



# Give Me My Health Records!

## OpenNotes: Status Update

Homer Chin, MD, MS

Associate, OpenNotes, Beth Israel Deaconess Medical Center

Emeritus Physician, Kaiser Permanente Northwest

Affiliate Professor, Oregon Health & Science University

Board Member, OCHIN

Physician-Computer Connection Symposium

AMDIS

Ojai, California

June 2017

# Agenda

- **OpenNotes:**
  - Clinician Worries vs. Actual
- **OpenNotes:**
  - Patient impact
- **Status of OpenNotes**
- **HIPAA regulations**
- **Check-List and Resources for Implementation**
- **Discussion**

# What is OpenNotes?

- **“OpenNotes” is simply giving patients’ access to their EHR notes via the internet. Not a specific vendor product or software.**
- Started with a research and demonstration project in 2010, involving more than 100 PCPs and 20,000 patients in Boston (BIDMC), rural Pennsylvania (Geisinger), and the Seattle inner city (Harborview)

*\*Supported by the Robert Wood Johnson Foundation*

# Principal Concerns of 105 Participating PCPs

## Impact on workflow

|  | Expectations<br>(%) | Post-<br>intervention<br>(%) |
|--|---------------------|------------------------------|
| 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

*Adapted from a presentation by: Tom Delbanco, MD, MACP and Jan Walker, RN, MBA  
Harvard Medical School and Beth Israel Deaconess Medical Center*

# Reports from Patients

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% “taking better care of themselves”
- 77-85% “better understanding of their medical conditions”
- 76-84% “remembering the plan for their care better”
- 69-80% “better prepared for visits”
- 77-87% “more in control of their care”
- 60-78% “doing better with taking my medications as prescribed.”

# The Bottom Line

- 99% of patients *wanted to continue* to be able to see their visit notes online
- 85% of patients said availability of open notes *would affect their future choice* of providers
- *Not one doctor asked to stop*
- All 3 institutions *expanded the practice widely*

# Patient Safety





# Patient Safety Anecdotes

**Delayed diagnosis:** 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. — A patient

**Medication error:** When I told her about [the wrong issues] she admitted she confused me with another pt. Also on one occasion she made a statement about *increasing the dose on a medication that I never took*. — A patient

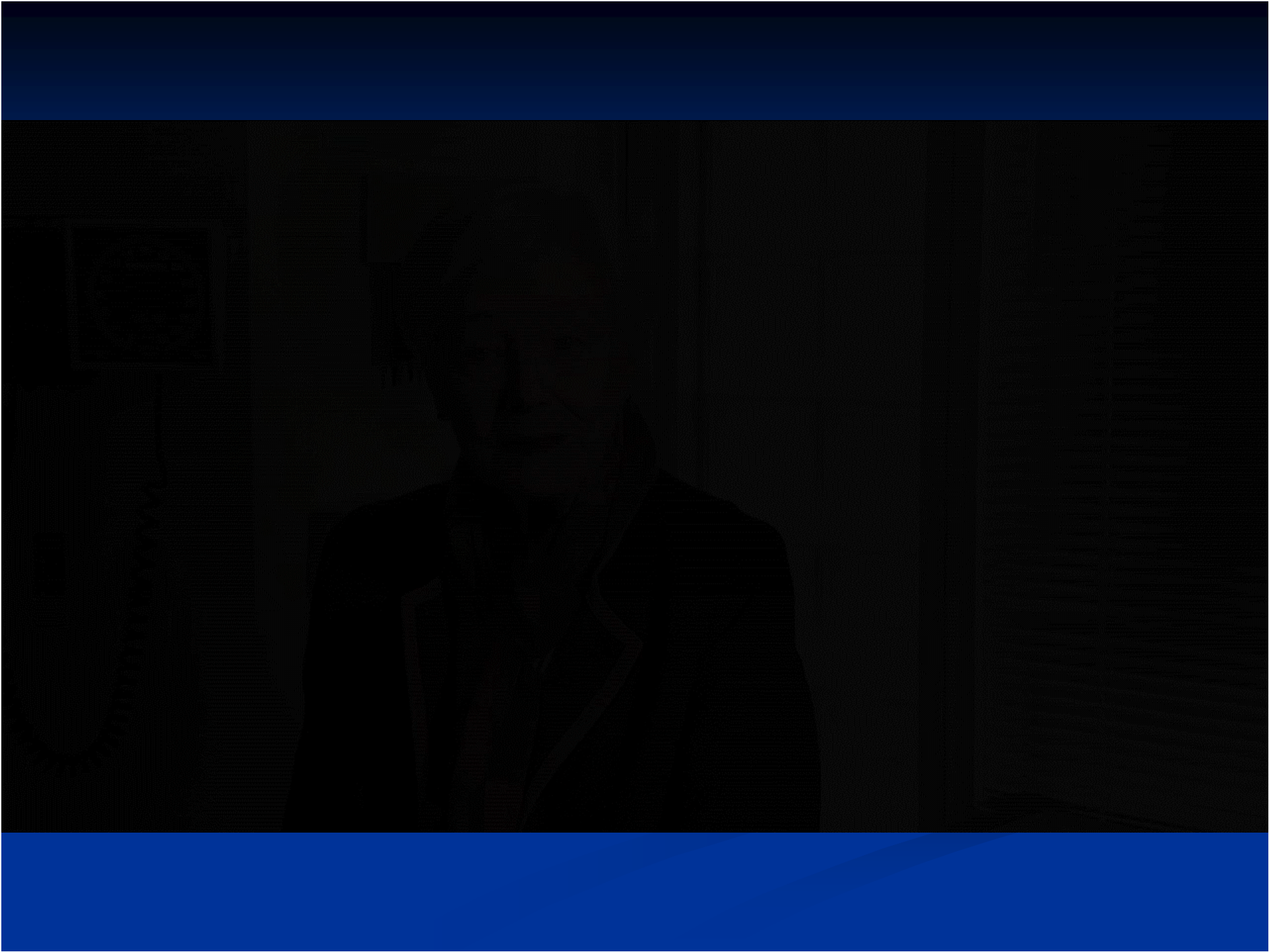
**Follow up adherence:** Weeks after my visit, I thought, "Wasn't I *supposed to look into something?*" I went online immediately. Good thing! It was a precancerous skin lesion my doctor wanted removed (I did). — A patient

