



# US perspective – OpenNotes: patients' rights, data access, and policy

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November 9, 2022



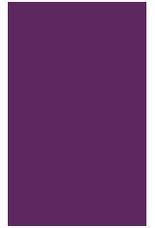
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# Conflicts of Interest

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- Agency for Healthcare Research and Quality
- Cambia Foundation
- CRICO
- John A. Hartford Foundation
- National Institute on Aging
- National Cancer Institute
- NYSHealth
- Office of the National Coordinator for Health Information Technology
- Patient Centered Outcomes Research Institute
- Ralph C. Wilson Jr. Foundation
- Swedish Ministry of Health and Foreign Affairs: Forte

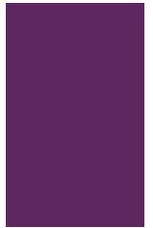


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# The OpenNotes Team



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# 1973

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“Four serious problems (maintaining high quality of care, establishing mutually satisfactory physician/patient relations, ensuring continuity, and avoiding excessive bureaucracy) could be alleviated, in part, if patients were given copies of their medical records.”

Budd N. Shenkin & David Warner. ***Giving the Patient His Medical Record: A Proposal to Improve the System.*** *The New England Journal of Medicine.* September 27, 1973; 289:688-692

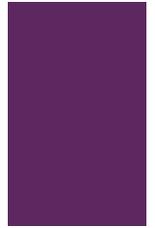


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# Patient's rights meet the EHR



- 1973: The American Hospital Association adopts “A Patient’s Bill of Rights”
  - Emphasizes – activities must be conducted with an overriding concern for the values and integrity of patients”
- 1980s - 90s: Measuring patient experience
- 1996: Health Insurance Portability and Accountability Act
  - Gives patients in the United States the legal right to access their medical record
- 2009: American Recovery and Reinvestment Act
  - Provide incentives to clinicians & hospitals to adopt electronic health records
  - A patient portal allowing “view, download & transmit” is required.



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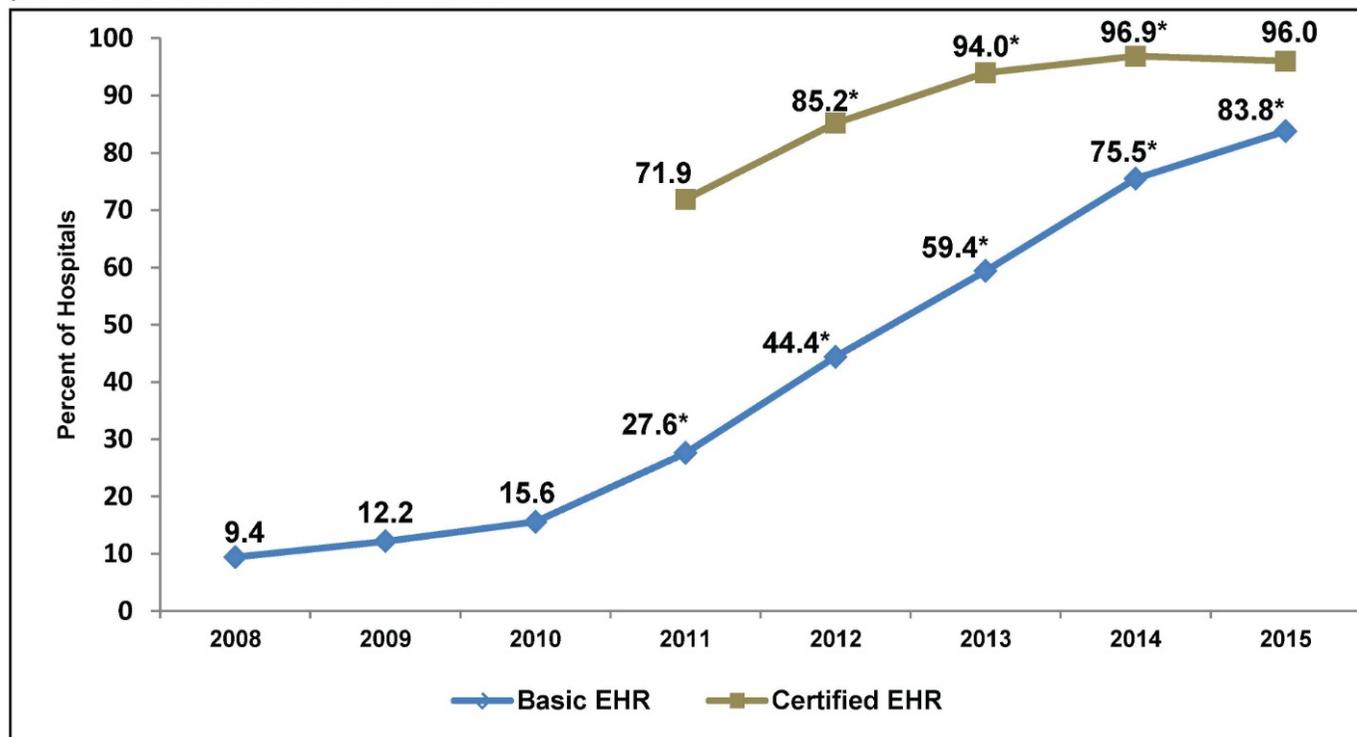
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# EHR adoption: US 2008-2015



