

# Open Notes:

## Increasing Transparency and Engagement in Care

Deborah Wachenheim, MPP  
Senior Project Manager  
OpenNotes



# EHRs and Patient Portals

- EHR/EMR: Electronic Health Record/Electronic Medical Record
- Patient Portal: tied to EHR, an online portal for patients to access their medical information
- Patients must register to use their health care provider's patient portal via secure log-in
- Patients can also designate care partners as "proxies" to be able to see their information through the portal

# Use of Patient Portals by Older Adults

45% of adults age 65-80 have not set up portal account (as of June 2020); slight improvement from March 2018 report of 49%

Reporting no portal account:

50% of Black older adults

53% of Hispanic older adults

39% of white older adults

Men less likely than women

54% of lower-income adults

35% of higher-income adults

53% of less than HS education

31% of college graduates

# Reasons Not Using Portal

2018 poll reported the following reasons older adults say they aren't registered for the portal:

- Lack of awareness (also of proxy access)
- Lack of need
- Lack of comfort using technology
- Dislike communicating about their health online

However-now more awareness/need due to telehealth, COVID test results, COVID vaccinations

# Information on Portal

2018 poll found following uses among older adults:

- See test results (84%)
- Request prescription refill (43%)
- Schedule appointment (37%)
- Requesting upcoming appointment reminders (34%)
- Getting advice on health problem (26%)
- Updating insurance or contact info (22%)
- Requesting a referral (13%)

## OpenNotes (the organization):

A philanthropically supported initiative focused on increasing transparency in health care.

## open notes (the practice):

When patients can easily read progress notes.

Not a technology or an app. Not a product.



Robert Wood Johnson Foundation



The John A. Hartford Foundation



The Commonwealth Fund



# What a patient sees

Back [Redacted] Past Visit Close

[Redacted]

### After Visit Summary


[Redacted] [Redacted]

11/28/2017 2:15 PM

[Redacted] [Redacted]

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**Instructions** from [Redacted] MD

 Return in about 9 months  
(around 8/28/2018).







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### Today's Visit

You saw [Redacted] MD on Tuesday November 28, 2017. The following issues were addressed:

- Astrocytoma, grade II (CMS code)

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 Blood Pressure 124/65	 Height 5' 7"
 Temperature (Oral) 98.2 °F	 Pulse 69
 Respiration 16	 Oxygen Saturation 100%

# vs. What the doctor writes aka *notes*

## ASSESSMENT AND PLAN:

In summary, Ms. [Redacted] is a 38 y.o. year old woman with grade II astrocytoma that is stable on imaging in follow-up. Neurologically, she has stably reduced sensation on the R side of her body, as well as occasional focal R hand seizures.

IMAGING SCORE: 0

NEUROLOGICAL SCORE: 0

STEROID SCORE: 0

OVERALL TUMOR ASSESSMENT: 0

1. Grade II astrocytoma: As such, we will simply continue to monitor her. It has been > 5 years since she completed chemotherapy, and so we will extend the interval between scans to 9 months. I would be comfortable with her continuing to do the scans locally, and we can plan to do the next appointment as a phone consultation.

2. Seizures: We discussed whether she might be able to taper down one of her seizure medications, but given that she continues to have focal events, I would be concerned that she might have a larger breakthrough event so I would recommend that we keep the doses stable for the moment, and she is in agreement with this plan.

## Follow-up:

- 9 months for next MRI and appointment. This scan is critical because based on the results, a change in the management plan for the patient may need to be made especially if there is any evidence to suggest tumor progression.

- All questions of [Redacted] and her family were answered to the best of my ability. They have our contact information and will call with further questions.

