

OpenNotes Office Hours

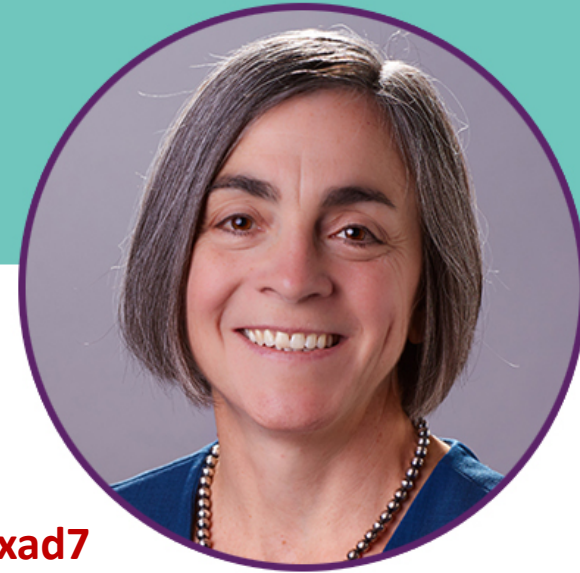
Topic: Open Notes Basics, Research & Practice

Friday, December 18, 2020 • Noon-1pm Eastern

Limited Spots Available



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Sara Jackson, MD, MPH

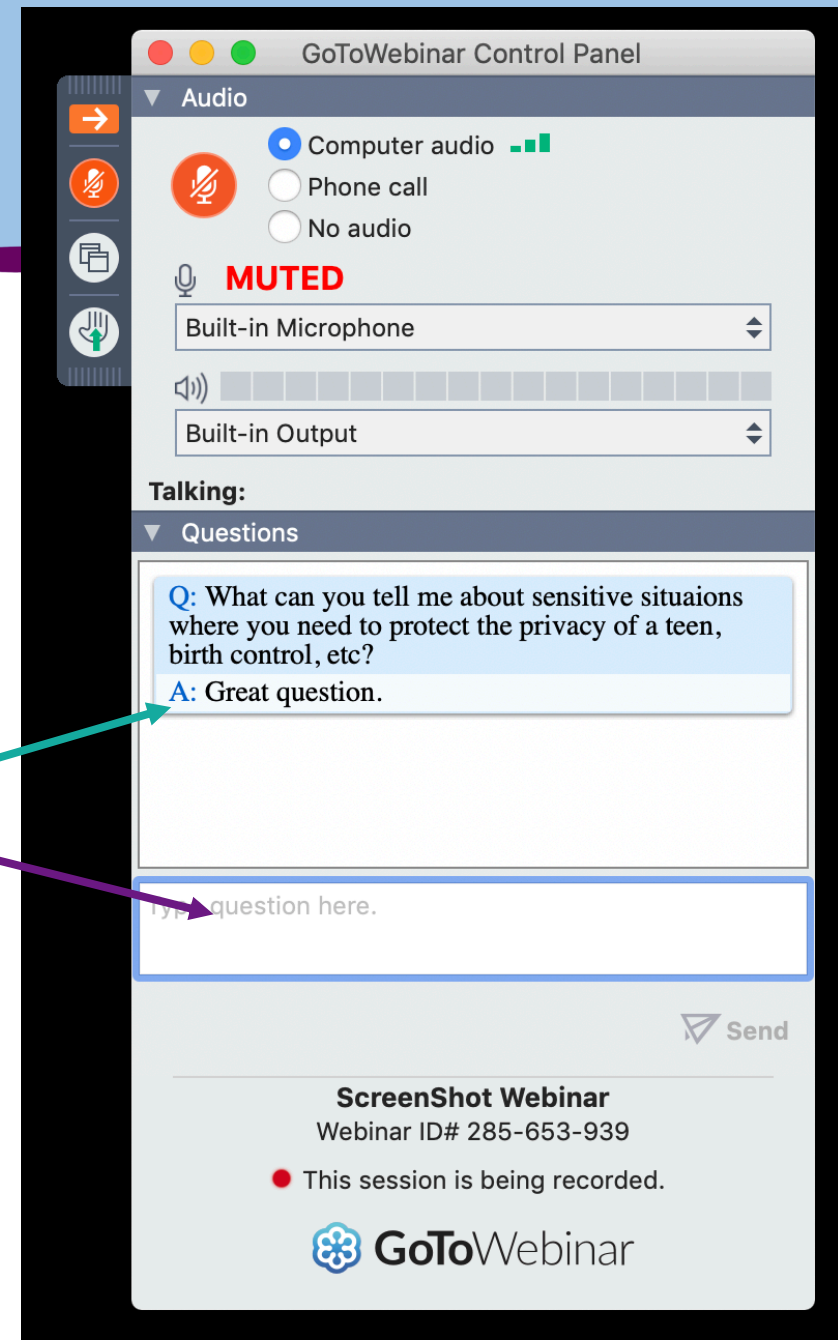
Medical Director, Adult Medicine Clinic
Harborview Medical Center, Seattle, WA

