

OpenNotes: A patient perspective

Liz Salmi



Beth Israel Deaconess
Medical Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL



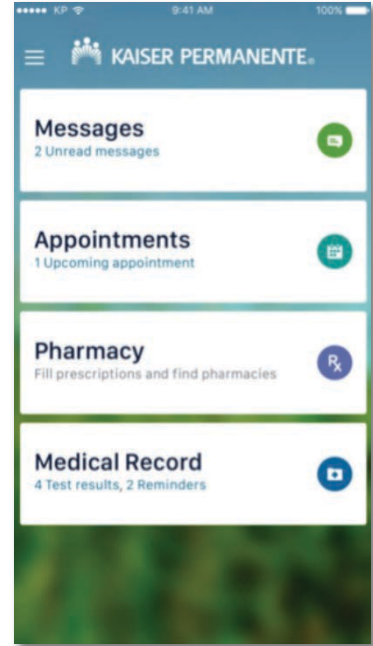
I am
a patient

2005



What mattered to me at 25

- ✓ Nice website
- ✓ Make appointments
- ✓ Email doctor
- ✓ View test results
- ✓ Order prescription refills

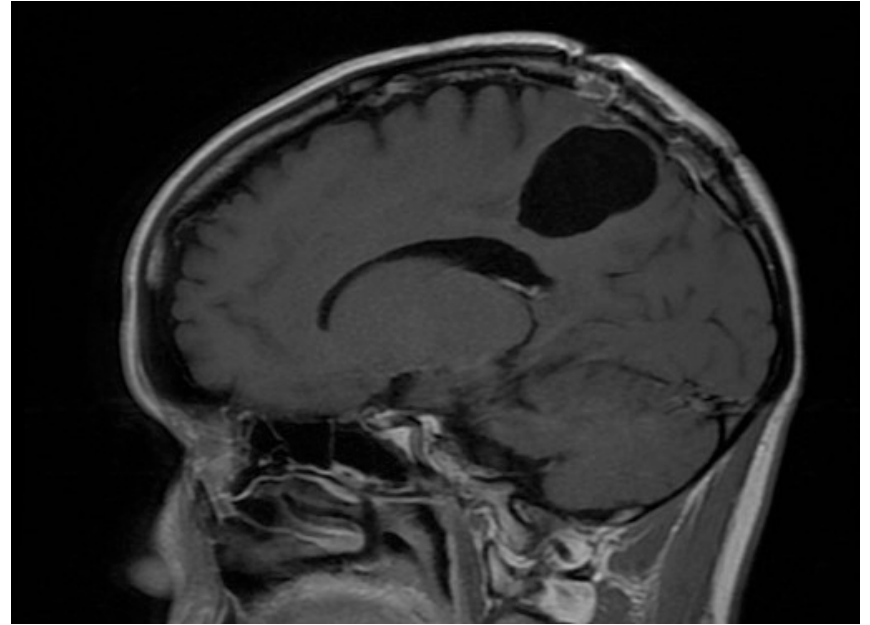


My 29th birthday

July 18, 2008
My 29th birthday



July 25, 2008
Astrocytoma





KAISER PERMANENTE
M. Stoyall 75975

LABORATORY REQUISITION
General Procedures

CHEMO PATIENT
PLEASE EXPEDITE

COMMENTS: R/O PC
 Hx of Pre-emp
 Follow Up Day of Cycle
 New result LHP
 Re Do Sample #

