The Development of a Swedish National Information Structure

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Abstract. Sweden has as part of its national eHealth strategy decided to develop a generic National Information Structure. It is based on three models: The Generic Process, Concepts and Information model. The models are intended to be specialised for various forms of care including social and community care. The importance of interacting models developed in an iterative approach with user involvement is emphasised.

Keywords. information structure, eHealth strategy, process, modelling, concept, analysis, semantic interoperability, shared care, business requirement, stakeholders

1. Introduction

Sweden has as other EU member states in response to the European Commission call to develop eHealth roadmaps [1] developed a National strategy for eHealth agreed in 2005 [2]. In the strategy it was emphasised that citizens, patients and relatives require quick trouble-free access to quality-assured information. The need for care givers to have access to efficient, interoperable eHealth solutions ensuring patient safety was also stressed. Emphasis was also put on the fact that authorities and other bodies providing care need information and communication technology (ICT) as an important tool for follow up of patient safety and quality but also to support management.

The basic health care legislation ensures all inhabitants health care based on their needs. A regulation issued in 2005 named “Good Care” [3] was directed to health care managers responsible for the delivery of care instructing them to develop and maintain quality management systems. This is aimed at six focus areas: evidence based and “fit for purpose”, safety, patient-centered, timeliness, efficiency and equity. The regulation is based on the general PDCA-cycle (Plan Do Check Act) approach also applied in the ISO 9000 family of quality management standards.

The Swedish eHealth strategy is divided into six areas, where area two, focuses on creating a common information structure. The other five areas being; bringing laws and regulations into line with extended use if ICT, creating a common technical infrastructure, facilitating interoperable supportive ICT systems, facilitating access to information across organizational boundaries and making information and services accessible to citizens. In Sweden as in other European countries, true exchange of information over boundaries to enable shared care and the further development of efficient ICT solutions for health and welfare is problematic. To ensure safe care, ICT systems need to exchange semantically well defined information between different

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interacting units and information systems, in order to achieve semantic interoperability an issue acknowledged by the European Commission in a communication to the member states [4].

Under action area two in the Swedish national strategy the National Board of Health and Welfare has been given the task to “take a national and strategic responsibility to make person-related care information more unequivocal, easier to follow-up and available”. This work is undertaken by two parallel projects, The National Information Structure (NI) and the National project for an interdisciplinary terminology (NF).

2. Objectives

This study presents a method for the development of a National Information Structure using an iterative modelling approach based on different user perspectives, resulting in three generic interacting model views (process, concept and information) for health and social care. The work is also taking into account other national projects, international standards, legal and security requirements. The generic model views are intended to be applicable for all different specialisations of health and social care.

3. Materials and Methods

3.1. The Project Context

This study is based on the results of the project’s developing group, the core group of the development of the information structure. The study is one part of the large National Information Structure project conducted in Sweden by the National Board of Health and Welfare 2007–2009 commissioned by the Department of Health and Social Affairs.

The Information Structure consists of three interacting model views, process, concept and information. These views make up different points of view of the model. The methodology used to define the three interacting views has been an iterative process building on dialogues between the core experts and the project’s user groups using models based on the different perspectives of the groups as a communication tool. Input from various national stakeholders based on a public review process as well as public review meetings were also contributing to the development.

The process model view describes the value adding chain that takes place in the business of a health care enterprise. The value is the outcome provided to the customers/subjects of care. When producing those values, information is required about health states, resources and results that are described in the information model view. The concept model view was used to define the information and the process steps. A more comprehensive description on the method and the terminology used can be found in [5, 6].
3.2. The Development of the National Information Structure and its Three Model Views

The main goal of NI is to provide the means for effective communication in various businesses of health and social care. This is achieved through a generic model that is the heart of the information structure. The generic model can be viewed through three perspectives: process, concept and information as described in Figure 1. It is intended that each business, project, agency etc. shall apply the information structure by adding their specifics to the generic model. Using a common generic structure shall facilitate co-operation and interaction as well as providing means for comparing different providers and units. The tenet of NI is that by providing a common denominator for concepts with a common context irrespective of where in the health and social care process it is applied, misunderstandings can be prevented.

![Figure 1. The relationship between generic and applied models](image)

An example of how the concept perspective of the generic model is applied is described in Figure 2. A generic concept like activity can be applied (in this example specialized) to three different business areas. Each application preserves applicable

![Figure 2. An example of a generic concept related to applied concepts](image)
properties (in the case of specialization all properties) of the generic concepts. Thus clinical procedure inherits that it aims at a healthcare state as do the other applied concepts. In the specialization properties are also added, e.g., that a clinical procedure is carried out on a patient. Similarly, investigation adds another property ‘may reveal healthcare state’. Hence the concepts of clinical procedure and investigation are more detailed than activity but we now know that they both are activities and we can therefore communicate them. If we provide the definition e.g., in terms of the relevant part of the concept model, we can do that without loss of semantics.

4. Results

4.1. Overview

The method as such has been presented in two reports [5, 6]. The project results have been documented in Swedish in two preliminary reports [7, 8] with annexes consisting of detailed models and concept definitions.

4.2. Generic Process Model

The process models are based on the value principles expressed in the Swedish legislation on health and the “Good Care” concept [3] and user requirements from health care representatives. A separate workshop was conducted with representatives of community and social care indicating that the generic process model is applicable as a specialization also in regard to these domains. The results of the first modelling phase have been documented in a separate report [7].

4.3. Generic Concept Model

The generic concept model was developed during the second modelling phase based on the results of the process modelling. The model was based on user requirements presented in concept models as well as views from the external review performed at the end of phase one. This led to some revision of the process model. The result was published in November 2008 [8] and subject to external review at the end of 2008/early 2009.

4.4. Generic Information Model

The information model developed during early 2009 is based on and harmonised with the results of phase one and two. The results were published May 2009 following an internal process with dialogue and interaction with the project’s user groups.

4.5. Harmonising and Integration

In order to support shared care across professional and organisational boundaries and to ensure semantic interoperability the integration and harmonisation between the models have been crucial and the iterative approach a way to ensure the stability and quality of the information structure. It is also imperative to harmonise and to identify boundaries
and interaction with implementation models in ongoing national and international projects i.e., The National patient overview and the European Patient summary (epSOS). Harmonisation has also been undertaken with national terminology projects such as the use of Snomed CT in a Swedish context, undertaken by NF.

The sequential development of the model views for process, concepts and information was a pragmatic decision. We could have developed all three views simultaneously but we chose to develop one at a time. As more views were developed, the previously developed ones were updated iteratively.

5. Discussion and Conclusion

The use of eHealth solutions to solve the issues facing health care both on a regional and national as well as on an international level is growing. It is our belief that integrated and harmonised modelling with an iterative approach based on the individual care processes is paramount to achieve the changes needed [9, 10]. The iterative approach undertaken by the project is time consuming and costly but it is our belief that this considerably facilitates the implementation process as well as the maintenance process following the project’s finalisation.

It is our view that the specialisation and implementation of the generic models in eHealth solutions will improve the delivery of patient health care with benefits including clinical decision support and enhanced patient safety. It will also provide and enable effective use of secondary data [11] to perform management and evaluation of patient outcomes without the need for resource consuming separate data collection or registration.

References