



Caregivers: Patients and Families

OpenNotes can be a tremendous resource for those who help manage the care of others nearby or at a distance. You'll find information here for patients and caregivers.

→ Are You a Caregiver?

→ How Does OpenNotes Help Caregivers?

→ Things to Consider When Asking for Caregiver Access?

Are You a Caregiver?

Navigating the health care system can be challenging. Family and friends often play a vital role as caregivers or care partners, who help “interpret” the experience of health care, advocating for loved ones and helping them manage care in a variety of ways. Care partners organize medical appointments and tasks and generally improve communication between the patient and the care team.

The need for doctors, nurses and others to more effectively engage with care partners has been written about in the New York Times, by the AARP, and in the recent National Academies of Sciences, Engineering and Medicine (NASEM) report, Families Caring for an Aging American. Online patient portals with OpenNotes can help patients and their care partners access their health information and participate more actively in care.

Among the first group of patients who were invited in 2010 to read their medical notes using online patient portals, up to 40% said that they shared their notes with someone other than their hospital care team. More recent research looked at the reasons patients choose to share notes and how they and their care partners benefit from this shared access.

Study Highlights:

- Patients of all ages 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.

↪ Patients, care partners, and shared access to the patient portal: online practices at an integrated health system, JAMIA (<https://academic.oup.com/jamia/article/doi/10.1093/jamia/ocw108/2631495/Inviting-patients-and-care-partners-to-read>)

↪ 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>)

↪ Inviting patients and care partners to read doctors' notes: OpenNotes and shared access to electronic medical records, JAMIA (<https://academic.oup.com/jamia/article/doi/10.1093/jamia/ocw108/2631495/Inviting-patients-and-care-partners-to-read>)



Why Share Notes with Care Partners?

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule gives patients the right to access their own medical records and permits sharing this health information with involved family members, friends, or professional caregivers. OpenNotes makes that process easier and more efficient.

Notes are the part of the medical record that includes a summary of the conversations that happen at medical visits. They may include a description of symptoms, a list of medications and dosages, an overview of the treatment plan, and goals for next steps. Recent research found that the benefits of note sharing are as powerful for care partners as they are for the patients themselves.

Study Highlights

- 88% of patients and 86% of care partners said they were able to prepare better questions for the doctor.
- 86% of patients and 82% of care partners said they 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 said they had a better understanding of patient health conditions, better remembered the patient's care plan and felt more in control.
- 71% of patient and care partners reported more often taking medications as prescribed.
- 33% care partners accessed notes because they weren't able to attend an appointment.
- Only 1 in 10 patients voiced concerns about privacy.

Giving Care Partners What They Need: Providing Family members and care partners with timely access to information about patients' health and treatments can help them support patients better in managing their health and illness, and coordinating their care.

"My husband is very hard of hearing, and so you can imagine, even with perfect hearing I miss what doctors say sometimes, and he's really lost. It's been a godsend that I can find out what the doctor told him because he doesn't get it right or he only heard part."

- MARY, A PATIENT



Helping Patients and Care Partners Navigate the Health System. Managing health care demands can be difficult, particularly for individuals with complex health needs who are often under the care of multiple health care professionals. Providing access to notes can help ensure that everyone on the care team, including the care partner, is on the same page.

Enhancing Patient Safety. Sharing notes with care partners may help them understand the patient's medical condition and be better prepared to join in managing care. Having care partners review the record also provides the opportunity to alert the health care team to inaccuracies or information missing from the patient's health record. These benefits may be particularly important when family members live at a distance and cannot be present during face-to-face encounters.

"I know what the doctor's plan is for my mom even when I am in Boston and she is in South Carolina. I can look it up and say okay they are changing her medicine, her blood pressure medication. I don't have to call them. He does not have to call me back which saves a lot a time for him because we are all on the same page and I can oversee it and know that she is getting what she needs."

—JENNIFER, A PATIENT

Help for English Learners/Patients Without Computers. Although there are many benefits from having easy access to information on patient portals, not everyone has a computer, and not everyone who has a computer knows how to access and use their medical record. By providing computer access or reading and explaining medical information that is not written in the patient's native language, care partners can help patients participate more actively in their own care.

"In some situations, she comes alone to the appointments and I would like to know what the doctor said in case she couldn't understand very well and the OpenNote is there for me, to teach me, for me to learn what was the communication between my sister and the doctor, what they say, what they recommend and how can I help her in order to become safe and healthy. So, I think the OpenNotes, is a wonderful tool for me and my family members."

—MERELYN, A PATIENT

Considerations for Sharing Notes with Care Partners

Ask for Notes Online or on Paper. Online patient portals let caregivers easily access information they need, when they need it. However, if you don't have computer access, as for the notes to be printed and mailed.

Proxy Access. Some health systems allow patients to grant a caregiver secure log in of their own that enables the caregiver to access the patient's health information, read the notes, schedule appointments, refill prescriptions, or communicate electronically with the health care team.

Respecting the Patient's Privacy. Ideally, patients could discuss and set preferences for what they want to share with their caregiver. For example, a patient might authorize a care partner to schedule appointments or refill prescribed medications, but choose not to share other health information

As consumer health information technology becomes more mainstream, the ability of clinicians to differentiate the identity of who—the patient or an involved family member or friend—is exchanging secure email messages, refilling medications, and viewing patient health information will become increasingly important in the delivery of safe and clinically appropriate care."

—JENNIFER WOLFF, PHD, JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH.