Patient Access to Medical Notes in Primary Care: Improving Engagement and Safety

Executive Summary

Primary care physicians at Beth Israel Deaconess Medical Center (BIDMC) provided patients with access to their clinical notes as part of a demonstration project, OpenNotes. The OpenNotes approach allows patients to read what their providers have written in their clinical notes, to supplement or reinforce what the providers discussed with them during the visit. The goals are to improve provider-patient communication and involve patients and families more actively in their care. The OpenNotes approach was associated with:

- Improved medication adherence,
- Improved communication,
- Increased understanding of care plans,
- Greater patient and family engagement, and
- Patient and provider satisfaction with the program.

Evidence Rating

Strong: The evidence consists primarily of a well-designed multicentered quasi-experimental demonstration and evaluation project. The project used mixed methods to evaluate the effect of the OpenNotes intervention on patients, providers, and practices. More than 100 primary care providers serving more than 25,000 patients volunteered for the project across three demonstration sites (BIDMC, Geisinger Health System [PA], and Harborview Medical Center [WA]). Comparisons of impact were drawn from pre-post evaluations, case-control (primary care physicians who volunteered to participate compared with those who did not), and stakeholder interviews. Additional qualitative studies found similar results.[1,2]

Use by Other Organizations

To date, more than 6 million patients have easy access to their clinicians' notes. A map of health systems who have adopted the OpenNotes approach is available at http://www.opennotes.org/who-is-sharing-notes/.

Date First Implemented

BIDMC began participating in the OpenNotes initiative in 2010.

Case Study

Problem Addressed

Patients often do not fully understand, or later do not remember, what their provider tells them during an office visit. This can lead to confusion about the diagnosis, the care plan, and any necessary followup activities.

- Communication breakdowns affect patient safety: Breakdowns in communication represent a significant contributor to medical error, near-misses, and unsafe conditions within primary care.[3] Failures in communication may be between the patient and provider, provider and practice staff, and patient and practice staff, or between the primary care practice and other health care providers (e.g., specialists, laboratory). Communication lapses between the patient and provider may lead to misunderstanding about the care plan or the expectations around testing and followup.

- Limited understanding of diagnosis and treatment affects care: Chronic disease management (or treatment) represents up to 75 percent of all medical care.[4] Patients with chronic disease are often subject to aggressive treatment goals and complex medication regimens, and are at significant risk of adverse events in ambulatory and primary care.[5,6]

Lack of understanding of how to take medications properly and maintain accurate drug lists, as well as limited understanding of the health condition for which the patient is treated may lead to less than optimal outcomes.

■ Lack of patient engagement affects patient outcomes: Engaging patients in their care is the cornerstone of health reform. Patients who do not understand or accept that they have an important role working with their provider to maximize their health are less prepared for provider visits than patients who are engaged.[7] Lack of active partnership between patients and providers may lead to less than ideal health outcomes, unmet medical needs, and delayed medical care.[7] Low patient engagement is also linked with increased medical costs and fewer preventive behaviors compared with patients with high levels of activation and engagement.[8]

Description of the Innovative Activity

Beth Israel Deaconess Medical Center (BIDMC) was one of three pilot sites for OpenNotes. OpenNotes is a national initiative, funded by a grant from The Robert Wood Johnson Foundation, that urges doctors and other clinicians to offer patients ready access to their visit notes. OpenNotes aims to improve communication between the provider and the patient and to involve patients and families more actively in their care. The approach allows patients to read what their providers have written in their clinical notes, to supplement or reinforce what the providers discussed with them in the visit. The notes can also remind patients of steps they need to take in their care plans.

Access to the clinical notes may help prevent harm, for example, from missed tests or followup. It also encourages patients to share information on their care plan with others, including family members and caregivers. The process for allowing open access to clinical notes includes the following elements:

■ **Ready Access to Encounter Notes:** At BIDMC, patients can view their encounter notes through an electronic patient portal. Providers encourage patients to sign up for the patient portal, which also includes a secure messaging function. Practices aim to make all patients aware of the availability of their clinical notes.

■ **Notification via Secure Email:** Once a clinical note is signed, the patient receives a secure message informing him or her that the note is available and encouraging him or her to sign in to the portal to review the note. The patient is sent a reminder message to review the note before the next scheduled visit. This process helps to provide reinforcement for reading the note and reminds the patient of the need for followup and any testing that he or she may have been asked to do before the next visit.

■ **Note Writing for Clinicians:** Knowing that patients can read their notes, clinicians may feel compelled to modify how they write the notes. The OpenNotes project found that providers generally did not need to change how they wrote their notes. However, to increase the usability of the notes for patients, clinicians should:

– Keep it simple – avoid jargon and abbreviations that may be misinterpreted or perceived as inflammatory.

– Provide context – use the note to stress important information and to incorporate lab or test results to give patients the full picture.

