OpenNotes Grand Rounds

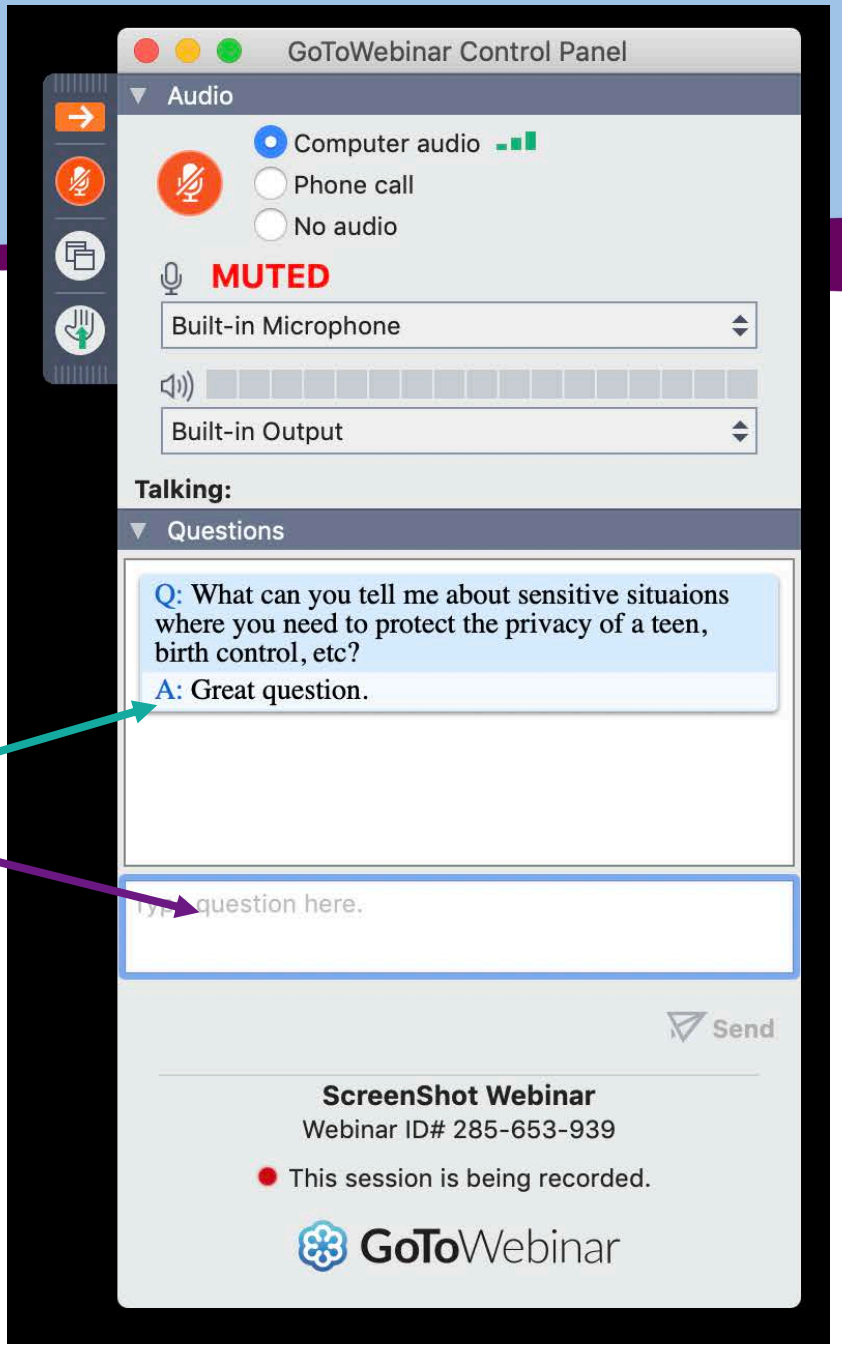
Sharing Palliative Care Notes

October 29, 2020

+ a few slides about the Information Blocking rule and open notes

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.



Hello, from OpenNotes

Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

"open notes"
When doctors and other healthcare professionals share the visit notes they write with patients

