

# OpenNotes Research: Patient Outcomes

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# 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*

# 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

# 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  $\geq 1$  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

Reason (multiple permitted)	Frequency, % (n=4592)
To know about my health	58
To be sure I understood what the doctor said	55
I was curious	48
To know what my doctor was thinking	45
To remember the visit	38
To check the notes were right	29

***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!”)

*“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

*“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?

#OpenNotes

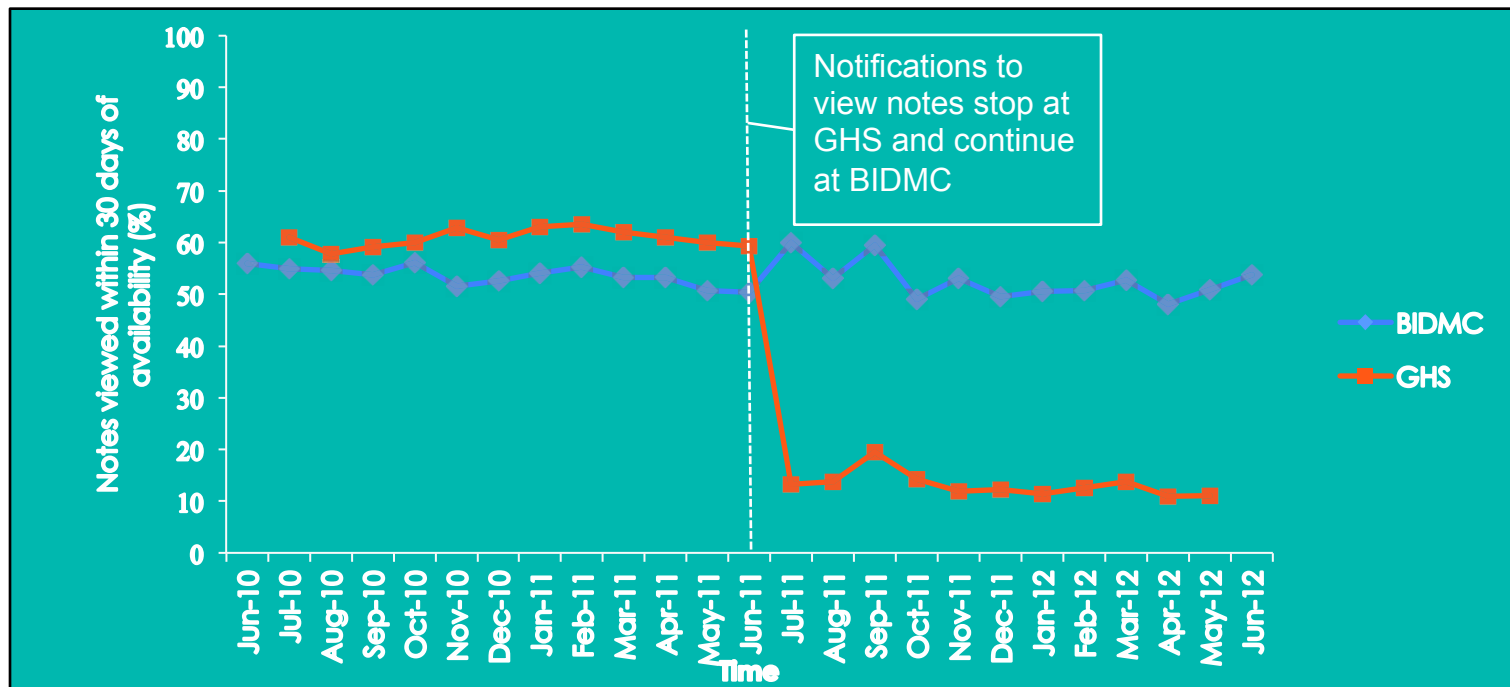


# Patient/Family advisor roles

- **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



(95% of Kaiser NW patients want reminders)