– Engage patients – use the note as a gateway for improved communication with patients and family members.

– Balance – use language that is nonjudgmental to avoid labeling. Highlight strengths and achievements to empower positive behavior change.

■ **Process for Correcting Notes:** Sometimes a patient identifies an error in the notes. Developing a process for receiving and responding to patient concerns over inaccurate information is important to setting expectations, building trust, and managing burden on busy health care providers.

Context of the Innovation

BIDMC is an urban academic medical center with community practices in and around Boston, MA, that volunteered as one of three demonstration sites for a multicenter study of OpenNotes. In the BIDMC pilot program, 39 primary care physicians allowed their 10,000+ patients access to their own notes. Based on the results of this pilot program, the BIDMC Clinical Operations Executive Committee decided to implement the program across all BIDMC ambulatory practices.

Impact

The OpenNotes approach was associated with improved medication adherence, improved communication, increased understanding of care plans, greater patient and family engagement, and patient and provider satisfaction with the program.

- **Improved Medication Adherence[9]:** In a study sample of 2,147 patients (756 OpenNotes participants; 1,391 controls with portal access but not part of the demonstration project), patients with access to their clinical notes had greater rates of antihypertensive medication adherence compared with controls (79.7% versus 75.3%). Medication adherence for patients on antihyperlipidemic medications was similar for OpenNotes subscribers and controls.

- **Improved Communication:** In the OpenNotes demonstration project, up to 92 percent of patients opened their notes. Patients reported doing better taking their medications (more than 60%), and more than 77 percent of patients felt more in control of their care.

- **Improved Understanding of Care Plans:** Interviews with BIDMC patients and providers indicate that one clear benefit of OpenNotes is greater patient understanding of the plan of care, including clarity of expectations for followup, additional testing, and reasons the provider prescribed a new medication.

- **Improved Patient and Family Engagement in Care:** Clinicians agree that the patient-provider dynamic changed for the better. According to one physician, open access to notes changes how the clinician and patient relate and is an "equalizing force that brings the patient in as a partner." It improves the feeling in patients that they can ask questions. A BIDMC leader reported that the "there is a feeling of equity in that what we are writing about patients and families is as accessible to them as it should be. The record is the patient's record."

- **Desire for Continued Use of OpenNotes[10]:** Almost 99 percent of patients at BIDMC and the other two pilot sites wanted continued access to their visit notes at the completion of the pilot study; no physician elected to end this practice. One patient stated that she felt more educated going into her appointments. Her questions were more specific, and the appointment was a more effective use of the time

with her provider. It gave her more confidence to ask questions and to ask for options. "I am more a part of the team than outside of the care itself," she said. In fact, she now looks for the availability of open access to her notes with all of her providers, and the unwillingness of providers to share their notes can influence whether she stays in their care.

- **Unexpected Benefit With Families and Caregivers:** One primary care physician found an additional unexpected benefit for patients who rely on family members to assist them in understanding their health and health care, particularly when the family members cannot accompany the patients on visits. Non-English-speaking patients who have English-proficient family members have provided the English-proficient family members with their notes to help them understand their plan of care. Likewise, some older patients have provided their children with their notes to help them better understand their care plan and need for medications and followup tests.

- **Improved Engagement With Explicit Invitations To View Notes11:** Note viewing persists in patients who received email alerts when a note was ready for viewing compared with a decline among patients who stopped receiving email alerts.

Evidence Rating

Strong: The evidence consists primarily of a well-designed multicentered quasi-experimental demonstration and evaluation project. The project used mixed methods to evaluate the effect of the OpenNotes intervention on patients, providers, and practices. More than 100 primary care providers serving more than 25,000 patients volunteered for the project across three demonstration sites (BIDMC, Geisinger Health System [PA], and Harborview Medical Center [WA]). Comparisons of impact were drawn from pre-post evaluations, case-control (primary care physicians who volunteered to participate compared with those who did not), and stakeholder interviews. Additional qualitative studies found similar results.[1,2]

Planning and Development Process

OpenNotes has a toolkit available for providers and institutions who are considering an open access approach to clinical notes (http://www.opennotes.org/toolkit/). The

toolkit contains guidance for patients, providers, and institutions, and includes tools such as frequently asked questions (FAQs) for patients and for providers, advice for providers on writing fully transparent notes, and tips for institutions for successful program launch.

To implement open access to clinical notes, a practice must design their own process, policies, and procedures. Practice leaders must determine how sharing visit notes will work for their practice. Early and extensive involvement of stakeholders, including providers, patients, and practice staff, is important to guiding the development process. For organizations with Patient and Family Advisory Councils (PFACs), it can be beneficial to involve the PFAC.