Catherine DesRoches, DrPH

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

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.



Welcome & Introductions



Liz Salmi

Senior Strategist, OpenNotes



OpenNotes Grand Rounds

OpenNotes 101 for Clinicians

Welcome!

December 14th, 2020



The New Era of Transparency in Healthcare

Sharing Clinical Notes with Patients



Cait DesRoches, DrPH

Director, Open Notes
Associate Professor, HMS



What is open notes?

When patients can easily read visit notes



Beth Israel Deaconess
Medical Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL



What a patient sees vs. What the doctor writes aka *notes*

Appointment Details

Visit Summary

Notes

Elizabeth [REDACTED] Department: Neuro-Oncology Description: Female DOB: [REDACTED]
11/28/2017 2:15 PM Office Visit Dept Phone: [REDACTED] Provider: [REDACTED]

Recommended Follow-Up

Return in about 9 months (around 8/28/2018).
Routing History
Follow-up and Disposition History

Upcoming Scheduled Appointments at UCSF

Aug 21, 2018 3:00 PM PDT

[REDACTED]
Neuro-Oncology (UCSF Medical Center)

To-Do List

Future Orders
MR Brain with and without Contrast

Complete On or After
As directed

Diagnoses this Visit

Astrocytoma, grade II - Primary

Previously Documented Problems as of 11/28/2017

Astrocytoma, grade II

Your Vital Signs

BP 124/65	Pulse 69	Temp 36.8 °C (98.2 °F) (Oral)	Resp 16
Wt 72.3 kg (159 lb 6.4 oz)	SpO2 100%	BMI 24.97 kg/m²	OB Status Implant

Allergies

Lamotrigine Rash

Your Current Medications

Accurate as of 11/28/17 11:59 PM. Always use your most recent med list.



Appointments

Office Visit

[REDACTED] MD
November 28, 2017
Neuro-Oncology

REASON FOR VISIT

Brain Tumor

VITALS RECORDED FOR THIS VISIT

124/65 Blood Pressure	5' 7" (170.2 cm) Height
98.2°F Temperature	69 Pulse
159 lb 6.4 oz (72.303 kg) Weight	16 Respiration

MEDICATIONS PRESCRIBED

No information was recorded for this item

ASSESSMENT AND PLAN:

In summary, Ms. [REDACTED] is a 38 y.o. year old woman with grade II astrocytoma that is stable on imaging in follow-up. Neurologically, she has stably reduced sensation on the R side of her body, as well as occasional focal R hand seizures.

IMAGING SCORE: 0

NEUROLOGICAL SCORE: 0

STEROID SCORE: 0

OVERALL TUMOR ASSESSMENT: 0

1. Grade II astrocytoma: As such, we will simply continue to monitor her. It has been > 5 years since she completed chemotherapy, and so we will extend the interval between scans to 9 months. I would be comfortable with her continuing to do the scans locally, and we can plan to do the next appointment as a phone consultation.

2. Seizures: We discussed whether she might be able to taper down one of her seizure medications, but given that she continues to have focal events, I would be concerned that she might have a larger breakthrough event so I would recommend that we keep the doses stable for the moment, and she is in agreement with this plan.

Follow-up:

- 9 months for next MRI and appointment. This scan is critical because based on the results, a change in the management plan for the patient may need to be made especially if there is any evidence to suggest tumor progression.