Robert Wood Johnson Foundation

The Commonwealth Fund

CAMBIA health foundation

GORDON AND BETTY MOORE FOUNDATION

PETER G. PETERSON FOUNDATION

crico

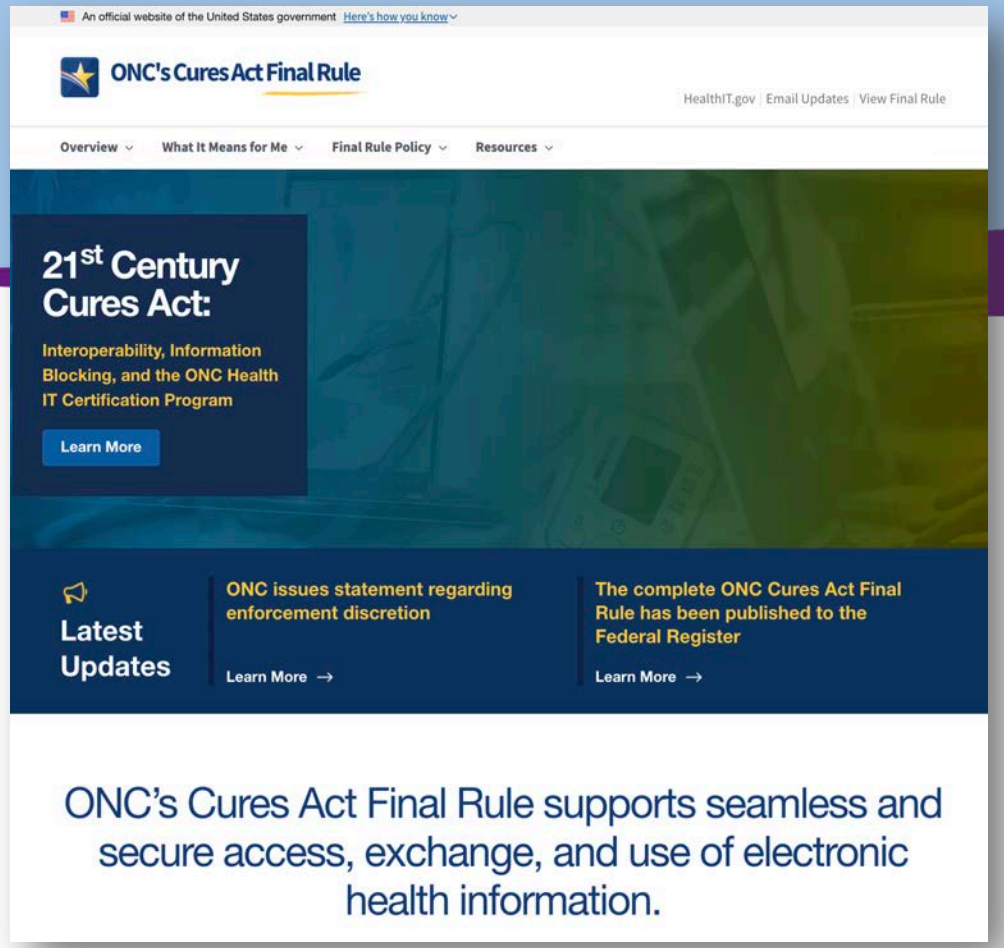
Quick Background:

The Information Blocking Rule, OpenNotes, and “open notes”

Cait DesRoches, DrPH
Executive Director, OpenNotes
Associate Professor, Harvard Medical School

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 expanded set of information to be electronically shared with patients without charge, including progress notes, starting Nov. 2, 2020. →

Now April 5th, 2021

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USCDI

Allergies and Intolerances

- Substance (Medication)
- Substance (Drug Class) *NEW
- Reaction *NEW

Assessment and Plan of Treatment

Care Team Members

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

Goals

Health Concerns

Immunizations

Laboratory

- Tests
- Values/Results

Medications

Patient Demographics

- First Name
- Last Name
- Previous Name
- Middle Name (incl. middle [illegible])
- Suffix
- Birth Sex
- Date of Birth
- Race
- Ethnicity
- Preferred Language
- Current Address *NEW
- Previous Address *NEW
- Phone Number *NEW
- Phone Number Type *NEW
- Email Address *NEW

Problems

Procedures

Provenance *NEW

- Author Time Stamp
- Author Organization

Smoking Status

Unique Device Identifier(s) for a Patient's Implantable Device(s)

Vital Signs

- Diastolic Blood Pressure
- Systolic Blood Pressure
- Body Height
- Body Weight
- Heart Rate
- Respiratory Rate
- Body Temperature
- Pulse Oximetry
- Inhaled Oxygen Concentration
- BMI Percentile (2-20 Years) *NEW
- Weight-for-length Percentile (Birth - 36 Months) *NEW
- Occipital-frontal Head Circumference Per (Birth - 36 Months) *NEW

www...

For more info:

