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From Free-Text to Structure in Electronic Patient Records

Gro-Hilde SEVERINSEN [a, 1], Line SILSAND [a], Gunnar ELLINGSEN [a, b] and Rune PEDERSEN [a, b]
[a] *Norwegian Center for E-health Research – University Hospital North Norway*
[b] *Telemedicine and E-health Research group, The Arctic university of Norway, Tromsø*

Abstract. We report from the initial steps of a collaboration project between two post-doctoral projects, both using a qualitative action research approach to address challenges related to shifting from a free text to a structured EPR system constituting important preconditions for establishing advanced decision support and reuse of healthcare data. We have started to explore three areas that may influence this process related to: 1) Legislative challenges of getting access to all relevant healthcare data. 2) Challenges of exchanging data between silo systems and open platform systems. 3) Replacing a free text silo EPR with an open platform system - and the practical challenges of defining the content of the context sensitive structured EPR. Hence, we ask the following research questions: How to address challenges related to the shift from free text to structured EPR systems? How will the need for semantic interoperability between different EPRs influence the goal of advanced clinical decision support? Empirically, we draw on the regional FRESK program (2017-2022), in the North Norwegian Health Region, which includes implementing both a new regional open platform based EPR system, and a proprietary medical chart system.

Keywords. Interoperability, open platform, silo systems, reuse, Electronic patient record, Clinical decision support

1. Introduction

The expectations for advanced ICT solutions in healthcare increases rapidly. Electronic Patient Records (EPRs) are considered to be crucial tools for supporting clinical processes across institutional boundaries, foundations for clinical research, as well as tools for informing managers and policy makers [1-3]. Particularly, advanced clinical decision support (CDS)[2] capabilities are in high demand, but yet not widely accessible. There has been a great effort to understand the reasons for limited availability due to this being an important demand for structuring the clinical information within the EPR is one of the absolute prerequisites to enable advanced CDS. Another reason is the lack of integrations between EPRs since healthcare organizations tend to use a plethora of specialized, non-standard electronic patient records (EPRs), defined as silo-systems [4], often developed to support specialized departments' internal processes. The silo system

[1] Corresponding author Gro-Hilde Severinsen, E-mail: Gro-Hilde.Severinsen@ehealthresearch.no

[2] Clinical decision support is an ICT tool that combines evidence-based knowledge, guidelines, procedures and treatment protocols with individual patient information to support decisions of the treatment and care to a specific patient.

approach gives access to only a single unified database for instance related to radiology, medical charts or EPR, which complicates exchanging clinical information between these systems. Information exchange between systems is of high importance for healthcare personnel to access all relevant clinical information and support patient pathways across organizational boarders. Consequently, the expected improvements of quality, as well as cost-effectiveness of treatment and care promoted through the use of advanced EPRs is at risk when clinical information during a patient pathway resides in more than one EPR. Based on the complexities described in previous research, there is a need to explore these intricacies related to the transition from today's silo systems to the deployment of structured EPRs enabling clinical process- and decision support [5-6].

This is a research in progress, were we have started to explore three environmental topics that may influence the process of shifting from free text to structured EPR system constituting important preconditions for establishing advanced decision support and reuse of healthcare data. Making such shift has not been done to the same extend as in Norwegian healthcare before, and structuring an EPR system is usually only done by system vendors today. Empirically, we will draw on the regional FRESK (Future systems in the clinic) program (2017-2022), in the North Norwegian Health Region, which includes implementing both a new regional open platform based EPR system, and a proprietary electronic medical chart system. Important aims of the program include structuring the clinical information within the new EPR system through the openEHR approach using archetypes as clinical standards 3 [9, 10], and defining how to integrate and share clinical information between the EPR and other healthcare systems, particularly the medical chart system. The empirical project is now facing the complex challenges related to the transition from silo systems to structured EPRs as an important precondition to enable advanced CDS. Hence, we ask the following overall research questions: How to address challenges related to the shift from free text to structured EPR systems? How will the need for semantic interoperability between different EPRs influence the goal of advanced clinical decision support? Responding to this, we have identified three important topics that need to be further explored: 1) Legislative challenges of getting access to all relevant healthcare data. 2) Challenges of exchanging data between silo systems and open platform systems. 3) Replacing a free text silo EPR with an open platform system - and the practical challenges of defining the content of the structured EPR. The research will be carried out as a collaboration between two post-doctoral projects both addressing the work with structuring the EPR, and establishing advanced clinical decision support.

