

# Improving Patient Access to Protected Health Information Final Recommendations

HKS DPI 663: Tech and Innovation in Government | Spring 2019 | Team HHS  
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**Benno Schmidt**



**Amy Gleason**



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Department of Health and Human Services (HHS)

## The Team



**Bill**



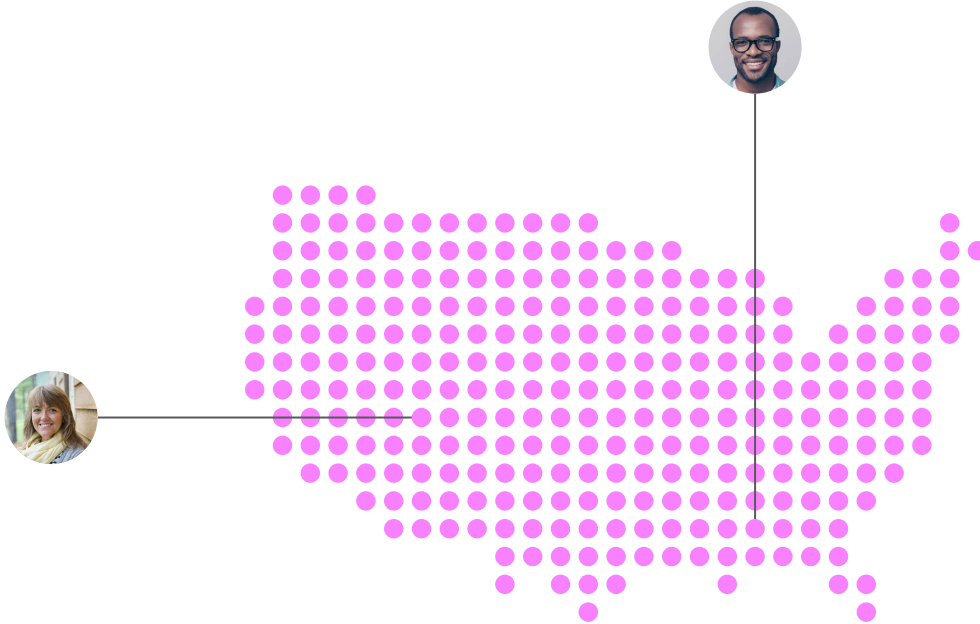
**Diane**



Worries the new doctors can't provide appropriate treatment without his medical history



Every moment spent waiting for records means unnecessary pain for her partner



# 85%+

Of adults have have had contact with a healthcare professional in the past year.

# 990m+

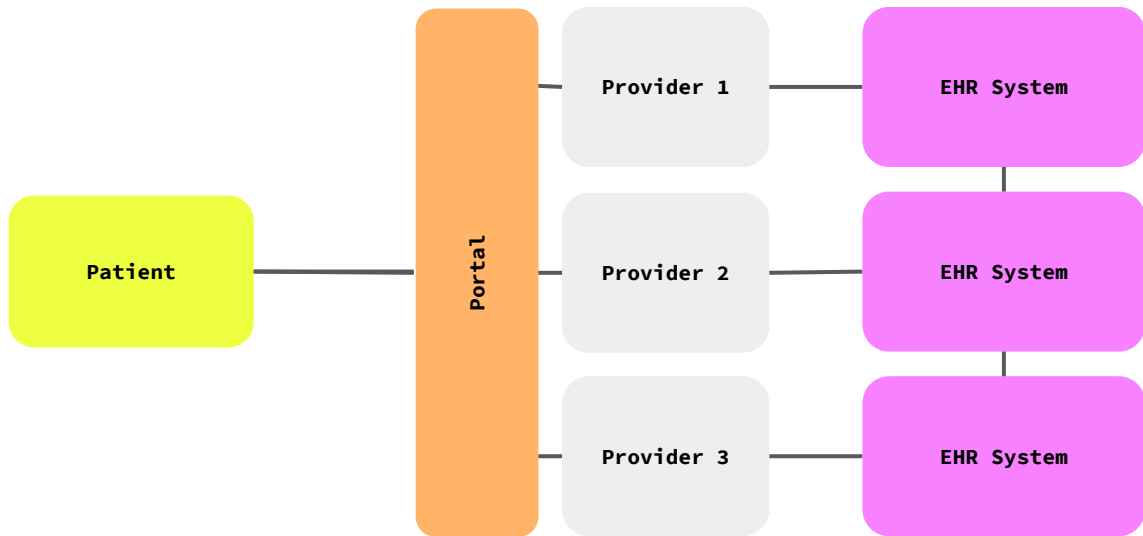
Visits to physicians in 2015

## Problem

How do we help people retrieve their Protected Health Information (PHI) in an **hassle-free** and **timely** manner?

# HIPAA

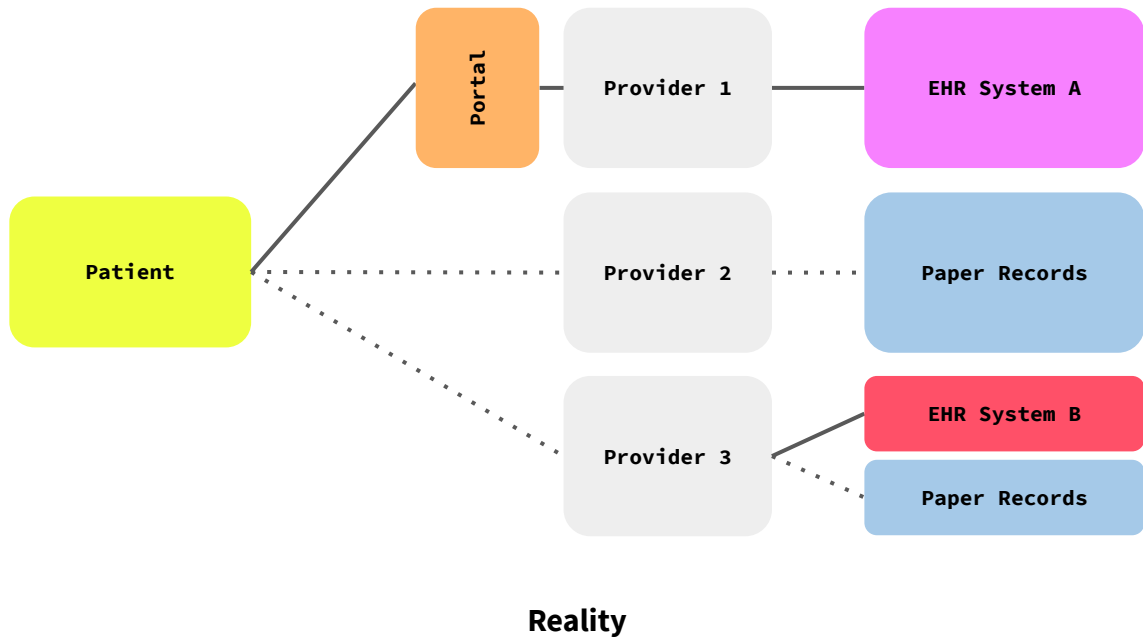
- \* **H** **e** **a** **l** **t** **h** **I** **n** **s** **u** **r** **a** **n** **c** **e** **P** **o** **r** **t** **a** **b** **i** **l** **i** **t** **y** **A** **c** **t** (1996)
- \* First piece of federal regulation establishing a set of **national standards** for healthcare information transaction
- \* Guarantees patients the **right to see and receive** a copy of their protected health information



