

# Sharing Mental Health Notes with Patients

## Office Hours

Tuesday, January 19, 2021 • 3-4pm Eastern



&



**Steven K. Dobscha, MD**

Director, Center to Improve Veteran Involvement in Care,  
VA Portland Health Care System, Professor of Psychiatry,  
Oregon Health & Science University

**Stephen F. O'Neill, LICSW, BCD, JD**

Mental Health Liasion, OpenNotes  
Adjunct Assistant Professor,  
Simmons College School of Social Work

# Welcome & Introductions



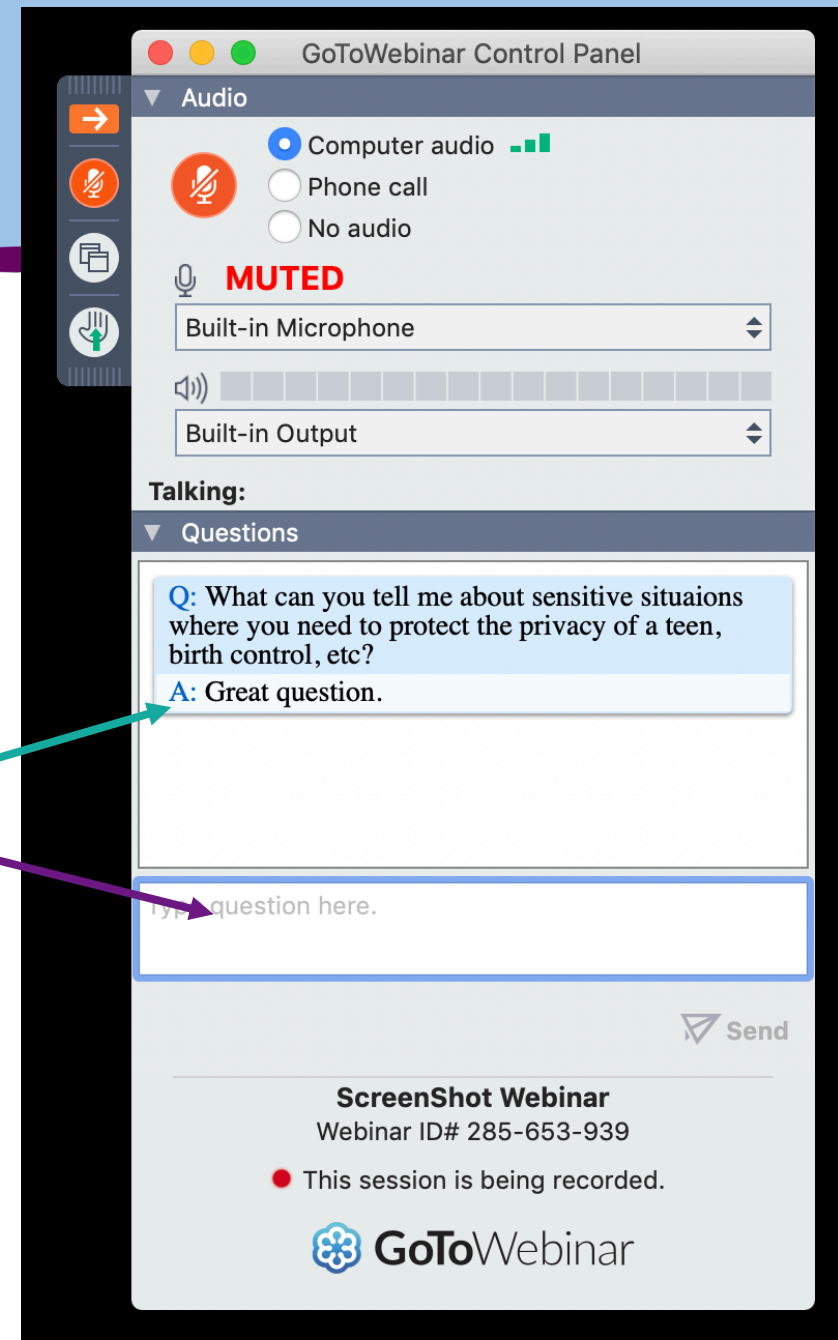
**Liz Salmi**

Senior Strategist, OpenNotes



# Housekeeping

- Attendees are muted.
- During the session, **type questions into the “question” section**, and we will address them at end of prepared comments.
- Some answers may be provided during the presentation. Those answers will appear underneath your question.
- The presentation recording will be available at **opennotes.org** and **youtube.com/myopennotes**
- You will receive an email with links to these presentations.



