Public Comment on CMS-0042-NC

Request for Information: Health Technology Ecosystem

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Disclaimer

I'm a co-founder at an open-source healthcare interoperability company called Metriport.

Response to PR-3: Importance of Full EHR Data Accessibility for Healthcare Delivery and Interoperability

It's extremely important for healthcare delivery and interoperability in urban and rural areas that all data in an EHR system be accessible for exchange, regardless of storage format (for example, scanned documents, faxed records, lab results, free text notes, structured data fields). Each point will be elaborated on in detail below:

a. Current challenges in accessing different data formats.

Many providers use Electronic Health Record (EHR) software to manage their patients' data, but many EHRs don't talk to each other, which means a patient's data is more often than not siloed across disparate systems with incompatible data formats. More recently, Health Information Exchanges (HIEs) emerged to make the exchange of patient medical data possible between different providers. HIEs are essentially a peer-to-peer network for clinical data exchange. These networks use mostly C-CDAs (XML files), PDFs, and images to exchange medical data. A patient with a chronic condition may have thousands of such files across dozens of providers, and they all contain messy, likely unstructured, and duplicate information. Even if you spend lots of dev time, and money, connecting to all of these exchanges (like we did), you're still left with the tough problem of making this medical data actually usable for providers.

A big part of this is the data mapping from one format to another. As alluded to in the question, healthcare data is stored in a variety of formats: scans, faxes, notes, structured documents, and

more. Being able to collate all of this information into a single, standardized, and accurate source of truth is difficult, as outlined below.

FHIR is the latest and greatest standard that's ubiquitous in modern systems, typically represented with JSON. The older standard is HL7v3 (C-CDA), which is what all healthcare information exchanges still use today, and what EHRs typically export - C-CDAs are messy XML documents that have structure, but also contain a lot of unstructured data in HTML format, or free text. So you can imagine, the ability to convert C-CDA medical records to something actually usable like FHIR, is pretty important. Given that it's important, you'd also think it's a fairly solved problem, with plenty of resources/tools to wrangle the data... nope. There are little to no standards here, both on the C-CDA generation and conversion side, and you're left with different vendors building proprietary systems in-house, attempting to solve the same problem, with mediocre black-box results that you can't trust.

b. Impact on patient care quality.

Having timely access to accurate data is absolutely critical to patient care quality.

If you've been to doctors in the US, you may have encountered the problem: how does a healthcare provider get access to your up-to-date medical history to treat you properly? Reliance on archaic methods is still the norm: typically, you, or your provider, need to call the facilities where you've previously received treatment (assuming you remember them all), just to have them send your records via fax (yep, fax). This can take weeks, only then to have a provider sift through hundreds of pages of unstructured docs, just to figure out basic things like your active medication list, what conditions you may have, latest lab results, etc. This not only delays treatment, it can cause improper treatment, since the medical history is critical for treatment decisions. As per a study published by the ONC in 2021 [1], 76% of hospitals still rely on faxes to receive patient medical records from outside sources.

For example, here's a crazy story from a customer of ours: recently a patient came to them asking for a specific medication. When the provider pulled their medical history through Metriport, they saw that the patient had had a heart attack in the last 6 months. (The patient had omitted to mention this.) In such a case, the medication they were asking for could cause death! Needless to say, the provider did not fulfill that request—but they did begin to look for medications that could actually work for that patient.

The story above is just the tip of the iceberg – you have cancer patients running around with 500+ page dossiers of paper medical records from doctor to doctor in order to inform their various providers of the state of their treatment, hospice patients that die before they're able to receive care while they're waiting for their medical records to be faxed over, to emergency room doctors not knowing how to treat their patients in critical moments when lacking allergy information, for example.

c. Technical barriers to full data accessibility.

One of the biggest barriers is technical teams having the tools to be able to pull data from many outside systems and transform it into a format understandable by their systems.

The only path to doing so is by encouraging healthcare interoperability vendors to use, and contribute to, open-source healthcare IT systems [2]. This would allow these critical data pipelines to be able to be used by healthcare IT professionals, organizations, and even government entities in the US - allowing them to build and innovate quicker, instead of re-inventing the wheel for every project. Also, these same organizations could contribute back to the open-source projects they leverage so that the data processing pipelines are improved over time, and everyone uses compatible paradigms to do these key data transformations where clinical accuracy is paramount for patient safety.

d. Cost or privacy implications of making all data formats interoperable.

Choosing whether to share data or not is a different topic, since making data formats more interoperable is separate from the mechanisms by which access is granted to that data. There would be a cost to upgrade the data processing pipelines for various healthcare IT systems in the US, however that cost would be insignificant compared to the amount of wasted resources that go to existing ineffective ways of exchanging healthcare information - leading to expensive, delayed, and sometimes life-threatening delays in patient treatment.

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