

Sharing Clinical Notes With Patients

A New Era of Transparency in Medicine



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How Will This Toolkit Help Me?

Learning Objectives

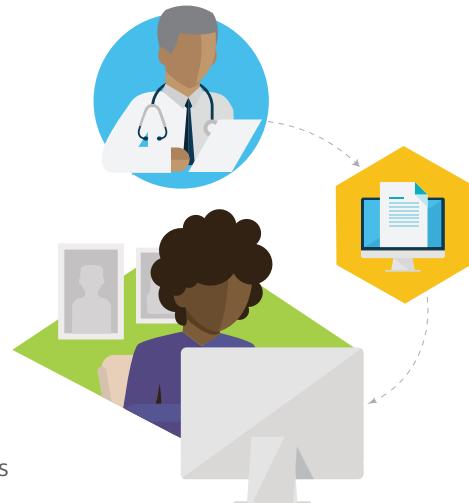
- 1 Examine evidence to supporting the case for sharing visit notes with patients
- 2 Identify how to educate team members on the new federal mandate for open notes
- 3 Discover resources to learn how to write notes that will be shared with patients and help clinicians, patients, and caregivers make the most of them



Introduction

Shared visit notes, which are also sometimes called open notes, are everyday clinician notes made readily available (“open”) to patients. There is no difference between an open note and a typical clinician note.

The concept of shared clinical visit notes is not new. Individual physicians and organizations started exploring the potential of transparency in clinical records in the 1970s.¹ The first efforts to study the impact of shared visit notes on physicians and patients began in 2010—and thus, the [OpenNotes](#) movement was born. The movement started as a pilot with 105 primary care physicians across 3 large medical institutions sharing notes with 20,000 of their patients.¹⁻³ OpenNotes is now an international movement based out of Beth Israel Deaconess Medical Center in Boston, a major Harvard Medical School teaching hospital. As a group, OpenNotes studies and disseminates its findings on the effects of shared visit notes on patients, care partners, and clinicians. OpenNotes works with collaborators around the country and overseas to study transparent communication in health care. OpenNotes does not develop software and it is not a technology company. OpenNotes is fully funded by grants and philanthropic gifts. Although as of 2020 more than 50 million patients in the United States and Canada had access to their visit notes, recent US legislation is mandating that visit notes be open to **all** patients.⁴



The Information Blocking Rule Mandate for Shared Visit Notes⁴⁻⁶

Effective April 5, 2021:

As part of the 21st Century Cures Act, the final rule on Interoperability, Information Blocking, and ONC Health IT Certification (“Information Blocking Rule”) nationally mandates that patients be granted access to all of the information in their medical records, electronically and without charge or delay, and through patient portals or, to the extent possible, through third-party smartphone applications (apps).

The Information Blocking Rule specifies that clinical notes are among the electronic health information (EHI) that must not be blocked, while allowing for some specific exceptions. The 8 types of clinical notes that must be shared include⁵:

1. Consultation notes
2. Discharge summary notes
3. History and physical
4. Imaging narratives
5. Laboratory report narratives
6. Pathology report narratives
7. Procedure notes
8. Progress notes

In addition to the 8 required types of clinical notes, there are 8 types of exceptions that fall under 2 general categories that involve (1) not fulfilling EHI requests and (2) procedures for fulfilling EHI requests.^{7,8} OpenNotes often highlights exceptions from the first category, which covers preventing harm, privacy, and safety concerns. These 2 examples are types of clinical notes excepted from the Rule's definition of EHI that would fall under the first category:

1. Psychotherapy notes, written by any health professional, which are separated from the rest of the individual's medical record; and
2. Information compiled in reasonable anticipation of, or use in, a civil, criminal, or administrative action or proceeding.

This toolkit will help you and your team address common clinician concerns and provide guidance on best practices for sharing clinical notes with patients. In addition, the AMA has developed a 2-part resource to help physicians understand and comply with the regulations.

Q&A

How do health organizations and practices give access to shared visit notes?