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Figure 1: Percent of non-Federal acute care hospitals with adoption of at least a Basic EHR with notes system and possession of a certified EHR: 2008-2015.

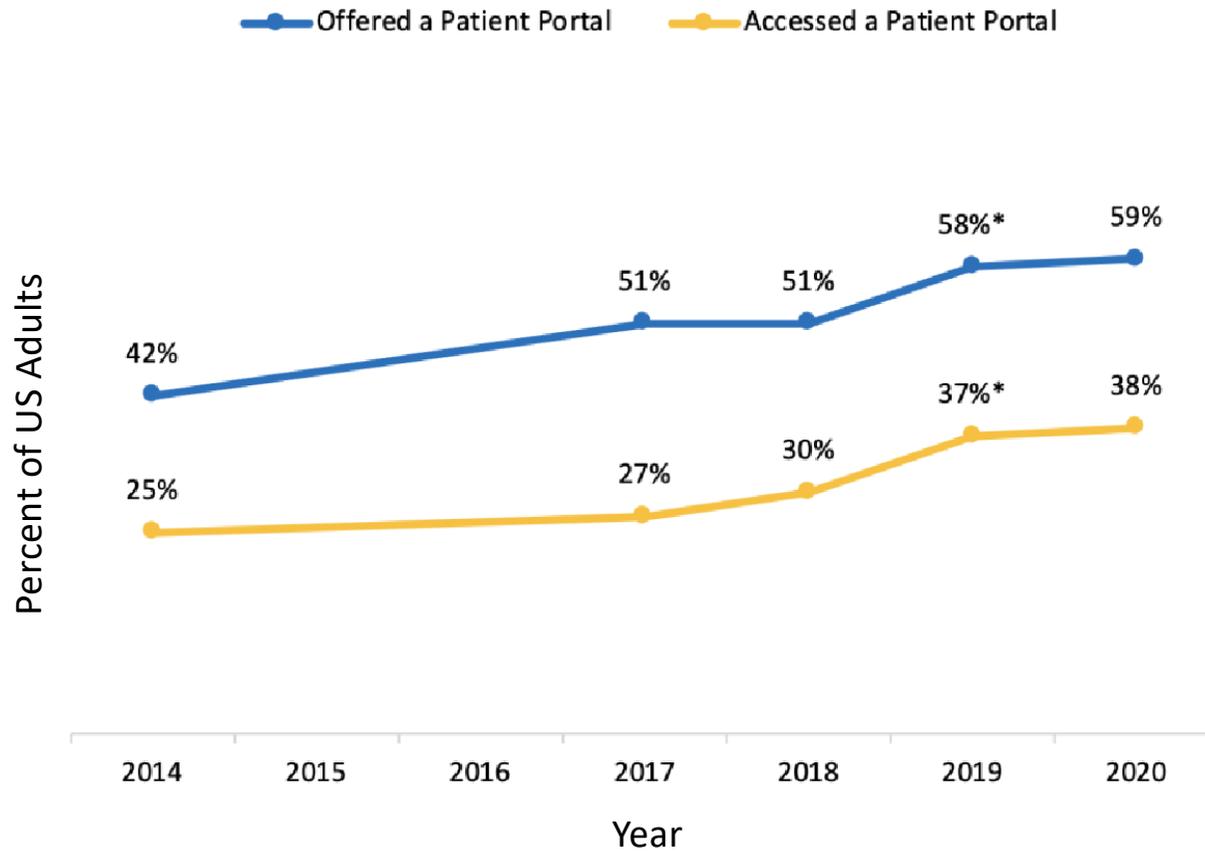
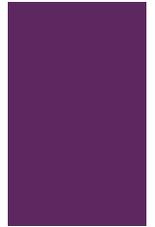


