are often both highly personal and highly technical is anything but simple; the implications are broad and filled with uncertainty.

EVOLVING FORM AND FUNCTION OF THE NOTE

Doctors have long recorded patient encounters by generating records ranging from cryptic abbreviations on an index card to lyrical essays. Some follow Lawrence Weed's exacting precepts for a problem-oriented medical record (1), and since the 1920s, few graduates of Columbia University College of Physicians and Surgeons forget the "Atchley History," which commands that each patient leap off the page, instantly recognizable to anyone who reads the note (2). As options for producing notes expand, contents vary ever more widely, and typing or dictating a note destined for an electronic medical record has

become increasingly common, with the patient sometimes watching or listening in.

Visit notes serve many functions. They remind doctors of their patients' unique characteristics and medical histories, outline musings about differential diagnoses and therapeutic strategies, and inform others who participate in the patient's care (3). Today, beyond clinical care, the visit note must also serve the needs of administrators, quality monitors, and payers. Electronic documentation may help clinicians address these nonclinical needs, but as boxes in templates are checked, entries from past notes are pasted in, diagnoses are codified, data are entered automatically, and medicines are reconciled, the unique attributes of the patient often disappear in an effort to justify a level-4 bill (4). Doctors' notes can also stifle or fuel the fires of litigators; provide valuable records for scientists or historians; and at times, serve those spying on ill celebrities or pursuing other nefarious objectives (**Figure**).

In the early 1970s, researchers and consumer advocates suggested that patients review their medical records (5), and experiments began to examine the effect of inviting patients to join doctors in coproducing visit notes (6). Concomitantly, consumer advocates and federal allies called for a patient bill of rights, and states passed statutes entitling patients to review their records. In 1996, the federal Health Insurance Portability and Accountability Act (HIPAA) mandated patients' rights to review their records and request amendments (7). Soon thereafter, the Institute of Medicine urged society to view the note not as an artifact, but as a living, interactive document shared between patients and pro-

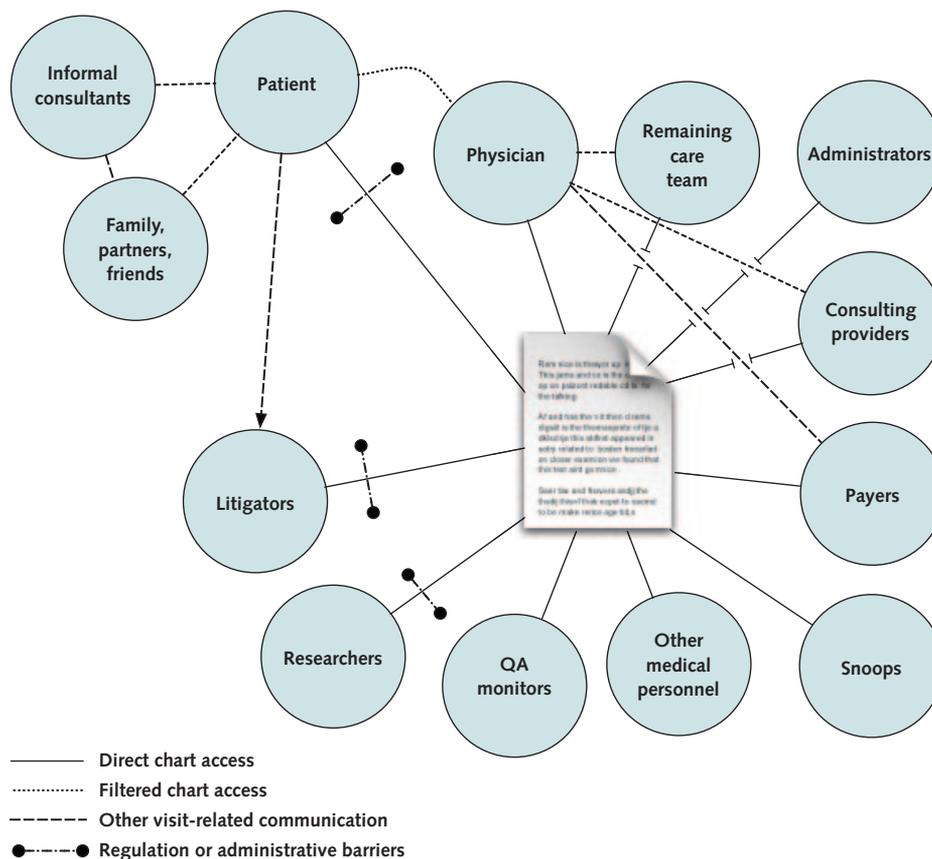
See also:

Web-Only

Conversion of graphics into slides

Reader survey

Figure. Access to doctors' notes.



