



Mental Health

This toolkit is for patients, families, and caregivers interested in asking for, and reading their mental health notes, as well as learning how notes can be a powerful tool in therapy.

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Why Open Notes in Mental Health Therapy?

Each year, 1 in 5 adults in the United States — nearly 44 million people — experiences mental illness and/or significant psychological distress. Many people delay treatment because they don't realize how much mental illness is affecting their day-to-day lives and other aspects of their health. They believe they can handle things on their own, or they worry about what others will think.

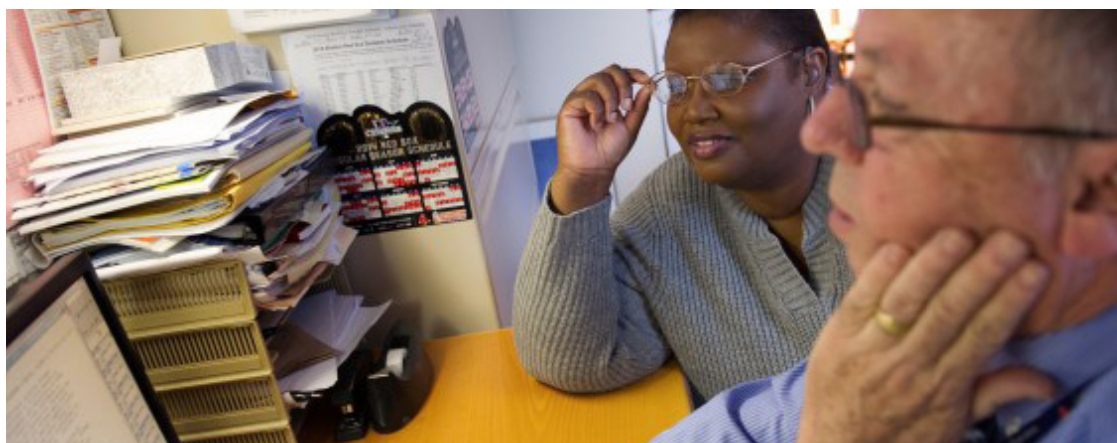
Research indicates that when clinicians share notes with patients, it helps them understand their conditions better and feel more in control of their health and healthcare decisions. Such open communication can help break down many barriers and may also encourage more people to get the care they need.

What Are Notes?

After you have a visit with your therapist or other behavioral or mental health provider, he or she summarizes information from the visit in a note that becomes part of your medical record.

In 1996, the federal Health Insurance Portability and Accountability Act (HIPAA) gave patients the legal right to receive and review the contents of their medical records, including therapy notes written by psychiatrists, psychologists, social workers, and others. However, HIPAA doesn't guarantee easy access to one's medical record. In fact, the process of requesting records can be tedious, time consuming, and sometimes expensive.

Therapists who join the OpenNotes movement are increasingly sharing visit notes with patients, either online using secure patient portals, or on paper. As this practice spreads to more and more health systems across the United States, many clinicians and patients are working to have mental health notes sit side by side with notes documenting the full range of visits to clinicians throughout the health care system.





In 2014, researchers and mental health professionals at Beth Israel Deaconess Medical Center (BIDMC) published an article outlining why they believe that open notes can be a valuable part of therapy for many patients managing mental/behavioral health and illness.

“By writing notes useful to both patients and ourselves and then inviting them to read what we write, we may help patients address their mental health issues more actively and reduce the stigma they experience.”

—KAHN, ET AL., JAMA, 2014

Health Systems That Share Therapy Notes with Patients

- Allina Health
- Banner Health
- Beth Israel Deaconess Medical Center
- Cambridge Health Alliance
- Citizens Memorial Healthcare
- CoxHealth
- Essentia Health
- Intermountain Healthcare
- Kaiser Permanente Northwest
- Ontario Shores Centre for Mental Health Sciences (Canada)
- Rush Medical Center
- The Vancouver Clinic
- UCHHealth (University of Colorado)
- University Health Network (Canada)
- University of Iowa Health Care
- University of Vermont Medical Center
- U.S. Department of Veterans Affairs
- UW Medicine (University of Washington)
- Virginia Mason

What Is Contained in Mental Health Notes?

The content of mental health notes can vary depending on your clinician and the type of care you receive. Like medical notes, mental health notes often include a diagnosis, a summary of what you shared with your clinician, medication updates, your clinician’s assessment of your health, a treatment plan or next steps, and other information from your appointment. The notes may also include information required primarily to satisfy professional and health insurance requirements.



It's okay to ask! If you're interested in gaining access to your therapy notes, it's a good idea to start by talking with your clinician. He or she may be able to print out your notes or support your request to read your notes online using the secure, patient portal. If it's more convenient, or you feel more comfortable sending a request by email, check out our template message on opennotes.org/join asking your clinician for your notes. You can also look at the OpenNotes map on opennotes.org/join/map to see the full list of the health systems that share notes with patients.

What Are the Benefits of Reading Mental Health Notes?

Become more involved and feel more in control of your health care. After a visit, you can read your notes to review what you discussed with your clinician, your treatment plan, any changes to your medications, and to remind you of any follow-up steps. In between visits, you can read your note to make sure you are following the treatment plan and to remind yourself to follow up on recommended procedures, tests or appointments. In preparation for your next visit, you can read your note to remind yourself what you discussed at your last appointment. You might also think about any steps you have taken, and any changes or new problems you may be experiencing since your last visit. The notes can also help you prepare a list of questions to review with your therapist at the appointment.

Feel empowered. If you have worries or concerns, it may be helpful to read through the first note or two together with your clinician so you know what to expect. It can take some time to get used to how mental health notes are written. But it can be empowering when you recognize your own capabilities in reading notes, discussing them with your therapist, and using them constructively in many different ways. We have learned that OpenNotes can build trust in yourself and between you and your clinician. Reading your notes may even improve your self-awareness and self-confidence.

