Point of View

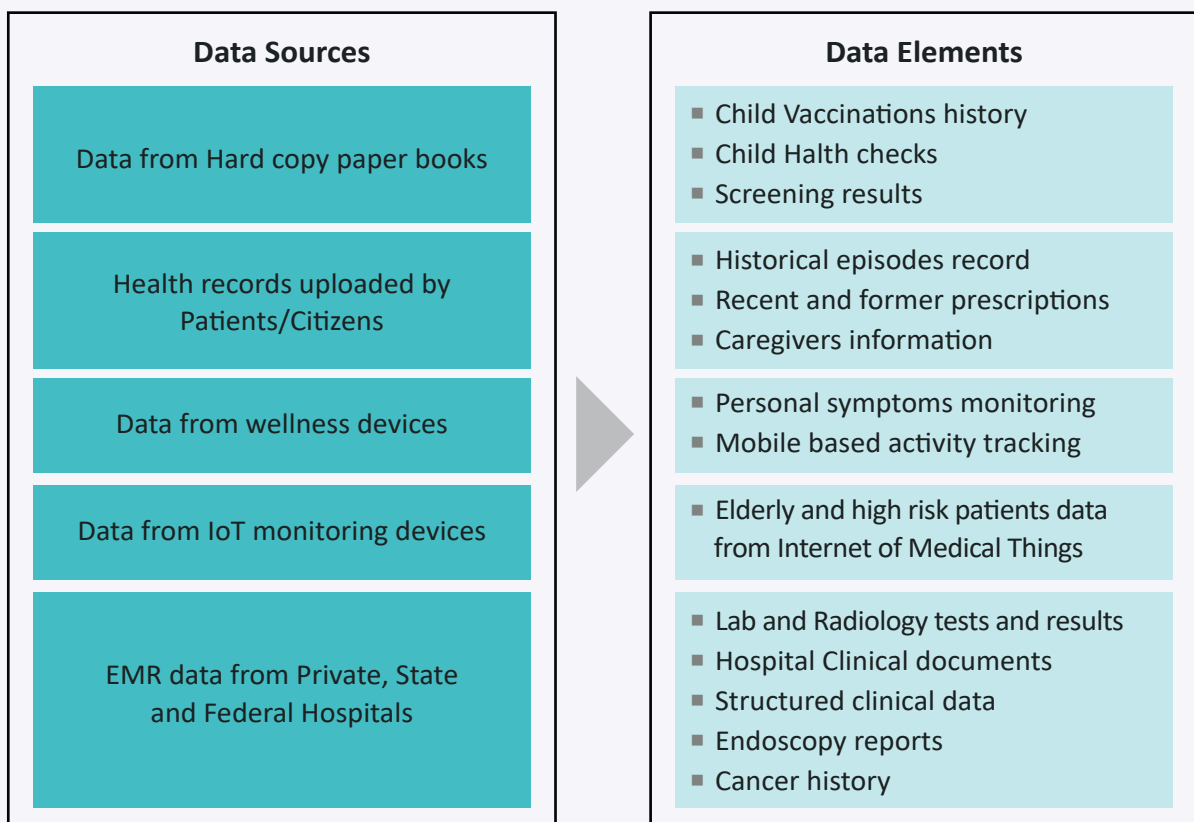# Single Longitudinal Health Record (SLHR) to manage patient data

Abstract

In general, patient/citizen healthcare data exists as data sets in multiple data sources. There is no single discrete view with this approach. Single Longitudinal Health Record (SLHR) addresses this with a holistic and longitudinal overview of patient/citizen health. Healthcare providers and governments are targeting SLHR to provide high-quality care delivery at optimal cost. While some care providers are planning to achieve SLHR at a hospital chain level, some nations have it planned at a state level, and others are starting out on foundation level API strategy.

An important aspect to keep in mind with respect to SLHR, is data privacy, and especially in the context of children's data. There are privacy regulations in many countries regarding personal data.

The objectives of SLHR are that patients/citizens should have the ability to easily discover, navigate, and share their complete health data, and caregivers should be able to access it.

