

Open Oncology Notes: Research & Real-World Experience

Office Hours: Thursday, March 11, 2021 • 3-4pm Eastern



Rosie Bartel

Patient advocate,
Collaborator, OpenNotes



Everett Weiss, MD

Associate Chief Health
Informatics Officer,
Memorial Sloan Kettering Cancer Center



Bertram Yuh, MD

Associate Chief Medical Information Officer,
Clinical Professor,
City of Hope National Cancer Center

Welcome & Introductions



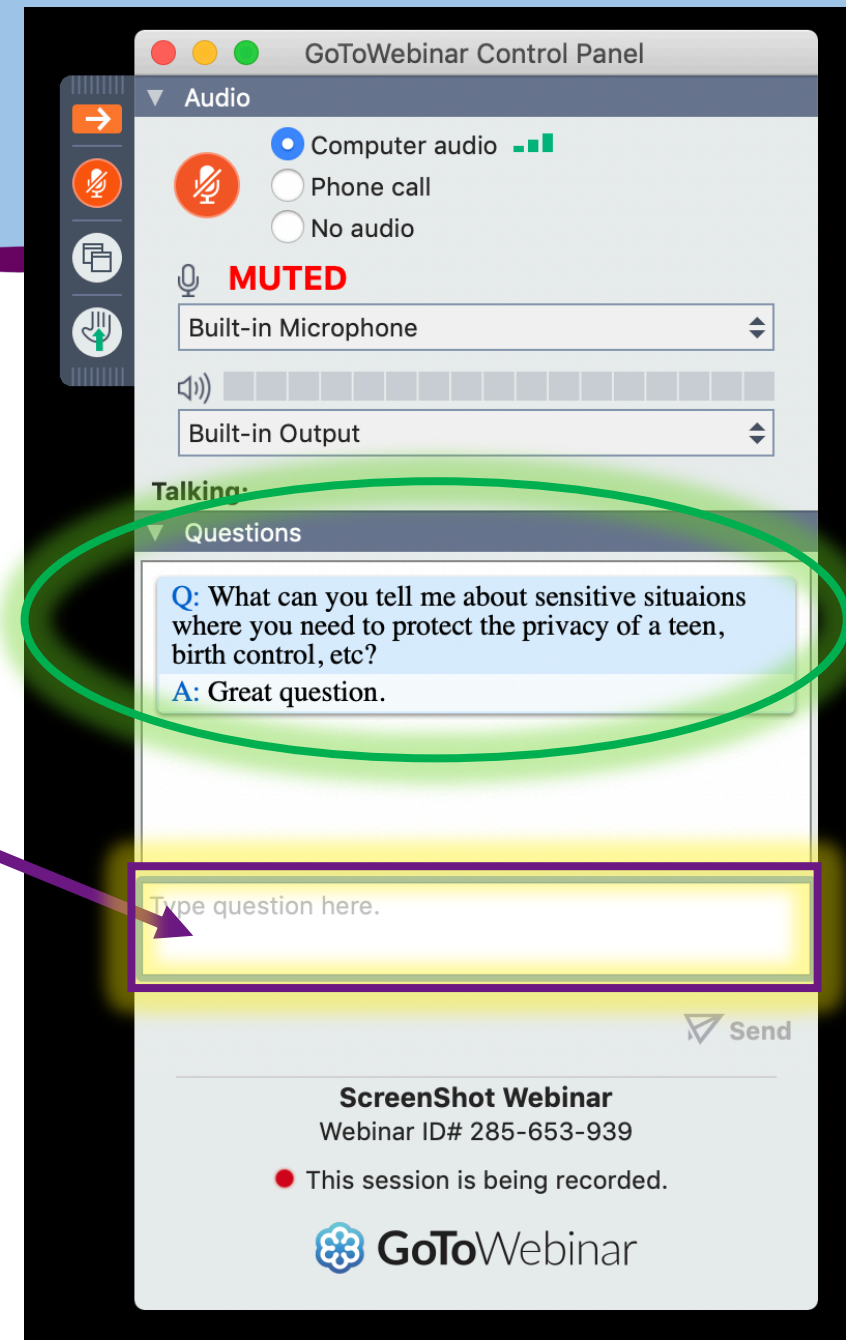
Liz Salmi

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 shows the GoToWebinar Control Panel interface. The top section is titled "Audio" and includes options for "Computer audio" (selected), "Phone call", and "No audio". A microphone icon is labeled "MUTED". Below this, there are dropdown menus for "Built-in Microphone" and "Built-in Output", along with a volume slider. The "Talking:" section is expanded to show a "Questions" area. A question is displayed: "Q: What can you tell me about sensitive situations where you need to protect the privacy of a teen, birth control, etc?" followed by an answer: "A: Great question." Below the question/answer area is a text input field with the placeholder "Type question here." and a "Send" button. At the bottom, the interface identifies the session as "ScreenShot Webinar" with ID# 285-653-939 and notes "This session is being recorded." The GoToWebinar logo is at the bottom.

