Patient Access to Their Health Record Using Open Source EHR

John CHELSOM[a] and Naveed DOGAR[b]
[a] *City University, London*
[b] *Seven Informatics Ltd, Oxford.*

Abstract. In both Europe and North America, patients are beginning to gain access to their health records in electronic form. Using the open source cityEHR as an example, we have focused on the needs of clinical users to gather requirements for patient access and have implemented these requirements in a new application called cityEHR-PA**.** The development of a separate application for patient access was necessary to address requirements for security and ease of use. The use of open standards throughout the design of the EHR allows the possibility of third parties to develop applications for patient access, consuming the individual patient record extracted from the full EHR.

Electronic Health Records, EHR, Open Standards, Open Source, Patient Access, cityEHR

Introduction

The implementation of widespread access to electronic health records is beginning to gather pace in some parts of Europe and North America. In England, all patients are due to have access to their primary care record by April 2015 [1]; in the US the 'Blue Button' was introduced in 2010 to provide patient access to records through the Department of Veterans Affairs portal [2, 3]; in Canada the MyOSCAR open source personal health record system has started to provide patient access to records [4].
The focus of many early implementations of patient access, or Personal Health Records (PHR) has been on the ability to view, download and transmit the full record, as defined by the Meaningful Use rules of the Office of the National Coordinator for Health Information Technology in the US [5].

In contrast, the focus of our study has been the requirements for patient access, as expressed by professional, clinical users of an Electronic Health Record (EHR) and the implementation of those requirements in the open source cityEHR health records system.

Requirements

We gathered requirements for patient access to the EHR from current and prospective clinical users of the cityEHR system in secondary care (in-patients and out-patients). The purpose was to determine how clinical users viewed the potential benefits and barriers in patient access to their own record.

From this process, the key requirements chosen for first implementation were:

- safe and secure access to the record
- access control to data determined by clinical users
- usable on any client device, particularly mobile and/or hand-held devices
- browse and view the full record (subject to access control permissions)
- annotate existing documents in the record
- add new documents to the record, particularly for completing assessment forms
- send/receive notifications to/from clinical users

The main Use Case considered in our requirements gathering was access to the record by users waiting in out-patients clinics or at home prior to admission as an in-patient. In both of these cases, an important benefit to clinical users is the ability for patients to complete assessment forms before the clinical encounter; in the case of patients awaiting admission, a review of those assessments may mean that the planned admission is postponed or cancelled, with significant benefit for both the patient and care provider.

Implementation Using cityEHR

The cityEHR is an open source health records system deployed in several sites in the NHS in England. It stores all clinical data as XML documents, in a native XML database, using the HL7 CDA standard [6]. Patients are identified in the system using a unique identifier; in the NHS is usually the NHS Number, issued and maintained on a national basis and proven to be a reliable identifier for patients [7].

The main objectives in implementing patient access were to:

- provide a safe and secure technical foundation for patient access
- implement the key functional requirements identified by clinical users
- make the record accessible and usable across a range of user devices

Patient access to cityEHR is implemented in a separate system called cityEHR-PA, using the same open source, technology platform as cityEHR - the eXist native XML database and Orbeon forms X-Forms engine, running in an Enterprise Java application server (Apache Tomcat, or similar).

The first key design decision in implementing cityEHR-PA was to encapsulate the patient's own record so that there is no possibility of patients gaining access to the wider range of information available to clinical users of the EHR.

Periodically (once every 24 hours, for example) the database is replicated for use in the patient-access system. A separate, standalone database holds the credentials used for user authentication. Once authenticated, the full record for the patient is extracted from the replicated cityEHR database and is held as a single XML document within the session running for the authenticated user. All access to the record is then made through this session-based document; there is no further interaction with the database until the session terminates.

Any new content created by the patient (saved forms, forms to be published in the record, annotations or notifications) is held in the server session until that session is terminated (user logs off or it times out).

On termination of the session, the replicated database is updated and this is then periodically synchronised with the cityEHR database.

A sequence diagram of the interaction with the database is shown in Figure 1.