**Ideal**

## A Complex System: Our Records Infrastructure





## A Complex System: Our Records Infrastructure

# Research

# Understanding the Issue

- \* Background Research
  - HIPAA Law, HITECH Act
  - Advocacy Groups
  - Patient Blogs
  - News Articles
- \* Experts vs the Everyday User

**6**

**Expert Interviews**

Including patient rights advocates, doctors, and healthcare law experts

**30+**

**In-person Interviews**

Most representative of the general public

**180+**

**Online Survey Respondents**

Skewed population reflected in the responses received

# Synthesis / Ideation

## Insights

Lack of engagement means  
poor health literacy



Concern over discrimination  
and identity theft



Empowerment through  
action



People think about  
healthcare when they need it



Complexity of our healthcare  
system



## Intervention

Must be easily understood  
without background  
knowledge

Requires no identifiable  
information

Give users agency and  
actionable information

Engages users right at the  
point the moment of need

Works within current systems  
and laws

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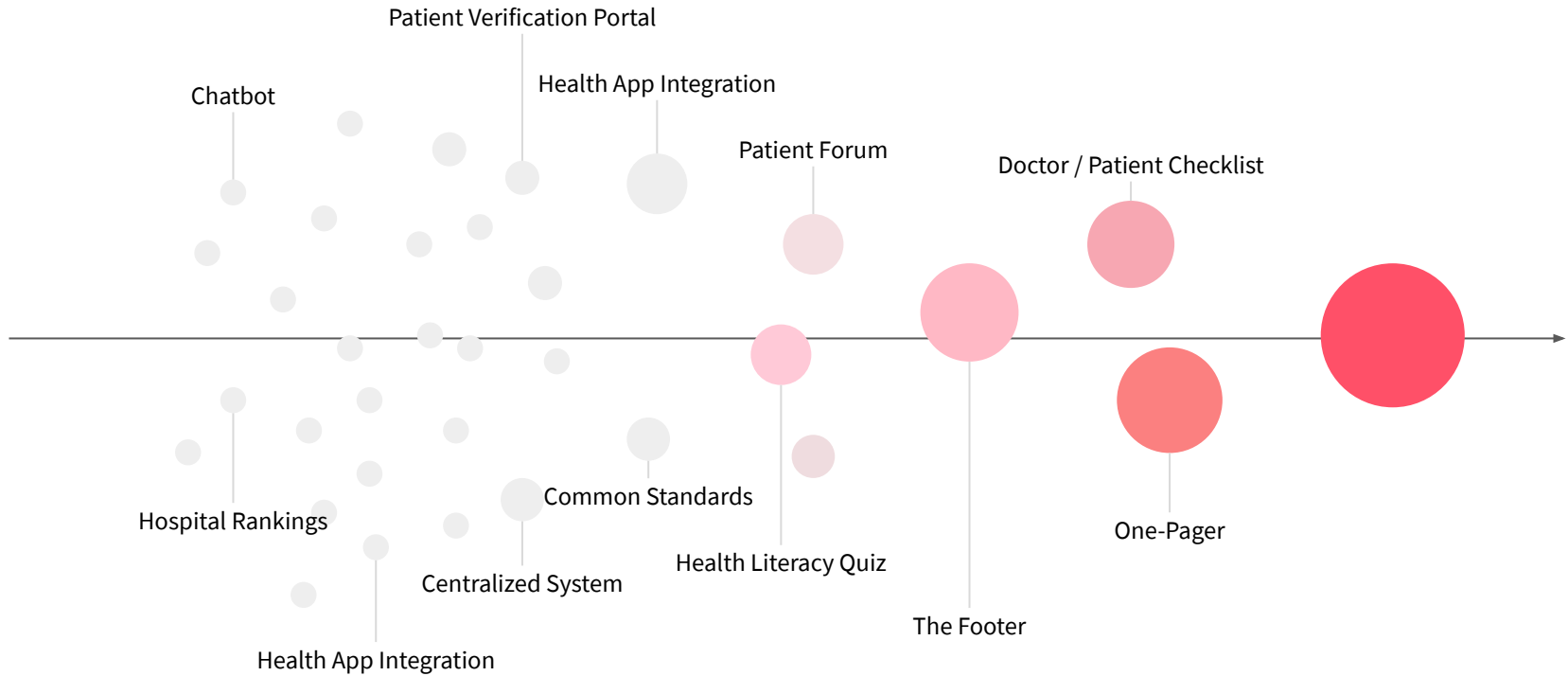
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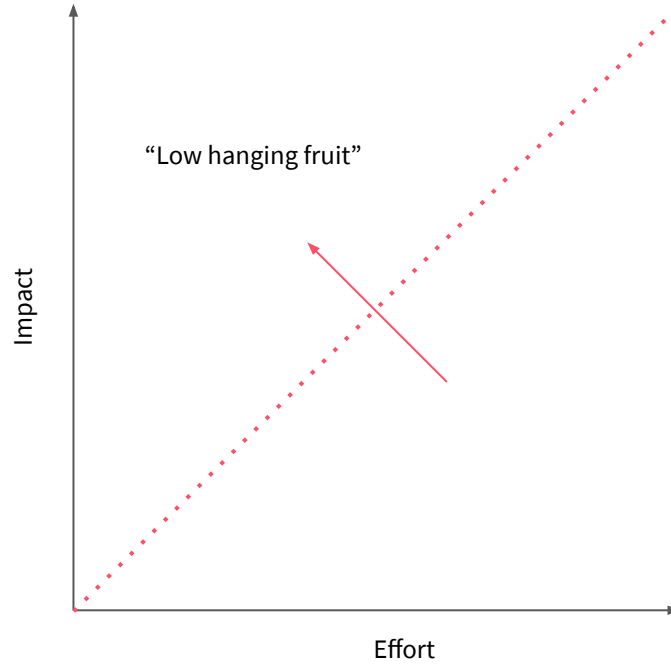
## Final Specifications

A **simple and intuitive tool** that a user can engage right at the **moment of need**, which requires no identifiable information, and can give **personalized** and **actionable** answers.