The screenshot displays the GoToWebinar Control Panel interface. On the left, there is a vertical sidebar with icons for navigation, audio, chat, and help. The main panel is titled "GoToWebinar Control Panel" and is divided into several sections:

- Audio:** This section shows "Computer audio" selected with a blue radio button and a green volume indicator. Other options include "Phone call" and "No audio". A red "MUTED" label is prominently displayed next to a microphone icon. Below this, a dropdown menu shows "Built-in Microphone" selected, and another dropdown shows "Built-in Output". A volume slider is also visible.
- Talking:** This section is currently empty.
- Questions:** This section contains a question and answer pair:
  - Q:** What can you tell me about sensitive situations where you need to protect the privacy of a teen, birth control, etc?
  - A:** Great question.
- Input:** Below the questions, there is a text input field with the placeholder text "Type question here." and a "Send" button with a paper plane icon.
- Footer:** At the bottom, it identifies the session as "ScreenShot Webinar" with "Webinar ID# 285-653-939". A red dot icon indicates "This session is being recorded." The GoToWebinar logo is at the very bottom.

Two arrows originate from the text in the first two bullet points of the "Housekeeping" list. A purple arrow points from the phrase "type questions into the 'question' section" to the question text in the "Questions" section of the screenshot. A teal arrow points from the phrase "Some answers may be provided during the presentation" to the answer text in the same section.

# OpenNotes Grand Rounds

## Sharing Mental Health Notes with Patients

Welcome!

January 12th, 2021



# What is open notes?

When patients can easily read visit notes



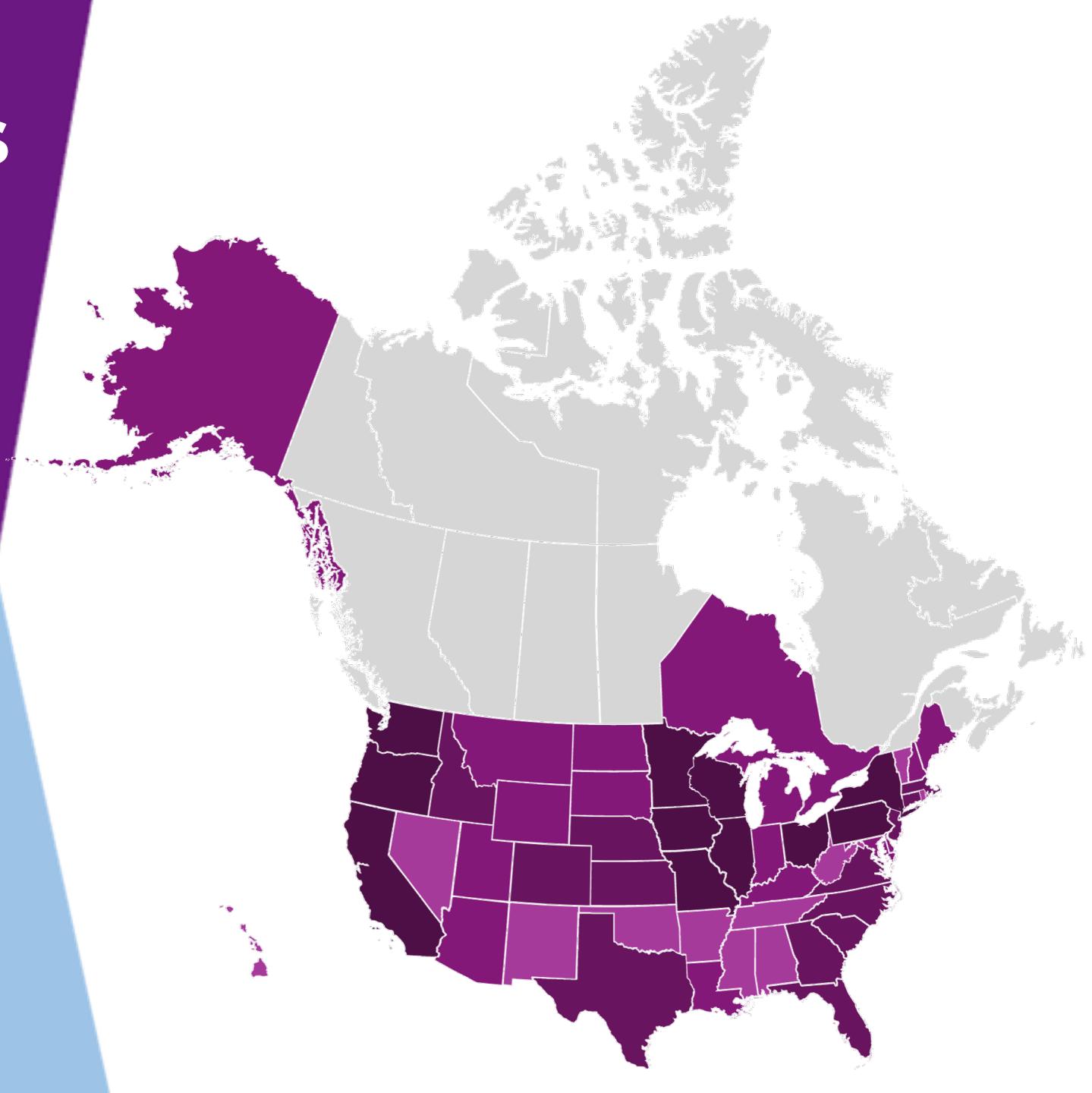
HARVARD MEDICAL SCHOOL  
TEACHING HOSPITAL



