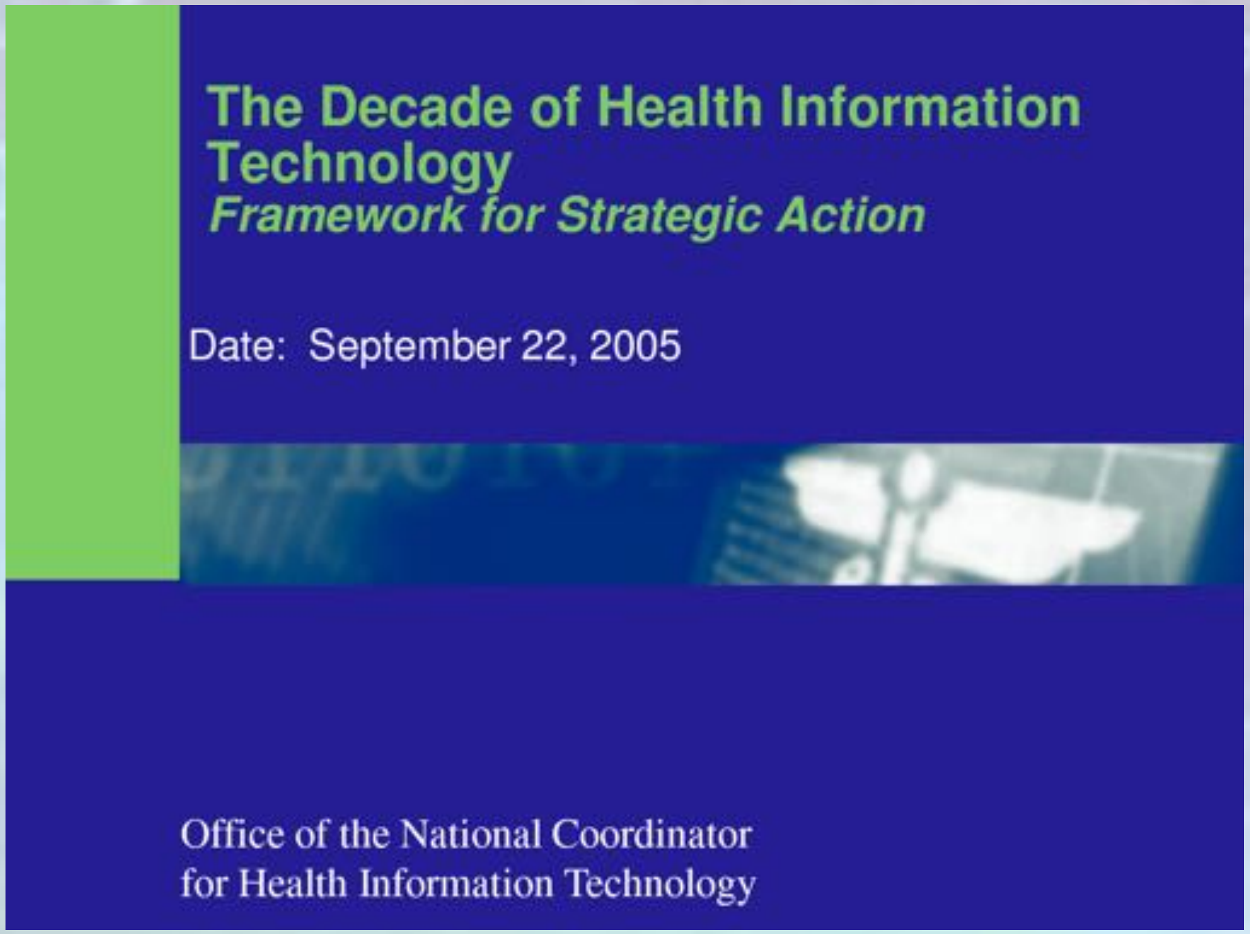
HIT's 2nd Decade: Getting Value

David J. Brailer, MD, PhD

Or, After 10 years and $35 Billion, Where Is My Data?

Health IT Plan - 2004

- Goal 1 - Inform Clinical Practice
- Goal 2 - Interconnect Clinicians
- Goal 3 - Personalize Care
- Goal 4 - Improve Population Health

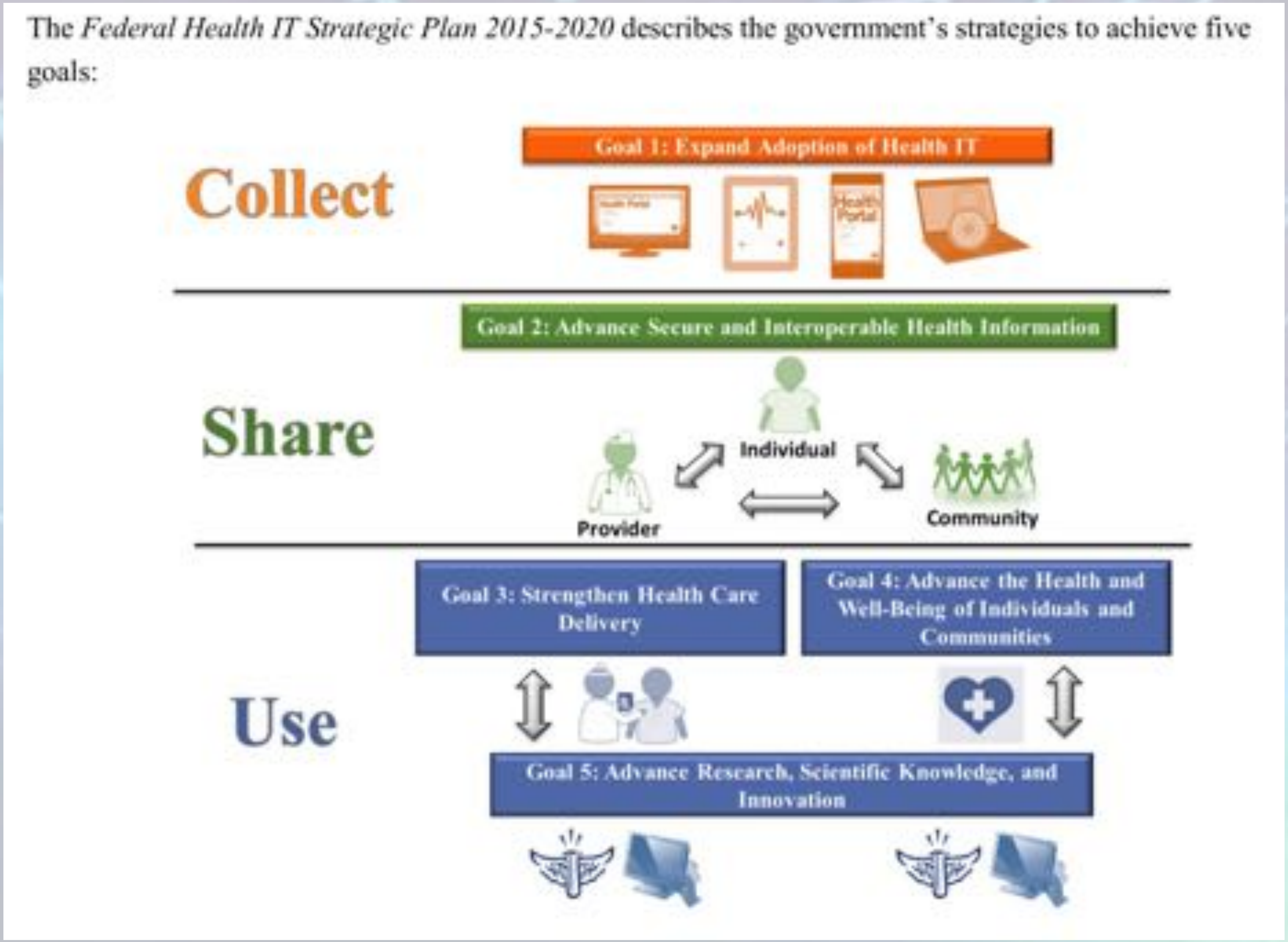


The Decade of Health Information Technology
Framework for Strategic Action

Date: September 22, 2005

Office of the National Coordinator
for Health Information Technology

Health IT Plan - 2015



The *Federal Health IT Strategic Plan 2015-2020* describes the government's strategies to achieve five goals:

