

Peering into the Doctor's Black Box

Early insights from OpenNotes

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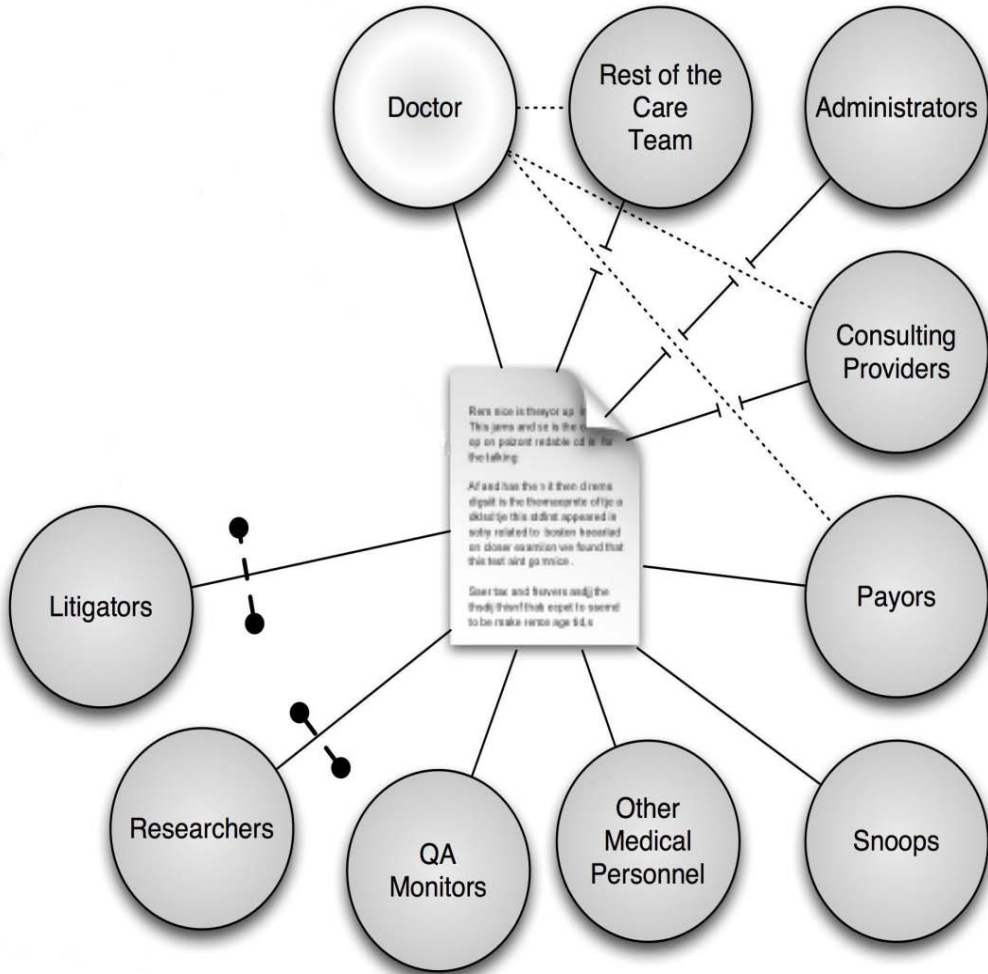
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The Hub of the Wheel: The Patient's Record

- Whose record is it?
- What should it contain?
- Who should write it?
- Who should be able to see it?

The Future...



- Direct Chart Access
- Other Visit Related Communication
- - - ● Regulation/Administrative Barriers

Patient Portals

Starting in the 1960s, open records were proposed, and since the late 1990s, patient portals have proliferated.

Through secure access via the Internet, patients can:

- Review problem lists
- Review medication lists
- Review lab, radiology, and pathology findings
- Request appointments
- Send secure e-mails to their doctors or other personnel
- Receive broadcast messages

But until now, no access to their doctors' visit notes

...a collaborative



Jan Walker, RN, MBA, and more than 20 colleagues at BIDMC, Geisinger Health System, U Washington, Group Health, U Colorado...

www.myopennotes.org

“Nothing about me without me.”

(Delbanco, Berwick et al, Health Expect, 2001)

What is OpenNotes?

- Patients invited to review their doctors' visit notes through secure patient portals
- Each patient notified automatically via secure e-mail message when a note has been signed...and reminded to review it before their next scheduled visit
- Research and demonstration project that started in the summer of 2010, involving more than 100 PCPs and 20,000 patients in Boston (BIDMC), rural Pennsylvania (Geisinger), and the Seattle inner city (Harborview)

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3 Overall Questions

- Does OpenNotes help patients become more engaged in their care?
- Is OpenNotes the straw that breaks the doctor's back?
- After living with this transparency, do patients and doctors want to continue?