HealthIT.gov/USCDI

Graphic adapted from: Office of the National Coordinator for Health IT

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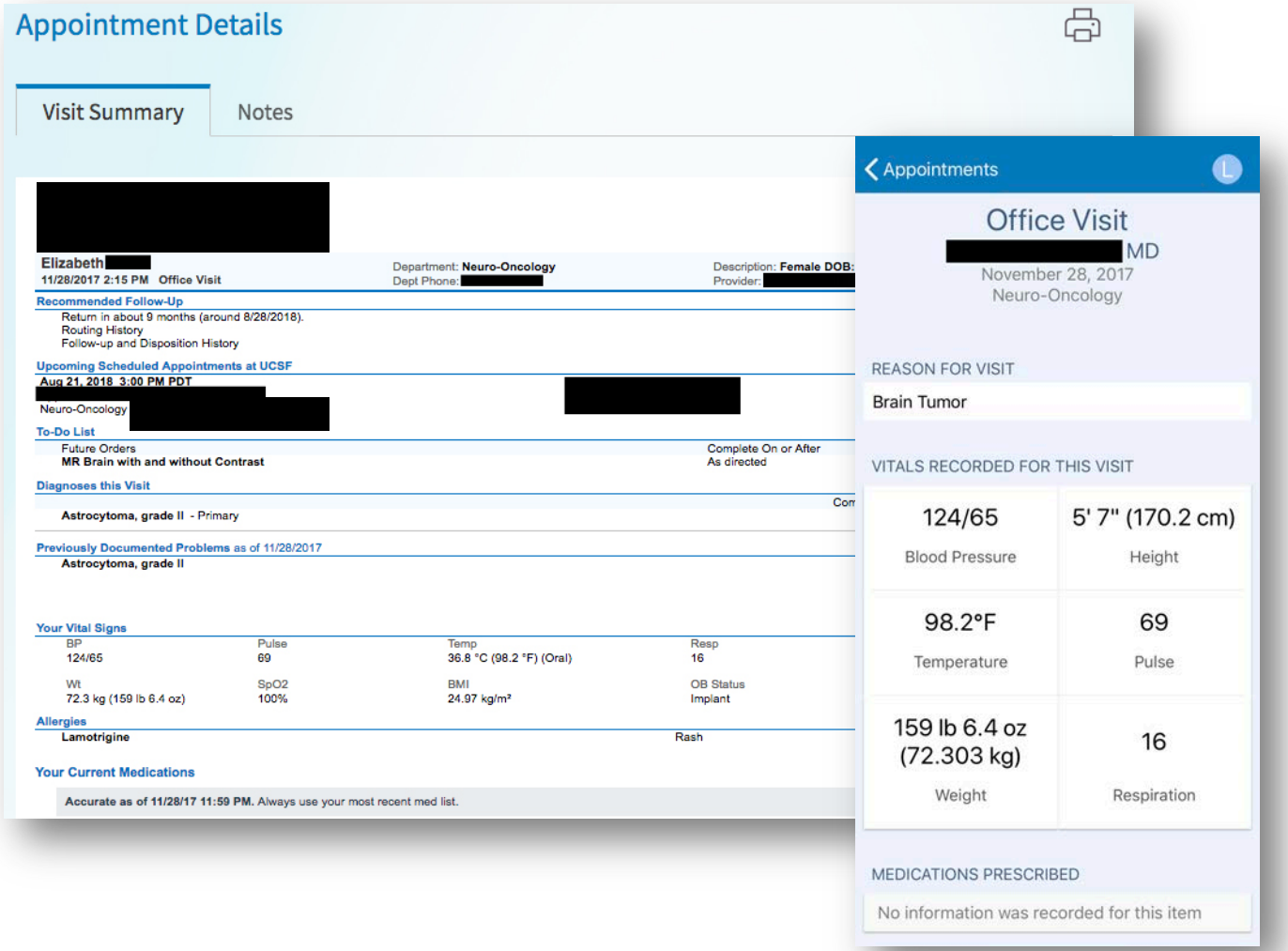
What the patient sees
(after visit summary)

vs

What the doctor writes
(notes)



Appointment Details

Visit Summary | Notes

[redacted]

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

To-Do List
Future Orders — Complete On or After
MR Brain with and without Contrast — As directed

Diagnoses this Visit
Astrocytoma, grade II - Primary

Previously Documented Problems as of 11/28/2017
Astrocytoma, grade II

Your Vital Signs

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

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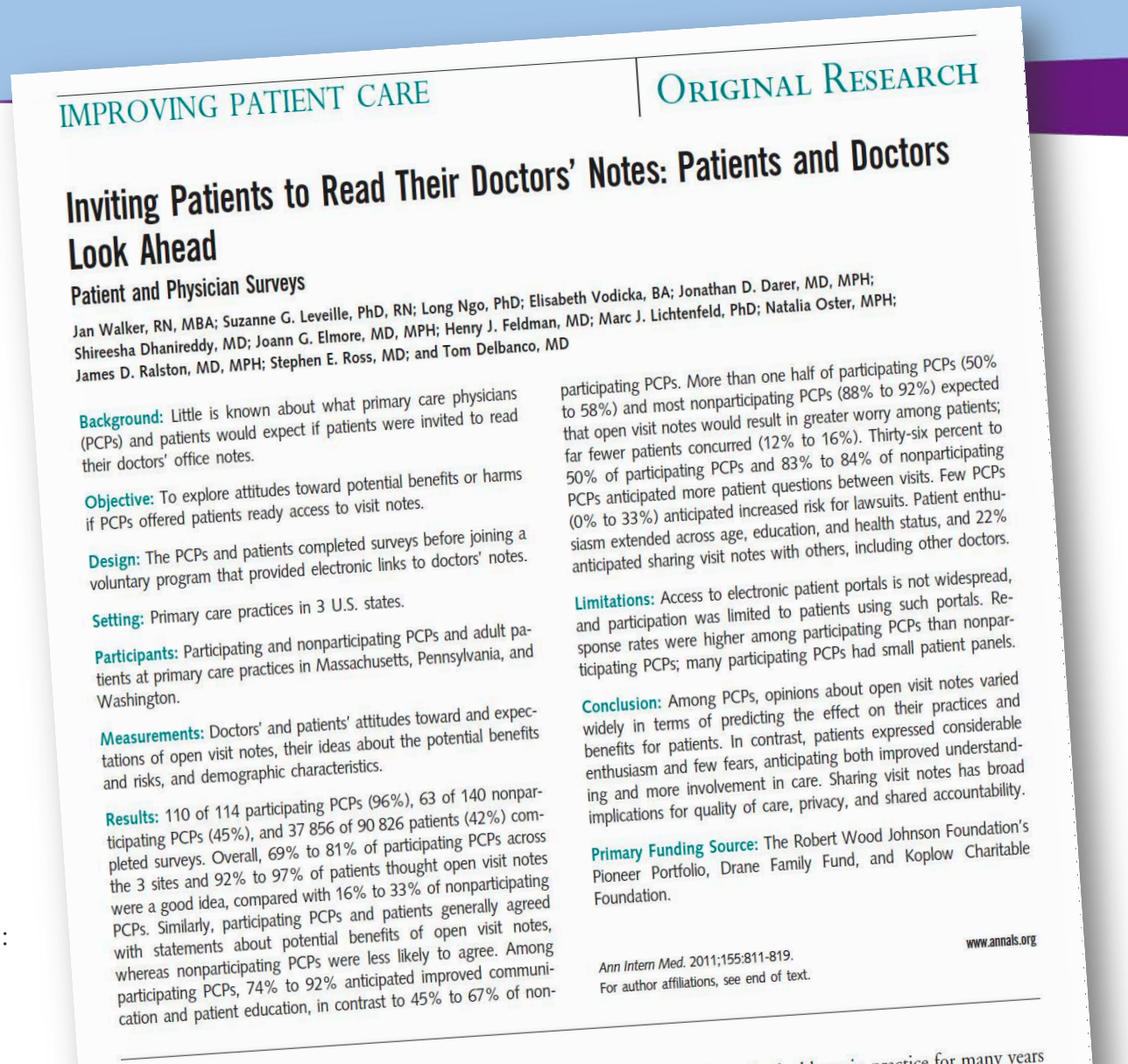
OpenNotes Begins: 2010

