

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

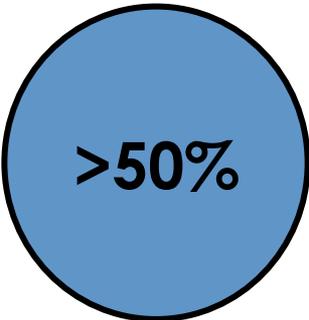
Doctor-patient relationship



99%

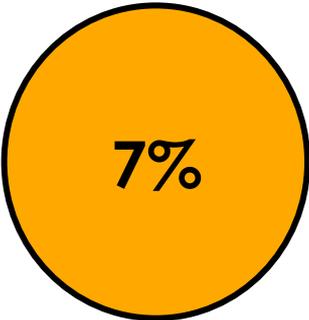
Patients felt better (37%)* or the same (62%) about their doctor after reading ≥ 1 note.

*Older, non-Caucasian patients, with poorer health, lower formal education were more likely to feel better about the doctor



>50%

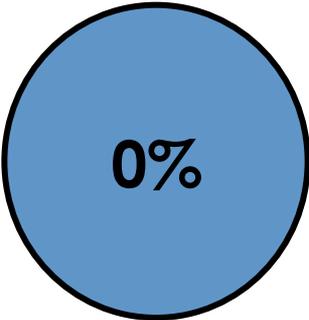
Doctors believed shared notes increased patient satisfaction and trust.



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?

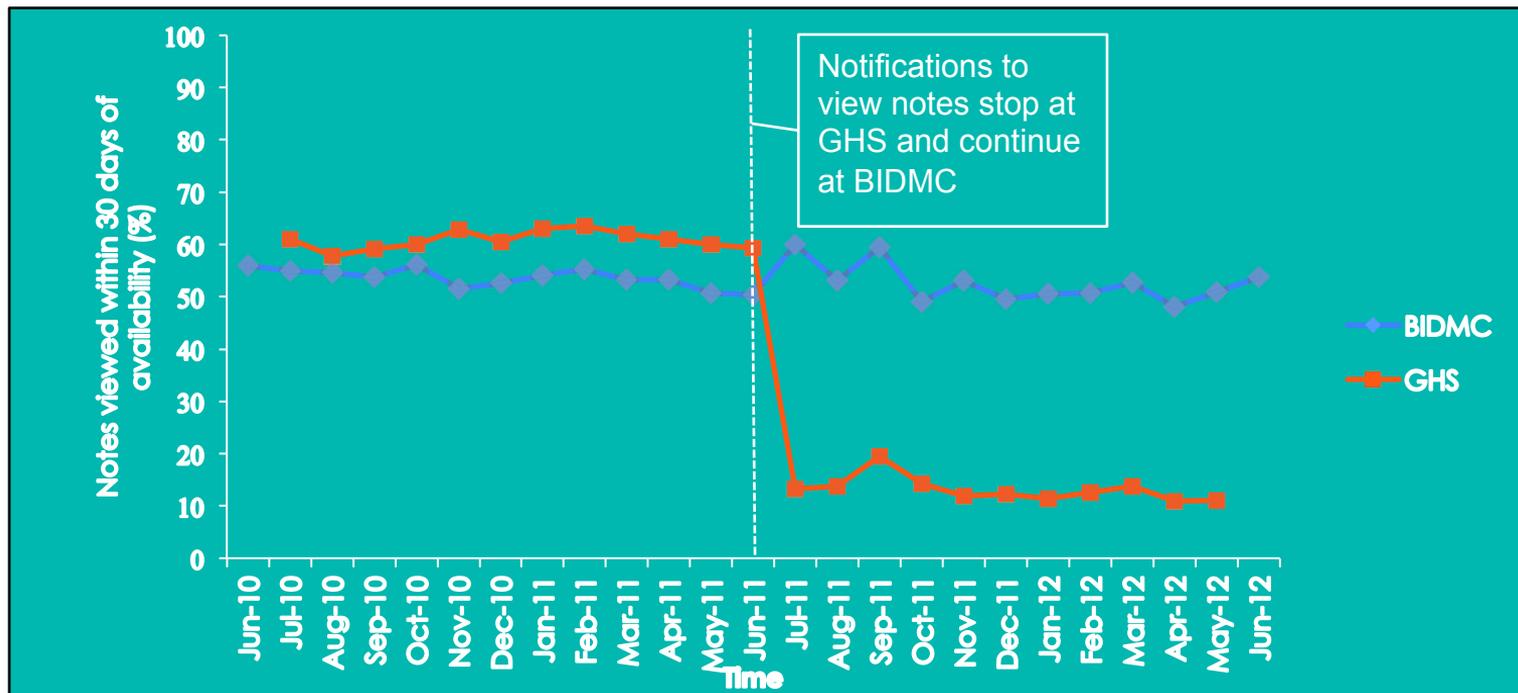
#OpenNotes



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)

MAYO CLINIC Patient Online Services

Welcome Testing, Ann | patientonlineserv@mayo.edu | Home | Help | Switch Site | Sign Out

Patient: Testing, Ann | Change patient

Appointments | Medical Record and Results | Billing and Insurance | Message Center | Account Settings

Lab Results
Clinical Notes and Hospital Summaries
Radiology Exams
Medical Record Index
Pathology Reports
Vital Signs
Medications
Continuity of Care Documents (CCDs)
Immunizations
Allergies
Research Consent Forms
Copy of Medical Record
Don't see what you need?

