



@TheLizArmy

Getting Ready for Open Everything

Liz Salmi

Communications & Patient Initiatives Director

OpenNotes

Beth Israel Deaconess Medical Center

Harvard Medical School



A woman with short blonde hair, wearing a black tank top and headphones, is playing a drum set in a dimly lit bar. The scene is bathed in a strong green light. In the background, several people are visible behind a bar counter. The text "How it started..." is overlaid in white in the center of the image.

How it started...

2005



Sign on

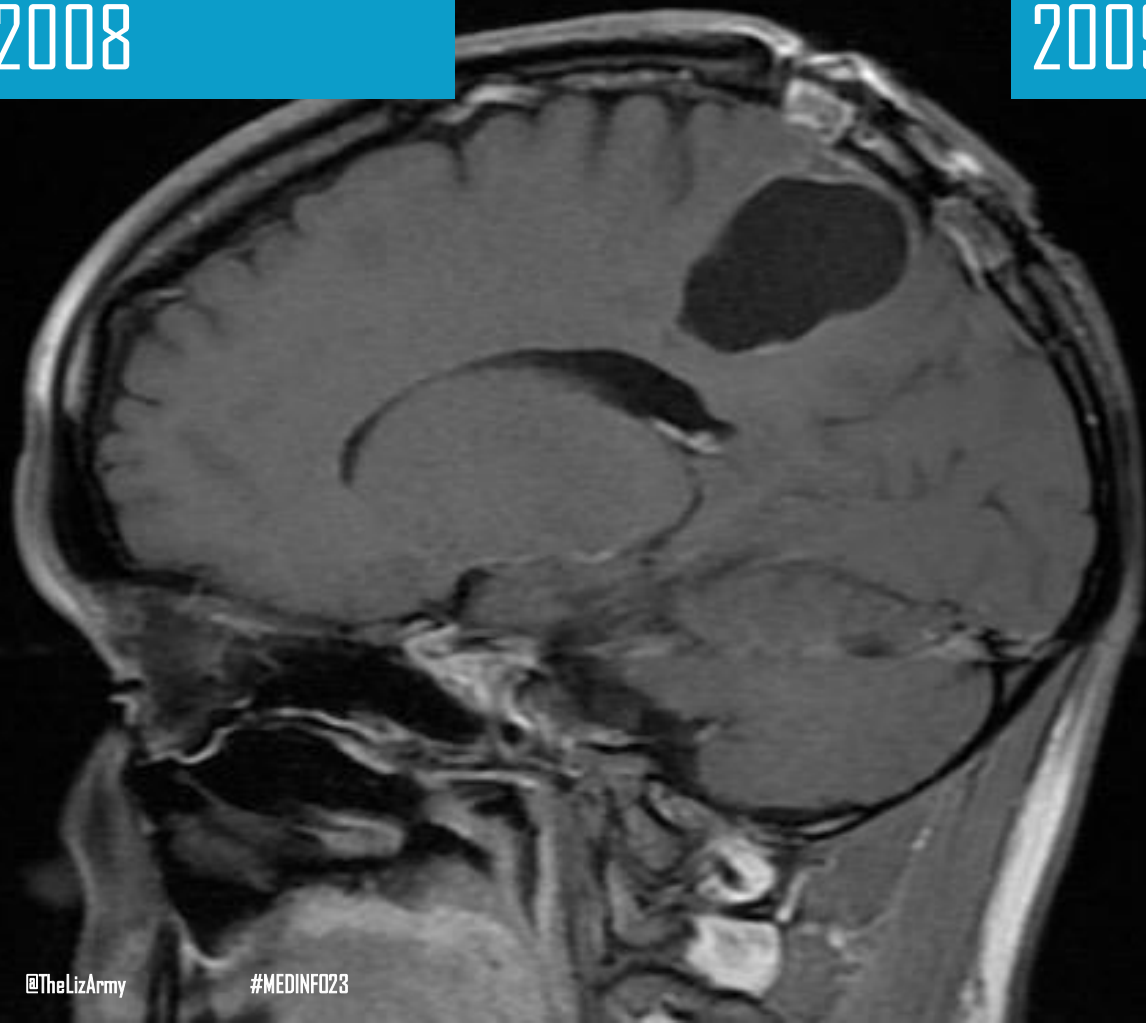


USER ID

PASSWORD

Sign on

2008



2009



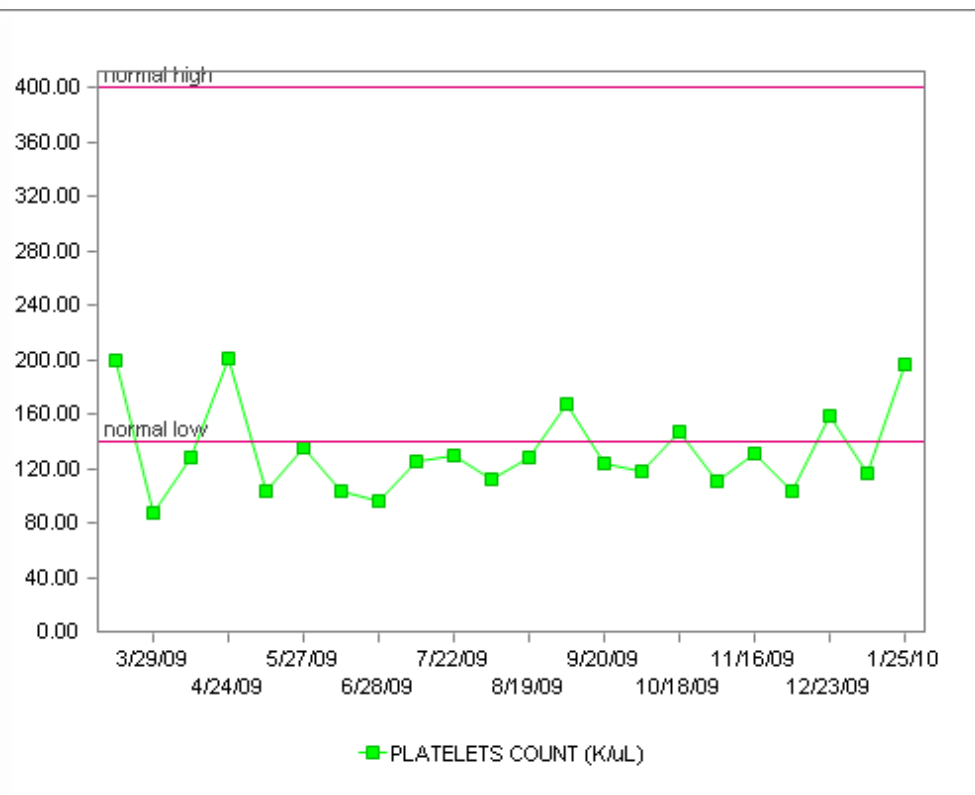
Sign on



USER ID

PASSWORD

Sign on



2017





4,839

pages



Progress Notes

Progress Notes by [REDACTED] (M.D.) at 12/16/2016 3:31 PM

Version 1 of 1

Author: [REDACTED] (M.D.)
 Filed: 12/16/2016 3:36 PM
 Editor: [REDACTED] (M.D.) (Physician)

Service: (none)
 Note Time: 12/16/2016 3:31 PM

Author Type: Physician
 Status: Signed

Neuro-Oncology Clinic Sacramento Medical Center

Follow-up Patient Evaluation

Elizabeth Salmi is a 37 Y female who is seen today for follow-up of low grade astrocytoma WHO grade II. She has been on observation and we have been checking MRI scans every 6 months. She reports normal activities without any restrictions. She exercises regularly and has problems with strenuous physical activity. She has good compliance with medications. She takes her anti-convulsants consistently and has not had any breakthrough seizures.