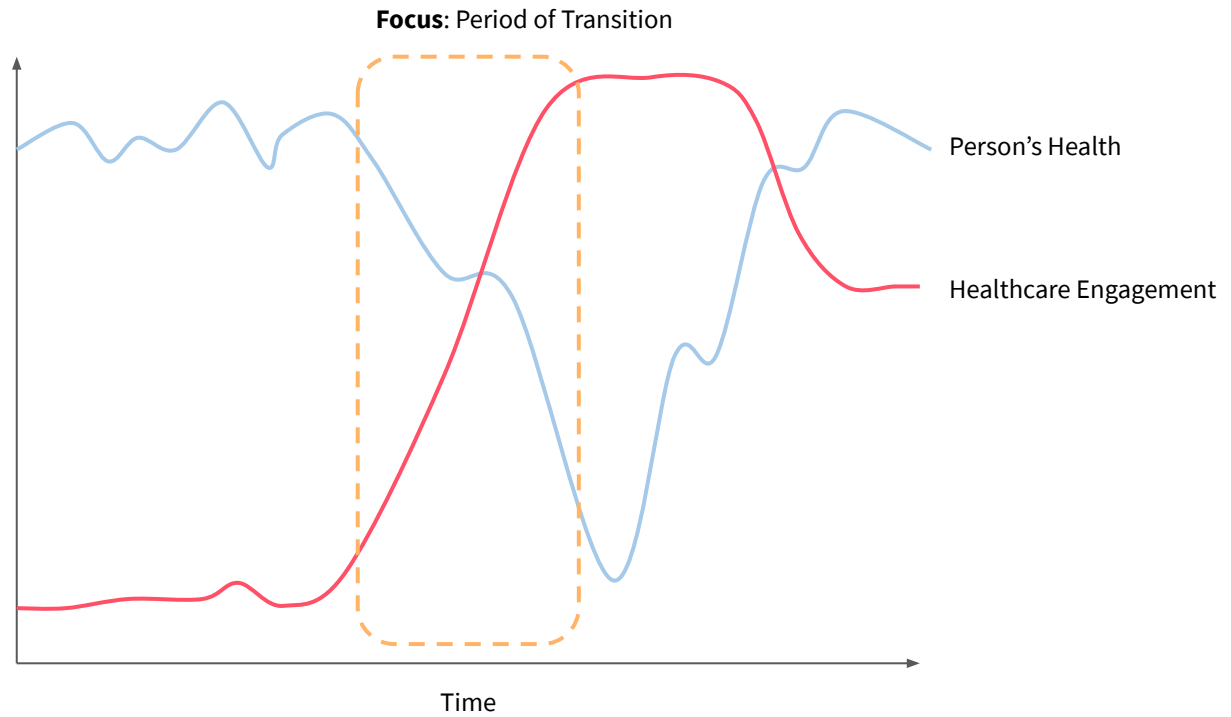




## Ideation



## Selecting: **Easy Wins**



## Selecting: **Maximizing Impact**

***“ I don’t think I’ll even seek it out... I have a CPR refresher app on my phone and I haven’t opened it since the day I downloaded it ”***



## Selecting: **User Feedback**

### **Patient Verification Portal**

- \* A technical problem outside our scope / collective area of expertise
- \* Requires massive infrastructural investment

### **Health App Integration**

- \* Difficult to get 3rd party buy-in
- \* Does not capture seriousness of issues
- \* Questions of access for the economically disadvantaged

### **Health Literacy Quiz**

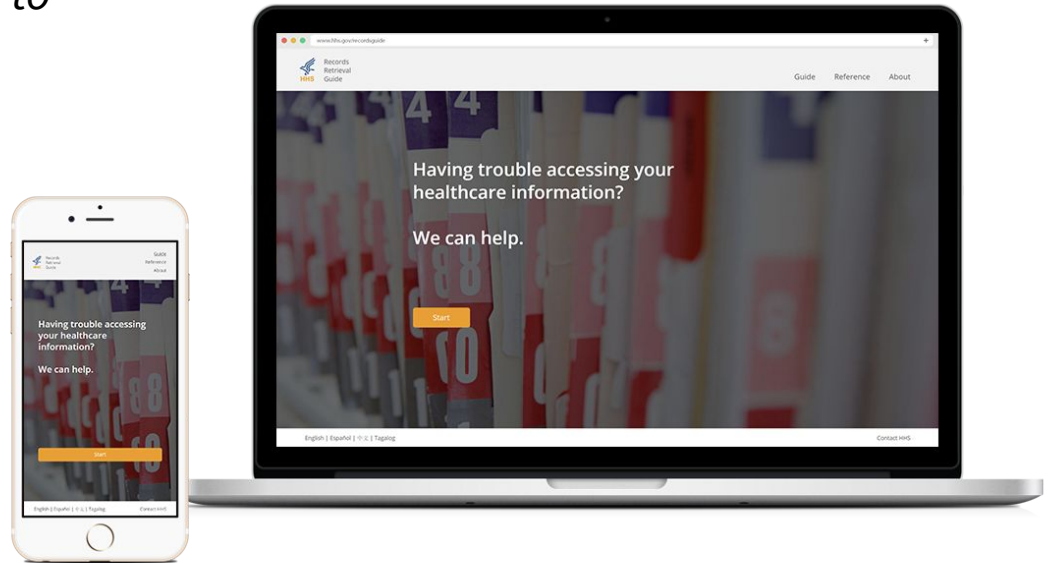
- \* No motivation or incentive to engage
- \* Doesn't personalize to individuals needs

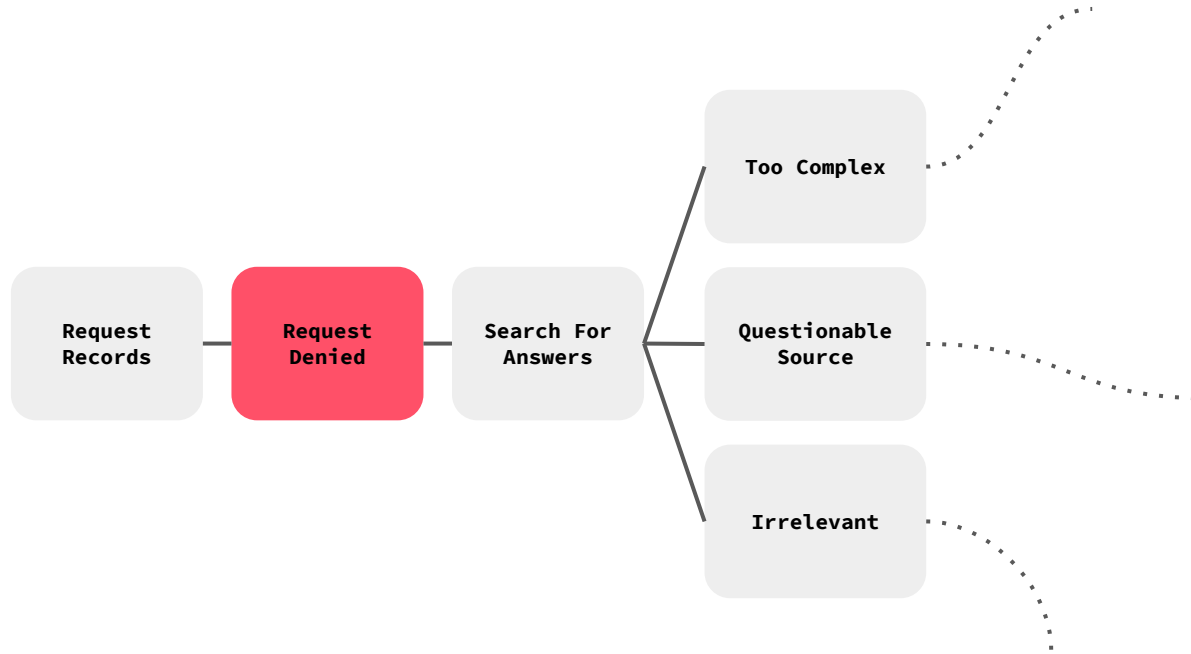
## **Evaluating Ideas**

# Intervention

# HHS Records Retrieval Guide

*A step-by-step, plain language guide for exercising your rights to access healthcare records*