Health organizations and practices accomplish this via a sharing functionality in their organization's electronic health record (EHR). Activating this feature allows the clinician's visit or progress note to be available to patients with portal accounts to read. There's no separate template for this—once the "switch is flipped," patients gain electronic access to their notes signed by clinicians. This is similar to how other health information, eg, lab reports, medication lists, among others, have been shared online with patients for years. Printed copies of notes can be shared by practices without an EHR or with patients who don't have access to a patient portal.

Is the confidential relationship between patients and clinicians different when using open notes?

No. The relationship remains confidential and regulated. Open note-sharing should utilize the privacy and security measures inherent to an organization's portal and EHR system. Patients may choose to share their own notes with whomever they wish.

Will clinicians need to change how they write notes?

For the most part, no. Clinicians can explain that notes are clinical documents and thus may not be written for the lay reader. However, the clinician may also choose to adapt their notes—with minimal effort—to accommodate varying levels of health literacy. Patients understand that notes are clinical documents and do not expect them to be written for a lay reader. Most clinicians reported that sharing notes with patients did not affect their notes' value for other clinicians.⁹ Further details on documentation style are included in STEP 4 of this toolkit.

Will patients be worried or confused by reading their notes?

During initial voluntary rollouts by early implementers, many clinicians were concerned that patients wouldn't understand, or would misinterpret, the information in their notes. However, survey data suggests that this rarely happens.^{3,10-12} Rather, most patients appreciate the window into what their clinician is thinking and value seeing themselves reflected in the note.^{3,10-12}

In a recent survey of patients at the 3 original OpenNotes pilot sites, 96% of patients understood their notes with little difficulty and few reported being very confused or more worried after reading their notes.^{11,12} It's important for clinicians to let patients know that any points of confusion regarding their visit notes can be clarified at the next visit or with an additional televisit. In the same study, patients rated reading their notes very important for helping take care of their health and for feeling in control of their health.^{11,12} It is important to note that less educated and non-White patients were more likely than White patients and those with more education to rate notes as very important for remembering their care plan and engaging in their care.¹³

Six STEPS For Your Practice to Successfully Share Open Notes

1. Educate Your Team About the Benefits of Open Notes
2. Address Practice-Specific Concerns
3. Prepare Patients and Their Care Partners
4. Adapt Documentation Style
5. Learn How to Handle Challenging Topics
6. Collect Feedback and Refine Your Approach

1

Educate Your Team About the Benefits of Open Notes

As with anything new, there may be some initial skepticism about open notes. Discuss the importance of transparency with your team and answer questions about open notes during team meetings. Educate team members on the benefits of open notes while addressing legal requirements. Studies have shown that note-sharing provides benefits to both patients and physicians.

Benefits for Patients

Research shows that patients who read their notes say they^{2,3,11-18}:

- Feel more in control of and engaged in their health care
- Recall their care plan more accurately
- Are better prepared for visits
- Have a better understanding of their medical conditions and medications
- Are more likely to adhere to their medications
- Are able to identify clinically important errors in their notes
- Are not more worried or offended after reading their notes
- Have more successful conversations and stronger relationships with their doctors

Benefits for Clinicians

Research shows physicians and other clinicians who shared their notes reported^{2,3,9,10}:

- Improvements in patient satisfaction, safety, communication, and education
- Improvements in the patient-physician relationship, including enhanced trust, transparency, communication, and shared decision-making
- Patients who are better prepared for their clinic visits and are becoming more actively involved in their own care
- No increase in time required needed to address patient questions about their notes
- Willingness among physicians to recommend to colleagues the use of open notes

As described previously, some organizations adopted open notes years ago. For example, clinicians at the Mayo Clinic have been sharing all visit notes with patients since 2013. There are opportunities to network and learn about best practices from other organizations and physicians who have already implemented open notes. OpenNotes and others have created resources that explain the benefits of shared visit notes and offer tips for using them in your practice.

**Pocket Card**

This card gives a brief overview of how open notes can benefit patients and clinicians.

**OpenNotes by the Numbers**

This fact sheet reviews the evidence for open notes.

**Implementation Toolkit from OpenNotes**

Additional information for practices preparing to use shared visit notes.