Open Oncology Notes

1. **Quick background** on open notes
2. A patient's perspective: **Rosie Bartel**
3. Open Oncology Notes at **City of Hope**
4. Open Oncology Notes at **Memorial Sloan Kettering Cancer Center**
5. **Q&A**



Who/what is open notes?



Cait DesRoches, DrPH

Executive Director, OpenNotes
Associate Professor of Medicine, Harvard Medical School

Beth Israel Deaconess
Medical Center



What is open notes?

When patients can easily read visit notes



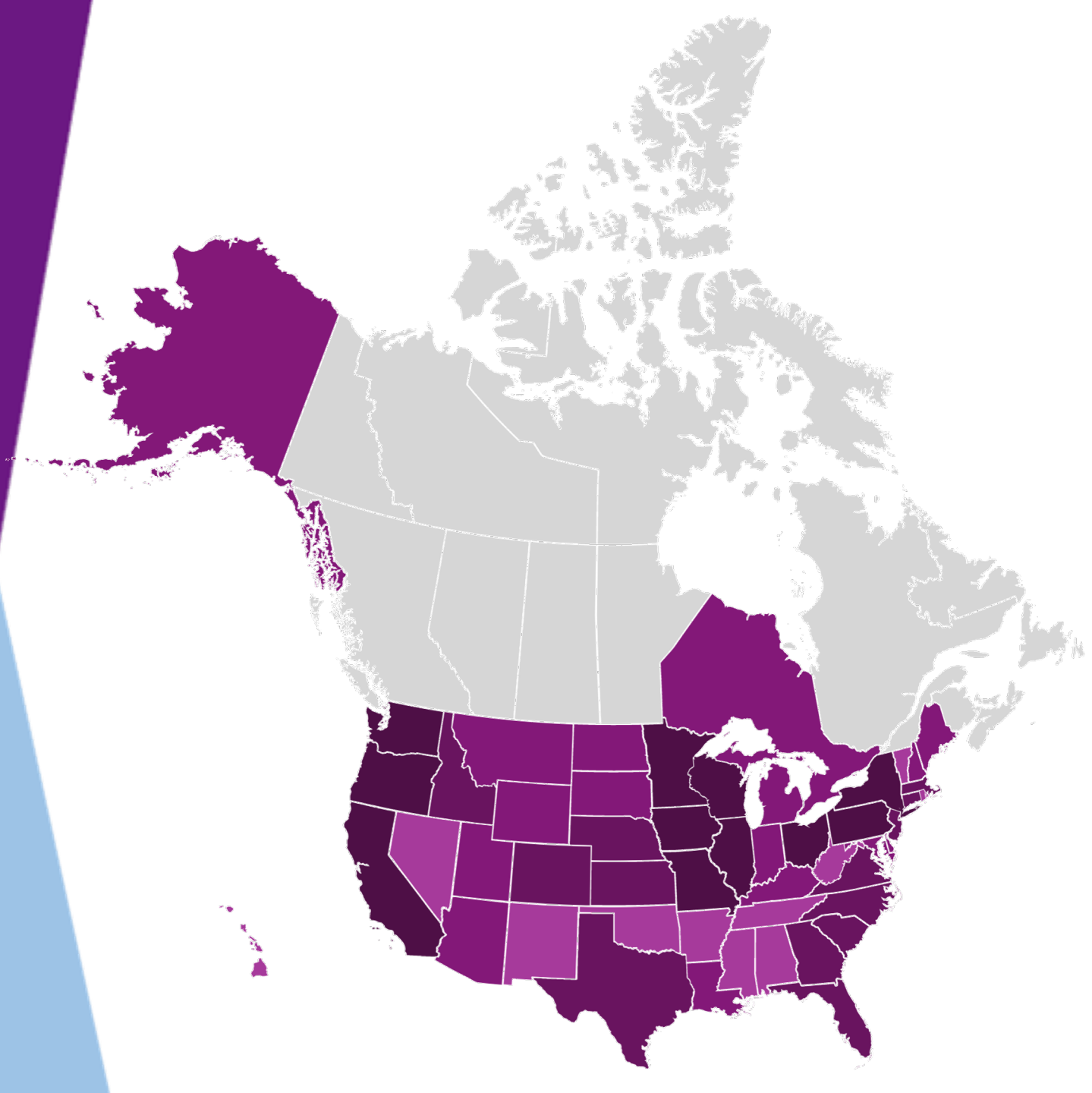
HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL