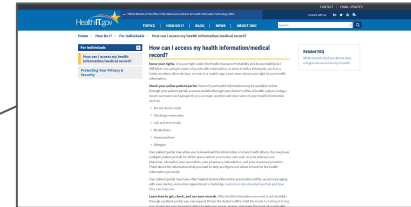
## A **Current** User's Journey



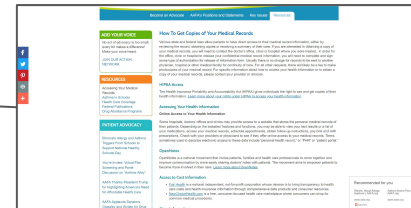
myhealthrecord.com



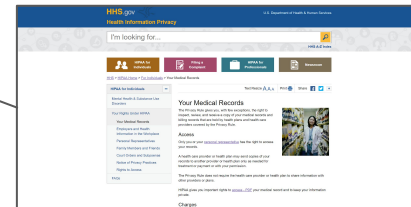
healthit.gov



aafa.org



hhs.gov



access my health records

All News Shopping Videos Images More Settings Tools

About 303,000,000 results (0.73 seconds)

**My Health Record**

<https://myhealthrecord.com/>

Your doctor has selected MyHealthRecord.com so you can access your medical records anytime, anywhere, manage your office appointments, talk privately to ...

**How can I access my health information/medical record? | HealthIT.gov**

<https://www.healthit.gov/faq/how-can-i-access-my-health-information-medical-record>

Apr 4, 2018 - Under HIPAA you have access to your health records. There are ways to get access to your protected health information. Find out the details ... You've visited this page 2 times. Last visit: 4/11/19

**Accessing Your Medical Records | Aafa.org**

<https://www.aafa.org/accessing-your-medical-records/>

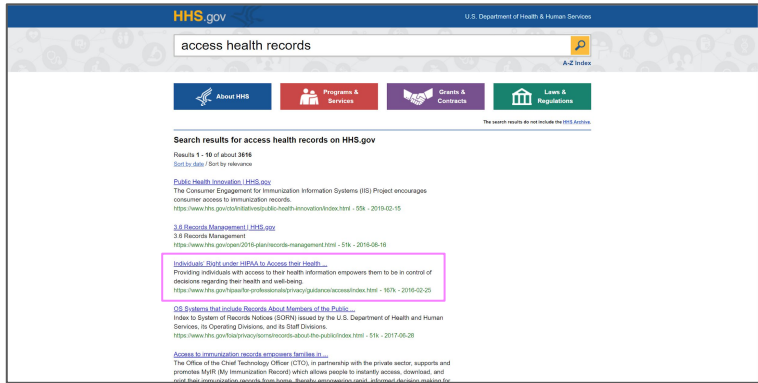
You have a right to access your medical record information. Follow these steps.

**Your Medical Records | HHS.gov**

<https://www.hhs.gov/hipaa/for-individuals/medical-records/index.html>

Access. Only you or your personal representative has the right to access your records. A health care provider or health plan may send copies of your records to ...

## Current Solutions



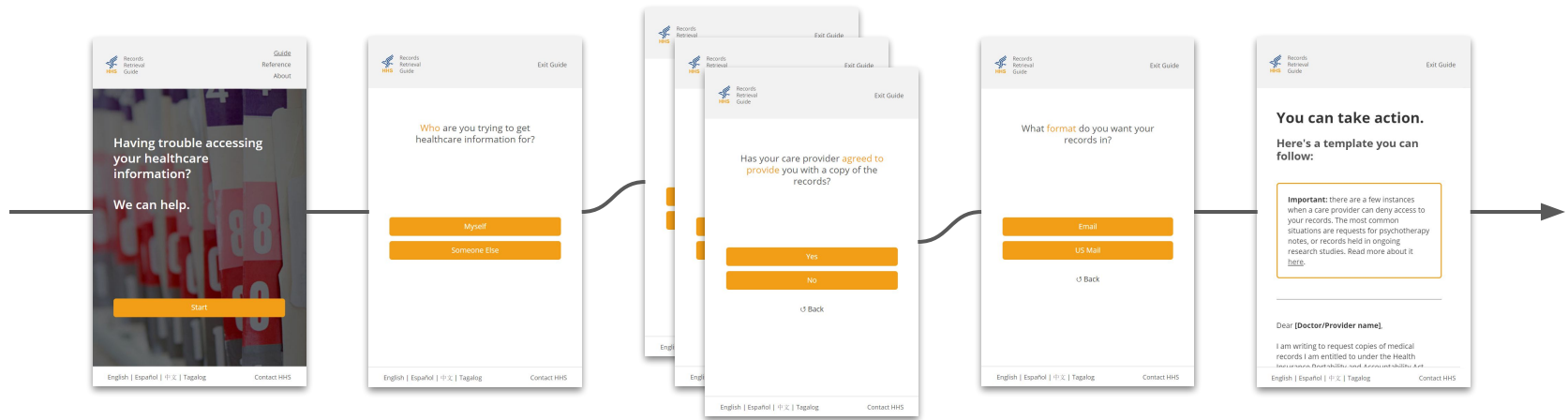
## Individuals' Right under HIPAA to Access their Health ...

Providing individuals with access to their health information empowers them to be in control of decisions regarding their health and well-being.

From HHS



From HHS



## Simplifying the Process



## A **Future** User's Journey

## You can take action.

### Here's a template you can follow:

---

Dear **[Doctor/Provider name]**,

I am writing to request copies of medical records I am entitled to under the Health Insurance Portability and Accountability Act (HIPAA) through Health and Human Services (HHS).

I was last treated at your office **[at facility]** on **[specify date]** by **[doctor/ care provider name]**. I request the following **[or all]** health records related to my treatment.

**[List specific requested records if applicable]**

I would like these records sent to me via email, a protected form of communication under HIPAA. To quote 45 C.F.R. § 164.530(c), "The Privacy Rule allows covered health care providers to communicate electronically, such as through email, with their patients, provided they apply reasonable safeguards when doing so."

I would like **[state specific records]** sent to me at **[enter email address]** within 30 days of when I filed my initial record request, as specified by HIPAA. Also, under HIPAA, you may not charge me to prepare or send these records because they are in a digital format.

If you refuse to meet my request within 30 days, or you inform me with a valid reason for a 30-day extension, I will be forced to file a HIPAA complaint through the Office of Civil Rights at HHS.

I look forward to receiving the above records in the next 30 days. If an extension does occur, please let me know by phone or email the date of their expected arrival.

## Actionable Outcomes

### Here's a template you can follow:

**Important:** there are a few instances when a care provider can deny access to your records. The most common situations are requests for psychotherapy notes, or records held in ongoing research studies. [Read more about it here.](#)

Dear **(Doctor/Provider name)**,

I am writing to request copies of medical records I am entitled to under the Health Insurance Portability and Accountability Act (HIPAA) through Health and Human Services (HHS).

I was last treated at your office **(at facility)** on **(specify date)** by **(doctor/care provider name)**. I request the following **(or all)** health records related to my treatment:

**(List specific requested records if applicable)**

I would like these records sent to me via email, a protected form of communication under HIPAA. To quote 45 C.F.R. § 164.330(c), "The Privacy Rule allows covered health care providers to communicate electronically, such as through email, with their patients, provided they apply reasonable safeguards when doing so."