I spent a total of 26 minutes face-to-face with the patient and 14 minutes of that time was spent reviewing the imaging with the patient, review of management options, side effects, counseling and coordination of care



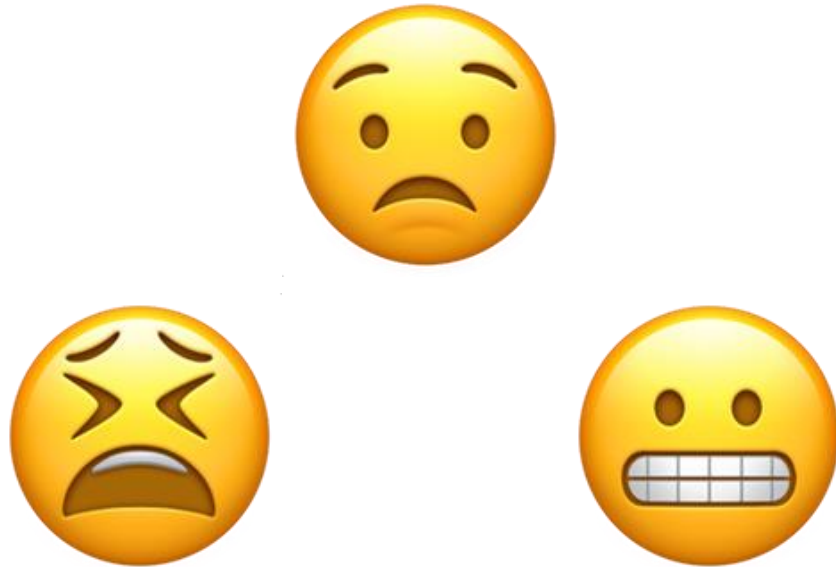
# Original study: 2010

- **105** primary care clinicians
- **20,000** patients:
  - **Boston** (BIDMC)
  - Rural **Pennsylvania** (Geisinger)
  - **Seattle** safety net hospital (Harborview)
- *Now replicated at numerous sites around the country*



# Surveyed *before* study

## Physicians



## Patients



# Surveyed *after* the study

## Physicians



## Patients



# Results for patients

- ✓ 80% read a note initially, **50-60% long term**
- ✓ **75% reported benefits** (replicated multiple times) in Engagement, Medication Adherence, Planning, Control, Understanding
- ✓ **99% wanted to continue** (replicated multiple times)
- ✓ 85% would use OpenNotes as a **criterion for selecting providers**
- ✓ 20-42% reported **sharing their notes with care partners**

# Results for Clinicians

- ✓ **Little impact** on workflow, email volume unchanged
- ✓ **Worries** about negative patient effects **didn't materialize**
- ✓ After study, **no clinicians stopped**
- ✓ Most **would recommend** the practice to colleagues
- ✓ Majority said sharing notes is **helpful for engaging patients**

7 years later...

Similar results, **replicated numerous times...**



# After 7 years... **patient views**

- ✓ Patients still say **notes are very important** for taking care of their health, feeling in control of their care, and remembering their care plans
- ✓ **Almost all** patients say they *understood all or nearly all* of their notes
- ✓ Reading notes **helps them understand their medications**
- ✓ Patients with less education or limited English proficiency reported the most benefit

Walker J, et al. OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians' Outpatient Visit Notes. *J Med Internet Res* 2019;21(5):e13876. DOI: 10.2196/13876

Leveille, SG, et al. Patients Evaluate Visit Notes Written by Their Clinicians: a Mixed Methods Investigation. *J GEN INTERN MED* (2020). <https://doi.org/10.1007/s11606-020-06014-7>

Desroches CM, et al. Patients Managing Medications and Reading Their Visit Notes: A Survey of OpenNotes Participants. *Annals of Internal Medicine*. 2019;171(1):69. doi:10.7326/m18-3197

3197

# Views of Older Patients (age 65+)

40% shared a note with someone (most often a family member)

4.5% reported a note was very confusing

4.2% said they were more worried after reading a note (29% said less worried and 56% said no change)

