

Improving the Health Records Request Process for Patients

Insights from User Experience
Research

The Office of the National Coordinator for
Health Information Technology



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Problem Statement



Patients don't have easy access to their health data.

More and more patient health information is available electronically — but patients and caregivers still face challenges in accessing their data. Patient portals may not include all the information patients need — and what's there may be inaccurate or incomplete. And often, health data can't be shared electronically or transferred to other health care providers.

We know that patients and caregivers who **do** have access to their data can better coordinate their health care, prevent repeat or unnecessary tests and procedures, and have greater control over their health and well-being.

So how do we make it easier for patients to request and manage their own data?

To answer this question, we need to understand the medical record request process from both sides — patients and health systems.



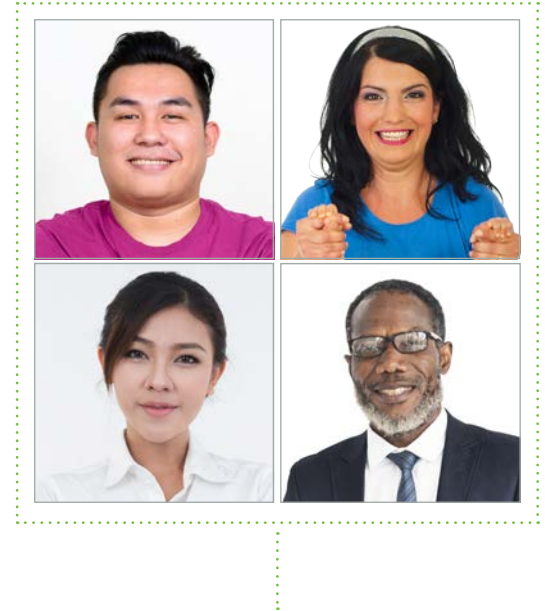
Discovery



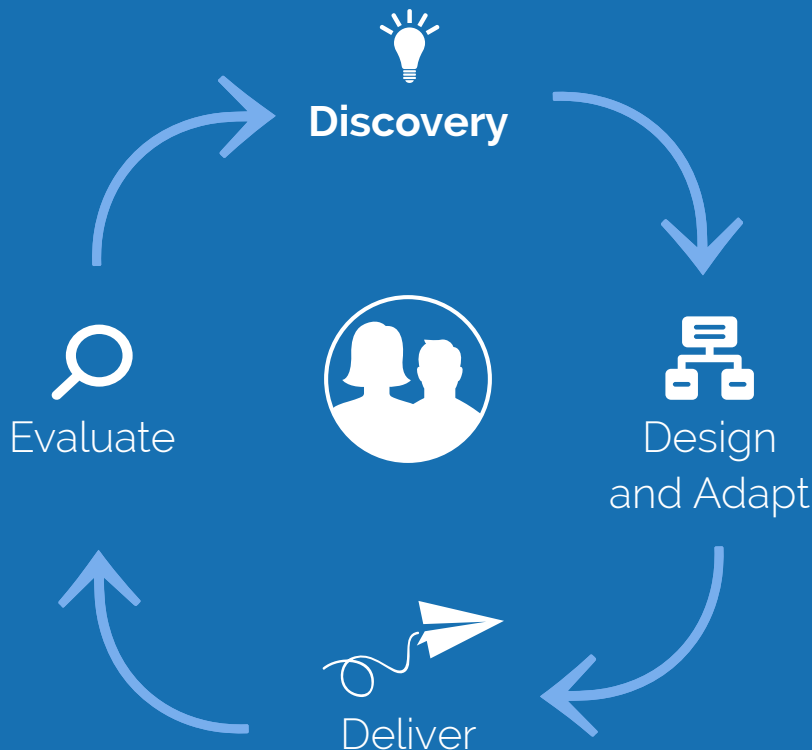
Overview of HCD Methods

Human-centered design (HCD), also called **co-creation** or **participatory design**, is a way of involving end users in developing and improving products. It's a multi-disciplinary methodology that draws from cognitive psychology, ethnography, and interaction design.

This report represents the “**Discovery**” phase of the HCD process: the initial research into the needs and behaviors of users, and the user experience of existing services. While this report is based on qualitative research with a limited number of users and may not be reflective of all patients’ experiences, the results can still be used to guide much-needed improvements to these services.

