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Sharing Our Clinical Notes Directly with Our Patients: Social Work and Patient Perspectives of OpenNotes and the Cures Act

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**Society for Social Work Leadership in Health Care
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OpenNotes

No Conflicts to Report

Funding from the Macy Foundation
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OpenNotes in Behavioral Health:

What is Open Notes?

What is Our Notes?

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Goals

- Share our own, as well as the national experience, with fully open clinical notes, particularly in mental health
- Notes as (narrative) therapy for behavioral health and mental illness
- OpenNotes as a movement to create a culture of transparency and respect, especially in establishing partnerships with the patients we serve!

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Relevant Beth Israel Deaconess Medical Center History

- First Electronic Health Record (1985)
- Ethics Note Sharing Policy (25 years)
- Sharing Notes in Mental Health (35+ years)
- Culture of Transparency and Trust
 - Apology and Disclosure
 - Preventable Harm Initiative

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Always start with.....

What is Best for the Patient??!!

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Underlying Values

Patient Autonomy

Professional Autonomy and Paternalism

Parental Autonomy

Beneficence & Non-Maleficence

Trust, Loyalty, Fidelity

Privacy/Confidentiality

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Who Do We Write Note For?

1. **Our Patients** - as if sitting our your shoulder
2. **Cross-coverage**, especially urgent/emergency care
3. **Professional Standard Obligations**, including legal/risk management
4. **Health Insurance Company** (or Disability; Workmen's Compensation, etc) as applicable
5. **Ourselves**

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21st Century Cures Act

Effective April, 2021!

- Requires Direct Patient Access to their Electronic Medical Record, really OpenNotes!
- Forbids "Information Blocking"!
- Mental Health ("Psychotherapy Notes") had been excluded but really appears to be included.....
- Complete record access through third party apps to be by 10/22!
- Prior to Cures Act, 55 million USA persons participated in OpenNotes for better than 3 years

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We miss a critical opportunity to build trust and advance equity!

- Trust is essential for:
 - Following care plans and other clinical advice
 - Getting recommended vaccinations (!)
 - Clinical trials (!)
 - Telehealth (!)
 - And establishing any relationship!!

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HEALTH CARE DISPARITY: BIAS AND STIGMA

■ 70/30 Rule

- Delivery of Difficult News ~ 70+% with solid metastatic cancer unaware of chemo's palliative intent

Weeks et al., "Patients' Expectations about Effects of Chemotherapy for Advanced Cancer," NEJM 2012



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How Can Sharing Mental Health Notes Help Patients?

- Demonstrating respect and reducing stigma
- Empowering patients
- Organizing care and tracking progress
- Providing a tool for behavior change
- Enhancing trust and the therapeutic relationship
- Making care safer
- Potential for reducing workload

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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Clinician Concerns

- Clinicians already struggle with **how to write notes**
- Concerns about patients feeling **judged, criticized or misinterpreting** our notes, particularly if triggering an '**angry**' response
- Worries about **harming our patients**
- Worries about establishing **therapeutic rapport/alliance** with hard to reach patients
- Might change the **power dynamics** of relationship
- Will OpenNotes enhance or diminish **trust**
- Will OpenNotes worsen **work burden**

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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OpenNotes Research

- Would OpenNotes help patients become more engaged in their care?
- Would OpenNotes be the straw that breaks the therapist's back?
- After 1 year, would patients and therapists want to continue?

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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What did we find??


- And they.....
 - want their notes!
 - are not scared stiff!
 - read the notes!
 - share the notes!
 - report important benefits!

Source: Delbanco, Walker, et al, Ann Intern Med, 2012
<https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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What did we find??

- Patients with '**adverse effects**' tended to clarify these concerns as underlying concerns such as privacy or already existing issues; or misinterpreted questions when asked
- Biggest issue, as in medicine, seems to be whether there is **concordance** between what the therapist says in session and what they write in the note

Source:
<https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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What did we find??

- ▶ The vast majority of patients **never mentioned** to their therapist about having read their notes
- ▶ Note Reading drops off due to **redundancy**.....

Source:
<https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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What about the 'nightmare' patient(s)?

Is this really an index for 'contagious' staff angst???

These are labor intensive patients irrespective of the therapeutic interventions.....!