Collect

Goal 1: Expand Adoption of Health IT

Share

Goal 2: Advance Secure and Interoperable Health Information

Use

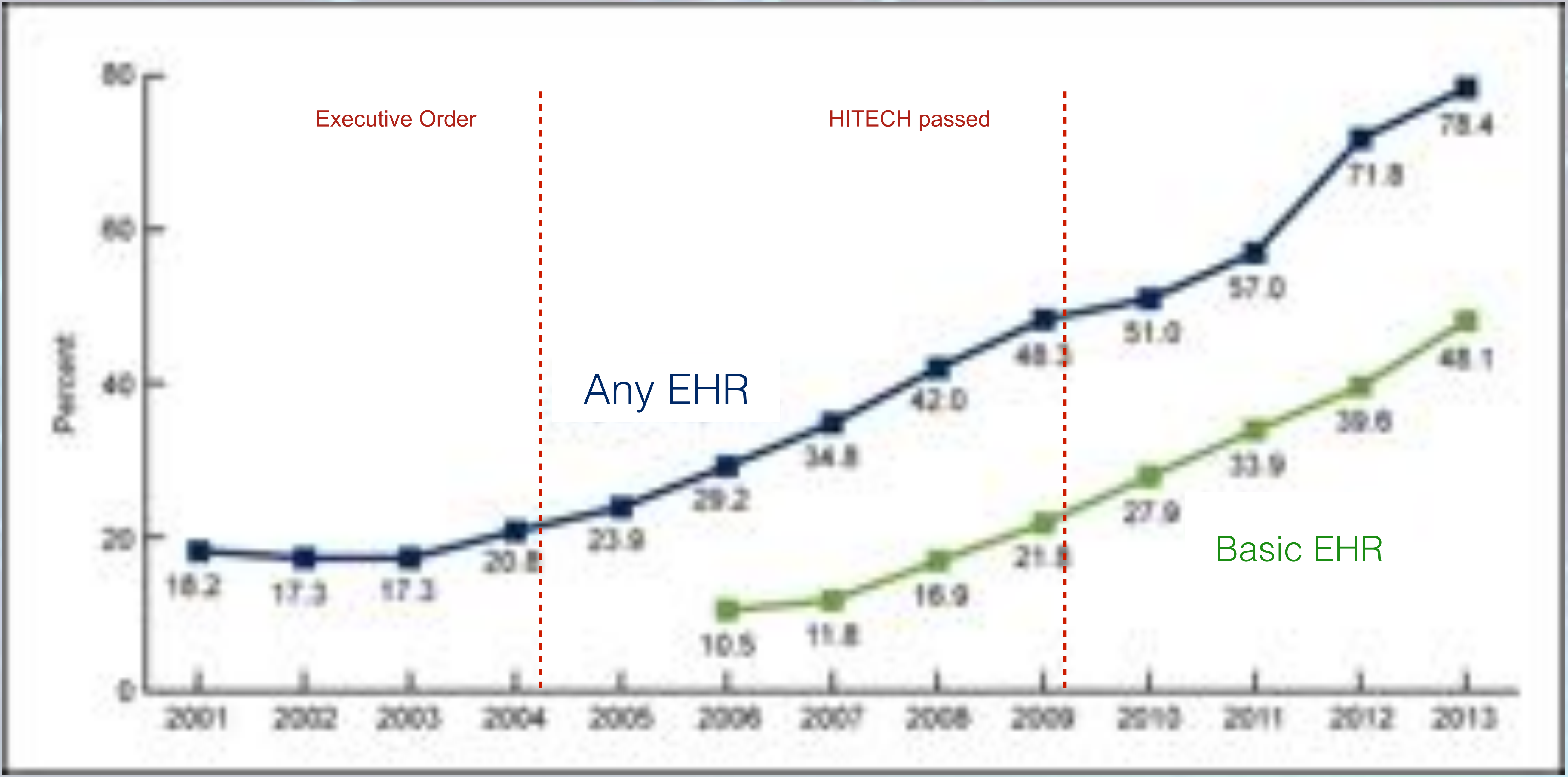
Goal 3: Strengthen Health Care Delivery

Goal 4: Advance the Health and Well-Being of Individuals and Communities

Goal 5: Advance Research, Scientific Knowledge, and Innovation

Breathtaking Progress

Rapid EMR Uptake



CDC/NCHS, 2014

Big Data Coming

Memorial Sloan Kettering & IBM Watson: Advancing the Future of Personalized Cancer Care

What if the most current information for treating and diagnosing cancer were available to physicians to help personalize care?

1.6 M =

New cancer cases are expected to be diagnosed in 2012

Population currently living in Manhattan

41%

Lifetime risk of being diagnosed with cancer

Medical expenditures for cancer in the year 2020 are projected to reach nearly $157 billion… an increase of 27%.

$124.57 billion

$157.77 billion

Sharing massive volumes of medical information and the latest cancer knowledge instantly could have a profound impact on helping cancer patients and their physicians.

Medical information is doubling every 5 years

6-12 months

Publishing the latest medical research information can be delayed up to one year

15 years

The time it can take for the latest evidence to be put into practice

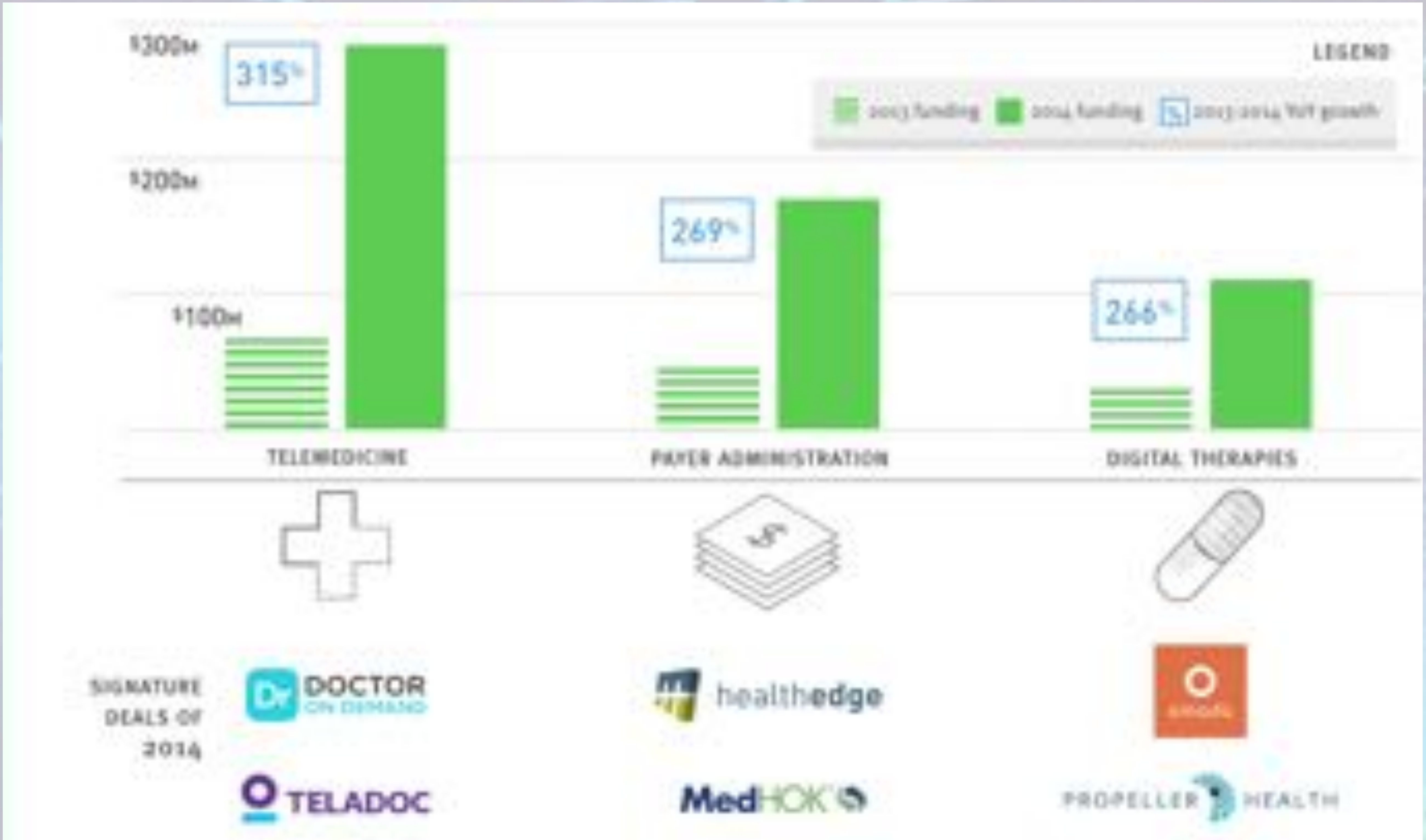
Pop Health Build-Up

53 unique vendors mentioned

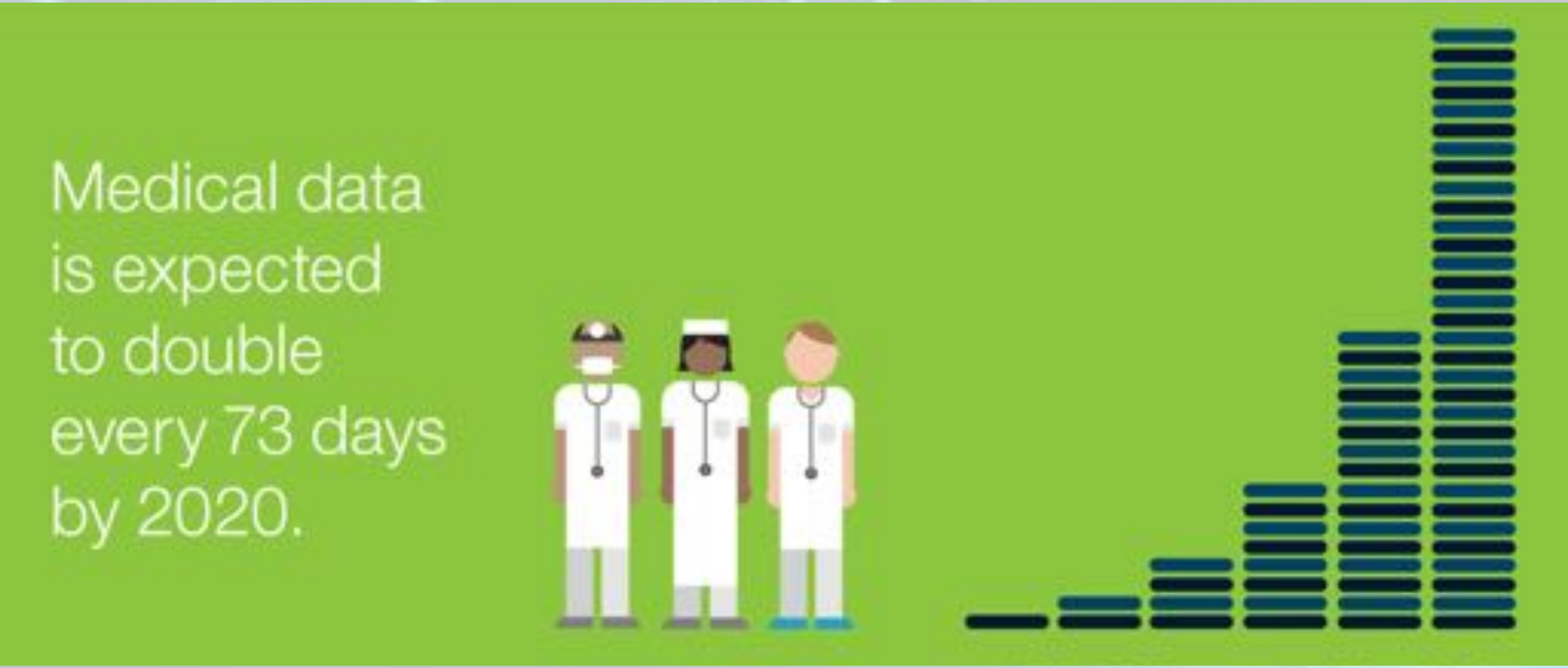
70% of "mature" organizations report multiple PHM vendors

