

Sharing and management of EHR data through a national archive: Experiences from Finland

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Abstract

The management of Electronic Health Records is a complex business ranging beyond just digital archiving. This article looks at the challenges involved, the different models for EHR data archiving and the impact on health-care provider systems.

Digital archiving is not a health-care specific question. Digital Libraries and many other organizations are developing both the necessary technology and requirements for digital archiving. However, based on the unique nature of health-care information, certain health-care specific questions remain to be solved (see Box 1).

Archiving is much more than just a simple preservation of papers, microfilms or bits. Archiving is a combination of:

- data reception management;
- data preservation and accessing management;
- security and privacy protection management;
- records management;
- information description methods, and
- storage media technology.

In health care an archive is defined as an organization that intends to preserve health records for access and use by an identified group of clients for a regulated period of time. Traditionally, health-care archives have been storages of paper documents and pictures. In many cases, even when the service provider is using an Electronic Health Record (EHR) system, it has been common practice to print the content of digital records in paper or film format for long-

term preservation purposes.

An electronic archive (eArchive) preserves information in digital format. The differences between paper and digital preservation are marked. Digital archiving is strongly dependent on software. New file formats, software, and platforms succeed each other rapidly and digital material requires constant maintenance in order to remain usable. In the case of digital archiving there is the risk that not only the functionality, but also the structure of the record and the context of archived bits and data streams may be lost after hardware and software migrations.

An eArchive has the responsibility of making information available in a correct and independently understandable form even after a long time. It is therefore necessary to know what each data object is and what it is meant to do. Data should also be undamaged and complete, and there must be proof of its authenticity: that it is what we believe it to be. As a result, eArchives store not only data, but also meta-information (e.g. representation, description, content and context information of the data, links between components, and required preservation information).

Alternative models of EHR data archiving

Different types of archives exist. An independent archive is a closed system aimed only for designated users. Co-operated archives have common standardized submission and dissemination methods, but no common retrieval tools (e.g. no link repositories). Federated archives are based on the fact that different organizations have interest in the maintenance of several archives. As the motive is to share some expensive resources, federated archives are systems with shared functional areas.

In practice, an eArchive system can be a separate archive ("a secondary storage") or an EHR-system can manage all archiving functions without a technically separate eArchive.

- Very long preservation time of health information (up to 100+ years)
- Dynamic nature of health care data objects and documents
- Sensitive data content, requiring high degree of security, confidentiality and privacy protection
- Strong legal and regulatory framework specifying who can access what, when and for what purpose
- Context-, purpose- and sensitivity-based access and disclosure rules for data objects

Box 1: Specific requirements of health-care archiving

Independent of which combination is used, the purposes of the eArchive and the EHR-system are different.

The eArchiving process is a long-term undertaking. During this process patient information is moved between the EHR-systems, the eArchive and customers/recipients.

There are differences between countries in how the eArchiving process is defined.

In its most basic form, archiving can take place through storage in local EHR systems and connectivity is ensured through a centralized link repository. However, it is questionable whether this practice truly constitutes archiving.

In some cases, as for example in Finland, the eArchiving process starts when the EHR is originally created by the EHR-system of the local service provider during the care process, and ends when the regulated preservation time is reached and the record is disposed by the archive. This means that the service provider organisation should manage at the same time both active records inside its own system, as well as the eArchiving process.

On the other hand, there are countries where the eArchiving process starts by a selection of records for permanent preservation and EHRs are stored by a specific archiving organization.

In the UK for example archives are records appraised for permanent preservation and the term archiving is used in connection to the permanent preservation of records in the Place of Deposit. The NHS definition for records management covers the creation, storage, management and disposal of records. The NHS code of good practice is based on national requirements.

The Japanese model for eArchiving of health records is based on the use of the Open Archiving Information System Reference Model (ISO 14721). The eArchiving process covers only occurrences inside the eArchive.

Background to the current solutions and practices in Finland

The Strategy for the Utilization of Information and Communication Technologies in Welfare and Health was first established by the Ministry of Social Affairs and Health in 1996. The strategy was built around the principle of citizen-centred, seamless service structures. Among the main targets of the strategy were the horizontal integration of services (social, primary, and secondary care) and the development of shared, coordinated services. The strategy was updated in 1998, placing specific emphasis on the adoption of digital patient and client records in all levels of care, combined with nation-wide interoperability between distributed legacy systems, and supported by a high level of security and privacy protection.

