FAQs for Patients/Consumers

April 2014

What is OpenNotes?

OpenNotes is a national initiative that provides patients with electronic access to the health care notes doctors, nurses and other clinicians write after a clinical appointment or discussion. This provides patients easy access to material that, through the federal Health Insurance Portability and Accountability Act (HIPAA), is already theirs to review and copy if they so desire.

How did OpenNotes get started?

In 2010, 105 volunteering doctors and 13,000 of their patients completed a one-year, multicenter trial of OpenNotes. In this research and demonstration project, primary care doctors invited patients to read their visit notes after each visit. At the end of the year, patients overwhelmingly supported the program and cited multiple health benefits, including increased engagement, safety, and education.

Doctors saw benefits for patients and little burden for themselves. And both patients and doctors wanted to continue to share notes. 99% of patients wanted open notes to continue, and when offered the chance, not a single doctor turned off note access.

To read the study results, please go to annals.org/article.aspx?articleid=1363511.

What is a note?

When a patient sees a clinician for an appointment, they may notice him or her taking notes during the visit. After the visit (or any discussion with a patient), the clinician composes a note summarizing the most important information. This becomes a part of the medical record.

The note may contain:

- A summary of what the patient told the clinician– also called the "history" or "history of present illness"
- The findings from a physical exam, such as blood pressure or how lungs sound
- Lab, radiology, pathology, or other results that help the clinician assess a condition
- The clinician's assessment or diagnosis of any medical conditions or symptoms – also called "Assessment" or "Impression"
- The treatment plan the clinician recommends
- Next steps recommended or planned, such as additional tests, studies, follow-up appointments, or referrals to a specialist

With the increased use of electronic medical records, many patients already get a printed visit summary at the end of their visit. What is the difference between a note and a visit summary?

A note contains a detailed account of a visit, including the history, exam, relevant lab or study findings, and the clinician's assessment and plan of care. It almost always comes from the clinician themselves and is in their words. It should provide a sense of past, present and future thinking related to a patient's issues.

A visit summary gives a more limited snapshot of a visit including the "vital signs" recorded at the visit, a list of medications and a list of any follow up visits that are already scheduled. The visit summary sometimes also includes information from the doctor about their condition and how to treat it. Often visit summaries emphasize summary information rather than providing a sense of how the doctor is thinking. The note should do that.

Together the visit summary and the note provide a far more complete picture of a visit.

How are the notes accessed by patients?

This may vary by health system, but in most cases the patient already has, or is sent, a link to access their information through a secure internet connection.

What are the benefits of reading notes?

In the 2010 research study, patients who read their notes reported several benefits. These included:

- o Better understanding of their health and medical conditions (81%)
- o Improved recall of their care plan (80%)
- o Feeling more in control of their care (81%)
- o Taking better care of themselves, and (70%)
- o Doing better at taking their medications as prescribed (69%)

Reading notes can also help strengthen the partnership between a patient and their clinicians.

How can a patient get the most out of their notes?

A patient should read the clinician's note from the visit to review what was discussed, the treatment plan, any changes to medications, and any follow-up tests or appointments needed to schedule or attend. If there are terms that are confusing, they should be looked up. It may help to ask the practice for reliable websites or other resources to learn more about medical conditions.

Between visits patients can read notes to review whether they are following the treatment plan and to make sure follow up on procedures, tests or appointments is completed.

Any interaction between patient and clinician is confidential. However, a patient may choose to share notes with their family members, caregivers or others involved in their care and discuss with the physician how to work together to carry out the plan.

In preparation for the next visit, patients can read their notes to remind themselves of what was discussed with their health care provider at their last appointment. Patients should think about any steps taken since the last visit and any changes or new problems experienced since the last visit. Patients can also review past visits, consider what has happened since then, and then prepare a list of questions to review with the clinician at their next appointment.

What if a patient has questions about information in the note?

There is a wealth of online resources that can help patients better understand the information contained in a note. A patient can perform a quick online search, jot down questions to discuss with the doctor at their next visit, or contact their health care provider's office. Patients may want to ask their provider about good websites or online resources to turn to with questions about their particular condition.

Keep in mind that the visit note is part of a specific patient's medical record, which is used by many doctors and other clinicians to take care of that patient. The visit note is not necessarily written in lay person's language since it is a document that is used professionally within the health care system. Some of the language may be difficult to understand—it may include abbreviations or terms a care team uses to communicate with each other efficiently so that members of the care team are kept updated about medical conditions.

Can I share my note?

While all clinician-patient interaction is considered confidential from the provider's standpoint, once a patient has access to their note, it is their personal decision whether to keep it private or share it with others. Indeed, some patients may find it extremely helpful to share notes with family members, friends, or caregivers who assist in their health care. In the 2010 research study, 21% of patients reported sharing their notes with others.

How long does it take for a note to be available?

This varies by health system. Typically, clinician notes are available for the patient to review within two to three days following an appointment, though some may take up to a week.