- All questions of Elizabeth [REDACTED] and her family were answered to the best of my ability. They have our contact information and will call with further questions.

I spent a total of 26 minutes face-to-face with the patient and 14 minutes of that time was spent reviewing the imaging with the patient, review of management options, side effects, counseling and coordination of care

Over the next few minutes...



- ✓ 10 years of open notes research
- ✓ What's next?



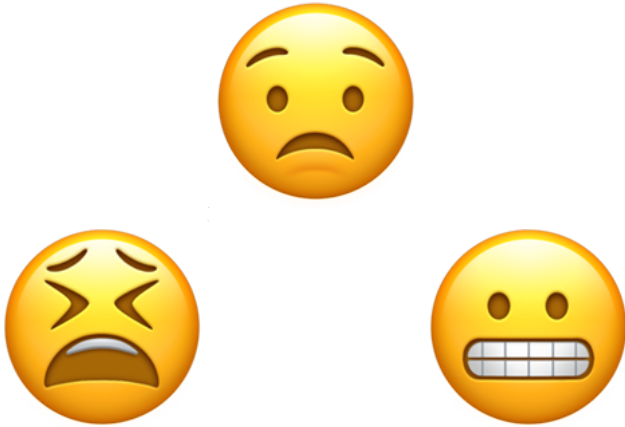


➤ 2010: OpenNotes Begins



Surveyed *before* study

Physicians

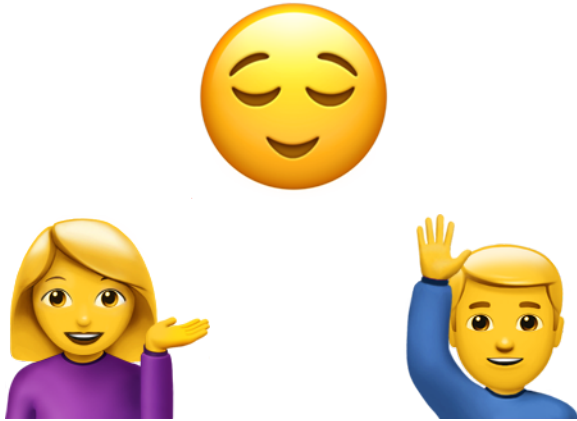


Patients

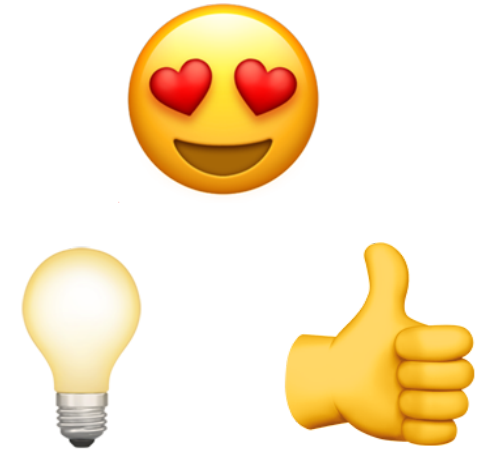


Surveyed *after* study

Physicians



Patients



Walker et al. Inviting Patients to Read Their Doctors' Notes:
Patients and Doctors Look Ahead: Patient and Physician
Surveys. *Ann Intern Med.* 2011;155(12):811-819. DOI:
10.7326/0003-4819-155-12-201112200-00003



After 7 years... patient views

- ✓ Patients still say **notes are very important** for taking care of their health, feeling in control of their care, and remembering their care plans
- ✓ **Almost all** patients say they *understood all or nearly all* of their notes
- ✓ Reading notes **helps them understand their medications**
- ✓ $\approx 20\%$ of patients **found an error** in their notes
- ✓ Important benefits for patients with less education or limited English proficiency

Walker J, et al. OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians' Outpatient Visit Notes. J Med Internet Res 2019;21(5):e13876. DOI: 10.2196/13876

Leveille, SG, et al. Patients Evaluate Visit Notes Written by Their Clinicians: a Mixed Methods Investigation. J GEN INTERN MED (2020). <https://doi.org/10.1007/s11606-020-06014-7>

