The New Era of Transparency in Healthcare: Sharing Clinical Notes with Patients

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Executive Director, OpenNotes
Conflicts of Interest

OpenNotes is not a vendor or a software package; I have no conflicts of interest to report.

The initiative is supported through grants from the Robert Wood Johnson Foundation, the Gordon and Betty Moore Foundation, the Peterson Center on Health Care, The Cambia Foundation, and the Shaw Family Foundation.
Three Main Points

- Patients like to have and benefit from easy access to their clinical notes.

- Most clinicians say patient access to notes does not increase workload.

- Change is coming!
A Growing Patient Movement

“How come as a patient, we’re last in line for our own data?”

STEVEN KEATING, THE OPEN PATIENT

To manage her Parkinson’s disease, Sara Riggare spends 1 hour in neurological healthcare and 8,765 hours in selfcare per year.

NIGHTSCOUT
#WeAreNotWaiting

www.riggare.se

Sara Riggare, 2014
OpenNotes: A Simple Idea

- **OpenNotes is a simple idea:** Flick the switch!
- **Patients have the right to read the notes their clinician writes (HIPAA);** OpenNotes just makes it easier.
- Evidence suggests increasingly that opening notes can **improve communication** and help patients become more **actively involved** with their care.
What is OpenNotes?

A philanthropy funded initiative grounded in research that encourages all clinicians to offer patients easy access to their notes.

- Began as a pilot in 2010; notes were shared for 1 year
- Three health systems
- 105 primary care clinicians
- 20,000 patients
Inviting Patients to Read Their Doctors’ Notes: A Quasi-experimental Study and a Look Ahead

Tom Delbanco, MD; Jan Walker, RN, MBA; Sigall K. Bell, MD; Jonathan D. Darer, MD, MPH; Joann G. Elmore, MD, MPH; Nadine Farag, MS; Henry J. Feldman, MD; Roanne Mejilla, MPH; Long Ngo, PhD; James D. Ralston, MD, MPH; Stephen E. Ross, MD; Neha Trivedi, BS; Elisabeth Vodicak, BA; and Suzanne G. Levelle, PhD, RN

Background: Little information exists about what primary care physicians (PCPs) and patients experience if patients are invited to read their doctors’ office notes.

Objective: To evaluate the effect on doctors and patients of facilitating patient access to visit notes over secure internet portals.

Design: Quasi-experimental trial of PCPs and patient volunteers in a year-long program that provided patients with electronic links to their doctors’ notes.

Setting: Primary care practices at Beth Israel Deaconess Medical Center (BIDMC) in Massachusetts, Gelinger Health System (GHS) in Pennsylvania, and Harborview Medical Center (HMC) in Washington.

Participants: 105 PCPs and 13,564 of their patients who had at least 1 completed note available during the intervention period.

Measurements: Portal use and electronic messaging by patients and surveys focusing on participants’ perceptions of behaviors, benefits, and negative consequences.

Results: 11,155 of 13,564 patients with visit notes available opened at least 1 note (84% at BIDMC, 82% at GHS, and 47% at HMC). Of 5,219 patients who opened at least 1 note and completed a postintervention survey, 77% to 87% across the 3 sites reported that open notes helped them feel more in control of their care; 60% to 78% of those taking medications reported increased medication adherence; 26% to 36% had privacy concerns; 1% to 8% reported that the notes caused confusion, worry, or offense; and 20% to 42% reported sharing notes with others. The volume of electronic messages from patients did not change. After the intervention, few doctors reported longer visits (0% to 5%) or more time addressing patients’ questions outside of visits (0% to 8%), with practice size having little effect; 3% to 36% of doctors reported changing documentation content; and 0% to 21% reported taking more time writing notes. Looking ahead, 59% to 62% of patients believed that they should be able to add comments to a doctor’s note. One out of 3 patients believed that they should be able to approve the notes’ contents, but 85% to 96% of doctors did not agree. At the end of the experimental period, 99% of patients wanted open notes to continue and no doctor elected to stop.

Limitations: Only 3 geographic areas were represented, and most participants were experienced in using portals. Doctors volunteering to participate and patients using portals and completing surveys may tend to offer favorable feedback, and the response rate of the patient surveys (41%) may further limit generalizability.

Conclusion: Patients accessed visit notes frequently, a large majority reported clinically relevant benefits and minimal concerns, and virtually all patients wanted the practice to continue. With doctors experiencing no more than a modest effect on their work lives, open notes seem worthy of widespread adoption.