**Informal caregivers:** "*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." — A patient

**More eyes on the chart:** *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. — A doctor

# Caregivers and Vulnerable Populations



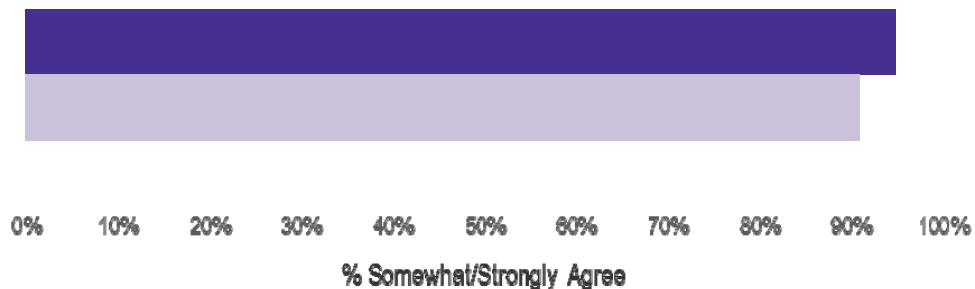


# Participants Report Notes are Accurate & Easy to Understand

“My notes are accurate”



“I can understand my notes”



# OpenNotes

**A New Medicine  
that brings  
benefits... and risks**

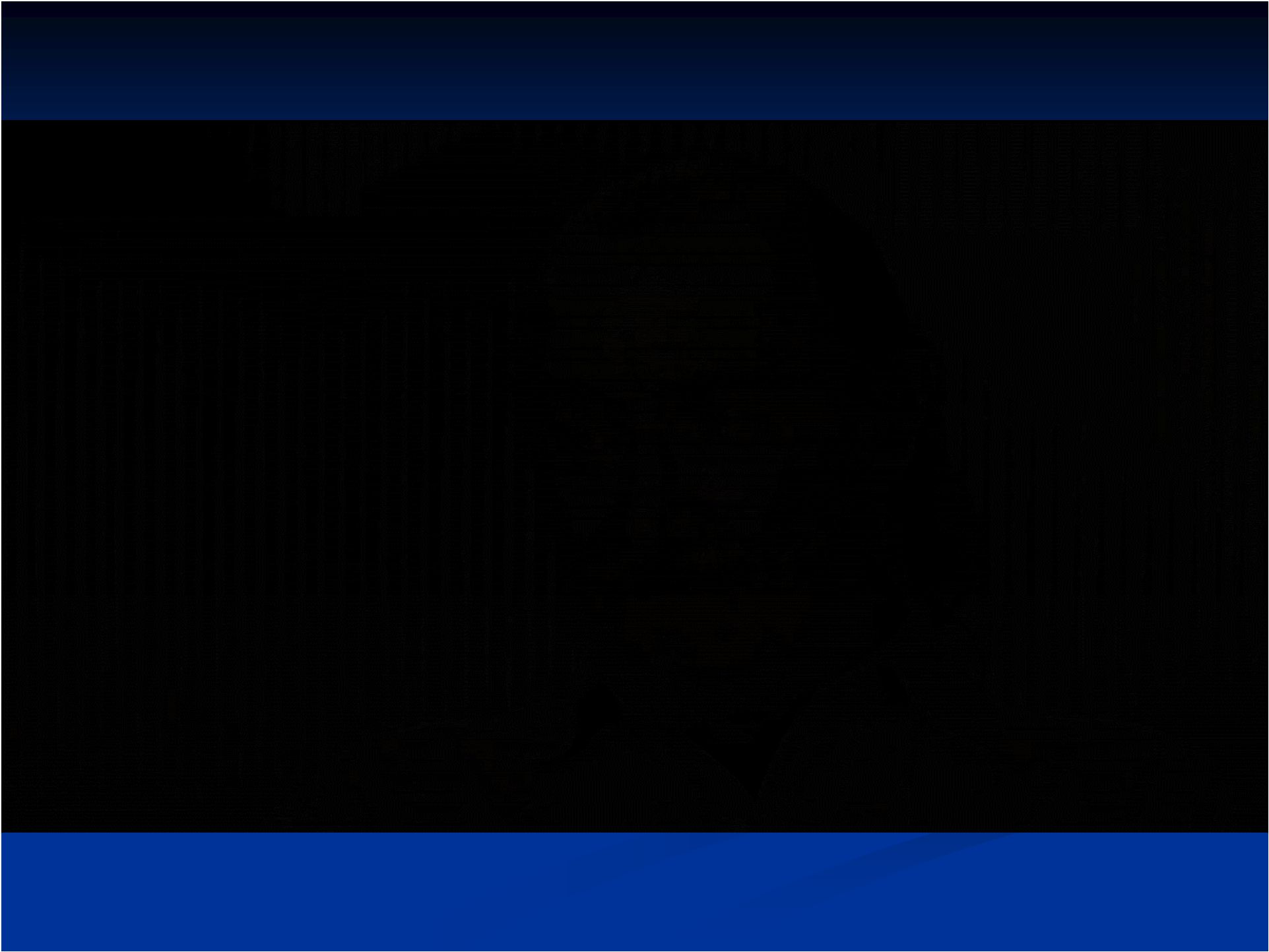


**A catalyst for  
change...and not only  
in ambulatory care**



**Patient Safety**







# OpenNotes Team

## BIDMC

- Tom Delbanco, MD
- Jan Walker, RN, MBA
- Cait DesRoches, DrPH
- Sigall Bell, MD
- Hannah Chimowitz, BA
- Brad Crotty, MD, MPH
- Rossana Fazzina, MS