105 primary care clinicians

20,000 patients:

- **Boston** (BIDMC)
- Rural **Pennsylvania** (Geisinger)
- **Seattle** safety net hospital (Harborview)

Now replicated at numerous sites around the country



IMPROVING PATIENT CARE | ORIGINAL RESEARCH

Inviting Patients to Read Their Doctors' Notes: Patients and Doctors Look Ahead

Patient and Physician Surveys

Jan Walker, RN, MBA; Suzanne G. Leveille, PhD, RN; Long Ngo, PhD; Elisabeth Vodicka, BA; Jonathan D. Darer, MD, MPH; Shireesha Dhanireddy, MD; Joann G. Elmore, MD, MPH; Henry J. Feldman, MD; Marc J. Lichtenfeld, PhD; Natalia Oster, MPH; James D. Ralston, MD, MPH; Stephen E. Ross, MD; and Tom Delbanco, MD

Background: Little is known about what primary care physicians (PCPs) and patients would expect if patients were invited to read their doctors' office notes.

Objective: To explore attitudes toward potential benefits or harms if PCPs offered patients ready access to visit notes.

Design: The PCPs and patients completed surveys before joining a voluntary program that provided electronic links to doctors' notes.

Setting: Primary care practices in 3 U.S. states.

Participants: Participating and nonparticipating PCPs and adult patients at primary care practices in Massachusetts, Pennsylvania, and Washington.

Measurements: Doctors' and patients' attitudes toward and expectations of open visit notes, their ideas about the potential benefits and risks, and demographic characteristics.

Results: 110 of 114 participating PCPs (96%), 63 of 140 nonparticipating PCPs (45%), and 37 856 of 90 826 patients (42%) completed surveys. Overall, 69% to 81% of participating PCPs across the 3 sites and 92% to 97% of patients thought open visit notes were a good idea, compared with 16% to 33% of nonparticipating PCPs. Similarly, participating PCPs and patients generally agreed with statements about potential benefits of open visit notes, whereas nonparticipating PCPs were less likely to agree. Among participating PCPs, 74% to 92% anticipated improved communication and patient education, in contrast to 45% to 67% of nonparticipating PCPs. More than one half of participating PCPs (50% to 58%) and most nonparticipating PCPs (88% to 92%) expected that open visit notes would result in greater worry among patients; far fewer patients concurred (12% to 16%). Thirty-six percent to 50% of participating PCPs and 83% to 84% of nonparticipating PCPs anticipated more patient questions between visits. Few PCPs (0% to 33%) anticipated increased risk for lawsuits. Patient enthusiasm extended across age, education, and health status, and 22% anticipated sharing visit notes with others, including other doctors.

Limitations: Access to electronic patient portals is not widespread, and participation was limited to patients using such portals. Response rates were higher among participating PCPs than nonparticipating PCPs; many participating PCPs had small patient panels.

Conclusion: Among PCPs, opinions about open visit notes varied widely in terms of predicting the effect on their practices and benefits for patients. In contrast, patients expressed considerable enthusiasm and few fears, anticipating both improved understanding and more involvement in care. Sharing visit notes has broad implications for quality of care, privacy, and shared accountability.

Primary Funding Source: The Robert Wood Johnson Foundation's Pioneer Portfolio, Drane Family Fund, and Koplow Charitable Foundation.