Oncologic history:

She was diagnosed on July 25, 2008 after presenting with a generalized tonic-clonic seizure. She underwent a resection of the lesion on September 17, 2008 by Dr. [REDACTED] in Sacramento. Pathological examination revealed a low grade astrocytoma WHO grade II with gemistocytic features. Surveillance MRI 3 months later showed enhancement in the resection cavity and she underwent a second resection on February 6, 2009. The pathology was the same which was confirmed with a second opinion at UCSF. Due to the presumed progression, she was offered adjuvant therapy and was advised to have temozolomide. She received

Progress Notes by [REDACTED] (M.D.) at 12/16/2016 3:31 PM (continued)
 temozolomide 150 mg/m2 5/23 for 24 cycles from 2/2009 to 4/2011.

Version 1 of 1

Active Ambulatory Problems

Diagnosis	Date Noted
• PARTIAL EPILEPSY.	10/09/2008
• ASTROCYTOMA, BRAIN GRADE 2	10/22/2008
• LEFT SENSORINEURAL HEARING LOSS.	02/05/2009
• ANXIETY DISORDER DUE TO ANOTHER MEDICAL CONDITION	02/11/2009
• ECZEMA	11/01/2010
• CONGENITAL KERATOSIS PILARIS	01/11/2011
• HX OF CHEMOTHERAPY	07/27/2011
• HX OF CRANIOTOMY	07/27/2011
• GENETIC CANCER RISK EVALUATION	11/17/2015

History

Substance Use Topics

- Smoking status: Never Smoker
- Smokeless tobacco: Never Used
- Alcohol Use: No

Physical Exam:

BP 127/67 mmHg | Pulse 59 | Temp(Src) 97.9 °F (36.6 °C) | Wt 156 lb (70.761 kg)

Constitutional: Appears well, no distress

Mental status: Alert, oriented X 3, able to name and repeat, good fund of knowledge, normal comprehension

Gait: Normal,

Secondary Review of Imaging:

MRI brain 12/12/16, 7/21/16, 4/26/13 are reviewed. There is a left parietal lobe resection cavity with small areas of FLAIR hyperintensity around it (residual tumor). There is no enhancement. The scans are stable and there is no evidence of growth.

Diffuse Fibrillary Astrocytoma WHO grade II

IDH mutant

ATRX mutant

MGMT methylated

Clinical Summary:

Elizabeth Salmi is a 37 Y woman with a left parietal lobe low grade astrocytoma WHO grade II with gemistocytic features. She had two resections (9/2008 and 2/2009) and 24 cycles of temozolomide 150 mg/m2 completed in April 2011. She is currently stable without any evidence of disease progression clinically and radiographically. She is being followed closely with clinical examinations and MRI scans. We will continue observation and surveillance MRI scans.

We will maintain current doses of anti-seizure medication and continue to observe.

Assessment:

- Neuro-Oncology: low grade astrocytoma, WHO grade II, left parietal lobe, stable
- KPS: 90
- Epilepsy, localization related, good control

Plan is as follows:

- Neuro-Oncology therapy: continue surveillance MRIs, no active treatment indicated at this time.
- MRI: 6 months
- Seizures: continue levetiracetam 1500 BID, lacosamide 200 mg BID
- Symptom management: None
- Social issues: none
- Psychological: no significant problems
- Advance directives status: completed
- Follow-up: 6 months



Patients like me
are created **every day**

2008





Beth Israel Deaconess
Medical Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL



2012

original
study published

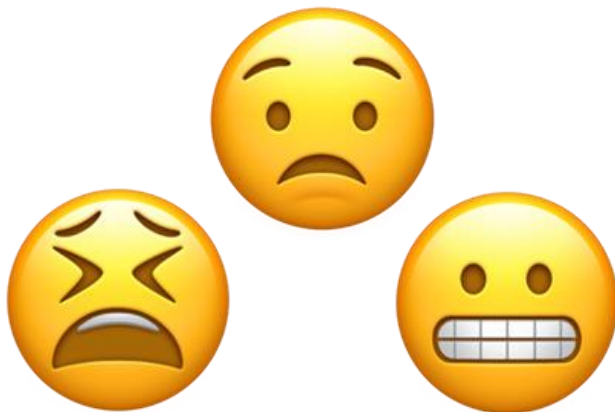
Annals
of Internal Medicine

- **105** primary care clinicians
- **20,000** patients:
 - Boston
 - Pennsylvania
 - Seattle

Since replicated around the world...

Surveyed before the study

Doctors

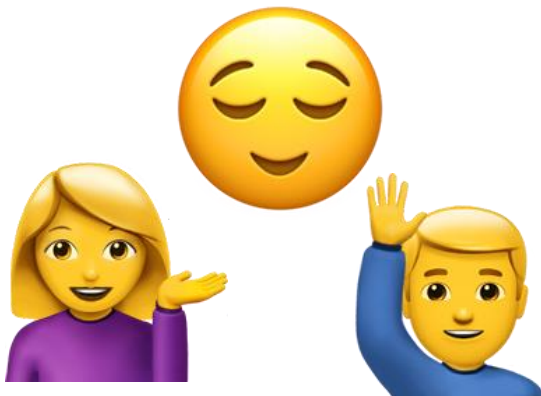


Patients

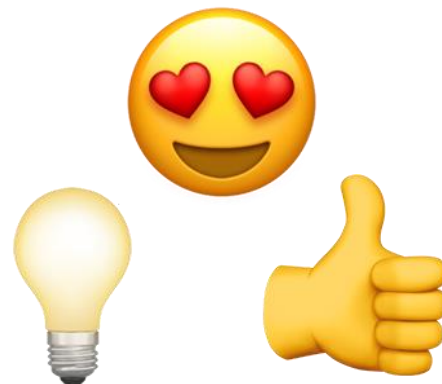


Surveyed after the study

Doctors



Patients





Patients who read notes **feel more engaged** in their care



1 out of 6 patients reported
**taking medications
more accurately**

Remember more
from medical visits

Caregivers
benefitted

Felt the same
or **better** about
their doctors

Mutual trust
between doctors and patients
increased



Sometimes I forget what is said to me...
it is so nice to be able to go back
and read exactly what my doctor
was telling me...

A patient
Mayo Clinic
Rochester, Minnesota



Patients who read notes
can **find errors** in time
to prevent harms



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

Beth Israel Deaconess Medical Center
Boston, Massachusetts



Historically disadvantaged populations
report the greatest benefit from
open notes



Most clinicians
report **little to no change**
in workflows



OpenNotes isn't a health IT project
—it is a **change management** project.

Christopher Longhurst, MD, MS
Chief Medical Officer, Chief Digital Officer
UC San Diego Health, San Diego, California