- Leonor Fernandez, MD
- Alan Fossa, MPH
- Macda Gerard, BA
- Danny Karnes, MA
- Kelly Lawman, BS
- Suzanne Leveille, RN, PhD
- Long Ngo, PhD
- Steve O'Neill, BCD, JD
- Deborah Wachenheim, MPP
- Kelly Lawman, BS
- Amanda Norris, MDiv, MTS

## Portland, OR

- Homer Chin, MD, MS
- Amy Fellows, MPH
- John Santa, MD, MPH

## UW

- Joann Elmore, MD, MPH

## Group Health

- James Ralston, MD, MPH

## Geisinger Health

- Rebecca Stametz, MPH, EdD

## UCLA

- John Mafi, MD, MPH

## Patient Safety Team

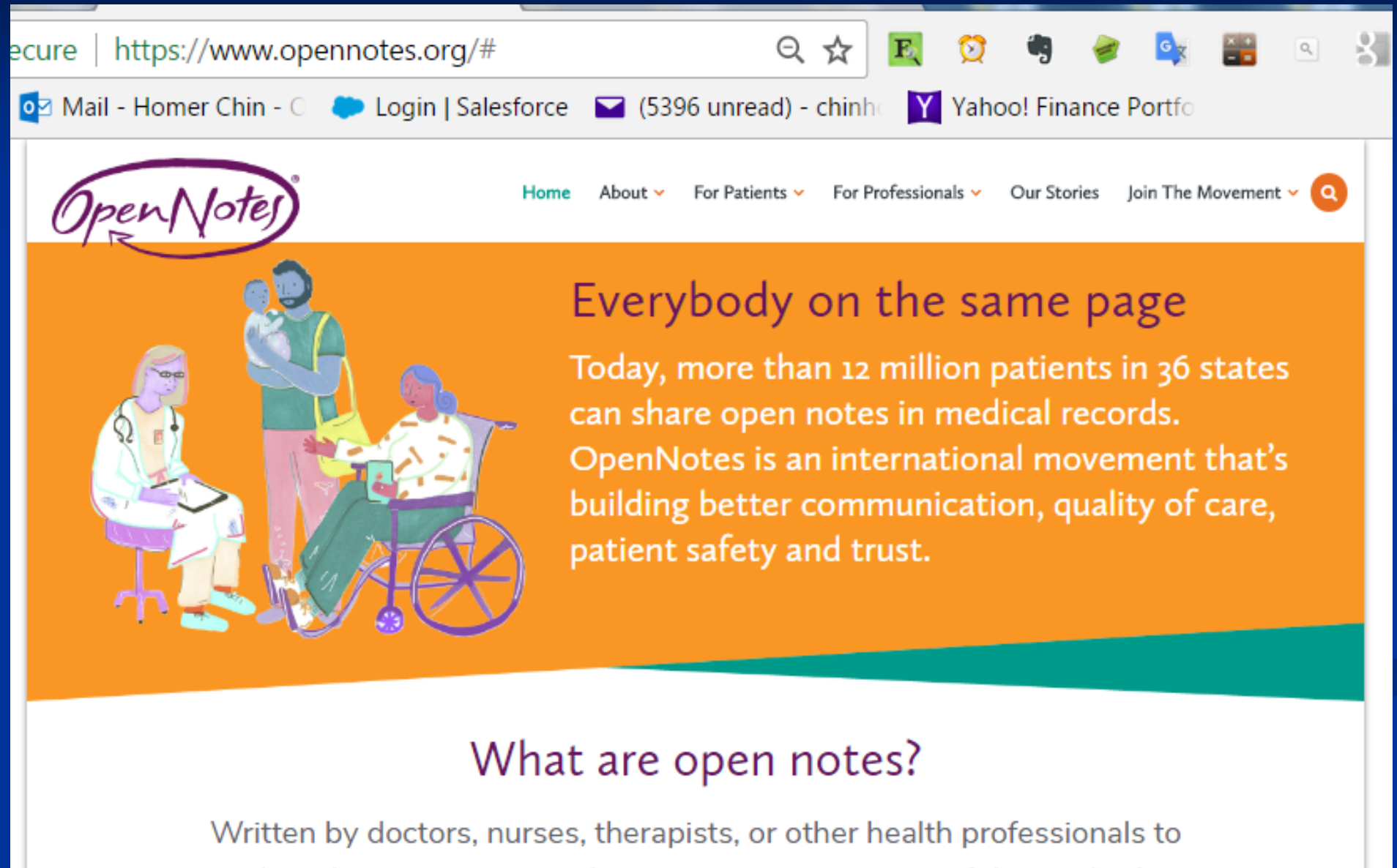
- Pat Folcarelli, RN, PhD
- Heidi Jay
- Lindy Lurie
- Gila Kriegel, MD
- Julia Lindenberg, MD
- Larry Markson, MD
- Roanne Mejilla, PhD
- Caroline Moore, LICSW
- Kenneth Sands, RN
- Barbara Sarnoff Lee, LICSW
- BIDMC PFAC