**How can sharing visit notes improve patient safety?**

Patient safety research from the OpenNotes team suggests that sharing visit notes could improve patient safety by^{2,3,10,15,16,19-21}:

- Helping patients remember recommended tests, immunizations, and procedures, thus preventing diagnostic delays.
- Encouraging patients to speak up when they have questions about symptoms, tests, or treatment plans. This is especially beneficial for patients whose symptoms do not improve with treatment or patients whose symptoms persist despite negative or inconclusive test results.
- Involving informal caregivers, giving them access to information that can help reconcile multiple treatment plans and recommended laboratory tests for chronically ill patients.
- Enhancing trust between the physician and patient, leading to less “doctor-hopping” or fragmented care that can result in delayed diagnosis.
- Detecting and correcting documentation errors earlier than current approaches.
- Helping patients better understand details about their medications and their medications’ possible side effects, making improved adherence more likely.
- Finding documentation errors that doctors determine are serious sooner. Twenty-five percent of doctors who were offering open notes for more than a year reported that patients have found errors that the doctors felt were serious.

2

Address Practice-Specific Concerns

It is important to take into account the various policy considerations that your practice or organization may have, such as:

- Whether any notes created prior to implementation will automatically be shared with patients
- How notes that deal with sensitive topics (eg, adolescent health, mental health, obstetrics) will be handled
- How patient questions regarding notes will be handled
- How important errors found by patients will be corrected
- How proxies (ie, care partners) will access patient notes
- Who will educate patients on registering for the patient portal and on how to find their notes within the portal
- Who will educate physicians about the changes

To further prepare team members, provide department leaders and/or your organization's CEO with a [template email](#) they can send to team members. It is also helpful to post information about adopting open notes on your practice or organization's intranet site.

Q&A

Does using open notes impact office workflows?

In the original pilot study, most primary care doctors reported little or no impact on daily workload, with less than 5% of physicians stating longer visits and less than 8% saying they spent more time addressing patients' questions outside of visits.^{2,3} In fact, many physicians involved in the open notes pilot study were surprised by how little effect the intervention had on their practice workflows.^{2,3}

The volume of phone messages and email communication from patients also did not change after open notes was adopted. In fact, 84% of physicians reported that patients reached out about something in their notes less than monthly or never.⁹

The most positive impact reported related to the efficiency of the visit. There have been many reports of patients with open notes coming to visits better prepared and remembering the care plan between visits.^{2,3,11,12}

What are the roles of individual care team members in making open notes work?

All team members should be aware that notes must be shared with patients. This means team members should have enough understanding to explain the concept and set expectations with patients about where and when they will see their notes. Medical assistants (MAs), health coaches, and/or front desk team members can assist patients with registering for the patient portal or locating their notes once the patients are registered and logged in.

Can open notes be used with any EHR?

Most major EHRs have the technical capacity to share notes online with patients easily. The implementation of the 21st Century Cures Act Information Blocking Rule requires all vendors to have this capability and to allow patients the option to access notes through any third-party app of their choosing. EHR vendors are expected to have this fully rolled out to their physician customers by late 2022.

Can notes be shared without a patient portal?

Many clinicians have shared visit notes widely with their patients throughout their careers, decades before EHR or online portal technology was available. Though most practices that use open notes share notes electronically through their patient portal, there are several options that may better suit your practice's workflow. Remember that you don't need specialized technology to take advantage of open notes. You may consider sharing visit notes with patients as printouts stapled to the after-visit summary or handed to them as they leave the exam room. This is a convenient option if your practice layout includes a printer located in or near the exam rooms. Printing notes is also helpful for patients who may not be able to access them via computer at home.

Should notes be shared in sensitive subspecialties such as oncology, obstetrics, behavioral/mental health, or adolescent medicine?

All specialties should share notes in order to facilitate interoperability. Some specialties, particularly those in which significant patient follow-up is required, such as endocrinology, oncology, and obstetrics, could benefit greatly from open notes.²²⁻²⁷ Patients can use the notes to understand and share follow-up care recommendations, including physical therapy guidance, referrals, and upcoming labs and exams. Sharing clinical notes may also be especially beneficial for a patient with complex chronic conditions whose health care is managed across specialties.