74% said reading notes is important for taking care of their health

69% said helps them feel in control of their care

65% said helps them remember plan of care

52% said helps them prepare for visits



# After 7 years... **clinician views**

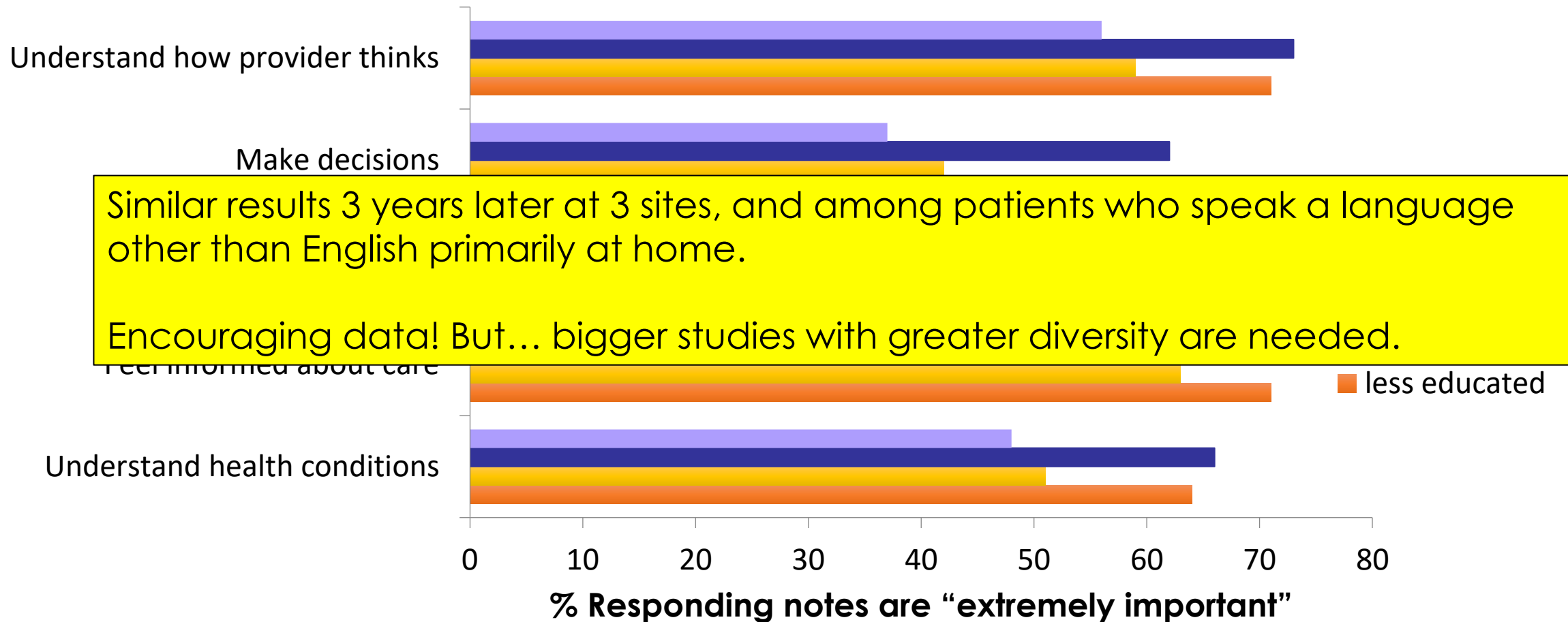
- ✓ Majority say sharing notes with patients is a **good idea** and **helpful for engaging patients**
- ✓ Most would **recommend** the practice to colleagues
- ✓ Few report questions or concerns from patients about notes
- ✓ 1/3 say they spend at least “somewhat” more time in documentation

# Doctor-patient relationship

- ✓ **99% of patients felt better (37%) or the same (62%)** about their clinician after reading at least one note
- ✓ Older, racially diverse patients, with poorer health, or lower formal education were **more likely to feel better about the doctor**
- ✓ **> 97% of patients reported same or greater trust** in their clinicians
- ✓ **> 50% of doctors believed shared notes increased patient satisfaction and trust (50+%)**
- ✓ No doctors reported ordering more tests or referrals

# Vulnerable populations:

How important are notes to engage in care (0-10)  
by Race and Education? (Single site, n=6913)



Gerard et al, JMIR 2018

## multivariable regression:

individuals self-identifying as black/African American, Asian, Hispanic/Latino, "other" or "multiple" races; or  $\leq$  high school education; were 2-3 x more likely to report notes were extremely important to engage in care than their counterparts

