

Improving Patient Access to Protected Health Information

Insights and Findings

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Context

HIPAA: In a Nutshell

- * **Health Insurance Portability and Accountability Act (1996)**
- * First piece of federal regulation which established a set of **national standards** for healthcare information transactions and **national identifiers** for providers, health insurance plans, and employers.
- * Guarantees patients a number of rights including the **right to see and receive** a copy of their protected health information

Problem

- * Users of the US healthcare system find **difficulty retrieving** their Protected Health Information (PHI) in an hassle-free and timely manner.
- * The healthcare industry is struggling to **balance** the **security** of patient information & communications with providing **efficient** service.

Cases Currently Under Investigation

This page lists all breaches reported within the last 24 months that are currently under investigation by the Office for Civil Rights.

[Show Advanced Options](#)

Breach Report Results							
Expand All	Name of Covered Entity	State	Covered Entity Type	Individuals Affected	Breach Submission Date	Type of Breach	Location of Breached Information
	AccuDoc Solutions, Inc.	NC	Business Associate	2652537	11/27/2018	Hacking/IT Incident	Network Server
	Iowa Health System d/b/a UnityPoint Health	IA	Business Associate	1421107	07/30/2018	Hacking/IT Incident	Email
	Employees Retirement System of Texas	TX	Health Plan	1248263	10/15/2018	Unauthorized Access/Disclosure	Other
	UW Medicine	WA	Healthcare Provider	973024	02/20/2019	Hacking/IT Incident	Network Server
	CA Department of Developmental Services	CA	Health Plan	582174	04/06/2018	Theft	Paper/Films
	CNO Financial Group, Inc.	IN	Health Plan	566217	10/25/2018	Unauthorized Access/Disclosure	Other
	Health Management Concepts, Inc.	FL	Business Associate	502416	08/22/2018	Hacking/IT Incident	Network Server
	Airway Oxygen, Inc.	MI	Healthcare Provider	500000	06/16/2017	Hacking/IT Incident	Network Server
	AU Medical Center, INC	GA	Healthcare Provider	417000	08/16/2018	Hacking/IT Incident	Email
	Columbia Surgical Specialist of Spokane	WA	Healthcare Provider	400000	02/18/2019	Hacking/IT Incident	Network Server
	UConn Health	CT	Healthcare Provider	326629	02/21/2019	Hacking/IT Incident	Email
	SSM Health St. Mary's Hospital - Jefferson City	MO	Healthcare Provider	301000	07/30/2018	Improper Disposal	Paper/Films
	Women's Health Care Group of PA, LLC	PA	Healthcare Provider	300000	07/15/2017	Hacking/IT Incident	Desktop Computer, Network Server
	Oklahoma State University Center for Health Sciences	OK	Healthcare Provider	279865	01/05/2018	Hacking/IT Incident	Network Server
	Med Associates, Inc.	NY	Business	276057	06/14/2018	Hacking/IT Incident	Desktop Computer

Provider's Perspective

“ I asked for my health information from a well known, large DC hospital and **NEVER got a response**. ”

“ My doctors wouldn’t talk to each other, so I had to go through **many visits and repeat tests** for a single issue. ”

“ Old records were not available to get copies of. But they were **important and relevant** to my current recently diagnosed situation. ”

“ I had to **drive across town twice** to get my child’s record, when the doctor had moved and I was forced to leave the practice. ”

Patient’s Perspective

Methodology

Sources



* Experts

- Phone
- In-person

* General Public

- Online
- In-person

* Existing information

- Breach reports, OCR RFI
- Articles, Case studies
- Advocacy groups

Experts

Interviewed **6 experts** in the fields of healthcare data, patient advocacy, EHS and HIPAA Law