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# Patient portal access and use: US 2014 - 2020



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[https://www.healthit.gov/sites/default/files/page/2021-09/HINTS\\_2020\\_Consumer\\_Data\\_Brief.pdf](https://www.healthit.gov/sites/default/files/page/2021-09/HINTS_2020_Consumer_Data_Brief.pdf)



# Healthcare in a land called PeoplePower: nothing about me without me

Tom Delbanco MD<sup>1</sup>, Donald M. Berwick MD<sup>2</sup>, Jo Ivey Boufford MD<sup>3</sup>,  
S. Edgman-Levitan PA<sup>4</sup>, Günter Ollenschläger MD<sup>5</sup>, Diane Plamping PhD<sup>6</sup>  
and Richard G. Rockefeller MD<sup>7</sup>

## Abstract

In a 5-day retreat at a Salzburg Seminar attended by 64 individuals from 29 countries, teams of health professionals, patient advocates, artists, reporters and social scientists adopted the guiding principle of ‘nothing about me without me’ and created the country of PeoplePower. Designed to shift health care from ‘biomedicine’ to ‘infomedicine’, patients and health workers throughout PeoplePower join in informed, shared decision-making and governance. Drawing, where possible, on computer-based guidance and communication technologies, patients and clinicians contribute actively to the patient record, transcripts of clinical encounters are shared, and patient education occurs primarily in the home, school and community-based organizations. Patients and clinicians jointly

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29 September 2000

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satisfaction. shared decision-making.

Health Expectations, 2001 4, pp.144±150



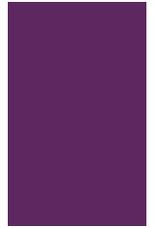
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# People Power

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“Not only do patients have nearly complete access to their medical records (although they don't have to review their record if they don't want to), but they also write in it – elaborating, tracking, and explicating problems, correcting mistakes, prioritizing needs, and at times suggesting both diagnoses and treatment plans.”



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# The pilot years: 2010 - 2012



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# Original OpenNotes Pilot

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- 2010-2011
- Three healthcare organizations
  - One urban serving historically marginalized populations
  - One rural
  - One academic medical center
- 100 primary care physicians
- 20,000 patients



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# Findings

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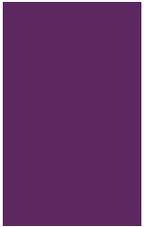
- Patients loved it – 99% wanted it to continue
- 80% of patients read at least one note
- 75% reported benefits
  - Remembering and understanding care plan, taking medications
- Few effects for clinicians
  - “Are you sure it is on?”
  - Email and phone volume unchanged
  - No providers stopped sharing after the pilot



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# The spread years: 2012-2018



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# The practice gap

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The average length of time between when a positive intervention is published in the medical literature and when it becomes standard of care

**17 years**



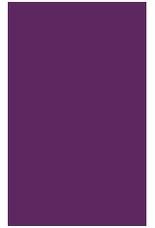
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# How did OpenNotes avoid the practice gap?

