

The Big Picture: Healthcare Data and Interoperability Video – Final Script

Data are essential to improving healthcare.

They help doctors make better decisions, support patients in managing their health, and enable researchers to find safe and effective treatments

Healthcare data reside in electronic health records, or EHRs. But there's a problem: the data are scattered, captured in different formats, and often hard to share.

This creates challenges for everyone involved:

- Clinicians waste time searching for information, delaying care.
- Patients face fragmented records spread across systems, making it hard to get a complete picture of their health.
- Researchers struggle to access the valuable data they need to answer important questions that can improve health.

In this discussion, we'll explore how data flow into EHRs and move between systems. We'll also cover the role of data standards and examine the barriers to building a more streamlined and connected healthcare system.

Healthcare data are incredibly diverse and come from many sources, including hospitals, clinics, labs, and pharmacies.

The data are captured in two main formats:

- Structured data, like test results or medication lists, follow standard formats.
- Unstructured data, like doctor's notes or imaging reports, are more freeform.

A single patient's record might include doctor's notes, lab results, prescriptions, medical images, and billing information.

Patients often receive care at multiple facilities, each using a different EHR system. Each EHR system has a unique way of storing information, which can make it difficult to create a complete health record

Some clinics use tools with common terms to standardize data entry and improve quality. However, these tools aren't used consistently across health systems, clinics, or even individual doctors.

Each type of data has unique requirements for its collection, storage, and sharing. For example, sending a prescription to a pharmacy follows very different rules than sharing an MRI with other clinicians. Because of this, one-size-fits-all solutions don't work well in healthcare data management, leading to various standards for capturing, moving, and storing data.

Incentives also play a big role in data collection. Data for billing or reimbursement are often recorded meticulously. On the other hand, patient-reported outcomes may be less reliable because there's no direct financial reason to prioritize their collection. The accuracy of the data varies, often depending on the incentives driving data collection

Once collected, healthcare data pose significant challenges for those seeking to use them. Inconsistency in healthcare data affects not only the quality of data stored in EHRs but also how easily those data can move across systems.

These differences create significant challenges when EHR systems need to communicate. Different systems often struggle to combine or share data effectively, leaving fragmented records that are difficult to access and integrate.

To be most useful, healthcare data must flow seamlessly between systems. Data exchange standards are critical to making this happen.

Data exchange standards make it possible for lab results, prescriptions, and patient information to be sent back and forth. They also support billing, ensuring that healthcare provider and insurance systems can communicate effectively.

One of the most important exchange standards is Fast Healthcare Interoperability Resources, or FHIR. FHIR is mandated by legislation, sets a common floor for industry, and can be used for a variety of purposes:

- Sharing test results among clinicians.
- Extracting EHR data for research.
- Allowing patients to access their health records via apps.

However, exchange standards like FHIR largely describe how information is shared.

They don't go into a great deal of specifics as to what should be included in the message. For that, the federal government requires EHRs to support the United States Core Data for Interoperability, or USCDI.

USCDI defines a basic set of health information—things like allergies, medications, and vital signs—that must be included in every EHR

Think of FHIR as the box for moving data, and USCDI as the contents of that box. But having a box and its contents isn't enough. We also need a way to move them.

That's where the Trusted Exchange Framework and Common Agreement, or TEFCA, comes in. TEFCA creates a single nationwide system for securely transporting data across states and networks for health data exchange. It's similar to a national postal service for healthcare information, helping clinicians share data efficiently and supporting population health responses.

Interoperability in healthcare data faces several barriers that make standardization challenging.

One question often asked is: why can't we use one system for everything? Can't we agree on all the data elements, put them in USCDI, design FHIR to handle all data, and use TEFCA to connect all systems nationwide?

The answer lies in the complexity of healthcare data. One size doesn't fit all. There is no consensus across the industry on what data should be collected. Health data are complex, and different types of data require different solutions. For instance, sending a text note follows very different rules than sharing a medical image, and prescribing medication differs from processing an insurance payment. Each task demands specialized tools and standards.

It's also that patients are complicated and different specialties have different requirements. We don't expect primary care docs to be able to capture information at the same specificity as a cardiologist.

Another significant challenge is legacy infrastructure. Many healthcare systems rely on older technologies that have been in place for decades. Updating or replacing these systems is costly and time-consuming, slowing progress toward standardization.

Priorities and funding also vary across organizations. A small rural clinic has vastly different needs compared to a large urban hospital or a research institution.

These diverse needs mean that a single standard won't work for everyone.

Some parts of industry have an incentive to keep things as they are or have incentives to minimize the cost of data collection.

Laws and regulations add another layer of complexity. Rules like HIPAA - the Health Insurance Portability and Accountability Act - ensure data security but make it harder to share information seamlessly. Updating regulations to align with evolving technology is a slow process. Privacy concerns also delay progress, as organizations must ensure that patient data are shared securely and responsibly.

While the industry is working toward more common solutions for data exchange, it's important to recognize that each type of data has unique requirements. This diversity is why standardization is a gradual process requiring collaboration and innovation.

The US healthcare system is gradually moving toward better interoperability, but it's a long-term process. Full standardization may not be achievable, but significant steps—like implementing USCDI, FHIR, and TEFCA—are already improving how healthcare data are shared. These efforts are helping make healthcare data more accessible, connected, and useful for everyone.

While progress takes time, the ultimate goal is clear: to ensure that the right data are available to the right people at the right time. By addressing barriers and embracing innovation, we can build a future where healthcare data enhance patient care and improve outcomes.