OpenNotes Research: Patient Outcomes

Liz Salmi
Original study: 2010

- Research and demonstration project
- **105** PCPs and **20,000** patients in Boston (BIDMC), rural Pennsylvania (Geisinger), and Seattle inner city (Harborview)
- Now replicated at VA, Kaiser, Cedars-Sinai, and many other sites

Delbanco et al, Ann Intern Med 2012

#OpenNotes
Original study: Patient results

✓ 80% read a note initially
✓ 50-60% regularly read notes long term
✓ 75% reported benefits (replicated multiple times) in engagement, adherence, planning, control, understanding
✓ 99% wanted to continue (replicated multiple times)
✓ 85% would use open notes as criterion for selecting providers

Delbanco et al, Ann Intern Med 2012
#OpenNotes
People who read notes...

• Have a better understanding of their health and medical conditions
• Better recall and follow their care plan
• Feel more in control of their health
People who read notes...

- Take better care of themselves
- **Do a better job taking medications as prescribed**
- Can identify inaccuracies in the record and **play a role in the safety of care**
People who read notes...

• **Feel comfortable** sharing notes with care partners and others involved in their care

• **Can communicate more clearly**, helping to strengthen the partnership between themselves and their health care team
“Weeks after my visit, I thought, *Wasn't I supposed to look into something?* I went online immediately. Good thing! It was a precancerous skin lesion my doctor wanted removed (I did).”

-- patient
Doctor-patient relationship

- **99%**
  
  Patients felt better (37%)* or the same (62%) about their doctor after reading ≥1 note.
  
  *Older, non-Caucasian patients, with poorer health, lower formal education were more likely to feel better about the doctor.

- **>50%**
  
  Doctors believed shared notes increased patient satisfaction and trust.

- **7%**
  
  Patients reported contacting their doctor about concerns in their note.
  
  Of those who did, 29% reported a perceived error; 85% were satisfied with its resolution.

- **0%**
  
  Doctors reported ordering more tests or referrals.
Older, non-Caucasian patients, with poorer health, and lower formal education... more likely to feel better about their doctor when reading notes.
Why people read notes

<table>
<thead>
<tr>
<th>Reason (multiple permitted)</th>
<th>Frequency, % (n=4592)</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>

A moderate proportion of patients reading notes may already be engaged as safety partners…
“In his notes, the doctor called me mildly obese. This prompted immediate enrollment in Weight Watchers and daily exercise. I’m determined to reverse that comment by my next check-up.”

-- patient
Safety catches by patients with open notes

- Pulmonary nodule follow up recommendation found by patient
- **Wrong provider** listed on colonoscopy report (results reaching wrong doctor)
- Note reports “new lesions” on MRI (but these are **old information**)
- Hyperthyroidism listed rather than hypothyroidism (**caregiver** catches)
- **Inaccurate** medication lists
- Family **history incorrect**/not updated
- “No malignancy” written as “Now malignancy” (**typos**)
- “Patient declined PSA testing” when in fact he wanted it done
- Note states plan for cardiac testing or lab work but **no requisition/referral**
- “Wrong side” documentation
- Patient misidentification
- (“Actually, I don’t agree with the plan!”)

#OpenNotes
“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.”

-- patient

#OpenNotes
“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. I find the notes more accurate than my recollections, and they allow my family to understand what is actually going on with my health, not just what my memory decides to store.”

-- patient
What can patients do?
Patient/Family advisor roles

- **Advocate** for OpenNotes
- **Spread the word** to connections – either have OpenNotes or speak up for OpenNotes
- **Involve** in designing and developing OpenNotes (many decisions to be made before implementation – need patient/family input)
- **Develop outreach and education** materials and efforts
- **Feedback and evaluation** post-implementation
Note viewing over two years at two sites

Notifications to view notes stop at GHS and continue at BIDMC

(95% of Kaiser NW patients want reminders)
Notes are the **most-accessed feature/downloaded** on the Mayo Clinic portal.
“Sometimes I forget what is said to me because it is emotional and it is so nice to be able to go back and read exactly what my doctor was telling me.”

-- Mayo patient
“I like to see my clinical notes. Sometimes it clarifies issues I may be confused about… My lab results are important to keep me aware of my condition and any progression. I'm more involved in my own care.”

-- Mayo patient
93% of patients on the MyCarolinas portal access their notes.
opennotes.org

lsalmi@bidmc.harvard.edu

#OpenNotes