Towards an Integrated Electronic Health Record – Current Status and Challenges

a report by

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Abstract

It is commonly accepted that sharing information is the main reason motivating all attempts to establish an integrated electronic health record (IEHR) environment. Such an environment will allow healthcare professionals and citizens to have a uniform system for accessing personal health record information that is located in disparate information sources physically. The usefulness of such an environment becomes apparent when used in conjunction with medical collaboration, homecare monitoring and/or health emergency services to provide seamless care without visible organisational boundaries.

Due to the complexity of the whole task, the development of any IEHR environment ought to be viewed as a process that involves multiple stakeholders and evolves through time, passing through a series of implementation stages. Materialisation and utilisation of such an environment has the potential of enhancing the productivity of healthcare professionals, improving the quality of care and ensuring patient confidentiality while, at the same time, setting the foundation for supporting health monitoring effectively at a regional/national level.

Introduction

Information used to assess the health condition of a person usually consists of composite sets of data that have been extracted from a variety of sources and that exist in multiple formats. Currently, there is no universal process, standard or format for the exchange and integration of personal health record clinical data, assuming that, at the same time, thorough information is acquired and managed in an efficient manner. This is mainly because healthcare is usually delivered within certain organisational limits, and information produced at each site is managed by isolated, autonomous clinical information systems. In contrast, an integrated health data network at a regional or national level[1] is in a position to enable seamless accessibility to information and services to support decentralised healthcare.

Message-based communication of EHR data is used extensively today to facilitate remote examination ordering and results acquisition. Despite the fact that this approach works well when the number of involved clinical information systems (CISs) is kept relatively small, when their number increases, complexity increases in an unmanageable way.[2] CISs that have mechanisms embedded in their structure for accessing host systems directly are not open and so are not scalable and easily maintainable. Clinical data repositories that contain and manage data from multiple sources usually have difficulty with data context and codification and their complexity of design, in most cases, leads to extensive delays in actual implementation and use.

The most pragmatic approach towards an IEHR relies on the existence of an underlying health information infrastructure (HII) that consists of co-operating software components and a reference architecture to support clinically significant health telematics services. Eventually, any successful IEHR environment ought to be able to deliver personal timeline health views and to be accessed from many different locations in an efficient manner (i.e. having low latency times). The process of accessing primary information (at the place acquired and stored) should be kept as simple and transparent as possible. In some cases, this interaction may require the intervention of a third person (for example, when primary health information does not exist in electronic form). Naturally, this should not happen, and multiple access methods and tools ought to be supported. For example, although the personal computer is the preferred platform, Web-based access, hand-held devices like personal digital assistants (PDAs)

1. D G Katehakis, M Tsiknakis and S C Orphanoudakis, "Information Society Technologies in Healthcare", SOFSEM 2000 – Theory and Practice of Informatics, (Ed. V Havlac, K G Jeffery and J Wiedermann), LNCS, Vol. 1,963, Springer-Verlang, 2000, pp. 152–172.

2. J Grimson, W Grimson and W Hasselbring, "The SI challenge in health care", Communications of the ACM, June 2000, vol. 43, no. 6, pp. 48–55.

or satellite television may be required for instant access to missing pieces of information. Technology-related challenges mainly involve proper patient identification, semantic interoperability among systems and services and the incorporation of legacy systems and issues related to confidentiality and security.

Current Status

Significant efforts that have been related to the development of a federated EHR have involved a number of projects in Europe and the US, as well as worldwide standardisation activities.

The Good European Health Record (GEHR) was a three-year project within the European Health Telematics research programme (Advanced Informatics in Medicine (AIM)) from 1991 to 1995 that developed a comprehensive multimedia data architecture for using and sharing electronic healthcare records while, at the same time, addressing clinical, technical, educational and ethico-legal aspects of the issue.[3] Since 1996, a standardisation project team within the European Committee for Standardization (CEN) technical committee for medical informatics drafted a European standards proposal for the Healthcare Information Systems Architecture (HISA)[4] independently of any specific technological environment and without implying the adoption of any specific organisational, design or implementation solution. Three co-operative layers describe the architecture, which is applicable to the information systems of any type of healthcare organisation:

- the healthcare application layer;
- the healthcare middleware layer; and
- the healthcare bitways layer.

At the same time, the Synapses Project[5] within the fourth European health telematics research and technological development (RTD) framework proposed to unite the main aspects of the GEHR architecture and the CEN technical committee for health informatics (TC251) PT1-011 standard (*WG ENV 12265*) with the generic components of other specialised architectures to provide a federated healthcare record architecture. In 1998, the telematics application programme in healthcare of the European Commission (EC) funded the InterCare Project[6] to consolidate some of the results of the previous five years of investment in RTD and to combine the results from the most important EC-funded healthcare telematics projects at the time in the areas of the electronic patient record (Synapses), security (Trusthealth), mobile communications (Hector), patient data cards (Cardlink 2) and regional telematics services (Star).