KLAS, 2014

Venture Records



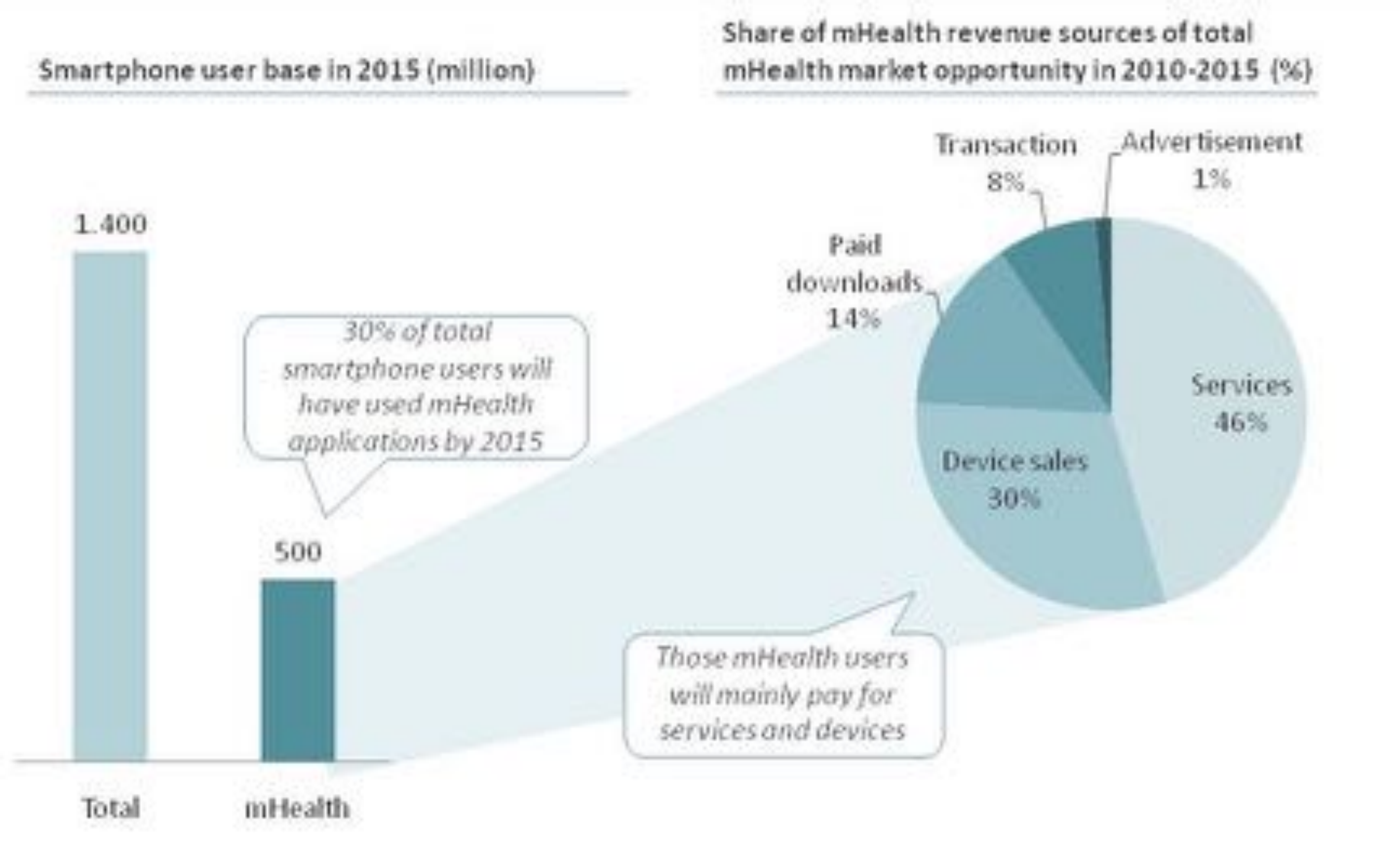
Information Explosion



Medical data is expected to double every 73 days by 2020.

IoT Data Growth

mHealth Growth



New Models of Care

The On-Demand Doctor

Several startups are putting a high-tech spin on old-fashioned house calls:

	heal	pager	MED+ZED	retrace health	TRUE NORTH
SERVICE	For a flat fee of $99, the service promises to send a doctor in under an hour	Dispatches doctors or nurses via Uber for $200 per urgent-care visit; $75-$100 for a wellness check	Nurse conducts initial visit and can video chat with doctor; $150 for an urgent-care house call; prices vary	Nurse practitioners consult via video for $50 or in-person visit for $200; $50 per month for unlimited visits	Responds to non-emergency 911 calls; offers on-scene care instead of ER visit; $200-$300
CITY/STATE	Los Angeles, San Francisco and Orange County, Calif.	New York City, San Francisco	Atlanta, New York City	Minneapolis, Wisconsin and North Dakota	Denver

Source: the companies

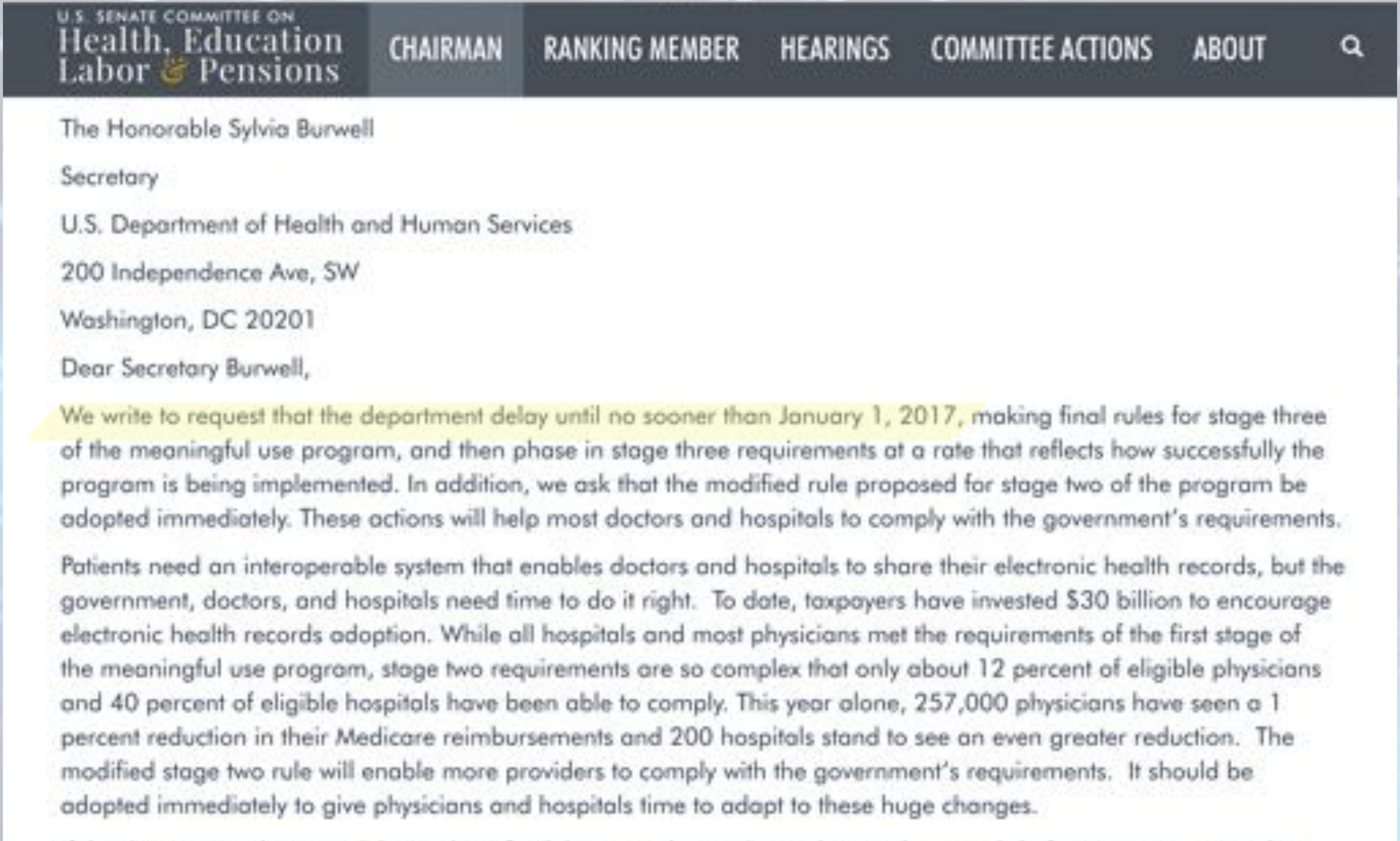
THE WALL STREET JOURNAL.

Rising Challenges

MU Frustration

BREAK the RED TAPE

The federal government should postpone its implementation of Meaningful Use (MU) Stage 3 regulations. Electronic health record systems (EHRs) should be designed to meet the needs of physicians and patients, not federal program requirements.