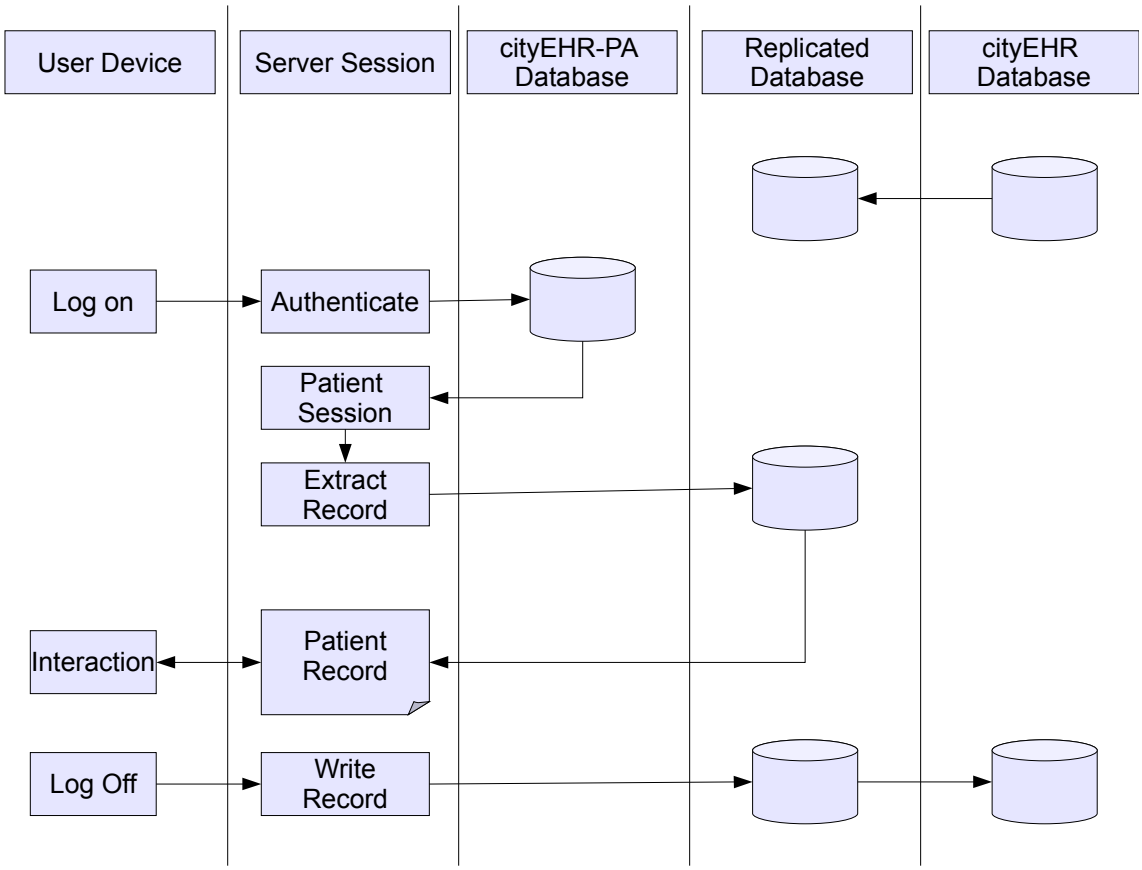

Figure 1. Sequence Diagram for Patient Access

The extracted record used in the patient access session is a single XML document which mirrors the structure of the XML database used in cityEHR. This database organises records by the unique patient identifier, with the set of HL7 CDA documents that comprise the patient record being held in a database collection specific to that patient. Similar database collections are used to hold transient data for 'work in progress' and notifications Figure 2 shows the top-levels of the XML document used to hold the patient record extract.

```
<?xml version="1.0" encoding="UTF-8"?>
<cityEHR_Extract xmlns="http://openhealthinformatics.org/ehr" xmlns:cda="urn:hl7-org:v3">
    <annotations>
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [79 lines]
    </annotations>
    <data>
        <forms>
            <ClinicalDocument xmlns="urn:hl7-org:v3"> [101 lines]
            <ClinicalDocument xmlns="urn:hl7-org:v3"> [101 lines]
        </forms>
        <letters>
            <ClinicalDocument xmlns="urn:hl7-org:v3"> [131 lines]
        </letters>
        <notifications>
            <ClinicalDocument xmlns="urn:hl7-org:v3"> [57 lines]
            <ClinicalDocument xmlns="urn:hl7-org:v3"> [57 lines]
        </notifications>
    </data>
    <records>
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [115 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [235 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [1191 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [325 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [341 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [336 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [288 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [1089 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [183 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [183 lines]
        <ClinicalDocument xmlns="urn:hl7-org:v3"> [268 lines]
    </records>
</cityEHR_Extract>
```

Figure 2. Structure of XML Data Used in Patient Session

The user interface for cityEHR-PA is much simpler than the interface for the full cityEHR system. This reflects the relative simplicity of the functions available to the user and is also a requirement to make the system easy to use on mobile devices. Like cityEHR, each page view uses an identical layout and each area of the page is reserved for a single functional purpose; there are three such functional areas in cityEHR-PA, compared with nine in cityEHR.

Figure 3 shows a comparison of the two user interfaces.