## **With support from:**

- CRICO/RMF
- Robert Wood Johnson Foundation
- Peterson Center on Healthcare
- Moore Foundation
- Cambia Health
- Oregon OHIT



# Resources: [www.opennotes.org](https://www.opennotes.org)



The screenshot shows a web browser window with the address bar displaying <https://www.opennotes.org/#>. The browser's taskbar at the bottom shows several open applications: Mail - Homer Chin, Login | Salesforce, an email inbox with 5396 unread messages, and Yahoo! Finance Portfolio. The OpenNotes website itself has a purple logo in the top left and a navigation menu with links to Home, About, For Patients, For Professionals, Our Stories, and Join The Movement. A search icon is located on the right side of the navigation bar. The main content area features a large orange banner with the headline "Everybody on the same page" and a sub-headline stating that over 12 million patients in 36 states can now share open notes. An illustration on the left shows a doctor, a man holding a baby, and a woman in a wheelchair, all using mobile devices. Below the banner, the text "What are open notes?" is displayed, followed by a definition: "Written by doctors, nurses, therapists, or other health professionals to..."

Secure | <https://www.opennotes.org/#>

Mail - Homer Chin - Login | Salesforce (5396 unread) - chinch Yahoo! Finance Portfolio

**OpenNotes**

Home About For Patients For Professionals Our Stories Join The Movement

## Everybody on the same page

Today, more than 12 million patients in 36 states can share open notes in medical records. OpenNotes is an international movement that's building better communication, quality of care, patient safety and trust.

### What are open notes?

Written by doctors, nurses, therapists, or other health professionals to



## Implementation

Designed for health professionals learning about open notes, the Implementation Toolkit provides materials to help you gain support in your health system, think through policy decisions and communication materials to prepare for launch, and get the most out of note sharing once you're up and running.

[Download Communications Materials](#)

[OpenNotes logo \(jpg\)](#)

[OpenNotes logo \(png\)](#)

[Letter to Staff about OpenNotes](#)

[Letter to Patients about OpenNotes](#)

[Email to Patients – Your Note is Ready to Read](#)

[Sample Clinic Poster](#)

[Sample Brochure](#)

[Sample Clinic Handout](#)

[Download Presentation Materials](#)

[PowerPoint file](#)

### Tools for implementation

For optimal success, it's critical to communicate with patients, health professionals, administrators, hospital leadership about what open notes are and how they will be implemented, as well as the potential benefits of sharing notes. We've seen that institutions that let patients know about the availability of open notes see substantial increases in portal registration.

*"We often find that clinicians are unaware that their own institution has OpenNotes, and that's only because a communications strategy has not been implemented with the roll out."*