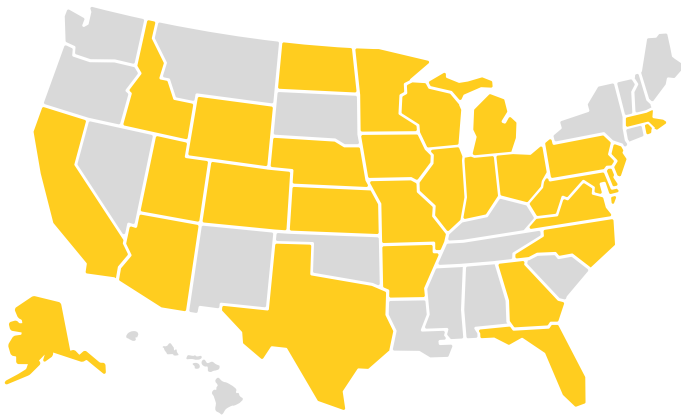


A human-centered design process



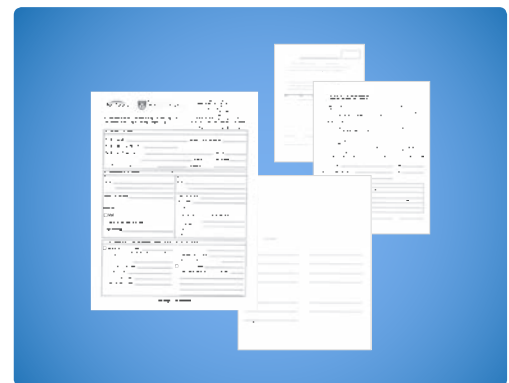
What We Did

ONC conducted interviews with **17 consumers** to understand their experiences — and challenges — accessing their patient data.



We also analyzed medical record release information and forms from **50 large health systems and hospitals across the country** representing **32 states**.

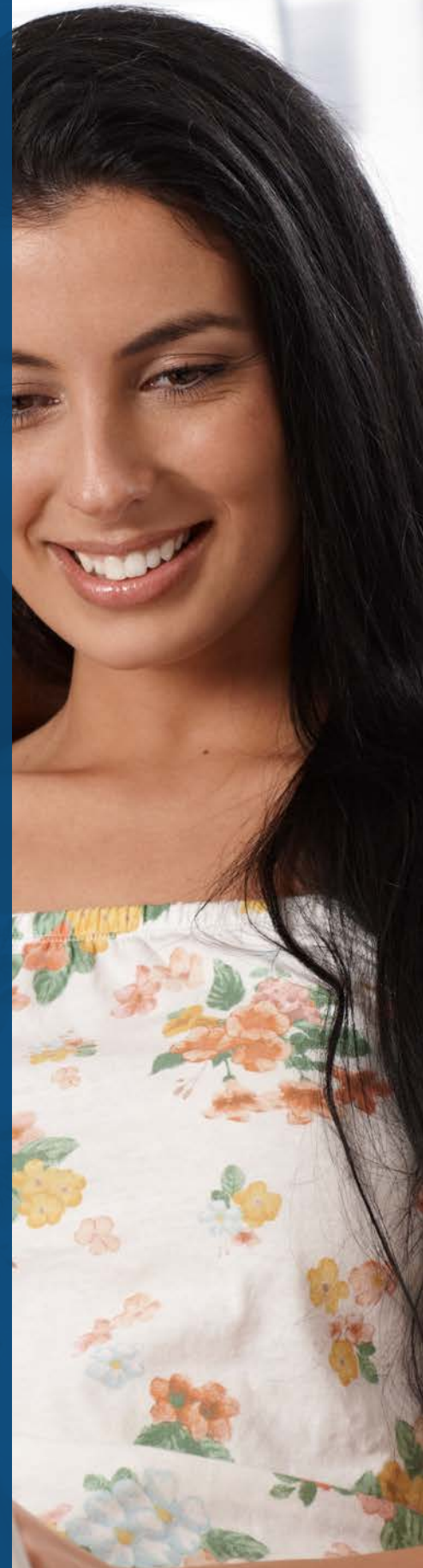
Then, **we talked to insiders** — ONC and partner stakeholders, as well as 4 medical record fulfillment administrators — to unpack the records request process and look for opportunities to make it better for consumers.



This is what we found.



The Records Request Experience



G.V.Y.N. - GATHERING RECORDS FOR SPECIALIST VISIT FOR SPECIAL NEEDS

Overview



The health data request process usually starts with a specific trigger — like a health crisis or event, moving to a new location, or an appointment with a specialist for a diagnosis or second opinion. Then...

FEELINGS:

Optimistic. How hard will this be? I have weeks before the health...

Surprised no one has done records. They all use computer during our visits.

Shocked - this is taking longer than I thought.