Overall, there are multiple data sources and medical data elements as depicted in the figure below.

Data Sources	Data Elements
Data from Hard copy paper books	■ Child Vaccinations history ■ Child Halth checks ■ Screening results
Health records uploaded by Patients/Citizens	■ Historical episodes record ■ Recent and former prescriptions ■ Caregivers information
Data from wellness devices	■ Personal symptoms monitoring ■ Mobile based activity tracking
Data from IoT monitoring devices	■ Elderly and high risk patients data from Internet of Medical Things
EMR data from Private, State and Federal Hospitals	■ Lab and Radiology tests and results ■ Hospital Clinical documents ■ Structured clinical data ■ Endoscopy reports ■ Cancer history

However, it is important to remember that expansive data history is not necessarily useful because clinicans primarily seek relevant and not exhaustive history. Business logic, therefore, needs to pull relevant history apart from that which is time-bound or timeline-centric. The challenge can be addressed in multiple, solution-led ways.

The Centralized / Cloud approach

This involves managing the data at a central location / cloud using a custom-developed solution. The data must be stored in a common place; if store in multiple locations, it is key to ensure that the data is replicated in the central instance.

Advantages:

- Zero duplication of patient registrations across hospitals and clinics
- Control of duplication of tests performed for a patient in laboratory and radiology departments

Limitations:

- Patient/citizen health records stored in a centralized database makes it vulnerable to data breaches
- Need to consider options such as mirroring or replication to avoid single point of failure
- If there are multiple instances of data, one must consider that this data may not be real-time; plus, network bandwidth is key
- A potential high wait time for patient discharges

Applicability:

- Not practical for regions / nations where work is already in place in terms of SLHR
- Not a practical solution for large scale use
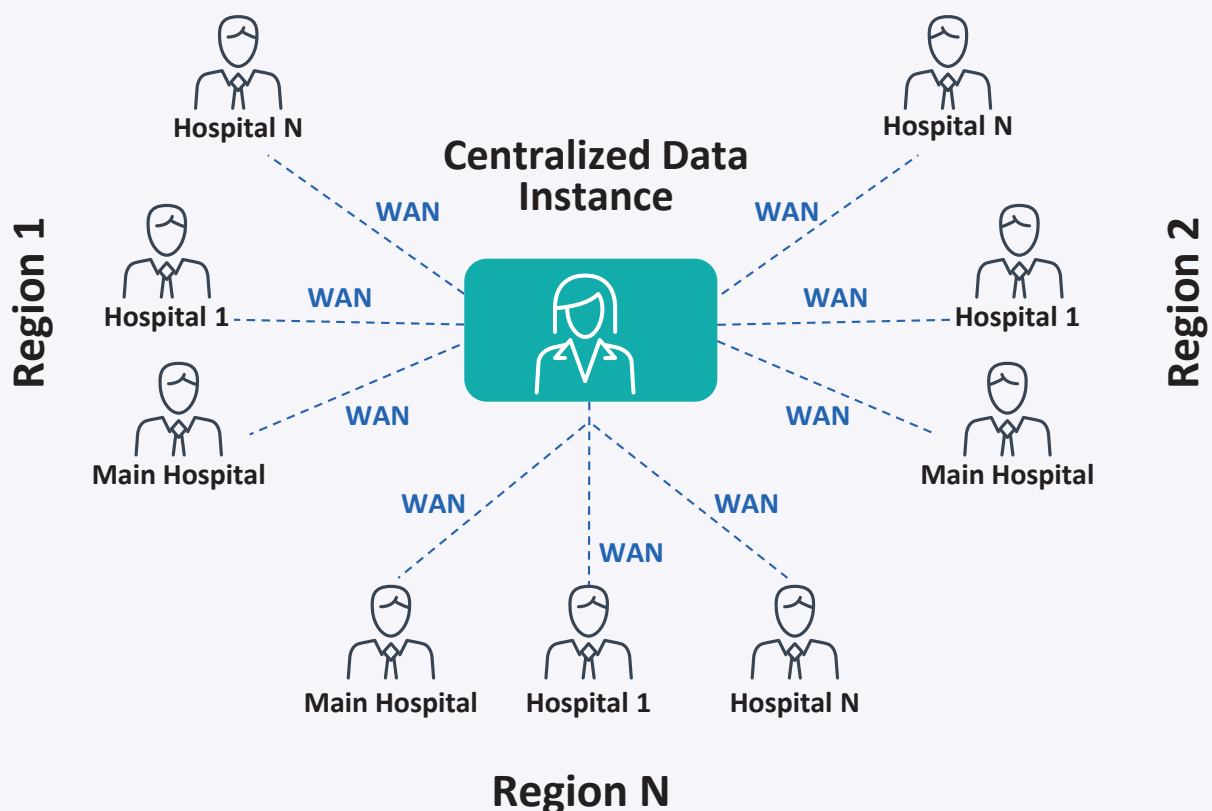
The decentralized approach with a hub-and-spoke model

