Implementation

Designed for health professionals working to adopt OpenNotes, the Implementation Toolkit provides materials to help you gain support for adopting OpenNotes within your health system, think through policy decisions and communication materials to prepare for launch, and get the most out of note sharing once you're up and running.

1. Getting Started

Making the Case for OpenNote?

Inviting patients to read and review their health information, especially the notes written after a clinical encounter, is an important way to improve communication between patients and clinicians, to enhance engagement, to help patients become more active in their own care. Moreover, research continues to show that engaged patients have better health outcomes.

Patients Want OpenNotes and Report Benefits from Reading Their Notes

The original OpenNotes study involving patients at Beth Israel Deaconess Medical Center in Boston, Geisinger Health System in rural Pennsylvania, and Harborview Medical Center in Seattle found that 80% of patients offered OpenNotes read at least one note over the year-long study period, and 99% wanted the practice to continue, whether or not they chose to read their notes. Subsequent survey data from Kaiser Permanente (NW) and the Department of Veteran's Affairs (VA), the first system to adopt OpenNotes across all disciplines, have shown similar results.

Study Highlights:

- 77-87% of patients said OpenNotes helped them feel more in control of their care.
- 60-78% of those taking medications reported better adherence.
- 85% of patients say they would choose a clinician based on the availability of OpenNotes.

OpenNotes Results
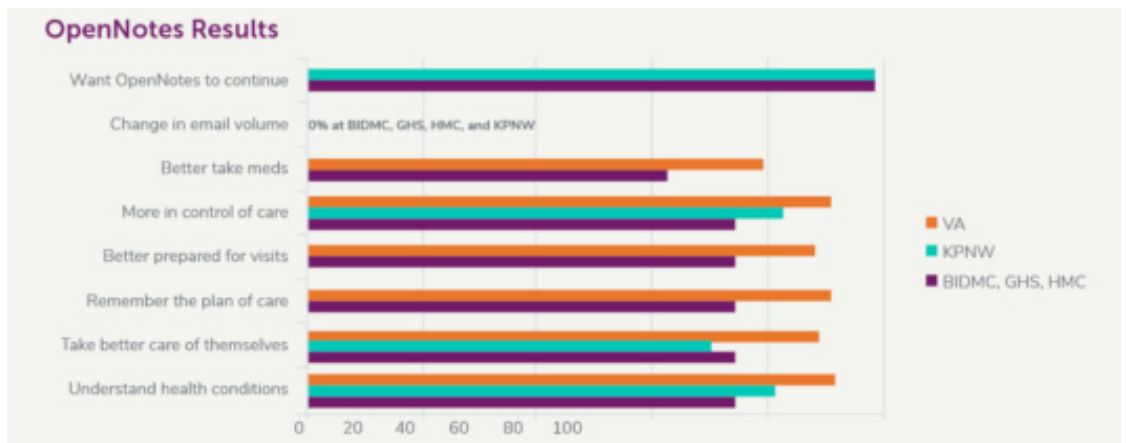
➦ Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead, Annals of Internal Medicine (http://annals.org/aim/article/1363511/inviting-patients-read-doctors-notes-quasi-experimental-study-look-ahead)

➦ When doctors share visit notes with patients: a study of patient and doctor perceptions of documentation errors, safety opportunities and the patient–doctor relationship, BMJ Quality & Safety (http://qualitysafety.bmj.com/content/early/2016/05/26/bmjqs-2015-004697)

Patient and Clinician Satisfaction Improves with OpenNotes

A recent study published in BMJ Quality and Safety showed that 99% of patients felt the same or better about their doctor after reading notes. Positive effects on the patient-doctor relationship were most dramatic among patients generally thought to be most vulnerable – older, non-Caucasian patients with lower self-reported health and fewer formal years of education – even after reading as few as one note. This suggests that the simple act of inviting patients to read their note has the power to break down barriers in care. Additionally, more than half of doctors felt that patient satisfaction and trust increased with OpenNotes.

> "Although some people worry that poorly written, offensive, or even erroneous notes might erode trust and damage the patient-doctor relationship, results of a recent study suggest the opposite. Overall, patients felt the same or better about the doctor, and clinicians thought sharing notes was a way to improve patient satisfaction, trust and safety."
>
> — *SIGALL BELL, MD, OPENNOTES, DIRECTOR OF PATIENT SAFETY AND DISCOVERY*

OpenNotes Makes Care Safer

As patients and their caregivers become increasingly interested in their health data, OpenNotes can provide a way for them to make health care safer. Clinicians review thousands of notes, but a patient reviews just one, his or her own. Giving patients the ability to review records offers the potential for enhancing communication and safety partnerships between patients and clinicians, identifying documentation errors, and preventing missed follow-up tests or referrals in the gap between visits.

