A Challenge: How Do You Build a Distributed Universal Patient Record?

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Abstract – Many health care organizations are automating their patient medical records. In order to share patient medical records across health care organizations for purposes of patient care, standards are now being developed, principally by people in the medical field. Such a sharing of patient medical records requires distributed systems. In order to properly design these distributed systems and connecting networks, this design must be developed in coordination with computer scientists, and also business analysts. This paper explores some of the many difficult computer science-oriented issues involved in such a design. As an example approach for such distributed systems, it presents my ideas for a Universal Patient Record.

Keywords: electronic patient record, interoperability, distributed systems, Universal Patient Record.

1 Introduction

Many health care organizations are automating their patient medical records through Electronic Patient Record (EPR) software and hardware systems. A concept being promoted by health care organizations and users of these systems is interoperability, meaning the EPR systems can work within and across health care organization boundaries to share patient medical record information.

To some makers of commercial EPR systems, interoperability means their EPR system can interface with another specific commercial EPR system, in which case these two companies gain a competitive advantage over other companies. Instead, I think there should be full interoperability between all EPR systems for purposes of sharing patient medical record information.

In order to support this full interoperability of EPR systems, there are a number of EPR data-interchange standards proposed, including the following: (1) United States approach: HL7 clinical document architecture (CDA); (2) European, Australian approach: CEN EN 13606; and (3) my approach: a universal patient medical record, or “Universal Patient Record” for short. [1,2,3,4]

I believe in full world-wide interoperability and have proposed a Universal Patient Record that would provide this interoperability by creating distributed systems that provide access to and summarize all of the patient’s medical records no matter where the medical records are located in a country or the world.

So far, these approaches for interoperability have been developed primarily by people in the medical field. If the full interoperability approach is taken then such an approach would require a distributed network. Such a network requires a design developed by computer scientists in addition to medical people. For purposes of illustration of distributed system issues that could arise, I will present my Universal Patient Record approach and explain some of the many possible distributed system issues that could arise in the design of such systems.

2 Any Patient Medical Record

Whether a patient’s medical records are automated or not, the patient’s medical records consist of documents developed for the patient during patient encounters with clinicians. An encounter can be an outpatient visit, a hospital stay, an emergency room visit, or a visit in another type of medical setting. Sets of medical records are developed for the patient during each encounter and could include progress notes recording the patient-client interview, prescriptions, and orders for clinical laboratory and other diagnostic tests, and procedures. Test or procedure results come back and are combined with the order.

Thus each medical record document is associated with a single encounter within a health care organization and facility within the health care organization. Medical record documents for an order and order results are associated both with the encounter and the order that took place during the encounter.

Once a particular document is signed by a clinician and added to the patient’s medical records, it can no longer be (legally) changed. An addendum document can be created to make corrections to a previous document.

Some medical record documents are very similar to each other—such as progress notes, prescriptions, clinical laboratory orders and clinical laboratory results—but most
differ somewhat from health care organization to health care organization. Other medical record documents are unique to health care organizations. Each document is for a particular patient.

There are many agreed-upon standards for data elements that may appear in these documents. These include drug ordering standards, digital imaging standards, clinical laboratory result standards, diagnosis and procedure code standards, and provider identifiers [3]. Europe has its own standards [5] and the United States has its own standards [6], with many of these standards being the same.

3 A Universal Patient Record

What I propose for a Universal Patient Record—see figure 1—are Source Document repositories that each store automated patient medical record documents for a health care organization or set of health care organizations. Each document would be in XML format as described later.

Another type of repository, a Computer-based Patient Record (CPR) repository, would exist for one or more Source Document repositories. A CPR repository identifies encounters for the patient, and for each patient encounter, identifies the location in a Source Document repository of each document for the encounter.

Figure 1 A Proposal for a Universal Patient Record

The CPR repository would also provide summary information for the patient and medically important additional information. The summary information in addition to a list of encounters for the patient might include allergies, significant health problems, vaccinations, and current medications. For each encounter, information on the encounter could also be stored in the CPR repository such as diagnosis, procedure that took place during the encounter, and clinician. Other medically important information that could be included are advance directives to identify the patient’s wishes when the patient is too sick to communicate with clinicians and genomic information—genomic information will likely become much more important in medical care in the future.

In order to provide a method to locate all encounters for a particular patient, there should also be Patient registries that together can locate all CPR repositories that have encounters for a given patient and through the CPR repositories locate all the patient’s medical record documents. For example, a country could have could have its own Patient registry for individuals residing or seen for medical care in that country; when a request for a patient’s medical record information is made, the Patient registry can also ask other Patient registries if there is patient medical record information for that patient known by the other Patient registries. A Patient registry could be subscribed to by health care organizations, insurance companies, public health organizations, etc. such that the organization would be informed by the Patient registry when an encounter was identified by a CPR repository for a patient of interest; that organization then, within security limits, could gather applicable parts of the patient’s encounter information from the CPR repository and associated Source Document repository.

I propose that documents within the Source Document repositories use XML. This approach allows use of XML to define the data in the document as it was entered at a local health care organization with additional data to translate data elements to agreed-upon universal values. There would be associated XML Schema for the document to define the format of each item of data. And there would be XSL for the document to define how the data would be displayed in a form at the local health care organization where the information was entered in the language that care was given; the XSL would also enable display of a universal value for a data item in place of a local value (e.g., a universal patient identifier in place of the local patient identifier) when required. Free-text information could perhaps be translatable to other languages.