"Remind me, what did my doctor say?"
Need to review a recent visit? View your clinical notes and hospital summaries [online](#).

Connect with us
Send a message
Refill/renew prescriptions

Upcoming
Appointment schedule
Forms and questionnaires

AT&T M-Cell 1:26 PM

Patient

HEALTH RECORD

- Appointments
Retrieving itinerary...
- Messages
- Lab results
- Notes and documents
- Medications
- Pathology reports
- Radiology results
- Vital signs
- Allergies

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 includes the logo and the text "Carolinas HealthCare System". Below the navigation bar are five menu items: "Find a Doctor", "Locations", "Make an Appointment", "Get Care Now", and "Donate Now". The main content area features the heading "MYCAROLINAS: TAKE CONTROL OF YOUR HEALTH RECORD" and the "MyCarolinas" logo. There are two buttons: "Enroll Online" and "Sign In". Below these buttons is the text "With MyCarolinas, you can manage your health information online anytime, anywhere:". A list of features follows: "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", and "Pay bills". The "View your doctor's visit notes" item is highlighted in yellow, and a red arrow points to it from the right.

Carolinas HealthCare System

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

MYCAROLINAS: TAKE CONTROL OF YOUR HEALTH RECORD

MyCarolinas

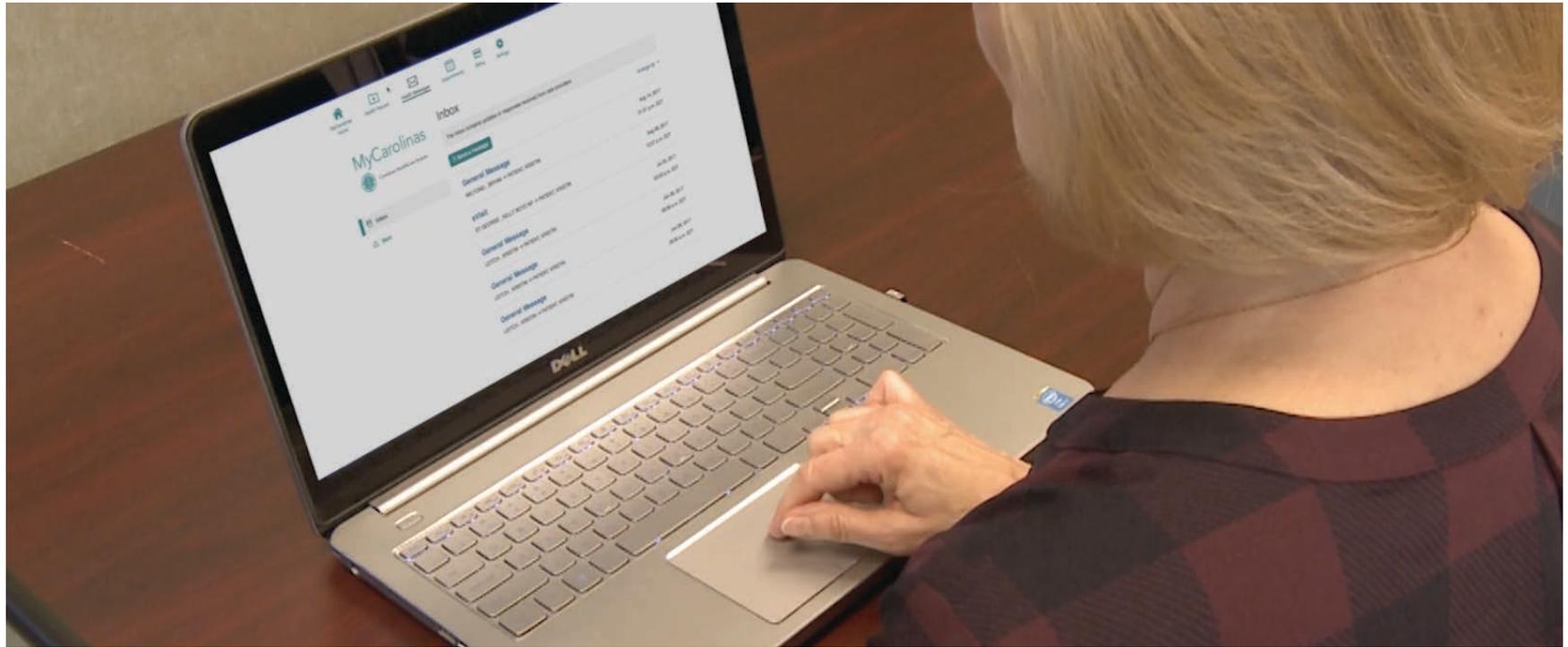
Enroll Online Sign In

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



Carolin's HealthCare System



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#OpenNotes

