The 21st Century Cures Act: Advancing Transparency to Improve Patient Care

Conflict of Interest

I have no relevant conflicts of interest to report.

21st Century Cures Act

- Signed into law December 13, 2016
- Overarching goal is to advance biomedical innovation
- Encouraging interoperability
- Leveraging EHRs to Improve Patient Care and Access to Information
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

Timeline to Transparency

Clinical Notes
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

Requires that healthcare providers give all patients free access to all the health information in their electronic medical records without delay

APRIL 05, 2021

Patients have had the ability to download their records for years…
The Wayback Machine

Apple Gets Into Healthcare
Open Notes Across North America

✓ 260 organizations
✓ 54 MILLION people

OPENNOTES PILOT (published 2012)

RECENTLY...
Why encourage patients to read their notes?

- The "big amnesia"
- Improved understanding of and adherence to medication
- Increased trust in provider
- Improved safety

Patients' Perceived Benefits of Note-Reading

- How important is reading your notes for:
  - Taking care of your health: 92%
  - Feeling in control of your care: 92%
  - Remembering the plan of care: 92%
  - Having an active role in your care*: 92%
  - Making the most of your visits*: 92%
  - Preparing for office visits: 92%

Patients and their medications

- Reading my visit notes:
  - Helped understand why a med was prescribed: 94%
  - Made me feel more in control of my medications: 92%
  - Answered my questions about the medication: 92%
  - Helped understand possible side effects: 92%
  - Made me seek more information about my meds: 92%
  - I am more likely to take meds as prescribed*: 92%
Patients Perceived Risks of Note-Reading

- Very concerned about the privacy of my visit notes: 24%
- Fell judged or offended by something in a note: 11%
- Reading my notes made me more worried about my medications: 8%
- Visit notes were very confusing: 4%
- Reading my notes made me confused about my medications: 2%

Patients feeling judged or offended

- Errors and Surprises:
  - Diagnosis not discussed
  - Confidentiality concern
  - Mistake
  - Did not happen in the visit
- Labeling:
  - Obesity
  - Gender/sexuality
  - Personal Descriptions
  - Other stigma
- Disrespect:
  - Condescension
  - Not heard or misquoted
  - Clinical language

When Patients Read Their Notes . . .

20% detected errors that may affect the safety and diagnostic accuracy of their care.
Clinicians experiences with patients findings mistakes in the chart

26% of doctors reported a time when a patient found an error that the doctor considered clinically important

Errors Found by Patients

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>The note said I was not BRCA1 when I am BRCA1.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical History</td>
<td>The diagnosis for the visit was incorrect, so that although I did receive a referral for physical therapy, it was for the wrong body part.</td>
</tr>
<tr>
<td>Physical exam</td>
<td>Wrong BMI; told I could not be placed on a heart lung transplant list.</td>
</tr>
<tr>
<td>Medications</td>
<td>Found an incorrect dosage on a note that was being used by a referred physician for an infusion. The dosage was incorrect by 10 fold.</td>
</tr>
<tr>
<td>Plan to change medication based on the lab results of another patient.</td>
<td></td>
</tr>
<tr>
<td>Wrong Patient</td>
<td>Someone else's records are listed under mine</td>
</tr>
</tbody>
</table>

CLINICIAN PERCEPTIONS OF OPENNOTES...

74% agree sharing notes with patients is a good idea
61% would recommend note sharing to other clinicians


Are clinicians changing their documentation due to OpenNotes?

63% no change in the amount of time spent on notes
7% spend “much” more time
30% spend “somewhat” more time

16% of clinician survey respondents reported spending more time writing/dictating/editing notes because of OpenNotes. A comparison of pre-post note authoring time:

- .14 second increase for PCP
- No increase for specialists

Because of OpenNotes, have you changed...?

| Use of language that could be perceived as critical to the patient | 56% |
| How you document sensitive information | 40% |
| How you document patient's perspectives | 41% |
| How you document differential diagnosis | 30% |
| Use of jargon or abbreviations | 22% |
| How you document patients' perspectives | 20% |
| Use of partnering language | 19% |
| Use of terms such as “non-compliant” | 18% |

Percent of physicians


Equity: Bias in notes of patients with sickle cell disease acute pain crisis

<table>
<thead>
<tr>
<th>Themes</th>
<th>Definition/mechanism</th>
<th>Example</th>
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<td>Casting doubt on patient report</td>
<td>Implies clinician disbelief claims, insists, repeatedly, but... Use of quotes (distancing)?</td>
<td>Patient reports 10/10 pain, but labs are fine (or sleeps through the night)</td>
</tr>
<tr>
<td>Perpetuating negative stereotypes</td>
<td>Unflattering (often unnecessary) description Often memorable May overlap with “physician disapproval”</td>
<td>Last po intake Swedish fish/chicken wings at 3am Spent the day hanging outside McDonalds</td>
</tr>
<tr>
<td>Blaming the patient</td>
<td>Nonadherence (without patient explanation)</td>
<td>Refuses O2</td>
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Mary Catherine Beach, MD. "Health Equity Jam Session."

Can a note written by one clinician influence the attitudes and behaviors of another clinician?

Compared reaction of 413 participants to two note versions (using neutral vs stigmatizing language) on the same patient

<table>
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<th>Stigmatizing</th>
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<td>He still has pain rated 10/10. His girlfriend is by his side but will need to go home soon.</td>
<td>He is insisting that his pain is &quot;still a 10.&quot; His girlfriend is lying on the bed with her shoes on and requests a bus token to go home.</td>
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Which negative themes/biasing mechanisms can you spot?

Transmission of bias in the medical record

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Clinicians reading the stigmatizing version...
- More negative attitudes toward patient
- Less aggressive pain management

Bias awareness training
- Respectful, supportive language
- "Micro-affirmations"
- "Not just a tome of doom and gloom"
- Empower SDM/Activation
- Extend the visit:
  - "It's like having the visit all over again"
- A new space (between visits, post d/c)
- Preventive health, ambulatory safety, accompaniment

Transparency as a change agent

"Perhaps we overestimate the importance of the patient's visit alone... a vast majority of people's time is spent not in the office visit. This is a powerful tool." - A physician
In summary

- OpenNotes is here – and it’s broader than we expected
  - Opportunities to learn.
- Outpatient evidence suggests that everything will be okay.
- But we won’t get to real benefits until patients and families are using the information in their medical records.

Questions?

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