



# Health Data Literacy Handbook

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Your Guide to Health Data, Your Rights, and How to Use It

*Your health data belongs to you.*

*This handbook helps you understand it, protect it, and use it.*

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# What's Inside

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## Why This Guide Exists

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### Part 1

What Is Health Data Literacy?

### Part 2

Your Rights — The Full Picture

### Part 3

The Rules, Plain and Simple

### Part 4

The Laws That Protect You

### Part 5

Why This Matters — Real Consequences

### Part 6

The Missing Piece: Communication

### Part 7

Using Your Data in Real Life

### Part 8

Secure Communication and Direct Messaging

### Part 9

Identity, Trust, and Who You're Sharing With

### Part 10

Your Role in Your Own Care

### Part 11

What the System Owes You

### Part 12

When Things Go Wrong

### **Part 13**

Becoming an Active Participant

### **Part 14**

The Future of Health Data

### **Closing**

Your Data. Your Story. Your Voice.

# Why This Guide Exists

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## THINK OF IT THIS WAY

*Think of it like jumping into a TV series halfway through the season. You don't know the characters, you don't know what's happened, and nothing quite makes sense. That's what healthcare feels like for most people — and not because they're not smart enough. It's because no one gave them the guide.*

Every year, millions of Americans go to the doctor, get tests, receive diagnoses, take medications, and navigate hospital systems — often without ever seeing their own records, without understanding what's been documented about them, and without knowing they have the legal right to all of it.

That's not an accident. Healthcare has historically been designed around the provider, not the patient. Records were kept in offices, written in jargon, and shared only when clinically necessary.

That has changed. Federal law now guarantees you the right to your complete health information, digitally, in days, for free. The problem is that most people don't know this.

**This guide exists to close that gap.**

Whether you're managing a chronic condition, supporting an aging parent, preparing for a specialist visit, or simply trying to understand what your doctor actually said — this handbook gives you the knowledge, language, and tools to engage with your health data on your own terms.

## PART 1

# What Is Health Data Literacy?

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### THINK OF IT THIS WAY

*Using GPS. You need more than a map — you need to understand where you are, where you're going, and how to recalculate when the route changes.*

Health data literacy is the ability to find, understand, evaluate, and use health information to make informed decisions about your care. It's a skill — and like any skill, it can be learned.

It means knowing not just that your records exist, but what's in them. Not just that you have rights, but how to exercise them.

## What Counts as Your Health Data?

Your health data is more expansive than most people realize:

- **Medical records and visit notes** — what your providers documented during every appointment
- **Lab results and imaging** — blood panels, X-rays, MRIs, CT scans, pathology reports
- **Medications and allergies** — your current and historical prescriptions and any documented reactions
- **Diagnoses and care plans** — every condition coded in your record and associated treatment plans
- **Insurance and billing information** — claims submitted on your behalf and what was covered
- **Behavioral health records** — mental health and substance use records (with additional protections)
- **Wearable and app data** — data from fitness trackers and health apps, depending on where it's stored

**Your lived experience is data too.** Your symptoms, your history, your cultural context, your preferences.

## Why Literacy Matters

Studies consistently show that patients who are engaged with their own health information have better outcomes — they catch errors earlier, adhere to treatment plans more consistently, and

ask more informed questions.

The inverse is also true. When patients can't access or understand their records, things fall through the cracks.

**THE BOTTOM LINE**

Health data literacy is not a nice-to-have. It is a patient safety issue.

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## PART 2

# Your Rights — The Full Picture

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### THINK OF IT THIS WAY

*Having the password to your own account. You shouldn't be locked out of information that is fundamentally about you — and the law agrees.*

Most patients are surprised to learn how comprehensive their rights actually are. Here is what you are entitled to.

## The Right to Access Your Records

You have the right to inspect and receive a copy of your health information from any covered entity. For electronic records, providers must respond within 30 days at little or no cost.

## The Right to Understand Your Information

You have the right to receive information about your care in plain language. If you don't understand a diagnosis or treatment recommendation, you have the right to ask for a clear explanation.

## The Right to Correct Your Record

If your health record contains an error, you have the right to request an amendment. The provider has 60 days to respond. Even if denied, they must document your disagreement.

## The Right to Know Who Has Seen Your Data

You can request an accounting of disclosures — a record of who your health information has been shared with, when, and why.

## The Right to Control How Your Data Is Shared

You have the right to authorize — and revoke — the sharing of your health information. No provider can share your data without your written consent, except for treatment, payment, or operations purposes.

## The Right to File a Complaint Without Retaliation

If your privacy rights have been violated, you can file a complaint with the HHS Office for Civil Rights at no cost. Providers are legally prohibited from retaliating against you.

**IMPORTANT NOTE**

These rights apply to covered entities. They do not automatically apply to consumer apps or wellness platforms not covered under HIPAA.

