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.
Hello, from OpenNotes

“open notes”
When doctors and other healthcare professionals share the visit notes they write with patients
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
What the patient sees (after visit summary)

What the doctor writes (notes)

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 [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.
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

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.
- Reading notes **helps them understand their medications**.
- Almost all patients say they understood all or nearly all of their notes.
- Approx. 20% of patients **found an error** in their notes.
- Important benefits for patients with less education or limited English proficiency.


✓ 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

250 + organizations
53 MILLION people
Thank you.

Cait DesRoches, DrPH

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opennotes.org
Sharing Palliative Care Notes

Christian T. Sinclair, MD, FAAHPM
University of Kansas Health System
Associate Professor, Division of Palliative Medicine
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
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).

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 (e.g., 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

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

is a PREREQUISITE
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

Delbenco, Annals Int Med, 2012; Fossa, JAMIA, 2018; DesRoches, Annals IM 2019; Bell, JAMA Network Open, 2020; Chimowitz, AHRQ, 2018
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
<table>
<thead>
<tr>
<th>Category</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TRUST</strong></td>
<td>“I saw that my doctor truly listens to what I have to say. I respect, trust, and appreciate her even more.”</td>
</tr>
<tr>
<td><strong>CONFIDENCE</strong></td>
<td>“…gave me insight into the evaluation process my doctor used and gave me confidence in his abilities.”</td>
</tr>
<tr>
<td><strong>COLLABORATION</strong></td>
<td>“A reminder of what she &amp; I agreed I should do to improve my health. I also see how much my doctor really makes an effort…”</td>
</tr>
<tr>
<td><strong>UNDERSTANDING</strong></td>
<td>“Reading the notes made it easier for me to understand what the doctor has said and what I need to do”</td>
</tr>
<tr>
<td><strong>ENGAGEMENT</strong></td>
<td>“…like a report card or a performance review. I can see what I am doing right and what needs improvement.”</td>
</tr>
<tr>
<td><strong>CONFIRMATION</strong></td>
<td>“I wanted to check to make sure I left with the correct impression…sometimes you can’t hear it all.”</td>
</tr>
<tr>
<td><strong>AID FOR RECALL</strong></td>
<td>“I’m more relaxed during the appointment in that I don’t have to remember every detail.”</td>
</tr>
<tr>
<td><strong>SAFETY PARTNER</strong></td>
<td>“I want to confirm accuracy. When providers copy and paste, errors just never get corrected unless we see our notes.”</td>
</tr>
</tbody>
</table>
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
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
    - Diabetic
    - Patient denies
    - Poor historian
    - Class 3 obesity OR Body Mass Index (BMI) 42
    - Person with diabetes (person-first language)
    - Tawnya did not report
    - Sam could not recall

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

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
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

• 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
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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opennotes.org / @myopennotes / #opennotes
Thank you

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