INSTRUCTIONS TO LAB / PATIENT
RBC CRITICAL RESULTS TO M. Stoyall USD - 261

<input checked="" type="checkbox"/> Sodium	<input type="checkbox"/> Magnesium
<input checked="" type="checkbox"/> Potassium	<input type="checkbox"/> Uric Acid
<input checked="" type="checkbox"/> Creatinine w/GFR	<input type="checkbox"/> Albumin
<input checked="" type="checkbox"/> BUN	<input type="checkbox"/> Serum Protein Elect.
<input checked="" type="checkbox"/> Glucose - fasting	<input type="checkbox"/> Ferritin
<input checked="" type="checkbox"/> Glucose - random	<input type="checkbox"/> Iron/TIBC
<input checked="" type="checkbox"/> Hemoglobin A-C	<input type="checkbox"/> High Electrophoresis
<input checked="" type="checkbox"/> Folate/B12	<input type="checkbox"/> TSH
<input checked="" type="checkbox"/> Carbon Dioxide	<input type="checkbox"/> Free T4 analog
<input checked="" type="checkbox"/> Chloride	<input type="checkbox"/> PSA
<input checked="" type="checkbox"/> Calcium	<input type="checkbox"/> Serum Pregnancy
<input checked="" type="checkbox"/> Phosphorus	<input type="checkbox"/> Quant. Beta HCG
	<input checked="" type="checkbox"/> Total Steroids

SEROLEGY

<input type="checkbox"/> RPR (VDRL)	<input type="checkbox"/> Hep A IgM (Acute)
<input type="checkbox"/> Monoc	<input type="checkbox"/> Hep A IgG (Immunity)
<input type="checkbox"/> ANA	<input type="checkbox"/> Hep B Surface Ag (Acute or chronic)
<input type="checkbox"/> Rheumatoid Factor	<input type="checkbox"/> Hep B Core Ab (Pre-treatment)
<input type="checkbox"/> C-Rep (C-Reactive Protein)	<input type="checkbox"/> Hep B Surface Ab (Immunity)
<input type="checkbox"/> Blood Group, Rh	<input type="checkbox"/> Hep B Surface Ab (Pre-treatment)
<input type="checkbox"/> Antibody Screen	<input type="checkbox"/> Hepatitis C Antibody
<input type="checkbox"/> Direct Coombs	

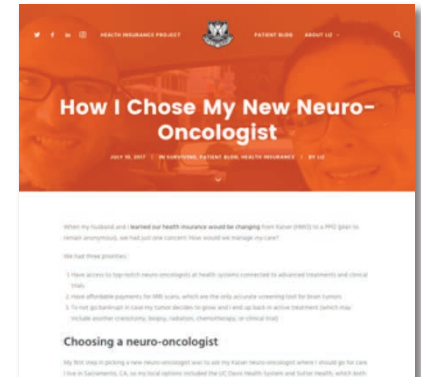
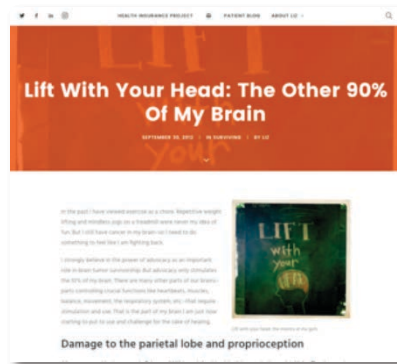
HEMATOLOGY

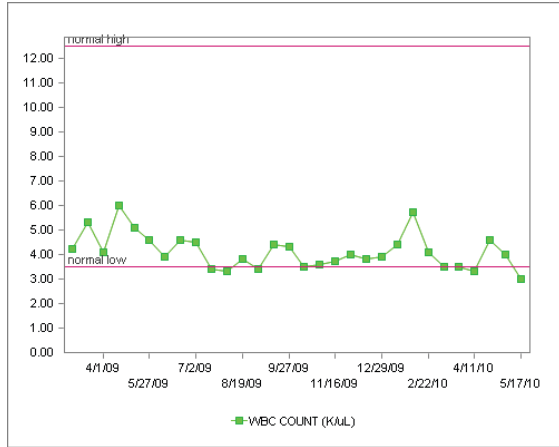
<input type="checkbox"/> Hemoglobin	<input type="checkbox"/> Hematocrit
<input type="checkbox"/> Hemoglobin	<input type="checkbox"/> Hemoglobin
<input type="checkbox"/> Hemoglobin	<input type="checkbox"/> Hemoglobin
<input type="checkbox"/> Hemoglobin	<input type="checkbox"/> Hemoglobin
<input type="checkbox"/> Hemoglobin	<input type="checkbox"/> Hemoglobin

