

Own Your Health Data

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1. Our Healthcare Is Broken.

Much like a broken puzzle, our healthcare system is in pieces. Records are generated for each medical appointment, data is generated by health apps and by wearable technologies and each piece of data is stored where it's collected, by whoever collects it.

When we think of health data, we usually think about medical records. Health data collected in a clinical setting usually includes information such as vital signs, notes from physicians, and a list of prescriptions and allergies. But health data is so much more and includes everything related to your health, both inside and outside the hospital.¹ Most “health” happens outside the hospital. Your primary health data comes from your personal circumstances and the choices you make.²

This other health data includes information about things you actively do now, like data from apps that log your workouts. It's information from your past, like trauma or adverse childhood events.³ Where you live, what you eat and drink, whether and when you exercise, your education, your salary, and your emotional and social history all impact your health and combine to become the whole of your health data.⁴

2. We Can't See The Big Picture

With our data scattered across each facility and provider we've ever visited, across each app and wearable we've used, we can't see the full picture of our health.

At the hospital, your blood pressure is measured. At the lab, your blood is drawn and a machine reads your cholesterol. In each of those places, the data is entered into a software program and, once there, becomes property of those businesses. In both cases the data came from your body, but the data is owned by the collector, not you, the patient.⁵

With the health care provider recognized as the data owner, obtaining our data is a major burden. Different healthcare providers have different record systems that don't communicate, and your data isn't aggregated between different healthcare providers.^{6,7} We can't fully control our healthcare, our providers can't give us the care we need, and we can't care for our loved ones efficiently or effectively.

Real-time access to medical data improves outcomes.⁸ While efforts to improve interoperability and modernize our health data systems are being made,^{9,10,11} the fact remains that hospital systems, clinics and providers still rely on fax and mail for 68% of all record transfers.¹² We can't get our health data when or how we need it. Why? Because we don't own it.

3. You Don't Own Your Health Data

While there are no federal guidelines, state laws require providers to keep medical records for all patients.^{13,14} These laws are different for each state, but they all explicitly¹⁵ or implicitly¹⁶ recognize the health care provider as the owner of the medical record. For health data from wearable technology to apps to text messaging, ownership is determined by the terms and conditions you agree to. This landscape is further complicated by the status of "data" under property law, which isn't viewed as wholly "ownable."^{17,18,19} And since federal, state, and local laws don't view people as the owners of their personal health data, both healthcare and service providers - such as Amazon and Google - treat your data as under their ownership^{20,21,22} - and data is lucrative.

4. Who Controls Your Health Data

American companies alone spent over \$19 billion in 2018 acquiring and analyzing consumer data, according to the Interactive Advertising Bureau.²³ While companies buy, sell, and use health data to make money, there is no transparency into who is using it, what they're using it for, and whether or not they're profiting from it.²⁴ Electronic health records make it easy to build aggregate healthcare data that can be used to build scientific and medical knowledge and improve public health, but without transparency and without access to our individual aggregated data, we have no say if our information is being used, regardless of how.^{25,26,27}

So how do we fix this? We need data ownership rights.

5. A Future We Can Trust

New rules²⁸ require providers and payers to provide you your health information when and how you request it. Using this new capability, it is possible to finally combine data from different places to create a more complete picture of health and wellness.²⁹ With these different pieces of information pulled together in one place, health is less a puzzle and more a picture. With this we can see the landscape and more confidently understand our path.

To build this, we must start with a data trust, a secure location for health data storage.^{30,31} This is a location where your lifetime health data will live. Within the data trust, a data steward³² will collect and maintain your health data for you. You then use the data steward to control your health information.

6. You Are In Control

With the data steward you can see your health records and build pictures of your health over time. Creating your own health models can help you identify patterns in your health. This knowledge gives you the power to make better decisions and take control of your health story; and in doing so know how to best provide self care and manage your healthcare costs.³³

With a complete, accurate, and constantly updated copy of your lifetime health data, you have the whole picture of your health, your habits, your choices, and your risks. Trusted data at ready access can answer questions, give you insights, identify patterns, and guide data-driven communication with services and providers.

7. Nothing About You, Without You

When you own your data, you control access to it. Owning the complete picture of your health data allows you, the patient, to decide how to use it, and who can see it and for how long. You can choose to share or withhold some or all of your information with your providers, family members, caretakers, researchers, or marketers.

8. Own Your Health Data

Owning a copy of personal health data does not change property law or the status of medical record requirements. But within the scope of an agreement with a data manager, you have the ability to acquire all the known data relevant to your health; creating a new complete record, and source of truth about your health and wellness.

Data ownership gives us the keys to our health puzzle; to how our data is used outside medical appointments, to further research, innovation and better healthcare for all, and the keys we need to care for ourselves and our loved ones. Data ownership unlocks the path to achieving our health and wellness potential.

By owning your health data, you own the right to:

1. Secure Health Data Storage In A Data Trust
2. Health Data Collection and Maintenance By A Data Steward
3. Access Your Lifetime Health Data
4. Share Your Health Data
5. Restrict Access To Your Health Data
6. Know Who Has Your Health Data and How They're Using It
7. Remove Your Data
9. Sell Your Data
10. Control Your Health and Self-Care

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