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](http://opennotes.org) and [youtube.com/myopennotes](http://youtube.com/myopennotes)

• You will receive an email with links to these presentations.
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
What is open notes?

When patients can easily read visit notes
Open Notes Across North America

- 260 organizations
- 54 MILLION people
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.
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

“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

Open Notes for Oncology: City of Hope Experience

Bertram Yuh, MD, MSHCPM, MISM
Clinical Professor, Associate CMIO
City of Hope National Cancer Center
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.
**Cancer Cell**

**Letter**

**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\(^1,3\)

\(^1\)Beth Israel Deaconess Medical Center, Boston, MA, USA
\(^2\)City of Hope Comprehensive Cancer Center, Duarte, CA, USA
\(^3\)Harvard Medical School, Boston, MA, USA

- Surveys from 1600 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
Leading Change Successfully

- Not a pilot
  - The original pilot was completed in 2012 by Delbanco et al.
  - Dozens of published studies have followed
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• What will happen if you do not do this?
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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

There is a remarkable discrepancy between what providers think and fear about OpenNotes and what patients think and don’t fear about open notes.
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### Post Implementation Survey

- **Patient (n = 1028)**
- **Clinician (n = 82)**

Assessed perceived:
- control over care
- worry and confusion after reading note
- remembering and understanding plan of care
- medication adherence
- readiness for next clinic visit
| Acceptance... | Questions we can ask... |

Next Level Thinking
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| 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 DesR Roches, 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
Open Discussion
Open Oncology Notes: 
Research & Real-World Experience

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