Open Notes: Toward a New Standard of Care

Transforming Health Care through Technology
Vermont Information Technology Leaders, Inc.
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Agenda

1. The original study of open notes in primary care
2. Open notes beyond primary care
3. Implementation considerations
4. Discussion
What are open notes?

Open notes are visit notes that patients can access online through patient Internet portals.
Welcome to mychart

mychart offers Bon Secours patients personalized and secure online access to portions of their medical records. It enables you to securely use the Internet to manage and receive information about your health - online, any time! mychart is a free service offered to Bon Secours patients.

With mychart, you can use the Internet to:
- Communicate with your doctor
- Request medical appointments
- View your health summary from the mychart electronic health record
- Access your test results
- Request prescription renewals
- View your recent doctor’s visits

How do I sign up?

Bon Secours patients who wish to participate will be issued a mychart activation code during their doctor’s visit. This code will enable you to login and create your own user ID and password.

About the OpenNotes Study

- 1-year Demonstration Project  summer 2010 – summer 2011
- Patients invited to view their PCPs’ signed notes via secure portals (only notes signed during the project – not retroactive)
- Each patient notified automatically via secure e-mail message when a note was signed, and later reminded to review note(s) before next visit
- Patients and doctors completed surveys before and after, and we collected administrative data (portal clicks, e-mail volume)

*Primarily funded by the Robert Wood Johnson Foundation*
Three Principal Questions

- Would OpenNotes help patients become more engaged in their care?
- Would OpenNotes be the straw that breaks the doctor’s back?
- After 1 year, would patients and doctors want to continue?
108 volunteer PCPs and more than 19,000 of their patients who use portals:

- BIDMC (urban and suburban Boston)
  39 PCPs & 10,300 patients

- Geisinger Health System (rural Pennsylvania)
  24 PCPs & 8,700 patients

- Harborview Medical Center (inner city Seattle)
  45 PCPs & 270 patients (new portal)
PCPs’ Concerns and Experiences
# Expectations

## Baseline Surveys

<table>
<thead>
<tr>
<th>% who think</th>
<th>Nonparticipating PCPs (%)</th>
<th>Participating PCPs (%)</th>
<th>Patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open notes is a good idea</td>
<td>25</td>
<td>76</td>
<td>95</td>
</tr>
<tr>
<td>Patients will better understand their health and medical conditions</td>
<td>53</td>
<td>85</td>
<td>92</td>
</tr>
<tr>
<td>Patients will worry more</td>
<td>90</td>
<td>51</td>
<td>14</td>
</tr>
<tr>
<td>Patients will find notes more confusing than helpful</td>
<td>76</td>
<td>48</td>
<td>11</td>
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</table>
### PCPs’ Main Concerns

Changes in workflow

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention (%)</th>
<th>Post-intervention (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visits significantly longer</td>
<td>24</td>
<td>2</td>
</tr>
<tr>
<td>More time addressing patient questions outside of visits</td>
<td>42</td>
<td>3</td>
</tr>
<tr>
<td>More time writing/editing/dictating notes</td>
<td>39</td>
<td>11</td>
</tr>
</tbody>
</table>

E-mail message volume did not change
### PCPs’ Main Concerns
Changes in documentation

<table>
<thead>
<tr>
<th>Changed the way they addressed:</th>
<th>Pre-intervention (%)</th>
<th>Post-intervention (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer/possibility of cancer</td>
<td>27</td>
<td>15</td>
</tr>
<tr>
<td>Mental health issues</td>
<td>43</td>
<td>24</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>38</td>
<td>19</td>
</tr>
<tr>
<td>Overweight/obesity</td>
<td>19</td>
<td>16</td>
</tr>
</tbody>
</table>
Comments from Doctors

- My fears: Longer notes, more questions, and messages from patients. In reality, it was not a big deal.

- I felt like my care was safer, as I knew that patients would be able to update me if I didn't get it right.

- I felt great about partnering with my patients, and the increased openness.