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## PART 3

# The Rules, Plain and Simple

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### THINK OF IT THIS WAY

*The rules of a game. Once you know them, you stop feeling like the game is happening to you — and you start playing it.*

#### → **You can ask for your data — all of it**

Any time. From any covered provider. You don't need a reason or a lawyer. A simple written request is sufficient.

#### → **You can ask for an explanation — in plain language**

If your doctor uses clinical jargon, you have the right to ask what it means in plain English. Understanding your care is part of informed consent.

#### → **You can correct what's wrong**

Review your records regularly. If you find something wrong, submit a written amendment request to the provider's Health Information Management department.

#### → **You decide who sees it**

Your health information cannot be shared with employers, family members without consent, or third parties without your authorization. You control the permissions.

#### → **You can carry it with you**

Request a Continuity of Care Document (CCD) — a standardized, portable electronic summary of your health record — and take it anywhere.

## PART 4

# The Laws That Protect You

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### THINK OF IT THIS WAY

*Referees. You don't always see them working, but they're keeping the game fair — and when the rules are broken, they have the authority to act.*

Your rights are codified in federal law. Here's what each major law does.

## HIPAA (1996)

The foundation of health privacy law. Gives you the right to access records, request corrections, receive a Notice of Privacy Practices, and file complaints.

## The 21st Century Cures Act (2016)

Prohibits information blocking — practices that interfere with your access to electronic health information. Violations can result in fines up to \$1 million per violation.

## HITECH Act (2009)

Strengthens HIPAA by increasing penalties, requiring breach notifications, and extending obligations to business associates — the vendors and technology companies that work with your provider.

## State Laws

Many states have laws that go further than federal law — covering mental health records, reproductive health data, genetic information, and more.

### WHAT TO DO IF YOUR RIGHTS ARE VIOLATED

File a complaint at [hhs.gov/ocr](https://www.hhs.gov/ocr). It's free and providers cannot retaliate against you.

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# Why This Matters — Real Consequences

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## THINK OF IT THIS WAY

*Cooking with the wrong recipe or missing ingredients. When the information isn't right, the outcome isn't right either.*

This is not an abstract issue. When patients can't access, understand, or act on their health data, real harm follows.

Consider what happens when a patient moves to a new city. If their records don't transfer, the new doctor starts from scratch. Medications get re-prescribed without knowledge of past reactions. Tests get repeated unnecessarily.

Consider what happens when a patient travels internationally and gets sick. If imaging and labs can't be transmitted, critical time is lost. Incomplete information in a medical context is not a minor inconvenience. It can be life-altering.

The research reinforces the stakes:

- Approximately 1 in 5 patients experience a preventable adverse event related to incomplete or inaccessible health information
- The majority of medication errors occur when providers lack complete patient history at the point of care
- Patients who actively engage with their own health records have measurably better outcomes
- Medical record errors can influence insurance decisions, clinical diagnoses, and downstream treatment

## PART 6

# The Missing Piece: Communication

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### THINK OF IT THIS WAY

*Planning a trip without a group chat. Everyone has different information, nobody's on the same page, and things fall apart at the worst possible moment.*

Having data is one thing. Getting it to the right person, at the right time, in a format they can use, is another challenge entirely.

You might have a primary care doctor, specialists, a pharmacist, and an urgent care clinic you visited once. Each may use a different electronic health record system. Many of those systems don't talk to each other.

When your primary care doctor refers you to a specialist, the specialist often doesn't receive your records before your appointment. Records get faxed — yes, still faxed — and may arrive late, incomplete, or not at all.

The solution: standardized data formats, secure transmission infrastructure, and patient control over what gets sent, to whom, and when. The infrastructure exists. What's lagging is awareness and adoption.

# Using Your Data in Real Life

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## THINK OF IT THIS WAY

*Having your boarding pass ready at the airport. Everything moves faster when you have exactly what you need.*

Understanding your rights is the foundation. Using them is where the real power is.

## Before any appointment

Request records from your previous provider. Download your Continuity of Care Document from your patient portal. Bring a list of current medications, allergies, and diagnoses.

## When seeing a specialist

Ask your primary care doctor to send your records before the appointment — and follow up to confirm they arrived.

## When traveling

Carry a health summary — especially internationally. Include diagnoses, medications, allergies, your doctor's contact, and insurance information.

## When managing a chronic condition

Request lab results after every visit. Track them over time. Ask what the trends mean, not just whether you're 'in range.'

## When supporting a family member

Understand your authorization rights as a caregiver. Have that conversation before a health crisis, not during one.

## When getting a second opinion

Request a complete copy of all relevant records, imaging, and lab results. You paid for those tests. The data belongs to you.

## PART 8

# Secure Communication and Direct Messaging

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### THINK OF IT THIS WAY

*Sending an important package with tracking and signature required — you know it got there, you know when, and you know who signed for it.*

Regular email is not appropriate for health information. Fax is still widely used in healthcare but is unreliable and has no tracking.