— John Santa, MD, OpenNotes Director of Dissemination

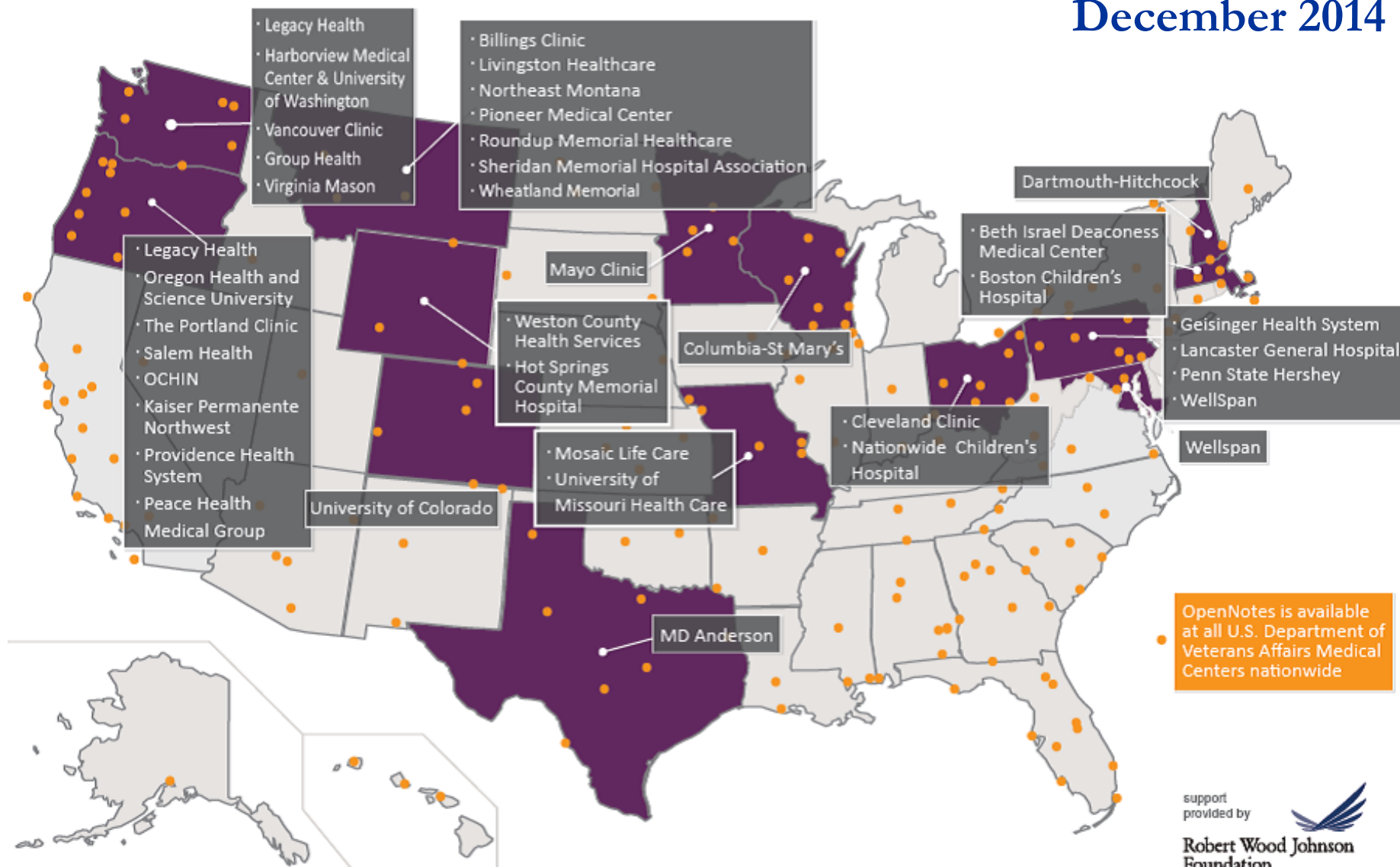
### Communicating with health professionals and other staff about open notes

- Organize grand rounds, town hall meetings, or smaller talks to present data about open notes.
- Identify 'Open Notes Champions' across specialties to help get the word out.
- Share communication from the CEO and other leadership about implementation plans, including data about the benefits of sharing notes.
- Prepare a set of FAQs that answers questions health professionals may have. Feel free to use these [FAQs](#) to start.
- Share OpenNotes materials on your intranet, including research, links to videos,



More than 5 million patients have easy access to their clinicians' notes thanks to OpenNotes