- Patients should not have access to their notes. The note already serves far too many purposes such as billing, research, etc, and adding one more is not a good idea. They are not intended as a vehicle for patient communication.
Patients’ Experiences
Among Patients with Notes (Visits)

- 82% of patients opened at least one of their notes
- Including patients who were older, sicker, less educated
- Few patients said reading notes made them feel
  - Worried (5-8%)
  - Confused (2-8%)
  - Offended (1-2%)
- 20-42% of patients reported sharing notes with others
- 60% wanted to comment on their notes
About 3 out of 4 patients reported:

- taking better care of themselves
- understanding their health and medical conditions better
- feeling more in control of their care
- feeling better prepared for visits
- doing better with taking their medications as prescribed
Comments from Patients

- I’d been taking losartan for a while ... but not really accepted the fact that I needed it. There wasn’t anything in the note that we hadn’t discussed, but to see it in writing just made a big impact.

- In his notes, the doctor called me "mildly obese." ... I’m determined to reverse that comment by my next check-up.

- If this had been available years ago I would have had my breast cancer diagnosed earlier. A previous doctor wrote in my chart and marked the exact area but never informed me. This potentially could save lives.

- It really is much easier to show my family who are also my caregivers the information in the notes than to try and explain myself ... they allow my family to understand what is actually going on, not just what my memory decides to store.
Comments from Patients

- Reviewing the notes I SEE why I need to lose weight. I cut the notes out of KP.org and posted in my kitchen. I DO NOT WANT TO BE A DIABETIC and this is in my face. It feels like my Doctor really cares about my health, I never knew that.

- I told my doctor I ran every day and now I think he knows I REALLY DON'T. This may hold me more accountable to myself and my doctor.

- LOVE the new feature on MU Healthe to view our doctors notes. Makes me feel informed and less worried about my condition – very comforting. Thank you!

- I want to be a partner. I don’t want the doctors to have access to things I don’t. I want to know.
The Bottom Line for PCPs

After a year, PCPs were asked whether:

*Taking all considerations into account, would you like your patients to continue to be able to see your visit notes online?*

- About 3 out of 4 said YES

- Even though some said NO: at the trial’s end, not one doctor asked to turn it off for their patients.
The Bottom Line for Patients

After one year, 99% of patients wanted to continue to be able to see their visit notes online.

When given a choice of doctors or health plans in the future: 4 out of 5 patients said availability of open notes would impact their choice of provider.
All 3 sites decided to expand OpenNotes

- Geisinger: 1,400 ambulatory doctors/NPs/PAs, and 200,000 patients

- Harborview: all UW primary and specialty clinics

- BIDMC: All clinicians' notes, vast majority of ambulatory clinicians
More than 5 million patients have easy access to their clinicians’ notes thanks to OpenNotes.
Guest and Quincy. Consumers gaining ground in health care. *JAMA*, 2013

<table>
<thead>
<tr>
<th>Source</th>
<th>Title</th>
<th>Date</th>
<th>Author(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Economist</td>
<td>More Patients are Getting to Read Their Doctors’ Scribblings</td>
<td>July 26, 2014</td>
<td>By Roger McShane</td>
</tr>
<tr>
<td>The Wall Street Journal</td>
<td>Health-Care Providers Want Patients to Read Medical Records, Spot Errors</td>
<td>June 9, 2014</td>
<td>By Laura Landro</td>
</tr>
<tr>
<td>The Washington Post</td>
<td>Boston Hospital Pilot Gives Patients Electronic access to Their Therapists’ Notes</td>
<td>May 18, 2014</td>
<td>By Lena H. Sun</td>
</tr>
<tr>
<td>JAMA</td>
<td>Let’s Show Patients Their Mental Health Records</td>
<td>April 2, 2014</td>
<td>By Michael W. Kahn, MD; Sigall K. Bell, MD; Jan Walker, RN, MBA; Tom Delbanco, MD</td>
</tr>
<tr>
<td>U.S. News and World Report</td>
<td>OpenNotes Helps Keep Patients Informed and Engaged</td>
<td>February 4, 2014</td>
<td>By Neil Versel</td>
</tr>
<tr>
<td>The New England Journal of Medicine</td>
<td>The Road toward Fully Transparent Medical Records</td>
<td>January 2, 2014</td>
<td>By Jan Walker, RN, MBA; Jonathan D. Darer, MD, MPH; Joann G. Elmore, MD, MPH; Tom Delbanco, MD</td>
</tr>
<tr>
<td>JAMA</td>
<td>Consumers Gaining Ground in Health Care</td>
<td>November 13, 2013</td>
<td>By James A. Guest, JD; Lynn Quincy, MA</td>
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</table>
Caregivers
Mental health
The note becomes part of the treatment

Let's Show Patients Their Mental Health Records

Should we health professionals encourage patients with mental illness to read their medical record notes? As electronic medical records and secure online portals proliferate, patients are gaining ready access not only to laboratory findings but also to clinicians’ notes. Primary care patients report that reading their doctors’ notes brings many benefits including greater control over their health care, and their doctors experience surprisingly few changes in workflow. While patients worry about electronic records and potential loss of privacy, they vote resoundingly for making their records more available to them and often to their families.