I would like **(state specific records)** sent to me at **(enter email address)** within 30 days of when I filed my initial record request, as specified by HIPAA. Also, under HIPAA, you may not charge me to prepare or send these records because they are in a digital format.

If you refuse to meet my request within 30 days, or you inform me with a valid reason for a 30-day extension, I will be forced to file a HIPAA complaint through the Office of Civil Rights at HHS.

Must be easily understood without background knowledge	→	Clear, plain language
Requires no identifiable information	→	Non-invasive questions
Give users agency and actionable information	→	Communication templates, tips and resources
Engages users right at the point the moment of need	→	Answering the question as it comes
Works within current systems and laws	→	No infrastructural or legislative change needed

## So... Why **This**?



# Intervention(s)

**New Cross**  
 A health insurance organization  
 1000 North Main Street  
 Alexandria, VA 22304

**NEW CROSS MEDICAL SERVICES**  
 Specialty: Health Plan (PH)  
 Billing Method: Facility  
 Billing Responsibility: Facility  
 Fee Assessment Form

**PATIENT INFORMATION**  
 Patient Name: \_\_\_\_\_  
 Date of Birth: \_\_\_\_\_  
 Social Security Number: \_\_\_\_\_  
 Patient ID: \_\_\_\_\_

Facility and provider must participate with HHS (42 CFR 156.31) or otherwise obtain information from the facility. Complete this form only if you are a participating provider.

**INCOMPLETE SUBMISSIONS WILL BE RETURNED UNPROCESSED.**  
 BILLING INFORMATION IS SUBJECT TO REVIEW AT DISCRETION

- NUMBER OF REFERENCE PROVIDER(S) IS NOT DATA VALID
- ALL REFERENCE PROVIDER(S) MUST BE ACTIVE AND IN GOOD STANDING
- REF REFERRER OR PROVIDER MUST BE AT LEAST 1 HOUR OF THERAPY A DAY A WEEK
- DATE MUST BE ENTERED IN RECEIVING SET UP AT LEAST 10 BUSINESS DAYS PER BEEN AND ABLE TO GET THE REFERRAL
- THE PROSTATE/UTERINE RECEPTION PROCESS IS NOT A GUARANTEE OF PAYMENT
- THIS FORM SHOULD BE COMPLETED BY LICENSED CLINICAL PERSONNEL

SIGN AND DATE HERE \_\_\_\_\_

**ASSESSMENT TYPE COVERAGE**  
 Facility type:  INF  HOME RESIDENTIAL  SKILLED NURSING

**MEMBER FACILITY INFORMATION**  
 Member name: \_\_\_\_\_  
 Facility: \_\_\_\_\_

*Know Your Rights:* The Health Insurance Portability and Accountability Act of 1996 (HIPAA) gives you rights with respect to your health information.

To learn more, visit [yourhealthyourrights.hhs.gov](http://yourhealthyourrights.hhs.gov)

**COMPLETION**  
 Date: \_\_\_\_\_

**MOBILE STATUS**  
 Mobile:  YES  NO


**MOBILITY CURRENT FUNCTIONING**  
 Mobility:  YES  NO

**CLINICAL SUPERVISION CONDITION**  
 Supervision:  YES  NO

**Other Information**  
 Other: \_\_\_\_\_

Know Your Rights: The Health Insurance Portability and Accountability Act of 1996 (HIPAA) gives you rights with respect to your health information. To learn more, visit [yourhealthyourrights.hhs.gov](http://yourhealthyourrights.hhs.gov).

## The Footer


 DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)  
**GETTING YOUR HEALTH RECORDS**  
 CHECKLIST

**STEP 1: SOME HOMEWORK**


- Full or partial Records? Know what you are asking for.
- Be clear on the Number of Copies You are Looking for
- Which Format? Here are some of the formats you can receive your records in: a) your personal email, b) snail mail, c) CD or a thumb-drive or d) in your patient portal.


**STEP 2: CHECK YOUR ONLINE PATIENT PORTAL**

- Some of your health information might be available in your patient portal.
- If your provider doesn't have an online portal: a) Phone or b) Visit the facility to know more.

**STEP 3: GIVE YOUR DETAILS**

- Once you have the form to access your records, fill in your details such as name, address, hospital care provider.


**KNOW YOUR RIGHTS!**  
 Both HIPAA and HHS require health care providers to give your records. This is YOUR right under the law


 DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)  
**GETTING YOUR HEALTH RECORDS**  
 CHECKLIST

**STEP 4: PAY (OR NOT)**


- Your provider may charge you a reasonable fee if: a) They are mailing you a copy of your records or b) making electronic copies of your paper records.

**STEP 5: WAIT**

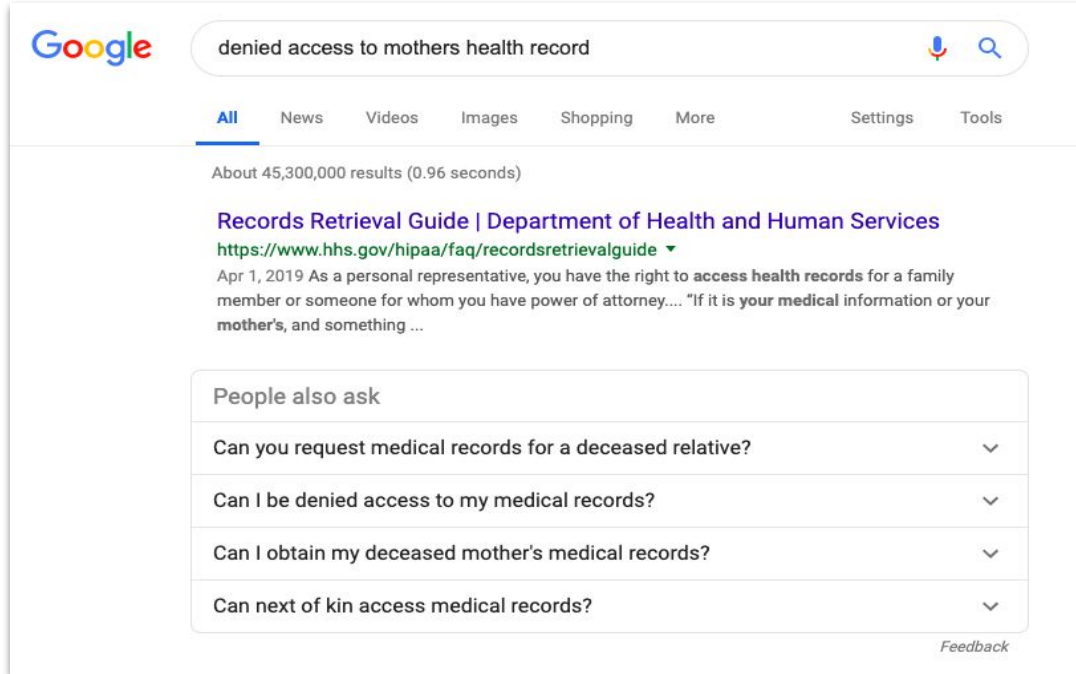
- According to the federal law, your provider can take up to **30 days** to issue your records.
- If your provider fails to provide it within first 30 days, they should specify the reason for the delay and give a new delivery date. This may take up another 30 days.