Research in oncology and behavioral health suggests that patients appreciate having access to these notes and report benefits from reading them.²²⁻²⁷

Note-sharing in adolescent medicine may pose additional challenges when the patients' parents may have access to the same account.^{28,29} In many instances, documenting a teen's confidential information (eg, sexuality or gender identity, drug or alcohol use, requests for contraception or abortion) within their medical record means that their proxy or parent could potentially also have access to the information. Many teens' EHR portals are established by their parents. Some EHRs may allow clinicians to segment sensitive information and prevent it from being shared, but not all have this functionality. Clinicians seeing adolescent patients should discuss these issues with their legal and compliance officers before sharing notes with patients, taking federal and state laws and regulations into account. Clinicians should also work with their EHR vendor to create processes that support safe and secure access to sensitive information. Further guidance on pediatric and adolescent medicine is also provided by OpenNotes experts.

3

Prepare Your Patients and Their Care Partners

To prepare patients and their care partners:

- Send an email introducing open notes and how it will impact them.
- Make patient-specific FAQs available in all waiting rooms, in exam rooms, on your patient portal, and wherever else your patients may easily access them.
- Post information about adopting open notes on your practice or organization website and patient portal.
- Supply easy-to-reference pocket cards that describe the benefits of open notes for patients and clinicians.
- Promote the adoption of open notes through your practice's and/or organization's marketing channels, such as the practice newsletter, Facebook page, or Twitter account.



**Patient FAQs**

This handout provides more background on open notes and answers common questions patients have about this new approach.

**Waiting Room Poster**

Add your logo to this poster that explains open notes and hang it in your practice.

Depending on the type of EHR your practice uses, you may be able to create an automatic reminder system so patients know to review their notes before their next visit. Reminders are proven to increase note-reading rates.³⁰

As your practice gains more experience with open notes, help spread the word and continue to engage your stakeholders by:

- Collecting stories from patients and clinicians in your practice who are using open notes and share them through your practice's and/or organization's marketing channels, such as the practice newsletter or website.
- Asking patients and clinicians to blog about their experiences with open notes and to consider sharing these experiences on social media using #opennotes.
- Committing to track open notes utilization by both patients and clinicians so you can regularly update stakeholders with the findings.
- Adding questions about open notes to your patient satisfaction survey.



Can patients give caregivers, family members, or proxies access to the patient's visit notes?

It's not uncommon for patients with chronic or complex illnesses to want to share their medical information, although not all organizations allow for proxy access via the secure patient portal.³¹ Patient safety and confidentiality are paramount, and there are protective measures you can take to minimize privacy concerns.^{32,33}

First, have a process in place for patients to privately and securely grant access to their records and visit notes to another person of their choosing. Procedures for signing up for proxy access vary across organizations. If your practice has a patient portal, you may have already dealt with this question.

Second, if your patient portal allows, be sure that your patients know that the proxy can view visit notes on the portal. Some organizations restrict the functions that the proxy can access, while others allow the proxy to view and use all functions. Lastly, let patients know that they can retract viewing privileges from a proxy or caregiver at any time. Granting caregivers, family members, and proxies direct access to a patient's visit notes and other medical information must be done in compliance with applicable privacy and security laws, including HIPAA and state law.

Are patients charged for accessing their notes like they are for a medical record?

The 21st Century Cures Act and its implementing rules mandate that patients have access to all of the electronic information in their medical records without charge or delay upon request.³⁴ Eventually, this will apply to access via third-party smartphone applications (apps).

4

Adapt Documentation Style

You or your team don't need to make dramatic changes to your writing style because patients will now be able to view notes. In the original OpenNotes pilot, clinicians were not required to change how they were writing their notes. In a recent follow-up survey of clinicians at the 3 original pilot sites, some did acknowledge adjusting their documentation to:

1. Eliminate language that might be perceived as critical of the patient.
2. Remove terms such as “non-compliant,” “patient denies,” and “patient refuses.”
3. Change how they document sensitive clinical, mental health, or social information.