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- Generous funding for dissemination and additional evaluation
- National trends
- New findings
- Vendors



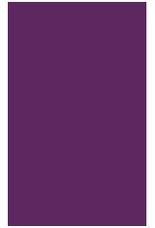
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# Generous foundation support

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- The OpenNotes “Road Show”



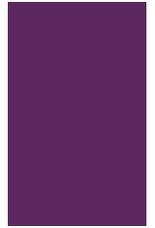
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# Other dissemination strategies

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- Social media
- Regional consortia to drive competition
- Vendor partnerships (not financial!)
- Partnering with professional organizations
- Partnering with patient advocacy organizations



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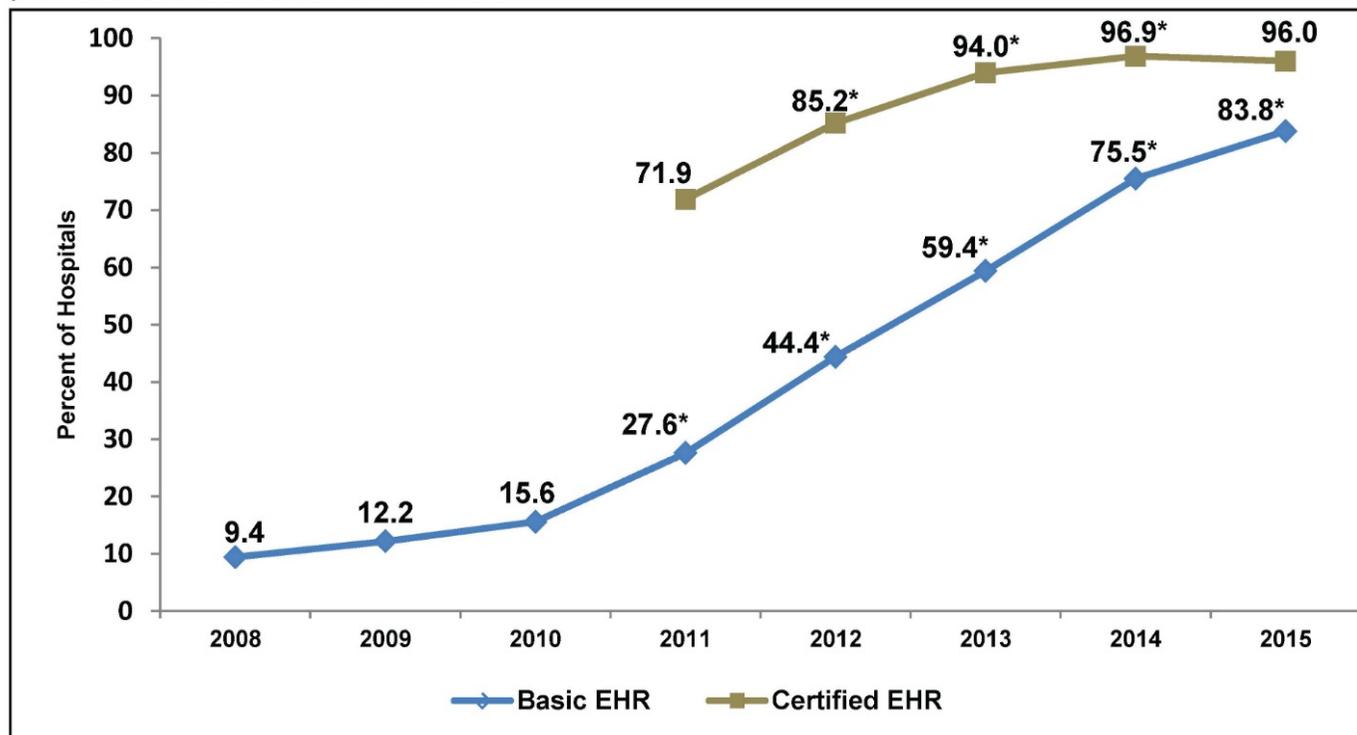
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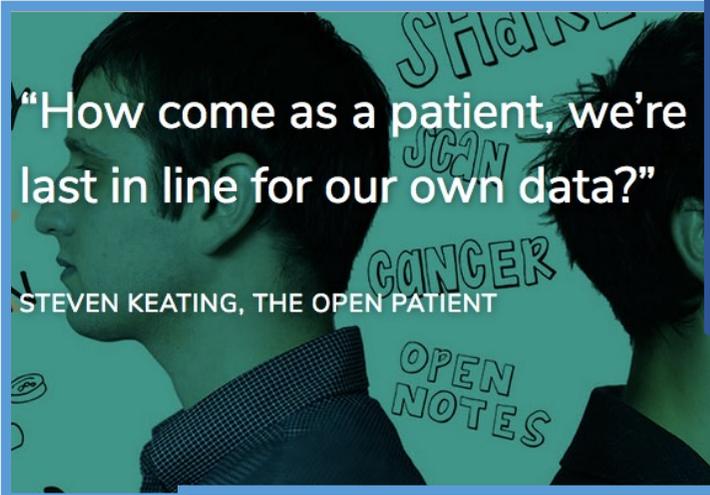


