



# Pediatrics & Adolescents

Access to notes allows families to manage health care that often happens across health systems, and helps children learn to be more engaged in their own health. You'll find information here for health systems and health care professionals.

- Why use open notes for pediatrics and adolescents?
- Which health systems share adolescent notes as well as pediatric notes?
- FAQs for clinicians

## Why use open notes for pediatric and adolescent medicine?

**Help patients and families remember what was said at the visit.** Open notes give parents, patients and care partners the ability to access medical information wherever and whenever they choose to remind themselves and their children what was discussed during an office visit. There's ample evidence that patients and families often forget what was said during a medical encounter. Reviewing the record and the notes can help make sure that everyone understands the treatment plan and 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, A PATIENT

**Communicate concerns.** Reviewing notes gives parents, patients and care partners an opportunity to identify possible inaccuracies, such as medication changes, new allergies, family history updates, or other information that may be useful to clinicians. Reviewing the note may also prompt patients and families to let care teams know if the child or family doesn't understand the care plan or is unable to follow the recommended next steps.

"Shared, ubiquitous, consent-modulated access to medical information promises reduced medical errors, improved efficiency and safety of medical care, and lower health care costs, as well as activated patients who take responsibility and become partners in managing their own healthcare."

—BOURGEOIS, ET AL, WHOSE PERSONAL CONTROL? CREATING PRIVATE, PERSONALLY CONTROLLED HEALTH RECORDS FOR PEDIATRIC AND ADOLESCENT PATIENTS, JAMIA, NOVEMBER 2008

**Share notes.** Schools often ask parents to fill out a health form at the beginning of each year. It might include a vaccination record or a description of how a child's asthma is managed. Accessing the child's medical record, including the clinic notes, can not only help with recalling important details, but it also allows the parent or care partner to share portions of the notes with the school nurse, another health specialist, or anyone they choose to give a more detailed and accurate description of a condition or treatment plan.

**Help adolescents learn to navigate the health system.** Especially for those with complex health issues, open notes can let parents help their children feel empowered and more in control of their health care. Reading notes can also help patients and families develop skills to become more informed users of the health system going forward.



## Which health systems share adolescent notes as well as pediatric 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 Clinic

*“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

## More FAQs for health care professionals

The questions and answers below were developed in partnership with Boston Children's Hospital and may be adapted for use in other health systems.

### **Which practices are participating in the OpenNotes initiative?**

At Boston Children's Hospital, most of the ambulatory clinics are sharing their notes through the MyChildren's patient portal, with the exception of Psychiatry, Adolescent, GYN, Adolescent Substance Abuse Clinic and the Child Protection team.

### **Who can access notes?**

Laws defining the types of health care services and minimum ages at which adolescents may independently seek 'confidential' services differ from state to state. In Massachusetts, for example, at age 13 adolescents may have such services, but parents retain access to non-confidential parts of the patient's record until age 18. Starting at age 13, Boston Children's Hospital offers parents and patients separate portal accounts. If parents are appointed medical guardians for patients who are 18+ years of age, access to the patient's record is continued after obtaining the appropriate court documents.

### **What if an adolescent discusses a confidential issue during the visit?**

Boston Children's Hospital has created 'confidential' note types that are suppressed from the portal, which individual health care professionals can elect to use for information they do not want the parent to access. They can choose to create two notes (a note with only the confidential information, and one with general information), so that the parent/patient can access some pertinent information, i.e. the care plan. Alternatively, clinicians may create a single confidential note that will be completely suppressed.

### **How can one handle situations with suspected medical abuse/neglect?**

At Boston Children's Hospital, for example, any note can be flagged as confidential, or separate notes can be created with confidential information. However, this has long been the case, these notes do not carry legal protections, and even though these notes are suppressed from the portal, families can request them from medical records. Clinicians need to seek local counsel if they are uncertain about how to document sensitive information.

### **What happens in cases where parents are divorced and both share custody?**

If both parents are legal guardians, they both have access to the patient portal at Boston Children's Hospital. However, a parent may share information with a health care professional with the expectation of confidentiality and would not want such information to be shared with the other parent or the patient. Health care professionals are therefore asked to consider this information sensitive/confidential. Again, even such information would not be suppressed if formal requests for a copy of the official medical record.

### **What happens if the patient is in Division of Children, Youth and Families (DCYF) custody?**

If the biological parents have lost custody of the patient, Boston Children's Hospital will disconnect the parent accounts, so they will no longer have access to any notes. Some social workers working for certified agencies, such as DCYF, can apply for an account. If the proper court documents are provided, access is granted.

### **How do patients and families know when a note is available in the portal?**

Boston Children's Hospital has created an alert via secure messaging that lets patients and families know when a note has been signed by the attending and is available for review.

### **What kind of feedback are we requesting from the patients and parents?**

Boston Children's Hospital is participating in the OpenNotes patient reporting tool. The reporting tool invites patients and families to review their notes and submit a short feedback form if they find any potential note inaccuracies, do not understand or are unable to follow the care plan, are concerned about diagnostic tests or study results, or have other feedback about their note. You can find more information about the OpenNotes patient reporting tool on: <https://www.opennotes.org/news/reporting-tool/>.