COAGULATION

<input type="checkbox"/> Prothrombin Time (PT)	<input type="checkbox"/> International Normalized Ratio (INR)
<input type="checkbox"/> Partial Thromboplastin Time (PTT)	<input type="checkbox"/> Fibrinogen
<input type="checkbox"/> D-Dimer	<input type="checkbox"/> Fibrin
<input type="checkbox"/> Fibrinogen	<input type="checkbox"/> Fibrin
<input type="checkbox"/> Fibrinogen	<input type="checkbox"/> Fibrin

My blog → TheLizArmy.com





Continuity of Care Document - Elizabeth Salmi (Female, born █████ 1979) As of Feb. 09, 2017

Patient Demographics

Patient Address	Communication	Language	Race / Ethnicity
██████████, CA ██████████	██████████ (Home) ██████████ (Work) ██████████ (Mobile) elsalmi@gmail.com	English - Spoken (Preferred) English - Written (Preferred)	White - Other White or European / American/United States

Note from Kaiser Permanente Northern California
This document contains information that was shared with Liz Salmi. It may not contain the entire record from Kaiser Permanente Northern California.

Encounter Details

Date	Type	Department	Care Team
02/02/2009	Office Visit	NEUROSURGERY ██████████, CA 95825-2115	██████████ (M.D.) SACRAMENTO, CA 95825-2115

Active Allergies and Adverse Reactions - as of 02/09/2017

Allergen	Noted Date	Severity	Reactions	Comments
Lamotrigine	05/04/2009	Medium	Rash	

Active Problems - as of 02/09/2017

Problem	Noted Date
GENETIC CANCER RISK EVALUATION	11/17/2015
HISTORY OF CHEMOTHERAPY	07/27/2011
HISTORY OF SURGERY INVOLVING OPENING THE SKULL	07/27/2011
ECZEMA	11/01/2010
ANXIETY DISORDER DUE TO ANOTHER MEDICAL CONDITION	02/11/2009
HEARING LOSS, SENSORINEURAL, LEFT	02/05/2009
CANCER OF THE BRAIN, ASTROCYTOMA, GRADE 2	10/22/2008
PARTIAL EPILEPSY	10/09/2008

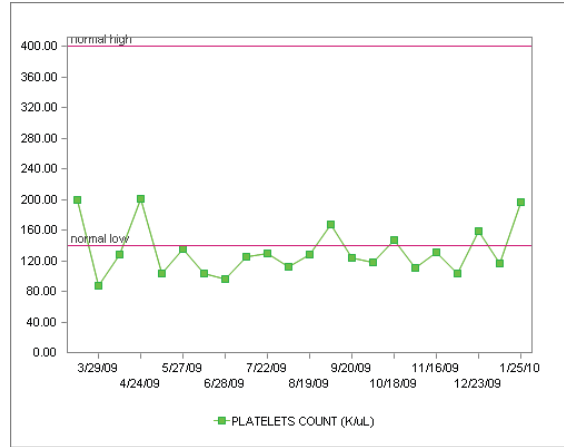
Last Filled Vital Signs

Vital Sign	Reading	Time Taken
Blood Pressure	119/70	02/02/2009 9:10 AM PST
Pulse	68	02/02/2009 9:10 AM PST
Temperature	-	-
Respiratory Rate	-	-
Height	-	-
Weight	-	-
Body Mass Index	-	-
Oxygen Saturation	-	-

Plan of Care
Not on file

Results
Not on file

Visit Diagnoses
CANCER OF THE BRAIN, ASTROCYTOMA, GRADE 2 - Primary





How I Chose My New Neuro-Oncologist

JULY 10, 2017 | IN SURVIVING, PATIENT BLOG, HEALTH INSURANCE | BY LIZ

When my husband and I learned our health insurance would be changing from Kaiser (HMO) to a PPO (plan to remain anonymous), we had just one concern: How would we manage *my* care?