"I read my notes because it helps me see the progress I've made and the successes I've already had. Being in mental health care is hard work. It's a lot of effort for me to come here and it can be draining at times. When I look back at my notes from last year, I get to view how far I've come."

— LARRY, VETERAN

Organize care and track progress. Just as in any other appointment, there's a lot to remember. Going back to read the notes after the appointment may help you manage your illness more effectively. Reading notes can help you understand your condition, your treatment, and your progress between visits. It can remind you of your responsibilities in your own care, including 'homework' or follow-up issues to work on between sessions.

Use your notes as a tool for change. You may find that discussing the information in your therapy notes with your clinician can decrease stress you might otherwise hold alone. In addition, you may find that the notes help you to benchmark your progress and motivate you to confront challenges and address difficult changes you hope to make.

"I have a tough time recognizing that I've made progress. So it's nice to read this as a reminder."

— PATIENT, DAVID, NEW YORK TIMES

➡ Let's show patients their mental health records, JAMA (<https://jamanetwork.com/journals/jama/fullarticle/1853164>)

Mental Health OpenNotes Empower Patients (<https://www.youtube.com/watch?v=oqi6AeMctw>)



Enhance trust and the therapeutic relationship. A trusting, therapeutic relationship between a patient and therapist is critical to progress and recovery. Being able to read what your therapist writes can help demystify what he or she is thinking. For many patients this can lead to a stronger relationship and richer conversations. It can also help you and your therapist initiate more open discussions about potentially difficult topics.

Help make your care safer. When you review your health record, including your medical history, current symptoms, medication dosages, and the care plan, you can help ensure that your record is accurate. When your medical record is up to date and accurate, your care is safer.

Make sure you're on the same page. Sharing notes serves as a cross check, improving the likelihood that you and your therapist have mutual understanding of what was discussed. The notes may also include comments from your therapist about differences in each other's perceptions and understanding. Understanding these differences can be an important part of any therapy.

"Confident in the communication between my therapist and myself, eager to tell more."

– A PATIENT

Share with a family member or other clinician. Interactions between you and your clinician, and the notes documenting those interactions, are confidential. However, whether they are entirely private is up to you. You can share your notes with anyone you choose. Indeed, you may find it extremely helpful to share your notes with family members, friends, or caregivers who assist in your health care. Sharing notes with trusted friends, family, or caregivers, or other clinicians involved in your care may help keep people up to date with any changes in your medications, health conditions, or care plan. It may also help caregivers or care partners to coordinate your care. But always remember that your personal health information is private, and only you should choose with whom to share it

Are There Any Downsides or Risks to Reading my Mental Health Notes?

Everyone's experience is different, and many people have questions or concerns. As you read your mental health notes, keep in mind that they vary in length, may include sensitive information, or could have unfamiliar terms or confusing language that's often required for meeting professional standards. You should feel free to discuss with your therapist issues for you that notes reveal. You may also choose not to read them! Reading such notes may not feel right for whatever reason, and that's okay too. You know yourself best. It's important to respect that, and to talk with your therapist about your preferences.

Talking about the things that affect our lives, especially topics that can be difficult to discuss, can be important for recovery in mental health. Here are some strategies for getting started with using open notes as a tool in your therapy:

Talk with your therapist about your expectations with note sharing. This conversation can also help you learn more about your treatment and your clinician's perspectives. Things you might want to discuss include:

- unfamiliar professional terms, abbreviations, or language;
- reading sensitive information;
- mistakes, errors, or missing information;
- too much or too little detail;
- differences of opinion about diagnoses or treatment; and
- reading surprising, confusing, or upsetting information.



If you're nervous or worried, you may want to consider asking your clinician if you can read some of your notes together.

Develop a plan for what you should do if you become worried or upset by reading your notes, or if you disagree with something written in the notes. This may include talking with a trusted friend or family member, taking a walk, or relying on other strategies that work for you.

“The most important thing is to talk with your therapist about all the typical ways you manage your well-being between visits and how those same strategies can be used while reading your notes.”

— STEVE O'NEILL, LICSW, JD, OPENNOTES SPECIALIST, SOCIAL WORK MANAGER FOR PSYCHIATRY AND PRIMARY CARE, BIDMC

The **U.S. Department of Veterans Affairs (VA)** was one of the first health systems to open all notes to all patients. The VA developed the R.E.A.D. Strategy to help patients get the most out of their mental health notes. Step 1 is to **REFLECT**. Think about what you hope to learn, and choose a reading environment that suits your learning or reading style. Step 2 is to **EXPLORE**. Take your time reading your notes because the contents or language may be unfamiliar and keep an open mind about what you are learning. Step 3 is to **ASK**. Let your clinician know if you want to discuss your notes or if you need follow up about something, like a test or appointment. And ask your clinician for reading material or trusted websites to learn more. Step 4 is to **DECIDE**. It's up to you to decide how you want to use your notes. Consider how often and how much of your notes you want to read.

Is There Anything Else to Keep in Mind?

Questions are good. You can ask your therapist, “How are you going to write about this in my note?” But, it's important to remember that while the patient has a right to access to the record, the health professional must still satisfy professional requirements and standards.

Sometimes notes are closed. If your therapist feels that reading the information in a note might be harmful to you, he or she may keep the note from being available on the patient portal. If a note is unavailable, talk with your therapist. Again, you might suggest reading the note together.

Open notes are not for everyone. For some patients, just knowing the notes are there and available is enough. Some use the notes as reminders of the work to do between visits, and, for a variety of reasons, others choose not to read their notes. OpenNotes is a good example of freedom of choice!