The legislation on Experiments with Seamless Service

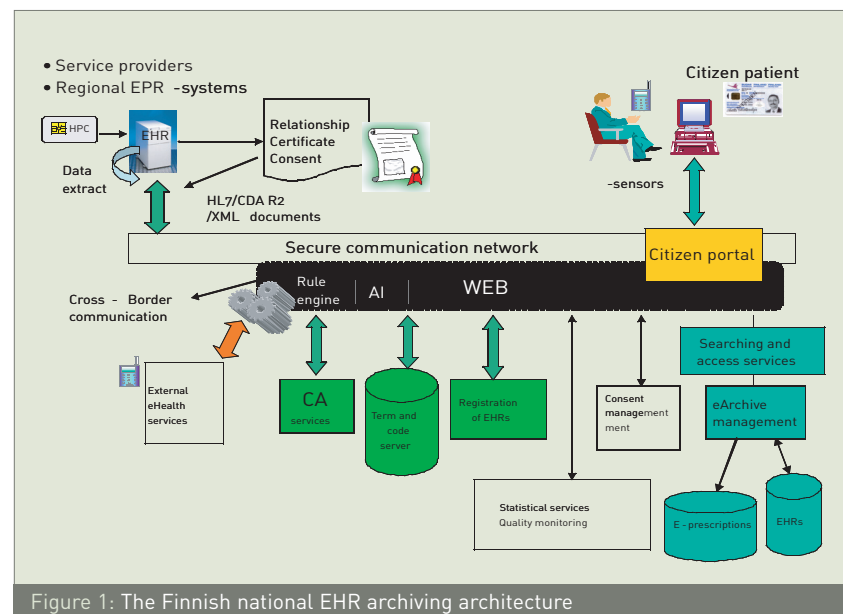


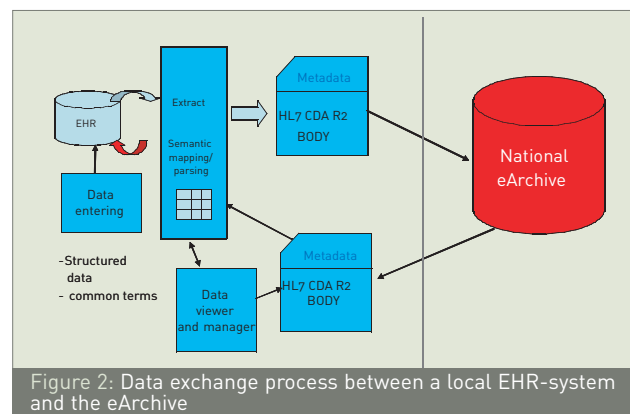
Figure 1: The Finnish national EHR archiving architecture

Chains in Social Welfare and Health Care Services was adopted in 2000 (Act 811/2000). The main focus of the legislation was to support the development of regional cooperation for seamless services, promote continuity of care, and advance the building of regional information service systems and adapters between existing legacy systems. Pilot-projects in accordance to the seamless service chains legislation were started. The participating regions started building reference databases to enable true usability of patient data across organisational boundaries.

During the implementation phase of the experimental legislation, a new initiative was started to improve the health care system of Finland. The Decision-in-Principle by the Council of State on securing the future of health care was given on 11 April 2002. The document states that "nationwide electronic patient records will be introduced by the end of 2007". The National Health Project Programme was launched and the electronic patient record project was included in the programme.

Every health-care organization in Finland has the responsibility to manage and archive health records. Inside the provider organisation the health record is personal and life-long. Based on current national regulations, health records shall be archived up to 100 years (images up to 20 years). According to the 2006 national survey, 95% of hospital districts (20 out of 21 in total) were using an Electronic Patient Record (EPR) for narrative texts with high rates of utilization. Progress has been truly rapid, since only two years earlier just 13 out of 21 hospital districts were EPR-users. High uptake of EPR systems within organizations has also impacted positively the regional exchange of information. Exchange of laboratory and radiological data has been commonplace already for sometime, but recently also eReferrals and eDischarge letters sent directly from one EPR-system to another have increased.

By the end of this year (2007) all hospitals should have an EPR system in use.