Ann Intern Med. 2011;155:811-819.
For author affiliations, see end of text.
www.annals.org

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

Patient Views After Seven Years

✓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**

✓≈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, at 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

Clinician Views After Seven Years

✓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

DesRoches CM, Leveille S, Bell SK, et al. The Views and Experiences of Clinicians Sharing Medical Record Notes With Patients. JAMA Netw Open. 2020;3(3):e201753. doi:10.1001/jamanetworkopen.2020.1753

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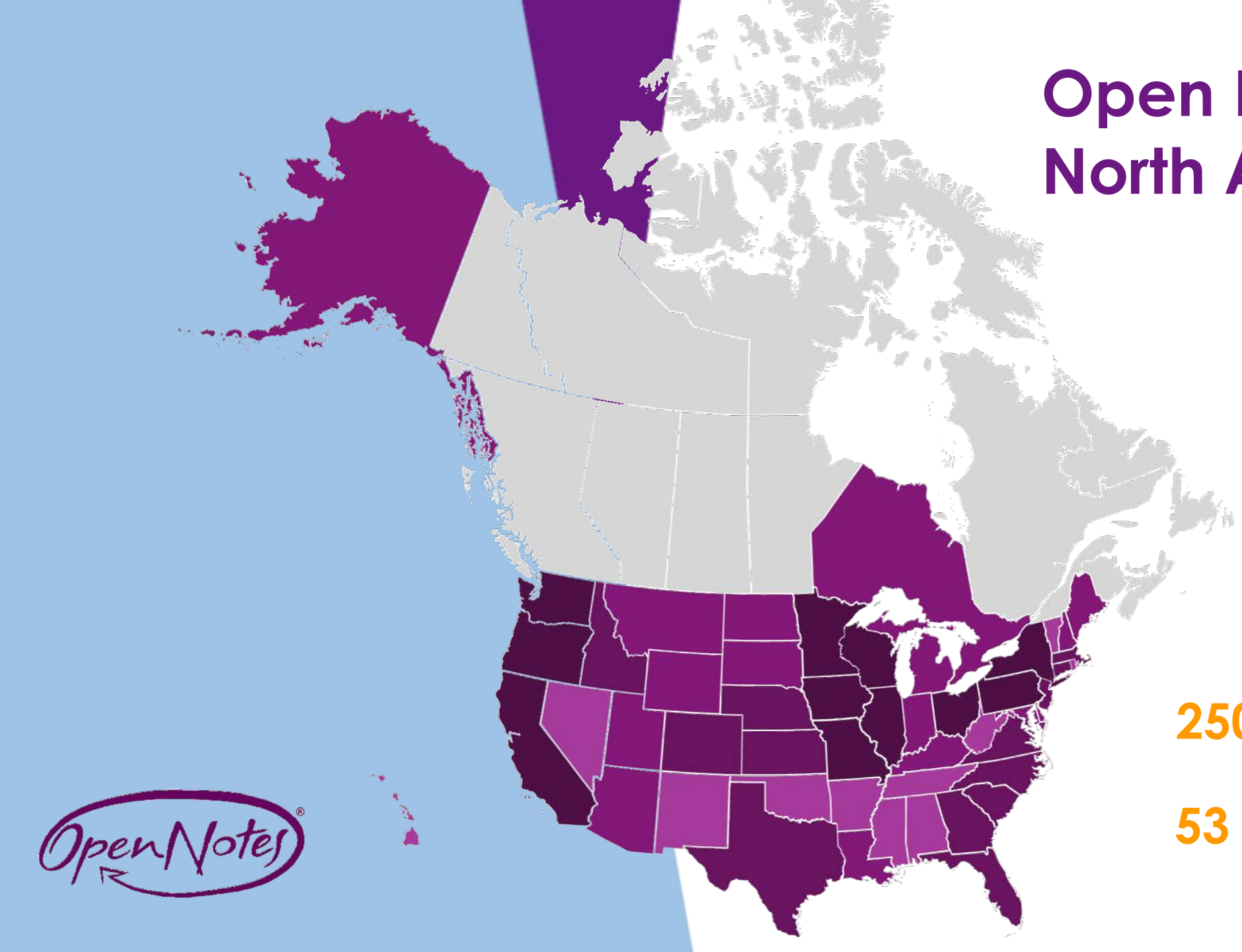
Open Notes Across North America



250 + organizations

53 MILLION people

OpenNotes®

Thank you.

Cait DesRoches, DrPH

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Twitter: @cmd418

opennotes.org

Sharing Palliative Care Notes

Christian T. Sinclair, MD, FAAHPM
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Overview

Shared Notes in General

- Potential Benefits
- What Patients Think
- Potential Concerns
- Tips and Tricks

Shared Notes for Palliative Care

- Prognostication
- Advance care planning
- Caregivers & proxy access
- Children and adolescents
- Social work, psychology & psychiatry
- Substance and opioid use disorder
- Requests for hastened death
- Evaluation of relationships & coping
- Inter- / Intra-team communication


Clinical Practice Guidelines for Quality Palliative Care
4th edition
National Consensus Project
for Quality Palliative Care
National Coalition for Hospice and Palliative Care

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Introduction to the 4th edition

In January 2017, the Gordon and Betty Moore Foundation awarded a two-year grant to enable the National Coalition for Hospice and Palliative Care to convene a Stakeholder Summit and develop, disseminate, and implement the 4th edition of the *National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines).

For a comprehensive overview of the Stakeholder Summit, read the National Consensus Project Stakeholder Strategic Directions Summit report available at https://www.nationalcoalitionhpc.org/ncp.

This edition of the NCP Guidelines expands upon the content in the 3rd edition, specifically focusing on two key concepts:

- Palliative care is inclusive of **all people with serious illness, regardless of setting, diagnosis, prognosis, or age**. As a result, language specific to the care of neonates, children, and adolescents was emphasized throughout the NCP Guidelines.
- Timely consideration of palliative care is the responsibility of clinicians and disciplines caring for the seriously ill, including primary care practices, specialist care practices (eg, oncology or neurology), hospitalists, nursing home staff, and palliative care specialist teams such as hospice, hospital and community-based palliative care teams.