Ill-equipped. How am I supposed to know what records I need?

I feel like a burden. I'm asking for more of my staff.

Frustrated. I want to call re-request official records - but I forgot.

Overwhelmed. Will I always have to do this and carry a binder?



Consumer makes initial inquiry: To start, consumers said they call their provider’s office to figure out how to send their records to another health care provider (or get their own copy).



Consumer requests the records: Usually, this means filling out an authorization form. Consumers might have to go online, download the form, print it, and then mail or fax it in. Or they may need to go to the records request office and fill out a form in person. Occasionally, health care practices ask consumers to write a letter authorizing release of their records.



Consumer waits: This is a bit of a black hole for consumers — they’re often in the dark about how long the process takes (up to 30 days under HIPAA) or when they can expect to hear back.



Health system receives and verifies the request: During this time, administrative staff must verify the patient’s identity and the record requester’s identity (for instance, by comparing name, signature, and date of birth) — as well as the accuracy of the recipient’s address and contact information. *Then* they can locate the requested records.



Health systems fulfill the request: The output can be surprisingly antiquated — usually a printed stack of records that is faxed or mailed, or sometimes a set of PDF files on a CD. These formats require the provider’s office receiving the records to manually enter them into their EHR.

Shared Needs

In the current records request process, patients and health systems are often at odds, as each struggles through an inefficient system to accomplish needed tasks with limited resources. But ultimately, these 2 user groups have the same goals — and shared needs. That means that **improving the records request process is a win-win.**