PCPs ' Experiences

Principal Concerns of 105 Participating PCPs

Impact on workflow

	Expectations (%)	Post-intervention (%)
Visits significantly longer	24	2
More time addressing patient questions outside of visits	42	3
More time writing/editing/dictating notes	39	11

...and, compared to the year preceding the intervention, the volume of electronic messages from patients did not change

Principal Concerns of 105 Participating PCPs

Impact on documentation

Changed the way they addressed:	Expectations (%)	Post-intervention (%)
Cancer/possibility of cancer	27	15
Mental health issues	43	24
Substance abuse	38	19
Overweight/obesity	19	16

Patients' Behaviors and Reports

Among Patients with Notes (visits)

- 82% of patients opened at least one of their notes
- 1-8% of patients across the 3 sites reported that the notes caused confusion, worry, or offense
- 20-42% shared notes with others

Reports from Patients

- 70-72% of patients across the 3 sites reported taking better care of themselves
- 77-85% reported better understanding of their health and medical conditions
- 76-84% reported remembering the plan for their care better

Reports from Patients

- 69-80% felt better prepared for visits
- 77-87% felt more in control of their care
- ...*and*, among those taking medications, 60-78% reported “doing better with taking my medications as prescribed.”

The Bottom Line for PCPs

After a year of experience with OpenNotes, PCPs were asked:
Taking all considerations into account, I would like my patients to continue to be able to see my visit notes online.

Some said no:

26% of BIDMC PCPs

17% of GHS PCPs

19% of HMC PCPs

But, when offered the option of turning off open notes at the end of the year-long intervention, not one doctor asked to do so.

The Bottom Line for Patients

After one year,

99% of BIDMC patients

99% of GHS patients

99% of HMC 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,

86% of BIDMC patients

85% of GHS patients

89% of HMC patients

said availability of open notes would have an important effect on their decisions.

OpenNotes is Like a New Medicine...

- It aims to make people better, has side effects, and may hurt some patients
- Doctors and patients will need to learn how to use it effectively
- It's expensive now, but the price should come down (Will insurance cover it?)
- It may even become *standard of care* (with room for some exceptions)

Transparency Makes Headlines (the horse is out of the barn)

Findings in the Annals of Internal Medicine, followed by:

- The New York Times
- Wall Street Journal
- Time Magazine
- Fox News
- Reuters
- Associated Press
- NPR
- Science Friday
- Newsweek
- LA Times
- MSNBC
- CBS
- ABC News
- Seattle Times
- iHealthBeat
- Here and Now

The Inexorable Rise of Online Access and Transparency

BIDMC, Geisinger, Harborview, and...

VA Blue Button, MD Anderson, Mayo Clinic...

Consumers:

- “I don’t know if I want to read my entire medical record, but I want to have it.”
- ONC direct-to-consumer promotion of HIT
- Give Me My DaM Data

Prediction: Consumer pressure will intensify...

Where may OpenNotes take us?

Some clues...

- 30-40% of patients wanted to be able to approve what is written in a note
- 59-62% of patients wanted the ability to add comments to their notes
- 49-56% of patients wanted patient proxies to have access
- 86-88% of patients wanted access to inpatient notes

...and implications

- Integral to a PCMH...and ACO
- A new type of peer review
- Education of emerging health professionals
- A special role for nursing
- Patients and families contributing to safety
- Better use of resources
- A therapy for caregivers
- And Facebook, tweets, chat rooms...

...and further ahead

- Patients and doctors share in negotiating, generating, and signing the note
- Virtual visits, with notes initiated by patients
- Co-generated notes as individual quality contracts, along with metrics for assessing both patient and clinician performance

Thank you!



www.myopennotes.org

Comments from Patients...

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).

In his notes, the doctor called me "mildly obese." This prompted immediate enrollment in Weight Watchers and daily exercise. I didn't think I had gained that much weight. **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. **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.

Baseline Surveys

Take a guess...

% who think	Nonparticipating PCPs (%)	Participating PCPs (%)	Patients (%)
Open notes is a good idea	25	76	95
Patients will better understand their health and medical conditions	53	85	92
Patients will worry more	90	51	14
Patients will find notes more confusing than helpful	76	48	11

...and patients who are older, or less educated, or sicker