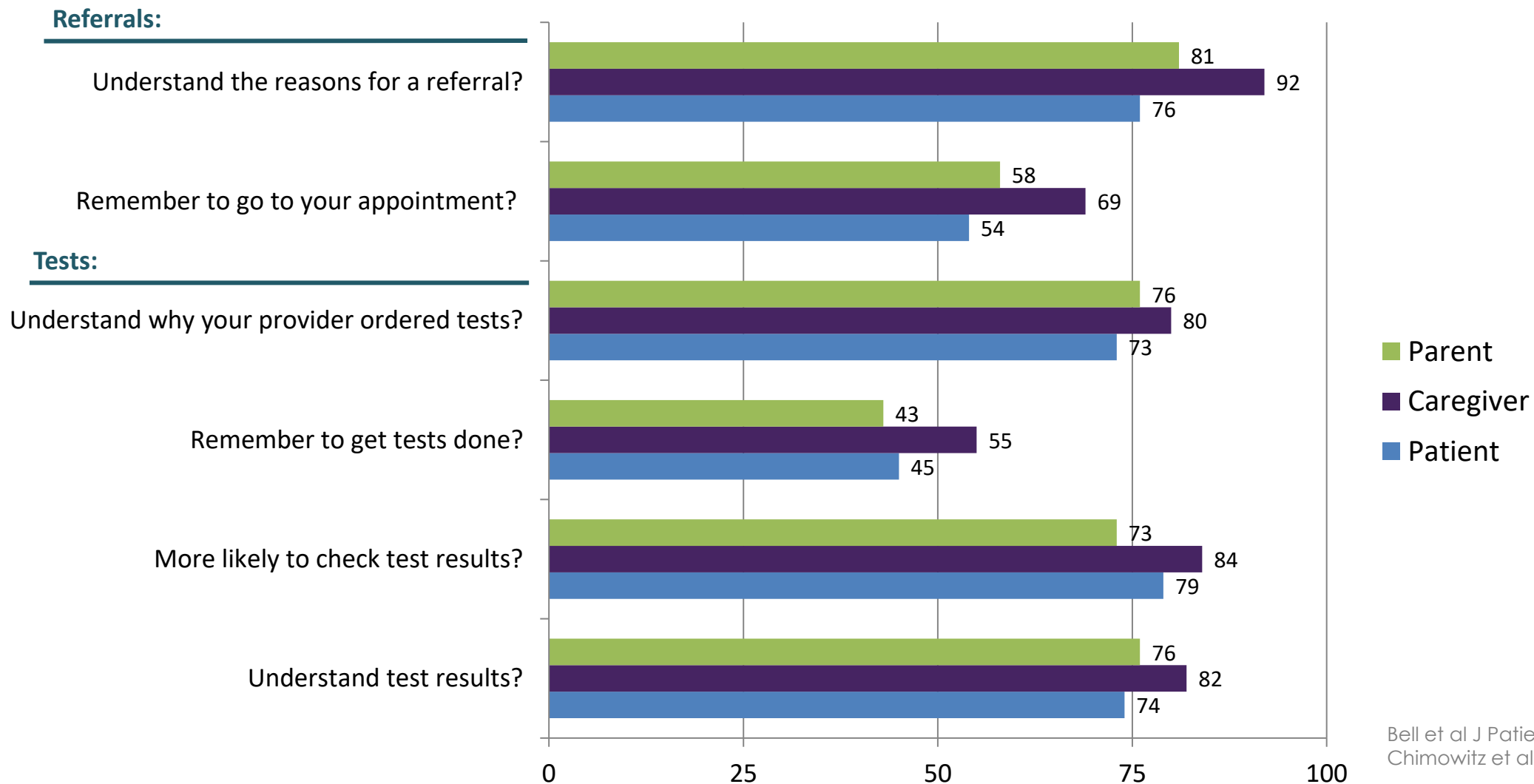


# Safety opportunities in the space between visits:

## What 10,000 patients and family members say

Has reading your/the patient's notes helped you...