Complete and accurate records:

Patient records often have mistakes or are missing sections of care, which can result in repeated or unnecessary tests and procedures — and make patients feel like they’re playing a game of telephone with their providers. Complete and accurate health records can help providers offer better-coordinated care and empower patients to take charge of their health and well-being.



I should be able to go to the immunizations [section] and see all my shots, but it says that I have none on file. But that's not true — the doctor has given me some shots."

– Consumer participant



Online records management:

In today’s world, paper just doesn’t cut it. Online records keep everything in one place, so patients and providers have easy access to everything in a patient’s health record at all times. This is especially important for patients who are dealing with complex or chronic conditions.



I used to have to do that [physically pick up records] all the time. I would hope that things would have evolved."

– Consumer participant



Portable records:

Consumers often wait to transfer their records until there’s a health crisis, which means that patients who need their records often need them quickly. To meet this need, providers and practices need an interoperable system that can seamlessly transfer patient data from one provider to another.



Nobody has direct [address]. Nobody does it. Any certified EHR has to be able to accept direct email [via direct address], but no one knows about it.

– Health professional participant



Transparency in the records request process:

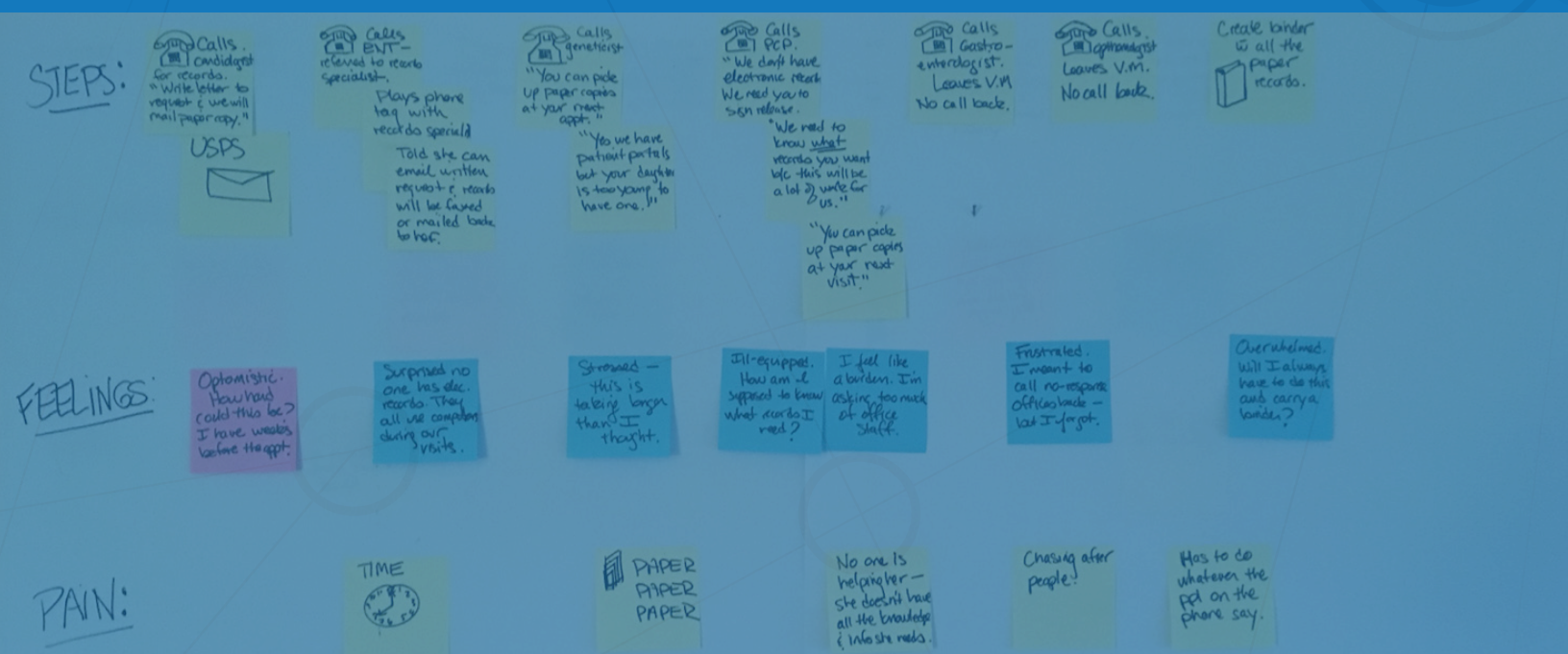
Consumers don’t know their options or their rights when it comes to transferring their records. For providers and practices, this comes down to making sure all their staff understand what HIPAA does and doesn’t mandate, and what their health record systems are capable of — so they can communicate clearly with their patients.