Studies show that patients forget between 40 and 80% of the information communicated during a visit. Patients and families report that ready access to notes reminds them about important next steps, tests and procedures, and allows them to review what happened at the visit in the comfort of their own homes.

> *"I felt like my care was safer, as I knew that patients would be able to update me if I didn't get it right."*
>
> *— A DOCTOR*

75% of patients who responded to a comprehensive safety survey reported that reading notes helped them better understand the meaning of results and the reasons for referrals and tests. Up to 50% reported that reading notes helped them complete follow up appointments, suggesting that better understanding of the rationale behind tests can lead to increased patient activation.

Improve Accuracy and Allow for Identification of Mistakes: Patients know themselves best. Allowing them to review their own notes helps them to identify and report documentation errors that may be clinically important.

Note sharing sends a strong message about transparency and inclusivity, empowering patients as safety partners. As demonstrated in medical error disclosure, open and honest communication can help decrease litigation.

OpenNotes may also build trust, a cornerstone to stemming liability.

Study Highlights:

- 7% of patients reported contacting their doctor's office about something they read in their note.
- Among those patients, 29% did so because of a perceived error in the record, suggesting an opportunity to improve safety.
- 85% of those who reported an error were satisfied with how their doctor handled the issue.
- No doctor ordered additional tests or referrals as a result of OpenNotes.

OpenNotes Helps Care Partners

The growing need to engage caregiver/care partners in care processes more effectively is documented in the September 2016 NASEM report, Families Caring for an Aging American, as well as articles from the AARP, and the New York Times.

Family members and other care partners are among the most vigilant of health system stakeholders. Work undertaken by Jennifer Wolff, PhD, from Johns Hopkins Bloomberg School of Public Health, demonstrates the benefit of shared access to notes.

Study Highlights:

- Patients of all ages elected to share access to their patient portal account.
- 42% say they share access because their care partner helps them manage health care activities.
- 30% say they share access with a care partner in case of emergency.
- 18% say they share access because they themselves do not use a computer.

Wolff also found that the benefits of OpenNotes were as powerful for care partners as they are for patients themselves. OpenNotes offers an invaluable tool for improving transparency, communication and continuity of care while enhancing a stronger patient-care partner therapeutic alliance involving more productive discussion and greater agreement about patient care.

More Study Highlights:

- A third of care partners accessed notes because they weren't able to attend an appointment.
- 86% of patients and 82% of care partners had more productive discussions about the patient's care.
- 85% of patients and 79% of care partners stated they were more likely to agree about the patient's treatment plan.
- 94% of patients and their care partners reported better understanding of patient health conditions, better remembered the patient's care plan, and felt more in control of care.

Clinicians Report Little Change in Workflow

Many clinicians are very concerned that their workload will increase with OpenNotes. They worry about the length of the visit, increases in email traffic, and changes in the way they document visits. In our research and in listening to the experience of the dozens of health systems that have implemented OpenNotes, the vast majority of clinicians report neither longer visits nor increased email traffic. If they notice a change at all, they are more likely to state that patients are more prepared for visits and more engaged in their care.

