Nordunet2 project HC-Interest

Healthcare Record Interoperability and Record Structure
Final report

Author: Torbjørn Nystadnes, KITH
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1 Introduction

This document is the final report from the HC-INTEREST project and contains a summary of the results from project.

HC-INTEREST is a joint Nordic project supported by the Nordunet2 programme. The main goal of this project is to create the basis for interoperable Electronic HealthCare Records (EHCR), resulting in that the information in different system can be communicated and thus re-used and information in a healthcare record can be retrieved as a whole.

1.1 Objectives

The main objectives of HC-INTEREST is:

- to propose key components of a harmonised EHCR architecture and seek support to the proposal from the national health authorities of the Nordic countries,
- to develop operational EHCR messages based on the proposed key components of the architecture and national terminology databases,
- to validate the EHCR messages through pilot implementation.

![Diagram](image)

*Figure 1. HC-INTEREST is developing operational EHCR messages and key components of an architecture based on EU standardisation work from CEN. The messages are validated in pilot projects.*

The HC-INTEREST project will link EHCR architecture and EHCR messages, and populate the general standards with terms, data elements and attributes. Based on existing work in the Nordic countries, the CEN standards will thus be made operational and be tested. Different technologies may then be tested, e.g., middleware, EDI-communication (XML/EDI, DCOM), Internet, etc. Regardless of the technology chosen, the basis will be key components of a harmonised record architecture connected to the national terminology sets and data definitions.
1.2 About the HC-Interest project organisation

A consortium of six partners from the Scandinavian countries has carried out the HC-INTEREST project. The following people from these partners have participated in the work.

**CFST - Danish Centre for Health Telematics**
- Knut Bernstein
- Morten Bruun Rasmussen

**KITH - Norwegian Centre for Medical Informatics**
- Anita Lorek Bjørgen
- Torbjørn Nystadnes
- Glen Thorsen
- Jim J. Yang (to 31 December 2001)

**MEDIQ (Denmark)**
- Søren Vingtoft.

**Norwegian University of Science and Technology**
- Øystein Nytrø

**Sahlgrenska University Hospital (Sweden)**
- Ragnar Nordberg
- Anders Thurin

**Aalborg University (Denmark)**
- Stig Kjær Andersen

The Danish company B-Data have been engaged by CFST for developing the prototype that has been used for testing. Michael Johansen has been responsible for this work.
2 Background

In all Nordic countries there is a clear statement from the governments that the status of the patient must be strengthened. This has, among other things, been manifested by the legal rights for the patients to read and have a copy of their healthcare records and the freedom of choice of healthcare provider. The role of the patient is also gradually changing from a passive receiver of treatment to an active, informed and demanding customer. As a result, the patients are expecting that relevant information stored in the Electronic HealthCare Records (EHCR) is available regardless where and by whom in the healthcare delivery system they are treated. An EHCR would also give the patient the possibility to decide to whom and what part of the record should be made accessible.

2.1.1 Information retrieval and reuse

We are moving from a hospital centred to a process oriented and seamless healthcare delivery system, where the patient is treated at many different and usually geographically distant units. Structured data from the EHCR also gives unique possibilities for following up the true costs of various treatments that are given to the patient, for both short and long term planning of the healthcare services. The information in the healthcare record can be retrieved not only as the whole but is designed to facilitate the retrieval of specific information for subsequent decisions to be made in the whole process of patient care and treatment. Reusing the information that is already registered will not only save time and resources, but also help eliminating extra sources for error in connection to manual registration for the same information.

2.1.2 Technological support

The technology must support interoperability between EHCR systems and between EHCRs and other information systems in the healthcare sector. Today, communication with structured messages is an important basis for creating interoperability. XML seems to be the preferred syntax and will take over the role of EDIFACT. Other standards like HL7 and DICOM will clearly also have a role, especially within hospitals. On a longer run this may lead to "one electronic healthcare record per patient", i.e., a virtual record with the whole patient history – even if the information originates from other information systems.

Regardless of the communication standards selected, a common architecture and common understanding of the semantics is crucial for achieving safe and faithful interoperability. Due to the many cultural and linguistic similarities in the Nordic countries, this region has a unique possibility to develop operational communication standards based on common architectural components and semantics. HC-INTEREST will start this process by building on the Nordic experiences, taking advantages of the strengths in the different countries.
3 Harmonised EHCR architecture

Objectives

To propose a Nordic HC-INTEREST EHCR Architecture covering a set of key components necessary for exchanging information between EHCRs.