Consumer Perspective:

Meet the 3 personas

The following 3 personas are intended to help us design a records request process that meets the needs of diverse users. They are based on the characteristics of real users ONC talked with during this discovery phase.

We've mapped their individual journeys through the records request system, starting with an initial trigger and ending with the fulfillment of their request. Along the way, we've captured their pain points and small successes — and noted their varying use of patient portals to coordinate their care.



Melissa and Ava Crawford | Ages 43, 2

- Location
 - » Concord, NH
- Health Conditions
 - » Ava has epilepsy and a congenital heart defect
- Frustrated by
 - » How slow the process is — it can take weeks to get records
- Record Request Workaround
 - » Uses a spreadsheet to keep track of the different portals, passwords, and records request processes for each doctor's office
- What would make the process easier for her
 - » A comprehensive health record to track her daughter's care over time
 - » Clear, consistent, and easy processes to get health records



Health Care Literacy



Digital Literacy



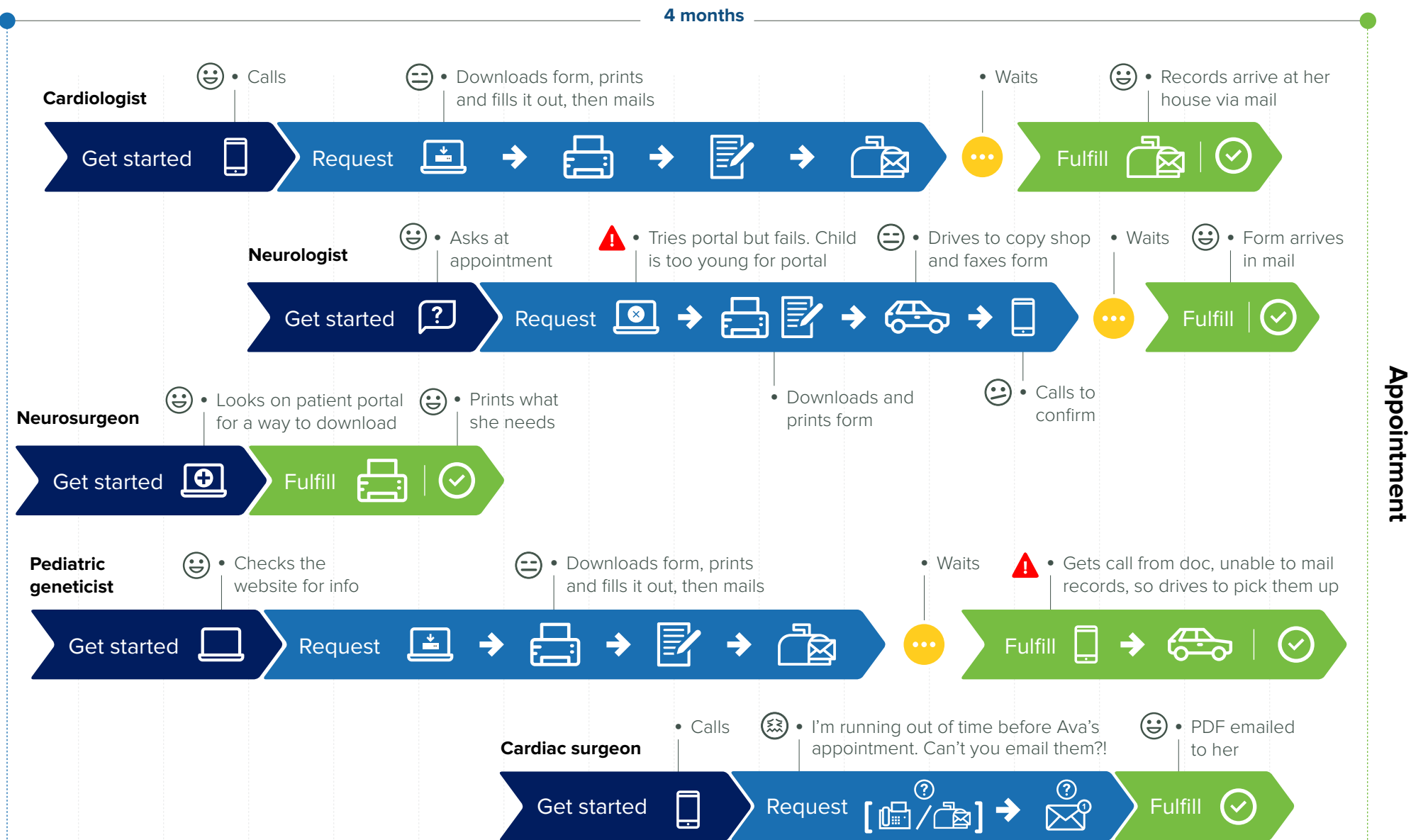
Motivation to Get Data



For Ava's 2-year pediatrician visit, I needed records from 5 specialists. The cardiologist mails me a copy. For the pediatric geneticist, I need to go in person, and it's a 90-minute drive to their office. The neurologist has a portal but I still have to fax a letter of release. **It takes so much time. I just wish the process was the same everywhere.**"

Trigger

Melissa needs to get records from all of Ava's specialists in time for the 2-year-old's visit with her pediatrician.



Darrell Mosley | Age 56

■ Location

» Cleveland, OH

■ Health Conditions

» Headaches and back pain from a car accident 6 months ago

■ Frustrated by

» Getting conflicting information from office staff about the best way to get his records

■ Record Request Workaround

» Went to the hospital's records office in person, after a follow-up appointment

■ What would make the process easier for him

- » Consistent, clear instructions
- » A streamlined process



Health Care Literacy



Digital Literacy



Motivation to Get Data



To spend all that time chasing down my records, when I was also dealing with trying to recover from my accident — **it was an extra stress at a time when I really didn't need it.** I don't care so much about the security — I just want them to talk to each other and figure it out without me being in the middle of it."



Darrell's Portals

Physical therapy clinic

PCP

Hospital

Portal Use

- » Didn't use his patient portal before his accident
- » Thought he would forget the passwords and it would be too much of a hassle