The Honorable Sylvia Burwell

Secretary

U.S. Department of Health and Human Services

200 Independence Ave, SW

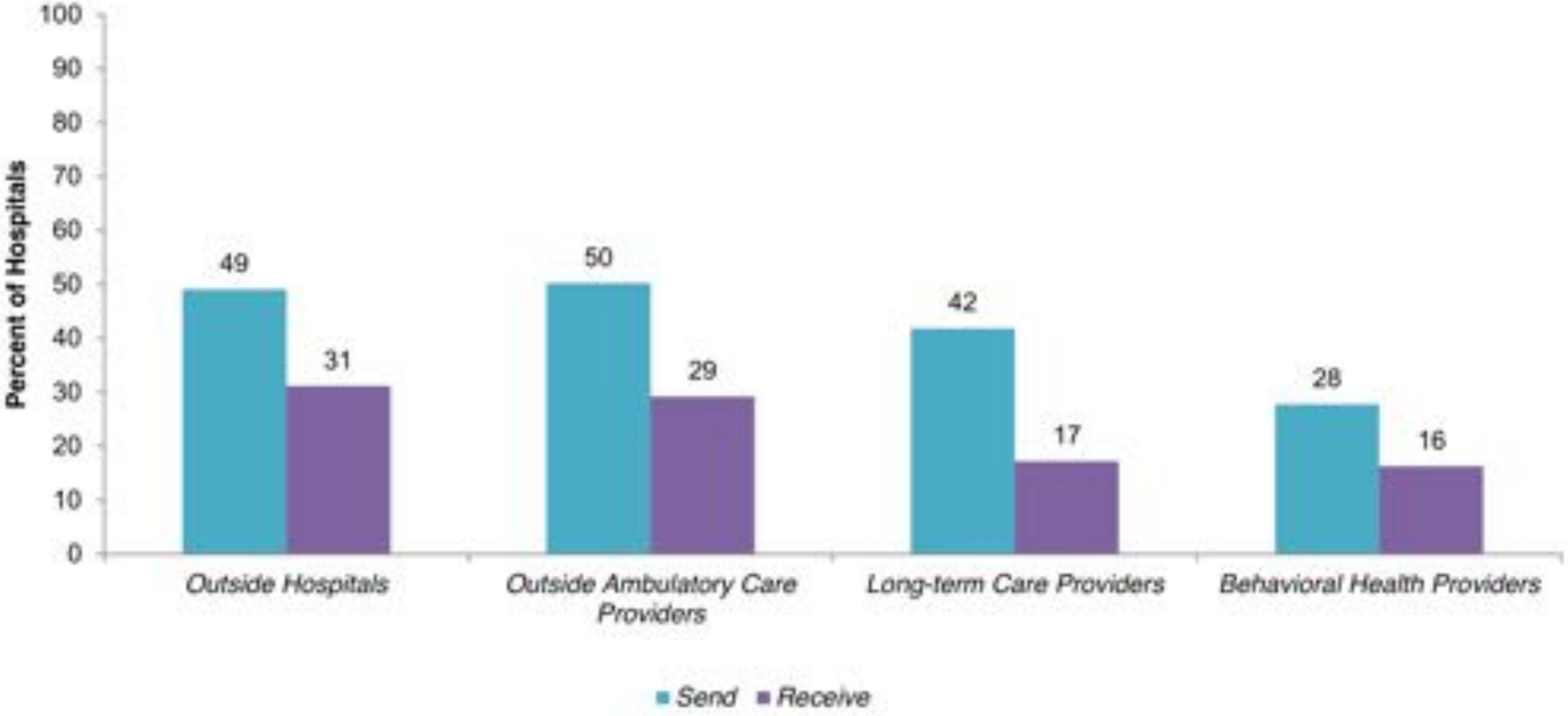
Washington, DC 20201

Dear Secretary Burwell,

We write to request that the department delay until no sooner than January 1, 2017, making final rules for stage three of the meaningful use program, and then phase in stage three requirements at a rate that reflects how successfully the program is being implemented. In addition, we ask that the modified rule proposed for stage two of the program be adopted immediately. These actions will help most doctors and hospitals to comply with the government's requirements.

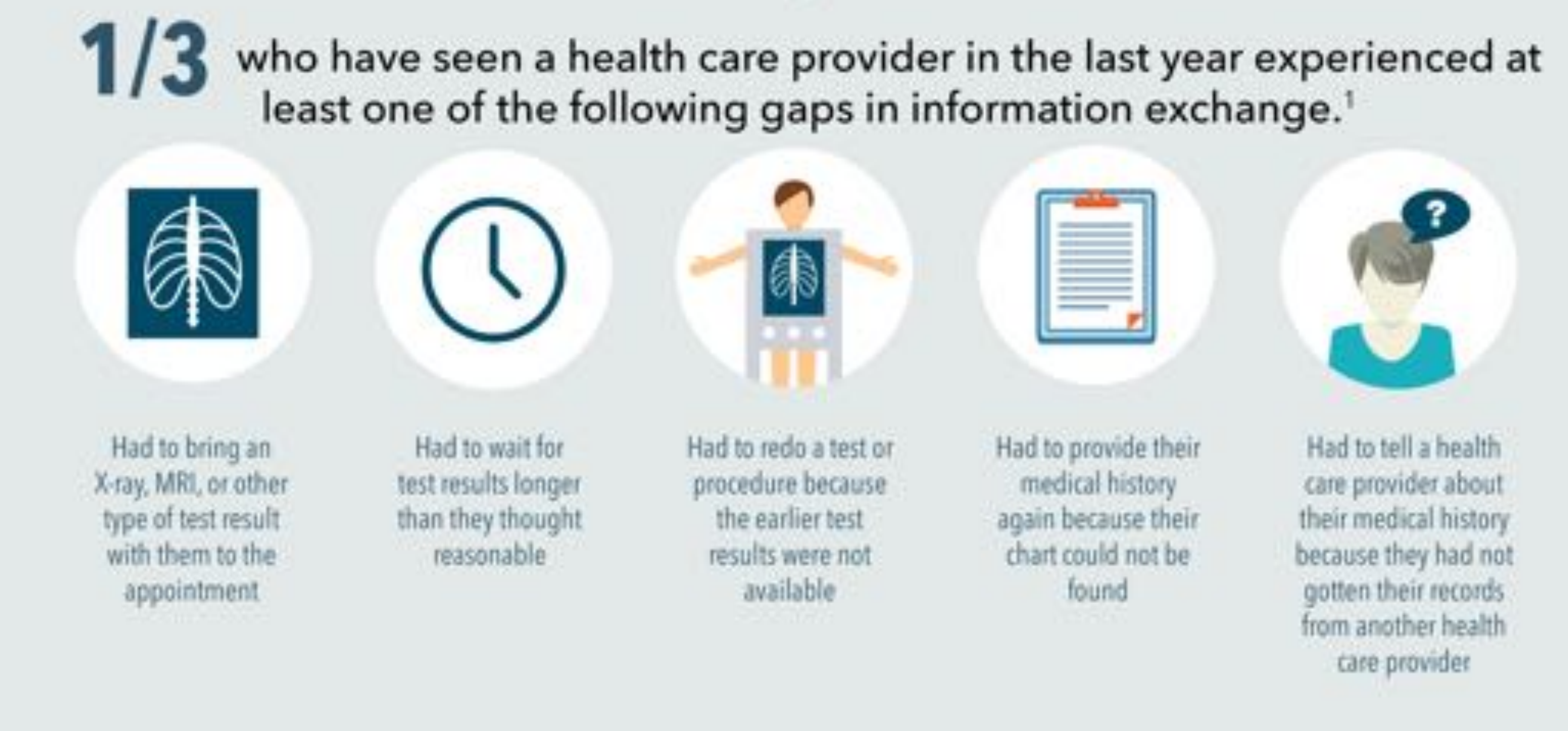
Patients need an interoperable system that enables doctors and hospitals to share their electronic health records, but the government, doctors, and hospitals need time to do it right. To date, taxpayers have invested $30 billion to encourage electronic health records adoption. While all hospitals and most physicians met the requirements of the first stage of the meaningful use program, stage two requirements are so complex that only about 12 percent of eligible physicians and 40 percent of eligible hospitals have been able to comply. This year alone, 257,000 physicians have seen a 1 percent reduction in their Medicare reimbursements and 200 hospitals stand to see an even greater reduction. The modified stage two rule will enable more providers to comply with the government's requirements. It should be adopted immediately to give physicians and hospitals time to adapt to these huge changes.

HIE Far Behind



SOURCE: ONC/American Hospital Association (AHA), AHA Annual Survey Information Technology Supplement.
Notes: Does not include "eFax." Summary of care records are in a structured format (e.g. CCDA).