Bell SK, et al. Frequency and Types of Patient-Reported Errors in Electronic Health Record Ambulatory Care Notes. JAMA Netw Open. 2020;3(6):e205867. doi:10.1001/jamanetworkopen.2020.5867

Desroches CM, et al. Patients Managing Medications and Reading Their Visit Notes: A Survey of OpenNotes Participants. Annals of Internal Medicine. 2019;171(1):69. doi:10.7326/m18-3197



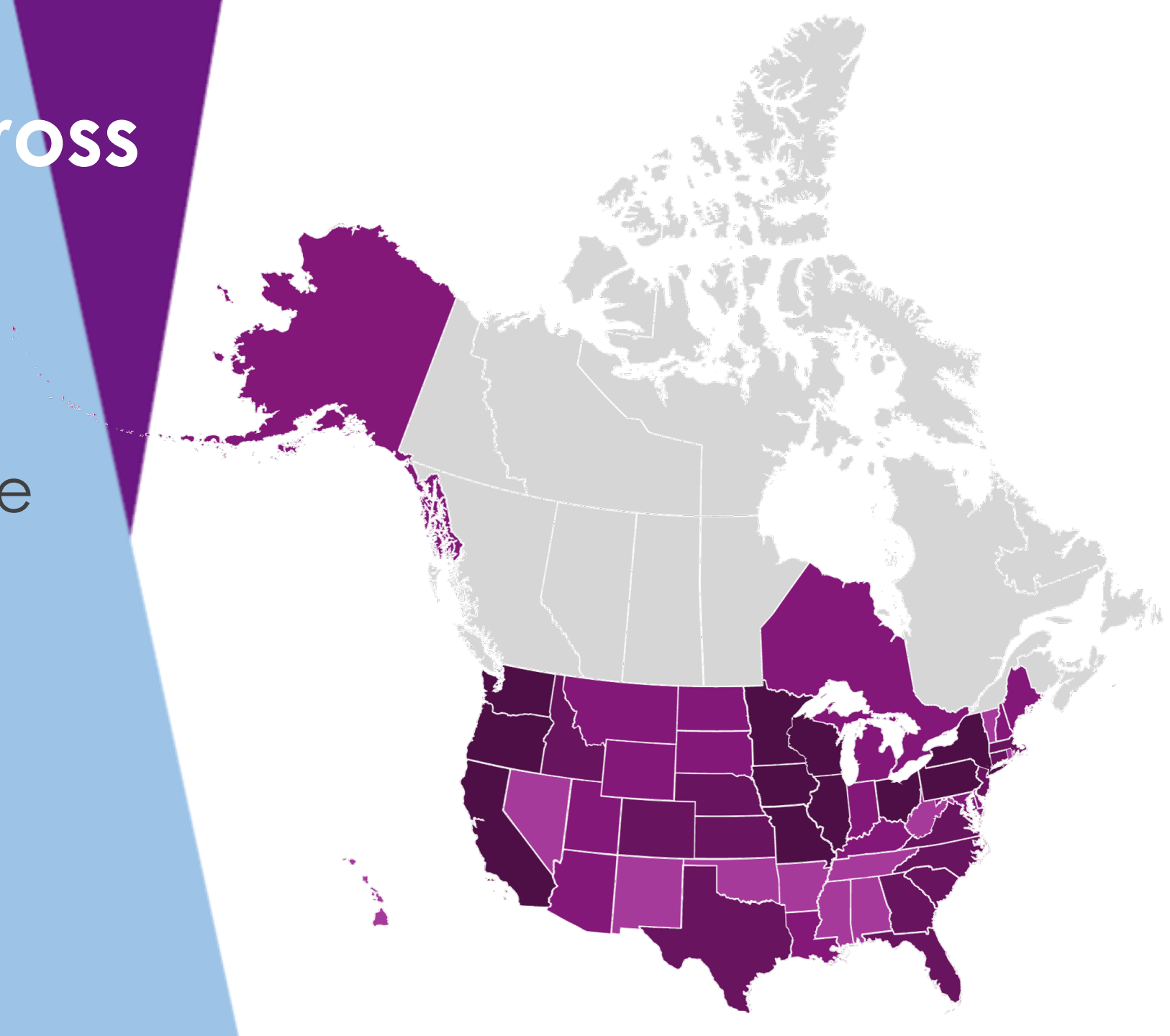
After 7 years... clinician views

- ✓ Majority say sharing notes with patients is a **good idea** and **helpful for engaging patients**
- ✓ Most would **recommend** the practice to colleagues
- ✓ Few report questions or concerns from patients about notes
- ✓ 1/3 say they spend at least “somewhat” more time in documentation