About 20% of clinicians do report making some changes in the way they document, though most of those changes are described as minor, appropriate, and productive. For example, clinicians note reducing the use of acronyms and potentially judgmental language, as well as defining medical terms and making language simpler where appropriate.
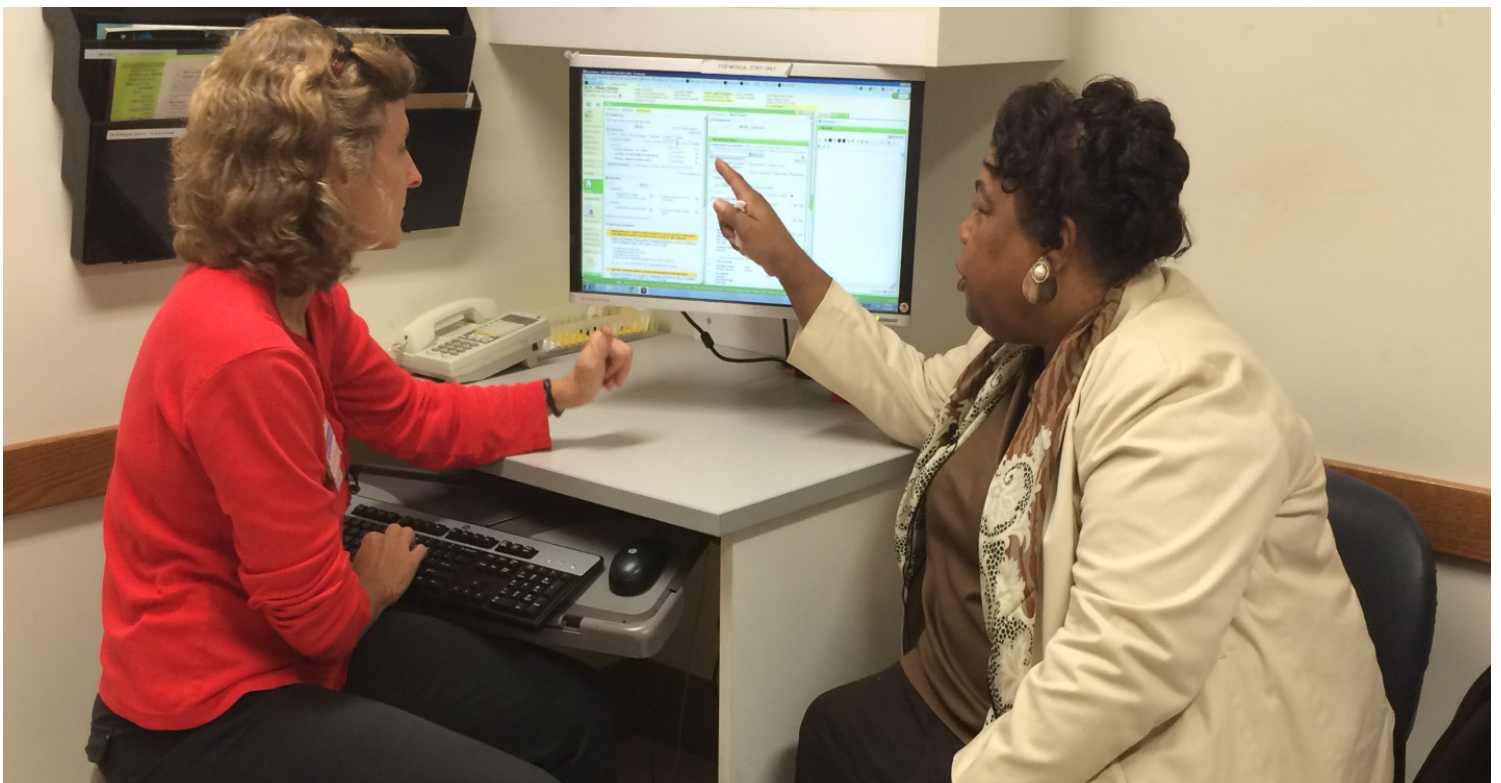
2. Getting Ready to Launch

Preparing to Roll Out OpenNotes

No two systems implement OpenNotes in exactly the same way. While in some respects it is a relatively simple intervention, there are many things to consider as institutions think through how the practice of sharing visit notes will work in their particular circumstance.

We encourage you to invite clinician and patient representatives from your institution to participate in planning for OpenNotes, and for monitoring its evolution once launched. We offer some suggestions based on what we have learned from many colleagues and collaborators nationwide.

Institutions Need to Make Some Decisions

About a half of those moving toward fully transparent medical records choose first to 'pilot' OpenNotes at the institutional level, or within specific departments. Our experience to date is that pilot programs have almost invariably yielded positive results and provide data that instill confidence and set the stage for broader implementation.

Which departments or settings will share notes? Some systems, institutions, or practices implement OpenNotes in all clinical settings at the same time. Others have felt more comfortable starting in one area, such as primary care, and gradually adding specialties, emergency medicine and inpatient notes over time.

We recommend either implementing OpenNotes either across the board as a matter of policy, or with a clinician "opt-out" policy. Our experience is that both approaches work well and can be reassuring to clinicians. We also know that some institutions have implemented with a requirement for clinicians to "opt-in" to note sharing at the clinician or patient level. This can create a frustrating patient experience, and it can take months or even years before the benefits of note sharing are recognized. Therefore, it is important to consider carefully both an "opt-out or "opt-in" process. Decide also how your institution will grant permission to those wanting to opt out. For example, at BIDMC, a clinician wishing to do so needs explicit permission from the department head.