Patient Inconvenience



1/3 who have seen a health care provider in the last year experienced at least one of the following gaps in information exchange.[1]

Had to bring an X-ray, MRI, or other type of test result with them to the appointment

Had to wait for test results longer than they thought reasonable

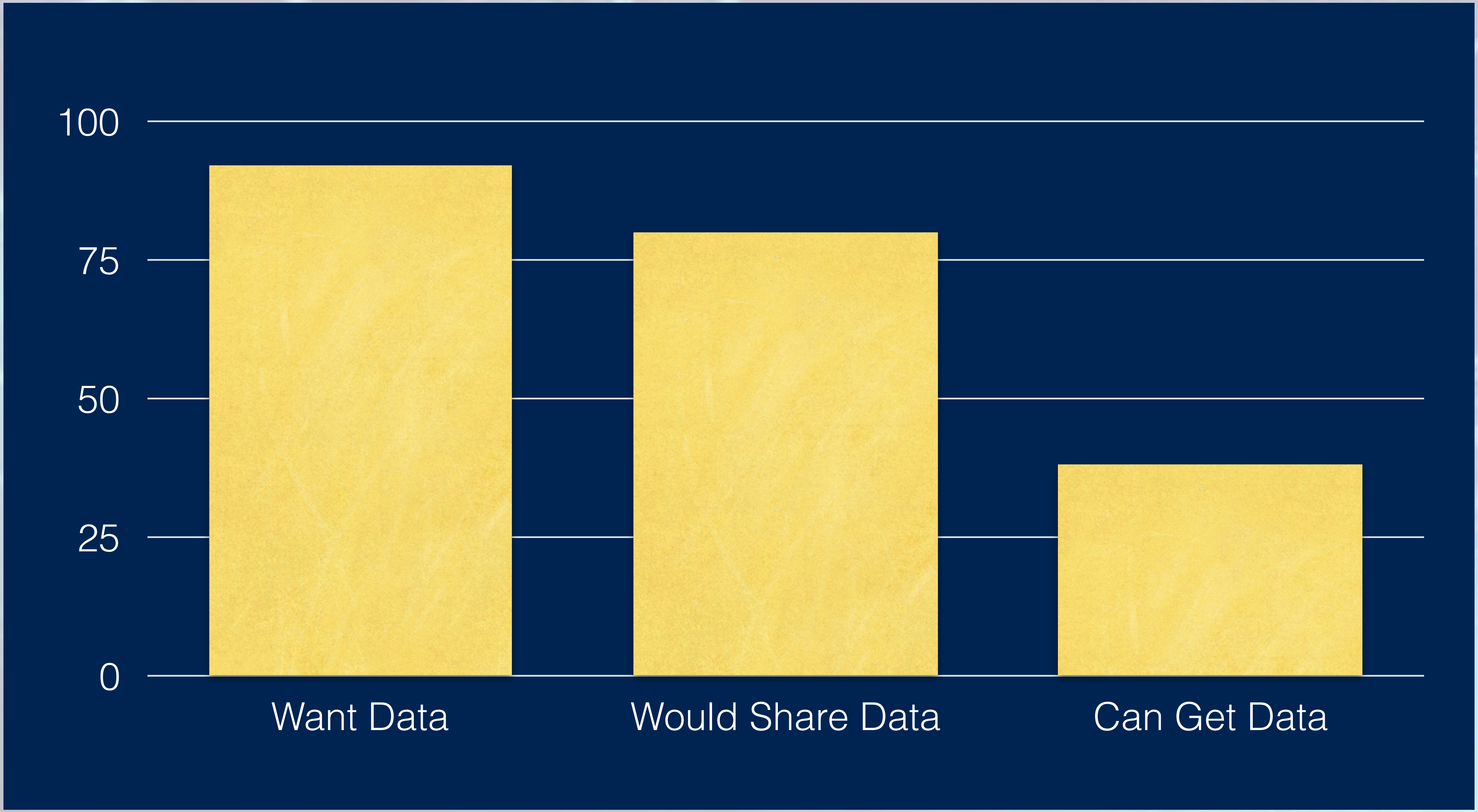
Had to redo a test or procedure because the earlier test results were not available

Had to provide their medical history again because their chart could not be found

Had to tell a health care provider about their medical history because they had not gotten their records from another health care provider

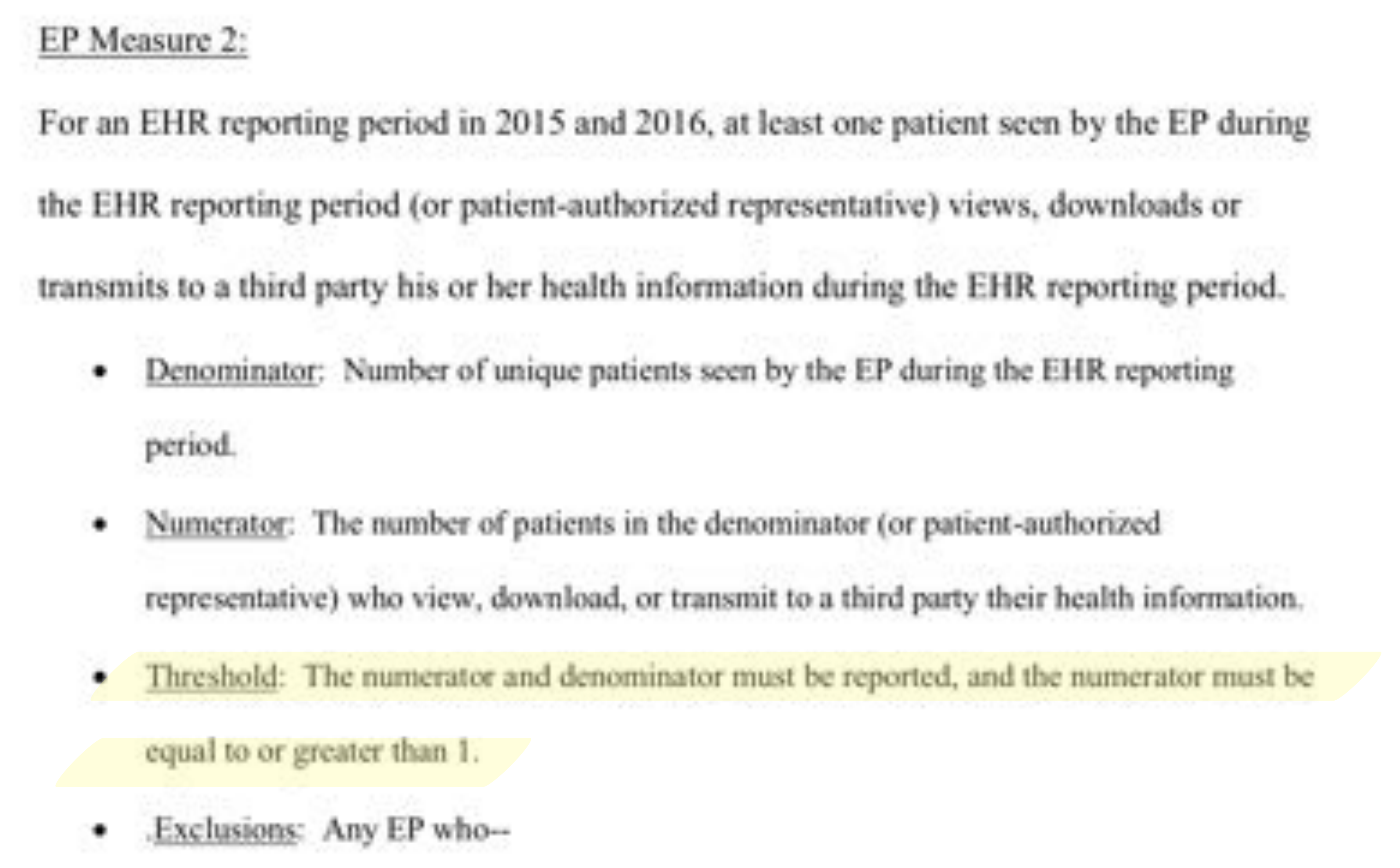
Source: ONC

Consumers Want Access



Source: Healthcare IT News, 10/19

Lax Rules



EP Measure 2:

For an EHR reporting period in 2015 and 2016, at least one patient seen by the EP during the EHR reporting period (or patient-authorized representative) views, downloads or transmits to a third party his or her health information during the EHR reporting period.

- Denominator: Number of unique patients seen by the EP during the EHR reporting period.
- Numerator: The number of patients in the denominator (or patient-authorized representative) who view, download, or transmit to a third party their health information.
- Threshold: The numerator and denominator must be reported, and the numerator must be equal to or greater than 1.
- .Exclusions: Any EP who--

Source: ONC

Apps Evade HIPAA

We have updated our Terms of Service, Privacy Policy, and Host Guarantee Terms and Conditions (collectively, "Terms"). Please read each one carefully. Learn more about what's changed.