>100
published studies &
commentaries

Annals
of Internal Medicine®



BMJ
**QUALITY
& SAFETY**



JGIM
Journal of General
Internal Medicine

JAMA
Network | **Open**™



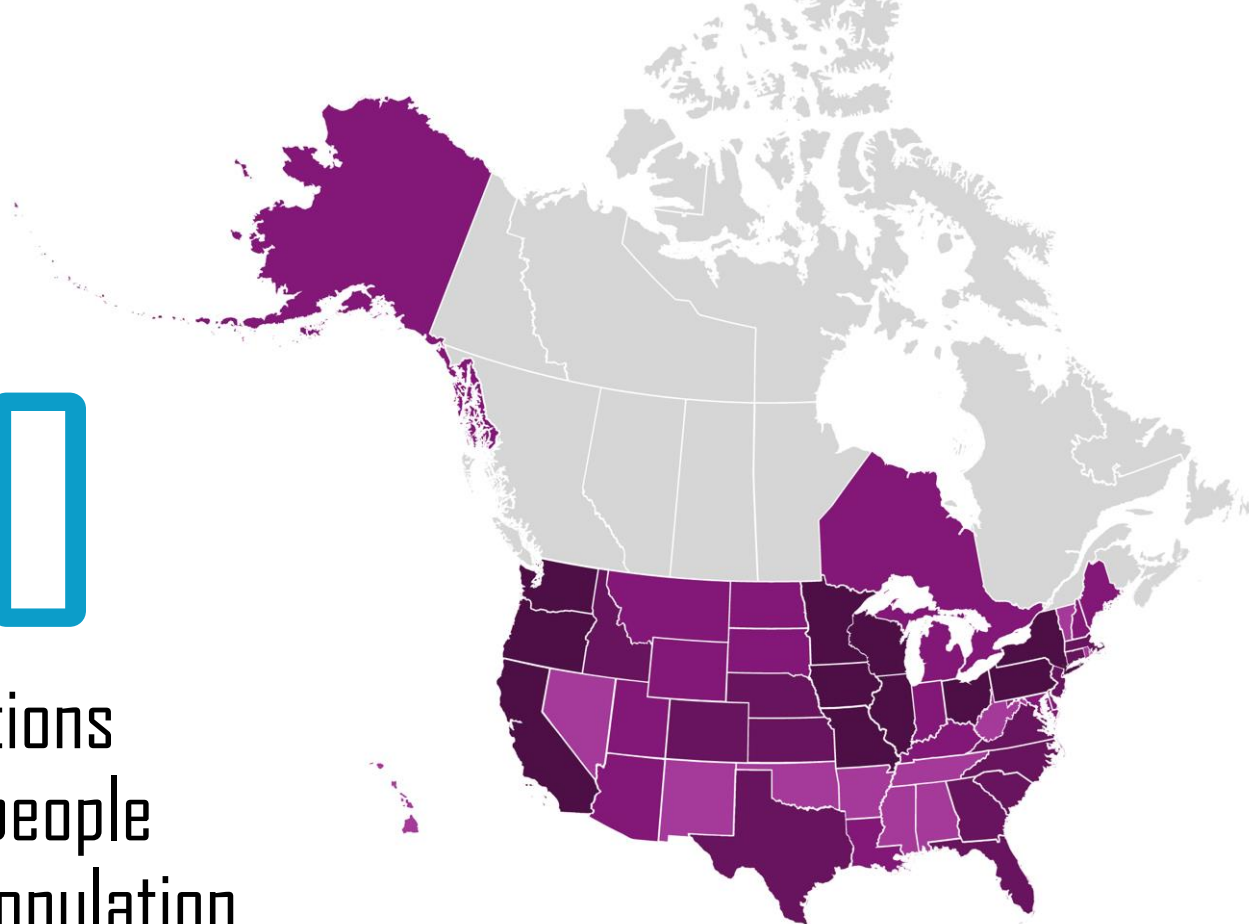
The NEW ENGLAND
JOURNAL of MEDICINE





2020

- ✓ **260** organizations
- ✓ **52 million** people
- ✓ **15%** of U.S. population