You can read more about specific recommendations in pediatric and adolescent medicine, mental health settings, and for caregivers.

Which clinicians will share their notes? We believe patients can benefit from reading notes written by most clinicians involved in their care. It's important to consider if you'll open only doctors' notes, or open notes more broadly by including nurses, nurse practitioners, case managers, social workers, physician assistants, occupational and physical therapists, clinical pharmacists, dieticians, or others who write notes. You may also need to think about processes for sharing notes written by fellows, by residents, by medical and nursing students, and other trainees.

What types of notes will you share? Will you open all types of notes (phone, office visit, letters, etc.) or limit them to certain encounters? Some systems make all electronic notes available, including those written prior to starting the open notes initiatives. Others choose to open notes beginning with the organization's implementation start date.

How will you accommodate care partners? Many patients tell us they share their health information with trusted care partners. In addition to secure access for patients, many systems have implemented proxy access for care partners with patient permission. It may also be helpful to give patients the ability to select which information they want to share with their care partners.

How will you share notes with patients?

- While most organizations implement OpenNotes electronically through patient portals, notes can also be printed at the end of a visit, or emailed or mailed to the patient at a later date.

- We strongly recommend reminding patients by email when a note is available.

- We recommend offering clinicians the ability to keep a note "private" (though our experience is that fewer than 1% of notes are hidden, and the percentage drops over time as clinicians and patients gain comfort with the new practice). In these cases it's important to communicate with patients about such decisions.

- It's also important to develop a workflow to manage patients' requests to change or amend their notes. **NOTE**: Very few patients contact the clinician's office about something in the note, but among those who do, nearly 30% discovered an error in the record, suggesting an opportunity to improve safety.

How will you facilitate amendments to the record? In most practices, changing a note is at the clinician's discretion. Patients and families may catch clinically important mistakes in notes, or find lapses in follow up that, once rectified, improve safety. Clinicians can often use existing mechanisms to modify a note as they move from paper to electronic records; for example, through addenda or other institutional procedures.

Institutions may also develop new methods for patients to report inaccuracies and receive notification that changes have been made.

You may want to designate a specific contact – a clinical staff person to triage concern or a member of a "patient relations" team – for patients who have concerns they would like to address with someone other than their clinician.

"It doesn't make me lose confidence in them and, in fact, I think I respect them more for admitting that there was a mistake and apologizing for it rather than sort of brushing it under the table."

— EILEEN, A PATIENT

Tools for implementation

For optimal success, it's critical to communicate with patients, clinicians, administrators, hospital leadership about what OpenNotes is and how it will be implemented, as well as the potential benefits of sharing notes. We've seen that institutions that let patients know about the availability of OpenNotes see substantial increases in portal registration. **Read sample Communications Materials in the Appendix of this document.**

"We often find that clinicians are unaware that their own institution has OpenNotes, and that's only because a communications strategy has not been implemented with the roll out."

— JOHN SANTA, MD, OPENNOTES, DIRECTOR OF DISSEMINATION

Communicating with Clinicians and Other Staff about OpenNotes

- Organize a grand rounds, town hall meeting, or smaller talks to present data about OpenNotes.

- Identify "OpenNotes champions" across specialties to help get the word out.

- Share communication from the CEO and other leadership about implementation plans, including data about the benefits of sharing notes.

- Prepare a set of FAQs that answers clinicians' questions. Feel free to use these FAQs to start.

- Share OpenNotes materials, including research, links to videos, and patient and clinician FAQs on your intranet.

- Write an article for your intranet and for newsletters.

- Create an OpenNotes button on your web portal for ease of patient navigation.

Communicating with Patients and Caregivers about OpenNotes

- Send an introductory e-mail about your web portal and OpenNotes.

- Create an OpenNotes page on your external website and patient portal; you can include links to the OpenNotes videos, FAQs, instructions for finding their notes in the EHR and other helpful resources.

- Use the OpenNotes logo and name on your website, portal and other communications materials so that patients know the notes are different from other parts of their medical record.

- Write an article for your patient newsletter and external website.

- Create waiting room posters and materials to give to patients at appointments.

- Let your patients know about OpenNotes on social media, including Twitter and Facebook.

- Distribute a press release and/or advertise in local media.

- Collect and share stories about clinicians and patients who are sharing notes.