Terms of Service
Privacy Policy
Host Guarantee Terms and Conditions

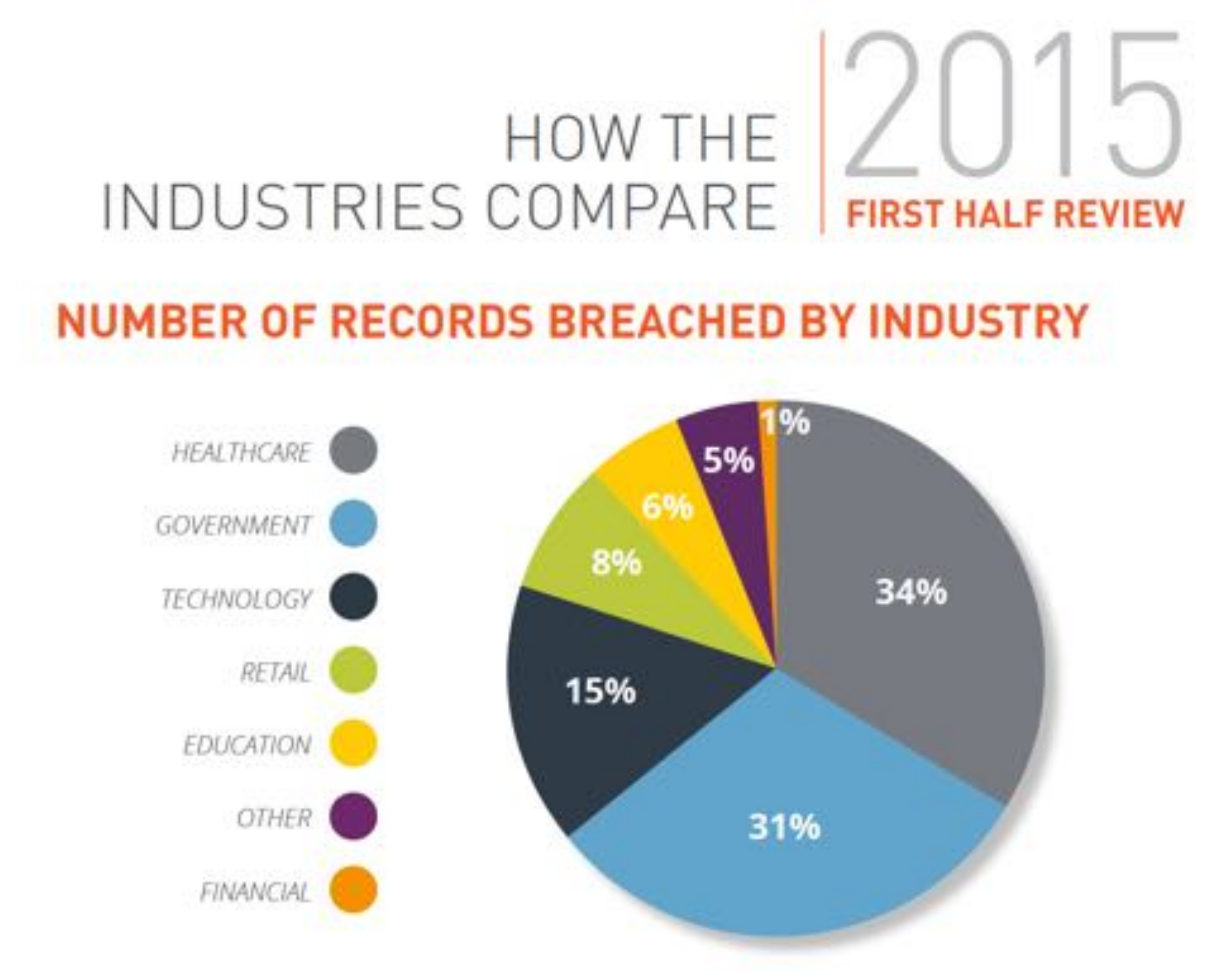
Terms of Service

PLEASE READ THESE TERMS OF SERVICE CAREFULLY AS THEY CONTAIN IMPORTANT INFORMATION REGARDING YOUR LEGAL RIGHTS, REMEDIES AND OBLIGATIONS. THESE INCLUDE VARIOUS LIMITATIONS AND EXCLUSIONS, A CLAUSE THAT GOVERNS THE

I agree to the updated Terms. ✓

"It's free, but they sell your information. "

Insecure Healthcare



Whose Data Anyway?

FOX NEWS

EDUCATION

Who owns your health data? You may be surprised

By **Dr. Sreedhar Potarazu** · Published April 03, 2013 · FoxNews.com

THE WALL STREET JOURNAL.

OPINION | COMMENTARY

They're Your Vital Signs, Not Your Medical Records

Americans don't own their own health information, and access to it is controlled by others. Time to change that.

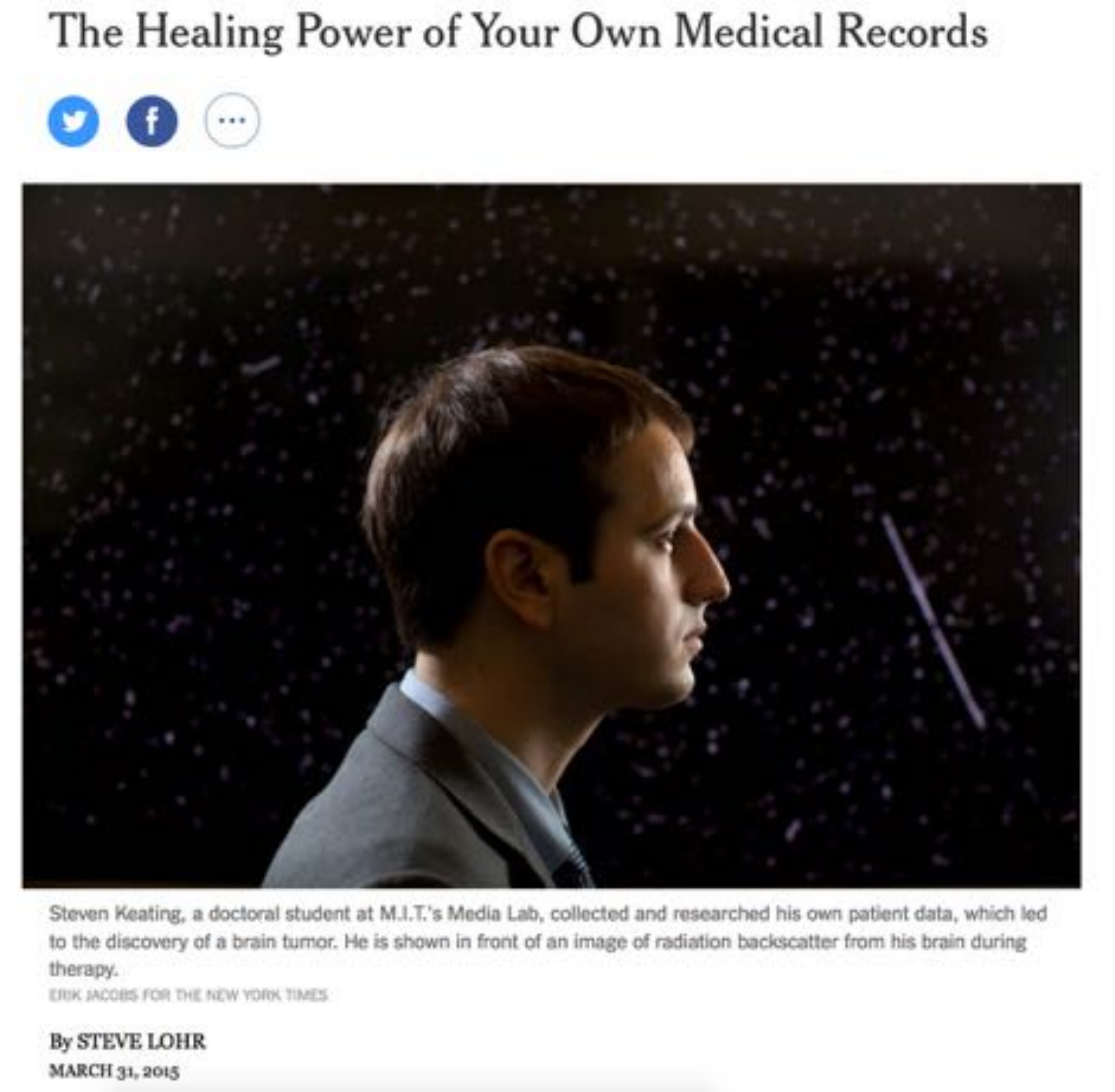
By DAVID J. BRAILER

April 30, 2015 7:36 p.m. ET

The Heart of the Matter

I can't access the data generated by my implanted defibrillator. That's absurd.

By Hugo Campos



The Healing Power of Your Own Medical Records

Steven Keating, a doctoral student at M.I.T.'s Media Lab, collected and researched his own patient data, which led to the discovery of a brain tumor. He is shown in front of an image of radiation backscatter from his brain during therapy.

ERIK JACOBS FOR THE NEW YORK TIMES

By STEVE LOHR

MARCH 31, 2015

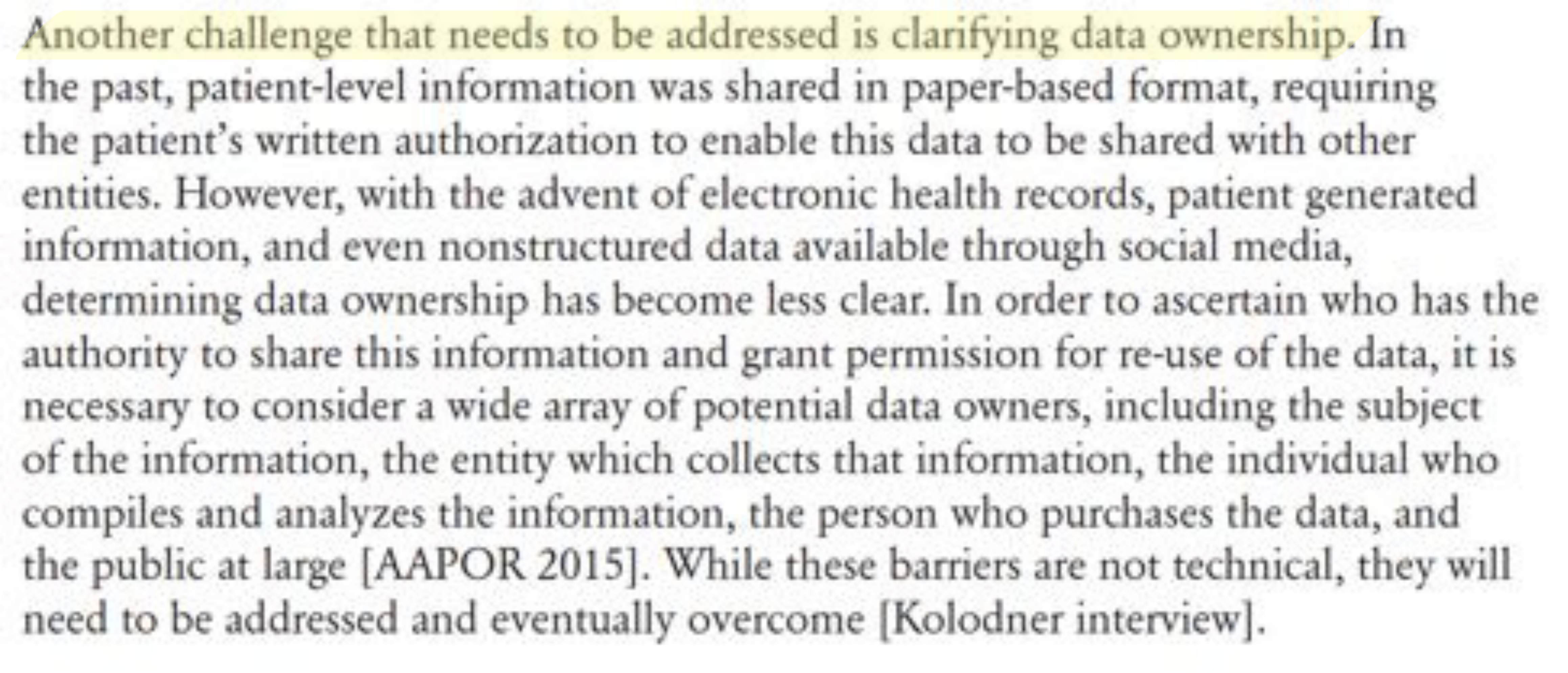
Unpatients—why patients should own their medical data