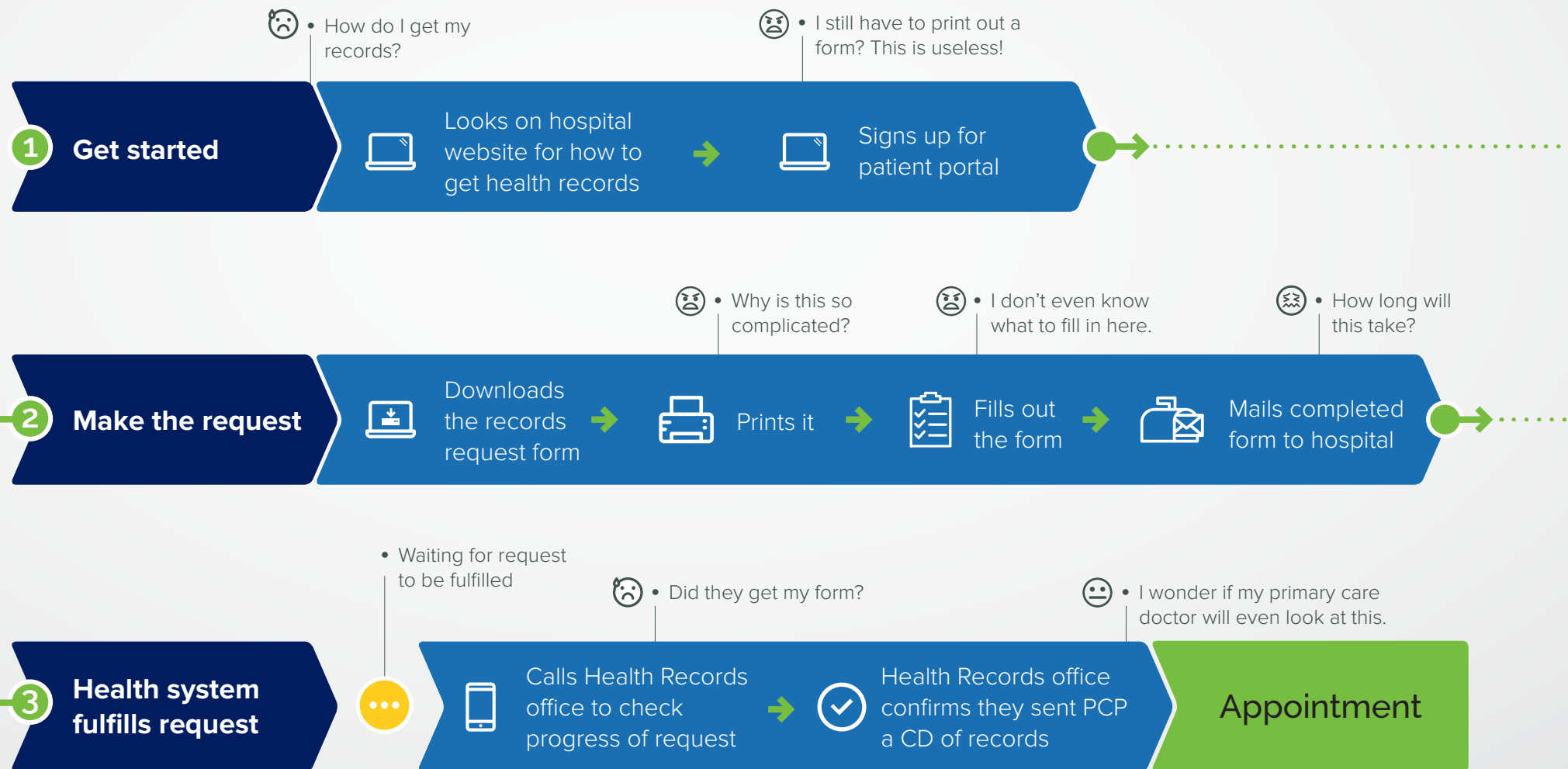


I got an account on the hospital portal because it said on the website I could use it to get my records sent to my doctor. But it turns out I also had to print a form, sign it, and give it to the records office at the hospital. So the portal wasn't very useful for me."

Trigger

Primary care doctor asked to have hospital and physical therapy records so she has a better understanding of Darrell's injury and care needs.

1 month



Rochelle Kim | Age 26

- Location
 - » San Diego, CA
- Health Conditions
 - » Mild asthma
- Frustrated by
 - » Even though her former doctor sent records when she changed practices, none of that information is reflected in her patient portal
- Record Request Workaround
 - » Called her doctor's office to figure out how to get her records, instead of using the patient portal

What would make the process easier for her

- - » Hands-off records transfer process
 - » Clear communication from her doctor's office



Health Care Literacy



Digital Literacy



Motivation to Get Data



I went through all the steps to get my records transferred, and in the end I felt like, why did I bother? My new doctor still made me fill out all these history forms, and none of my old vaccination records are in their electronic system."



Rochelle's Portals

Old PCP

New PCP

Portal Use

- » Only uses her patient portal when required — typically, to see test results — but didn't find it very useful
- » Has her password auto-saved in Chrome



I've never really used patient portals. Maybe if my health care needs were different I would use it more. **It's a hassle to log on, and then there's not really any information I need.** It's easier to just call my doctor's office."

Trigger

Rochelle switched health insurance plans and her former doctor isn't in network, so she needs to send her records to her new primary care doctor.