Open notes across North America

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



New public policy

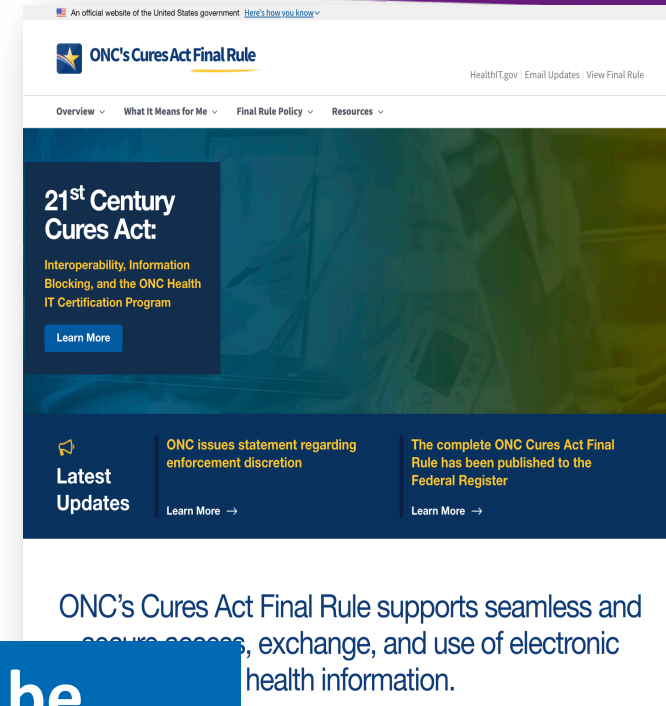
1996: HIPAA (Office of Civil Rights)

2008: HITECH Act

2016: 21st Century Cures Act passes in U.S. Congress

2020: Interoperability & Information Blocking Rule

Requires a greatly expand set of information to be electronically shared with patients without charge, including progress notes, starting April 5th, 2021



OpenNotes and...

- Care partners / caregivers
- Vulnerable populations
- Mental health
- Bioethics
- Patient engagement
- Patient safety
- OurNotes





Thank you.