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For author affiliations, see end of text.
* Dr. Delbanco and Ms. Walker contributed equally to this manuscript.
Current Details

- >200 health care organizations have implemented or are piloting note sharing

- At least one private, non-governmental healthcare organization in each state is sharing clinical notes

- The entire VA through the Blue Button
40+ Million Patients Have Access to Notes
What's Next
You currently have no upcoming appointments scheduled.

Changes to Your Medication List

1️⃣ Accurate as of 4/12/19 11:55 AM.
Please bring an up-to-date copy of your medication list to any future appointments. If you have any questions, please ask your provider or pharmacist.

CONTINUE taking these medications

acetaminophen 325 mg tablet
Commonly known as: TYLENOL
Take 2 tablets (650 mg total) by mouth every 6 (six) hours.

acyclovir 400 MG tablet
Commonly known as: ZOVIRAX
Take 1 tablet (400 mg total) by mouth 3 (three) times a day.

aspirin 81 MG EC tablet
Take 81 mg by mouth daily.

Today's Visit
You saw Erika L Rangel, MD, MS on Friday April 12, 2019. The following issue was addressed: Unilateral femoral hernia without obstruction or gangrene, recurrence not specified.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood Pressure</td>
<td>95/59</td>
</tr>
<tr>
<td>Weight</td>
<td>133 lb 8 oz</td>
</tr>
<tr>
<td>Height</td>
<td>5' 5&quot;</td>
</tr>
<tr>
<td>Pulse</td>
<td>54</td>
</tr>
<tr>
<td>Oxygen Saturation</td>
<td>99%</td>
</tr>
<tr>
<td>BMI</td>
<td>22.22</td>
</tr>
</tbody>
</table>
Clinical Notes

Erika L Rangel, MD, MS at 4/12/2019 10:30 AM

Status: Signed

Ms. Desroches returns to clinic as 3-week follow-up (3/25/19). She reports her pain is well controlled, only notes intermittent discomfort around the incision. She took a couple of her pain control tablets for the first couple days after surgery and then transitioned to tylenol, and she no longer is taking any pain medications. She also notes mild numbness over the incision. Otherwise, denies nausea and has been avoiding heavy lifting or strenuous activity.

Physical exam:
Vitals: BP 95/59 | HR 54
Gen: NAD, AOx3
Resp: Non-labored breathing on RA
Extrem: WWP, no edema
Wound: Well-healing surgical incision, non-erythematous, non-tender to palpation

Assessment/Plan: Ms. Desroches is recovering well postoperatively. Her pain is well controlled, and her incision has healed nicely. She is leaving for vacation this weekend and was educated on activity limitations to prevent hernia recurrence. She understands to follow-up in clinic as needed.

Patient seen and discussed with Dr. Rangel who agrees with assessment and plan.

Christine Wu, MD
General Surgery
Pager 33420

Attending Attestation:

I have seen and examined the patient, reviewed the labs and imaging, and agree with Dr. Wu's note documented today with the below additions and changes: Catherine is doing great 3 weeks after surgery. She has no residual pain. She is leaving for Costa Rica this weekend and was cautioned to avoid heavy lifting or core abdominal exercises. I would prefer that she avoid surfing. Otherwise, walking and cardiovascular exercise will be fine. She is very pleased with the results of her operation and will return to see me as needed.
Why do patients read notes?

<table>
<thead>
<tr>
<th>Reason(s) - multiple permitted</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>To know about my health</td>
<td>58</td>
</tr>
<tr>
<td>To be sure I understood what the doctor said</td>
<td>55</td>
</tr>
<tr>
<td>I was curious</td>
<td>48</td>
</tr>
<tr>
<td>To know what my doctor was thinking</td>
<td>45</td>
</tr>
<tr>
<td>To remember the visit</td>
<td>38</td>
</tr>
<tr>
<td>To check the notes were right</td>
<td>29</td>
</tr>
</tbody>
</table>

When patients read their notes . . .

- **99%** Felt better (37%)* or the same (62%) about their doctor after reading ≥1 note.
- **7%** Reported contacting their doctor about concerns in their note.
- **>50%** Doctors believed shared notes increased patient satisfaction and trust.
- **0%** Doctors reported ordering more tests or referrals.

*Older, non-Caucasian patients, with poorer health, lower formal education were more likely to feel better about the doctor.
Patients’ Perceived Benefits of Note-Reading

How important is reading your notes for....