The screenshot displays the Mayo Clinic Patient Online Services interface. At the top, the Mayo Clinic logo and 'Patient Online Services' are on the left, while the user's name 'Testing, Ann' and email 'patientonlineserv@mayo.edu' are on the right. A navigation bar includes 'Appointments', 'Medical Record and Results', 'Billing and Insurance', 'Message Center', and 'Account Settings'. The 'Medical Record and Results' menu is open, listing options like Lab Results, Clinical Notes and Hospital Summaries, Radiology Exams, Medical Record Index, Pathology Reports, Vital Signs, Medications, Continuity of Care Documents (CCDs), Immunizations, Allergies, and Research Consent Forms. A central banner asks 'Remind me, what did my doctor say?' and provides a link to view clinical notes. A 'Connect with us' section offers to send a message or refill prescriptions. On the right, a mobile app interface shows a 'Patient' health record menu with 'Notes and documents' selected.

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*



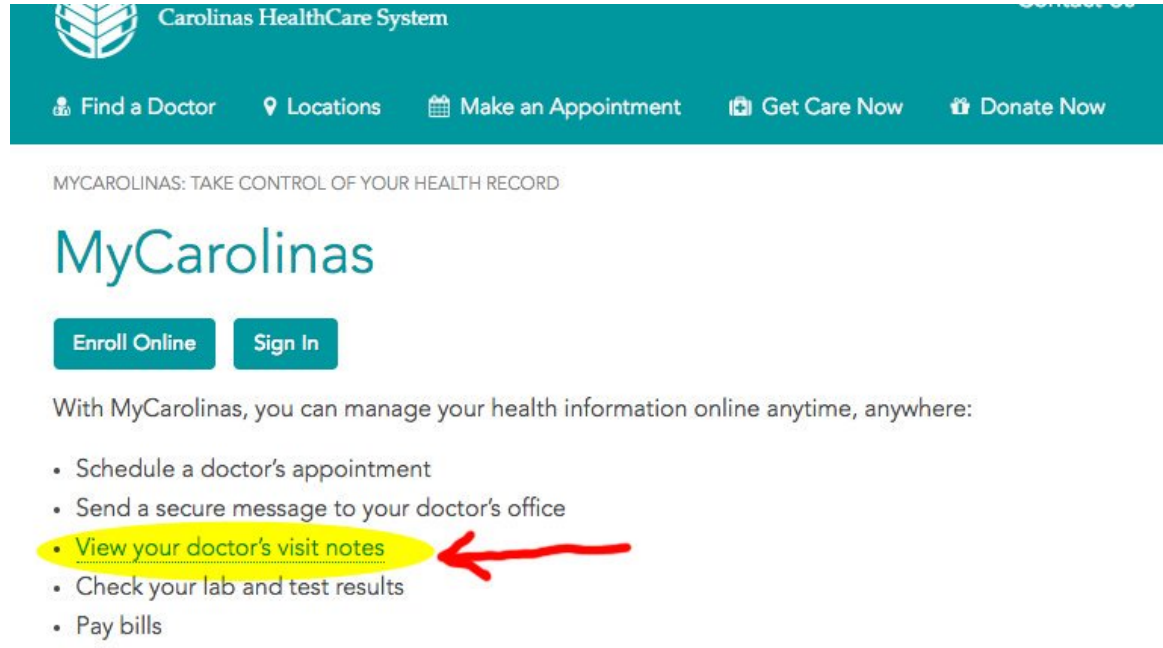
*“I like to see my clinical notes. Sometimes **it clarifies issues I may be confused about...** My lab results are important to keep me aware of my condition and any progression. I'm more involved in my own care.”*

*-- Mayo patient*

#OpenNotes



→  
**93%** of patients  
on the  
MyCarolinas  
portal access  
their notes.



The screenshot shows the top navigation bar of the Carolinas HealthCare System website. It features the organization's logo and name on the left, and five navigation links: 'Find a Doctor', 'Locations', 'Make an Appointment', 'Get Care Now', and 'Donate Now'. Below the navigation bar is a sub-header 'MYCAROLINAS: TAKE CONTROL OF YOUR HEALTH RECORD' followed by the 'MyCarolinas' logo. Two buttons, 'Enroll Online' and 'Sign In', are positioned below the logo. A descriptive sentence follows: 'With MyCarolinas, you can manage your health information online anytime, anywhere:'. A bulleted list of features is provided, with the first item, 'View your doctor's visit notes', highlighted in yellow and pointed to by a red arrow.