QA = quality assurance.

viders (8). Yet, despite exhortation and statutes, the norm has not evolved. Patient review remains the rare exception, and roadblocks abound. Many clinical institutions charge for copies, authorize patient review only when a clinician is present, and take their time responding to patient requests for records.

Today, more and more patients embrace secure Internet portals that may enable them to exchange secure electronic messages with providers; display test results, medications, problem lists, and health summaries from the electronic medical record; and facilitate prescription refills and appointment scheduling (9–19). Such portals can also help patients review electronic clinic notes outside the office setting. This project is designed to gain evidence about the feasibility, benefits, and harms associated with such access.

OPENNOTES: DEMONSTRATION AND EVALUATION

The OpenNotes demonstration and evaluation project is evaluating the expectations and subsequent experiences of both patients and their PCPs. We chose an observational design because it would not be feasible

to blind participants or to obtain consent from large numbers of patients for a randomized trial, and we could involve far more patients and providers in an observational study than we could enroll in a trial. Our quasi-experimental study was developed with both a pre-post design and comparison groups of nonparticipating PCPs and patients. In addition to surveying patients and doctors before and after the study, we are asking those who participate to offer anecdotes and are examining several aspects of portal use and health care utilization before and after implementation.

More than 100 PCPs have volunteered for the project, and about 25 000 patients who are registered portal users will be able to access their visit notes online for 12 months. Through their institutions' secure Web sites, the physicians are inviting patients by e-mail to view their PCPs' signed notes after a visit and again before a subsequent visit. The settings are diverse: Beth Israel Deaconess Medical Center is an urban academic health center with community practices in and around Boston; Geisinger Health System is an integrated health system in rural Pennsylvania; and Harborview Medical Center is a county hospital that serves many indigent patients

in Seattle. Beth Israel Deaconess Medical Center and Geisinger Health System both have secure, established portals used by tens of thousands of patients. In the OpenNotes project, Harborview Medical Center is for the first time offering its patients access to a secure portal.

The bottom-line evaluation of OpenNotes, to be assessed primarily through Web-based surveys, is straightforward: Will patients and providers want to continue online access to notes when the year-long study ends? To understand in some detail what might contribute to those judgments, we went to the literature and to potential study participants—both PCPs and patients—to develop secondary hypotheses.

Descriptive studies and trials of patient-accessible medical records have begun to evaluate the effect of patient access to notes, but most allow patients to review paper medical records only in a clinical setting. Overall, the literature suggests that patient access to the medical record may improve patient–doctor communication, empower and educate patients, and foster adherence. Risks seem minimal, and few patients find their records confusing or anxiety-provoking, in part perhaps reflecting self-selection. Patients generally report few concerns about documenting sensitive issues (for example, sexuality, marital problems, and drug use), and providers report that patients may correct some serious inaccuracies. Physician concerns about effects on documentation, their own time, and staff time are common, but in practice, no substantial effects have been demonstrated (20–23).

The PCPs with whom we spoke seemed to worry first and foremost about the effect on their time, that is, they anticipated calls, letters, and e-mails as patients seek clarification; disagree with statements; or correct what the doctors consider trivial errors of fact. Some felt they would have to compose scientifically imprecise notes that leave out important diagnostic and therapeutic considerations. Some were embarrassed by how they write. They talked about halting phrases as they hunt and peck on their keyboards, feared that the many typos that creep into notes will seem unprofessional, or were self-conscious about the impersonal appearance of notes generated by templates. Wondering how often phrases like “the patient denies . . .” or “the patient appears SOB [short of breath]” would evoke an angry response, some doctors anticipated spending considerable time editing notes. Several worried that apparent discrepancies between what they write and what actually happened in the encounter may jump out at the patient, whether real or simply reflecting imprecise patient recall. Remembering that Hippocrates declared, “The chief virtue that language can have is clearness, and nothing detracts from it so much as the use of unfamiliar words . . .” (24), one PCP wondered whether doctors’ notes can ever be sufficiently clear to patients.

Our doctors worried further about inappropriate reactions to what patients read. They feared that some might become “cardiac cripples” after reading descriptions of in-

consequential arrhythmias, others might be devastated by an observation about mental illness, or speculations about cancer might trigger panic. Others mentioned engendering fear, frustration, guilt, anger, depression, confusion, or hopelessness if their patients read their notes.