**STEP 6: CHECK YOUR RECORDS**

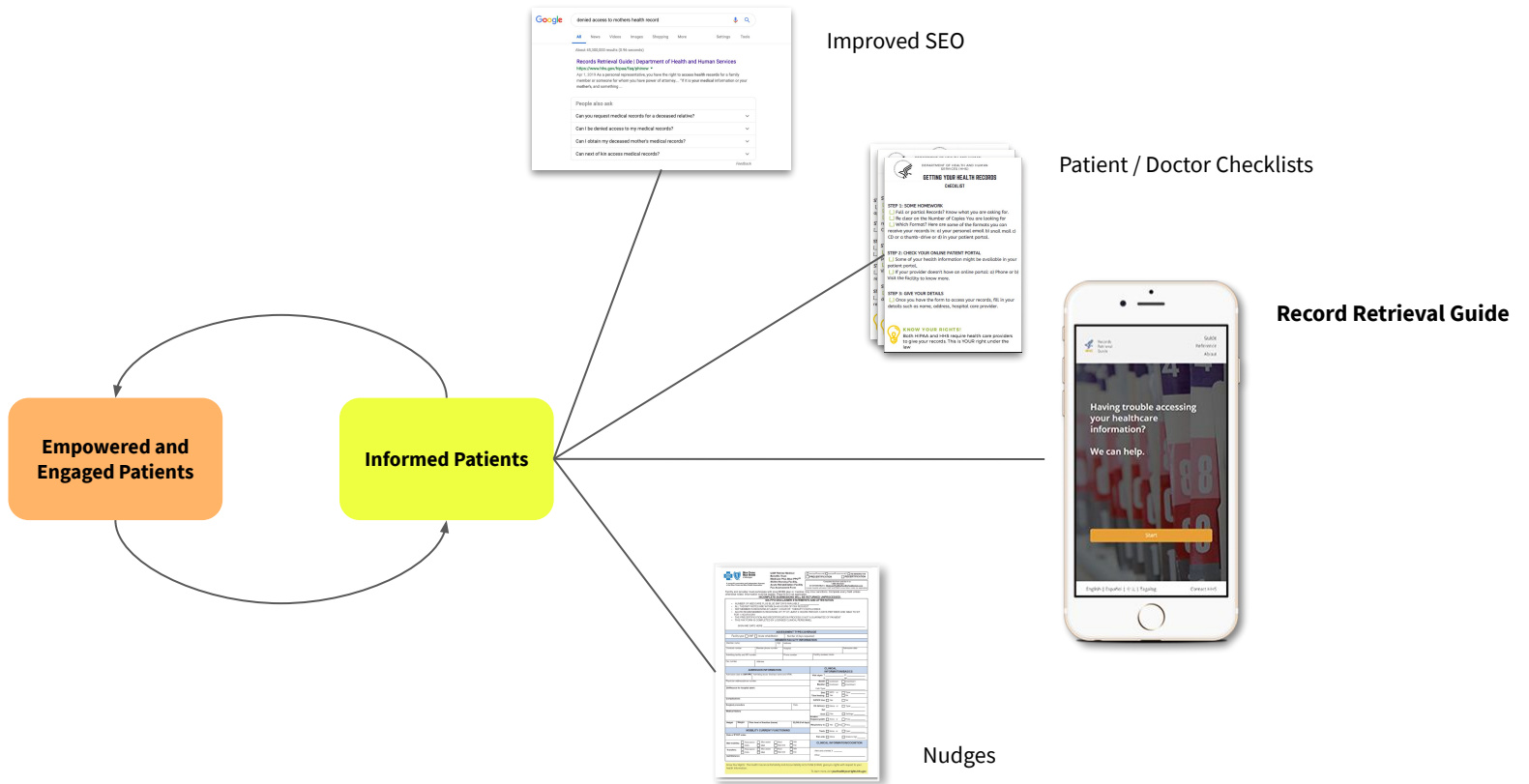
- Once you receive your records, check it for any errors. In case of any error, contact your provider with a request to amend.


**KNOW YOUR RIGHTS!**  
 You can access health records on the behalf of your loved ones if you possess the medical power of attorney.

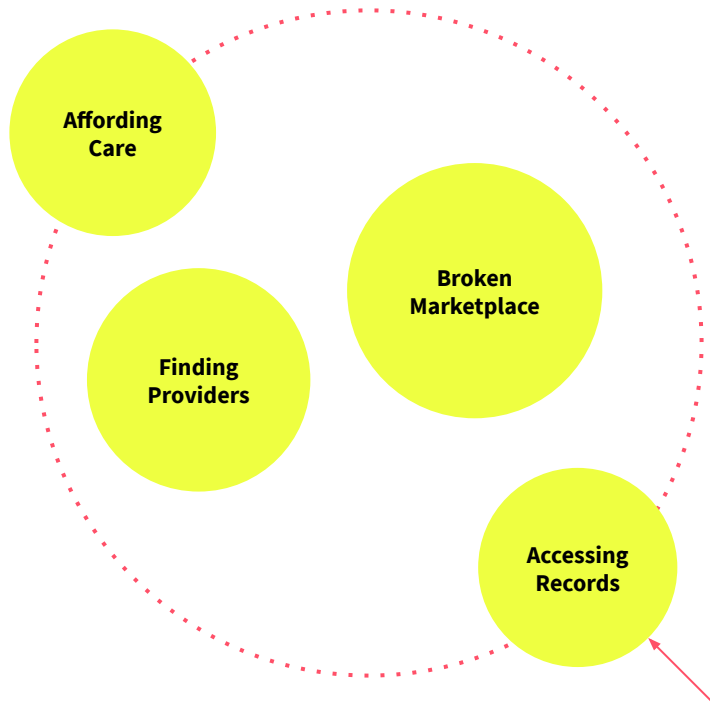
## Doctors / Patient's Checklist



## Search Engine Optimization (SEO)



## Building A Network of Interventions



## The **Broader Issues**



**Thank You!**



# Appendix

- Filing a Complaint**
- Complaint Process
- File a Complaint Online
- What to Expect
- File a Patient Safety Confidentiality Complaint

## Filing a Complaint

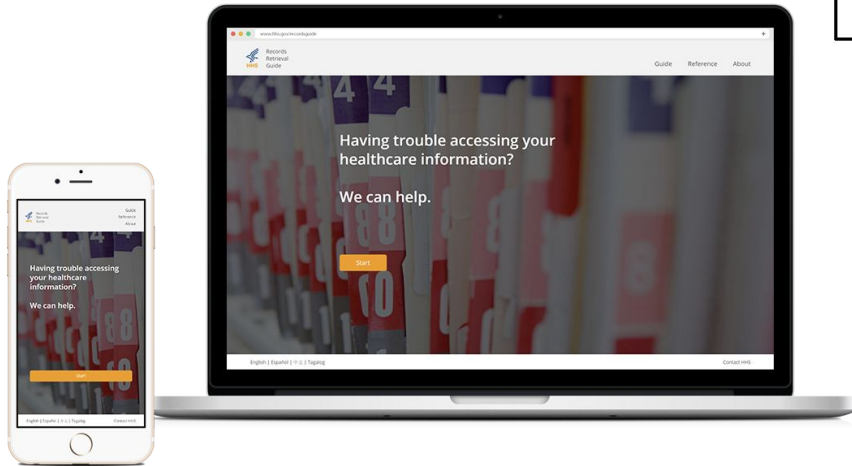
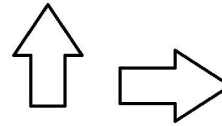
If you believe that a HIPAA-covered entity or its business associate violated your (or someone else's) health information privacy rights or committed another violation of the Privacy, Security, or Breach Notification Rules, you may file a complaint with the Office for Civil Rights (OCR). OCR can investigate complaints against covered entities (health plans, health care clearinghouses, or health care providers that conduct certain transactions electronically) and their business associates.