Description of work

Activities include:

- Investigation and harmonisation: Investigation and description of existing EHCR architectures and/or ongoing work within the participating countries. Suggestions for harmonising existing EHCR architectures with the outlined HC-INTEREST EHCR architectures.

- Architecture outline: Outline description which will describe the key components of the architecture; Review of the key components in relation to the national EHCR architectures.

Provide feedback to the Nordic countries and CEN.

The technical committee for health informatics in the European committee for standardisation, CEN/TC251 published in 1999 a pre-standard on Electronic Healthcare Record Communication, ENV 13606. This pre-standard which a number of EHCR solution providers in the Nordic countries and in the rest of Europe claims to be (partly) compliant with, have been one of the main foundations of the WP2.

In February 2002 a Task Force, EHRcom, was started to review and revise this pre-standard. It is the goal that the result of the revision can lead to a definitive European standard (EN). The result of the WP2 work have been submitted to this Task Force.

Different countries have initiated national programmes for development of EHCR architectures - including the Nordic countries. At the same time, significant national implementations of CEN TC251 EDI standards for communication between EHCR systems and other information systems are taking place, e.g., in major pilot EHCR implementation projects within the Nordic countries forming this HC-INTEREST consortium. This Nordic work has been the second foundation of WP2.

The third foundation has been the ongoing international EHCR-work. The main sources that have been used are:

- The openEHR foundation, which is an international, on-line community which aims to facilitate progress towards good quality electronic healthcare records, for patients and clinicians world-wide.

- The Electronic Healthcare Record Support Action (EHCR-SupA), which is a EU Framework IV project, has produced several reports that are highly relevant for the HC-Interest work.
3.1 **Introduction to the EHCR architecture**

3.1.1 Architectural overview

The figure below is a simplified version of the EHCR architecture.

Under the root of the EHCR (class name: EHCR Root Architectural Component), three different kinds of record components (class name: Record Component) may be used for organising the EHCR content in a hierarchical structure:

- Folders (class name Folder OCC)
- Compositions (class name Composition OCC)
- Headed sections (class name Headed Section OCC)

The information content of the record components is recorded in data items (class name: Data Item). There are several different kinds of such data items: Strings, Integers, Boolean, Coded Values etc.
The headed section is used to aggregate data items and/or other headed sections to represent a compound concept.

The composition contains a set of headed sections. There are two different kinds of compositions, documents (class name: Document) and folder headings (class name: Folder Heading).

- A document is used for recording information relating to one time and place of care delivery, a single session of recording or a single document received from some external party and included in the EHCR. The document is main level of attestation in the EHCR. When a document is approved, all headed sections that are a part of that document is approved too.

- A folder heading is used for describing the content of one single folder.

Folders are used for organising the content of the EHCR. A folder may contain a number of other folders and/or a number of documents. It may also contain an optional folder heading.

In addition to the record components that are used for creating the hierarchical structure of the EHCR, there is also a specialisation of record component (class name: Link Item) that can be used for creating links from one instance record component to any number of other instances of record components.

### 3.1.1.1 Original context and re-use of recorded components

Each instance of record component will either have another instance record component or the root of the EHCR as its original context. This is the place in the EHCR where the record component was recorded originally and where the actual information content of is placed.

But it should be possible to re-use already recorded components without having to make copies of the actual content of the components.

**Example 1: Re-use of headed sections in new documents**

Discharge letters for instance, will often include sections from already recorded documents that may have been attested by other persons than the one that produces the discharge letter. The one who writes the discharge letter will of course have to take the responsibility for using those particular sections in the discharge letter. But nevertheless, the one who originally recorded and attested the information will still be responsible for the actual content of those re-used sections.

**Example 2: Multi-dimensional organising of the EHCR**

Folders may be used for organising the content of the EHCR according to the needs of those who are involved in providing healthcare to the patient. As the need for information will vary depending of the activities that are to be performed, it may be practical to use folders to group the EHCR content. There are many ways such grouping can be done, e.g. according to problems, according to topics or according to episodes of care and activities. Often it may convenient to have the content of the EHCR organised after several principles at the same time.
The above figure shows an example of multi-dimensional organising of (parts of) the content of an EHCR. Three folders are shown:

- A "problem-folder" containing all documents related to the patient's diabetes. The figure shows three of the documents in that folder. Only one of those documents is also shown as a part of another folder, but when using this kind of organisation, most documents will be a part of two or more folders.
- An "episode-of-care-folder" where four documents is shown. One of those documents is related to diabetes and another is the results from a laboratory test.
- A "topic-folder" containing laboratory results.