Robert Wood Johnson Foundation


Open Notes Across North America

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



April 5, 2021

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.



Clinical Notes *NEW

1. Consultation Note
2. Discharge Summary Note
3. History & Physical
4. Imaging Narrative
5. Laboratory Report Narrative
6. Pathology Report Narrative
7. Procedure Note
8. Progress Note

<https://www.healthit.gov/curesrule/final-rule-policy/empowering-patients-us-health-care-system>



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.

A Patient's Perspective



Rosie Bartel

Patient advocate and collaborator with OpenNotes



PHOTO: Rosie Bartel presenting on behalf of OpenNotes at the Epic User Group Meeting in Verona, WI. August 29, 2019.



“While some physicians have struggled with the use of Open Notes, our oncologist wrote the most honest Open Notes, and even now I find them a comfort. **They provided the real time information I needed to understand I did everything possible for David, even though the outcome was not what anyone had hoped for.** Providers understand that patients just want the truth told to them with compassion and understanding.”

– Rosie Bartel

PATIENT & FAMILY VOICES

THE LOSS OF DAVID

Rosie Bartel, Patient Advisor

On June 26, 2020, my wonderful husband, David, got the beginnings of a very hard-to-swallow diagnosis. He had been dealing with a backache since March. After trying exercises and a chiropractor, it was decided he probably should get an MRI to find out what was causing the back pain. On the morning of June 26, he had the MRI. By early afternoon, his primary care provider called him. He asked him to come to the office to discuss the MRI. When he got to the office, the doctor walked into the room and said that he couldn't believe he had to tell David that he had two types of bone cancer. He said that the other bad news was that these cancers were secondary to some other kind of cancer. The primary care doctor began setting up appointments for testing with oncologists he knew. When David and I discussed the situation we decided we didn't want to use the doctors or healthcare systems that the primary care physician had arranged for him. I contacted the primary care provider telling him we knew an oncologist that we trusted and we wanted to use. The doctor was so understanding and willing to work with the oncologist we knew. He trusted us to make this decision, and he volunteered to work with him in any way he could, especially taking care of pain management because he worked a lot with hospice patients.

I reached out to the oncologist we knew, and he got us in the next day. He had CT scans done at his office on that day. After reviewing them with us, he felt the liver, pancreas, gallbladder and upper GI were involved, and he scheduled liver and stomach biopsies during the next few days. He scheduled an appointment for us to get results the following week. He told us he would call us with results as he got them. He was very honest from the beginning that David's cancer was terminal, and the only kind of treatment he would be able to offer would be comfort treatment. He also said he would try to locate the primary source of the cancer, but it was all terminal; the only reason to try to locate the primary source was to help decide what kind of comfort chemotherapy to help with the pain. From the beginning, he made it clear that the comfort chemotherapy could either help the pain or make the pain worse. David asked him how much time he thought he had left. He very honestly told us less than six months, and he thought it was on the lower end of six months. He also made it clear that the comfort chemotherapy wouldn't extend the timeline.

While we worked to put together a care plan, he was supportive and willing to hear David's concerns, especially his need to have myself, his wife, as part of his care team. This request wasn't going to be honored by the healthcare system he worked for, but he made it very clear to them that at this stage of cancer, a patient needs someone close to them to be part of their team. David was telling him he was having trouble putting his thoughts together. He told us that this happens to cancer patients like David, because even though you don't have brain cancer, the cancer is attacking your nervous system. This causes the inability to think clearly.

David received one dose of comfort chemotherapy, but it didn't help him. It made it worse, and eight days later, July 28, 2020, he died. Since the time of his death, this oncologist has reached out to me. He wants to make sure I have an avenue to deal with this sudden loss.