2. Method

This study adheres to a qualitative action research approach. The purpose of an action research approach is to contribute to a co-constructive learning process based on feedback from healthcare personnel, developers, and stakeholders participating in the empirical field. The research will be carried out in the regional program FRESK. The

[3] The openEHR architecture based on archetypes designed to manage, store and retrieve structured health data in an EPR system [11], through an open platform where the data are completely shareable and independent of programming language, human language and database technology. Archetypes are the information models set to standardize clinical concepts in openEHR systems. This includes facilitating reuse of information, evidence-based practice and semantic interoperability. Archetypes are clinical standards including the context they are used for, established in a socio technical consensus process [12].

researchers' will through action research bring back scientific knowledge and relevant findings to FRESK and successively evaluate the ongoing processes [9].

The data will be collected through interviews (we have already conducted four), knowledge summaries, participatory observations, discussions and document studies. The interviews will be audio recorded, transcribed, and analyzed in relation to the context. The objective of analyzing collected data is to organize and structure the gathered material to generate an understanding of how the socio-technical interdependencies influence the evolving empirical process [10].

3. Case

In the North Norwegian Health Region, the goal is to shift from a free text EPR system combined with a paper based medical chart, to an open platform EPR system based on the openEHR architecture and a proprietary medical chart system. In relation to the work with structuring the EPR system, to reach the goal of CDS, we have started to explore three important areas of the existing socio-technical context influencing the implementation of the new EPR, with a particular focus on legislation, integration and practical design

3.1. Legislative challenges of getting access to all relevant healthcare data

The National eHealth Strategy (2017-2022) [13], addresses that EPR systems must be able to provide CDS functionalities where evidence-based knowledge is used directly to support patient treatment and care. However, important preconditions to enable CDS are structured clinical information, and access to all relevant patient specific clinical information, independent of where or in which system the information is stored [14]. In addition, exchange and reuse of clinical information still implies that confidentiality, legal regulations and restrictions of sharing personal information ("*GDPR Personal Information Act")* need to be taken care of. Today's situation in the North Norwegian Health Region does not comply with these preconditions.

First, even if clinical patient specific information is stored in one common database, this database is separated into four units belonging to each of the regional health trusts. Second, the present EPR system is built in such way that clinical information is written in free-text, and stored in document-files belonging to different journal groups within the EPR. Healthcare personnel get access to the documents through a very strict and complex hierarchy of access control aimed to ensure the confidentiality legislation. However, patient pathways often cross organizational borders and healthcare trusts, which means that patient data is recorded and stored in more than one health trust's database. According to the patient record legislation the health trusts are responsible for the healthcare information within their trust, and they decide if they want to partially or fully share the healthcare information. *"There are no legal restrictions against reuse of data or extracting data for decision support. However, in which format (sharing document, read-only document, sharing specific clinical information) this information is presented may be an issue to discuss (Legal professional)."*

Using a structured EPR seemingly provides more possibilities than limitations, and makes it easier for healthcare personnel to access significant and necessary information like blood pressure or weight without accessing an entire free text document. Still, it is important to explore how to enable CDS meanwhile ensuring confidentiality, legal

regulations and restrictions of sharing personal information according to GDPR. Hence, it may be necessary to reevaluate the existing hierarchical access control system to facilitate the goal of CDS with the need for exchanging and reusing clinical information in new ways. "The laws regarding healthcare information is designed first of all to ensure that healthcare personnel get access to necessary information related to a patient. (legal professional)." It is important to discuss:

(1) The balance between confidentiality, and protection of privacy in relation to the overview of relevant healthcare data within and across EPR system and potentially reuse in relation to accessing all relevant healthcare data.
(2) The need to change today's journal structure and access control system.

3.2. Challenges of exchanging data between silo systems and open platform systems

Implementing a structured EPR system demands for reevaluating the silo system structure in Norwegian healthcare, since one of the main prerequisite for advanced CDS is the possibility to extract and reuse relevant information about a patient regardless of in which healthcare system the information is stored. This is not possible with today's silo systems and potentially generates a risk of missing relevant information when treating a patient. The ideal data exchange includes converting all data into the same standards, preferably an open standard, to seamlessly exchanging healthcare data. However, the present systems in the North Norwegian Health Region are built on differing standards, demanding complex integrations to enable data exchange. Systems like the EPR, and the medical chart, which both includes numerous overlapping patient data, and demand for close integrations to provide a seamless information flow in between. Integrations between similar systems were conducted in the Southern and Eastern Norway Regional Health Region some years ago, including patient administrative terms, allergy import and FEST (medication). There was also provided a CCOW - real time synchronization of information as a HL7 standard, to provide seamless integration for users of both systems. These integrations have been adopted to the North Norwegian Health Region, due to close collaboration between the two programs. In FRESK, they now work with integrations of vital parameters, where to store master data, and what secondary systems/software to integrate towards to avoid double registration.