Leonard J Kish & **Eric J Topol**

Affiliations | **Corresponding author**

Nature Biotechnology **33**, 921–924 (2015) | doi:10.1038/nbt.3340

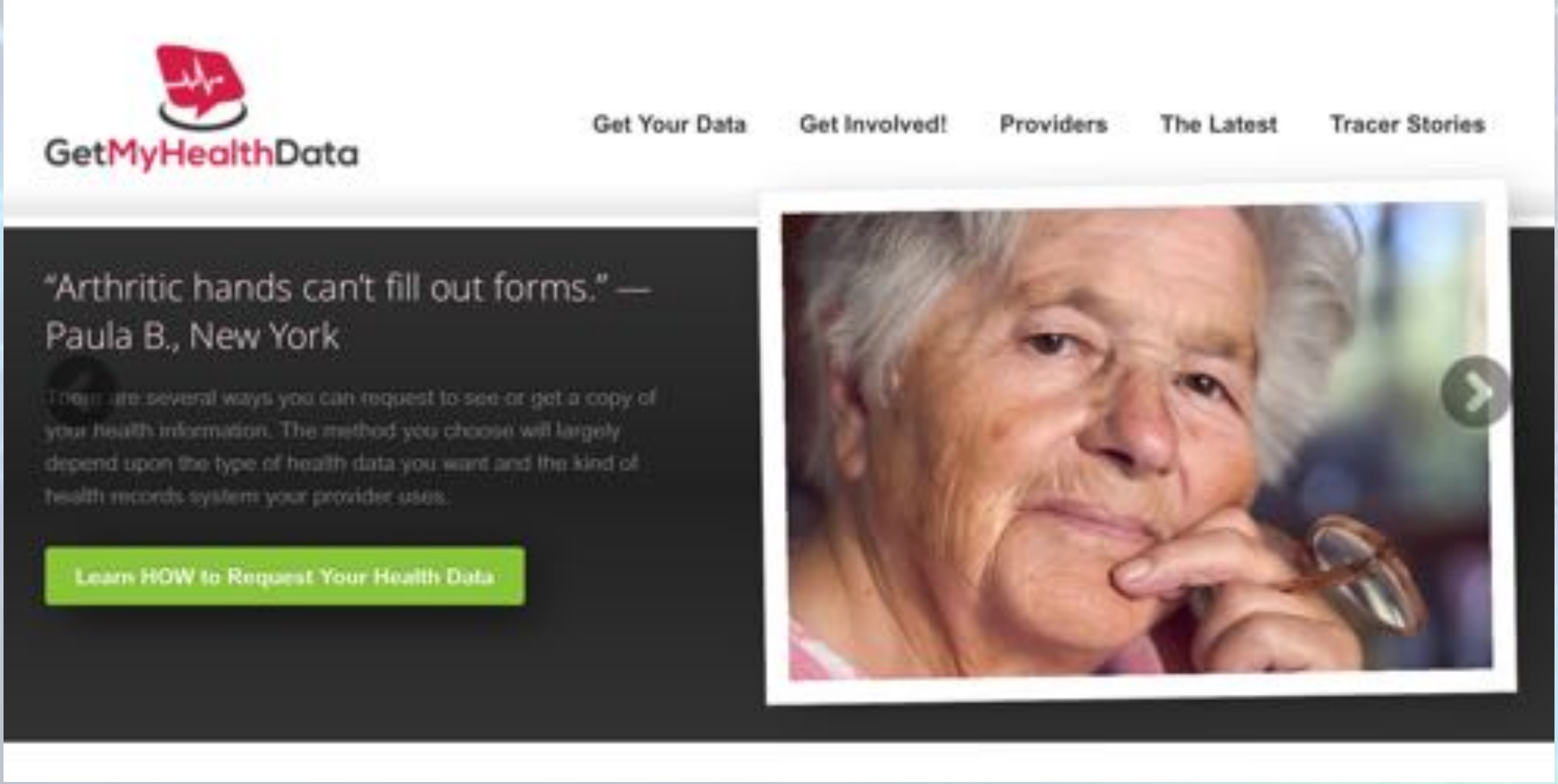
For the benefits of digital medicine to be fully realized, we need not only to find a shared home for personal health data but also to give individuals the right to own them.



Another challenge that needs to be addressed is clarifying data ownership. In the past, patient-level information was shared in paper-based format, requiring the patient's written authorization to enable this data to be shared with other entities. However, with the advent of electronic health records, patient generated information, and even nonstructured data available through social media, determining data ownership has become less clear. In order to ascertain who has the authority to share this information and grant permission for re-use of the data, it is necessary to consider a wide array of potential data owners, including the subject of the information, the entity which collects that information, the individual who compiles and analyzes the information, the person who purchases the data, and the public at large [AAPOR 2015]. While these barriers are not technical, they will need to be addressed and eventually overcome [Kolodner interview].

Source: Robert Wood Johnson Foundation

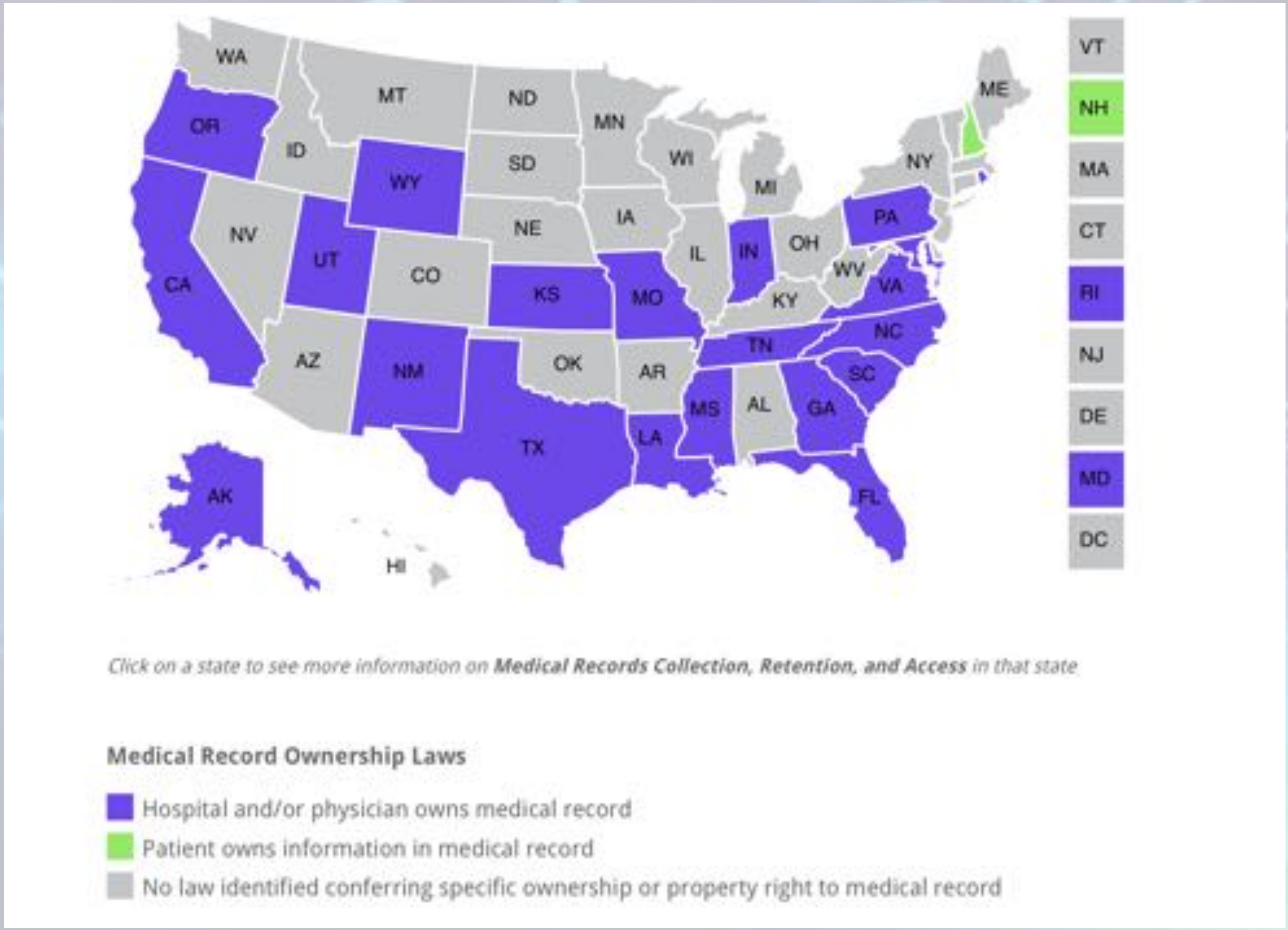
Consumer Activism



"Arthritic hands can't fill out forms." — Paula B., New York

There are several ways you can request to see or get a copy of your health information. The method you choose will largely depend upon the type of health data you want and the kind of health records system your provider uses.