We had three priorities:

1. Have access to top-notch neuro-oncologists at health systems connected to advanced treatments and clinical trials
2. Have affordable payments for MRI scans, which are the only accurate screening tool for brain tumors
3. To not go bankrupt in case my tumor decides to grow and I end up back in active treatment (which may include another craniotomy, biopsy, radiation, chemotherapy, or clinical trial)

Choosing a neuro-oncologist

My first step in picking a new neuro-oncologist was to ask my Kaiser neuro-oncologist where I should go for care. I live in Sacramento, CA, so my local options included the UC Davis Health System and Sutter Health, which both have neuro-oncology programs. (I could have also considered Dignity Health, but they do not specialize in neuro-oncology.) With the PPO plan, I could also choose from UCSF and Stanford, which are both known for having world class neuro-oncology teams.

My Kaiser doctor immediately said I should go to University of California, San Francisco (UCSF) because of their



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Rights under HIPAA

- ✓ **See** a copy of your medical record
- ✓ **Get** a copy of your medical record
- ✓ **Change** incorrect information
- ✓ **Find out** who has seen your health information

Printed record = \$725.40

Digital record = \$45 for 3 DVDs



4,836-page
medical
record

- ✓ Emails
- ✓ Lab results
- ✓ Surgical reports
- ✓ Pathology reports
and biomarkers
- ✓ **Clinical notes**

Progress Notes

Progress Notes by [REDACTED] (M.D.) at 12/16/2016 3:31 PM Version 1 of 1

Author: [REDACTED] (M.D.) Service: (none) Author Type: Physician
Filed: 12/16/2016 3:36 PM Note Time: 12/16/2016 3:31 PM Status: Signed
Editor: [REDACTED] (M.D.) (Physician)

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 temozolomide 150 mg/m² 5/23 for 24 cycles from 2/2009 to 4/2011.

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

I have confirmed with the patient and/or the medical record the presence of the above diagnoses, and the diagnoses are followed or will be followed by his or her PCP or appropriate specialist.

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.

Pathology:

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

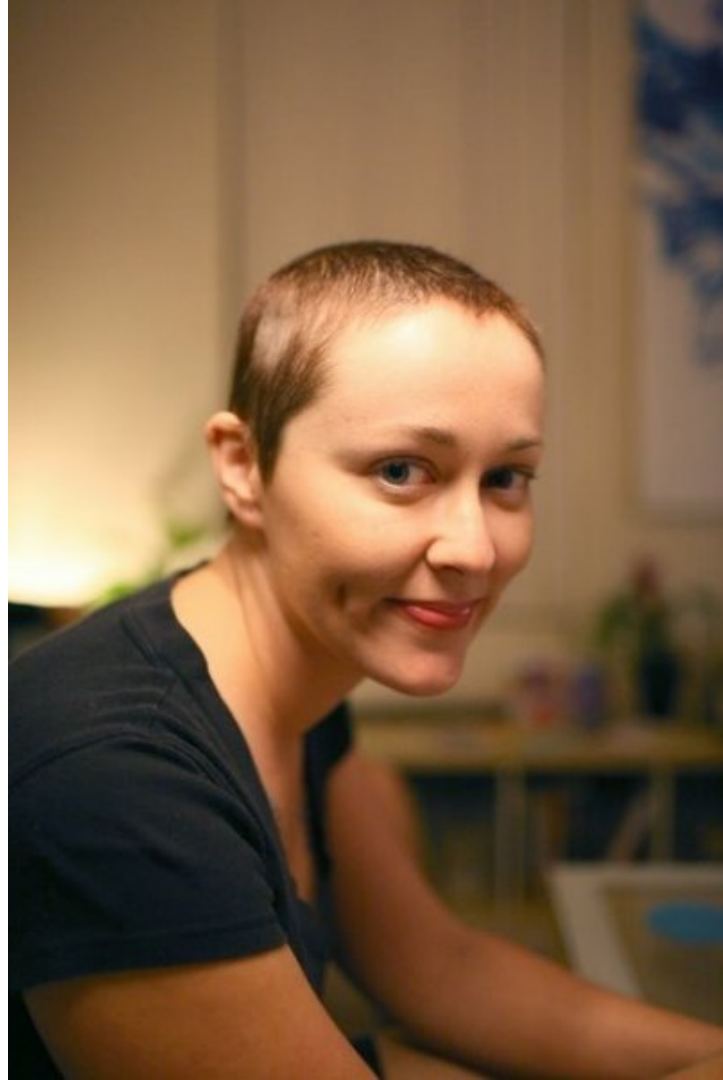
The total visit time face to face with the patient was over 30 minutes.