Remember the primary care provider who offered his support? As David became sicker during those last eight days, we needed to get hospice involved in his care and pain management. Two nights before David died, my son and I were struggling trying to keep him even a little comfortable. We knew he wanted to die at home, so calling 911 wasn't an option for us. At about midnight my son said to me, "Mom, you need to get hospice now." I looked at him and thought, how am I going to do that? Then I remembered the primary care provider had given me his cell number and told us to use it to call him for anything. So I called him and told him we needed help and that we probably needed hospice. He told me that he would get back to me in a half hour, and he did. He said that hospice would be at our home in about two hours. We live in a small rural town, and yet hospice was at our home in two hours and they helped David's pain and helped him have some peace as he died. Yes, this was a really tough time, but two doctors and hospice helped us through it, and they continue to help us.

A note: While some physicians have struggled with the use of Open Notes, our oncologist wrote the most honest Open Notes, and even now I find them a comfort. They provided the real time information I needed to understand I did everything possible for David, even though the outcome was not what anyone had hoped for. Providers understand that patients just want the truth told to them with compassion and understanding.

Open Notes for Oncology: City of Hope Experience



Bertram Yuh, MD, MSHCPM, MISM

Clinical Professor, Associate CMIO
City of Hope National Cancer Center



City of Hope



- Founded in 1913
- Based in Los Angeles, CA
- One of original National Comprehensive Cancer Network hospitals

Providing open notes to our outpatients and inpatients since 2019



Special Considerations for Oncologic Care

- Complexity of cancer conditions and cancer care
- Information overload and challenges with full comprehension
- Special role for caregivers
- Differential expectations, from patient to patient or between patient and care provider



Complexity of Cancer Conditions and Cancer Care

- Many cancer treatments, in particular ongoing treatments such as chemotherapy, transplant, or complex surgeries require frequent follow-ups
- The impacts of treatment can lead to physical, mental, emotional, social, and psychologic changes in profound ways
- Our understanding of cancer is vast but still growing daily

Information Overload and Challenges With Full Comprehension

- Science and research is ever-changing
- More information is oftentimes better but..
 - Effects of cancer or treatment – eg. anxiety/depression, effect of medications (chemo), stress, fear, loss of work, etc.
- After a given visit why how patients use their open notes –
 - Recap – summarizes complex care plans for patient and caregivers. Includes verification of labs and imaging results
 - Reinforce – “I can tell that the main 3 care points that my oncologist wants to focus on are x, y, and z”
 - Remember – “I can see specifically how to take my oral chemo” as opposed to just recalling what was said.
 - Remind – “Reminds me of discussions I forgot and reminds me to do my part in the treatment regimen”



Special Role for Caregivers

- Caregivers play a critical role in cancer patients and can significantly impact the outcome of treatment.
- Particularly in our present COVID environment, caregivers are unfortunately not allowed to physically be there with the patient.
- Along with telemedicine, provider notes play a crucial role in reinforcing care plans, medication information, etc.



Differential Expectations

- Not all cancers are the same – some very aggressive, some very indolent
- Cancers behave differently in different people – personalized or precision medicine
- Personal history, preferences, influences, social factors, cultural factors and other variables impact how we deal with cancer.
- Very wide spectrum of expectations and the ways we manage them
 - wives that don't want husbands to know anything, wives that want their husbands fully engaged
 - some really want to know what is going on with their cancer, some don't
 - patients fatigued or feeling the effects of treatment (chemo brain)
 - status of cancer - active treatment, remission, recurrence, progression, end-of-life, etc.



Open Notes in Oncology: Patient versus Oncology Clinician Views

Liz Salmi,^{1,*} Zhiyong J. Dong,¹ Bertram Yuh,² Jan Walker,^{1,3} and Catherine M. DesRoches^{1,3}

¹Beth Israel Deaconess Medical Center, Boston, MA, USA

²City of Hope Comprehensive Cancer Center, Duarte, CA, USA

³Harvard Medical School, Boston, MA, USA

- Surveys from 1 600 providers and 23000 patients
- Oncology focused
- 98% of patients felt open notes were a good idea compared to only 70% of providers
- 56% of patients felt open notes were important in preparing for their visit compared to 28% of providers
- 44% of providers felt patients would be confused by reading their notes but only 4% of patients reported feeling confused

Takeaway Points

- Open notes provides a very valuable resource for patients and can be a key communication tool
- Much more education is needed for both providers and patients on open notes
- Patients should be encouraged to ask physicians to make changes to their notes - improves documentation, data capture, communication
- Especially as it comes to cancer care, there needs to be heightened awareness and focus on personal preferences and communication



Thank you.