One way of integrating systems using different standards are profiling, using a common language for messaging between systems, e.g. HL7`s FHIR (Fast Healthcare Interoperability Resources). FHIR is designed to exchange healthcare information through resources, reflecting clinical and administrative information [15]. It is necessary to include a great deal of clinical work in forming consensus around how detailed clinical information should be captured and shared in FHIR resources since they have no defined structure [15]. Another challenge is that there is no established repository of FHIR resources available in Norway even if some FHIR resources, like observation, are already defined. Observation is useable for exchanging information on all vital parameters "the observation FHIR Resource is generic to integrate any vital parameter, or all observation archetypes (integration specialist)."

Accordingly, it is crucial to discuss how to establish high quality integrations and messaging language to provides seamless integrations and semantic interoperability between healthcare systems. Three important challenges need to be explored:

(1) The importance of agreeing on a format for message exchange and code to use, to enable CDS system to extract and understand information from all systems involved.
(2) If FHIR is to be used, there is a need for designing regional resources as soon as possible, and preferably within the next six months according to the implementation plan for the new EPR and medication systems.
(3) How to include metadata for information to be reusable from one system to another, to enable clinicians to know for instance when a blood pressure has been registered and how to evaluate the value before reusing it. Archetypes are information models that includes the context the data was registered in.

3.3. Replacing a free text silo EPR with an open platform system - and the practical challenges of defining the content of the structured EPR

Shifting from a free text based EPR system to a structured EPR demands for changing the way healthcare data are registered and presented. Based on previous experiences with converting clinical forms/schemas from unstructured to structured forms [16]. These processes often turn out to be more complex than initially expected. Hence, important challenges have been recognized for instance in the work with designing a structured registration form based on the free text schema in the existing EPR system described by Ulriksen and Pedersen [16]. The work resulted in a very long and complex schema including 58 standards, resulting in endless variables and boxes to check. The conclusion was that it is very important to define the reusable data necessary to structure, the rest should remain as free text. Other important lessons learned from this work, correlates well with the challenges recognized in the work with structuring forms in the FRESK program, these issues need to be further explored:

(1) The importance of include clinicians in designing forms used in the structured EPR to define values to reuse to end up with forms useful for clinical practice [16].
(2) The possibility for reuse of data depend on the granulation level of the standards. If one scheme is designed as one standard, the whole form has to be reused. If each variable is connected to a specific standard, all the elements are separately reusable.
(3) How to establish a socio technical network of different actors, in addition to clinicians including regional and national archetype specialist to identify the right structured elements to use and design new archetypes if needed, IT personnel with programming competence to design, queries, dependencies and so on to for instance make calculations like BMI is also needed. This includes the need for close collaboration with the system vendor since they are the only ones that are familiar with the form building tools and archetype design for the structured EPR system today.

4. Preliminary discussion

Shifting from free text to a structured based EPR is a socio-technical process, were it is not sufficient to focus only on the technical part of the process, hence including organizational issues, legal considerations, clinical practice and system users are just as

important to succeed. As a consequence, we have selected three important focus areas for our project related to accessibility, integration and registration of patient data in a EPR 1) Legislative challenges of getting access to all relevant healthcare data, 2) Challenges of exchanging data between different healthcare systems, 3) Transferring healthcare data when shifting from a free text-based EPR to an a structured-based EPR and registering data in a structured EPR.

Altogether, the focus areas enable receiving all relevant healthcare data necessary for treating a patient regardless of where the data is registered and stored. Advanced CDS demands for establishing close collaboration between necessary actors including a network of clinicians to gain high quality standards. Further to decide what information to structure, and how to reuse information during patient pathways. In addition, it is necessary to collaborate about how standards used for structuring information must be designed and governed. Accordingly, how these focus areas best are to be solved, will be given attention during the FRESK program. It is however important to consider also what information that has to be structured since registering structured data makes clinicians spend more time in front of the computer, which again makes for less time face to face with the patient.

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