As consumers urge that fully open medical records become the standard of care, policy makers, clinicians, and patients advocate also that mental illness gain far more attention and support. Primary care physicians and medical and surgical subspecialties have long managed many patients with mental illness, but with the exception of the Department of Veterans Affairs, most systems implementing open records continue to carve out from patients’ view “behavioral health” notes written by psychiatrists, psychologists, and social workers. We believe that such exclusions are unnecessary.

Inviting patients to read what clinicians write about their feelings, thoughts, and behaviors does more than expose the tendency to use ‘black-or-white-thinking’ in ways that make her relationships at work problematic. “Mr Smith and I continue to ‘agree to disagree’ about his conviction that his apartment is bugged.” Ms Williams expressed dissatisfaction with my treatment decisions quite clearly, but preferred not to talk about that today. I encouraged her to discuss our disagreements in the future.

This approach—descriptive, nonjudgmental summarizing—can help with documenting many potentially value-laden subjects. A patient’s addiction to Internet pornography may be deeply troubling, and his doctor or social worker would be justifiably worried about shaming him further by documenting it. This might be noted as “Mr Martin and I continued our discussion of his addictive behavior and reviewed techniques for dealing with it.” This principle can also be applied to a variety of sensitive topics, including psychodynamic issues. The medical record should offer a practical synopsis of a patient’s history and treatment, but it does not need to contain an exhaustive catalog of vulnerabilities.

Caring for patients with substance abuse provides fertile ground for conflict, but here too reading the clinical notes is likely to give the patient and doctor the useful information needed to inform the interplay of these factors.
Patient Safety
## Not one size fits all

<table>
<thead>
<tr>
<th>Health System</th>
<th>Cleveland Clinic</th>
<th>BIDMC</th>
<th>Boston Children's</th>
<th>Geisinger</th>
<th>KP Northwest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Push notifications to patients about note availability</td>
<td>No</td>
<td>Yes</td>
<td>Soon</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Patients on portal</td>
<td>600,000</td>
<td>100,000</td>
<td>30,000</td>
<td>220,000</td>
<td>270,000</td>
</tr>
<tr>
<td>Track note look-ups (% opened)</td>
<td>No</td>
<td>Yes (63%)</td>
<td>Soon</td>
<td>Turned off, then back on</td>
<td>Soon</td>
</tr>
<tr>
<td>% of notes hidden</td>
<td>&lt;2%</td>
<td>0.18%</td>
<td>Pending</td>
<td>Pending</td>
<td>&lt;0.2%</td>
</tr>
<tr>
<td>Adolescent access</td>
<td>No</td>
<td>N/A</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Mental health notes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

(last updated 2014)
Once You Decide to Open Notes .. Some Decisions

- Which clinicians
  - Nurses and other non-MD clinicians?
  - Behavioral health?
  - Students and trainees?

- Which notes
  - Options for clinicians to hide individual notes?

- Which patients
  - Can a clinician exclude patient?
Once You Decide to Open Notes .. Some Decisions

- Big bang or phased rollout
  - Phased by department

- Opt-in or opt-out
  - Mandatory for clinicians?
  - Chief’s permission to opt out?
  - Opt in?
Once You Decide to Open Notes .. Importance of Communications

- **Clinicians**
  - It’s a culture change: communicate, communicate

- **Patients**
  - Sometimes overlooked
  - Marketing, media
  - NOTIFICATIONS when notes available
Resources for Adopters

- Visit our website www.myopennotes.org and sign up for the mailing list

- Toolkit for implementers
  - Roadmap and advice about key decisions
  - Sample FAQs for patients and clinicians
  - Communications checklist and sample materials

- Resources for evaluators
  - All open notes surveys are available free of charge
  - Links to all open notes papers are on the website

- Need something else? Contact us:
  - myopennotes@bidmc.harvard.edu
Let’s discuss ..

www.myopennotes.org

contact
myopennotes@bidmc.harvard.edu