During the same period, SynEx[7], the continuation of Synapses, addressed the issues inherent in the provision and use of multimedia patient records across large enterprise-wide networks. It brought together leading-edge European work on federated healthcare records (Synapses), the HISA, terminology services (Generalised Architecture for Languages, Encyclopaedias and Nomenclatures in medicine (GALEN) Project) and decision-support formalisms (ProForma) and focused on the deployment of intuitive healthcare services to support evidence-based clinical practice in a range of settings across Europe.

In addition, OpenEMed (formerly known as TeleMed)[8] had the goal of developing a nationally scalable high-performance network environment to facilitate the dynamic assembly of distributed industrial and scientific applications in the US. Part of its work was based on a series of specifications to develop and deploy distributed applications for vertical markets.

Specifications related to standardised object-oriented interfaces were developed through work related to the Healthcare Domain Task Force (DTF) of the Object Management Group (OMG).[9] OMG specifications that have been adopted by the industry for the healthcare domain include standards for the Person Identification Service (PIDS – 1998), the Lexicon Query Service (LQS – 1998), the Clinical Observations Access Service (COAS – 1999) and the Resource Access Decision Facility (RAD – 1999).

Today, the largest health information standards developer in the world, Health Level Seven (HL7)[10], prepares version three of its standard (due for publication in December 2001) that is expected to carry important semantic improvements from its predecessors. The new version uses an object-oriented development methodology and a reference information model to create messages, focusing on

3. *The Good European Health Record Project (http://www.chime.ucl.ac.uk/HealthI/GEHR/Deliverables.htm).*
4. *European Pre-standard CEN/TC251/WG1/PT1-013: "Medical Informatics: Healthcare Information System Architecture", Brussels, CEN, November 1995.*
5. *The Synapses Project public website (http://www.cs.tcd.ie/synapses/public).*
6. *The InterCare Project website (http://intercare.imsgrp.net).*
7. *The Synergy on the Extranet (SynEx) Project (http://www.gesi.it/synex).*
8. *The OpenEMed Project (http://www.acl.lanl.gov/TeleMed).*
9. *The Object Management Group (http://www.omg.org).*
10. *Health Level Seven (http://www.hl7.org).*

the electronic interchange of clinical, financial and administrative information among independent healthcare-oriented computer systems. HL7 recently approved the clinical document architecture standard that is intended to describe clinical documents to be transferred by means of eXtensible Mark-up Language (XML). Work that influences and has a strong impact on this development is related to the development of CEN's *ENV 13606*[11] on electronic health record communication.

The issue of providing online access to patient data stored in different locations and applications is also one of the main domains of focus of the Information Society Technologies' programme (2000–2002) PICNIC Project for a Professionals and Citizens Network for Integrated Care[12]. Within the context of the project, several components have been specified to be implemented, studied and evaluated across different regional settings, aiming towards developing the next-generation of regional healthcare networks to support new ways of providing health and social care.

The need for more integrated routine care is also depicted in the UK's National Health Service (NHS) information strategy, aiming towards achieving a national EHR by 2005.[13] Its three objectives call for patient access to electronic medical records, 24-hour emergency care access and full implementation of first-generation person-based EHRs at the primary care level.

Challenges

It is a common belief that any IEHR environment ought to provide a decentralised view of the patient medical record by composing information dynamically that resides in a variety of heterogeneous clinical information systems. Any approach ought to take under consideration a set of fundamental principles to guide to effective implementations and solutions[14] based on modular architectures that are scalable, secure, effective and affordable even for small hospitals. Therefore, it becomes apparent that an underlying infrastructure is required to provide the framework where individual modules:

- are responsible for autonomous and self-consistent functional areas;

- inter-work through public and stable interfaces;

- are configurable and able to operate in a distributed environment; and

- can evolve according to the specific requirements and characteristics of the individual organisation[15].