In this scenario, patient data is stored locally in regional instances. A central instance is maintained to store relevant data (demographic and clinical) belonging to all-regional instances. Data from regional instances is replicated during off-peak times within the central instance. Clinicians can pull the data from the central instance to get a single view if the patient moves to another instance from the current, where the data originally belongs. Consolidated data at the central instance, is also used to generate enterprise-wide MIS reports.

Advantages:

- Reduced turnaround times for key processes: Patient discharge, patient registration, diagnostic report generation and availability across hospital locations

- Quick patient diagnosis with access to tests (laboratory, radiology) done in another city/region

Limitations:

- Certain data may not be real-time; again, network bandwidth is key

Applicability:

- Applicable at small scale, not a practical solution at a larger scale

- Not applicable for cases where network bandwidth is limited or expensive
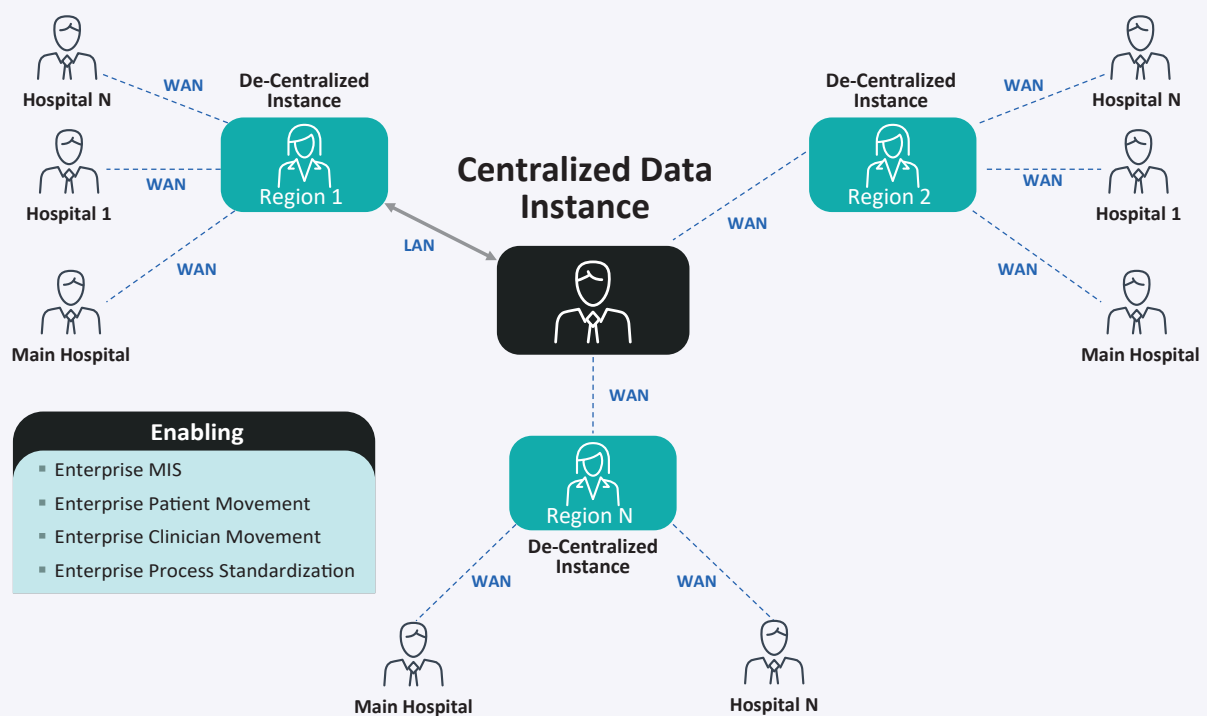
The HIE approach