Source:
<https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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PRIVACY VS CONFIDENTIALITY



18% shared notes with others (20-42% in medicine), mostly family

OpenNotes

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**60-78% of those taking
medications reported “doing
better with taking my
medications
as prescribed”**

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Patients with Severe Mental Illness Study (Blease et al, 3/21, JAMA)

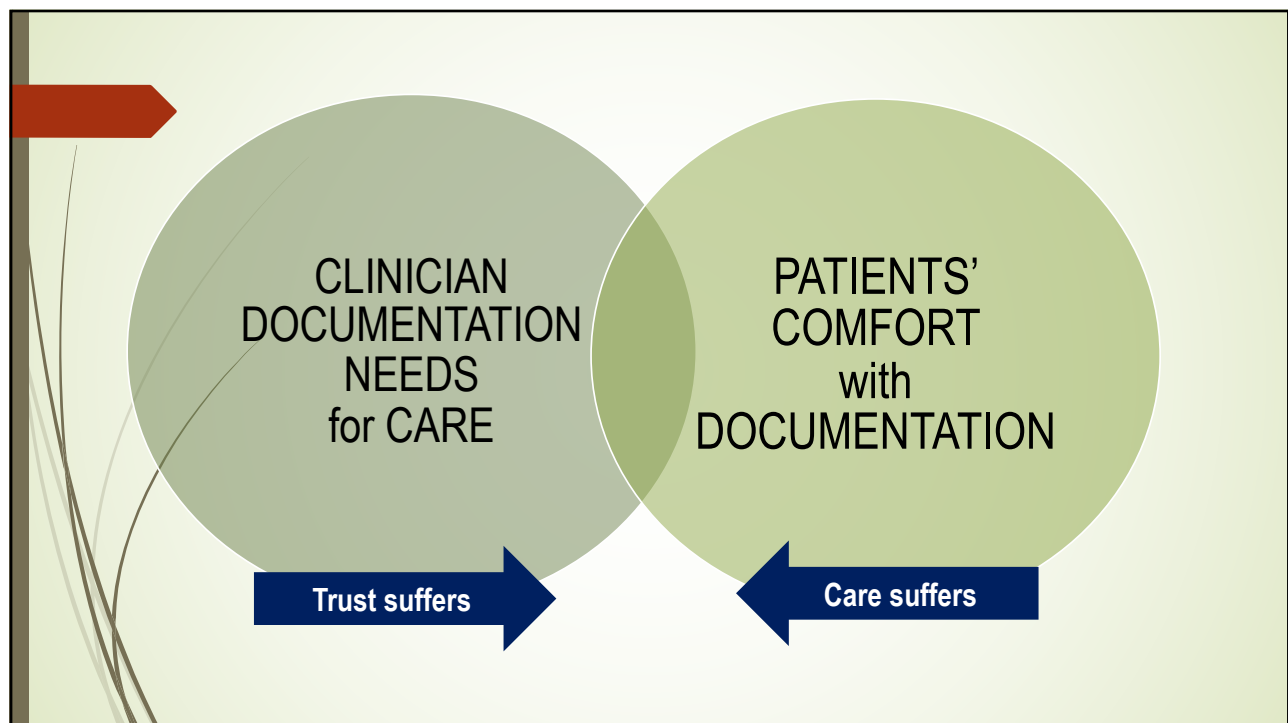
-136,815 patients with Bipolar D/O, Schizophrenia or Major Depression; 29,656 responded (22%)

-67% reported being helped to understand why their med(s) were prescribed



-65% reported feeling more comfortable with taking their med(s)

-60% reported feeling that reading their note(s) helped to answer their questions

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Writing Open Notes Tips

- The invitation is important
- Promote transparency
- Use plain language
- Engage patients in the documentation
- Develop options if a patient's access to notes may carry more risk than benefit
- Discuss the diagnosis
- Use Patient Quotes!

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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Writing Open Notes Tips


- **Overdocumentation** Issues
- **Domestic Violence and Safety** Exclusions
- **Patients with Trauma** History
- **Obsessive patients** ("I've spent my whole life learning not to double think."; "When I go to my mechanic, I don't want to look under the hood. Same here!")
- **Paranoid patients** ("I'd be petrified to look. I'm not gonna do it.")
- Patients **"in denial"** and **'premature'** info

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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Writing Open Notes Tips


- 1, Patient who Distorts and Decompensates
2. Patient who Declines Reading His Notes
3. Delusional Patient
4. Patient whose Child Suicided

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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Adolescents/Pediatrics

Access Issues

Default Settings

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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Challenging Situations: The delusional patient

- Scenario:** Mr. A is a man with schizophrenia who believes that the FBI has placed "invisible" microphones and cameras in his apartment. He takes 1 mg of risperidone daily "to keep my family off my back," but you are trying to get him to take a higher dose. You have tried to discuss his diagnosis with him, but he dismisses it, and believes that "schizophrenia was made up by the FBI to incarcerate subversives."
- Sample note:** Mr. A says he is taking risperidone 1 mg daily, but continues to be convinced that the FBI is monitoring him. We disagree on this, as we do about whether he has a psychiatric problem in the first place. I believe that a higher dose of risperidone would help him with the anxiety he feels about being monitored, but he firmly refused to increase the dose to 2 mg daily. I nevertheless urged him to consider a brief trial of the higher dose, to see if he noticed any benefit. We will continue to assess his overall level of anxiety and how it affects his daily functioning. I am concerned that his anxiety limits his ability to feel safe on a day-to-day basis. But on a happier note, he continues to be very interested in current events and reads newspapers and books extensively.