In addition, **key themes** were added to each domain:

- The elements of a **comprehensive assessment** are described
- **Family** caregiver assessment, support, and education are referenced in numerous domains
- The essential role of **care coordination**, especially during care transitions, is emphasized
- **Culturally inclusive** care is referenced in all the domains and expanded in the Cultural Aspects of Care domain
- **Communication** (within the palliative care team, with patients and families, with other clinicians, and with community resource providers) is a prerequisite for delivery of quality care for the seriously ill and is emphasized throughout

COMMUNICATION

(within the PC team, with patients & families,
with other clinicians, and with community)

is a PREQUISITE

for delivery of quality care

for the seriously ill

and is emphasized throughout.

Benefits of OpenNotes

- Improved communication
- Patient engagement
- Improved outcomes
- Improved safety
- Optimized care
- Fulfilled patients

Delbanco, Annals Int Med, 2012; Fossa, JAMIA, 2018; DesRoches, Annals IM 2019; Bell, JAMA Network Open, 2020; Chimowitz, AHRQ, 2018

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Majority of Patients Report

- Want continued access
- Helps with adherence
- Feel more in control
- Better prepared
- Better understanding
- Take better care

Delbanco, Annals Int Med, 2012; Fossa, JAMIA, 2018; DesRoches, Annals IM 2019; Bell, JAMA Network Open, 2020; Chimowitz, AHRQ, 2018

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TRUST	"I saw that my doctor truly listens to what I have to say. I respect, trust, and appreciate her even more."
CONFIDENCE	"…gave me insight into the evaluation process my doctor used and gave me confidence in his abilities."
COLLABORATION	"A reminder of what she & I agreed I should do to improve my health. I also see how much my doctor really makes an effort…"
UNDERSTANDING	"Reading the notes made it easier for me to understand what the doctor has said and what I need to do"
ENGAGEMENT	"…like a report card or a performance review. I can see what I am doing right and what needs improvement."
CONFIRMATION	"I wanted to check to make sure I left with the correct impression…sometimes you can't hear it all."
AID FOR RECALL	"I'm more relaxed during the appointment in that I don't have to remember every detail."
SAFETY PARTNER	"I want to confirm accuracy. When providers copy and paste, errors just never get corrected unless we see our notes."

Bell, BMJ Qual Saf. 2017

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Potential Concerns

Patient factors

- ⊗ Time spent responding to patient corrections
- ⊗ Patients will get upset, anxious, sad, angry
- ⊗ Patients will get confused
- ⊗ Increased malpractice liability

Documentation factors

- ⓘ More time documenting
- ⓘ Less accurate notes
- ⓘ Change in billing
- ⓘ Sensitive topics

Walker, BMJ Qual Saf, 2015; Walker, JMIR, 2015; Bell, JAMA, 2020; DesRoches, JAMA Network Open, 2020

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General Shared Note Tips

- Pre-Visit
- During Visit
- Documenting
- Follow-Through

"Suggestions for implementing open notes in clinical practice" Tip Sheet, opennotes.org

Entry Level

- **Expect patients to read, download, and share**
- **Explain to patients what they can expect to see**
- **Be clear and succinct**
  - Avoid jargon
  - Spell out acronyms (SOB, BID, CAD, etc)
- **Be direct and respectful**
  - Avoid speculation, especially about intent, motives
  - Use neutral, factual language
    - Morbid obesity — Class 3 obesity OR Body Mass Index (BMI) 42
    - Diabetic — person with diabetes (person-first language)
    - Patient denies — Tawnya did not report
    - Poor historian — Sam could not recall

Klein, Am J Med , 2016

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Entry Level

- **Use supportive language**
  - Your notes can help people see their strengths
- **Use quotes selectively**
  - Direct quotes for short, memorable phrases
  - Long quotes may open up to dispute
- **ICD 10 codes important but may stigmatize**

- **Don't oversimplify notes**
- **Don't avoid sensitive issues**

Klein, Am J Med , 2016

Pre-Visit: Pro Level

- Go read opennotes.org
- Prepare with your group
- Are your note templates patient-centered?
- What common phrases might need to be altered?
- Have acronyms? – Make a list to give your patients

- Know what your org is doing
- Volunteer to be on your org OpenNotes team
- How many of your patients are on your EHR portal?

During Visit: Pro Level

- Discuss your use/support of shared notes
- Encourage use of patient portal
- Encourage feedback
- Document/dictate with the patient
- Can your EHR include patient-generated notes?
    - OurNotes initiative

- Team – Work to share documentation efforts

Documenting: Pro Level

- Have an updated patient-centered template
- Use EHR to spell out acronyms
- Use EHR to correct non-patient centered phrases
- Document potential future plans
  - Use phrases like ‘may consider’ to avoid confusion
- Include a shared note statement