2 months



Health System Perspective:

Unpacking the process

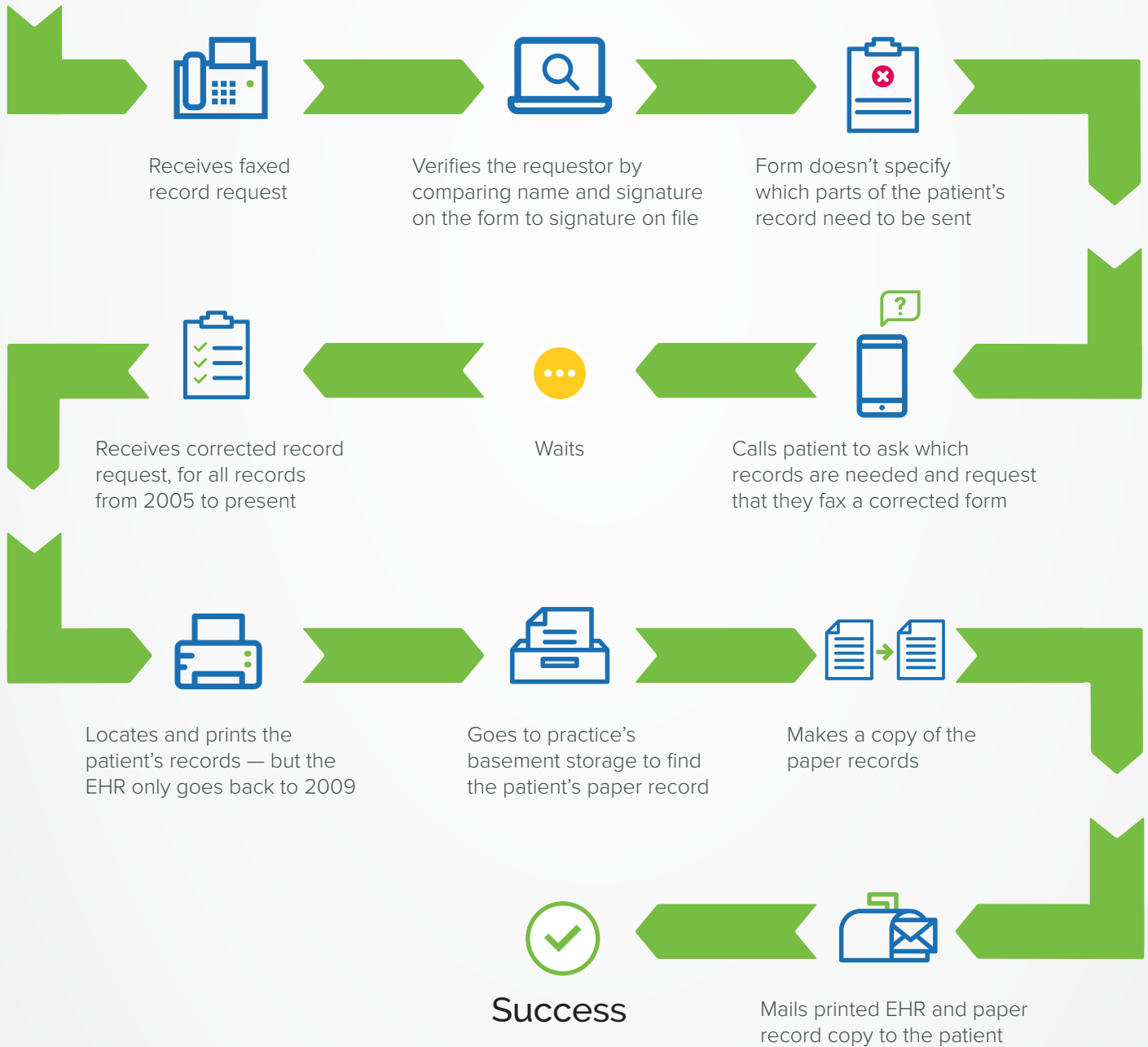
Patients often feel as though they're sending their record requests into a black box — they are rarely notified if their request was received and processed and have little understanding of what is involved in fulfilling a request.

Like patients, medical records fulfillment administrators are equally hindered by fragmented and incomplete records — some of which exist only in hard copy format. Health systems face an additional administrative hurdle: verifying the identity of the requestor. This step can dramatically impact the speed and overall success of the fulfillment process.