Convey this need to medical assistants, nurses, and anyone else on the team who contributes to team documentation.

General note-writing strategies include:

- Being positive and supportive.
- Writing only about things discussed with the patient during that visit.
- Not including commentary that could be interpreted as labeling or judgmental. For example, instead of “patient is obese,” write “Patient has BMI >30.” Instead of “Patient refuses to take his medications,” state “Patient has been non-adherent to medications due to [provide a reason].”
- Minimize the use of medical jargon, acronyms, and abbreviations. Dot phrases, the autocorrect function on Epic, and other EHR tricks can help streamline this. This change may feel overwhelming for some clinicians, but do not panic—not all medical terms need to be changed, only the ones that may be misinterpreted as offensive. At the end of the day, there are not many of these. Some examples of important ones are “sob” (expand to “shortness of breath”) and “FU” (expand to “follow up”).



Does it take more time to write an open note?

One study found that the actual amount of time spent by clinicians in documentation after open notes implementation increased by 0.14 minutes (approximately 8 seconds) per note for primary care, with no increase found across specialty care.³⁵ However, another study that included both primary care physicians and subspecialties showed that 37% of all physicians reported spending more time on documentation.⁹ More female physicians reported increased time spent on documentation compared with their male counterparts, as did those licensed to practice after 2000 compared with those licensed prior to 2000.⁹

5

Learn How to Handle Challenging Topics

Long before the open notes initiative, clinicians worried about how to document challenging topics such as mental health, obesity, substance use, physical abuse, driving privileges, visits with potentially litigious patients, or suspicions of life-threatening illness. Sensitive issues clearly require special attention.

Although it is natural to want to curb or avoid some challenging conversations, patients may benefit from direct dialogue. For example, when a clinician notices signs of dementia, depression, or impaired driving, the chances are high that the patient and/or family members are already worrying about these issues as well. They may find that a balanced discussion helps alleviate their anxiety.

The best approach in many situations is to discuss with the patient everything you are putting in the patient's visit notes. Use the same words in conversation that will appear in the notes. Many clinicians already follow this practice, and some dictate notes with their patients present. Also, be direct and respectful when addressing concerns with the patient. Document your discussion using supportive language.³⁷ You could also "monitor" notes if this functionality is allowed through your EHR vendor.

Because of the complexity and sensitivities with mental health, OpenNotes has a comprehensive section devoted to this topic.

DOWNLOAD



Examples of Well-Written Mental Health Open Notes

Experts share scenarios and sample notes.

Q&A

What if the note could potentially be harmful for a patient?

If you believe that accessing a specific note will harm a patient, you could decide to make that note "private" or "confidential" if your EHR has this option. The note will remain part of the patient's medical record and will be available to them if they ever request their complete file. Remember that HIPAA entitles patients to obtain copies of their complete medical records.

Independent of open notes, it is best to write notes with the understanding that patients may read them. If you're uncertain about security or a patient becoming combative about what you document, contact a supervisor or risk management officer at your organization before sharing the notes. You may also want to reach out to your EHR vendor and see how they plan on meeting the Information Blocking Rules implemented in 2021 and 2022. Some EHR vendors may automatically turn on access to all patient notes. Be sure to ask your EHR vendor how they are supporting your ability to meet the goals of open notes and your patients' privacy and safety needs while also supporting your compliance with state and federal laws.

Does it take longer to draft a transparent note on a sensitive issue?

In the initial open notes study, only a few clinicians reported changing the way that their notes addressed these topics. Doing so ultimately did not result in more time preparing their notes, but they found themselves using different language as they drafted the notes.³ A more recent follow-up study discusses some of the changes in documentation reported by physicians.⁹

What are the benefits of using transparent notes to address sensitive health issues?

Clinicians in the open notes study found that when some patients read visit notes about obesity or substance abuse, they were more motivated to attempt difficult behavioral changes. Some patients reported that "seeing it in black and white" made it more real.³⁷ As an overarching strategy, promoting transparency may encourage more open and active communication in these challenging areas.