To show how re-use of components are solved in the EHCR architecture, headed sections are used as an example in the above figure. Headed sections may either be a part of a composition or a part of another headed section. To connect instances of headed sections to compositions, the class
Composition Content Element is used, to connect them to other instances of headed sections the class HS Content Element is used.

Each instance of headed section should be recorded as a part of one, and only one, instance of another record component, either a composition or a headed section. This is shown in the figure by using two composite aggregations, shown by the filled diamond symbol (♦) and the cardinality 0..1 at "...Content Element" side. This composite aggregation represents original context of the headed section and shows where the actual information content of is placed.

Already recorded instances of headed sections may be re-used in any number of other compositions or headed sections. This is shown in the figure by using two sharable aggregations, shown by the unfilled diamond symbol (◊) and the cardinality 0..* at "...Content Element" side.

Each instance of the "...Content Element"-classes contains information related to the inclusion of a single instance of record component in an instance of another record component. This includes identification of the service provider that was responsible for the inclusion and the time the inclusion took place. If an instance of record component for some reason must be removed after inclusion, the relation (i.e. the instance of the "...Content Element"-class) cannot be deleted, it can only be marked as invalid.
3.1.1.2 Using templates to describe EHCR content

An important conclusion of the HC-Interest project is that there is a need for a mechanism that could be used for describe how the components in the EHCR architecture should be used to represent specific clinical information.

This project has, however, had the recourses needed to explore this area in necessary depth. A way of solving the problem may be to introduce clinical templates. This is briefly sketched in the figure below.

Here, separate templates are indicated for the major categories of record components, and there is also a template for data items.

A Folder Template contains a set of Folder Structure Elements that each refers either to a Folder Template or a Composition Template that represents those kinds of folders and compositions that may be included in any folder based upon the template.

Correspondingly, Compositions Template contains rules for the content of compositions and Headed Section Templates rules for the contents of headed sections.

Data Item Templates will have a somewhat different function than templates for the different kinds of record component templates. The Data Item Template should contain information on which of the basic data item types (string, integer, coded value etc.) that should be used and any constraints regarding the use, e.g. which set of codes that are legal to use for a specific coded value data item.
3.1.2 Accessing the EHCR and changing the EHCR content

In this project the focus has been on EHCR interoperability. The project has not had the resources necessary to do a thorough work on access control or revision handling. However, a few classes have been included to indicate which kinds of information that needs to be included to control the access to the EHCR for reading and/or amending the EHCR content, and for documenting such accesses and the changes in the EHCR that is the results of an amendment process.

The figure above shows an extract from the EHCR architecture that includes only the classes needed to illustrate the main principles of access control and revision handling.

A service provider is a person that, based upon formal qualifications, is given a role related to the provision of healthcare in a healthcare enterprise, e.g. a hospital. The service provider belongs to an organisation unit and works with the provision of healthcare to the patients treated by that unit. The same person may act as service provider in more than one role in different organisational units.

Being a service provider in an organisation unit represents a (more or less) static role and shall not automatically give access to the EHCR of the patients treated by that unit. To get access to a patient's EHCR, the service provider must take an active part in the provision of healthcare to that specific patient. Instances in the class Service Provision is used for describing the dynamic roles that links the service providers to the patients in order to carry out some task that has been decided (class name: Decided Task) related to the treatment of the individual patient.

What kind of access rights the service provider should be granted when acting in such a dynamic role, e.g. which parts of the EHCR that should be available, should be a part of the role description (in the class Service Provision).

The use of dynamic roles doesn't solve all problems related to the access to EHCR. There is also a need to access the EHCR in order to record at least the initial decision (as an instance of the class
Decided Action) concerning the provision of healthcare to the patient, thus allowing the dynamic roles to be established (as instances of the class Service Provision). A similar situation occurs when an EHCR has to be accessed in connection with emergency healthcare. In such situation, the service providers are entitled to access the EHCR in order to get the necessary information about the patient.

A solution to this kind of problems may be to associate the (static) role of the service provider with the right to initiate a number of different healthcare-related "tasks", corresponding to the formal qualifications of service provider. One of those "tasks" may then be "emergency care".

As mentioned before, the HC-Interest project has not had the possibility to investigate the access control area in detail, so the description above should only be considered as a rough sketch of some principles that may be used for controlling access to EHCRs.

The revision control mechanisms of this architecture are strongly related to the access control mechanisms. All amendments to the EHCR should be associated with a service provision, identifying the service provider responsible for the amendment and in which (dynamic) role the service provider acted when the amendment was done.

Each instances in the class Revision Info describes a single session of amendment, and all changes that are done to the EHCR during that session, refers to that instance.