There is a better way. It's called Direct Secure Messaging — a federally supported, encrypted communication standard built specifically for healthcare. It works like email but operates on a secure, certified network with strict identity verification.

## What a Direct Secure Address Lets You Do

- Receive your health records directly from any provider in the country
- Send records to a new provider, specialist, or second-opinion physician securely
- Share records with authorized family members or caregivers
- Receive test results and clinical summaries directly
- Transmit records across providers with full encryption

## How to Get a Direct Secure Address

Consumer Direct Secure Addresses are available from accredited vendors. I ♥ Data is working with trusted partners to make Direct addresses accessible to patients directly — visit [iheartdata.org](https://iheartdata.org) to learn more.

PART 9

# Identity, Trust, and Who You're Sharing With

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THINK OF IT THIS WAY

*Showing your ID at the airport. Before you board, someone confirms you are who you say you are. Healthcare needs the same standard.*

Identity proofing verifies that someone is who they claim to be before they are given access to sensitive information.

Most consumer health apps are not covered by HIPAA. They may collect, store, and share your health-related data under terms of service you've agreed to — often without reading. This data can be sold to third parties or used in ways that could disadvantage you.

Before connecting any app to your health data:

- Read the privacy policy
- Check whether the app is HIPAA-covered
- Understand what data it collects and shares
- Know whether and how you can delete your data
- Be especially cautious with apps that request access to your full health record

# Your Role in Your Own Care

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## THINK OF IT THIS WAY

*You're not just a passenger — you're the main character in your own story.*

Research is unambiguous: engaged patients have better outcomes. They catch errors their providers miss, ask questions that reveal important clinical information, and advocate for themselves when the standard of care falls short.

Being an engaged patient means bringing your full self to every clinical encounter — your history, your concerns, your preferences, your knowledge of your own body.

You have the right to ask: What does this diagnosis mean? What are my options? What are the risks? These questions lead to better care.

# What the System Owes You

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## THINK OF IT THIS WAY

*Like customer service — the system should work for you, not the other way around.*

Healthcare organizations must maintain your records accurately, provide access in a timely manner, protect your privacy, and not block your access to your own information.

The 21st Century Cures Act introduced strong anti-information-blocking provisions because restricting patient data access was widespread. Providers that engage in information blocking are subject to significant financial penalties.

If your access has been improperly denied or delayed, file a complaint with the HHS Office for Civil Rights or the Office of the National Coordinator for Health IT. Both processes are free and both provide whistleblower protections.

# When Things Go Wrong

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## THINK OF IT THIS WAY

*Like when your phone app crashes — it's frustrating and disruptive, but not your fault.*

Systems fail. Records get lost in transitions. Providers retire without adequate notice. These are predictable features of a complex, fragmented system.

The best protection is to maintain your own copy of your health information. Request your complete records at least annually and save them somewhere safe.

If you experience a breach, the covered entity must notify you within 60 days. Monitor your financial accounts and follow up about what information was exposed.

If a provider goes out of business, request your records immediately — don't wait.

# Becoming an Active Participant

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## THINK OF IT THIS WAY

*Like being the driver instead of the passenger — you help decide the destination.*

Active participation starts with the belief that your engagement matters — that what you know about yourself is clinically valuable.

It means preparing for appointments, following up on results, asking for written summaries, and calling when you haven't heard back.

It means being an advocate — for yourself and for others. Every person who knows their rights and uses them makes the system slightly more accountable for everyone who comes after them.

# The Future of Health Data

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## THINK OF IT THIS WAY

*Like moving from DVDs to streaming — everything becomes faster, more connected, and more personal.*

Healthcare data interoperability is advancing rapidly. FHIR standards and the 21st Century Cures Act are driving a shift toward health information that moves with you seamlessly across providers and your lifetime.

APIs now allow patients to access records through apps of their choosing. Wearable devices generate continuous health data. AI is being applied to clinical records in ways that will change how diagnoses are made.

The future belongs to informed patients. I ♥ Data is here to make sure that future is equitable — that the patients with the most to gain are not the last ones to benefit.

## Closing

# Your Data. Your Story. Your Voice.

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Your health data is not just a collection of numbers, codes, and clinical notes. It is the documented record of your life.

You deserve to see it. To understand it. To correct it when it's wrong. To carry it with you and share it on your own terms.

These are not aspirational goals. They are your legal rights today. The gap between what patients are entitled to and what they actually receive is a gap of knowledge and power. That is the gap I ♥ Data exists to close.

### I ♥ Data because:

- It helps people make better decisions about their own care
- It ensures critical information reaches the people who need it
- It connects patients, providers, and systems in ways that improve outcomes
- It gives people a voice — and a role — in their own health story

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**Your health data is your story.**

**Understanding it helps you decide what happens next.**

I ♥ DATA™

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