Semantic Interoperable Electronic Patient Records: The Unfolding of Consensus based Archetypes

Rune PEDERSEN\textsuperscript{a,b}, Rolf WYNN\textsuperscript{a,b}, Gunnar ELLINGSEN\textsuperscript{a,b}

\textsuperscript{a}University Hospital of North Norway, Tromsø, Norway
\textsuperscript{b}Telemedicine and eHealth research group, Arctic University of Tromsø, Norway

Abstract This paper is a status report from a large-scale openEHR-based EPR project from the North Norway Regional Health Authority encouraged by the unfolding of a national repository for openEHR archetypes. Clinicians need to engage in, and be responsible for the production of archetypes. The consensus processes have so far been challenged by a low number of active clinicians, a lack of critical specialties to reach consensus, and a cumbersome review process (3 or 4 review rounds) for each archetype. The goal is to have several clinicians from each specialty as a backup if one is hampered to participate. Archetypes and their importance for structured data and sharing of information has to become more visible for the clinicians through more sharpened information practice.

Keywords. Electronic patient record, interoperability, semantics, integrated care, openEHR

Introduction

Shared care and integrated care has over a decade been a focus area for the health authorities in Norway and more recently \cite{1, 2}, which particularly emphasises the need for Electronic Patient Record (EPR) systems to be organized in a more structured manner and for such systems to be more interoperable in order to communicate information across heterogeneous practices. The reason for this is an increasing demand for rapid feedback on results, and an urge to compare organizational or clinical data internally, regionally, or nationally. Structured data will make it possible for clinicians to categorize variables in order to build meaningful reports, to extract data for quality registers, and for clinical research. Structured data elements will also make it possible to organize information that supports process support- and decision support inside an integrated EPR portfolio with focus on patient pathways.

A national initiative to deal with this has gradually gained foothold in Norwegian healthcare. Initiatives using an openEHR architecture have been established both for the purpose of building a national repository (a so-called Clinical Knowledge Manager) of common semantic data elements for collaborative EPR systems, and large EPR vendors are building their system portfolio around the openEHR technology.

\textsuperscript{1} Corresponding Author.
Archetypes are formalized information models based on the specification of openEHR. Archetypes are information elements of clinical concepts, where observations, options, instructions, and actions form the iterative process of treatment and care [3]. The archetype for Blood Pressure is a classic example of an observation archetype.

By using openEHR, it is possible to make EPR content structured in a multilevel modelling approach that includes templates, archetypes, and a reference model intended to improve semantic interoperability and the reuse of data [4]. Archetypes are re-usable structured models of clinical concepts and knowledge made to standardize the content of EPRs. How do different pieces of software know what the data means, is give an increased opportunity for interoperability. “How to build a patient –centric longitudinal EPR across enterprises” and how to secure sharing of data among stakeholders in different areas of healthcare includes a focus on semantics with a standardized language for EPR variables. For example, a study by Garde et al. [5] concerns the modelling of clinical content of EPR systems that could become available internationally. The study shows how clinical content can be made available using archetypes and templates from openEHR and ISO 13606. Through this, the openEHR platform could become the foundation for safe sharing of the information the clinicians need as tool for decision support inside the EPR system (ibid). A study by Chen et al. [3] describes how chemotherapy guidelines could be established using openEHR, which provides decision support and facilitates the use of clinical guidelines in clinical treatment.

The Clinical Knowledge Manager for archetypes is planned to contain more than 1000 archetypes, archiving information about how new archetypes are translated, modelled, and shared. A precondition for success is that clinicians agree on the content of each archetype in the consensus process. In turn this will secure a common understanding of the clinical content of EPR systems over regional and national boundaries. This paper concerns the regional work accomplished to support this efforts. Clinicians from the four Regional Health Authorities will be active contributors in the process of developing archetypes coordinated by the national editorial group, the National Administration Office of Archetypes (NRUA).