Daniel Sands MD
Co-founder, Society for
Participatory Medicine



Deven McGraw
Chief Regulatory Officer,
Citizen



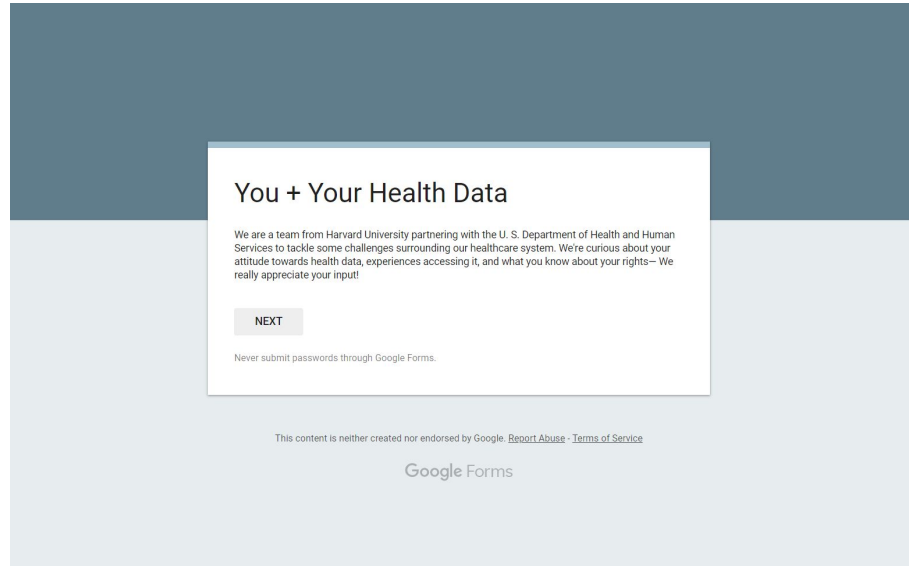
Regina Holliday
Patient rights advocate

General Public

180+ online respondents
(likely skewed)

30+ public interviews (more
representative of general
sentiment)

Qualitative answers provided
the most insights

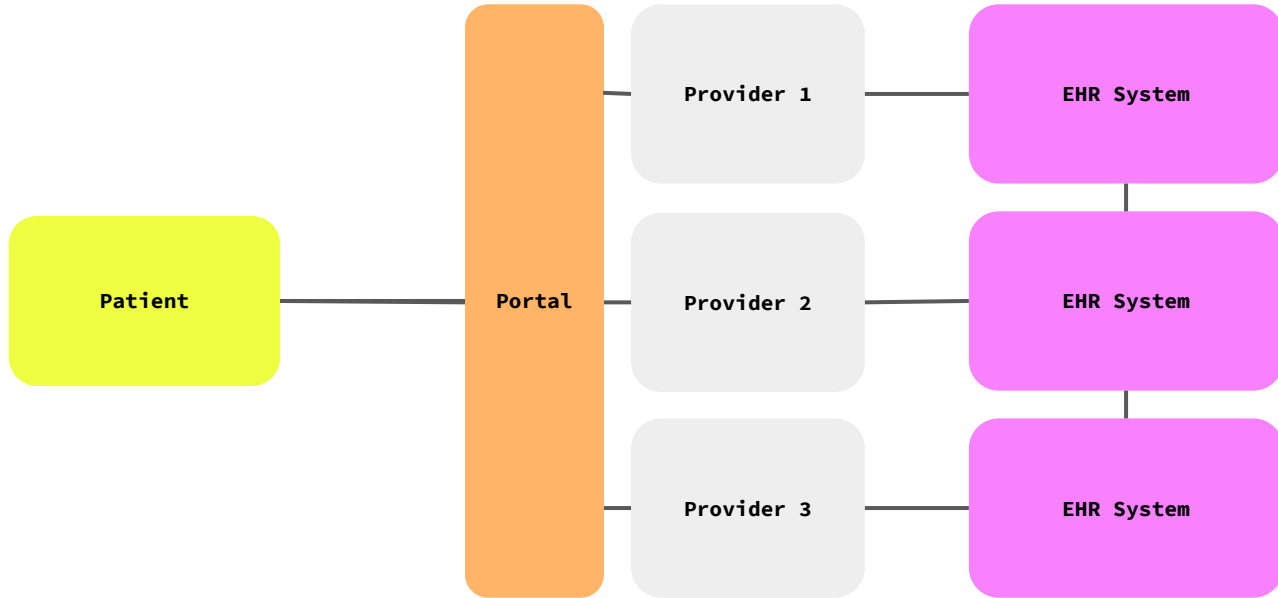


The image shows a screenshot of a Google Forms survey. The title is "You + Your Health Data". The text of the survey reads: "We are a team from Harvard University partnering with the U. S. Department of Health and Human Services to tackle some challenges surrounding our healthcare system. We're curious about your attitude towards health data, experiences accessing it, and what you know about your rights— We really appreciate your input!". Below the text is a "NEXT" button. At the bottom of the form, there is a disclaimer: "This content is neither created nor endorsed by Google. [Report Abuse](#) - [Terms of Service](#)". The Google Forms logo is visible at the bottom of the page.

