What are open notes?

Written by doctors, nurses, therapists, or other health professionals to describe interactions with patients, notes are part of the medical record. They have various names – visit notes, clinic notes, progress notes, or chart notes, to name a few. But when patients are invited to read these notes, they become open notes.

What is OpenNotes?

OpenNotes is not a product. It’s a growing international movement that gives patients easy access to open notes, and it’s backed by the federal Health Insurance Portability and Accountability Act (HIPAA), which makes it well within patient’s rights to review and copy their visit notes.

In 2010, 105 volunteering doctors and 20,000 of their patients completed a yearlong, multicenter trial of open notes. As part of the project, primary care clinicians invited patients to read their signed visit notes. At the end of the year, patients overwhelmingly supported the program. Doctors also saw benefits for patients and little burden for themselves. At the end of the study, both patients and doctors wanted to continue sharing notes. The findings of the trial had considerable impact, and less than 5 years after its publication, millions of patients in the US have gained ready electronic access to notes.
Why share notes?

Engage your patients. The multicenter OpenNotes study found that approximately 4 out of 5 patients, when actively offered the opportunity, read their notes. More recent research suggests that when patients are offered access to their notes, clearly marked patient portals and sending email reminders are important for keeping them engaged.

Patients who read notes report that they:

- have a better understanding of their health and medical conditions;
- recall their care plan more accurately;
- are better prepared for visits;
- feel more in control of their care;
- take better care of themselves;
- more frequently take their medications as prescribed; and
- have better conversations and stronger relationships with their doctors.

Promote patient safety. Patients may notice errors in their notes. Correcting them helps make the record more accurate and can improve patient safety.

Help caregivers optimize care. Many patients, including chronically ill or elderly patients, rely on family members or other care partners to coordinate appointments, tests, medications, and general care plans. Data suggest that care partners benefit from note sharing as much as the patients themselves.

Patients want it. As experience spreads, a clear majority of patients want ready access to their notes, and they have the legal right to such access. In the OpenNotes study, approximately 4 out of 5 patients read their notes, and whether or not they read them, virtually all patients wanted them to be readily available.

Even if patients don’t understand everything in the notes, they strongly indicate that this type of transparency and partnership is valuable to them.

In the initial study, a great majority of patients said that the availability of open notes would influence their future choices of doctors and health plans.

What about sensitive issues?

A minority of doctors in the initial OpenNotes study reported that they changed how they documented sensitive topics, including mental health, obesity, substance abuse, sexual history, elder, child or spousal abuse, driving privileges, or suspicions of life-threatening illness. This is not a new dilemma, but it gains urgency in an era of shared visit notes.

Things to consider:

- Unless you believe a conversation might harm your patient, a good rule of thumb is to write about things you discussed, and conversely, to talk about content you’ll write about with your patients. Many clinicians already follow this practice. For instance, some dictate notes with their patients present. If you have concerns about how to document encounters that may relate to potential litigation, please contact a risk manager.
• Although it’s natural to want to curb or avoid some challenging conversations with patients, they often benefit from direct dialogue. For example, when a clinician becomes concerned about dementia, malignancy, or impaired driving, chances are good the patient or family members already worry about these possibilities. They may find a balanced discussion helps with the anxiety they may otherwise hold alone.

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

• But some patients may not benefit. You can compare open notes to a “medicine” – helpful for most, but harmful to some, with “side effects” and “contraindications” to consider. If you believe that accessing a specific note may harm a patient, you can consider using your usual EHR mechanism or talk to an institutional representative on how to write a “private” note. Remember that HIPAA entitles patients to obtain copies of their complete medical records, including such private notes. Therefore, independent of open notes, it’s best to write notes with the ongoing understanding that patients may read them.

• Without a doubt, documentation of “sensitive topics” warrants more research. Some studies are underway nationally, but we have a lot to learn about eliciting and responding to patient preferences and how documentation affects desired health outcomes. In the meantime, sharing stories about OpenNotes — good and bad — in appropriate settings, and incorporating such experiences in case discussions, conferences, team meetings, etc., will only boost our collective wisdom and skill.

Will I need to change the way I write my notes?

A large majority of doctors in the initial OpenNotes study reported they did not change the way they wrote their notes. Clinicians who now have more experience with sharing notes, report that over time their writing does change, and overall, they feel it has improved.

In general, patients do not expect doctors to write notes in layperson language. They’re not bothered by terms they don’t understand and report researching terms, preparing better questions for clinicians and in general feeling fortunate to have a window into more information about their own health. Nonetheless, the following suggestions may help maximize the educational potential of notes.

• Avoid jargon or abbreviations, especially ones that patients might easily misinterpret (e.g., “SOB” or “patient denied”).

• Patients may also benefit from the list of common abbreviations on MedLine Plus, where they may also look up medical terms or diagnoses.

• Briefly define medical terms when feasible.

• Incorporate lab or study results into your notes to give patients the full picture.

• Include educational materials or links to trusted content for your patients.

• Be mindful of sensitive topics, and remember patients have rights under HIPAA to access their record.

What if patients disagree with what I wrote and want the note changed?

Changing a note is at your discretion. If you feel the change improves the note, you can simply document the change as an addendum or use the usual mechanism in place at your institution to edit/correct a note. In the initial OpenNotes study and in wide-spread subsequent experience nationally, patients rarely request that clinicians change the record. Overall, institutions report little or no uptick in requests for changes to the record after the implementation of open notes.

Recent research suggests that inviting patients, families and care partners to review notes may help them identify clinically important inaccuracies, address confusion about the care plan, or find lapses in follow up that, once rectified, improve safety.

Will sharing notes with patients take more time?

Patients generally respect your time, and most doctors report little, if any, impact on their daily practice. Indeed, many doctors in the initial study reported forgetting they were participating once it was underway. But some say they take more time to write notes, and many report writing better and more educational notes. Only a small minority report that writing open notes takes more time, while others indicate that it’s actually a time saver.

Will patients contact me more between visits?

While some patients may contact you after reading their notes, experience to date suggests this is uncommon. Moreover, many health professionals find that giving patients the ability to respond to the notes improves patient care and satisfaction. Contrary to what some of you may fear, patients may contact you less as a result of ready access to their notes.

Will this practice increase my liability?

Data on liability risk with other forms of transparent communication in health care, such as disclosure of medical error, suggest open and honest communication may decrease lawsuits (Kachalia, Ann Intern Med 2010). Some providers list improved patient safety as the ‘best thing’ about OpenNotes. For any specific concerns about how to document something in your notes, contact your supervisor or risk management officer.