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# A Growing Patient Movement



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# New findings

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- Prominent healthcare organizations are early adopters and report similar experiences
- OpenNotes can be an important part of safer care
  - Following up on referrals and test results
  - Finding clinically important mistakes
  - Increasing feelings of trust in provider
- Benefits hold as sharing notes moves beyond primary care



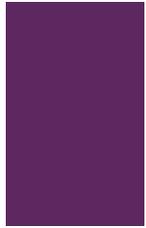
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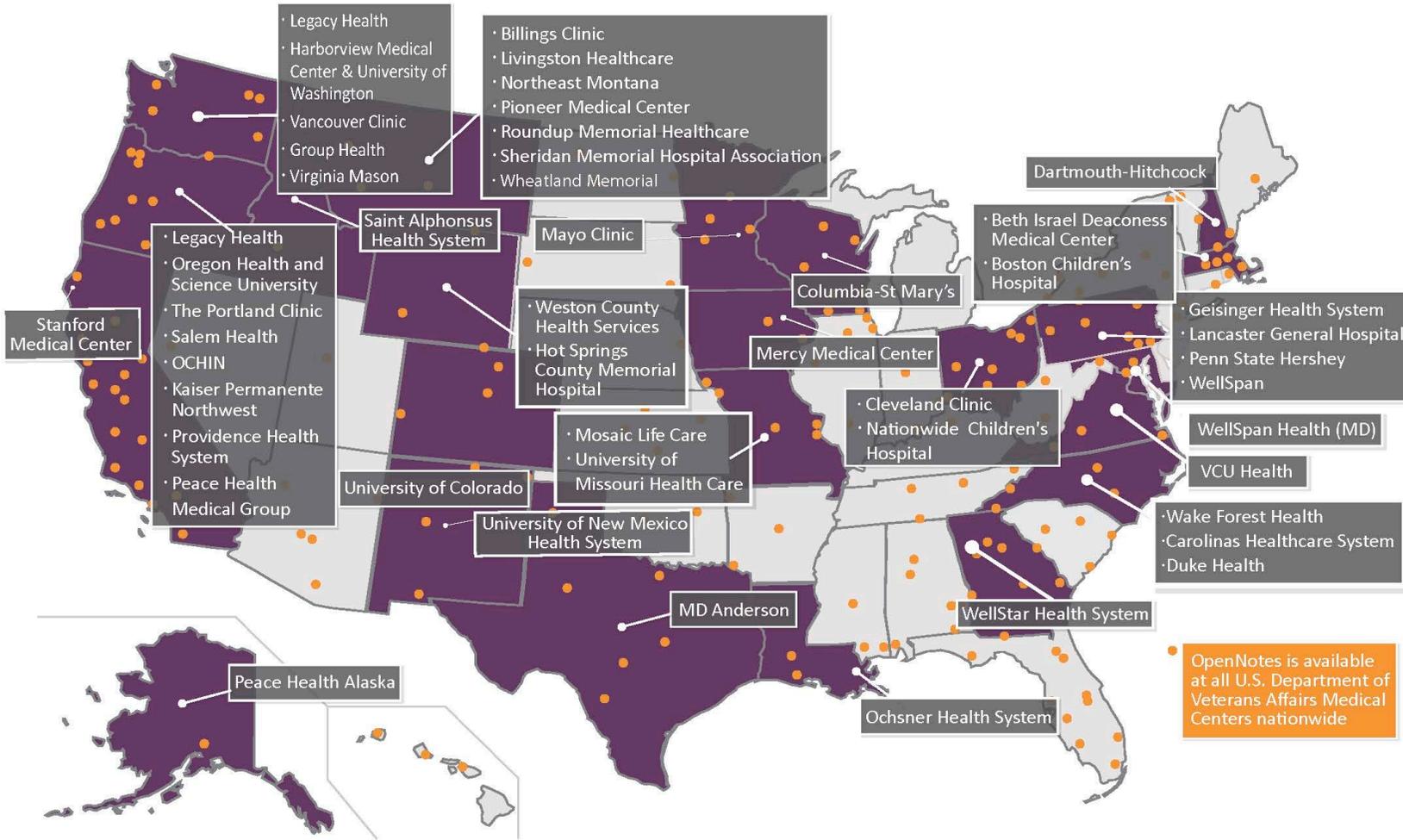
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More than 6 million patients have easy access to their clinicians' notes



