


Proof-of-concept solution to create an interoperable timeline of healthcare data

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ABSTRACT

Objectives To overcome the barriers of interoperability by sharing simulated patient data from different electronic health records systems and presenting them in an intuitive timeline of events.

Methods The ‘Patient Story’ software comprising database and blockchain, PS Timeline Windows interface, PS Timeline Web interface and network relays on Azure cloud was customised for Epic and Lorenzo electronic patient record (EPR) systems used at different hospitals, using site-specific adapters.

Results Each site could view their own clinical documents and view each other’s site specific, fully coded test sets of (Care Connect) medications, conditions and allergies, in an aggregated single view.

Discussion This work has shown that clinical data from different EPR systems can be successfully integrated and visualised on a single timeline, accessible by clinicians and patients.

Conclusion The Patient Story system combined the timeline visualisation with successful interoperability across healthcare settings, as well giving patients the ability to directly interact with their timeline.

BACKGROUND

Using electronic health records (EHRs) has facilitated safer and more efficient healthcare delivery.^{1 2} Accessing data within a single facility is relatively straightforward but patients often attend multiple healthcare settings and accessing information across sites, essential for quality decision-making, remains an unmet need.^{3–5} Consequently, the lack of coordination in these settings adversely affects patient experience.⁶

Fast Healthcare Interoperability Resource (FHIR) standards provide a standard for exchanging information electronically and are promoted by NHS England for real-time healthcare data exchange.⁷ Although global and national level FHIR standards are considered state of the art, EHR vendors have been slow to adopt these. Additionally, vendors and trusts are often tied in complex contractual relationships that limits transparency in describing data structures sufficiently to be conducive to interoperability between organisations.

The “Patient Story” (PS) software (Patient Story Health Tech Limited) comprises

database and blockchain, Timeline Windows interface, Timeline Web interface and network relays on Azure cloud. PS provides a timeline visualisation of a joined up medical record from the patient’s interactions across multiple care providers. This timeline is not directly based on any existing technology, although the concept is a familiar one and has been shown to assist clinicians in gaining a deeper understanding of the data.⁸ Patients can enter free text notes directly into the timeline, which differs from other software tools providing timeline views⁹ (online supplemental file S2).

Our aim was to develop, implement and test an architecture for interoperability that can be customised at multiple healthcare settings. Our objectives were to set up the PS software at two sites using different EHR systems and visualise the combined data in a single timeline, test the ability for patients to interact with the timeline, and test the scalability by simulating large volumes of data.

METHODS

The system was customised for Cambridge University Hospitals (CUH) and Royal Papworth Hospital (RPH) using the Epic and Lorenzo EPR systems, respectively. To test scalability, a further 50 sites were artificially created and populated with simulated data to represent multiple encounters by multiple patients.

The CUH Patient and Public Involvement panel provided input and feedback (online supplemental file 1).

PS software

The software uses a FHIR-based blockchain and centralised SQL server technology to access data from encounters across settings. The amalgamated data are presented in a comprehensive single view of the record in the form of a clinically meaningful timeline, accessible regardless of the originating EPR system.

The system leverages the FHIR standards for definition and exchange of clinical



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resources, and NHS Care Connect APIs (NHS Digital/INTEROPen),¹⁰ to form a database and blockchain based architecture (online supplemental file S3, figure S1). This provides an egalitarian system for use by patients and clinicians without any dependencies on proprietary EHRs.

PS workstation application

A graphical user interface (GUI) provided a timeline visualisation of the data referenced in the database and blockchain and displayed both on-chain data (clinical statements entered by the clinician or patient) and off-chain data, from the originating source for example, discharge summary (online supplemental file S4). The advantage of the design was an elimination of the need to recreate or copy data from the original source, instead amalgamating the data in one timeline.

Extending PS with the integration adaptor framework

To enable site-specific integration, a localisation adaptor API was developed to allow a composition of modules to pull data from existing data sources such as Epic at CUH, Lorenzo at RPH and from FHIR, XML, HL7, legacy systems, and so on.