This approach involves storing the data as-is. The patient ID/ Unique Health Identifier is used to correlate records across data storages. The Health Information Exchange (HIE) platform with Fast Health Interoperability Resources (FHIR) is used to populate the longitudinal health record. Optimize the search functionality with the appropriate design patterns.
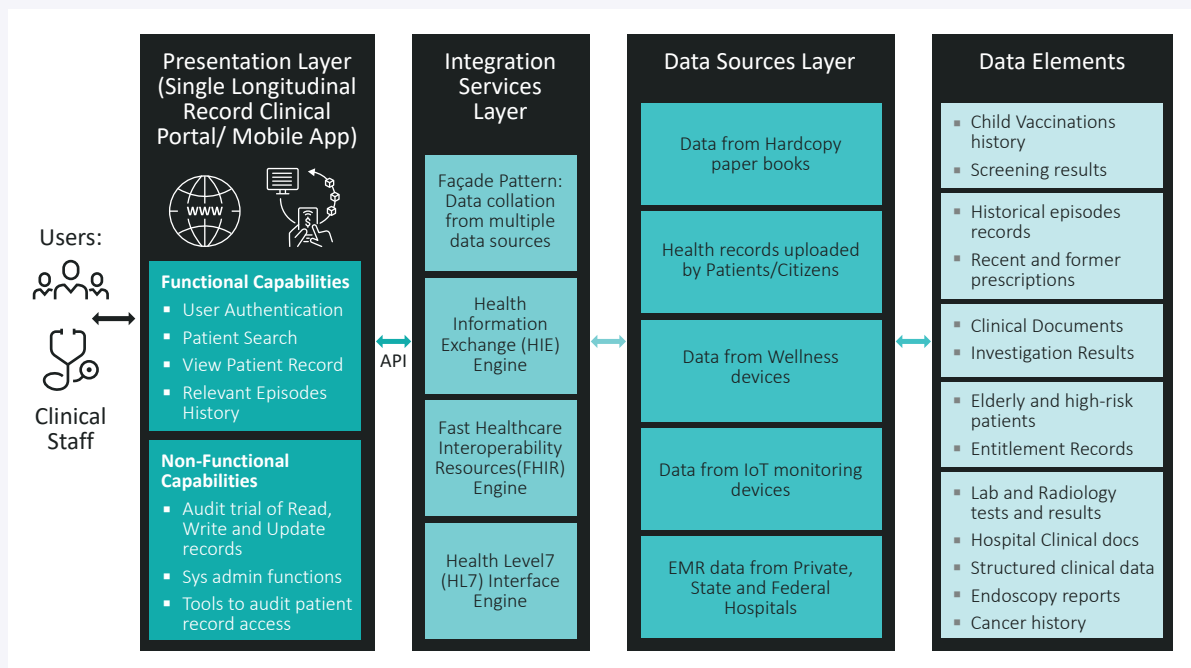
Advantages:

- Minimal changes to the existing setup
- Proven solution and technology
- Has been adopted by many nations

Limitations:

- Need to build a unique health identifier, if it isn't present in the as-is setup
- Need to fetch data from multiple data sources

Applicability:

- Most suitable for cases, even though work is done towards SLHR

The blockchain approach

This is a continuation of the decentralized approach. It is important that one not store medical records in the blockchain (off-chain storage of records). It is also important to store reference to where the data is currently present, in addition to storing references to the type of info, and when the visit is made in the blockchain. The approach uses FHIR and share the data with patient consent. Each user has an updated copy of the blockchain; thus, hackers cannot obtain control over the ledger and hold it ransom.
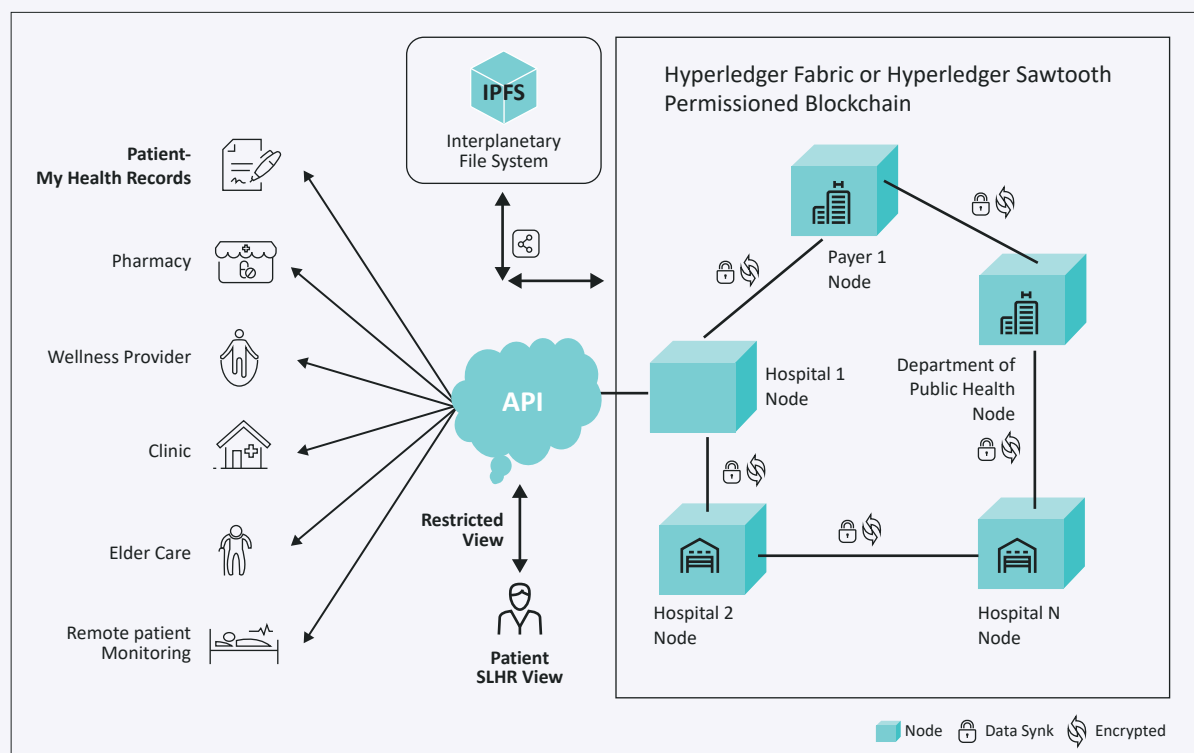
Advantages:

- A decentralized ledger in EHRs, means data cannot be held ransom

- Multi-level permissioned access to Electronic Health Records

- Secure sharing of patient information with consent to ensure regulatory compliances

- Citizen/Patient stays custodian of their medical records

Limitations:

- Lack of universally defined standards

- Giving that the technology is evolving, there could be unknowns

- Shortage of skilled IT specialists who can understand both the healthcare domain and blockchain

Applicability:

- First requires a prototype proving proof of concept

- Applicable for those nations / regions where limited work has been done so far on SLHR

While each of the solutions outlined above has its advantages, limitations and is applicable only within certain contexts, the blockchain solution, particularly, is at a conceptual level and yet to be proven. The centralized approach and HIE approaches are most suitable in major contexts.

Contact

Visit the public-services page on tcs.com

Email: publicservices.mkt@tcs.com

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