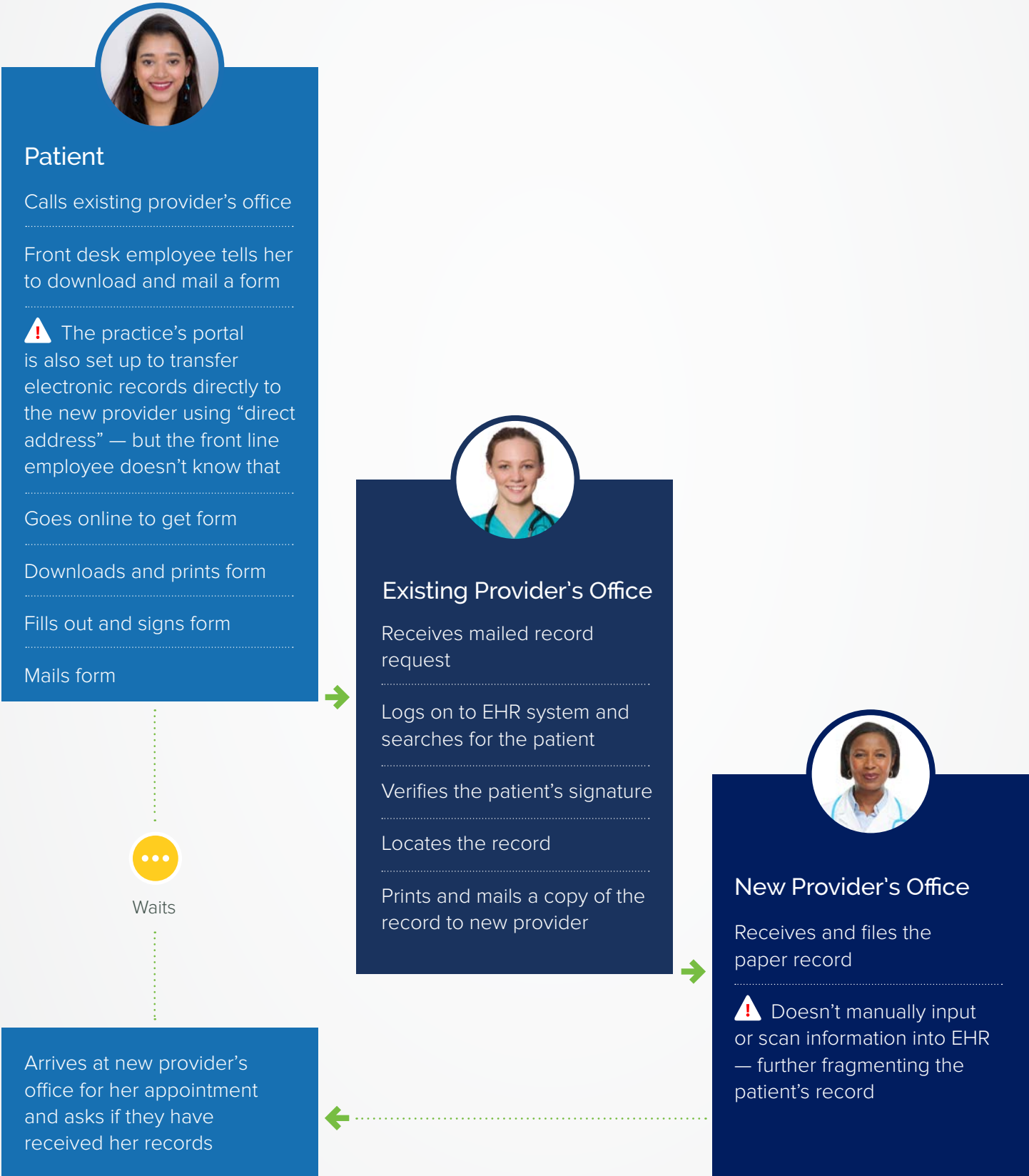
Task Flow: Health System Perspective



Health Records Administrator



Task Flow: Patient and Health System Perspectives



Take Action: Improve the Process



Health care practices have the opportunity now to improve their records request processes and reduce the burden on consumers. Many of the actions identified below won't solve larger-scale access and portability issues, but they have the potential to make the records request process less stressful for patients and health systems in the short-term.

Creating a streamlined, transparent, and electronic records request process may include:

- » Allowing patients to easily request and receive their records from their patient portal
- » Setting up an electronic records request system outside of the patient portal
- » Creating a user-friendly, plain language online request process
- » Using e-verification to quickly confirm the record requestor's identity
- » Including a status bar or progress tracker so consumers can see where they are in the request process — for example, indicate when the request is received, when their records are being retrieved, and when they're ready for delivery
- » Making sure consumers know that they can request their record in different formats (such as PDF or CD) and delivered in the way they choose (such as by email or sent to a third party)
- » Providing user friendly, plain language instructions for patients and caregivers on how to request health records, what to expect, and who to contact with questions
- » Encouraging patients to use patient portals by promoting features like online appointment scheduling, secure messaging, and prescription refills

A patient-centered request process benefits consumers **and** health systems.