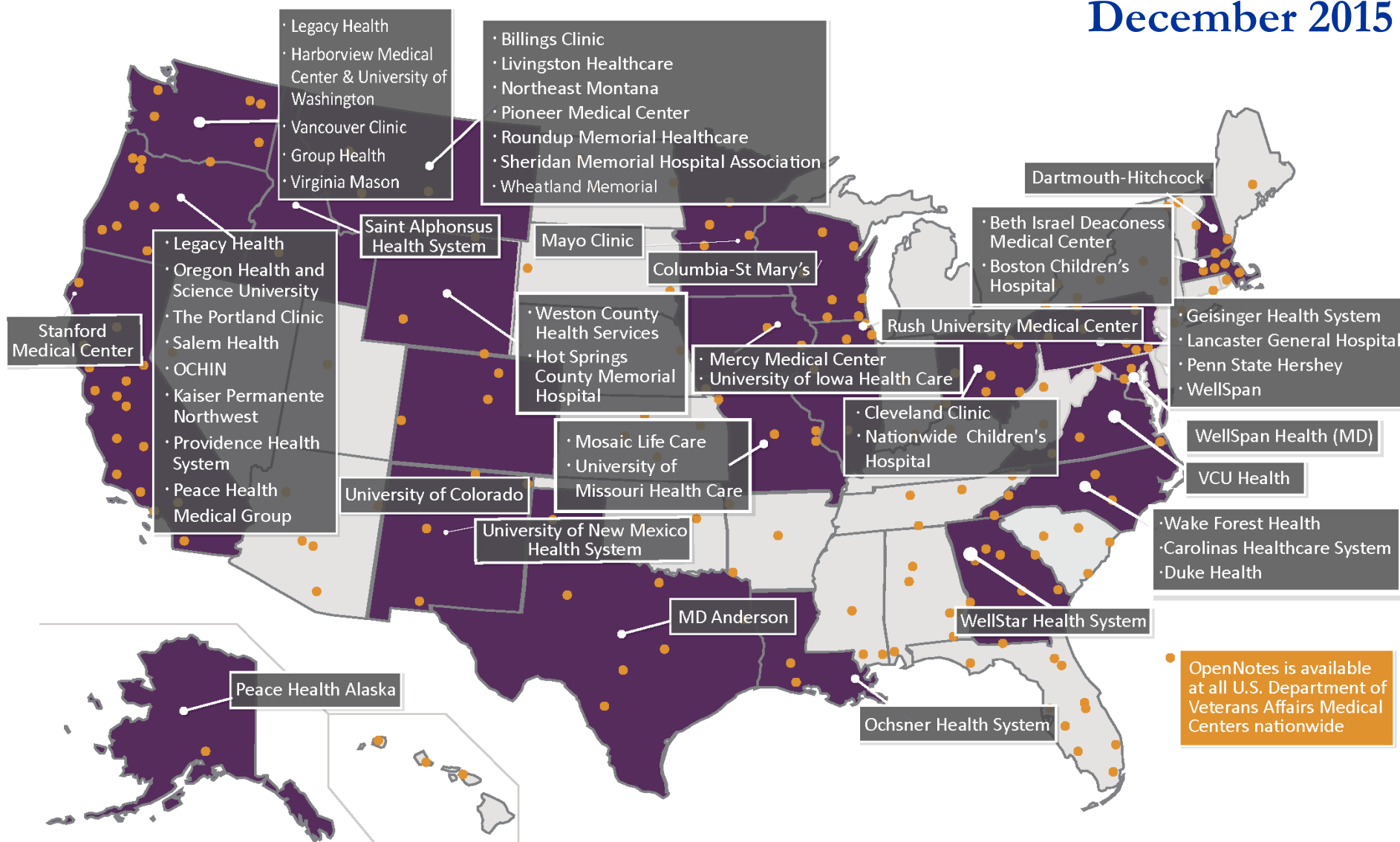
December 2014





More than 7 million patients have easy access to their clinicians' notes

December 2015







# January 2017

Map of the United States showing the locations of OpenNotes participating hospitals and VA Medical Centers as of January 2017. The map is color-coded by region: West (purple), Midwest (blue), South (orange), and Northeast (green). Callout boxes list the names of the participating institutions. An inset map shows Alaska and Hawaii. A legend in the bottom right corner states: "OpenNotes is available at all U.S. Department of Veterans Affairs Medical Centers nationwide".

**West (Purple):**

- Harborview Medical Center & University of Washington
- Vancouver Clinic
- Group Health
- Virginia Mason
- Peace Health Medical Group
- Everett Clinic
- University of Utah Healthcare (NV)
- Stanford Medical Center
- Sutter Medical Foundation
- Open Door Community Health Center
- Oregon Health and Science University
- The Portland Clinic
- OCHIN
- Kaiser Permanente Northwest
- Providence Health & Services
- Samaritan Health Services
- Legacy Health
- Winding Waters Clinic
- Mayo Clinic (AZ)
- Peace Health Alaska

**Midwest (Blue):**

- Billings Clinic
- Livingston Healthcare
- Northeast Montana
- Pioneer Medical Center
- Roundup Memorial Healthcare
- Mayo Clinic
- Sanford Health
- Essentia Health
- Agnesian Healthcare
- Sanford Health (SD)
- Avera Health (SD)
- Sanford Health (NE)
- Avera Health (NE)
- Children's Hospital & Medical Center
- Sanford Health (OK)
- Kansas Health Information Network
- MD Anderson
- Baylor Health Care System
- Texas Health Resources

**South (Orange):**

- Avera Health (ND)
- Columbia-St Mary's
- Fort Health Care
- Mercy Medical Center
- University of Iowa Health Care
- Great River Health Systems
- Covenant HealthCare
- Cleveland Clinic
- Nationwide Children's Hospital
- University of Kentucky Medical Center
- Carolinas Healthcare System (SC)
- WellStar Health System
- Ochsner Health System (MS)
- University of Mississippi Medical Center
- Ochsner Health System

**Northeast (Green):**

- Ontario Shores Centre for Mental Health Sciences
- Dartmouth-Hitchcock
- Beth Israel Deaconess Medical Center
- Boston Children's Hospital
- Geisinger Health System (NJ)
- Geisinger Health System
- Lancaster General Hospital
- Penn State Hershey
- WellSpan
- WellSpan Health (MD)
- VCU Health
- Wake Forest Health
- Carolinas Healthcare System
- Duke Health
- Mayo Clinic (FL)

OpenNotes is available at all U.S. Department of Veterans Affairs Medical Centers nationwide

# Experiences

Implementation was easy; it has been a non-event for **providers**

*“Honestly, I couldn’t believe how few problems we had when we started OpenNotes.”*

*“For us, in general, I think it’s been a non-event.”*

*“Don’t worry about it. Sharing notes is a step in the right direction.”*

**Patients** report great value in reading notes

*“Makes me feel like I’m more a part of the care...now I’ve been brought in right away. I’m more connected with what’s going on.”*

*“Having these notes...means everything to me.”*

*“I have a serious medical condition. Reading my notes, gave me a better understanding of how I was going to get through this.”*

Providers continued to provide care “**business as usual**”