- Taking care of your health: 73%
- Feeling in control of your care: 70%
- Remembering the plan of care: 66%
- Having an active role in your care*: 64%
- Making the most of your visits*: 63%
- Preparing for office visits: 50%

Percent of patients reporting “top-box” scores

*Asked at BIDMC and Geisinger Health System

Confidential and unpublished data; please do not share.
Patients Report Benefits Related to Medications

Reading my visit notes…

- Helped me understand why a med was prescribed: 64%
- Made me feel more in control of my medications: 62%
- Answered my questions about the medication: 57%
- Helped me understand possible side effects: 45%
- Made me seek more information about my meds: 32%
- I am more likely to take meds as prescribed: 14%

*Asked at BIDMC and Geisinger Health System

Embargoed and in press; please do not share.
Clinician perceptions of OpenNotes... 

74% agree sharing notes with patients is a good idea

61% would recommend note sharing to other clinicians

Embargoed and in press; please do not share.
<table>
<thead>
<tr>
<th>All Clinicians</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>39%</strong> - notes were more confusing than helpful for patients</td>
<td><strong>5%</strong> - notes were confusing</td>
</tr>
<tr>
<td><strong>26%</strong> - patients who read visit notes were more prepared for visits</td>
<td><strong>50%</strong> - reading notes helped them prepare for visits</td>
</tr>
</tbody>
</table>

*In press and embargoed; please do not share.*
Clinicin worries + patient realities

“Patients will be offended by something they read in their notes.” (38%)

10% of patients reported feeling judged or offended by something they read in their note.
What do patients find judgmental or offensive in the note?

- Terms such as “patient denies” or “complains”
- References to obesity and substance use
- Descriptions of patients’ demeanor
- Concerns not described accurately
- Perception that the clinician lied in the note
- Surprise when language in the note did not reflect what the patient recalled about the visit
- Mistakes
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

Embargoed and in press; please do not share.
## Errors found by patients

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>The note said I was not BRCA1 when I am BRCA 1.</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>I 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. Plan to change medication based on the lab results of another patient.</td>
</tr>
<tr>
<td>Wrong Patient</td>
<td>Someone else's records are listed under mine</td>
</tr>
</tbody>
</table>
Clinician perceptions of OpenNotes... 

63% no change in the amount of time spent on notes

7% spend “much” more time

30% spend “somewhat” more time
Change is Coming

And in some cases, it’s already here . . .
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
21st Century Cures Act

- Establishes an HIT Advisory Committee within ONC charged with developing recommendations related to interoperability defined as:
  - Exchange information “without special effort”
  - Allows for complete access, exchange and use of ALL electronically accessible health information
Leveraging EHRs to Improve Patient Care + Access to Information

- Support the certification and development of patient centered EHRs.

- Requires HHS to educate patients and providers on rights patient access to information.

- Clarifies rules around patient requests to provider business associates for access to personal health information.
Meaningful Use: Stage 3

Requires
Open API

Recommends
Fast Healthcare Interoperability Resources (FHIR)
Very Recently...

This is big. @donrucker of @ONC_HealthIT tells us here at the White House, ‘Patients WILL have access to their Notes.’

12/4/18, 2:38 PM
The Argonaut Project

Private sector initiative to advance the adoption of modern, open interoperability standards

Sponsored by all major EHR vendor + other stakeholders

Advance use of FHIR-based APIs

Added notes to their 2018 priorities

If Argonaut recommends a standard, ONC usually adopts it
The USCDI Version 1 (USCDI v1) is proposed as a standard (§ 170.213). It reflects the same data classes referenced by the CCDS definition and includes new required data classes and data elements, noted below.