- AI is working on plain-language interpretation

Bala, JMIR Form Res, 2020

Shared Note Statement

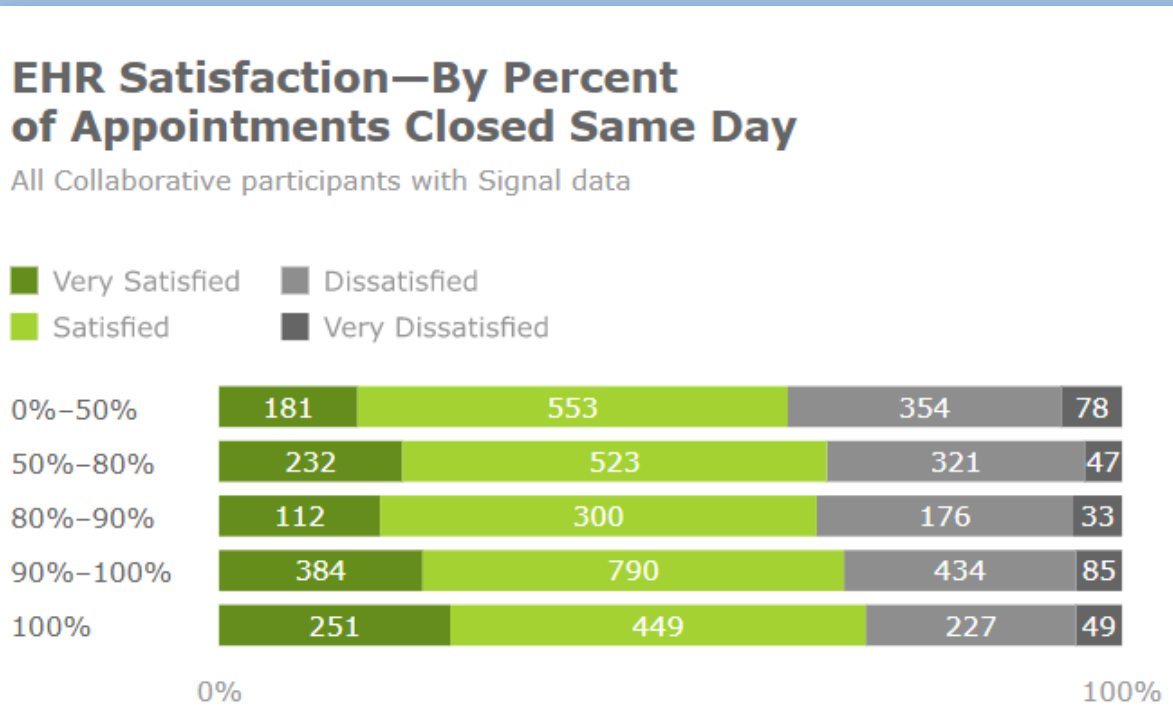
This is a shared note. I support your right to access your health information in an open, easy manner. We are partners together to improve your health.
If you are a patient or caregiver with concerns about this note, please contact us by one of the following ways:

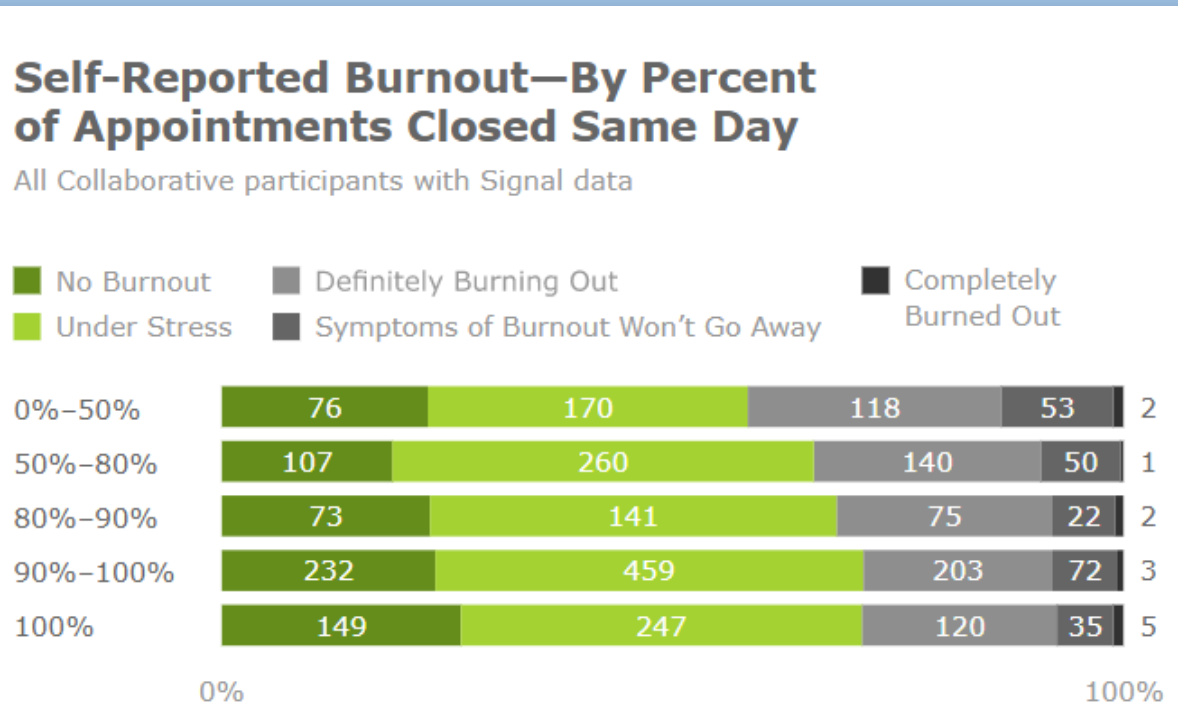
1) send a MyChart message to myself and our team
2) call us during business hours at XXX-XXX-XXXX
3) talk to us at your next visit.