As an example three such references are shown in the above figure.

From the class Composition Content Element there are two such associations, a mandatory one named Added and an optional one named Removed. As the name indicates, the first one is used when a new instance of headed section is added to the composition. The other association is established only if the instance of headed section for some reason must be removed later on. (The instance of the Composition Content Element"-class cannot be deleted.)

The third reference to the Revision Info class is from the class Component event. Instances in this class are used for recording any "event" relating to the content of the record components. Examples of such events are:

- Registration started
- Registration completed
- Component content approved by author
- Component content approved by other qualified Service Provider
- Component content is invalid (logically deleted)
- Component replaced
4 Termlink – Semantic Interoperability

Objectives:

- To identify possible areas of and reasons for “semantic non-interoperability” between EHCR-systems.
- To suggest links between EHCR architecture, data elements and messages.

Description of work

Activities include:

- Survey of relevant terminology work done in the participating countries that may help increasing the semantic interoperability.
- Point out necessary terminology systems that are missing.
- Identify missing data sets (data structures and attributes) that are necessary for increasing semantic interoperability between the EHCR systems.

The work done by WP3 consists of 2 parts.

One part describes and defines terms in order to standardize the terminology used in different Scandinavian electronic healthcare record (EHCR) systems.

The other part describes the terms used in the pilot project described in the report from WP2. The terminology used in part two is described in section 6.

It has been observed in this work that standards like 13606 and HISA are not updated to the to-day’s situation. It has therefore been difficult to transform the terms from those standards to the excising Nordic vocabulary.

The results have been fed into WP4 on Message Development and WP5 on Prototyping.

4.1 1.3 WP3 Results

The result of the analysis, interpretation and translation of the terms is shown in the paragraphs 2.0 to 6.0. of deliverable D3: Proposal for Nordic terms and classifications for EHCR communication [2].

4.2 The EHCR terminology

The group has discussed, on request from WP3, crucial terms used in the electronic healthcare records and produced a list of such terms with comments explaining their origin, interpretation and type. Definitions of terms and codes from other standard documents like ENV13606-2 and the ISO 5218 have been used in order to confirm to internationally accepted terminology and coding.
5 Message development

The objectives of this part of the project were to enable interoperability between heterogeneous EHCR systems by using different technologies, mainly XML.

A general-purpose message intended for use within all parts of healthcare where whole or parts of electronic healthcare records are being exchanged has been developed by the project. The message is very flexible. In addition to the possibility of including any kind of documents, un-standardised or specified in separate standards, it provides "request and reply" functions, consent communication and the possibilities to identify actors participating in the provision of care.

5.1 Message usage

The message contains some fixed structured information to describe the parties:

- The healthcare professional that has authorised the transmission of the healthcare record information.
- The organisation where the healthcare record information is being communicated from, and the healthcare person’s role within this.
- The patient in question.

One or more Documents can be attached to the patient. They can be categorised as follows:

1. Standardised EHCR information. Is utilised for whole or parts of healthcare records conform to the national EHCR standard.
2. Non-standardised EHCR information. Is utilised for whole or parts of healthcare records not conform to the national EHCR standard, i.e. pure text documents, PDF-documents, scanned documents, Word-document etc. Such documents are described with a set of attributes describing the content and where the information originally was recorded.
3. Other document. Can for instance be utilised for documents conform to other standards. Under the condition that this is agreed upon among the communicating parties, proprietary formats can be communicated this way.
4. Request and reply.

With the exception of request and reply, each Document should be communicated as a separate body-part in the message.

The general-purpose message for communication of EHCR documents also gives the opportunity of communicating EHCR information related to several patients in one single message.

5.1.1 Communication of standardised EHCR information

The chosen solution implies a separation of the EHCR content itself from the information related to the transmission of the content. Even though the message in this project only has been used for EHCRs based on the somewhat simplified architecture developed by the project, no changes in the message is needed to communicate electronic healthcare records based on future European or international standards.

5.1.2 Communication of non-standardised EHCR information

For non-standardised information, a set of codes could be used to describe the different categories of information in the EHCR. For each category it should be specified which storage formats that are
allowed. While simple text format may be sufficient for many categories of information, other formats, like PDF and TIFF, can be used for others.

### 5.1.3 Communication of other document types

This option can for instance be used for documents that conform to other standards. As long as the communicating parties agree upon this, proprietary formats may also be used. Even documents produced in MS Word or similar "off the shelf products", can be communicated this way.

