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To: David Blumenthal, M.D., M.P.P.
Office of the National Coordinator for Health Information Technology
Department of Health and Human Services
200 Independence Avenue S.W., Suite 729-D
Washington, D.C. 20201

Re: Request for Comment - Stage 2 Definition of Meaningful Use of Electronic Health Records

Dear Dr. Blumenthal,

The “OpenNotes” team, a group of clinicians and researchers working in Massachusetts, Pennsylvania, Colorado, and the State of Washington with the support of the Pioneer Portfolio of the Robert Wood Johnson Foundation, welcomes the opportunity to comment on the Stage 2 definition of the “meaningful use” of electronic health records (EHRs). As advocates for more transparency in the nation’s health care system, we enthusiastically support the objective of engaging patients and families in their care through the “meaningful use” of EHRs. The inclusion of this objective will help guide national health policy toward greater emphasis on patient involvement and improved patient-clinician communication, and research over now many years has clearly documented the value of such objectives. Empowering patients, families, and other care givers through the transparency that EHRs and patient portals can facilitate holds enormous potential, and we believe that some of the insights we are gaining in our research and demonstration project will prove useful to policy makers, the general public, and clinicians.

OpenNotes is a multi-site effort in which more than 100 participating primary care doctors are inviting approximately 12,000 of their patients to read and review their encounter notes through secure electronic patient portals.¹ As of March 2011, we have passed the midpoint of this year-long intervention. Before we started, we asked eligible patients and doctors to complete on-line surveys probing for their expectations, including both positive and negative outcomes. We are now analyzing baseline surveys completed by more than 38,000 patients and 170 doctors (2/3 of these doctors volunteered to participate in OpenNotes). Our preliminary findings suggest that patients are overwhelmingly interested in having access to their notes, and physicians also appreciate the potential for open records to improve their care for patients.

¹ Delbanco T, Walker J, Darer JD, Elmore JG, Feldman HJ, Leveille SG, et al. Open Notes: Doctors and Patients Signing On. *Ann Intern Med.* 2010; 153:121-5.



Of note, three categories of patients are most enthusiastic. As one might anticipate, those patients who rate themselves in fair or poor health (16% of our sample) are particularly excited at the prospect. But we have been surprised, and frankly delighted to learn also that those 65 or older (17% of our sample) and those with high school education or less (27%) share such enthusiasm. Extensive evidence suggests that these three patient populations are particularly vulnerable to disparities in health outcomes. They are those that may stand to benefit most from open records and other new technologies, and their excitement about our intervention may prove particularly important for future policy and clinical initiatives.

We can report also that only one doctor who volunteered to participate has dropped out of the study, and our early sense is that doctors are not experiencing significant disruptions to their work, although quite a few voiced initial concern that patients would be contacting them more frequently and inappropriately for clarifications on their note. It may be that for every patient who seeks more doctor time as a result of such an intervention, another seeks less, as questions are answered and uncertainties clarified through the written word.

We believe that the potential for open notes and records to improve medical care is virtually unbounded, both for individual patients and their families and for the health system overall. At the patient level, by enhancing the quality of communication between the patient and clinician, open records may improve adherence to medical regimens and help patients to better understand and follow treatment plans. Open records also fosters accountability, with doctors more likely to complete the encounter note in a timely fashion and to ensure that notes are accurate. It allows patients to contribute to the accuracy of records. Such improvements in the efficiency and quality of medical care have the potential to save lives, boost patient satisfaction, and improve the patient experience during illness. At the system level, improvements in communication, adherence, and accountability resulting from open records may, with time, have a beneficial impact on health costs and quality of care.

As we discuss open notes with a wide variety of audiences, concerns about patient confidentiality and privacy frequently come to the fore. This highlights an important distinction between confidentiality, as determined by the Health Insurance Portability and Accountability Act (HIPAA), and privacy, as determined by the patient. Open records do not per se affect confidentiality. Secure patient portals can protect confidentiality. It may, however, have a striking impact on patients' handling of privacy, which moves beyond the professional responsibility of the provider to the personal preference of the patient. Our preliminary findings indicate that many participating patients intend to share their notes with others. Who will they be: family members, caregivers, other doctors, nurses, or even lawyers? We are eager to find out and believe that with the proliferation of social media the ability for patients to instantly download a clinician's note may have enormous impact on health care delivery over time.

Open records extend new vistas for peer review, quality improvement, and the further evolution of transparency, all of which we believe may improve both health processes and outcomes. Indeed, studies suggest that particularly for a patient who is acutely or chronically ill, concerns about privacy fade rapidly in the face of need for full, rapid, and efficient communication among all parties vested in helping the patient get better. In this context, caregivers, family members, friends, and any other party a patient shares his/her record with can be viewed as members of the health care team that will profit from the knowledge such transparency confers.

We want to highlight also another potential benefit from such transparency: the impact on caregivers. Caregivers play a critical role in the dynamic between a growing number of patients and providers as they take on a wide range of functions, ranging from medical care, to patient advocacy, to the management of



administrative tasks. As the U.S. population ages and the burden of chronic illness and disability grows, the burgeoning role of caregivers presents an opportunity to involve caregivers in a more transparent world. Open notes and other related innovations can help engage caregivers more effectively by formalizing their role in the care relationship, thereby enlarging the clinician-patient dyad to a clinician-patient-caregiver triad. Empowering caregivers through such enhanced communication may well have a positive impact on both patient health outcomes and the extraordinary stress that caregivers experience. Indeed, it may improve the health of both the patient and the caregiver. We view caregivers' access to records as particularly promising for improvements in patient outcomes.

Finally, mental health is a special case that deserves particular attention, with strong feelings held on all sides of the glass wall. Some mental health professionals view sharing their notes with patients as something that should happen far more often; others are aghast at the thought. Virtually no data exist to clarify who might be helped, and who might be hurt. Examining how open records affect patients with mental illness deserves carefully focused attention now and in the future. Our hypothesis is that it will help far more patients than it will hurt, but we need to find out far more about this important aspect of health care and its interface with the transparency that we believe will inevitably spread further.

Thank you for considering our commentary. We would be pleased to provide further detail; requests should be directed to Tom Delbanco, M.D. We hope that meaningful use will evolve toward increased transparency, and that the insights we are gaining will prove useful in the voyage ahead.

Sincerely,

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