Time spent in counseling and discussion with the patient was over 25 minutes.

Topics discussed: diagnosis, imaging findings, prognosis and follow-up plan.

INTERVAL HISTORY:

The patient was last evaluated in the neuro-oncology clinic in October 2008. Since that time, her main issue has been related to difficult seizure management. She has had increasing frequency with a changing characteristic to the seizures over the past few months. The last seizure occurred on Jan. 14th and was a partial seizure. Her aura is now "feeling a little out of it... Things aren't clear... Then something more happens... I'll take ativan... And then afterwards get dizzy, can feel my eyes twitching". It starts in the right hand, stating "it doesn't really feel like it belongs to me" and then may progress up the arm or over the chest. This often causes more anxiety. She notes on Dec 21 had an episode where her chest was "pulsating" and Bret noted "her abdomen was quivering." He had to call 911 at that time.



Patients like me
are created
every day



ANDROID



@TheLizArmy



change.org



Of the 40,000
Google searches made
every second,
2,000 are health-related

Published research →

Annals of Internal Medicine
Journal of the American Medical Association
New England Journal of Medicine
American Journal of Medicine
Journal of American Health Information Management Association
British Medical Journal of Quality and Safety
Journal of the American Medical Informatics Association
Academy of Medicine
Journal of General Internal Medicine
BMJ (British Medical Journal)
Journal of Medical Care
Journal of Medical and Internet Research
The Joint Commission Journal on Quality and Patient Safety
Journal of the International Association of Providers of AIDS Care
American Medical Informatics Association
Journal of the American College of Radiology
Journal of Hospital Medicine
Health Expectations
New England Journal of Medicine *Catalyst*
BMC Medical Informatics and Decision Making
Society of General Internal Medicine Forum

opennotes.org/case-for-opennotes

Patients 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
- 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
- **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