Templates were created which autogenerated the timeline content using reference links to the medical record. The data source was securely viewed by the appropriate visualiser, for example, PDF, HTML, etc. Folders were created to allow clinical documents to be uploaded into the timeline, and FHIR-based webservice were used to call for diagnoses, medications and allergies in a structured format.

Data security

PS uses high strength AES256 end-to-end encryption, meaning that patient data are not visible at any level (system, network, cloud, server, etc) other than to the authenticated patient or clinician user in the application (online supplemental file S5).

RESULTS

The software was successfully installed, configured and tested on a Microsoft Windows server at both CUH and RPH. A PS Azure relay node was activated and used to exchange the encrypted messages between sites.

The patient timeline could be viewed at both sites. Each site could view their own clinical narrative statements,

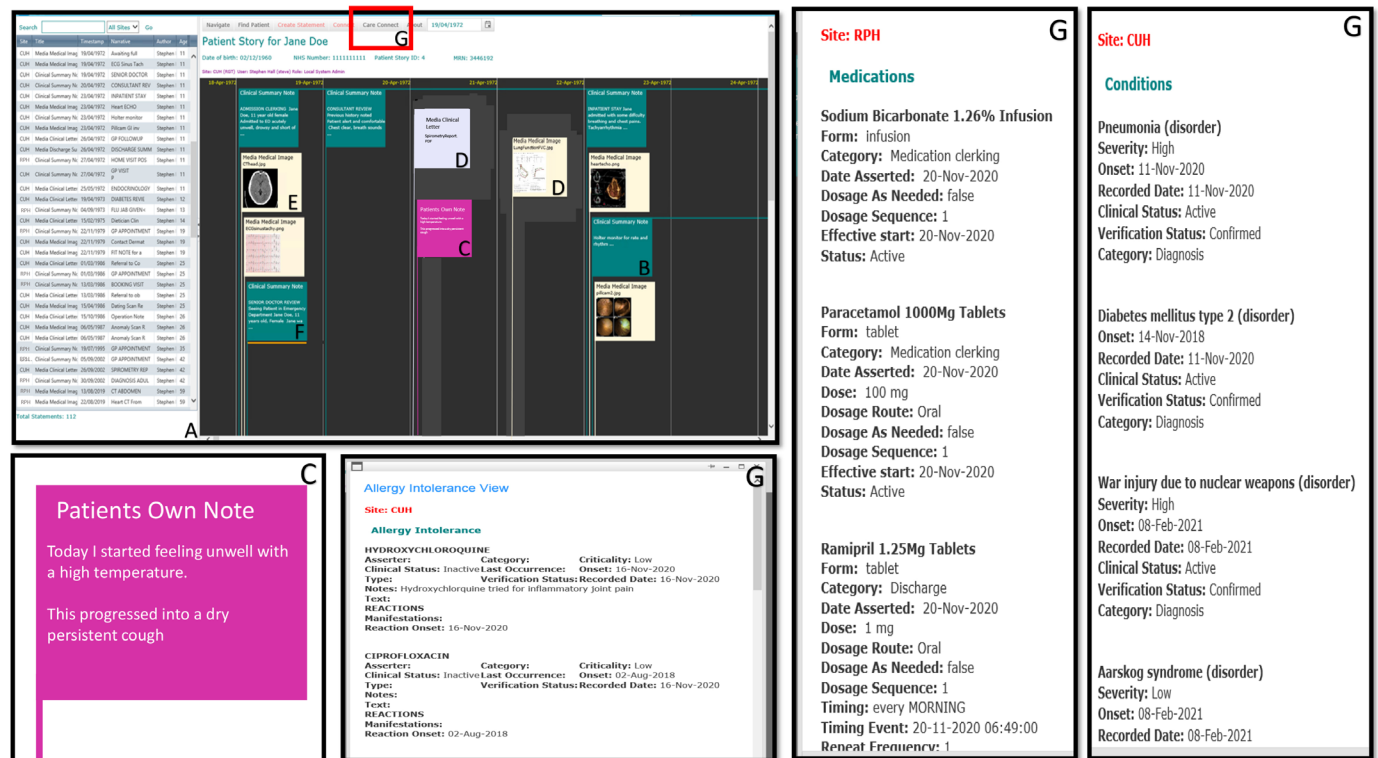


Figure 1 Patient Story timeline V1.0 and FHIRChain Version software. (A) Document List—A list of all elements on Patients Timeline and relevant details about the element. This panel is fully searchable and allows easy navigation across the Patient’s life. (B) Clinical summary note—a free text statement produced by a clinician. (C) Patients own note—a free text note created by the patient. (D) Media Clinic Letter—A clinical document such as discharge summary that is summarised on the timeline and can be opened to be fully readable. (E) Media Medical Image—A medical image such as an X-ray that can be uploaded onto the Patient’s timeline. (F) Highlighter to indicate the element that is currently selected on the Document list. (G) Care Connect profiles that accumulate data via Fast Healthcare Interoperability Resource (FHIR) Care Connect Profiles from each EPR. CUH, Cambridge University Hospitals; RPH, Royal Papworth Hospital.

media images and documents. Furthermore, each site could view each other's site specific, fully coded test sets of (Care Connect) medications, conditions and allergies, in an aggregated view (figure 1).

Patients were able to log into the system, view simulated data entries and add personal statements onto the timeline. All patients providing feedback wanted data from different healthcare facilities in one place and the majority wanted the ability to write their own statements in the timeline. Patient's questions about data security, the consent process, speed and accuracy of the system were addressed (online supplemental file S6).

Scalability and concurrency testing

The software successfully passed a full set of user GUI functional tests, security tests, and data server and communication testing between servers.

The Azure node connectivity was established and volume and concurrency testing was successfully undertaken on 50 nodes (each representing a separate simulated site) with 55 million simulated test patients, and 30 thousand clinical statements per patient (online supplemental file S7).