Follow-Through: Pro Level

- Discuss with patients if they read your note
- Discuss with patients if they read other notes

- Track patient success/failure with shared notes
- Track your population % notes accessed
- Track your clinicians time documenting
- Intra- and extra-mural best practice sharing
- QI, research and publish





- Chart from Klas Research
- EPIC systems – Ask about Signal
- Cerner has clinician utilization tools too

Unique Areas in Palliative Care

- Prognostication
- Advance care planning
- Caregivers & proxy access
- Children and adolescents
- Psychology & psychiatry
- Substance and opioid use disorder
- Requests for hastened death
- Opinions on relationships & coping
- Inter- / Intra-team communication

Prognostication

- Prognosis is important for clinical care
- Avoid documenting without communicating
- Document what you said, not what you think
- Use all your comm skills around prognosis
- Share that you will document it
- If patient declines discussion, document that
- Use the note as an asynchronous tool
  - Smartphrase – "Prefers to avoid prognosis discussion. I am hopeful we can discuss in future to better plan together."

Advance Care Planning

- Does your org share these note types?

- Important to actively solicit feedback
- Consider reviewing note at end of visit or in future
- For parts of discussion avoided, document attempt

- Great chance to QI your ACP completion rates
- Great chance to improve training/consistency

Caregivers and Proxy Access

- Caregiver roles vary
  - Providing technical support to representing patients
- Sharing passwords vs proxy accounts
- Full vs customized access
- Changes in relationships
- If concerned about sensitive info, ask patient
- If safety concern, consider marking note sensitive
  - Note your org will track these numbers
- Unique issue for incarcerated person

Park, J Particip Med, 2015; Weis, BMC Med Info Dec Mak, 2020

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Children & Adolescents

- Ask how your org is handling these notes
- What are the current capabilities?

- Sexual health in adolescence – well-covered topic
  - Also substance abuse, genetic data, adoption
- Growing autonomy of adolescents
- Similar issues to the previous slide
- Download the Pediatric Toolkit at OpenNotes.org

Park, J Particip Med, 2015; Bourgeois, Pediatrics, 2018; Bourgeois, JAMIA, 2008

Social Work, Psychology & Psychiatry

- Behavioral health - long history with confidentiality
- Discuss possible diagnoses before documentation
- If read before heard, can stigmatize
- Beware ICD-10 codes
- When documenting differential diagnoses
  - Use probability – probable, possible, rarely
  - Explain if formal assessment or more time is needed
- Benefits – respect, destigmatize, tool for change
- Download Mental Health Toolkit at OpenNotes.org

Denneson, JAMIA, 2019; O'Neill, J Mental Health, 2018; Chimowitz, Social Work, 2020; Denneson, Psych Serv, 2018

Substance & Opioid Use Disorders

- Covered by confidentiality laws
- Disclosure of SUD from Federally Assisted Programs is COMPLEX.
- State laws are even more complex.
- Discuss possible diagnoses before documentation
- If read before heard, can stigmatize
- Beware ICD-10 codes, talk with addiction specialists
- When documenting differential diagnoses
  - Use weighted words – probable, possible, rarely
  - Explain if formal assessment or more time is needed
- Avoid becoming a detective with speculation

Get more information at SAMHSA.GOV

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Requests for Hastened Death

- Know your state laws
- Know your org policies
- Document respectfully, humanely & factually
- If documenting values, reason – use patient's words
- Avoid speculation

Evaluations of Relationships

- Patients and caregivers share intimate details
- Patients and caregivers trust their clinicians
- If a safety issue, ask about shared notes
- Consider marking note sensitive
- Area to highlight strengths

Evaluations About Coping

- For positive coping
  - Great opportunity to highlight strengths
  - May be a place to model possibilities
  - Something a patient may reflect on
- For negative coping
  - Find language that captures the situation
  - Workshop best wording with your team
  - Aim for factual, neutral and professional
  - Use similar language that you use in the visit

Inter-/Intra-Team Communication

- Notes can be used to
  - Teach
  - Talk to future self
  - Hand-off to colleague
  - ~~Fight~~ ~~Argue~~ Discuss with other teams
- Are we asking too much of a note
- Think about if there are better ways to do that

In-Visit Language for Sensitive Issues

"I appreciate what you shared today. Thanks for trusting our team. I want to make sure my note summarizes what we discussed, so if you read it and have feedback, please let me know."

"We covered some difficult topics today. I'll summarize it in my note as best I can. I recognize we may have different thoughts on this. If you see areas we disagree on, please reach out to us."

Things to Acknowledge

This is a change you may not have wanted
This is a change which may feel sudden
This is a change which can bring anxiety
But…
Now you have more information
Now you can make a plan
Now you can work with your team
And ride this rollicking wave and improve your QOL

COMMUNICATION

(within the PC team, with patients & families,
with other clinicians, and with community)

is a PREQUISITE

for delivery of quality care

for the seriously ill

and is emphasized throughout.

Actions Items

- Review opennotes.org
- Talk about it as a group
- Update your current note templates
- Make use of documentation tools to reduce burden
  - i.e. SmartPhrases, dictation, embedding results in note
- Ask for feedback from patients during & after visit
- Make palliative care a champion for access and info
- Research and publish – it's a new world!

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Thank you

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OpenNotes®

Q&A

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