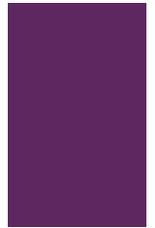
2015



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2018



# 33+ Million Patients Have Access to Notes

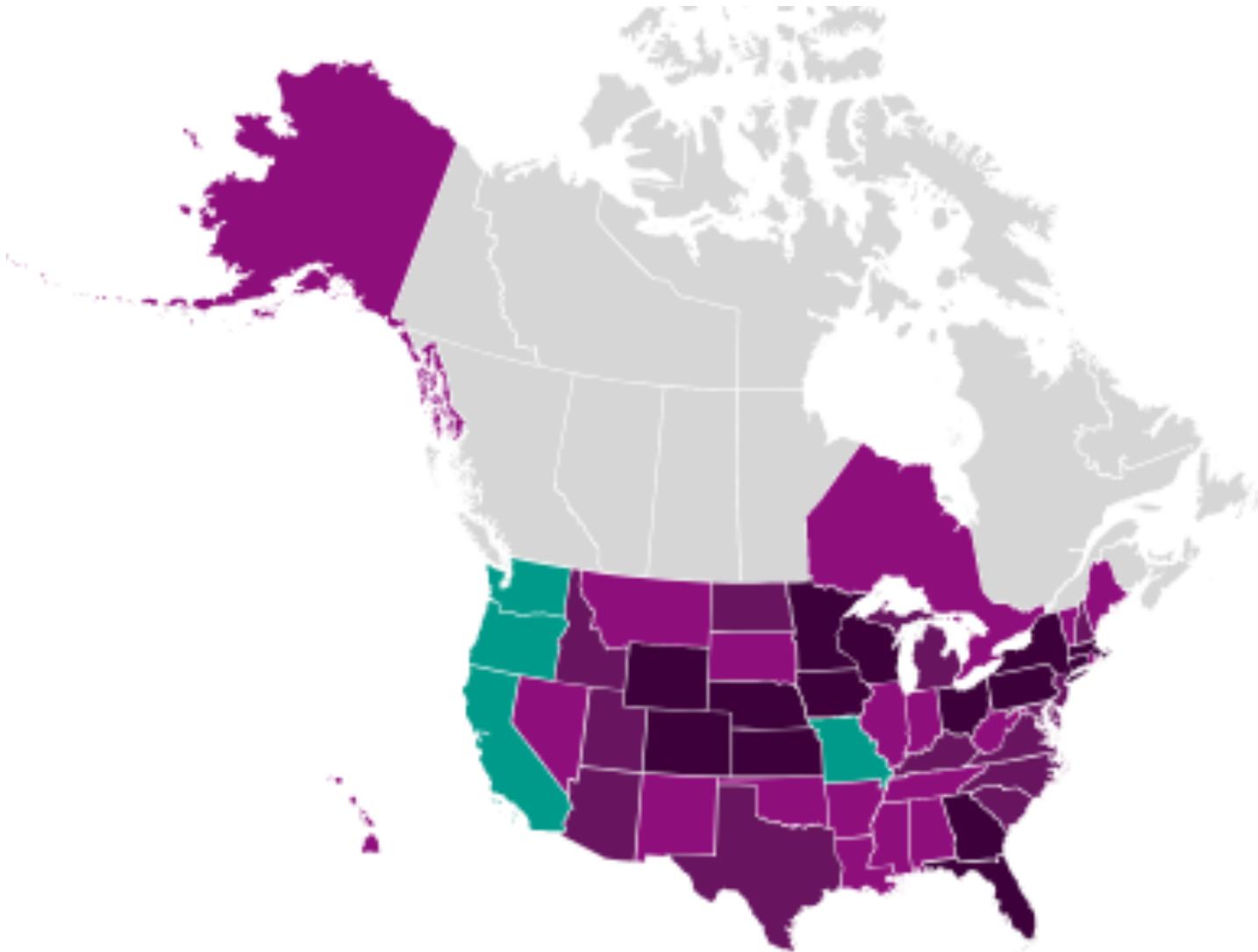


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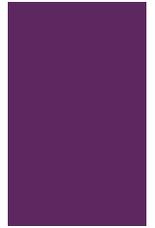
Map Key: = 0 institutions | = 1 institution (The Department of Veterans Affairs) | = 2-3 institutions |

= 4-5 institutions | = 6-10 institutions | = over 10 institutions



# Vendors

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- 2015: OpenNotes is the default setting in all new Epic installations
- Cerner makes note sharing increasingly easy and adds a “notes” button to their patient portal landing page



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# The policy years: 2019-2022