Bertram Yuh, MD, MSHCPM, MISM

Clinical Professor, Associate CMIO
City of Hope National Cancer Center



Open Oncology Notes at Memorial Sloan Kettering



Everett Weiss, MD

Associate Chief Health Informatics Officer
Memorial Sloan Kettering Cancer Center



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- Not a pilot
 - The original pilot was completed in 2012 by Delbanco et al.
 - Dozens of published studies have followed



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- Anticipate where OpenNotes in oncology differs from rest of organization
- Differentiate result/report release from note release – they are not the same
- Offer support for better documentation and conversations with patients



Lessons Learned

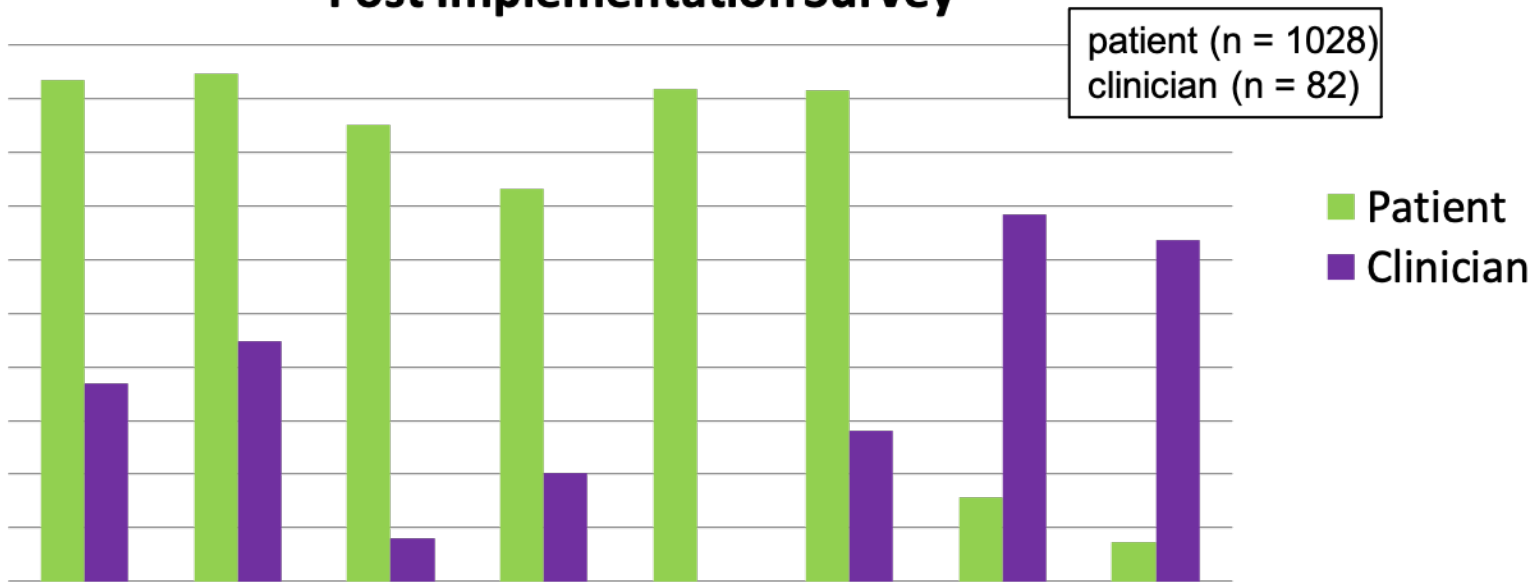
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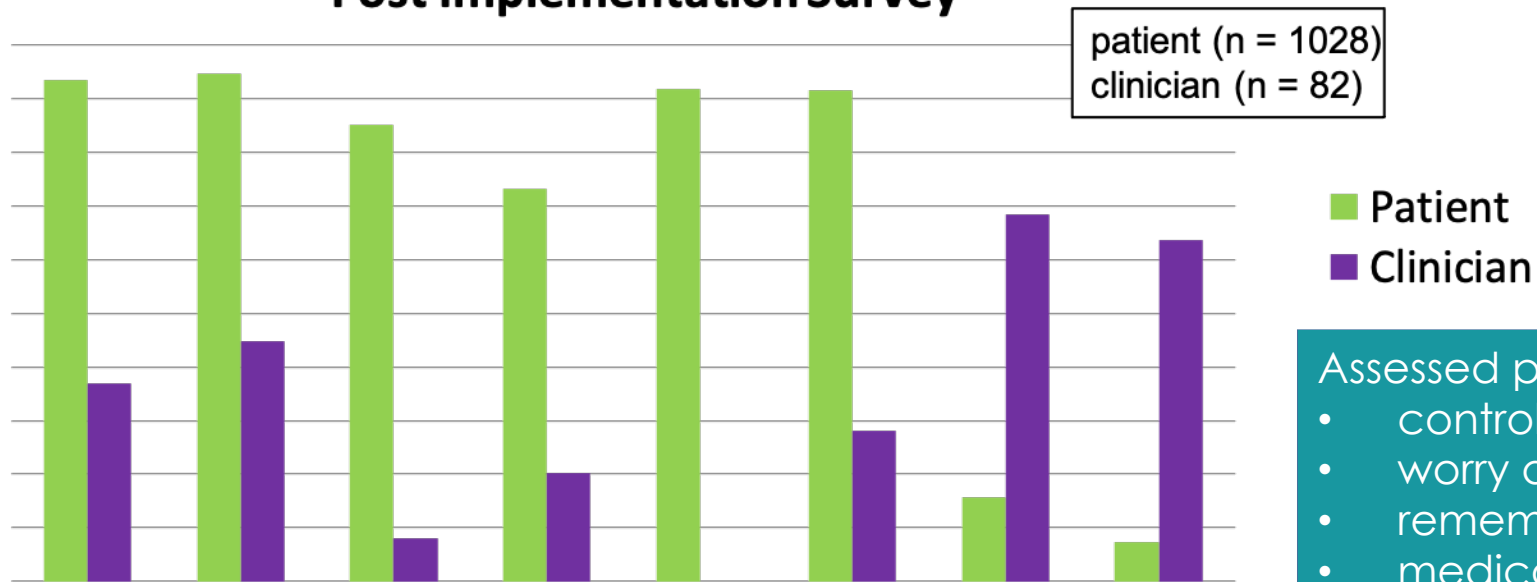
Post Implementation Survey