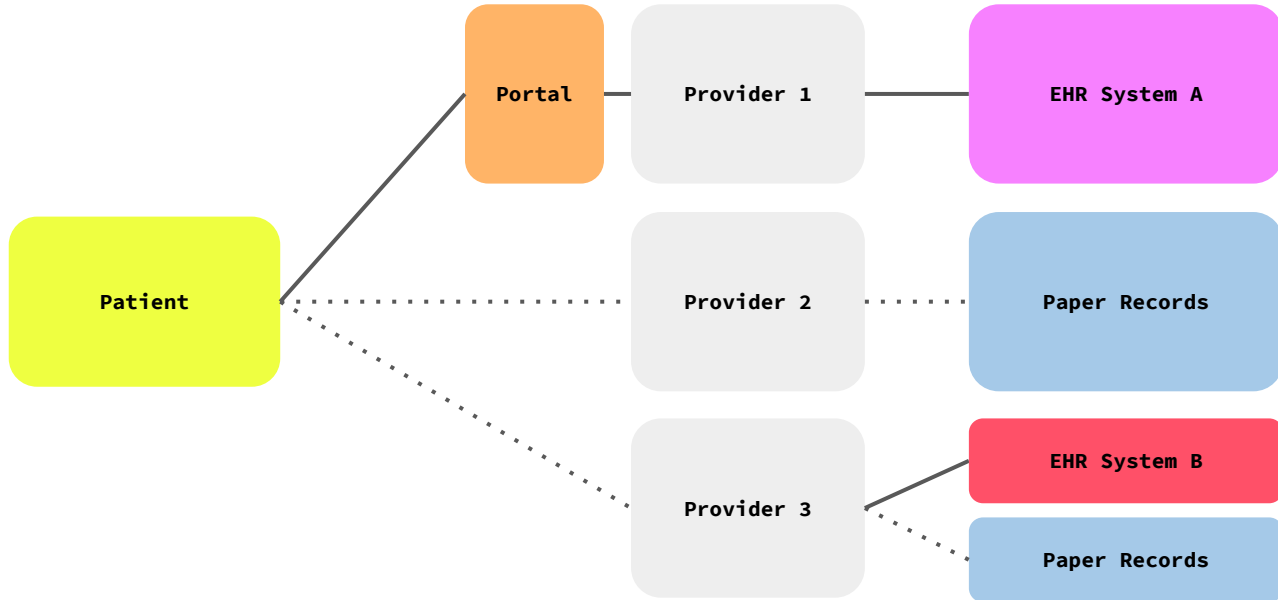
Findings

Current State of Electronic Health Records (EHR)

- * Lockheed developed what was then known as the first 'clinical information system' in the **mid-60's**
- * Since then, a whole industry has emerged spearheaded by companies like Epic, Allscripts, and Cerner.
 - Many EHR systems are employed, none with universal adoption
 - Competition between multiple players each with their own **proprietary infrastructure** for data storage
 - **Little interoperability** because of **heavy costs** for information security across vendors
- * This market is projected to grow to **30.4 billion** by 2023
- * **HITECH Act** (2009) was the last major government intervention



Expectation



Reality

Personas



Colin
Care Provider



Erin
Empowered Patient



Raj
Passive Patient

Care Provider

- * Worries about lack of patient health literacy and engagement
- * Often don't deal directly with transfer of records
- * Irritated by inefficiencies in system
- * Understand needs for patients' privacy protection
- * Fear HIPAA repercussions



Colin

“[The chart] will come an hour later, two hours later, the next day later, a few days later... It’s very inefficient.”

Quote from Provider Interview

Empowered Patient

- * Vocal advocates of patient rights
- * Most likely they themselves or someone close has dealt with a serious medical condition
- * Understand the value of having control and comprehension of their PHI



Erin

**“Without transparency of data,
and being an informed consumer,
you can’t stop bad things from
happening to you.”**

Quote from Advocate Interview

Passive Patient

- * The majority of the population
- * Little movement needed for healthcare records
- * All types of interactions with healthcare system, sometimes a lot, sometimes none
- * Data privacy concerns are usually tied to discrimination and identity theft
 - There is a subset (usually older) without any data concerns. Trusting their care providers to 'know what's best'



Raj

“UPMC sends so much stuff to be honest. The information is there all of the time. I don’t really know and I don’t have any interest to be frank.”

Quote from User Interview

Insights

Insight #1

There's a general **lack of engagement** and understanding surrounding health data.

There are **tangible benefits** to being engaged with your PHI.

Insight #2

Concerns surrounding data privacy are centered on employer and insurance **discrimination** and **identity theft**.

Insight #3

There is **power** in **knowing your rights**
under HIPAA.

Insight #4

Healthcare operates on a **spectrum**.

We **transition** along the spectrum
between healthy and unhealthy
throughout our lives, which affects how
much we value our healthcare records.

Insight #5

The social, cultural and political
complexities of our reality are mirrored
in the **complexity of our EHR**
infrastructure.

Next Steps

Defining Constraints

- * Works **within the confines of current HIPAA law** without the need for further legislative action
- * Within the limits of **current technologies** but also **forward compatible** with future development
- * It should be **easily understood** by both your grandparents and the HHS Secretary
- * **Scalable**

Exploring Areas

- * **Nudging** public sentiment towards **active engagement** with healthcare data
- * Creating a **patient verification system** for healthcare providers
- * An **accessible** portal where patients can **learn about their rights** in plain language.
- * Email **templates**, backed with **legal references**, for patients to send to uncooperative care providers.

*The local health care system recently upgraded its health portal. Previously, in spite of numerous requests, I was unable to get results, relying only on a verbal report from the doctor. **I find having the results is [sic] very motivating in my efforts to maintain and improve health.***

Thank you!