### USCDI v1

<table>
<thead>
<tr>
<th>Assessment and Plan of Treatment</th>
<th>Laboratory</th>
<th>Provenance <strong>NEW</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Team Members</td>
<td></td>
<td>Author</td>
</tr>
<tr>
<td>Clinical Notes <strong>NEW</strong></td>
<td>Tests</td>
<td>Author Time Stamp</td>
</tr>
<tr>
<td></td>
<td>Values/Results</td>
<td>Author Organization</td>
</tr>
<tr>
<td>Medications</td>
<td>Medications</td>
<td>Smoking Status</td>
</tr>
<tr>
<td></td>
<td>Medication Allergies</td>
<td>Unique Device Identifier(s) for a Patient’s Implantable Device(s)</td>
</tr>
<tr>
<td>Laboratory Report Narrative</td>
<td>Patient Demographics</td>
<td>Vital Signs</td>
</tr>
<tr>
<td>Pathology Report Narrative</td>
<td>First Name</td>
<td>Diastolic Blood Pressure</td>
</tr>
<tr>
<td>Procedure Note</td>
<td>Last Name</td>
<td>Systolic Blood Pressure</td>
</tr>
<tr>
<td>Progress Note</td>
<td>Previous Name</td>
<td>Body Height</td>
</tr>
<tr>
<td></td>
<td>Middle Name</td>
<td>Body Weight</td>
</tr>
<tr>
<td></td>
<td>(including middle initial)</td>
<td>Heart Rate</td>
</tr>
<tr>
<td></td>
<td>Suffix</td>
<td>Respiratory Rate</td>
</tr>
<tr>
<td></td>
<td>Birth Sex</td>
<td>Body Temperature</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pulse oximetry</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inhaled oxygen concentration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pediatric Vital Signs <strong>NEW</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- BMI percentile per age and sex for youth 2-20</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Weight for age per length and sex</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Occipital-frontal circumference for children &gt;3 years old</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Smoking Status</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unique Device Identifier(s) for a Patient’s Implantable Device(s)</td>
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<tr>
<td></td>
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<td>Vital Signs</td>
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<tr>
<td></td>
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<td>Diastolic Blood Pressure</td>
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<td></td>
<td></td>
<td>Systolic Blood Pressure</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Body Height</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Body Weight</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Heart Rate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Respiratory rate</td>
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<tr>
<td></td>
<td></td>
<td>Body Temperature</td>
</tr>
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<td></td>
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<td>Inhaled oxygen</td>
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<td></td>
<td></td>
<td>concentration</td>
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<tr>
<td></td>
<td></td>
<td>- Occipital-frontal circumference for children &gt;3 years old</td>
</tr>
</tbody>
</table>

If adopted, health IT developers will need to update their certified health IT to support the USCDI for all certification criteria affected by this change.
Common Clinical Data Set → U.S. Core Data for Interoperability
Clinical Notes *NEW
- Consultation Note
- Discharge Summary Note
- History & Physical
- Imaging Narrative
- Laboratory Report Narrative
- Pathology Report Narrative
- Procedure Note
- Progress Note

Goals
- Patient Goals
Apple Gets Into Healthcare

Health Data

- Activity
- Mindfulness
- Nutrition
- Sleep
- Body Measurements
- Health Records

Cancel Search

Search

- Partners HealthCare
  - Partners Healthcare
  - Boston, Massachusetts
- Northampton Health Center
  - Valley Medical Group
  - Florence, Massachusetts
- Yale New Haven Hospital
  - Yale New Haven Health
  - New Haven, Connecticut
Apple Gets Into Healthcare

Health Data

Health Records

<table>
<thead>
<tr>
<th>All Records</th>
<th>218</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allergies</td>
<td>0</td>
</tr>
<tr>
<td>Clinical Vitals</td>
<td>44</td>
</tr>
<tr>
<td>Conditions</td>
<td>2</td>
</tr>
<tr>
<td>Immunizations</td>
<td>7</td>
</tr>
<tr>
<td>Lab Results</td>
<td>159</td>
</tr>
<tr>
<td>Medications</td>
<td>3</td>
</tr>
<tr>
<td>Procedures</td>
<td>3</td>
</tr>
</tbody>
</table>

Jun 14, 2017
Partners HealthCare

Blood Pressure
Collected

Systolic blood pressure 94 mmHg

Diastolic blood pressure 61 mmHg

Weight
Amazon, Google, IBM, Microsoft, Oracle and Salesforce pledge to remove interoperability barriers

At the White House, technology heavy-hitters promise to work together improving data exchange by embracing FHIR, the Argonaut Project and more.

By Tom Sullivan | August 13, 2018 | 02:08 PM
Who is in the Game?
So what’s the problem?

• Flipping the switches enabling the OpenNotes functionality is necessary, but not sufficient!

• The nation may mandate spread, but that’s not the same as assuring scale!
Very early findings in 2018

- 26 Organizations reported data (24 Epic, 2 homegrown systems). Other vendors could not report.

<table>
<thead>
<tr>
<th># of organizations</th>
<th>Range of note opening rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>21-34%</td>
</tr>
<tr>
<td>8</td>
<td>6-10%</td>
</tr>
<tr>
<td>14</td>
<td>0.27-5%</td>
</tr>
</tbody>
</table>

White Paper – Implementing OpenNotes: Improving Access to Notes on Patient Portals
Early inferences...

- **Ease of navigation** likely crucial. The fewer the clicks, the higher the note opening rates (so, what’s new?)
- **Communication** efforts help, but impact unclear so far
- **Reminders** to read notes are likely powerful, but details matter
- **Cellular device access** is important
Final Questions

- How can we avoid “checkboxitis?”
- What counts as success?
Questions?

Thank you!