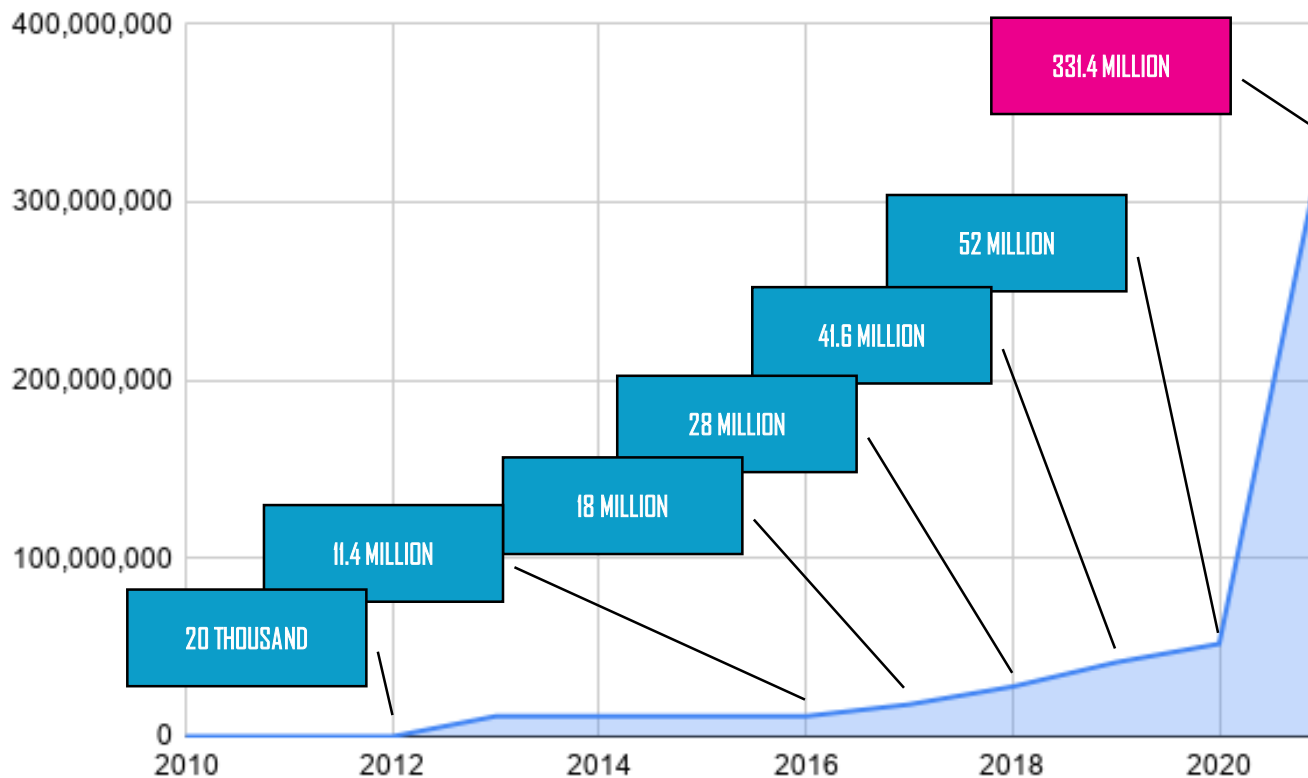
2021

21st Century Cures Act

- ✓ Empowered Americans with their health data
- ✓ Delivered to computers, cell phones & mobile apps
- ✓ Without charge, without delay
- ✓ All federally-funded research must be open access



People with access to ambulatory progress notes in the U.S.



OpenNotes spread in the U.S. (2010-2021)

Source: unpublished data
at opennotes.org

Open everything catalyzes culture change

- **2005:** Estonia **EE**
- **2012-2018:** Sweden **SE**
- **2021:** United States **US**
- **2023:** England
- 
- Australia? **AU**



Implementation tips

- Publications alone are not enough
- Find your champions right away
- Dissemination strategies needed for all stakeholders (*clinicians, executives, policymakers, EHR vendors, patient advocates*)

Getting
ready for open
everything

**What is the
sequencing?**

- Education first?
- Share everything
all at once?

How it started...

