Empowering Patients Through Information Sharing: Cures Act Compliance Series

December 2021 / **OpenNotes Overview** Q & A

The following questions were submitted by participants before and during the December 1 webinar and December 15 Ask the Experts sessions. The answers provided are for informational purposes only; they do not, and are not intended to, constitute legal advice. Only your attorney can provide assurances regarding the application of this information to your particular circumstances.

Topics

Open Notes and OpenNotes

Q: Would you please address exclusion of notes for services protected by 42 CFR 164.524(a) (1) and (2)?

A: The rule pertains to sharing between providers about Substance Use Disorders (SUDS) information, not the patient receiving their own information. I think there is a lot of confusion that OpenNotes means open to everyone, when really it means easy and open access for the patient.

Q: If OpenNotes is not software, how does this work with an organization's established EHR software?

A: Organizations should speak to their EHR vendors about their system's OpenNotes functionality.

Q: So the provider can choose which notes are "open" or not – for example if there is a note that can be excluded within the regulations, the provider doesn't have to share that particular note, am I understanding that correctly?

A: Yes, providers can exclude an individual note if they feel the note meets one of the exceptions. The provider should be prepared to indicate which exception they believe is met.

Have you ever been in a situation where a note should have been hidden but wasn't, and how was that handled?

A: I am not aware of any published studies of "note hiding." We are still in the early days of sharing notes, so such experiences are likely not currently common. It is much more common to hear about a note that should been written better or differently.

Q: What are the most frequent errors noted by patients?

A: Early OpenNotes studies showed that patients most frequently found errors in drug lists, problem lists and family history. Those can be important, but the most important errors in notes relate to the diagnostic process. You can find more information on the topic here: https://www.opennotes.org/ourdiagnosis/

Q: How often do patients share notes with others?

A: Patients often share notes with caregivers with significant benefits for both (see https://www.opennotes.org/care-partners-patients/). Children and parents benefit when parents can access notes of the child (see https://www.opennotes.org/pediatrics-adolescents-clinicians/). There can be benefits for adolescents to share notes with parents, especially when significant chronic disease is present. But there also are privacy concerns for many adolescents, and these concerns need to be addressed consistent with the health organization culture and state law. Most sharing of patient notes currently occurs informally through the patient providing their portal username and password to the caregiver. Formal proxy access should be encouraged in order to protect privacy.

Q: Would you share a few success strategies for facilitating organizational culture change around note sharing?

A:

1. Find a provider champion.
2. Create a strong communication plan (see https://www.opennotes.org/communications/).
3. Organize a Patient and Family Advisory Council to advise clinical leadership and IT leadership on culture change related to open notes (see https://www.opennotes.org/pfac-patients/).
4. Measure note opening rates in order to determine the success of the above strategies. Some vendors already provide the ability to do so.

Therapy Notes

Q: Does OpenNotes encompass therapy notes?

Q: How would you describe the difference between Psychotherapy Notes and Progress Notes that a psychiatrist/psychologist/mental health counselor may document? Many times they state their psychotherapy notes are the same as their encounter progress notes.

Q: Can all mental health notes be considered psychotherapy notes and not be shared?

A: The word 'therapy" could apply to several situations, but I think most commonly it applies to two. The first is straightforward: Therapy notes for physical therapy, occupational therapy, speech therapy and other rehabilitation therapies are included in the Cures Act as progress notes and need to be released if electronic, unless one of the exceptions applies.

The second situation is tricky. Psychotherapy notes are excluded from the Cures Act. Most mental health notes do not involve psychotherapy. BUT please recall the advice from the legal consultant[1], psychotherapy notes are usually paper notes that focus on the reaction of the therapist to a therapy session. They originate almost entirely from trained mental health clinicians conducting multisession psychotherapy and tracking their own reactions. So when the term "psychotherapy notes" is used it applies to a very small subset of clinicians' and mental health notes. That said, if a therapist wants to release psychotherapy notes they can do so.

Other

Q: What is best practice, or do you have experience to share, regarding adult patients with intellectual or developmental disabilities and sharing patient notes with legal guardians? I'm assuming great leeway in determining the individual patients understanding and asking them for permission first in applicable situations? Do you do a written consent with them or verbal? Is there any legal guidance for sharing levels between patients who live in designated group homes and the patients who live in the community or with guardians?

A: Each of these would probably need to be a case-by-case decision based on the patient and what is written in the note, with the clinician having discretion. It would be best in these situations to have well documented proxy processes that the patient, guardian and other caregivers with need for information can follow.

Q: Also related to group homes: family history documentation includes much information about family members that may not be relevant to a patient's care. Is there a way to hide portions of the family history?

A: Technology-wise, this would depend on the vendor. It the question is about non-medical staff seeing the family history, that may vary, depending on the EHR security. It is important to emphasize to clinicians the privacy issues that arise when family history is recorded. For example, in newborn charts there is often health information about mother and father that can create concerns downstream.

[1] Helen Oscislawski; please see "Information Blocking Rule Learning Session Resources" on the CHCANYS website for her presentations.