6

Collect Feedback and Refine Your Approach

You can collect information on the use of and perspectives about open notes through informal hallway conversations, at team meetings, and by adding questions about open notes to your patient satisfaction survey. Another option is to track the volume of patient emails and phone calls before and after open notes as an indirect measure of the effect of open notes on clinician time spent fielding patient questions. You can also work with your EHR vendor or IT team to quantify how many patients view their notes via the patient portal.

At the end of the day, most practices are surprised by how much of a non-event transitioning to open notes is. Share stories about open notes (good and bad) in appropriate settings, and incorporate such experiences in case discussions, conferences, and team meetings. Sharing both good and bad experiences will bolster the collective wisdom, empower all roles on the care team, and guide writing better, more transparent notes.

The Future of Open Notes

Practices are encouraged to innovate and tailor how they use open notes to increase patient involvement in collaborative care. As you explore new features and functionality for your patient portal, consider ways that you can make it easier for patients to contribute to their medical records and visit notes. Some ideas for engaging patients include:

- Equipping patients to upload home measurements, such as blood pressure and glucose readings.
- Enabling patients to update or correct family and social histories in their own words.
- Asking patients to contribute to the note by writing the “subjective” portion of the “subjective, objective, assessment, and plan (SOAP)” note before a visit. This may be especially useful in the current era of COVID-19 and telemedicine visits.³⁸

“

With open notes, I found I was more likely to write my note with the patient in the room rather than after the visit. While I was writing the note—especially the plan—I was reviewing it with the patient. It actually saved me time. I wasn't trying to remember exactly what the patient said later that day. Instead, she was right there!

”

—Marie Brown, MD

DOWNLOAD



Patient Satisfaction Survey

This patient satisfaction survey includes basic questions about how patients are using open notes.

Q&A

Have organizations witnessed an uptick in requests for changes to the medical record after implementing open notes?

Evidence suggests that organizations currently using open notes are not seeing an increase in the number of requests for changes to the medical record. Requests for changes typically come from the same patients who were asking for changes before the use of open notes.

Conclusion

Giving patients access to information in their medical records can improve the patient–physician relationship. Research emerging from the now decade-old open notes movement has demonstrated benefits for both patients and physicians. What was once a voluntary practice taken on by early implementers has now become a federal mandate as a component of the 21st Century Cures Act and the Interoperability and Information Blocking Rule. Sharing open notes engages patients, builds trust, and enhances transparent communication practices. Research and dissemination efforts continue on both a national and an international level.



AMA Pearls

- Clinical note-sharing with patients is beneficial to both patients and clinicians
- Though it may seem a daunting change at first, the transition to open notes ends up being relatively seamless for most individual clinicians as well as organizations, especially with proper preparedness
- Open notes promote patient engagement as well as trust and transparency between patients and physicians

Further Reading

Journal Articles and Other Publications

- American Medical Association. Part 1: what is information blocking? 2021. Accessed March 16, 2021. <https://www.ama-assn.org/system/files/2021-01/information-blocking-part-1.pdf>
- American Medical Association. Part 2: how do I comply with info blocking and where do I start? 2020. Accessed March 16, 2021. <https://www.ama-assn.org/system/files/2020-11/info-blocking-compliance.pdf>
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Videos and Webinars

- Will I need to change the way I write my notes? OpenNotes YouTube channel. December 30, 2013. Accessed March 16, 2021. https://www.youtube.com/watch?v=hgd6_KxGoAk.
 - *Watch early adopter physicians at Beth Israel Deaconess Medical Center share their reflections.*
- How should I approach sensitive topics? OpenNotes YouTube channel. December 30, 2013. Accessed March 16, 2021. <https://www.youtube.com/watch?v=eY1W-C0ytls>

Websites

About the Information Blocking Rule Mandate

- Federal rules mandating open notes. OpenNotes. Updated March 2, 2021. Accessed March 16, 2021. <https://www.opennotes.org/onc-federal-rule/>

About shared clinical notes/open notes

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 - A toolkit that includes information about using the OpenNotes logo and materials for patients and care team
- Pediatrics & adolescents. OpenNotes. Accessed March 17, 2020. <https://www.opennotes.org/pediatrics-adolescents-clinicians/>
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