The Finnish choice – centralized archiving

On the basis of the experience gained in the aforementioned pilot projects, permanent legislation on both ePrescription and eArchiving came in effect in 2007. The legislation on handling electronic patient information covers centralized archive services, encryption and certification services, and the patient's access to the data. The law makes mandatory the incorporation of all public health care units into the electronic archiving system, as well as of those private health care units that do not use paper-based archives. The transition period is four years.

The creation of a centralized archiving system was chosen for the following main reasons:

- Cost reduction.
- Simplicity of the necessary architecture, which allows for:
 - one point for EHR disclosure;
 - one centralised consent- and opt-out management service;
 - possibility to use HL7 CDA messages between EHR-systems and the eArchive;
 - single entry point for patients and citizens (eg to access audit-logs and own EHRs).

The new national communication architecture (Figure 1) aims to support both technical and semantic interoperability of EHRs and provide a solution to the problem of their long term availability and usability. Security services are also one of the key functions of the platform.

The Web-service platform acts as an integration machine. Information between legacy systems and common services is transferred in the form of documents. Technical interoperability is achieved by using standardized messages (at present HL7CDA R2 and DICOM). A basic level of semantic interoperability is achieved by making mandatory the use of the national core data set, selected classifications and EHR-headings. All necessary terms and classifications are available for download and use through the term and code server.

Key common national services are the registration of EHRs, eArchive, consent management, the certification service and the aforementioned code server. The registering service is the key tool for tracing the location of EHRs and managing their actual status.

Citizens and patients will be able to connect to the national eArchive as of 2011, via secure Web services utilizing the citizen smart card and certification services.

Impact on hospital and other health-care provider systems

The construction of the national communication platform is financed both by the Ministry of Social Affairs and Health and public and private provider organizations. Its services will be launched in spring 2008 and it should be fully operational by the end of 2011.

The new legislation of July 2007 states that all EHR systems storing digitized EHRs shall use the national services after 2011. At present, most EHR systems are typically based on relational database technology and are not intended to function as trusted long-term archiving systems.

Therefore, before health-care service provider organizations are accepted to join the national services a number of new functionalities and services must be implemented into existing legacy systems, which will subsequently have to be certified against specific criteria for functionality, interoperability and security.

Health-care service providers will need to bear the costs of updating their own systems, as well as the maintenance costs of the platform after 2011 through the usage fees that will then come into effect.

From a technical point of view, the transfer of data from the organizational EHR system to the eArchive and, reversely, the possibility to retrieve from the archive and view both own records, but also other existing records of a certain patient requires the development and implementation of the following applications and functionalities (see Figure 2):

- Data entry interface which supports common headings, terms, classifications and the EHR core data set.
- Creation of patient consent document and physician-patient relationship credential.
- Capturing data from the local database.
- Generation of HL7CDA and DICOM messages.
- Generation of the preservation and access requests which are sent to the eArchive.
- Viewing of received EHR-messages.
- Generation of audit logs.
- New services ensuring access of citizens to their own data and to the respective local and national audit logs.

In addition to the above mentioned basic development requirements, there are also some future challenges to be addressed:

- achieving true semantic interoperability will necessitate further development in the structure, terminology and vocabulary of the EHR;
- selecting the optimal distribution of intelligence between legacy systems and the eArchive;
- developing user-friendly retrieval tools for professionals;
- ensuring the usability of systems and their successful integration into personnel workflows.

Finally, the overall future of the present local/regional EHR systems poses an interesting question, since technologically

it will be possible to utilize the eArchive as online storage, so that locally there is only an application utilizing centralized Web services.

The update of organisational systems will certainly also affect the work processes of healthcare professionals, who will need to modify their data entry practices but will also gain much wider access to their patients' existing data, allowing them to provide better quality care. At this point however it is too early to predict what the end balance will be.

Expected benefits

The creation of a common archiving system is expected to promote patient and client care quality and confidentiality, as well as increase the efficiency of health-care services. Through using the national archive it will be possible to create, on the basis of patient consent, one virtual, life-long, personal health record for every citizen. Theoretically, that record can then be utilized for profiling, proactive prevention and prediction of future health status and risks. From an organisational point of view, it is envisioned that by 2015 it will be possible to have available statistical and process management information based on real-time data. □

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