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# Lessons from the OpenNotes Program

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## About the OpenNotes Study

- Demonstration project Summer 2010 – Summer 2011 (and still ongoing)
- 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 reminded to review it before next scheduled visit
- Collected administrative data (portal clicks, email volume) and surveyed doctors and patients

## 3 Questions

- Does OpenNotes help patients become more engaged in their care?
- Will OpenNotes negatively affect doctors' workflow?
- After 1 year, will patients and doctors want to continue?

# Participants

108 volunteer PCPs and almost 20,000 of their patients who use portals participated for 12 months

- BIDMC
  - 39 PCPs
  - 10,300 patients
- Geisinger Health System, Pennsylvania
  - 24 PCPs
  - 8,700 patients
- Harborview Medical Center, Seattle
  - 45 PCPs
  - 270 patients (new portal)

# PCPs' Experience

# PCPs' Main Concerns

## OpenNotes impact on workflow

	Pre-intervention	Post-intervention
	% BIDMC / GHS / HMC	% BIDMC / GHS / HMC
Visits significantly longer	23 / 32 / 21	3 / 5 / 0
More time addressing patient questions outside of visits	49 / 45 / 34	8 / 0 / 0
More time writing/editing/dictating notes	46 / 36 / 34	21 / 14 / 0

...and the volume of electronic messages from patients did not change

# PCPs' Main Concerns

## OpenNotes impact on patients

	Pre -intervention % BIDMC / GHS / HMC	Post-intervention % BIDMC / GHS / HMC
PCPs think patients who read their notes will:		
Find notes more confusing than helpful	48 / 54 / 43	13 / 21 / 12
Worry more	50 / 58 / 45	15 / 42 / 12
Feel offended	33 / 8 / 29	18 / 8 / 2

# PCPs' Main Concerns

## OpenNotes impact on documentation

	Pre-intervention % BIDMC / GHS / HMC	Post-intervention % BIDMC / GHS / HMC
Changed the way they addressed:		
Cancer/possibility of cancer	33 / 18 / 26	26 / 18 / 3
Mental health issues	44 / 27 / 53	36 / 27 / 11
Substance abuse	38 / 32 / 42	28 / 23 / 8
Overweight/obesity	18 / 18 / 21	33 / 5 / 5



# Patients' Experience

## Among Patients with Notes (Visits)

- 82% of patients opened at least one of their notes
- Few patients said reading notes made them
  - Worried (5-8%)
  - Confused (2-8%)
  - Offended (1-2%)
- 20-42% of patients reported sharing notes with others

# Reports from Patients

## Post Intervention

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

Comments  
and  
The Bottom Line

# Doctors' Comments

I had to have **better documentation**, which is a good thing.

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

For me the most difficult thing was having to be **careful about tone** and phrasing of the notes knowing the patient would be reading them.

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 also 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' Comments

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.

## 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

On the other hand, 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.



# The Bottom Line for Institutions

- All 3 sites decided to expand OpenNotes
  - Geisinger and Harborview: doctors in most ambulatory practices
  - BIDMC: all clinicians who sign notes
- Also MD Anderson Cancer Center, Mayo Clinic, Veterans Administration, Group Health
- More coming: transparency is here to stay

## Future Directions ..

- Project team's next focus areas
  - Implementation: amending notes, excluding patients/notes
  - Can patients report errors
  - OpenNotes for caregivers
  - Impact of OpenNotes on NURSES, social workers, PTs, clinical pharmacists, PAs, other clinicians
- How will OpenNotes change nursing practice, particularly in ambulatory care?
- Opportunities for nursing informatics? Augment other innovations being developed?

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*Thank you!*



[www.myopennotes.org](http://www.myopennotes.org)

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# The Inexorable Rise of Online Access and Transparency

Retailing

Consumer finance and banking

Health care becoming more transparent: lab results,  
open disclosure, patient portals, VA Blue Button

Consumers:

- “I don’ t know if I want to read my entire medical record, but I want to have it.” (focus group participant)
- ONC direct-to-consumer promotion of HIT
- Give Me My DaM Data (e-Patient Dave)
- Consumer pressure will only intensify!