What is OpenNotes?

OpenNotes is not a software or product, but rather a movement that urges doctors, nurses and other health care professionals to share the medical notes they write after an appointment or discussion with the patients they care for. Opening notes helps patients to read material that, through the federal Health Insurance Portability and Accountability Act (HIPAA), is already theirs to review and receive if they so desire.

In 2010, 105 primary care doctors and 20,000 of their patients participated in a one-year study of OpenNotes. The patients were invited to read their visit notes online using a secure patient portal. At the end of the year, patients overwhelmingly supported the program and reported multiple health benefits. Doctors saw benefits for patients and little burden for themselves. And both patients and doctors wanted to continue to share notes.

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

What is a note?

After a visit or discussion with your doctor, nurse or other health care professional he or she writes a note that reflects the visit, summarizing the most important information. The note becomes a part of your medical record and may contain:
• a summary of what you told the doctor or nurse, also called a history;
• findings from an exam, such as your blood pressure, weight, or how your lungs sounded;
• lab, radiology, pathology, or other test results;
• your doctor’s assessment or diagnosis of any medical conditions or symptoms, also called assessment or impressions;
• the treatment plan recommended by your doctor and discussed with you, and
• next steps, including upcoming tests, follow up appointments, or referrals.

What are the benefits of reading your notes?

Patients who read their notes report that they:

• have a better understanding of their health and medical conditions;
• can better recall and follow their care plan;
• feel more in control of their health;
• take better care of themselves;
• do a better job taking their medications as prescribed;
• can identify inaccuracies in the record and play a role in the safety of care;
• feel comfortable sharing notes with care partners and others involved in your care;
• can communicate more clearly, helping to strengthen the partnership between themselves and the health care team.

To learn more, visit opennotes.org.

How can I get the most out of my notes?

• Read your notes after a visit to carefully to review what has discussed, including the care plan, medication dosages and instructions and recommendations for follow up appointments or referrals.
• If there are terms you don’t understand, look them up, or ask your practice for reliable websites or other resources to learn more about your medical conditions.
• Review your note to make sure the information is accurate and up to date. Let you doctor or practice know about any changes that should be made to ensure the safety of your care.
• Read notes between visits to remind yourself of the treatment plan and to remember upcoming procedures, tests, or appointments.
• Use the note to make a “to do” list for yourself, or your note and take it to a visit with another clinician on your care team.
• You may decide to share your note with family, informal care partners, or others who are involved in your health. Sharing is a great way help manage care and to make sure your entire care team is on the same page.
• Before your next visit, read your note to remind yourself about your last conversation with your doctor or nurse and to prepare for your next visit. Think about the things you’ve done since you last saw your doctor and the questions you’d like to ask.
• When you read the note it may trigger questions or remind you of additional information potentially important for your care. Try to take appropriate action. Some issues can wait for a next visit; others are best addressed quickly.

What if I’m worried about what I might read or don’t want to read a particular note?

Note reading may not be right for everyone.
• For some patients just knowing that the notes are available if they ever want to read them or share them with a care partner is enough.
• It can be helpful to think of note reading like a medication, and talk with your doctor or care team about the benefits and side effects to determine if it’s right for you.
• If you’re nervous, it may be a good idea to start by reviewing a note with your doctor.
• You don’t need to read every note, but referring back to them, even occasionally, to remember what was discussed can help you feel more in control of your health care.

What can I do if my doctor or health care practice doesn’t use OpenNotes?

You have a legal right to receive and review all of your medical records, including the notes. If the notes are not yet available online, or your doctor or nurse doesn’t use a patient portal, you can always request a paper copy of your notes. You may also want to communicate with your health care team, and let them know you’re interested in accessing your notes online. You can read more here: 10 things patients can do right now.

I can’t see any of my notes or a specific note I expected to see. Why?

Possible reasons include:
• You may need to locate the note within the electronic record.
• The note may have been written before OpenNotes started.
• The doctor, nurse or other health care professional may not yet be sharing notes.
• The note may not be ready. After the note is written and approved electronically, it will become available.
• Your doctor or nurse may have chosen not to share this particular note. We encourage you to talk with the doctor or nurse to make sure you understand the reason for not making a particular note available.

If you have questions, talk with your health care team.

What if I have questions about the information in my note?

Because your note is part of your larger medical record, it may contain medical language, abbreviations, or terminology that’s not so easy to understand. A list of common abbreviations and acronyms can be found here, that can help you with medical terms or diagnoses. If you have questions about your note, write them down so you can email them to your clinician’s office or share them at your next appointment, and ask your doctor or nurse for websites or other resources that might help you better understand your note.
What should I do if I think I may have found an error in my note?

If it’s a serious issue, like a potential mistake that could affect your care immediately, contact the office of the health care professional who wrote the note and tell them about your concern. For other inaccuracies, be sure to write down the correction and bring it to your team’s attention so your records can be updated. Use your best judgment about small mistakes, such as spelling or grammar. Doctors often dictate their notes and rely on others to type them. If these less immediate issues feel important, bring them up at your next visit.

How does OpenNotes affect confidentiality and privacy?

It’s important for you to know that OpenNotes does not change the confidential relationship you have with your health care team. Only you and the care team directly involved in your care can access your note. What does change is your ability to share. With OpenNotes, it is easier to share your medical information with a care partner, family member, or others, but only if you choose. You are in full control of who has access to your note, which means you are in full control of your privacy.

To help ensure your privacy, please remember to:

• keep your login name and password private; and
• wherever you look at your account, always exit by selecting “sign out” when you are done.

How can I send general suggestions or thoughts about OpenNotes? Whom should I contact?

If you have a specific comment about your own notes, please contact your doctor, nurse or the medical practice where you receive your care.

For general suggestions or thoughts about OpenNotes, please e-mail myopennotes@bidmc.harvard.edu