Because some medical record documents in all health care organizations have a similar format (e.g., progress notes, medication orders, clinical laboratory orders and results), it is proposed that health care organizations agree to include some of the same data elements in these types of automated documents. Within such documents in the XML both a local value and a universal value of the agreed-upon data element would be included. This agreed-upon information with universal values would be used to build information in the CPR repository. Every automated medical record document would have both a local and universal value for a patient identifier and an encounter identifier to associate the document with a patient encounter within a CPR repository. Other data elements in automated documents
could have data elements unique to the health care organization and could contain only local values.

EPR systems could function for health care organizations and output documents to a Source Document repository. For each automated document after an encounter, the Source Document repository would send the universal patient identifier, encounter identifier, and document name to the associated CPR repository; for the common documents, the universal values of the agreed-upon data elements would be sent to the CPR repository to build summary information. The CPR repository would in turn inform a Patient registry that could inform other Patient registries of the encounter. Patient registries would then inform subscribing organizations who had interest in the patient (e.g., inform an HMO of a member’s encounter outside the HMO, inform a public health agency of a medical event of interest, inform the patient’s insurance company).

Using the CPR repository information (possibly from multiple CPR repositories identified by Patient registries), and EPR could display summary information for a patient including a total list of encounters. For each encounter, a CPR repository would locate automated medical record documents for the encounter in Source Document repositories and could allow display of each document. (The CPR repository could also be built to locate and retrieve scanned medical record documents and digitized diagnostic image documents, likely located in other storage locations, and to locate and allow ordering of paper medical record documents.)

The Universal Patient Record is proposed to be on a secure network. See figure 2.

Figure 2  EPR Systems and Secure Healthcare Network [4]

Large health care organizations would probably want their own EPR systems, as they could interface other health care organization clinical systems directly to their EPR system such as encounter systems and ordering systems; the EPR system could directly interface to the secure network. Smaller health care organizations might want to use an EPR system outside the health care organization through an ASP connected to the organization through an Intranet; the ASP would have contracts with companies that could provide clinical laboratory, pharmacy and other ordering services. For both large and small organizations, patients could have access to their medical information over the Internet. An “assigning authority” would be available to assign new universal patient identifiers.

Such a Universal Patient Record would benefit health care in a number of ways, including the following [4]:

- It would provide a complete, always available medical record for a patient, enabling a clinician to retrieve medical record documents for any past encounter.
- It would provide the equivalent of a past medical history for a patient, which could be life-saving in an emergency situation, such as providing significant health problems, allergies, current medications, etc.
- It would allow a patient to view and verify the correctness of their medical record and allow better communication of care information from the clinician to the patient.
- It could provide information to support public health and medical research.

4  Distributed System Issues

World-wide interoperability or a Universal Patient Record is not possible without decisions being made on a number of distributed system issues. Thus, it is unrealistic to expect such a system to be built by medical personnel without the significant input of computer scientists.

Some of the generic distributed system issues in creating interoperability between EPR systems include the following:

- Should patient medical record information be assessable to an EPR system through a secure medical network outside the Internet or be accessible over the Internet?
- Is there a common ground in the interoperability approaches? Is there a better approach?
- How is a patient uniquely identified? One approach is a universal patient identifier—How would such an identifier be assigned? Another is a
Master Patient Index cross-referencing patient identifiers from different health care organizations.

- How do you create a complete patient medical record given different data and documents in the EPR systems? How can potentially disparate information be presented in a way this is useful to clinicians and useful to patients?

- How can you control security so that medical information for a patient is only available to the patient or his guardian and to clinicians caring for the patient? How do you control more limited access to others such as public health agencies?

Assuming a Universal Patient Record as described above, some these distributed systems issues are as follows:

- Assuming the architecture in figure 2, which technologies apply (application streaming, utility computing, service-oriented architecture)?

- What processes would be involved in creating patient history information in a CPR repository from encounter information and patient medical record documents added to a Source Document repository? When and how should a Patient registry be informed of the patient encounter?

- What processes would be involved in a Patient registry notifying subscribers of a patient encounter? What processes are involved in a subscriber picking up information from CPR repositories and associated Source Document repositories so a complete patient medical history can be created and viewed or so medical documents for an encounter can viewed? How would you control what type of information a subscriber could access (e.g., an HMO where the patient is a member, an insurance company, a public health agency)?

- Can the data part of XML, like the Universal Patient Record approach requires, optionally contain two values for a data element: a local value (e.g., a local patient identifier, a locally-used diagnostic code) and sometimes a second universal value (e.g., a universal patient identifier, a SNOMED diagnosis code)? How could an EPR system convert local values to universal values?

- Proposed is that—using XML, XML Schema, and XSL documents—a patient medical record document would be displayed in the form of a form document at the health care organization where it was created with local data values. How could the international data values be presented?

- Can two clinicians in two health care organizations using different EPR systems collaborate in the care of a patient (e.g., via telemedicine) viewing the same medical record document? Updating the same medical record document?

- Can a CPR repository be recreated from Source Document repositories if it is corrupted, and is there a need for this? What should happen if a medical record is found to be assigned to the wrong patient?

- For a large HMO would it be useful to copy an HMO member’s patient medical record and summary information to its EPR system for an encounter outside the HMO just after the encounter occurred? This would later save on transmission time.

- Is there a better design for a Universal Patient Record than described here?

5 References