Robert Wood Johnson Foundation

# Open Notes Across North America

- ✓ **260** organizations
- ✓ **54 MILLION** people



# April 5, 2021



## 21st Century Cures

An official website of the United States government [Here's how you know](#) ▾

 **ONC's Cures Act Final Rule** MENU

[Home](#) > [Final Rule Policy](#) > Patient Access

## Empowering Patients in the U.S. Health Care System

**Patients in the U.S. need better access to information about their care – information ranging from their medical records to data about the costs and quality of the care they receive.**

The Cures Act aims to empower Americans with their health data, delivered conveniently to computers, cell phones, and mobile applications.

Nationwide, patient-centric health IT, once achieved, can deliver a variety of benefits to patients, including:

- Transparency into the cost and outcomes of their care
- Competitive options in getting medical care
- Modern smartphone apps to provide convenient access to their records
- An app economy that provides patients with innovation and choice

Under HIPAA, patients already have a legal right to their data electronically. The ONC Cures Act Final Rule is one step in this process by enhancing access to clinical data.

- ✓ Consultation notes
- ✓ Discharge summaries
- ✓ History and physical
- ✓ Imaging narratives
- ✓ Lab report narratives
- ✓ Pathology report narratives
- ✓ Procedure notes
- ✓ Progress notes



# Federal “Preventing Harm Exception”

(See 45 CFR § 171.201)

- There are 4 scenarios in which a provider may block information under the “Preventing Harm Exception”.
- Under **each** of these 4 scenarios:
  - The provider must reasonably believe that blocking access to information will **substantially reduce the risk of harm to the patient or another person**.
  - Blocking access to information should be **no broader than necessary** to substantially reduce the risk of harm.



# OpenNotes Grand Rounds

## Sharing Mental Health Notes with Patients



# Impacts of Open Notes In The Context of Mental Health Care:

Lessons Learned From a Study of OpenNotes In the VA



## **Steven Dobscha, MD**

VA Portland Healthcare System  
Oregon Health & Science University



# Support/Disclaimer

This material is based upon work supported by the Department of Veterans Affairs, Veterans Health Administration, and Health Services Research & Development (Project #13347).

The views expressed in this presentation are those of the presenter and do not necessarily reflect the position or policy of the Department of Veterans Affairs or United States government.



# Background

- All authenticated users of VA's My HealthVet gained ability to access to notes in January 2013
- **No** provision to block notes including mental health notes
- 2.5 million VHA users have viewed/downloaded notes to date



# Multiple Studies Support Use of Open Notes in General

- Delbanco et al study of open notes at 3 hospitals (Annals Int Med 2012):
  - 105 PCPs and 13,564 patients surveyed and followed for 12 to 19 months
  - 77% to 87% of *patients* reported open notes helped them feel more in control of their care
  - 60% to 78% of reported increased medication adherence
  - 70% of 105 *primary care clinicians* reported strengthened relationships with their patients; specifically, enhanced trust, transparency, communication, and shared decision making.
  - PCPs reported modest impacts on practice activities
- Walker 7-year follow-up survey (2019): Very positive patient experiences; but fewer than half of clinicians/patients discussed notes during visits



# Open Notes In Mental Health— The Concerns

- Mental health notes typically contain more details and sensitive information
- Special factors:
  - Documentation of trauma
  - Personality disorders
  - Violent behaviors
  - Psychosis/delusions
  - Private information about other individuals close to patient



# Early Studies On Paper Mental Health Notes

- Upsides

- Better understanding of problems
- Most patients felt comfortable
- Increased self confidence
- Clinicians may accommodate

- Downsides

- Offensive and stigmatizing language
- Patient upset
- More pessimistic about care



• References: McFarlane 1980; Essex 1990; Parrott 1988; Bernadt 1991; Miller 1987; Sergeant 1986; Schwartz 1985; Stein 1979; Gill 1986; Bloch 1994; Crichton 1992; Shenkin 1973