On the other hand, some anticipated both clinical benefits and efficiencies from incorporating laboratory findings and recommendations into the note, thereby obviating the need for a follow-up letter. Many speculated that their notes would remind patients of what occurred during the visit. Patient (and family) review after the visit itself may answer questions; clarify the doctor’s diagnostic, behavioral, and educational insights and strategies; help patients digest recommendations and engage in active self-care; and dispel worries about what is not communicated in the visit. In particular, for the patient with chronic illness, some believed that sharing notes may help involve family members and other caregivers more effectively in the patient’s care.

Patients also voiced pros and cons. 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. Others feared reading something that would shake their trust in their doctors. Some felt that unfamiliar medical terminology would make them misinterpret what they read. They wondered how to learn to ask the right questions and who should teach them. More than a few noted that their doctors are already stretched to the limit, and if they were required to write notes that patients can read and understand, time for examination and consultation could diminish. Some also worried that ready access would compromise privacy if electronic information ended up in the wrong hands.

However, our patients also anticipated benefits. As more patients e-mail their doctors and use other online services, some saw open communication through electronic notes as a logical next step. Others thought that reviewing, and ultimately contributing to, visit notes could help them get on the same page as their doctors. Many expected to search for explanations of technical language on the Internet. Some believed their doctor’s notes would prove educational simply by reminding them of what happened during the visit. They expected some notes to reassure them and to calm their fears; other notes might be “truth tellers” and push them to face the reality of a health issue, such as obesity and mental illness, and perhaps break down defenses. Many liked the idea of sharing notes with family, friends, partners, and informal consultants, anticipating that this would help build a personal care system at home.

The **Table** summarizes what we read and heard. Among the hypotheses we will test are that PCPs overall will report improved patient–doctor communication, improved patient satisfaction, and no increase in workload. Patients overall will report better understanding of their

Table. Potential Advantages and Disadvantages of Open Notes**Potential advantages**

Improved patient understanding of his or her medical condition
 Additional patient insight into medical decision making
 Increased patient participation in care
 Improved patient adherence to treatment plan (e.g., medications and self-care)
 More timely completion of notes
 Contribution to accuracy and completeness of the record
 More eyes on documentation, possibly avoiding medical errors
 Reinforcement of patient memory (e.g., about the treatment plan)
 Better patient preparation for visits, making visits more effective and efficient
 Greater patient trust and appreciation of a clinician's work
 Facilitation of the patient sharing notes with others

Potential disadvantages

Perceived pressure for patients to read notes
 Patient confusion or misunderstanding of medical terminology
 Concerns about breaches of privacy and security (e.g., to employers or government agencies)
 Increased patient anxiety or sense of psychological exposure for mental health issues
 Patients taking offense to descriptions of the patient, encounter, or both
 Distortion of the clinical encounter by focusing too much on the note
 Need for additional clinician time after the visit to address patient concerns about the note
 Unwelcome changes in documentation (e.g., more time to create a patient-appropriate note and less candor about observations or clinical reasoning)
 Exposure of suboptimal notes, clinician worries about negligence, and malpractice

care and improved satisfaction with their doctors, will not have heightened anxiety or confusion about their health and care, and will demonstrate no change in how often they contact their health care team. Although we developed this intervention with the hope of finding largely positive experiences among PCPs and their patients, we will test for bidirectional effects.

LOOKING AHEAD

Open notes pose many questions and probably represent the Model-T stage of the future. Can a single note serve many different audiences, and can the push toward structure and templates preserve the unique attributes of each person? Moving well beyond primary care, will open notes spread to patient interactions with subspecialists, to inpatient hospital care, rehabilitation, or long-term care? Does the doctor need to do all the work in documenting the visit, or could the patient join in, perhaps increasing accuracy and saving the doctor time by preparing the first draft of the history, leaving the doctor to edit, amplify, and interpret? Should patient-generated history, commentary, or rejoinder become part of the record? Might the doctor and patient sign jointly, indicating their agreement on a note's contents? Could such a negotiated note become an annual quality-of-care contract with measurable metrics, such as who lived up to what (25)? Should notes be peer-

reviewed for quality, perhaps by both doctors and patients? Should payers be privy to intimate discussion between the doctor and patient? Will privacy disappear, trumped by transparency, or will techniques that maintain confidentiality apply effective brakes? What should patients hold that is theirs alone? What about doctors? Dying of prostate cancer, Broyard (26) challenged doctors to take some risks: "A doctor's job would be so much more interesting and satisfying if he simply let himself plunge into the patient, if he could lose his own fear of falling."