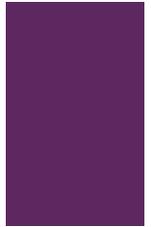


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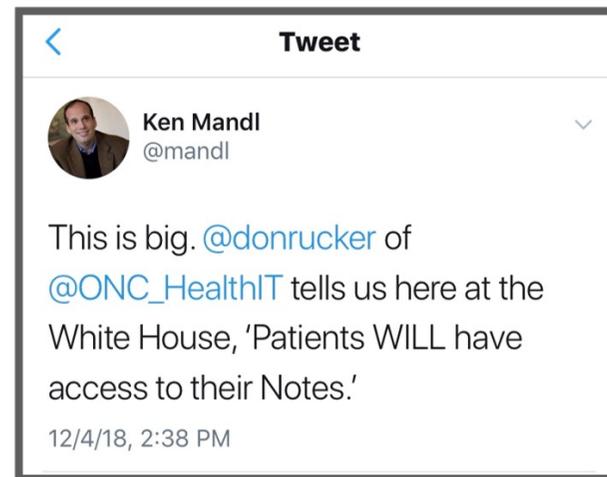
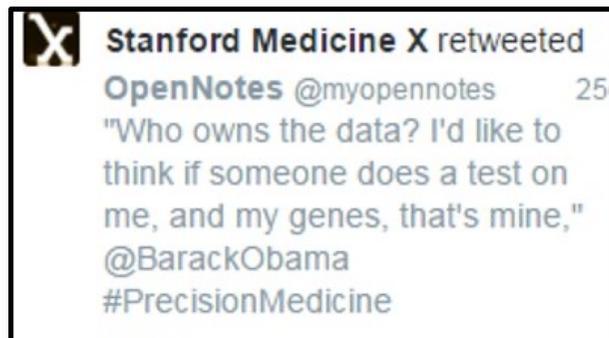
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# Federal legislation - 2016



## The 21<sup>st</sup> Century Cures Act

Patients must have access to all electronic health data held about them in electronic health records **without special effort or additional charge**

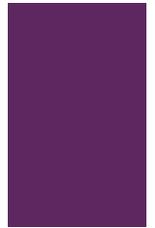


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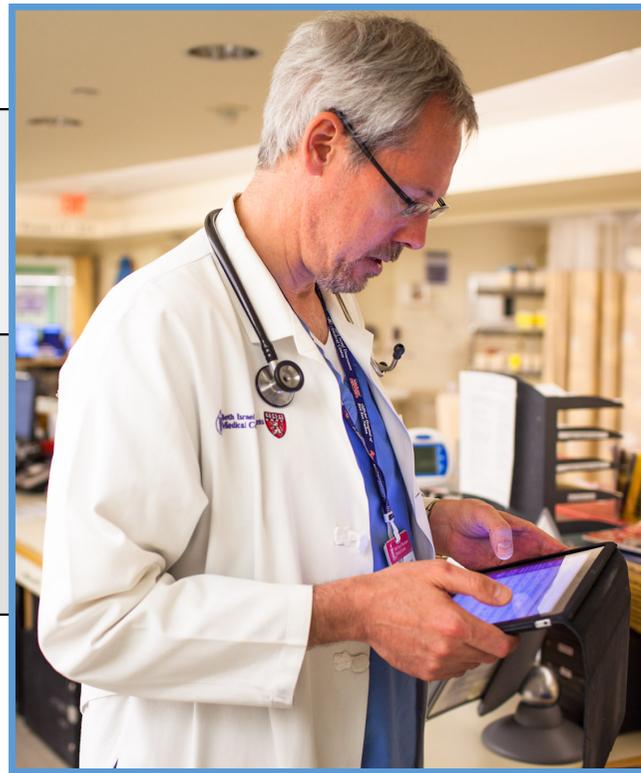


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# Meaningful Use: Stage 3



<b>Required Open API</b>
<b>Fast Healthcare Interoperability Resources (FHIR)</b>

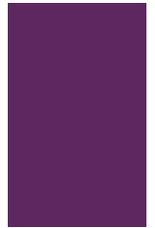


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# Common Clinical Data Set → U.S. Core Data for Interoperability



October 5, 2022

Patients must have electronic access to virtually ALL of  
the information in their electronic health records  
AND  
the option to access that data through any third party  
app of their choice

21. Provenance

22. Clinical Notes



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# Questions remain

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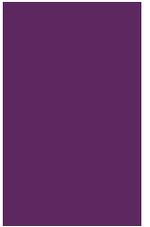
- How to implement note sharing in a way that helps patients to
  - Know what notes are?
  - Know why they should read them?
  - Know how to find them?
- Share with adolescents?
- Share with care partners?
- Ensure we aren't widening the digital divide?
- Clinician workload?



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# Questions?

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