# Optimizing Benefits and Reducing Negative Effects of Mental Health Open Notes: Study Aims

- Understand Veteran and clinician perspectives and experiences with VA OpenNotes in the mental health care
- Use this information to develop and evaluate web-based courses for clinicians and Veterans that are designed to:
  - 1) minimize unintended consequences of OpenNotes
  - 2) optimize collaboration and communication

## **SPECIAL THANKS TO:**

- Lauren Denneson
- Sue Woods
- Risa Cromer
- Anais Tuepker
- Sarah Ono
- Maura Pisciotta
- Holly Williams
- Aysha Crain
- Anne Kovas
- Ken Weingardt
- Stephanie Veazie
- Wen Pen (Kevin) Lai
- April Lee
- Barbara Snyder
- Martha Gerrity
- David Philipps-Moses
- Laura Jacobson
- Our Veteran consultants
- Our Clinician consultants
- Tom Delbanco
- Jan Walker





# How do VA patients who receive mental health care feel about open notes?



# Key Findings From *Veterans* —*Qualitative*

Trust is critical to the therapeutic relationship and reading clinical notes can either strengthen or strain trust in clinicians

- “I would like [my clinician] to take it seriously too, not just spit something out on paper and not proofread it.”
- “Did the [clinician] actually listen to me?...It seems like a very different person written [about] in the notes at times.”
- “He sees me as a human being...and he focuses on seeing my strengths.”
- “I like the way that [my clinician] puts them in because he’s very blunt and honest. He pretty much says exactly what I’ve said. And what I really like about it is that he also puts in there what we’ve talked about and what I said I would do.”



# Key Findings From Veterans—Quantitative

<b>Veteran Characteristics (n = 359)</b>	
Age, Mean	58 yrs.
Gender (% Male)	80%
Education: 4 years college or more	40%
Race-ethnicity: Non-Hispanic white (vs. Other)	89%
Employment status: Disabled, or retired	81%
Marital status: Married	57%
Rural (vs. Urban)	20%
Diagnoses (prior year)	
PTSD	58%
Major Depression	62%
Psychotic/Bipolar Spectrum Disorders	17%
eHEALS score, Mean	28.5



# Veteran Attitudes/Experiences (n=359)

Very to extremely supportive of the VA making mental health notes available online to Veterans	77%
Very to extremely important to have access to personal health information using VA Blue Button for health and recovery.	71%
Very to extremely likely to be able to understand mental health notes	66%
Very to extremely likely for mental health notes to accurately describe what happens in mental health appointments	65%
Very to extremely likely to help you with following mental health clinician's treatment recommendations	51%
After reading mental health notes, patient has a little to a lot more trust in mental health clinician	45%
Very to extremely likely for mental health notes to help with self-care	40%
Very to extremely likely to help prepare for mental health appointments	30%
Reading mental health notes often or always causes stress or worry	8%



# Veteran Attitudes/Experiences (n=359)

Very to extremely supportive of the VA making mental health notes available online to Veterans	77%
Very to extremely important to have access to personal health information using VA Blue Button for health and recovery.	71%
Very to extremely likely to be able to understand mental health notes	66%
Very to extremely likely for mental health notes to accurately describe what happens in mental health appointments	65%
Very to extremely likely to help you with following mental health clinician's treatment recommendations	51%
After reading mental health notes, patient has a little to a lot more trust in mental health clinician	45%
Very to extremely likely for mental health notes to help with self-care	40%
Very to extremely likely to help prepare for mental health appointments	30%
Reading mental health notes often or always causes stress or worry	8%



# Veteran Attitudes/Experiences (n=359)

Very to extremely supportive of the VA making mental health notes available online to Veterans	77%
Very to extremely important to have access to personal health information using VA Blue Button for health and recovery.	71%
Very to extremely likely to be able to understand mental health notes	66%
Very to extremely likely for mental health notes to accurately describe what happens in mental health appointments	65%
Very to extremely likely to help you with following mental health clinician's treatment recommendations	51%
After reading mental health notes, patient has a little to a lot more trust in mental health clinician	45%
Very to extremely likely for mental health notes to help with self-care	40%
Very to extremely likely to help prepare for mental health appointments	30%
Reading mental health notes often or always causes stress or worry	8%



# How do VA mental health clinicians feel about OpenNotes?



# Key Findings From Clinicians

## —Qualitative

- Theme: Clinicians expressed concern that by reading notes, patients could negatively misinterpret their notation, or feel judged or stigmatized
  - “There’s lots of technical information that’s included in notes that could be scary or off-putting or confusing without context or someone to help explain it.”
- Theme: Clinicians expressed strong desires to protect patients from potential harms that might result from reading notes.
  - “It’s going to be that one time, that one Veteran is going to read something and is going to hurt themselves. And then I’m going to feel like have to live with that.”