New Hampshire Alone

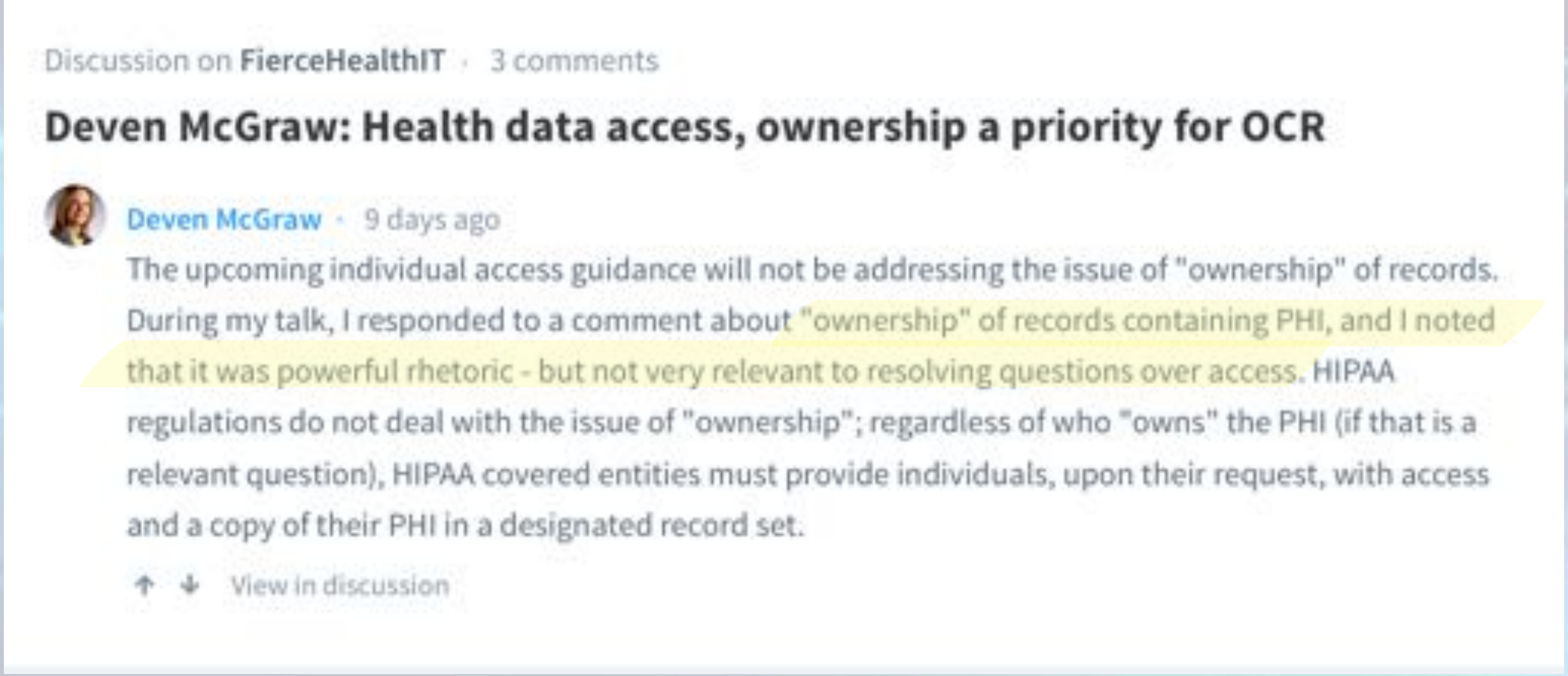


Click on a state to see more information on ***Medical Records Collection, Retention, and Access*** *in that state*

Medical Record Ownership Laws

- 🟪 Hospital and/or physician owns medical record
- 🟩 Patient owns information in medical record
- ⬜ No law identified conferring specific ownership or property right to medical record

Executive Branch Response



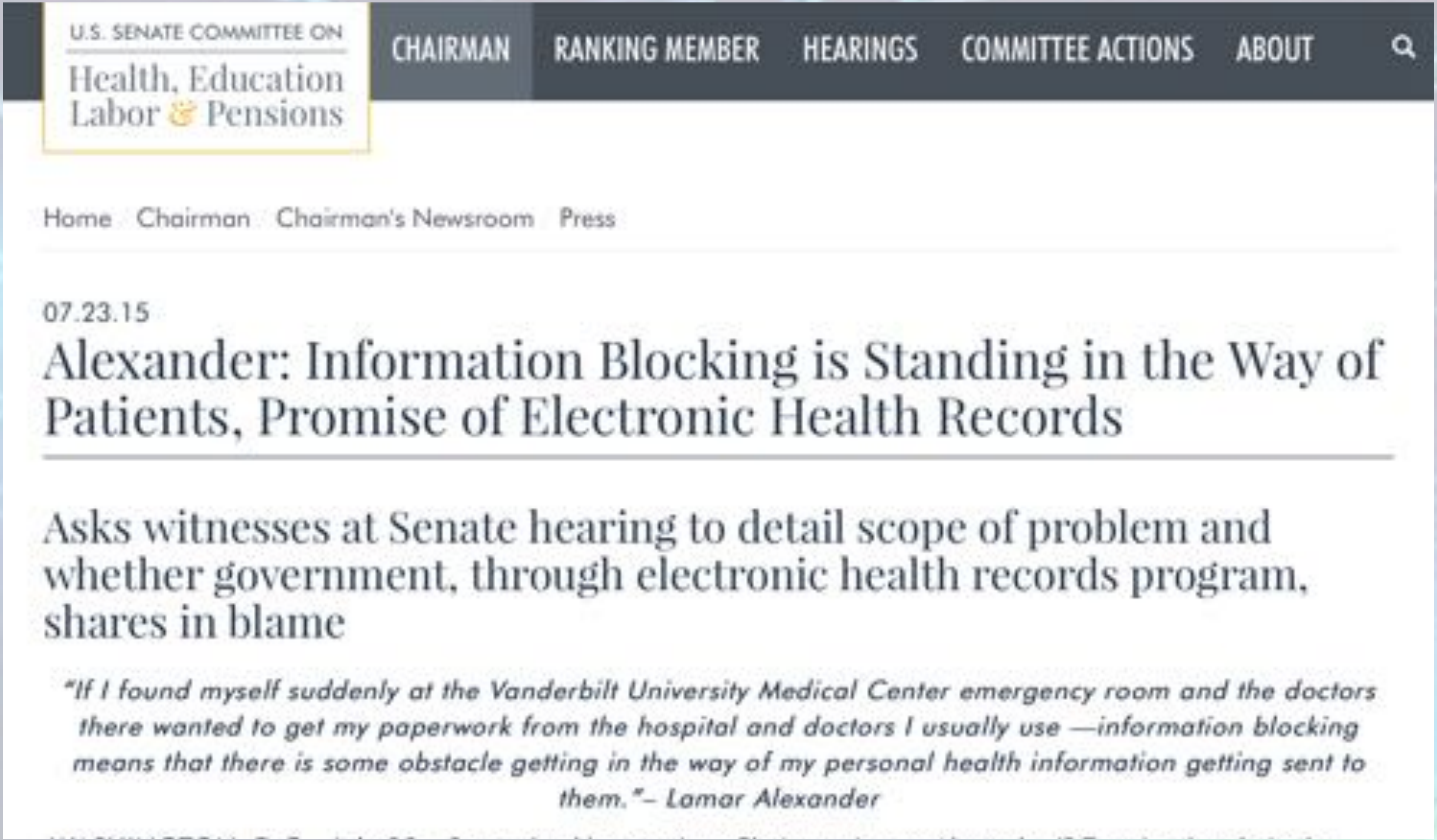
Discussion on **FierceHealthIT** · 3 comments

Deven McGraw: Health data access, ownership a priority for OCR

Deven McGraw · 9 days ago

The upcoming individual access guidance will not be addressing the issue of "ownership" of records. During my talk, I responded to a comment about "ownership" of records containing PHI, and I noted that it was powerful rhetoric - but not very relevant to resolving questions over access. HIPAA regulations do not deal with the issue of "ownership"; regardless of who "owns" the PHI (if that is a relevant question), HIPAA covered entities must provide individuals, upon their request, with access and a copy of their PHI in a designated record set.

Senate Information Blocking



07.23.15

Alexander: Information Blocking is Standing in the Way of Patients, Promise of Electronic Health Records

Asks witnesses at Senate hearing to detail scope of problem and whether government, through electronic health records program, shares in blame

> *"If I found myself suddenly at the Vanderbilt University Medical Center emergency room and the doctors there wanted to get my paperwork from the hospital and doctors I usually use —information blocking means that there is some obstacle getting in the way of my personal health information getting sent to them."– Lamar Alexander*

OIG ALERT

For Immediate Release
October 6, 2015

Office of Inspector General
330 Independence Ave., SW
Washington, DC 20201
Media: media@oig.hhs.gov
(202) 619-1343

OIG Policy Reminder:
Information Blocking and the Federal Anti-Kickback Statute

As the Department of Health and Human Services marks "National Health IT Week" 2015 and focuses on the flow of information across the care continuum, the Office of Inspector General (OIG) would like to take the opportunity to remind the public about how information blocking[1] may affect safe harbor

A New Approach

Three Principals

Every person should be able to:

- Have a complete, lifetime "consumer health record" under their control
- Designate a qualified custodian to manage their consumer health record
- Compel all health data holders to send their data to their custodian

Consumer Health Record

- Real time collection of health information from multiple sources, including hospital, physicians, apps, devices, wellnesses monitors, etc.
- Follows consumer for life across providers and plans
- Consumer can access at any time or share with family, caregivers or researchers
- Anonymized data for public purposes such as quality evaluation and transparency
- Not a legal medical record

Custodian

- Entity that consumer designates to collect, store, validate and transmit their health information

- Custodians certified by government agency and compete for consumers

- Fiduciary obligation to consumer to use best efforts to collect, protect and share data as directed

- Enforce standards and security for exchange with data holders

Participation

- Data holders required to share consumer information with their custodian
- Data meets form, format and timeliness standards
- Participation required by all data holders - including all apps
- Unlike HIPAA Business Associate, data holders will be waived of liability for actions of custodian

What NAHDO Can Do

- Debate and advocate for potential solutions
- Measure information access and blocking
- Use your role as trusted stewards and conveners
- Advise policymakers on the real long term issues
- Experiment at the state level