While earlier research on openEHR archetypes has demonstrated success in small-scale prototypes [5], this paper focuses on the effort to establish a national repository for archetypes where clinical specialists are included in national consensus processes. Based on this we present the following research questions: How are clinicians recruited to participate, what inspires clinicians to participate in the consensus processes, and what are the key challenges?

1. Methods

The research has mainly been carried out in the North Norway Regional Health Authority and in coordinated with NRUA. Qualitative methods (interpretive, and ethnographically oriented) have been applied, grounded in the first author’s participation and contribution in the work accomplished [6]. Analysis of longitudinal research is a continuous and iterative process with an ever-changing intensity. As Klein and Myers 1999 [7] suggest, it can be understood as a hermeneutic circle that refers to relating the whole to the part, and the part to the whole. As of this, firstly the fieldwork has been focused on the first authors’ role as a contributor to the regional work accomplished, and secondly the forthcoming process were numerous archetypes will be
tested as structured elements in the new process oriented EPR system. During the last two years several meetings, courses, and workshops with focus on archetypes has been held to establish the regional and national processes. Conversations, discussions, and debates from these meetings are the foundation of this work. The observations and description of on-going work has been followed by interviews with members of the regional and national initiative, which so far includes three interviews, and conversations with end users of the Clinical Knowledge Manager while guiding them to become users.

2. Results

NRUA was established in 2013 by National ICT with the goal to produce high quality archetypes. The NRU A employs three people whereof two in full positions and one in a part-time position. NRU A further includes representatives from each of the four Regional Health Authorities. There are between two and three members from each of the four regions. As an example, there were three members from the North Norwegian Health Authority, one physician with special interest in health informatics, one nurse with a PhD in information Systems, and one project manager from the regional ICT development program were the new process oriented EPR is developed.

The overall goal with NRU A is to coordinate the development and use of archetypes on a national level, both handling translations of international archetypes as well as handling local initiatives. It is called “Do-ocracy” where doers make the decisions, but where the reviews are initiated by the Editorial Group which also covers the recruitment of the reviewers to the national Clinical Knowledge Manager. The further approval is done by the Editorial Group if the requirements are met. The requirements are factors such as the right number of clinical specialists for the right archetype (national level) where all four regions are included.

Since the beginning in January 2014 NRU A has focused on the translation of already existing archetypes, observation-archetypes like blood pressure, body weight, nutritional risk, height, and temperature. During this period of time, national consensus has been reached for the archetype Blood pressure. Clinicians have been invited to participate through the national Clinical Knowledge Manager after coordination between the regional groups and the secretariat at NRU A. Other archetypes are also considered, all based on regional programs or initiatives such as a specific nursing registration scheme in the West Norway Regional Health authority, archetypes for national clinical registers, archetypes ordered by clinical work-groups with focus on the development of the new EPR system, and a number of archetypes ordered by cooperating vendors on a global level.

The recruitment of clinicians for the consensus processes is relatively easy in terms of access and usability of the Clinical Knowledge Manager which is web–based and leads the clinician directly to the clinical decisions. The members of NRU A has used a lot of time to define which type of specialists that fits with knowledge to determine the content of each variable for the consensus process. As an example; for the observation-archetype bodyweight the twelve specialties needs to be included and active in the process to reach national consensus. Of the twelve, ten are on the “have to” list, and two are on the “should” list. The list includes specialties such as pediatricians, oncologists, psychiatry, cardiology, nephrology, hematology, genetics, and endocrinology.
Further, a close follow-up on activated clinicians (invited and active CKM users) is important, with the purpose of managing to recruit several specialists from each clinical specialty such as for instance oncology or internal medicine. Another step is to translate the Clinical Knowledge Manager content to Norwegian, especially the information about access and use of the application, and to get a design group up running who can contribute to the development of new archetypes. Today the focus is on the translation of existing archetypes from the global Clinical Knowledge Manager. Inside the CKM the specialist only need to adapt to what is clinically relevant. Specialists from all of Norway discuss the clinical content of variables that are important for clinical processes. However, some specialists are harder to recruit than others like for instance endocrinologist who are a small group compared to for instance the oncologists. Another problem has been late coming requests for structural changes which so far have led to several review-rounds that in turn can lead to an increased drop-out rate. However, there have still not been disagreements of severe character. Except from this, there are always questions and skeptical engagement when it comes to tools like the Clinical Knowledge manager both towards usability and log-in errors: “In both our experience, and based on feedback from newly recruited users, the CKM has an intuitive user interface making it easy to understand how comments are entered and saved. Some users experience problems with error pop-ups during login, but this seem to be related to older versions of Internet Explorer.” (Member of NRUA)