Carolinas HealthCare System

Find a Doctor Locations Make an Appointment Get Care Now Donate Now

MYCAROLINAS: TAKE CONTROL OF YOUR HEALTH RECORD

## MyCarolinas

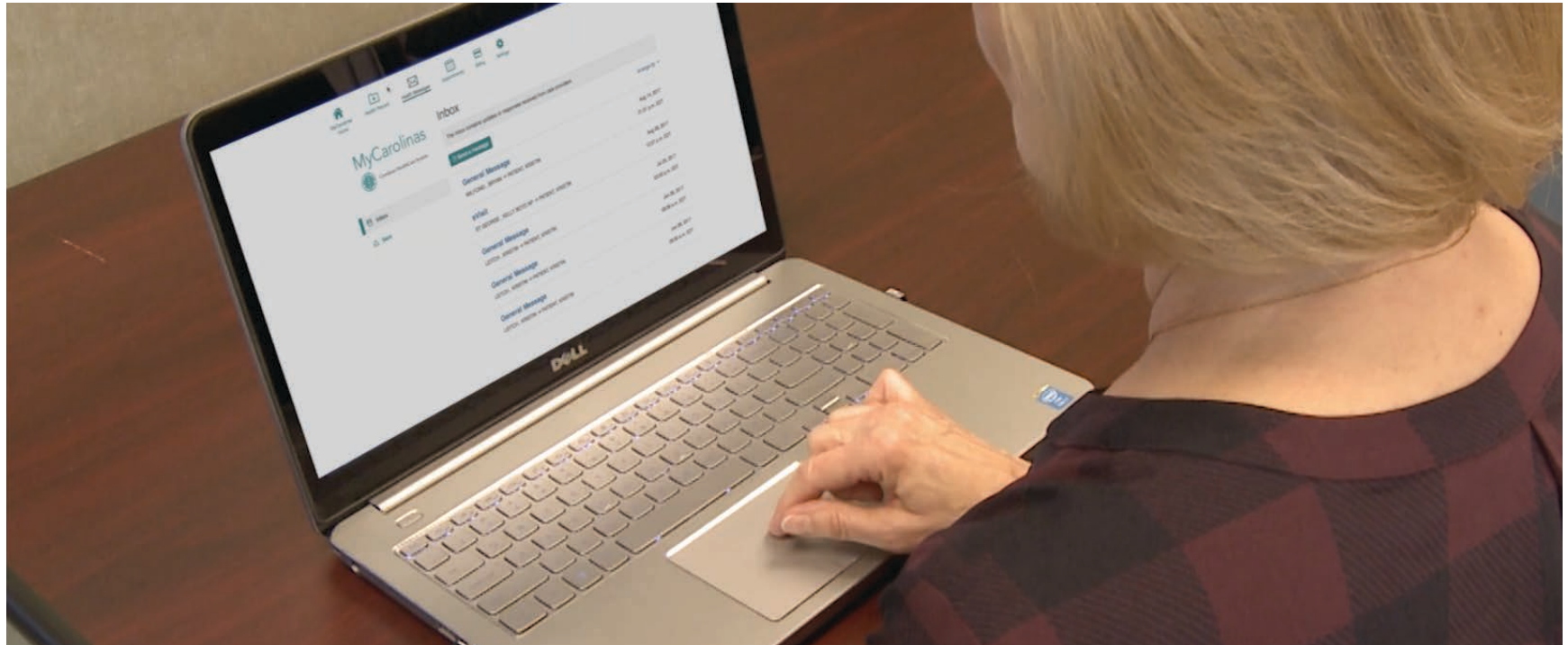
Enroll Online Sign In

With MyCarolinas, you can manage your health information online anytime, anywhere:

- Schedule a doctor's appointment
- Send a secure message to your doctor's office
- **View your doctor's visit notes**
- Check your lab and test results
- Pay bills



## Carolinah HealthCare System



opennotes.org

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#OpenNotes