3: Making OpenNotes Work Well

Getting the More Out of the EHR and Notes

Once you're up and running with OpenNotes, there are many opportunities to create efficiencies for you and your patients. Reading the notes helps patients remember treatment plans. Patients also say note reading helps them take their medications as prescribed. Many patients say they email or call their clinicians less because they were able to answer a question by reading their notes. And both clinicians and patients report that engaging with the note helps with agenda setting, making the visit more efficient, and helping the clinician and patient feel more satisfied with the visit and ongoing relationship.

More than 90% of patients say they want easy access to their notes. Messaging patients about the benefits of communicating using the portal, including access to OpenNotes, can be an effective way to increase portal registration. We also suggest sending patients home with print materials and providing in person support at office visits to help patients register on the portal.

Improving the Patient Experience

The Invitation is Important: We find that the simple act of inviting patients to read their notes means a lot to many of them. Our research has shown that patient satisfaction and trust improve with note sharing, and that patients traditionally considered among the most vulnerable report the biggest change in the clinician-patient relationship, even with as little as one shared note.

↱ Patients learning to read their doctors' notes: the importance of reminders, JAMIA (https://academic.oup.com/jamia/article/23/5/951/2379793/Patients-learning-to-read-their-doctors-notes-the)

Create an OpenNotes Button: Even the most tech savvy patients sometimes find patient portals difficult to navigate, and many give up before locating the information they're looking for. Using the word "OpenNotes" can help patients get where they need to go, and creating an OpenNotes button that takes the patient from the landing page to the notes page ensures that they won't get lost.

Assessing Satisfaction: Add OpenNotes specific questions to existing patient surveys to gain greater knowledge about how patients feel about using their notes and learn about the ways they want to engage with their health information.

Talk About the Notes: Investing a few minutes at an appointment talking about the notes can strengthen the relationship. Checking in with the patient to see if the notes accurately capture the visit can help the patient feel understood and allow the clinician to gauge the level of understanding of the care plan.

Send Email Reminders: Research has shown that sending an email message to patients when a note is signed and ready to read is a very effective way to remind patients to engage with their medical information. Institutions that send email reminders have a read rate roughly three times that of those practices that do not send reminders.

Get Feedback: Work with a staff member, for example, a patient relations staff person, to streamline processes for patient feedback, especially as it relates to helping patients locate their notes on the portal or correcting inaccuracies in the record.

> *"When I read the notes, I realized I hadn't described my daughter's condition in a way that helped the doctor understand what she needed. I was able to go back and clarify so we could develop a better treatment plan."*
>
> — AMY, A MOM

Improving Note Writing

Writing Transparent Notes: Since HIPAA entitles virtually all patients to obtain copies of their complete medical records at any time, it is always best to write notes with the assumption that patients may read them.

In the initial OpenNotes study, most doctors reported that they did not change the way they wrote their notes. In fact, while in a pre-study survey, 50% of clinicians worried that OpenNotes would impact their note writing, after they worked with OpenNotes, the number dropped to 20%, with most reporting that the changes were minor and doable. Patients did not expect clinicians to write notes differently. They more often reported being resourceful enough to research anything they didn't understand, or bringing it up at their next appointment.

Over time, however, many clinicians do report changing the way they write their notes, most often to provide clarity. Most clinicians who say they have changed the way they write their notes believe the changes have made the notes better, not just for the patient, but for other clinicians who also rely on the notes.

Still, a minority of clinicians reported that they changed how they documented potentially sensitive topics. These included mental health, obesity, substance abuse, sexual history, elder, child or spousal abuse, driving privileges, or suspicions of life-threatening illness. These are not new dilemmas, but they gain urgency in an era of transparency, as exemplified by shared visit notes.

Note Writing Suggestions:

- **Difficult Conversations:** If it's important enough to put in the note, it's important enough to talk about. Knowing that "you're on the same page" can improve trust and the relationship.

- **Highlighting Strengths:** Describing the patient's strengths and achievements alongside his/her clinical problems can help the patient gain a broader context within which to consider his or her illness and tackle difficult behavioral changes.

- **Avoid Jargon, Acronym, and Abbreviations:** Avoid jargon and abbreviations, especially ones that might easily be misinterpreted (e.g., "SOB" or "patient denies"). Briefly define or simplify medical terms (short of breath, rather than dyspneic).

- **Provide a Balanced Perspective**: Complement sensitive mental health diagnoses with non-judgmental descriptive information. To empower positive change, highlight the patient's strengths and achievements, balancing thereby descriptions of their symptoms and clinical problems.