The initial list of essential HII components that have been identified as required include the following:

- patient identification (ID) components for identifying patients based on their demographic data and correlating their IDs across different ID domains;

- authentication components for certifying the role and authority of both users and services (or applications) within a regional/national healthcare network in conjunction with a properly certified regional/national certification authority;

- encryption components for the secure communication of sensitive personal information over the regional/national healthcare network as well as over the Internet;

- auditing components for recording all HII component and/or end-user application and services interactions;

- resource location components for identifying availability of related resources such as organisations, devices or software and the means for accessing them;

- IEHR indexing components for locating fragments of primary health information maintained by different clinical information systems;

- primary health information access components for direct access to the sources of primary healthcare information where the complete, original (physician-generated) clinical information is kept;

- terminology components for the association of existing coding schemes and to enable the transformation of information from one form or representation to another;

11. European Committee for Standardization (CEN/TC 251), WG I, Information Models, "ENV 13606 – Electronic Healthcare Record Communication", 1999.
12. Professionals and Citizens Network for Integrated Care (http://www.medcom.dk/picnic).
13. Electronic Record Development and Implementation Programme (http://www.nhsia.nhs.uk/erdip).
14. D G Katehakis, M Tsiknakis and S C Orphanoudakis, "Enabling Components of HYGEIAnet", Proceedings of TEPR 2001, Your Connection to Electronic Healthcare, Boston, MA, 8–13 May 2001, vol. 1, pp. 146–153.
15. M Tsiknakis, D G Katehakis and S C Orphanoudakis, "Intelligent Image Management in a Distributed PACS and Telemedicine Environment", IEEE Communications Magazine, vol. 34(7), 1996, pp. 36–45.

- user profile components for tracking the long-term interests of users and maintenance of personalised preferences; and

- collaboration components for allowing general practitioners and medical experts to share patient-related information in the context of teleconsultation sessions.

Due to the fact that users seek selective information following specific paths depending on their personal preferences, navigational issues and facilities are expected to become even more important in the future. Due to end-user requirements for similar interfaces in terms of look and feel, it is also expected that the IEHR concept will eventually lead to a uniform applications and services environment.

Discussion

It is evident that a number of projects worldwide address the problem of locating, indexing and accessing the distributed segments of a patient's EHR. The level of integration supported by each of these efforts varies, as does the complexity of the effort. In essence, there is a trade-off between the diversity of clinical objects stored in centralised repositories and the generality and expressiveness of models supporting integration.

The more information that is placed inside centralised EHR repositories, the richer the query model that is supported.[16] This, however, limits the range of clinical information systems that can be federated due to the underlying complexity of the task.

Significant factors that influence the level of success of any IEHR development effort are mainly linked to the following:

- the existence of reliable and useful information that is essential for the effective care of patients – poor or missing information may undermine good care and pose certain risks;

- proper patient identification for the subjects of care within the boundaries of a regional/national healthcare system;

- high availability of information to facilitate proper indexing and propagation of primary health information from the sources to the middle layer of the HII through the use of fast information propagation gateways;

- examination coding schemes mappings and the subsequent use of clinical terms in a structured way;

- systems interoperability in a standardised, fast and easy-to-implement manner. Public interfaces (e.g., HL7 and Digital Images and Communications in Medicine (DICOM)) can support functional integration of healthcare processes in and across individual healthcare facilities, promoting cost-effective healthcare delivery and continuity of care. This requires strong involvement and commitment on behalf of the applications and services developers/suppliers;

- patient consent on sharing personal information;

- security and confidentiality – the process to determine which security controls are appropriate and cost-effective is quite often a complex and subjective matter that needs to be addressed carefully and in parallel with the establishment of the required public key infrastructure; and

- the evolution from the currently available status of the infrastructure will require acceptance by the local culture. In order for this to happen, both the concept of the IEHR and the related benefits must be convincing enough and any implementation should impose minimum (or preferably no) additional effort on clinicians.

In the future, healthcare professionals will continue to deliver care but will also increasingly be required to share their knowledge and expertise with other colleagues while citizens will demand that they participate actively in medical decision-making concerning their own health by seeking better information regarding medical procedures and wellness pathways. Priorities are expected to shift towards citizen-centred services, wellness and prevention. Allowing access to services for patients will require significant organisational commitment at the early stages in order to improve the quality and usability of information.

In this context, decentralised healthcare can be supported by integrated services for seamless and personalised information delivery, while services and information must be accessible without (visible) organisational boundaries. The strategic objective is therefore to ensure that citizens can be confident that the healthcare professionals caring for them have reliable and rapid access, 24 hours a day, to the relevant personal information necessary to support their care – especially in cases of emergency. ∎

16. D G Katehakis, S Kostomanolakis, M Tsiknakis and S C Orphanoudakis, "An Open, Component-based Information Infrastructure to Support Integrated Regional Healthcare Networks", Proceedings of MEDINFO 2001, Tenth World Congress on Health and Medical Informatics, London, UK, 2–5 September 2001, pp. 18–22.