



Pediatrics & Adolescents

Access to notes can help families and caregivers manage care across health systems more effectively, while teaching children to be more engaged with their health.

- How families and caregivers can use open notes
- Which health systems share adolescent notes?
- FAQs for families & caregivers

How families and caregivers can use open notes

Manage your child's health care. Open notes provide the ability to access your child's visit notes wherever and whenever you want to remind yourself and your child what was discussed during an office visit. Reviewing the record and the notes can help make sure that everyone understands the treatment plan and is on the same page with the care team for next steps.

"My husband calls me the Chief Operating Officer of our family. With three kids, each with different schedules and different health concerns, access to the notes is a tremendously valuable tool to help me manage our health."

— BETSY, MOM

Communicate concerns. Reviewing the notes is important for several reasons. Some families and care partners may help identify possible mistakes in the note, and can help improve note accuracy by sharing these with their health care team. It is also important to let the care team know if you and your child don't understand the care plan, or are unable to follow the recommended next steps after reading the note.

Share notes with others involved in care. Schools often ask parents to fill out a health form at the beginning of each year. It can include a vaccination record or a description, for example, of how a child's asthma is managed. Accessing your child's medical record can not only help you recall important details, but it also allows you to share portions of the notes with the school nurse, another health specialist, or anyone you choose to give a more detailed description of a condition or treatment plan.

Help children learn to navigate the health system. OpenNotes can help parents help their children, especially those with complex health concerns, feel empowered and more in control of their health. Reading notes can also help patients and families develop skills to become even more informed users of the health system going forward.

Which health systems share adolescent notes?

Many health systems share pediatric notes. The following systems share adolescent notes as well.

- Avera Health
- Boston Children's Hospital
- Essentia Health
- Mercy Medical
- Peace Health Medical Group
- Saint Alphonsus Health System
- Sutter Health Medical Foundation
- UC Health
- University of Utah
- The Vancouver Clinicd Assessment or Impressions

"Our approach to sharing notes with adolescent patients was brought to us by our family physicians, who felt that we should not withhold portal access from these young people. Using our decision making standard 'what is the best thing for the patient?,' we felt that in this age group especially, digital tools were likely to be important in developing responsible engaged patients who partnered with their clinicians."

— MARCIA J. SPARLING, MD, MEDICAL DIRECTOR FOR INFORMATICS, THE VANCOUVER CLINIC





FAQs for Families & Caregivers

What is a note?

After a visit or any discussion with you and your child, the clinician writes a note summarizing the most important information discussed, for example details you or your child provide about symptoms, a description of the exam, an overview of lab results, and details about the treatment plan and next steps. All of this becomes a part of your child's medical record.

What is OpenNotes?

OpenNotes is an international movement encouraging clinicians to offer patients, parents and their care partners ready access to the health care notes doctors, nurses and other clinicians write after a clinical appointment or discussion. Making notes open helps patients or parents to read material that, through the federal Health Insurance Portability and Accountability Act (HIPAA), is already theirs to receive and review, if they so desire.

"We believe it's important to allow parents access to their adolescent child's non-confidential medical information, as many parents continue to play an important role in helping adolescents assume responsibility for their medical care guiding them through healthcare decisions."

— FABIENNE BOURGEOIS, MD, MPH, PEDIATRIC HOSPITALIST AND THE MEDICAL DIRECTOR OF PATIENT-FACING APPLICATIONS, BOSTON CHILDREN'S HOSPITAL.

Where can I read my child's notes?

Parents can access their child's medical records using the health care system's secure, patient website or portal or by requesting a paper copy. By creating a secure, online account on the web portal, parents and care partners can request appointments, communicate with the health care team and view portions of your child's health record, including the notes, in systems that have OpenNotes. Parents can sign into the portal – at their convenience – using an internet enabled computer or smartphone. If the child's doctor or nurse does not use a web portal, parents can ask for the notes to be printed.

How does OpenNotes affect confidentiality and privacy?

All clinicians involved in your child's care already have access to the information contained in the medical record. Doctors, nurses and all health care professionals operate under strict confidentiality rules, and open notes do not change that relationship, though parents and care partners can choose to share medical information with others involved in a child's care. This collaborative approach ensures that patients and specialists are well-informed on treatments and progress, a vital consideration for patients with multiple specialists.

To help ensure your privacy, keep your login name and password private, and whenever you look at your child's health record, always remember to sign out.

How is confidentiality affected when children become adolescents?

Because laws defining the types of health care services and minimum ages at which adolescents may independently seek those "confidential" services differ from state to state, it's important to discuss access to health information with your adolescent and the care team. At Boston Children's Hospital, adolescents can create their own accounts to access their health information without parental consent, but cannot view secure messages sent between the parent/guardian and the health care team. Parents/guardians cannot view secure messages between the adolescent and the health care team, confidential appointments, or confidential health information. This confidential information may include: confidential laboratory results, confidential diagnostic studies reports, visit notes that may include confidential/sensitive information, and confidential problems and medications.



What should I do if I can't see any of my notes or a specific note I expected to see?

- The clinician may not yet be sharing notes. We encourage you to talk with the clinician and let him or her know that you would like to read your child's notes.
- The note may not be ready. After the clinician writes and approves the note electronically, the note will become available.
- Your clinician may have chosen not to share this particular note or type of note. If you have questions, we encourage you to talk with your child's clinician or the clinician's practice to make sure you understand his or her reasons for not making the note available.

What if I have a question about something in the note?

Please keep in mind that the note is part of your medical record. Doctors and/or other clinicians use the note to manage your individual circumstances and to communicate efficiently with others involved in your care. You may find the note difficult to read because it includes unfamiliar abbreviations or terms. It's okay to use trusted online resources to look information up or to contact your health care team if there's something you don't understand, if you are unable to follow the care plan, or are concerned about a diagnostic test, study results, or other aspects of your care.

What if I find an error or inaccuracy?

If you see an error or inaccuracy that could affect your child's care, your care team will want to know. Never hesitate to call or send a secure message.