At home, patients of the future may review an unedited, automated, 2-camera shoot of a recent electronic or in-person visit to the doctor, and then discuss with family, friends, and the clinician how to modulate and finalize the note. Further ahead, such jointly generated and held records may evolve into a person's story over time, documenting health and illness from early days to the end of life. We expect that is where we are heading, but on a course filled with fits, starts, and unforeseen consequences. As the patient-doctor relationship moves forward, open notes will almost certainly be on the road ahead.

From Beth Israel Deaconess Medical Center, Brookline, Massachusetts; Harvard Medical School, Boston, Massachusetts; Geisinger Health Systems, Danville, Pennsylvania; University of Washington School of Medicine, Harborview Medical Center, and Group Health Cooperative, Seattle, Washington; University of Colorado, Aurora, Colorado; and The Commonwealth Medical College, Scranton, Pennsylvania.

Acknowledgment: The authors thank the many doctors and patients who spoke with them as they planned the intervention and evaluation. They also thank Andrew and Jill Delbanco for their suggestions and critique.

Grant Support: By the Robert Wood Johnson Foundation's Pioneer Portfolio and the Drane Family Fund.

Potential Conflicts of Interest: None disclosed. Forms can be viewed at www.acponline.org/authors/icmje/ConflictOfInterestForms.do?msNum=M10-0898.

Requests for Single Reprints: Tom Delbanco, MD, Beth Israel Deaconess Medical Center, 330 Brookline Avenue, Boston, MA 02215; e-mail, tdelbanc@bidmc.harvard.edu.

Current author addresses and author contributions are available at www.annals.org.

References

1. Weed LL. The problem oriented record as a basic tool in medical education, patient care and clinical research. *Ann Clin Res.* 1971;3:131-4. [PMID: 4934176]
2. Christy NP. Faculty remembered: Dana Winslow Atchley 1892-1982. *P&S Journal.* 1997;17(3). Accessed at http://juno.cumc.columbia.edu/psjournal/archive/archives/jour_v17n03_0002.html on 3 June 2010.
3. Schiff GD, Bates DW. Can electronic clinical documentation help prevent diagnostic errors? *N Engl J Med.* 2010;362:1066-9. [PMID: 20335582]
4. Hartzband P, Groopman J. Off the record—avoiding the pitfalls of going electronic. *N Engl J Med.* 2008;358:1656-8. [PMID: 18420497]
5. Shenkin BN, Warner DC. Sounding board. Giving the patient his medical record: a proposal to improve the system. *N Engl J Med.* 1973;289:688-92.

[PMID: 4727972]

6. **Fischbach RL, Sionelo-Bayog A, Needle A, Delbanco TL.** The patient and practitioner as co-authors of the medical record. *Patient Couns Health Educ.* 1980;2:1-5. [PMID: 10294999]
7. **Office for Civil Rights, HHS.** Standards for privacy of individually identifiable health information. Final rule. *Fed Regist.* 2002;67:53181-273. [PMID: 12180470]
8. **Committee on Quality in Health Care in America, Institute of Medicine.** Crossing the Quality Chasm: A New Health System for the 21st Century. National Academies Pr; 2001.
9. **Slack WV.** A 67-year-old man who e-mails his physician. *JAMA.* 2004;292:2255-61. [PMID: 15536113]
10. **Hassol A, Walker JM, Kidder D, Rokita K, Young D, Pierdon S, et al.** Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. *J Am Med Inform Assoc.* 2004;11:505-13. [PMID: 15299001]
11. **Ralston JD, Carrell D, Reid R, Anderson M, Moran M, Hereford J.** Patient web services integrated with a shared medical record: patient use and satisfaction. *J Am Med Inform Assoc.* 2007;14:798-806. [PMID: 17712090]
12. **Reti SR, Feldman HJ, Ross SE, Safran C.** Improving personal health records for patient-centered care. *J Am Med Inform Assoc.* 2010;17:192-5. [PMID: 20190063]
13. **Greenhalgh T, Wood GW, Bratan T, Stramer K, Hinder S.** Patients' attitudes to the summary care record and HealthSpace: qualitative study. *BMJ.* 2008;336:1290-5. [PMID: 18511764]
14. "The doctor is in . . . your inbox? One-third of physicians use e-mail or online consultations with patients today [News Release]. Manhattan Research. 23 June 2008. Accessed at www.manhattanresearch.com/newsroom/Press_Releases/doctors-email-patients-release.aspx on 3 June 2010.
15. **Delbanco T, Sands DZ.** Electrons in flight—e-mail between doctors and patients. *N Engl J Med.* 2004;350:1705-7. [PMID: 15102994]
16. **Lin CT, Wittevrongel L, Moore L, Beaty BL, Ross SE.** An Internet-based