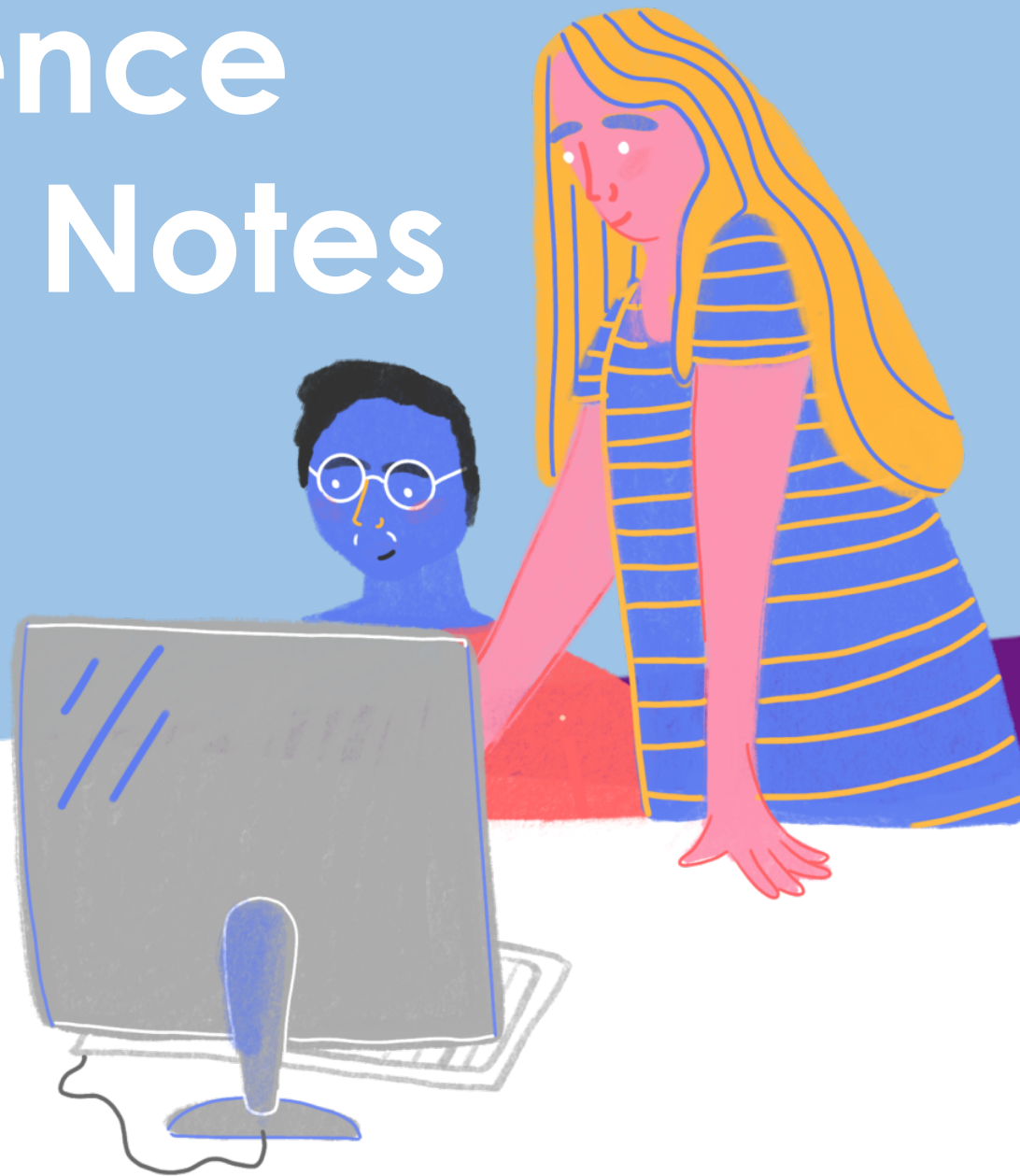
Cait DesRoches, DrPH

cdesroch@bidmc.harvard.edu



@MyOpenNotes
#opennotes

Patient Experience Reading Open Notes



Open Notes Experience at Harborview



Building Transparency and Trust with Patients



Sara L Jackson MD MPH

Harborview Medical Center
Seattle, Washington



Harborview
Medical Center

Safety-net for
King County WA



Patient Focus Groups in 2009

- Patients' perceived benefits:
 - Improved patient understanding of health and disease
 - Convenience
 - Empowerment
 - Stronger relationship with provider
- Concerns:
 - Threats to privacy
 - Worry about ability to understand the record
 - Fear that computer would replace direct provider contact
 - Hesitancy about potential demands on provider time

The urban underserved: attitudes towards gaining full access to electronic medical records

Dhanireddy, et. al. Health Expectations, 2012: 17, pp.724–732



Original OpenNotes study in 2009

Annals of Internal Medicine

ORIGINAL RESEARCH

Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead

- **Harborview patients reported (similar to other sites):**

- Feeling more in control of their care (87%)
- Better understanding of health and medical conditions (85%)
- Doing better with taking their medications (73%)

- **Harborview patients were rarely confused (8%), worried (8%), or offended (1%) by what they read in their doctors' notes**

- **42% at HMC shared access** to their notes with family/caregiver (more than ~20% at BIDMC and Geisinger)

- **Harborview Patients:**

89% reported Open Notes would be somewhat or very important factor in choosing a future doctor or health plan.