On the regional level the project has invited 90 clinicians, nurses, nutrition specialists, and doctors. The clinicians chosen were based on the “have to” and “should” lists, and the most of them had earlier relations to regional IT projects. The project has also recruited nurses and physicians from National Centre for Telemedicine (NST), where most still are working clinically in minor positions. In present time the project have 40 activated clinicians and approximately 10 members from the regional NRUA group and National Centre for Telemedicine that also include researchers with technological background. The regional members are so fare the clinicians from NST and one representative from SKDE which is in quality registers. This group has gathered once every fourth week to discuss and coordinate with the national development. For the six archetypes that now are in the loop of getting consensus (Body-weight, Pulse, Respiration, Boy-Temperature, Height-Length, and MEWS-score which is a modified early warning score to detect the degree of illness) there have been challenges due to getting the right number of specialist doctors, and nurses to participate. The work to recruit and get response from clinicians started with getting the Regional Resource Groups operative. Based on the already established work in the North Norway Regional Health Authority with the regional ICT program we had an activated number of resources from the start, and NRUA had used the Regional Group’s experiences actively every month.

Throughout the first six months the project invited clinicians using a standardized email with attached information about archetypes, the national work, and regional EPR in development. In this process the project has been struggling hard to reach out for the specialties needed to reach consensus for some of the archetypes.

The latest initiative has been to go directly to the top, ask the clinical director for permission to send out standardized invitations to all the clinical specialties at the University hospital where the leader is asked to point out one or two clinicians that will represent the field of knowledge in future processes.
3. Discussion

With the overall goal to produce a national repository of consensus made clinical variables for use in EPR systems and make clinicians responsible for clinical content reorganization is needed. The number of consensus made archetypes per year is in particular a challenge. The structured EPR data will make it possible for clinicians to categorize variables to build meaningful reports, to extract data for quality registers, and for clinical research. Structured data elements will also make it possible to organize information that supports process and decision support inside an integrated EPR portfolio and using openEHR will support the clinicians with a more open, adaptive, and collaborative system which enables modeling of clinical content. However to achieve this, the clinicians needs to engage in, and be responsible for the production of archetypes. The consensus processes have so far been challenged by a low number of active clinicians, a lack of critical specialties to reach consensus, and a cumbersome review process (3 or 4 review rounds) for each archetype, which easily could cause clinicians to drop out.

Hence, key lessons learned from this study, is that the regional work to include engaged clinicians for each clinical specialty is very important when it comes to ensuring a robust consensus process when the overall goal is 1000 or more archetypes. As a part of the process, it is crucial to provide sufficient technical support to participating clinicians, such as giving access to the Clinical Knowledge Manager and guide them through the consensus process. This is important work that contributes to ease the process and time used by giving easy access to former discussions about the actual archetype and by giving a quick overview of the clinical content and how to make comments. Another critical point to follow up is the new strategy to include a redundant number of clinicians to fill in empty spaces during the ongoing consensus processes. The goal is to have several clinicians from each specialty as a backup if one is hampered to participate. Archetypes and their importance for structured data and sharing of information has to become more visible for the clinicians through more sharpened information practice. The vision of the project needs a strong anchorage both top-down and bottom-up in the clinical organizations.

4. References