How it's going

April 6, 2021

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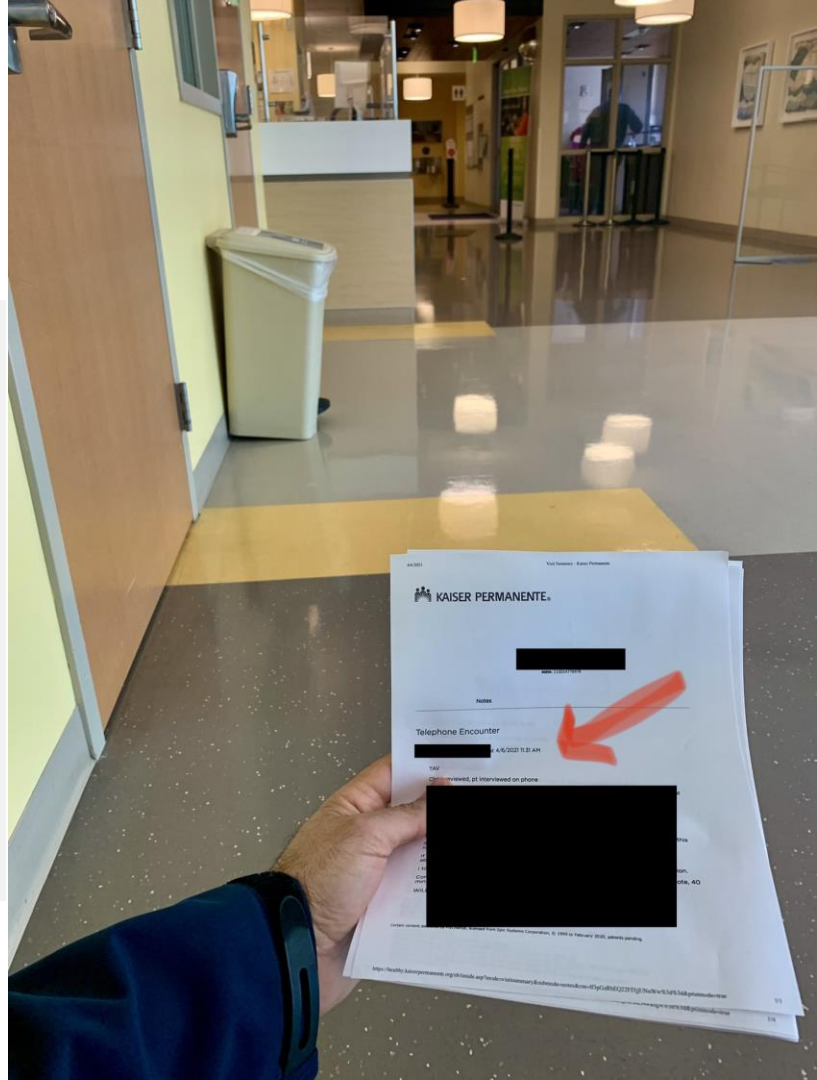
In the ER again for another
electrical cardioversion... this time armed with
instant notes from
an appointment not even two hours ago. Thank you
#opennotes.

This is real patient #empowerment 🧠

@HugoOC

@TheLizArmy

#MEDINFO23



June 14, 2023

//

Don't assume older adults aren't interested in using patient portals.

Last week, my patient in their late 70s asked when my clinical notes would be available for them to see in the portal. Today they complimented me on them! 😊

Andrea Bradford, PhD (@ABradfordPhD)
health psychologist, Houston, Texas

2021



@TheLizArmy

#MEDINFO23

2022



This time...

- ✓ Remind me of the plan
- ✓ Answer questions
- ✓ Spot inaccuracies

December 2021

//

I noticed my surgical report says I am
a 'right handed' person, but I am left handed. I believe
this is a typo...

12/10/2021 12:49 PM Operative Report addendum by [REDACTED]



Transparency
is logical
and ethical

Salmi L. Deciding on My Dimples. NEJM 2022

@TheLizArmy

#MEDINFO2022POINTMENT

We don't own the
open notes movement.
You do.



Liz Salmi

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@TheLizArmy

OpenNotes.org



Beth Israel Deaconess
Medical Center



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TEACHING HOSPITAL