Provider results - 2009

Annals of Internal Medicine

ORIGINAL RESEARCH

Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead

- **Harborview Physicians:**
 - 0% reported visits took longer
 - 0% spent more time on notes
 - 11% were less candid in documentation
- 99% of patients wanted to continue access
- 0% of MDs wanted to withdraw



Patients with HIV

- HIV patients not different from other primary care patients regarding risks and benefits
- MORE LIKELY to share notes with friends, other health professional, or another doctor
- HIV doctors were LESS LIKELY to change the level of candor in notes compared to other PCPs

2014 UW opened notes system-wide

- Messaged by clinical leaders throughout the UW system for all ambulatory sites on EPIC, via email and at clinical meetings
- Note availability was not actively messaged to patients
- Tips for providers about how to write shared notes, and FAQs for patients and providers
 - Klein, et.al. Your patient is now reading your note. AJM 2016



Tips for Writing Open Notes

BEFORE a visit

- Create an organized, clear template
- Explain *why* patients should read their notes
- Consider writing notes *with* patients



Tips for Writing Open Notes

DURING a visit

- **Conceptualize note as a communication tool**
 - Address sensitive issues directly
 - Obesity, malignancy, substance use, etc.
 - Patients are likely concerned about these issues!
 - Highlight accomplishments & strengths
 - Opportunity to motivate patients
 - Possible “placebo” effect



Tips for Writing Open Notes

DURING a visit

- Be objective, not judgmental
 - “shirt untucked” rather than “disheveled”
 - “declined” rather than “refused”
- Avoid jargon & abbreviations, when possible
 - “AED”: defibrillator or seizure med?
 - “shortness of breath” rather than “SOB”



Tips for Writing Open Notes

After a visit

- Complete notes in a timely manner
- Ask for, and *use*, patient feedback
- Be familiar with procedures for amendments



Patient Focus Groups after 2 years of note access

- Read a note just prior to survey and focus group
 - 89% note content was useful
 - 19% note was inaccurate
 - 26% too much medical jargon
 - 26% too long

Patient comments

Oh yeah, give me all the information. Because I'm going to go look it up otherwise. So at least here it is... This is more bulk, more data. I think it's good.

This is good information to have and it would be good for my kids to know and have. I don't have to explain every detail to them, they would know what is what and how to go about it and take care of it.



Open Notes in the time of COVID-19

eCare Activation Trends Harborview Adult Medicine Clinic

2019



32 %

Patient Visits -
MyChart Active
Mar

2020



43 %

Patient Visits - MyChart
Active
Nov

During COVID pandemic medical student volunteers did a pilot study to better understand and support patients with tech needed for zoom/telehealth visits



In Summary – 10 years of Open Notes at HMC

- It has not been a burden for physicians
- Patient feedback has been positive
 - Trust
 - Strengthening provider relationships
 - Access to their own health information
- Some increase in note amendment requests (UW-wide) for inaccuracies – a good thing
- Developing support for instruction and utilization of electronic tools is needed for safety-net populations – particularly with COVID



Thank you.

Sara L Jackson MD MPH

Harborview Medical Center
Seattle, Washington



Q&A

Open Discussion



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UPCOMING WEBINARS & OFFICE HOURS Dates TBA	PRESENTERS
How to Write An Open Note	<ul style="list-style-type: none"> • Leonor Fernandez, MD (Beth Israel Deaconess Medical Center) • CT Lin, MD (University of Colorado)
Open Notes in Pediatrics/for Adolescents	<ul style="list-style-type: none"> • Fabienne Bourgeois, MD (Boston Children's) • Cindy Kuelbs, MD (Rady Children's)
Open Therapy Notes	<ul style="list-style-type: none"> • Steve Dobscha, MD (U.S. Department of Veteran's Affairs, Oregon Health & Science University) • Steve O'Neill, BCD, JD (OpenNotes, Harvard Medical School)
Open Oncology Notes	<ul style="list-style-type: none"> • Everett Weiss, MD (Memorial Sloan Kettering) • Bertram Yuh, MD (City of Hope Cancer Center) • Rosie Bartel (patient advocate)
Open Inpatient & ED Notes	<ul style="list-style-type: none"> • Brian Clay, MD (UC San Diego Health) • ED physician TBD
Open Notes in the Safety Net	<ul style="list-style-type: none"> • Anshu Abhat, MD (LA County Department of Healthcare Services) • TBA (Institute for Family Health Services)