I am worried about privacy. Will others be able to see my note?

No, OpenNotes does not increase the likelihood that anyone else will see your note without your permission. If you are concerned about others viewing your notes, we recommend taking precautions to secure information and computer so that someone can't view your information online. These are very similar precautions that you would take when accessing banking or credit card sites. For example, make sure others are not also looking at your computer screen as you review your private information. Make sure to log off of the website or close your browser after reviewing your information. Don't share or automate the entry of your password.

But I hear there are problems in health systems with privacy of information?

Electronic information has many advantages over paper information in terms of privacy. Health systems, including doctors' offices, have very specific policies about privacy of patient information whether the information is on paper or in electronic format. These policies restrict who has access to patient information and when information can be accessed. Most health systems actively monitor for anyone looking at private information without a medical reason. Any breach of privacy is taken seriously and often results in severe consequences including termination of the employee. OpenNotes does not change or reduce the safeguards around the privacy of your medical information.

Does OpenNotes create a database or other collection of notes that hackers or other could access?

No. Your notes remain part of your record and are not moved into any database separate from your record as part of the OpenNotes process.

What if my doctor does not have electronic records or an electronic portal?

Electronic records and internet portals make it easier for patients to access their notes but if that option is not available, a doctor who wishes to engage in opening their notes should be prepared to work with a patient to provide other ways to share their notes, including providing paper copies or electronic copies on a disc or memory stick.

Will patients be charged for accessing their notes?

No one involved in a current OpenNotes project has charged patients or insurers for providing patients access to their notes. The costs for electronic access are usually quite low especially on a per person basis. It is possible that if notes cannot be provided electronically that there may be copying costs or costs involved in providing a disc or memory stick.

Will open notes increase patient safety?

Data on transparent communication in health care (such as disclosure of medical error) suggest that open and honest communication may improve patient safety and decrease lawsuits (Kachalia Ann Intern Med 2010). In the OpenNotes study, some providers listed improved patient safety as the "best thing" about sharing their notes with patients.

Will open notes affect clinicians' work flow?

Research on OpenNotes indicates that most doctors experience little to no negative impacts on their daily practice. After a year, only a small minority reported that participating took more time, 2% reported longer visits, 3% took more time addressing patients' questions outside of visits, and 11% reported taking more time writing notes

Will patients contact their doctors more between visits?

While a small number of patients will contact their doctor, nurse or clinician more after reading their notes, the OpenNotes study participants found this uncommon. Moreover, many health professionals found that these communications were important for patient care and satisfaction. Some patients may contact providers less by virtue of having access to their notes.

Will patients be more confused or anxious by reading their notes?

In the OpenNotes study, only a small minority of patients found the notes more confusing than helpful (3%), felt offended (2%), or worried more as a result of reading their doctors' visit notes (6%). Patients were not generally bothered by medical terms, but rather reported looking up or "Googling" medical terms online to better understand the information contained in their doctors' notes.

Can doctors be selective with which notes patients can view?

Yes and no.

With a few exceptions, all notes are already "open" because under the Health Insurance Portability and Accountability Act (HIPAA), patients are entitled to obtain a copy of their complete medical record. Some providers may choose to suppress specific notes if, for example, they are concerned that it may create a dangerous situation for a patient. In many implementations of OpenNotes, certain notes, such as mental health or addiction medicine visit notes, have not been shared. However, evidence suggests that some patients may be encouraged to make difficult behavior changes if given access to these notes. Each system will make decisions about these issues but there seems to be an increasing consensus on the benefits of making all visit notes available to as many populations as possible with few exceptions.

What if a patient disagrees with the note and wants it changed?

In the OpenNotes study, patients only rarely requested a change in the note. In some cases it was because of inaccuracy of information, and the change may well have improved their safety. If patients feel there is a misstatement in the record, organizations are already required to have a process to respond, note the concern, and modify the record if it is felt to be appropriate. The patient is entitled to a response to these requests.

What kinds of costs are involved for systems to implement OpenNotes?

The costs for electronic access are usually quite low especially on a per person basis. But moving to open notes requires substantial time and resources in communicating and explaining to all the providers and patients what is happening, when and how it works. So the "human" costs can be significant.

Can any health system implement OpenNotes or does it require a specific technology platform?

All health systems and medical groups that have electronic health records should be able to implement open notes, although the amount of work involved, and the approach used, may be different depending on the type of software used in that system. Clinicians who are not using electronic health records can share their notes with patients by sending copies of notes by regular mail or through secure email.

Is there concern that this could lead to more lawsuits filed on behalf of patients?

Almost any change in health care can cause some to be worried about lawsuits. In general research suggests that anything that improves communication between doctor and patient results in less lawsuits. As mentioned previously in the questions about safety, data on transparent communication in health care (such as disclosure of medical error) suggests that open and honest communication may improve patient safety and decrease lawsuits (Kachalia Ann Intern Med 2010). In the OpenNotes study, some providers listed improved patient safety as the "best thing" about sharing their notes with patients.