(% responding "quite a bit " or "very much")



# Note errors: How often do clinicians and patients anticipate/find them?

24%

Clinicians anticipate non-trivial errors in notes

21%

Patient reports include a possible note mistake

21%

Patients report finding at least 1 error in a survey of >22,000 users

- ✓ 40% "somewhat or very serious"
- ✓ Older, sickest approximately 2x as likely to find a mistake

# Patient-reported “very serious” errors

## Diagnosis-specific:

- “Said I am BRCA positive when I am NOT BRCA [positive]”

## Medical history/exam:

- “Wrong eye mentioned for upcoming surgery”
- “Doctor reported that I did not claim to have pain in my hand. I am a pianist and I went specifically because pain was in my hand.”
- “Wrong BMI; told I could not be placed on a heart lung transplant list”

## Wrong patient:

- “Plan to change medication based on the lab results of another patient”

## Meds:

- “I found an incorrect dosage on a note that was being used by a referred physician for an infusion. The dosage was incorrect by 10 fold.”



# Strengthening partnerships with care partners

- ✓ >40 million Americans
- ✓ Costly, preventable, and high stakes errors and readmissions
- ✓ Often lack access to critical information
- ✓ Family members are among the most vigilant of health system stakeholders

Care partners are **more likely** than patients to report benefits from note-reading.



**“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.”**  
-a patient

# Care Partners as Portal Proxies

- Promoting portal proxy option:
  - Helps clinic staff know who communicating with
  - Clinic staff know who is completing questionnaires, etc.
  - Privacy of patient information
  - Patient has control-can grant and revoke access
- 2/3 of U.S. hospitals offer adult patients the option of granting portal access
- Not always easy process
- URMC example-what happens when educate/inform; flexibility of options (need even more)



# 21<sup>st</sup> Century Cures Act Information Blocking Rule

Did you know?

As of April 2021, a federal mandate requires that patients must have immediate electronic access to all of the information in their medical records at no charge.

More details here: <https://www.opennotes.org/onc-federal-rule/>

# What Types of Notes Must Be Shared

**Consultation notes**

**Discharge summary notes**

**History & physical**

**Imaging narratives**

**Laboratory report narratives**

**Pathology report narratives**

**Procedure notes**

**Progress notes**

Do not have to be shared: psychotherapy notes

# What Can Patients/Advocates Do? Accessing Notes

- Register for patient portal and encourage others to register for patient portals
- If you help someone manage their care and/or someone helps you, explore the option of portal proxy
- Look for your notes-go to patient portal and look for links to page with visit notes, look at individual visits (may be hard to find them)
- Read your notes before and after healthcare visits-to prep and to remind (also to catch any errors)
- Encourage others to find and read their notes
- <https://www.whereismymedicalrecord.org/>

# What Can Patients/Advocates Do? Urging Sharing of Notes

- If hard to find notes, talk to someone at your doctor's office or contact someone in patient advocacy or Health Information Technology (HIT)
- If your clinician isn't sharing notes, ask them why and encourage them to do so; if clinic/health system isn't sharing make sure they know about the federal rule-can reach out to patient advocacy or clinic administrator
- If on a Patient and Family Advisory Council (PFAC): work with the health system to inform patients/care partners about the portal and about notes and how to find them and utilize them; work with the health system to determine how patients can report errors/concerns

# OpenNotes Resources

**New Federal Rules and Open Notes:** <https://www.opennotes.org/onc-federal-rule/>

**Finding Your Notes/Reporting Info Blocking:**  
<https://www.wherismymedicalrecord.org/>

**Reading Your Notes: FAQs for Patients:** <https://www.opennotes.org/reading-your-notes-faqs-for-patients/>

**Webinars:** <https://www.opennotes.org/webinars/>

**Research:** <https://www.opennotes.org/research/>

**OpenNotes.org toolkits for patients:**

- Pediatrics/Adolescents
- Mental Health
- Patient & Family Advisory Council
- Care Partners

# Thank you

**Deborah Wachenheim, MPP**  
[dwachenh@bidmc.harvard.edu](mailto:dwachenh@bidmc.harvard.edu)

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