### Complaint Process

Anyone can file a complaint if they believe there has been a violation of the HIPAA Rules. Learn what you'll need to submit your complaint online or in writing.

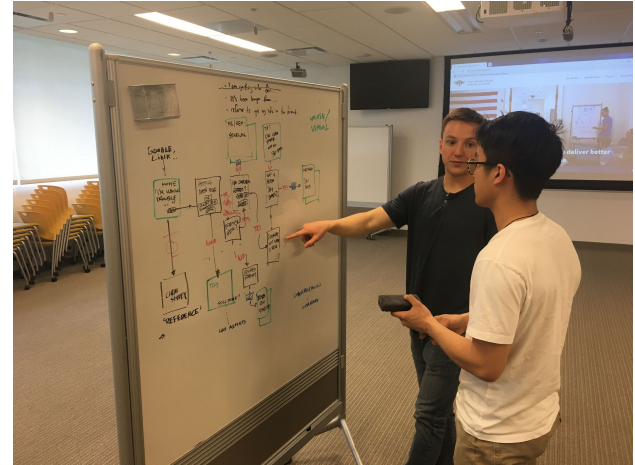
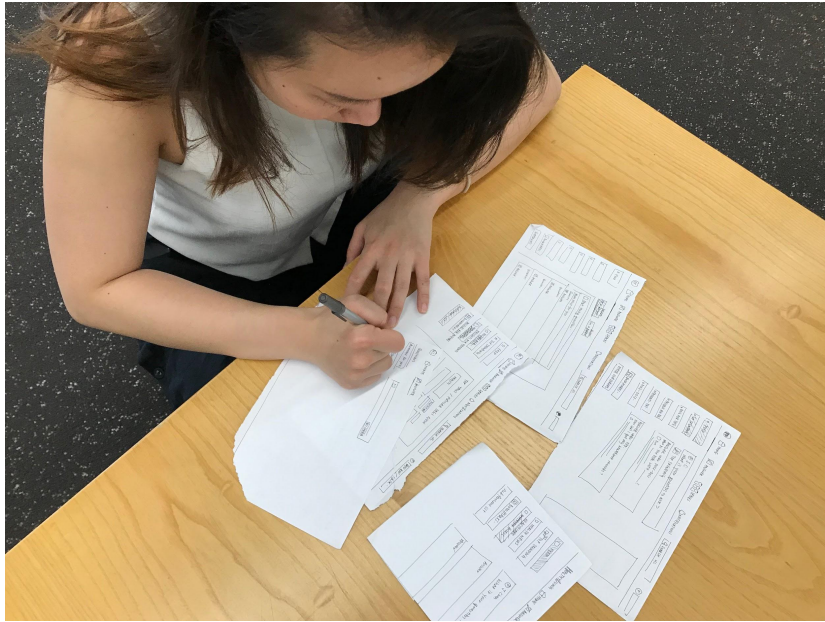
### File a Complaint Online

File your complaint electronically via the OCR Complaint Portal.

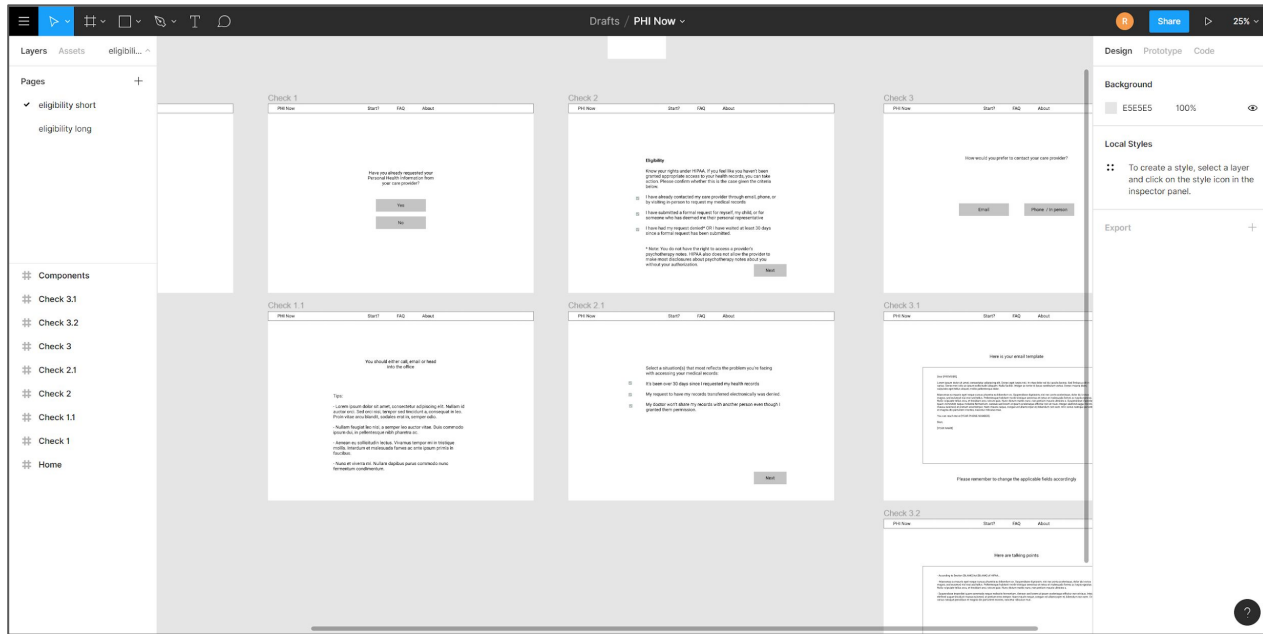


## Where to Implement Our Tool

# Prototyping



## Prototyping



# Prototyping

“ Overall the functionality was **very simple** which I liked but and provided me with a **quick solution** vs. a long response and waiting period. ”

“ I like how it **leads you** question by question rather than being presented as a form where you fill out all of the information on one page. ”

“ It's also good that the rules were included, so the student knows that the records can still be emailed to him/her and he/she **doesn't have to physically go to the hospital.** ”

“ I think it helps, but the patient needs to know to go access this site somehow **before they call the hospital** and get upset. ”