Important development questions include:

- Which clinician notes will be shared?
- What types of notes will be shared? Will they be limited by the type of encounter?
- Will all patients have access to their notes?
- How will notes be shared with patients?
- How will patients be educated about the accessibility of their notes?
- How will patients be notified of the availability of a new note?
- Will providers be able to opt in and opt out?
- How will feedback be collected from patients and providers?
- How will notes be shared in the absence of an electronic patient portal or for patients with low computer literacy/access concerns?
- What process will be used to make corrections to notes and to provide feedback to patients that corrections have been made?

Resources Used and Skills Needed

- **Staffing:** At BIDMC, the program required no additional personnel, as the patients, providers, and practice staff integrated the open notes process into their regular care routines.
- **Costs:** After the initial development and implementation period, there should be no program-related ongoing costs. In the pilot study, there was no net increase in messaging between patients and providers through the portal (i.e., email volume did not change).

- **Infrastructure:** While BIDMC elected to integrate the OpenNotes approach within their electronic patient portal, interviews with BIDMC leadership indicated that all that is really needed is a willingness to try and a photocopier or printer.

Funding Sources

The OpenNotes approach was developed with a $1.4 million grant from the Robert Wood Johnson Foundation's Pioneer Portfolio. This grant funded the initial OpenNotes research study at three institutions and included principal investigators at each site, research staff, and analysts. It also funded building functionality into the electronic health record to allow patients access to notes. (Since then, major vendors including Epic, Cerner, and AllScripts have made this functionality easily available.) In December 2015, four foundations (the Robert Wood Johnson Foundation, the Gordon and Betty Moore Foundation, the Peterson Center on Healthcare, and the Cambia Health Foundation) agreed to jointly fund a 3-year, $10 million expansion of the OpenNotes movement to spread access to clinical notes to 50 million patients nationwide (http://www.opennotes.org/foundations-unite-to-support-access-to-clinical-notes-for-50-million-patients-nationwide/).

At BIDMC, efforts continue to further enhance patient safety and patient safety reporting through a research grant funded by their self-insurance trust.

Getting Started With This Innovation

- Make the case to your institution: Before development of an OpenNotes approach starts, it is important to obtain support from institutional stakeholders. Stakeholders should understand the benefits of the improved communication and increased patient engagement that have been demonstrated with open access to notes.
- Prepare clinicians and frontline staff for the launch: Preparing clinicians and staff is an important part of the development process. This includes giving presentations about the process to the practice, answering clinicians' questions, communicating with the administration and staff, and ensuring that staff have access to patient-facing materials and handouts for patients.

- Inform patients and their caregivers: A comprehensive communication plan is important to let patients and their families know what the program is, how to access the notes, and why the organization has decided to move forward with this approach.

Sustaining This Innovation

- **Ease of Use for Patients:** It is imperative for patients to be aware that they have open access to their notes. One patient reported, *"It's so important to get the word out. I am amazed at how many people don't know how effective this tool can be."* It is also necessary that use of the notes be easy for patients. This includes easy access, easy navigation, and easy error recovery (such as retrieving a lost password). Some training or coaching in using and navigating the system is beneficial to patients. To prepare for widescale implementation, BIDMC solicited feedback from patients and families on the usability of the system to find areas where patients had questions. In addition, one BIDMC physician stated that she is currently tasked with looking into how to make the notes more accessible and interesting to patients to improve patient engagement and increase shared decisionmaking. Another BIDMC physician suggested that better formatting and presentation of the notes could make them easier for patients to read and better highlight important next steps in their care.

- **Robust Infrastructure for Responding to Patients:** It is important to have the infrastructure in place to handle the impact of shared notes. Based on the notes, the patient may have questions about the plan of care or a safety concern or may have identified an error in the chart. It is important for the institution to be able to accommodate patients' inquiries and to meet patients' expectation of a prompt response.

- **Solicitation of Feedback:** BIDMC has an ongoing pilot program as part of the OpenNotes Patient Safety Initiative funded by their self-insurance trust. BIDMC has embedded a patient safety reporting tool within the electronic patient portal that requests feedback from patients on what they thought about the note and whether they think there are any mistakes in it.

The consensus at BIDMC is that open access to clinical notes is sustainable because it must be. It is the ethical thing to do and consistent with the goal of patients taking ownership of their own care. *"Once patients have access to their notes, they are not likely to be willing to give it up."*

Use by Other Organizations

To date, more than 6 million patients have easy access to their clinicians' notes. A map of health systems who have adopted the OpenNotes approach is available at http://www.opennotes.org/who-is-sharing-notes/.

Spreading This Innovation

At BIDMC, open access to clinical notes has spread from the initial 39 primary care physicians of the pilot project to all ambulatory practices. Nationally, the OpenNotes initiative is working to make sharing visit notes with patients a routine part of care. Expansion plans are underway at other health systems across the country.

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Innovator Disclosures

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For a complete listing of OpenNotes publications, see: http://www.opennotes.org/research/publications/.