DISCUSSION

This work shows that data from two different EPR systems at separate healthcare facilities can be successfully integrated and visualised on a single timeline, accessible by clinicians and patients. The process is scalable and time efficient (response times were typically less than 2s to recall a Care Connect dataset from an adjacent site). The integration adapters are designed to be deployed at facilities using different EPR systems, by providing standards-based APIs (online supplemental file S8).

Patient engagement helped to steer the development of the timeline.

Quote from patient representative

"Patient Story will be particularly pertinent to people seeing several healthcare providers at once as healthcare in hospitals has become so specialised that one sees different specialists for different parts of one's body and it is not clear that a holistic approach is always taken, that is, there is a danger of clashes in medication and advice on what to do next and aftercare. It also often feels at the moment that as a patient we have to 'carry' our own story as it currently isn't all joined up".

Although interoperable solutions have previously been proposed, we have combined this with a timeline visualisation for both patient and clinician interaction. It is a unique blend of original and tried and tested concepts driven from the perspectives of patients and clinicians, rather IT system providers.

The work was limited to simulated patient data and limited to two different EPR systems. Nonetheless, it demonstrates the ability of the site-level adapters to be customised by healthcare facilities using different EPR

systems. Further development around the aggregation and visualisations may allow separate timelines, for example, for medications to be created.

CONCLUSION

To the best of our knowledge, the PS system is the first to combine the timeline visualisation with successful interoperability across healthcare settings using different EPR systems, as well as giving patients the ability to directly upload free text statements and clinically relevant documents from non-NHS healthcare providers into their timeline.

The system requires engagement from multiple healthcare providers but has the potential for providing a national-level solution to create and visualise a lifetime record for patients.

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Competing interests ST and SH are directors of Patient Story Health Tech Limited.

Patient consent for publication Not applicable.

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Data availability statement Data are available upon reasonable request. We would be happy to provide a demonstration of the Patient Story software to those wishing to consider implementing the software.

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