### 5.1.4 Request and reply

Using the request option, complete healthcare records or any extract consisting of information belonging to a set of information categories and recorded in a specified interval of time can be requested. Requests may also be written in text attributes, thus making it possible to pose all kinds of questions.

Similar, when using the reply option, the reply may both consist of extracts form the patients EHCR and/or answers in text attributes. It is of course also possible to deny answering the request. The reason for such denial can either be given using a coded value or it may written in a text attribute.

As it is possible to send several questions in a single request message, the reply message may contain a set of answers, each connected to the corresponding question in the request.
5.2 Message information model

The figure above shows the main classes in the message information model.
6 Prototype development

Objectives

- To test-implement the HC-INTEREST architecture and messages in prototypes or pilot sites.

To study interoperability experiences with the HC-INTEREST architecture and messages.

Description of work

Based primarily on the results from WP2 (Architecture), WP3 (Termlink) and WP4 (Messages) some prototype implementations have been made and the practical aspects of the linkage between architecture and messages have been studied.

6.1 The aim of the pilot

The aim of the pilot implementation was to try to extract data from a real electronic healthcare record system (EHCR) according to the Danish Medication Model and according to the model (architecture) proposed in the HC-INTEREST project.

The medication area was selected for the pilot development. The reason for this was that the medication was the most mature part of the model from the National Board of Health. Furthermore, that the communication of medication data has a high priority and that it was necessary to restrict the domain due to time and resource limits.

This exercise had the potential to point out how difficult it would be to extract data from a running system according to the models mentioned. Differences between the system and the models could be related to structures, data content or semantics.

For the pilot implementation, an adapted version of the EHCR system from the Danish supplier B-Data was used. In this system, information can be accessed from various “angles”, depending on the users intentions and needs. A specific patient may be selected from a list of patients connected to a ward, or a search may be made based on the unique person identifier or other patient information.

6.2 Methodology: Using the standards

Three main strategies were followed in order to explore different possibilities for extraction and communication of medication data:

1. Extracting a separate XML document based on the Danish medication model from the National Board of Health (G-EPJ).

2. Creating a XML document containing an EHCR Extract based on the EHCR architecture with the XML document containing the medication extract embedded in a Composition.

3. Creating a XML document containing an EHCR Extract based on the EHCR architecture where the medication data is placed in a Composition containing a set of Headed Sections and Data Items extract embedded in a Composition.
6.2.1 XML based on the Danish Medication Model

The Danish Basic Model is based on three main classes as shown below: “Medicinering” (what drug), “Dosering” (what period) and “Dosis” (how much and when). An example of a medication is shown in the blue boxes.

Based on this structure it was possible to extract medication data from the EHCR system, even if the internal structure of the system was different from Danish Basic Model.
6.2.2 The Danish Medication XML embedded in the HC-INTEREST model

One solution for using the HC-INTEREST model with systems compatible with the Danish Model was to embed the complete XML generated as mentioned above in a Composition.

The benefit for two systems already using the (same) Danish Model is limited, but as a migration strategy it might be useful.

The figure below shows where in the HC-INTEREST model the XML-document is placed.

```
...<Folder>
    <folderCat>inpatientStay</folderCat>
    <closed>true</closed>
    <compID>2</compID>
    <FolderCont>
        <Composition>
            <compCat>Medication</compCat>
            <approved>true</approved>
            <compID>3</compID>
            <XMLDoc>
                <docRef>file://medication.xml</docRef>
                <XMLDocCat>GEPJ_SST(dk)</XMLDocCat>
                <note>XML-file with complete set of medication info for 0102030LP2</note>
            </XMLDoc>
        </Composition>
    </FolderCont>
...<Folder>
```

*Figure 2 The proposal for key components in a Nordic HC-Interest EHCN Architecture with the Danish Medication XML embedded*
6.2.3 Data decomposed according to the HC-INTEREST model

Another solution – which is more in the spirit of the HC-INTEREST model – was to decompose the medication data from the EHCR system and structure them according to the generic model.

The figure below shows a simplified version of the HC-INTEREST model with the same medication example as in the previous examples.

Figure 3 A simplified version of the HC-INTEREST model with a medication example

In this case, the data from the EHCR had to be organised in a new way, and mapped to the generic structures compositions, headed sections and data items.
Annex A: References


[4] HC-Interest deliverable D5: Experiences from the validation site


[9] Preliminary drafts of standards from CEN/TC251 PT41 Data types and General Purpose Information Components

[10] Deliverables from the project: Electronic Healthcare Record Support Action (EHCR-SupA) These documents and other information about the SupA-project is available at http://www.chime.ucl.ac.uk/HealthI/EHCR-SupA/documents.htm.