# Key Findings From Clinicians

## —Qualitative

- Theme: Some clinicians felt that notes have the potential to undo the considerable work they do in session to develop the therapeutic relationship.
  - “But reading that caused a separation that I think might not have been disturbing to him if he had not seen that in print.”
- Theme: Clinicians also felt that their discomfort with open notes helps keep them accountable, ultimately resulting in improved care or documentation.
  - “When you know that other people are looking at the work that you do, particularly the people who it directly pertains to, then you want to make sure it’s the best, it’s the most accurate...”



# Key Findings From Clinicians— Quantitative

Clinician Characteristics (n = 146)	
Clinician type	%
Nurse Practitioner	4%
Psychiatrist	16%
Psychologist	33%
Social Worker	46%
Gender (% female)	61%
> 20 hours per week direct patient care	56%
> 10 years of practice since last formal training	49%



# Clinician Attitudes Towards OpenNotes

Somewhat to very pleased if mental health open notes were discontinued.	47%
Believed very to extremely likely to cause patients to disagree or find errors in notes	43%
Very to extremely likely to cause patients to be confused by their notes	42%
Very to extremely supportive of providing patients with online access to their entire medical record, including progress notes.	41%
Very to extremely likely to cause patients to worry more	35%
As a result of open notes, very or extremely likely to change the way clinician writes notes	32%
Very to extremely supportive of making mental health notes available to patients online.	30%
Often or always discusses in advance what is contained in notes to be written	25%
Very to extremely likely to report that patients who read their notes online will trust them more	11%



# Clinician Attitudes towards Open Notes

Somewhat to very pleased if mental health open notes were discontinued.	47%
Believed very to extremely likely to cause patients to disagree or find errors in notes	43%
Very to extremely likely to cause patients to be confused by their notes	42%
Very to extremely supportive of providing patients with online access to their entire medical record, including progress notes.	41%
Very to extremely likely to cause patients to worry more	35%
As a result of open notes, very or extremely likely to change the way clinician writes notes	32%
Very to extremely supportive of making mental health notes available to patients online.	30%
Often or always discusses in advance what is contained in notes to be written	25%
Very to extremely likely to report that patients who read their notes online will trust them more	11%



# Clinician Attitudes Towards Open Notes

Somewhat to very pleased if mental health open notes were discontinued.	47%
Believed very to extremely likely to cause patients to disagree or find errors in notes	43%
Very to extremely likely to cause patients to be confused by their notes	42%
Very to extremely supportive of providing patients with online access to their entire medical record, including progress notes.	41%
Very to extremely likely to cause patients to worry more	35%
As a result of open notes, very or extremely likely to change the way clinician writes notes	32%
Very to extremely supportive of making mental health notes available to patients online.	30%
Often or always discusses in advance what is contained in notes to be written	25%
Very to extremely likely to report that patients who read their notes online will trust them more	11%



# Clinician Experiences of Negative Events (n=141)

	n	%
“Are you aware of any specific, negative consequences that you or your patients have experienced in the <u>past 3 months</u> as a result of your pts reading their mental health notes online?”	“Yes”: 27	19%
<i>Reasons reported among 27 who reported (-) consequences)</i>		
Patient disagreed with or was upset by documentation of a specific <b>diagnosis</b>	18	67%
The therapeutic relationship was adversely affected	16	59%
Patient disagreed with or was upset by something I documented other than diagnosis	13	48%
Patient disengaged from care	12	44%
Patient was concerned about effects <b>of compensation or insurance</b>	12	44%
Patient reported a note-related concern to a supervisor or patient advocate	6	22%
Other	5	19%
Patient expressed violent ideation (toward self or others) in response to reading notes	2	7%



# Clinicians' Negative Experiences Over Time

“Are you aware of any specific, negative consequences that you or your patients have experienced in the past three months as a result of your patients reading their mental health notes online?”

