Supplementary Material

A proof of concept solution to create an interoperable timeline of healthcare data

S1 CUH Patient and Public Involvement Panel

The CUH PPI panel was set up by the Trust to enable members of the public interested in research to work with researchers by providing feedback on projects.

S2 Free text note entry into a timeline visualisation

The free text notes can serve as reminders of important medical information for patients and can allow documents from healthcare settings not using PS to be directly uploaded by patients or clinicians. The inclusion of filtering functionality allows the user to review data according to their needs for more simplified viewing if required.

S3 Figure S1. PS architecture

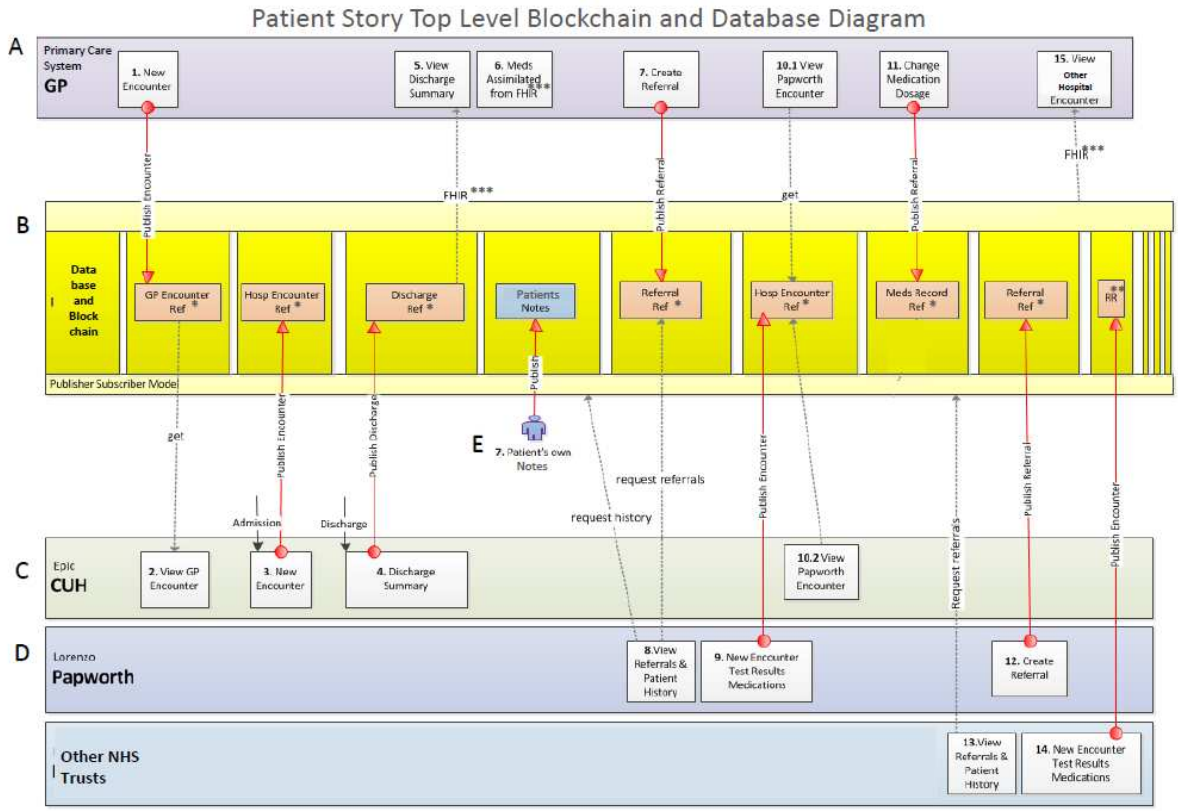

Figure S1: Patient Story architecture

A. Primary Care Organisation, that can upload and view information on the timeline
B. Patient Story Infrastructure layer including a GUI that displays all references to a patient in one timeline
C. Secondary care trusts are able to add, display and view encounters, referrals, discharges of individual patients
D. Tertiary care Trusts can also have access, add and view all information about the Patient from other Trusts
E. Patients are able to add their own notes as reminders for themselves. These are only visible to them and not the clinicians.

*REF Reference
**RR Referral reference
**FHIR Fast Healthcare Interoperability Resource

S4 PS software

The PS timeline is based on a multi-layered approach with discrete interchangeable architectural components enabling a high degree of plasticity when needing to adapt to future requirements.

The GUI enabled media images and documents to be uploaded and a full text search of clinical statements. The PS web application maintains all the same functionality, including the content rich timeline visualisation.

S5 Data Security

The system complies with the requirements set out in the NHS Digital Data Security and Protection Toolkit, the Health and Social Care Data Security Policy and the Azure Good Practice Guide

S6 Patient testing and feedback

A total of fourteen patients participated in this work. They were able to log into one of three different patient timelines, each containing 10-15 uploaded documents, using one of three generic credentials. Patients could interact with the system by scrolling along the timeline to view simulated data entries, search for specific documents such as discharge summaries, and view scan reports and images such as X-rays. They were able to add their own comments directly into the timeline, which were viewable only to themselves (as the specific generic user). There were over 30 patient statements added to the three different timelines.

The artificial simulated data were created in our testing environment based on documents that are routinely created in EHRs e.g. discharge summaries and scan reports. We further discussed this with the patient representatives and clinicians at CUH and Papworth. The documents uploaded into the timelines and the medications, diagnoses and allergies in the Care Connect profiles were examples to demonstrate how the functionality would work with any document or Care Connect profiles rather than being limited to just the ones we used in our examples.

The feedback from patients, in addition to those already mentioned, included the need for larger fonts and education to use the system. These suggestions helped to improve the usability for patients. There was also a request to load legacy data into the timeline, which is something we hope to include in future iterations and with further development.

S7 Synthetic data and scalability

The synthetic data were all generated programmatically from a purely fictitious baseline and then propagated into a full dataset by applying recursive random element injection. A simulation of real-life exchange was achieved by generating new nodes based on a factory pattern with randomised timing parameters.

We used the PC lab for real-life user experience interactions, simultaneously simulating high user and data volumes through spawning multiple user processes with randomised configurations.

The GUI functional tests, white box, black box and 'smoke' tests, and data server and communication testing between servers, ensured the highest quality is met for the PS application, in terms of security, speed, volume, accuracy, reliability and usability.

S8 Installation at other healthcare facilities

Installation at Trust sites is relatively straightforward and summarised in the following steps:

i) A PS folder of files is copied to the server.
ii) A unique site name and (Organisation Data Service (ODS) code are allocated to the configuration file. The ODS code is a unique national identification code, used by IT systems to allow interaction between different areas of the NHS
iii) A command line script is run to install the Windows Services.
iv) No firewall update is generally required if the server can call out to the Internet.

The localisation adapters can be easily installed (as described in step iii above). A document importer for unstructured media is provided, needing no configuration or database. The Trust IT team simply creates specialty named folders and drop in files. A framework as a service is provided for structured API calls. The Trust facing side of this requires local configuration and some custom development depending on the local EPR/systems which the PS team can assist with.