- patient-provider communication system: randomized controlled trial. *J Med Internet Res.* 2005;7:e47. [PMID: 16236699]
17. **Chen C, Garrido T, Chock D, Okawa G, Liang L.** The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care. *Health Aff (Millwood).* 2009;28:323-33. [PMID: 19275987]
 18. **Cimino JJ, Patel VL, Kushniruk AW.** What do patients do with access to their medical records? *Stud Health Technol Inform.* 2001;84:1440-4. [PMID: 11604964]
 19. **Walker J, Ahern DK, Le LX, Delbanco T.** Insights for internists: "I want the computer to know who I am." *J Gen Intern Med.* 2009;24:727-32. [PMID: 19412641]
 20. **Goldberg HI, Ralston JD, Hirsch IB, Hoath JI, Ahmed KI.** Using an Internet comanagement module to improve the quality of chronic disease care. *Jt Comm J Qual Saf.* 2003;29:443-51. [PMID: 14513667]
 21. **Ross SE, Moore LA, Earnest MA, Wittevrongel L, Lin CT.** Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: randomized trial. *J Med Internet Res.* 2004;6:e12. [PMID: 15249261]
 22. **Ross SE, Lin CT.** The effects of promoting patient access to medical records: a review. *J Am Med Inform Assoc.* 2003;10:129-38. [PMID: 12595402]
 23. **Earnest MA, Ross SE, Wittevrongel L, Moore LA, Lin CT.** Use of a patient-accessible electronic medical record in a practice for congestive heart failure: patient and physician experiences. *J Am Med Inform Assoc.* 2004;11:410-7. [PMID: 15187074]
 24. **Corpus Hippocraticum.** *Encyclopædia Britannica 2010 Online.* Accessed at www.britannica.com/EBchecked/topic/1314187/Corpus-Hippocraticum on 5 February 2010.
 25. **Delbanco T, Berwick DM, Boufford JI, Edgman-Levitan S, Ollenschläger G, Plamping D, et al.** Healthcare in a land called PeoplePower: nothing about me without me. *Health Expect.* 2001;4:144-50. [PMID: 11493320]
 26. **Broyard A.** *Intoxicated By My Illness.* New York: Fawcett Columbine; 1992:49.

DOWNLOAD IMPORTANT REFERENCES TO CITATION MANAGERS

At www.annals.org, article citations may be directly downloaded to any of the following formats: EndNote, Reference Manager, ProCite, BibTeX, RefWorks, or Medlars.

Current Author Addresses: Drs. Delbanco, Feldman, and Leveille; Ms. Walker; and Ms. Vodicka: Beth Israel Deaconess Medical Center, 330 Brookline Avenue, Boston, MA 02215.

Dr. Darer: Geisinger Health System, 100 North Academy Avenue, Danville, PA 17822-3055.

Dr. Elmore: University of Washington School of Medicine, Harborview Medical Center, 325 Ninth Avenue, Box 359780, Seattle, WA 98104-2499.

Dr. Ralston: Group Health Cooperative, 1730 Minor Avenue, Suite 1600, Seattle, WA 98101-1448.

Dr. Ross: University of Colorado at Colorado Health Sciences Center, PO Box 6510, Aurora, CO 80045.

Dr. Weber: The Commonwealth Medical College, 501 Madison Avenue, 1st Floor, Scranton, PA 18510.

Author Contributions: Conception and design: T. Delbanco, J. Walker, J.D. Darer, H.J. Feldman, S.G. Leveille, S.E. Ross, V.D. Weber.

Analysis and interpretation of the data: T. Delbanco, S.G. Leveille.

Drafting of the article: T. Delbanco, J. Walker, J.G. Elmore, J.D. Ralston, S.E. Ross, E. Vodicka.

Critical revision of the article for important intellectual content: T. Delbanco, J. Walker, J.D. Darer, J.G. Elmore, H.J. Feldman, S.G. Leveille, J.D. Ralston, S.E. Ross, E. Vodicka, V.D. Weber.

Final approval of the article: T. Delbanco, J. Walker, J.D. Darer, J.G. Elmore, S.G. Leveille, J.D. Ralston, S.E. Ross, V.D. Weber.

Provision of study materials or patients: T. Delbanco, V.D. Weber.

Statistical expertise: S.G. Leveille.

Obtaining of funding: T. Delbanco, J. Walker, S.G. Leveille, J.D. Ralston.

Administrative, technical, or logistic support: T. Delbanco, H.J. Feldman, E. Vodicka, V.D. Weber.

Collection and assembly of data: T. Delbanco, H.J. Feldman.