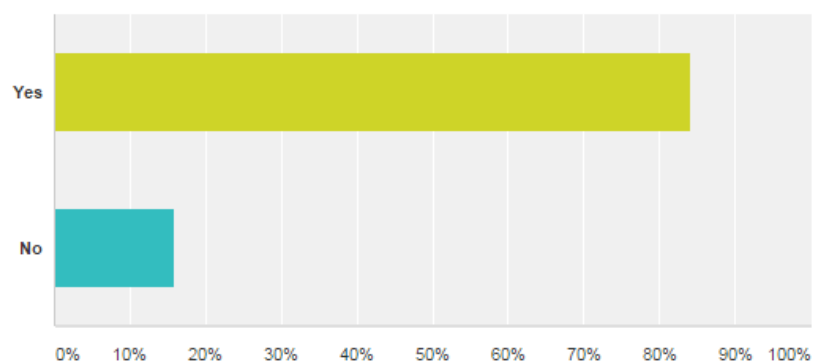
*“Don’t change way you write the language; it should always be clear in medical terminology.”*

*“I was nervous ... but not a single patient contacted me about a note, and I do a lot of clinic work.”*

*“It’s been business as usual... It was one of the most seamless implementations I think we’ve done in a long time.”*

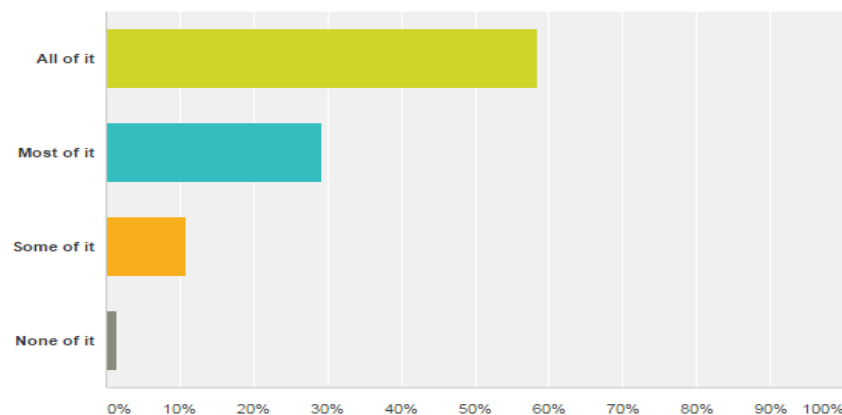
### Did you think seeing your note helps you take better care of yourself?

Answered: 428 Skipped: 266



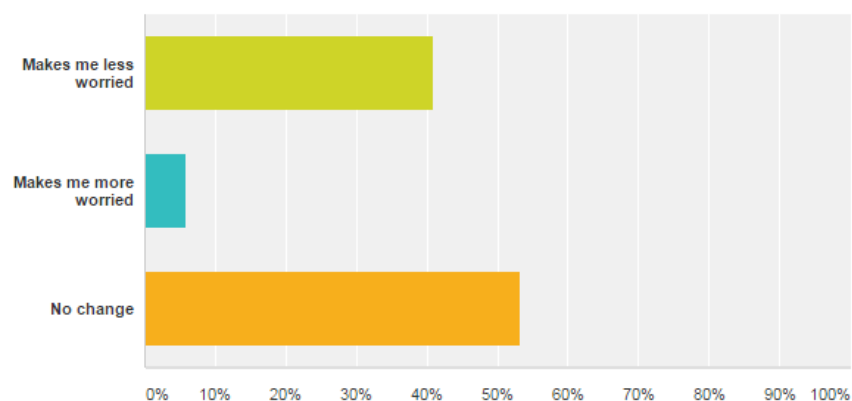
### How much of what was in the note did you understand?

Answered: 433 Skipped: 261



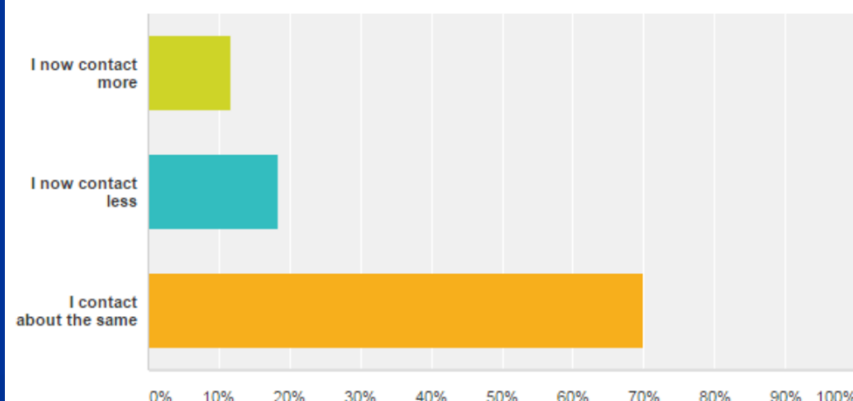
### How does reading a note affect how worried you are about something?