Lessons Learned

There is a remarkable discrepancy between what providers think and fear about OpenNotes and what patients think and don't fear about open notes.

Post Implementation Survey



Assessed perceived

- control over care
- worry and confusion after reading note
- remembering and understanding plan of care
- medication adherence
- readiness for next clinic visit

Next Level Thinking

Acceptance...

Questions we can ask...



Next Level Thinking

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Notes aren't error free.

Questions we can ask...

How can we capitalize on an extra set of eyes?



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Reading another's recollection of an event can trigger clarifying questions.	How can we direct the patient to the right person at the right time?
Visits often feature life-changing diagnoses or treatment decisions.	How can we better talk with patients? How can we document conversations differently? How can we document sensitive observations differently?

Thank you.



Everett Weiss, MD

Associate Chief Health Informatics Officer
Memorial Sloan Kettering Cancer Center



UPCOMING EVENTS

**Case Study:
Open Inpatient Notes**
TUESDAY, MARCH 23 / Webinar

- **Brian Clay, MD**, UC San Diego Health
- **Cait DesRoches, DrPH**, OpenNotes



**OpenNotes
Drop-in Clinic**
MARCH 29-APRIL 2
Live, 2-hours, every day

- **Fabienne Bourgeois, MD**
- **Tom Delbanco, MD**
- **Cait DesRoches, DrPH**
- **Steven R. Lane, MD, MPH, FAAFP, FAMIA**
- **Steve O'Neill, LICSW, BCD, JD**
- **John Santa, MD, MPH**
- **Deb Wachenheim, MPP**
- + special guests

**Open Notes
in the Safety Net**
THURSDAY, APRIL 15 / Webinar

- **Anshu Abhat, MD, MPH**, Los Angeles County Department of Health Services
- **Ruth Lesnewski, MD**, The Institute for Family Health
- **Nandini Shroff, MPH**, The Institute for Family Health

Q&A

Open Discussion



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