## User-Testing the Troubleshooting Guide

# Data Collection Details

# 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

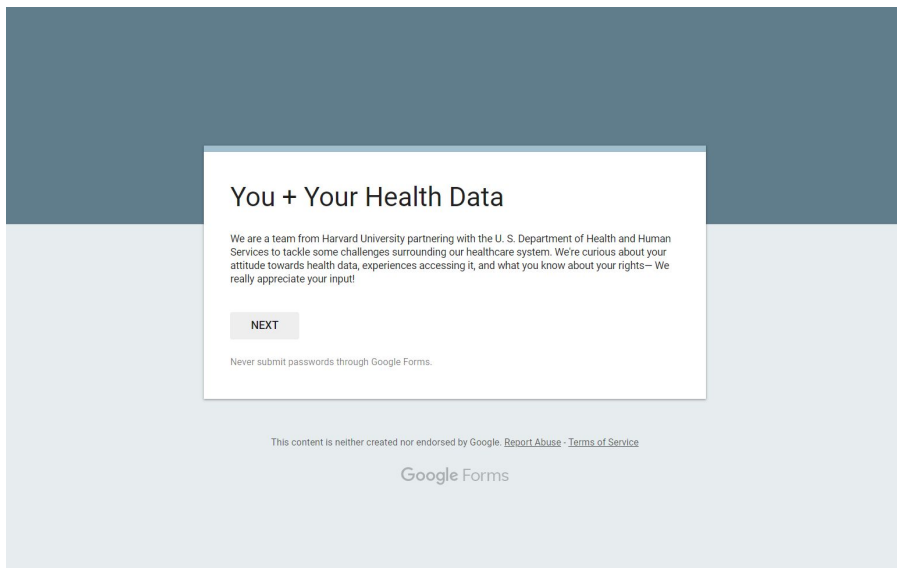


Being **hacked** is **inevitable**

Complaints about **lack of information infrastructure**

People in great health **don't care** about health history

**Fear of Discrimination**

A screenshot of a Google Forms survey. The title is "You + Your Health Data". The text 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, it says "Never submit passwords through Google Forms." Below 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 at the bottom center.

**You + Your Health Data**

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!

**NEXT**

Never submit passwords through Google Forms.

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Google Forms

## Common Online Poll Sentiments

“ 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. ”

## Online Survey Stories

## Locations

- Harvard Square
- Smith Center
- South Station
- Cambridgeside Mall

Length: 15-30 minutes

## Question Topics (Followed This Template)

- Demographics
- Interaction with healthcare system
- Thoughts on records
- Changes they would like to see

- Demographic information
  - Name
  - whether if you move around a lot
- How often do you go to the doctor?
- Have you ever had an experience where you had to access your healthcare records, or someone else's healthcare records? How did that go?
- Do you care more about the privacy aspect or the convenience of accessing your healthcare records?
- Do you know about HIPAA/ what do you know about HIPAA?
- How often do you think about accessing your healthcare information?
- In the ideal world, how would you want your healthcare information to be shared?

-----

- When was the last time you visited a hospital, clinic or seen a doctor?
  - Process?
  - Documents?
- How often do you go to the doctor's office?
- How do you think about your personal health?
- How much do you remember about your past medical history?
  - Do you think it matters? ... Why?
  - Do you think it's accurate? ... Why?
- How's your 'health' literacy? (Can reference financial literacy)
- What did you think about the check in process
- The stuff that they made you sign? What was it that they made you sign?
- When in your life do you think about health information?
- Do you see any value in having your own healthcare data?
- What do you know about your own medical records?
- Do you know how to get access of your medical records if you need to get there?
- How often do you think about your healthcare records? Why?

## User Interview Details

“ I’m still under the impression that it would be a **ream of paper**” (in reference to her old medical records) ”

“ 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. ”

“ It is **their medical record**, and we are just holding their medical record for them. But it’s the medical record **they own**. ”

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

## User Interview Quotes

## 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](#)

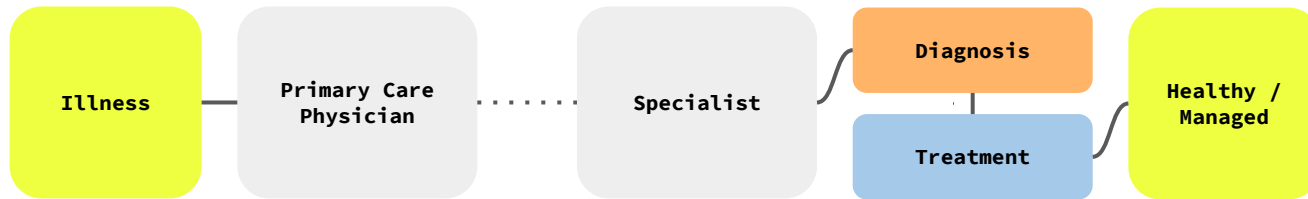
Breach Report Results							
Expand All	Name of Covered Entity	State	Covered Entity Type	Individuals Affected	Breach Submission Date	Type of Breach	Location of Breached Information
	AccuDoc Solutions, Inc.	NC	Business Associate	2652537	11/27/2018	Hacking/IT Incident	Network Server
	Iowa Health System 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

# The Patient Experience...Visualized

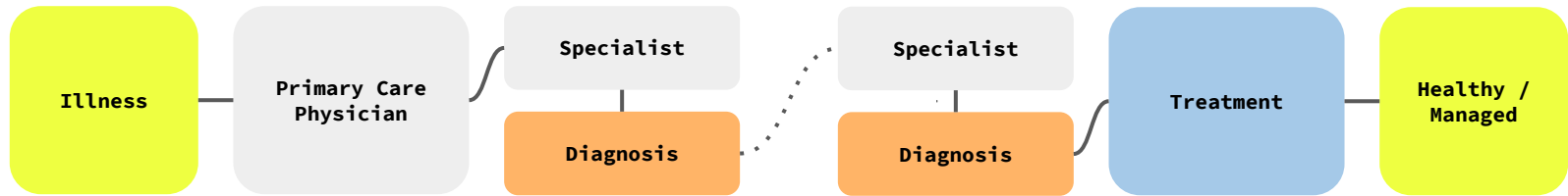


## Ideal Patient Experience

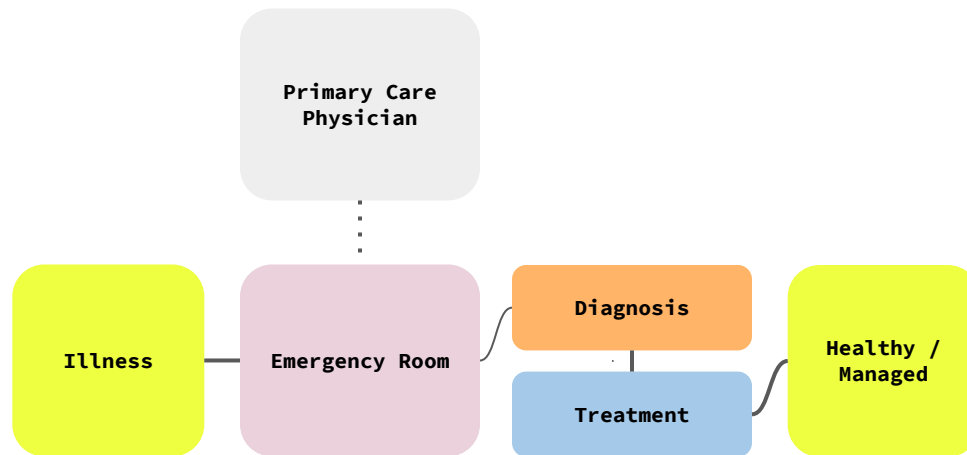


## Out of Network





## Second Opinion



## Emergency