Answered: 425 Skipped: 269



### Does reading your note change how often you contact your provider?

Answered: 419 Skipped: 275



# Key Takeaways

- Sharing Clinician Notes with patients: Good evidence for significant benefits
- Impact to physician work-life neutral (may actually be positive)
  - No additional work
  - Better patient engagement & physician satisfaction?
  - Decreases physician burnout??
- **Clinician Leaders MUST sponsor the effort (Not an “IT” initiative!)**
- MU/MACRA is an enabler for this; one of the tangible benefits of widespread EHR adoption.
- HIPAA requires organizations to provide patients with their EHR information!
- \* EHR/patient portal should be intuitive and easy to navigate to the clinician’s note \*



# HIPAA: Right to access information

4/18/2017

Individuals' Right under HIPAA to Access their Health Information | HHS.gov

HHS.gov

U.S. Department of Health & Human Services

Health Information Privacy

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## Individuals' Right under HIPAA to Access their Health Information 45 CFR § 164.524

Newly Released FAQs on Access Guidance

### Timeliness in Providing Access

In providing access to the individual, a covered entity must provide access to the PHI requested, in whole, or in part (if certain access may be denied as explained below), no later than 30 calendar days from receiving the individual's request. See 45 CFR 164.524(b)(2). The 30 calendar days is an outer limit and covered entities are encouraged to respond as soon as possible. Indeed, a covered entity may have the capacity to provide individuals with almost instantaneous or very prompt electronic access to the PHI requested through personal health records, web portals, or similar electronic means. Further, individuals may reasonably expect a covered entity to be able to respond in a much faster timeframe when the covered entity is using health information technology in its day to day operations.

<https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/>

6/41

# Fee Calculation

**How can covered entities calculate the limited fee that can be charged to individuals to provide them with a copy of their PHI?**

The HIPAA Privacy Rule permits a covered entity to charge a reasonable, cost-based fee. The following methods may be used,

- Actual costs. A covered entity may calculate actual labor costs to fulfill the request, as long as the labor included is only for copying and the labor rates used are reasonable. The covered entity may add to the actual labor costs any applicable supply (e.g., paper, or CD or USB drive) or postage costs.
- Average costs.
  - Per page fees are not permitted for paper or electronic copies of PHI maintained electronically.
- Flat fee for electronic copies of PHI maintained electronically. A covered entity may charge individuals a flat fee for all requests for electronic copies of PHI maintained electronically, provided the fee does not exceed \$6.50, inclusive of all labor, supplies, and any applicable postage. Charging a flat fee not to exceed \$6.50 is therefore an option for entities that do not want to go through the process of calculating actual or average allowable costs for requests for electronic copies of PHI maintained electronically.

# Office of Civil Rights: Enforcing the rights of patients to see their medical records

## News Release

FOR IMMEDIATE RELEASE  
February 22, 2011

Contact: HHS Press Office  
(202) 690-6343

### **HHS imposes a \$4.3 million civil money penalty for violations of the HIPAA Privacy Rule**

OCR found that Cignet violated 41 patients' rights by denying them access to their medical records when requested between September 2008 and October 2009. These patients individually filed complaints with OCR, initiating investigations of each complaint. The HIPAA Privacy Rule requires that a covered entity provide a patient with a copy of their medical records within 30 (and no later than 60) days of the patient's request.

## Remind patients that they are entitled, by law, to copies of their medical records

□ MARCH 15TH, 2016 | □ POSTED IN CONSUMER FOCUS, PATIENT TOOLS

HHS' Office for Civil Rights (OCR) recently issued guidance reminding consumers they're entitled to copies of their medical records.

OCR has also signaled it will crack down on providers who do not comply.

# Check List for OpenNotes

- ☐ Review and develop materials (Support materials available at [opennotes.org](http://opennotes.org))
- ☐ Identify and convene sponsors to make decision to implement
- ☐ Get agreement from key sponsors and reinforcing sponsors to move ahead; must be an operational effort, not an “IT effort”
- ☐ Make it an organizational standard; no opting-out individual
- ☐ Make choices about processes, roll-out, configuration, etc.
- ☐ Communication process
- ☐ Map out time-line (short pilot with planned rollout)
- ☐ Technical configuration and technical pilot; optimize web-site
- ☐ Modify, fix issues
- ☐ Go-live with rest of organization
- ☐ Follow-up, monitor, adjust, tweak, improve
- ☐ Study effects?

# Decisions (and suggested “best practice”)

- Change management:
  - Clinician leaders need to sponsor this effort
  - Do not let individual clinicians block progress (→ allow individuals to hide individual notes—i.e. give them an “out”)
- Roll-out:
  - Plan for small pilot to iron out technical issues, then planned organizational roll-out; determine those departments that can go later (MH, addiction, pain clinic, etc.)
- Clinician opt-in, vs. opt-out
  - Make it organization-wide; no opt-out unless extenuating circumstances
  - All primary care & all specialty care; include OT, PT, social workers, etc.
  - Mental Health, Occupational health, Drug addiction, etc., can be exceptions
- Proxy access, adolescents
  - 0-12, parental proxy access
  - 13 – 18, adolescent access only?
- Release on signing
- Ability to block a particular note vs. hidden note type
- Include ED? UC?
- All outpatient notes, full Inpatient discharge summary
- Internal organizational communication plan
- External and patient communication plan; publicity?
- Monitoring and improvement plan

# Vendors That Support OpenNotes

- Cerner
- Epic
- Meditech
- Allscripts
- eCW (just starting)
- Working on: Athena, NextGen



Website: [www.opennotes.org](http://www.opennotes.org)

Contact information:

- Homer Chin: [chinh@ohsu.edu](mailto:chinh@ohsu.edu)