	Survey 1 (n=141)	Survey 2 (n=115)	Survey 3 (n=110)
“Yes”	27	21	20
%	19.0%	18.3%	18.2%



# Additional Research On Open Notes In Mental Health Care

- Sub analysis original OpenNotes Study data (Klein et al 2018):
  - No significant differences in perceptions when reading *primary care notes* when comparing patients with MH diagnoses (n=400) to those without MH diagnoses (n=2,134)
- 52 pts and 12 providers from outpatient mental health clinic completed surveys (Peck et al (2017):
  - Patients: Valued info; Did not tell clinicians; 20% concerned about security
  - Clinicians: No increase in burden but did change notes





# Summary of Findings— Veterans

- Veterans find benefit in OpenNotes in context of mental health care
- A minority note more stress or worry
- Therapeutic relationships are critically important to recovery,  
...Trust is critically important to therapeutic relationships, and  
...Open notes can either enhance or diminish trust
- Often don't tell clinicians they are reading notes unless asked<sup>1</sup>.
- Veterans who often felt upset often chose not to read their notes (from qual. interviews)
- Veterans with PTSD are more likely to report *negative* emotional response and *increased* patient-alliance from reading notes<sup>2</sup>, and are twice as likely to read notes<sup>1</sup>
- When patient dissatisfaction occurs, it is often driven by disagreements with what is written in notes (diagnosis) and concerns about legal/compensation impacts

<sup>1</sup>Dobscha SK, et al. *Journal of the Medical Informatics Association Open*, 1(1):122-127. 2018)

<sup>2</sup>Denneson LM, et al. *Psychiatric Services*, 69(5):593-596. 2018. PMID: 29493408


# Summary of Findings— Clinicians

- Clinicians have range of opinions and ambivalence about open notes
- Often like idea, but worry about particular relationships and scenarios
- Have elevated concerns about patients misinterpreting or feeling judged or stigmatized
- Often concerns driven by desires to protect patients from harm and may feel responsible for possible negative outcomes
- While sometimes uncomfortable, some clinicians also felt open notes helps keep them accountable





## VA OpenNotes for Mental Health Clinicians

 Select **Next** to get started

  
MENU

  
RESOURCES

  
HELP

  
BACK

  
NEXT



[https://www.sharedfedtraining.org/external\\_content/2018-BIS7278-VAOpenNotes/opennotes\\_cln/index.html](https://www.sharedfedtraining.org/external_content/2018-BIS7278-VAOpenNotes/opennotes_cln/index.html)



## C.L.E.A.R. Strategy

Clinicians should strive to write notes that are accurate and representative of what occurs during appointments, while demonstrating professionalism and respect for the patient. The C.L.E.A.R. strategy provides guidance to enhance note writing and avoid common pitfalls.

Select **Next** to learn more.

- C** Connect
- L** Language
- E** Encouragement
- A** Audience
- R** Respect



See also Pisciotta M, et al. [Providing mental health care in the context of online mental health notes: Advice from patients and mental health clinicians.](#) *Journal of Mental Health*, 28(1):64-70. 2019. PMID: 30468100



# Challenging Situations – Documenting Sensitive Information

- Openly discuss with patient what you document, and reasons for including to limit surprises.
- *Consider* asking patient about his or her preferences regarding how much detail to include in note, especially regarding more sensitive topics.
- Consider writing note or part of the note with the patient
- Get advice by talking to colleagues or a supervisor before completing a note.
- Consider which details are essential to include in the note.
- For especially sensitive information/circumstances
  - Keep in mind family members may access a patients' notes
  - Consider keeping psychotherapy notes

# What Can Really Help – Orient the Patient

- Discuss the availability of progress notes through Blue Button
- Describe progress notes, their various purposes, and what patients can expect
- Discuss how patients can incorporate notes into their recovery
- Provide opportunities for patients to discuss notes or ask questions

Orienting patients to open notes was associated with 4x increase in odds of patients reading their mental health notes<sup>1</sup>

<sup>1</sup>Dobscha SK, et al. *Journal of the Medical Informatics Association Open*, 1(1):122-127. 2018)