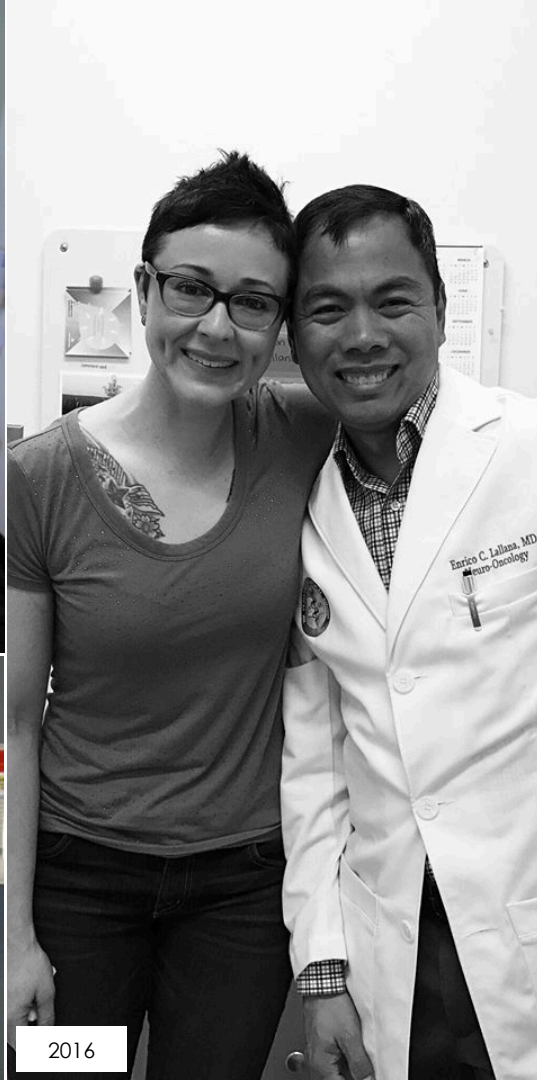
People are
capable of
amazing things

You can
make it easier
for patients
to be engaged

Transparency is
logical & ethical



2008



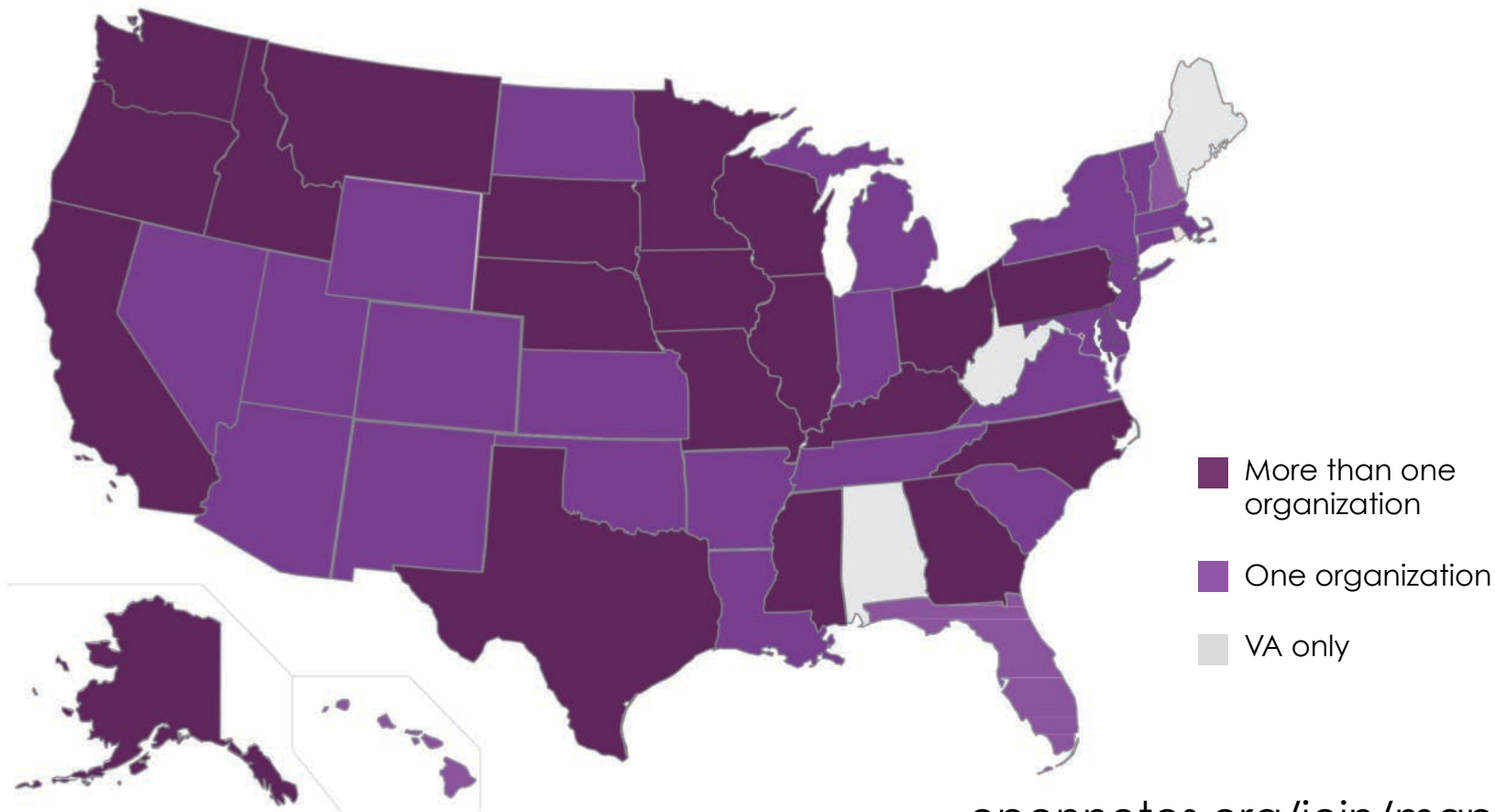
2016



2011



17+ million people have access to clinical notes



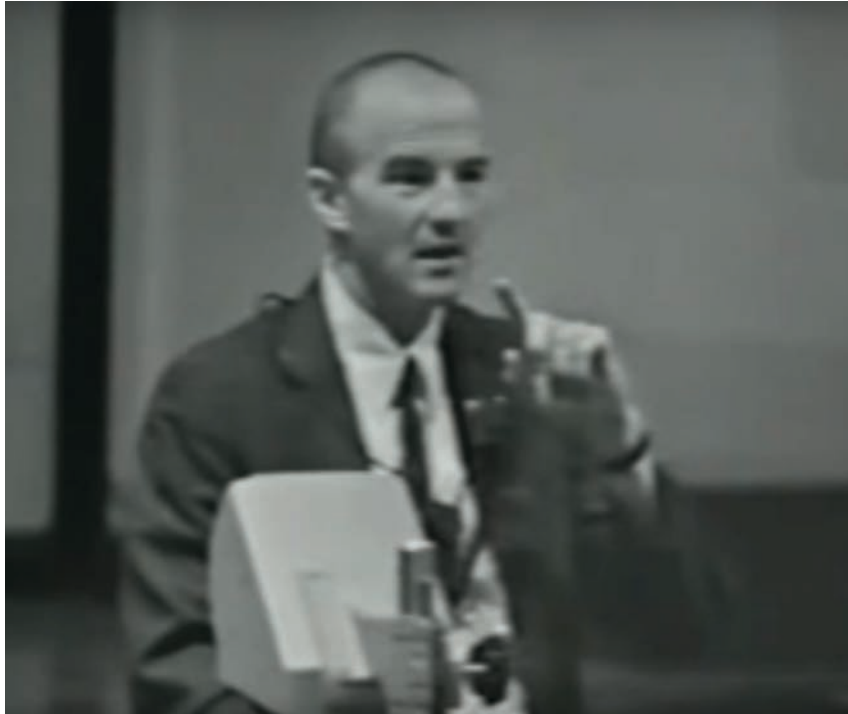
OpenNotes available at all U.S. Department of Veterans Affairs Medical Centers nationwide.



opennotes.org/join/map

5% of U.S.
population

Larry Weed, MD



“A doctor has to be a guidance system. He is not an oracle that knows answers. And once he accepts the concept of being a guidance system ... **the record suddenly becomes an unbelievably important document in education, in care, and in research ...** The new knowledge we need now is how to use knowledge.”

Internal Medicine Grand Rounds, 1971

Are you a
patient?

Share your notes

Patients & Doctors on the Same Page





Thank you

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@TheLizArmy



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