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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Challenging Situations: The borderline patient

- Scenario:** Ms. B is a young woman who frequently self-mutilates to manage stress. She is taking fluoxetine and aripiprazole for anxiety and depression, which help to increase her stress tolerance to a certain extent, but she finds that ongoing use of alcohol and marijuana "help me more" with anxiety. Her relationship with her boyfriend continues to be marked by frequent verbal fights, and occasional pushing. You are trying to explore other medication options and also to encourage her to try dialectical behavior therapy.
- Sample note:** Ms. B's condition remains about the same as it was during our last visit. She feels the medication helps somewhat, but I have shared my concerns with her that her continued use of marijuana and alcohol likely interferes with the ability of the medication to help. She recognizes her frustration and unhappiness, however, and was open to discussing a referral for dialectical behavior therapy. I think this could be very helpful for her. I also raised the question of AA. We agreed to see how she felt after a week of going without alcohol, and if she can do this we will consider a low dose of lithium to help her with her moods. While she has her ups and downs at her job as a receptionist, she does feel her boss is supportive, and that's encouraging.

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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Challenging Situations: The survivor of sexual trauma

- **Scenario:** Ms. C is a woman in her thirties whom you have seen for a year for depression and who now reveals that she was molested by an uncle several times when she was 9. She has never revealed this to anyone before and was overwhelmed with feelings when she mentioned it. She asks you not to reveal this in the medical record.
- **Sample note:** Ms. C is functioning well on citalopram 40 mg qd, sleeping and eating well, and doing well at work. Today she mentioned some incidents in her past that we have not discussed before and that were very significant for her. We will continue the citalopram and explore the incidents when we meet next.

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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Challenging Situations: The dishonest patient

- **Scenario:** Mr. D. is a man in his twenties whom you have been treating for anxiety. You get a call from a pharmacy saying he has been filling prescriptions for a benzodiazepine from a physician you have never heard of. You tactfully confront Mr. D with this information and he gets very upset and leaves the visit prematurely, saying he can't trust you anymore.
- **Sample note:** Mr. D. said he has been doing well on fluoxetine 20 mg qd and clonazepam 1 mg bid for anxiety, and that he enjoys his new job as a mechanic. I told him I had been contacted by a pharmacy to ask me if I knew he was getting alprazolam from a different doctor, and I asked him if we could discuss the issue. Unfortunately, he became very upset and told me that the alprazolam was "none of your business." I told him I thought perhaps his anxiety was undertreated on the regimen I have been giving him, but he did not want to discuss it, and left the office suddenly. He did not make a follow-up appointment, and I will send a letter inviting him to do so.

Source: <https://www.opennotes.org/tools-resources/for-health-care-providers/mental-health/>

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RECENT RELATED PUBLICATIONS

O'Neill, S, Blease, C, and Delbanco, T, "Open Notes Become Law: A Challenge for Mental Health Practices" Psychiatric Services May 11, 2021, 00:1-2. doi:appi.ps.202000782

Blease, C, O'Neill, S, Touros, J, DesRoches, C, and Hagglund, M, "Patient Access to Mental Health Notes: Motivating Evidence-Informed Ethical Guidelines" Journal of Nervous and Mental Disease (2021) 209: 4: 265-269 doi: 10.1097/NMD.0000000000001303

Blease, C, Touros, J, O'Neill, S, Hagglund, M, and Walker, J "Sharing Notes with Mental Health Patients: Balancing Respect with Risk" Lancet Psychiatry (2020) 7:P924-5. doi: 10.1016/S2215-0366(20)30032-8

Blease, C, Walker, J, Touros, J, and O'Neill, S "Sharing Clinical Notes in Psychotherapy: A New Tool to Strengthen Patient Autonomy" Front. Psychiatry, 28 October 2020 | <https://doi.org/10.3389/fpsyt.2020.527872>

Chimowitz, H, O'Neill, S, Leveille, S, Welch, K, and Walker, J, "Sharing Psychotherapy Notes with Patients: Attitudes and Experiences" Social Work, 65:2: 159-168 (2020) doi: 10.1093/sw/swaa010

O'Neill, S "Flattening the Mental Health Curve During the Pandemic" Social Work Voice 3:4, 8-9 2020

O'Neill, S, Chimowitz, H, Leveille, S, RN, PhD, and Walker, J "Embracing the New Age of Transparency: Mental Health Patients Reading their Psychotherapy Notes Online" Journal of Mental Health, 28, 527-535 (2019)

Klein JW, Peacock S, Tsui JI, O'Neill SF, DesRoches CM, Elmore JG. "Perceptions among Patients with Mental Health Diagnoses About Reading Psychiatric Primary Care Clinic Notes" Annals of Family Medicine, 16: 4: 343-345, 2018

Whyte, R and O'Neill, S "Disclosures in Surgical Care: Errors, Surgeon's Experience, Conflicts of Interest, and Truth Telling" in Ethical Issues in Surgical Care, American College of Surgeons, 2017

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Thanks!
Questions??

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