# Selected References

- Dobscha SK, Denneson LM, Jacobson LE, Williams HB, Cromer R, Woods S. VA Mental Health Clinician Experiences and Attitudes toward OpenNotes. *Gen Hosp Psychiatry*, 38:89-93. doi: 10.1016/j.genhosppsych.2015.08.001; 2016.
- Dobscha SK, Cromer R, Crain A, Denneson LM. Qualitative Analysis of U.S. Department of Veterans Affairs Mental Health Clinician Perspectives on Patient-Centered Care. *International Journal for Quality in Health Care*, 28(3):355-362. doi: 10.1093/intqhc/mzw028; 2016.
- Cromer R, Denneson LM, Pisciotto M, Williams HB, Woods S, Dobscha SK. Online Access to Clinical Notes Affects Patients' Trust of Mental Health Clinicians. *Psychiatric Services*, 68(5):520-523. doi: 10.1176/appi.ps.201600168; 2017. PMID: 28142383
- Denneson LM, Cromer R, Williams HB, Pisciotto M, Dobscha SK. A qualitative analysis of how online access to mental health notes is changing clinician perceptions of power and the therapeutic relationship. *J Med Internet Res*, 19(6):e208. doi: 10.2196/jmir.6915; 2017. PMID: 28615152
- Denneson LM, Chen JI, Pisciotto M, Tuepker A, Dobscha SK. Patients' positive and negative responses to reading mental health clinical notes online. *Psychiatric Services*, 69(5):593-596. doi: 10.1176/appi.ps.201700353; 2018. PMID: 29493408
- Dobscha SK, Denneson LM, Pisciotto MK, Bourne DS, Chen JI, Philipps-Moses D, Woods, SS. Predictors of viewing progress notes among users of VA's electronic health portal who receive mental health care. *Journal of the Medical Informatics Association Open*, 1(1):122-127. doi: 10.1093/jamiaopen/ooy007; 2018.
- Pisciotto M, Denneson LM, Williams HB, Woods S, Tuepker A, Dobscha SK. Providing mental health care in the context of online mental health notes: Advice from patients and mental health clinicians. *Journal of Mental Health*, 28(1):64-70. doi: 10.1080/09638237.2018.1521924; 2019. PMID: 30468100
- Denneson LM, Pisciotto M, Hooker ER, Trevino A, Dobscha SK. Impacts of a web-based educational program for veterans who read their mental health notes online. *JAMIA*, 26(1):3-8. doi: 10.1093/jamia/ocy134; 2019. PMID: 30445648
- Dobscha SK, Kenyon EA, Pisciotto MK, Niederhausen M, Woods S, Denneson LM. Impacts of a web-based course on clinician attitudes and communication behaviors related to the use of OpenNotes in mental health care. *Psychiatric Services*, 70(6):474-479. doi: 10.1176/appi.ps.201800416; 2019. PMID: 30890047
- Chimowitz H, O'Neill S, Leveille S, Welch K, Walker J. Sharing psychotherapy notes with patients: therapists' attitudes and experiences. *Social Work*, Volume 65, Issue 2, April 2020, Pages 159-168, <https://doi.org/10.1093/sw/swaa010>
- Klein JW, Peacock S, Tsui JI, O'Neill SF, DesRoches CM, Elmore JG. Perceptions of Primary Care notes by patients with mental health diagnoses. *Ann Fam Med* 2018;16:343-345. <https://doi.org/10.1370/afm.2287>





# Thank you.

## **Steven Dobscha, MD**

VA Portland Healthcare System  
Oregon Health & Science University





# The Experience of Opening Notes in the Context of Mental Health Care



## **Steve O'Neill, LICSW, BCD, JD**

Social Work Manager, OpenNotes Program  
Beth Israel Deaconess Medical Center

Faculty, Center for Bioethics  
Harvard Medical School

Adjunct Faculty  
Simmons University School of Social Work



# Goals

- Share our own, as well as the national experience, with fully open medical records, especially 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!



# Always start with. . .

What is Best for the  
Patient??!!



# Relevant BIDMC History

- Ethics Note Sharing Policy (20+ years)
- Sharing Notes in Mental Health (35+ years)
- Culture of Transparency and Trust
  - Apology and Disclosure
  - Preventable Harm Initiative



# 21<sup>st</sup> Century Cures Act

- Effective November, 2020 ... and now moved to April, 2021!
- Requires Direct Patient Access to their Electronic Medical Record, really OpenNotes!
- Forbids “Information Blocking”!
- Mental Health (“Psychotherapy Notes”) had been excluded but now appears to be included ...



# Three Principal Questions

- 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?



# Behavioral Health Roll Out

1. BIDMC Psychiatry Department- 3/1/14 start  
Opt-in Model: 10 patients apiece
2. BIDMC Social Work Department- 4/1/14 start
  - a.) Opt-out Model: All patients in  
unless specifically excluded or
  - b.) Ramp-up Model: Start with smaller  
cohort and build up



# Staff

- 15 Psychiatrists/Therapists In Psychiatry Department
- 28 Social Work Staff agreed to pilot; 4 declined; pediatric therapists and fellows excluded; staff turn over; or no eligible patients = 24 started
- 440 patients at start; Currently better than 4000 participating in open therapy notes





# Common Concerns About Open Notes In Mental Health:



**Open notes  
causes harm.**



# BIDMC Clinical Staff Fears:

1. Increased Work Burden—“feeling a sense of pressure to get notes entered in a timely manner so that they can be useful to the patient”



# BIDMC Social Work Staff Fears

1. Increased Work Burden—“feeling a sense of pressure to get notes entered in a timely manner so that they can be useful to the patient”
2. Misunderstanding: “I’m concerned about patients misunderstanding information in the notes.....”