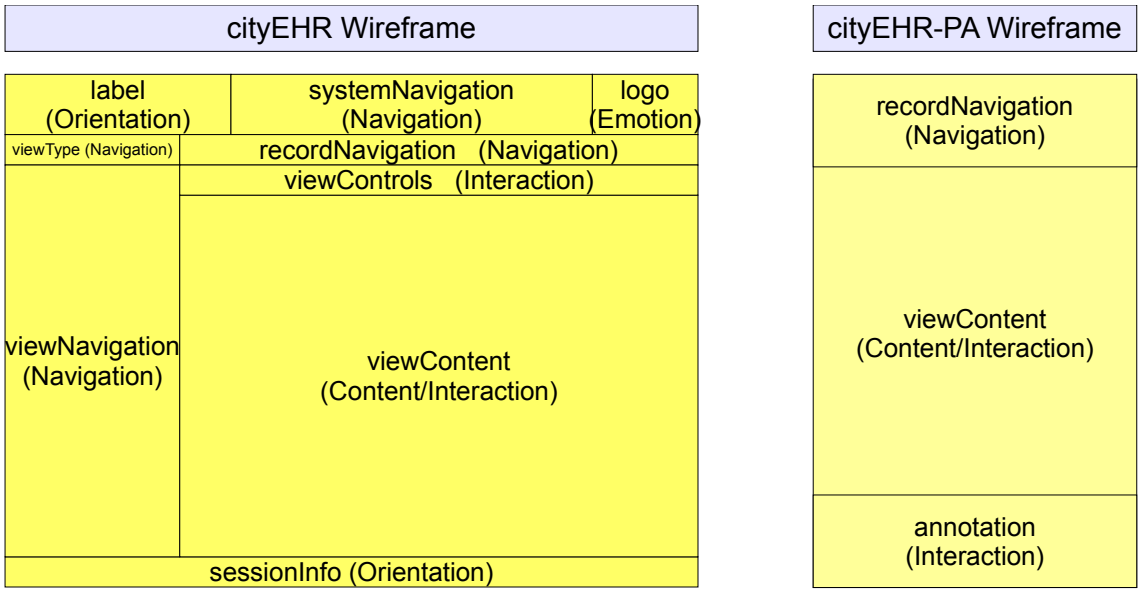

Figure 3. Wireframes for User Interface in cityEHR and cityEHR-PA

In addition to the implementation of cityEHR-PA, it was necessary to create some new functionality on cityEHR itself in order to support patient access. The key capabilities added were to:

- designate the type of clinical documents that can be accessed by patients (created or read)
- target notifications to patient users and view notifications from patients
- see patient annotations made against clinical documents in the record
- view clinical documents created by patients

Within cityEHR, patient created content is stored and handled in exactly the same way as content created by clinical users, but the provenance of that content (as stored in the HL7 CDA header) allows the clinical user to identify and filter appropriately. For example, cohort searches used for clinical studies can exclude patient created data

Conclusions

Our implementation of patient access to clinical records in the cityEHR system has highlighted the need to take account of the needs of both clinical and patient users of the EHR. Our focus in this instance was on the needs of clinical users: what functionality do patients need in terms of access to their own record which would enhance the clinician-patient interaction, in the opinion of clinicians.

Key to implementing secure access to the same information used in the full clinical record is to separate the data accessed by the patient and restrict

access to the full EHR to the minimum required to extract and update the record of each individual patient.

Using open standards in the implementation of the cityEHR has made the implementation of the basic view-download-transmit features quite straightforward, with the use of HL7 CDA similar to the approach taken in implementation of the Blue Button functionality in the US.

The user interface of the cityEHR-PA allows for the more interactive use of the patient's own record and the use of the record as a communication tool, in the manner envisaged by other studies [8. 9].

Finally, the approach to extracting the patient's record and implementing a separate application for patient interaction lends itself to the development of third-party tools and applications for patient access.

References

[1] Fisher, B. (2013). Patients' access to their electronic record: offer patients access as soon as you can. British Journal of General Practice, 63(611), e423-e425.

[2] Woods, S. S., Schwartz, E., Tuepker, A., Press, N. A., Nazi, K. M., Turvey, C. L., & Nichol, W. P. (2013). Patient experiences with full electronic access to health records and clinical notes through the My HealtheVet Personal Health Record Pilot: qualitative study. Journal of medical Internet research, 15(3).

[3] Evolution of Blue Button. http://bluebuttonplus.org/history.html

[4] Chan, D., Howard, M., Dolovich, L., Bartlett, G., & Price, D. (2013). Revolutionizing patient control of health information. Canadian Family Physician, 59(8), 823-824.

[5] US Department of Health and Human Services. (2012). Health Information Technology: Standards, Implementation Specifications, and Certification Criteria for Electronic Health Record Technology, 2014 Edition; Revisions to the Permanent Certification Program for Health Information Technology Federal Register/Vol. 77, No. 171/Tuesday, September 4, 2012/Rules and Regulations.

[6] Dolin RH, Alschuler L, Boyer S et al. HL7 Clinical Document Architecture, Release 2. J Am Med Inform Assoc. 2006;13(1):30-9.

[7] Hippisley-Cox, J. (2013). Validity and completeness of the NHS Number in primary and secondary care: electronic data in England 1991-2013.

[8] White, A., & Danis, M. (2013). Enhancing patient-centered communication and collaboration by using the electronic health record in the examination room. JAMA, 309(22), 2327-2328.

[9] Delbanco, T., Walker, J., Darer, J. D., Elmore, J. G., Feldman, H. J., Leveille, S. G., ... & Weber, V. D. (2010). Open notes: doctors and patients signing on. Annals of internal medicine, 153(2), 121-125.