# BIDMC Social Work Staff Fears

1. Increased Work Burden—“feeling a sense of pressure to get notes entered in a timely manner so that they can be useful to the patient”

2. Misunderstanding: “I’m concerned about patients misunderstanding information in the notes.....On the other hand, I am hopeful that the open notes may actually enhance the therapy process and promote greater communication/understanding on both sides.”



# BIDMC Social Work Staff Fears

## 3. Re-languaging Notes and Processing of Notes-

“...will they be angry about certain content?!”



**We will have to change  
our notes, possibly  
double chart, and  
important information  
will be lost.**



# BIDMC Therapist Fears

3. Re-languaging Notes and Processing of Notes- “....will they be angry about certain content?!”
4. Patients with severe mental illness, especially psychosis and paranoia will flee
5. “It’s one thing to tell them in session we think they are having paranoid thoughts and another for them to read it at home alone”



# Therapist Work Group:

- FAQ's and scripts/info sheets developed
- Anticipating reactions or feedback from patients and colleagues and staff
- Thesaurus approach for altering language



# What did we find?



# Patients were pleased...

They want the notes

They are not scared stiff

They read them

They share them

They report  
important  
benefits



# Patients were pleased...

- 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

# Note Reading

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



# Privacy vs Confidentiality



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

# The NIGHTMARE Patient

Recurrent staff concerns about the “nightmare patient” reported at BIDMC, as well as other practices.....



# The NIGHTMARE Patient

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

These are labor intensive patients irrespective of the therapeutic interventions.





# Patient Who Regresses

- Reads her notes and increasingly paranoid
- Group therapy

# Two Patients Who Prints Out Notes

- Unable to recall what was talked about in session
- One prints out note to review regularly
- Other declines looking at note for some time

# Delusional Patient

- Couple's therapy
- Belief that smoke/carbon detectors are bugged

# Patient Struggling with Depression

- “Declined” reading notes for 2 ½ years
- “I’d be petrified to look. I’m not gonna do it.”
- Convinced notes will affirm his being a “horrible” person



# Looking Under the Hood



# The Bottom Line

- Better than 80% of patients *wanted to continue* to be able to see their visit notes online.
- Better than 60% of patients said availability of open notes *would affect their future choice* of a therapist.
- *Not one therapist or patient asked to stop*
- *And now . . .*



# Lessons Learned

- 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



# Lessons Learned

- 70/30 Rule
- Stigma, especially in mental health!  
Mainstream!!



# Lessons Learned

- 70/30 Rule
- Stigma, especially in mental health! Mainstream!!
- Professionals Fears: looking foolish or incompetent
- Active vs. Passive Utilizers



# What Is Best for Our Patients?

Communication

Engagement

Trust



# Sources

- 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/fpsy.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 their Primary Care Clinic Notes” *Annals of Family Medicine*. 16: 4: 343-345, 2018





# Thank you.

## **Steve O'Neill, LICSW, BCD, JD**

Social Work Manager, OpenNotes Program  
Beth Israel Deaconess Medical Center

Faculty, Center for Bioethics  
Harvard Medical School

Adjunct Faculty  
Simmons University School of Social Work



## UPCOMING WEBINARS

## PRESENTERS

**Friday, January 29**  
**How to Write An Open Note**

- Leonor Fernandez, MD (Beth Israel Deaconess Medical Center)
- CT Lin, MD (University of Colorado)

**Thursday, February 18**  
**Open Notes in Pediatrics/for Adolescents**

- Fabienne Bourgeois, MD (Boston Children's)
- Cindy Kuelbs, MD (Rady Children's)

**Monday, March 8**  
**Open Oncology Notes**

- Everett Weiss, MD (Memorial Sloan Kettering)
- Bertram Yuh, MD (City of Hope Cancer Center)
- Rosie Bartel (patient advocate)

**TBD late March**  
**Open Inpatient Notes**

- Brian Clay, MD, UC San Diego

**TBD late March**  
**Open Palliative Care Notes**

- TBA
- *Collaboration with the Center to Advance Palliative Care (CAPC)*

**TBD April**  
**Open Notes in the Safety Net**

- Anshu Abhat, MD (LA County Department of Healthcare Services)
- TBA (Institute for Family Health Services)

# Q&A

## Open Discussion



# Sharing Mental Health Notes with Patients

## Office Hours

Tuesday, January 19, 2021 • 3-4pm Eastern



&



**Steven K. Dobscha, MD**

Director, Center to Improve Veteran Involvement in Care,  
VA Portland Health Care System, Professor of Psychiatry,  
Oregon Health & Science University

**Stephen F. O'Neill, LICSW, BCD, JD**

Mental Health Liasion, OpenNotes  
Adjunct Assistant Professor,  
Simmons College School of Social Work