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Interoperability and Governance; Important Preconditions for Establishing Large-Scale Healthcare Infrastructures Like the Akson Program in Norway

Gro-Hilde Severinsen[a], Line Silsand[a], Kristian Malm-Nicolaisen[a], Rune Pedersen[a]

[a] Norwegian Center for e-Health research, Tromsø, Norway

Abstract

In Norway there is an overall goal to establish a national digitalization platform for primary healthcare named Akson to improve information exchange. We participated in the work with Akson and through qualitative research including interviews, we found that the project could benefit from other similar infrastructuring processes. First, a national process of defining clinical standards and establishing a governance organization to handle them. Second, improving data exchange between an EHR system and a national quality registry. The aim of the paper is to outline some lessons learned from these previous processes, for Akson and similar large-scale projects focusing on how to govern the digitalization platform at different healthcare levels and how to reuse healthcare information within and across healthcare institutions. Hence, we ask the following research question: Which experiences from previous large-scale infrastructuring processes should be considered when establishing a national digitalization platform for sharing data?

Keywords:

Health Information Interoperability, Electronic Health Records, Clinical Governance

Introduction

Establishing infrastructures in healthcare play a key role in the ongoing transformative processes of digitalization. Clinicians depends on intuitive and seamless Health Information Technology (HIT) in order to provide efficient and high-quality care. Patient information need to be accessible across both geographical and organizational boundaries, and data should be in a format that allows for flexible use in multiple use-cases [1]. Ambitions for improved patient data usefulness and seamlessness demands for increased attention to interoperability issues and standardization efforts, not only locally but also coordinated across organizational, professional and institutional boundaries [2]. Semantic interoperability is defined as the ability for different information systems in healthcare to understand each other's contexts and meanings when exchanging information [3].

A central component in provision of quality care in the HIT portfolio is the Electronic Health Record (EHR). Norway early adopted the EHR, to document, access and exchange patient information. Still there is a fragmentation of procurement and management responsibilities within the Norwegian health care sector and lack of national governance and strategic guidance regarding the EHR [4]. Subsequently, the healthcare sector struggles with a fragmented HIT portfolio with limited and resource-intensive options for integrations, numerous legacy systems, costly data migrations, and siloed data repositories that challenge interoperability, seamless data exchange and continuity of care [2,5,6] This includes two major primary care systems for homecare services and nursing facilities, and several systems for general practitioners (GPs). Hospital EHR is gathered in regional or local EHR systems. In addition, generation of personal health data and solutions for digital support and self-management of health contributes to an even more fragmented infrastructure. Consequently, patient information is scattered across different systems, often in non-interoperable formats, hampering safe and efficient patient trajectories and information flow. To address these challenges, the 2012 government white paper "One citizen – one journal" [7] defines overall aims for the development and progression of HIT in the Norwegian healthcare services, emphasizing that healthcare professionals should have easy and secure access to all necessary patient information. Strategically, the Norwegian healthcare sector operates towards an overall aim to make patient information available regardless of where a patient is admitted [7,9, 10]. There is also a national initiative on establishing a common language for exchanging and reusing data within Norwegian healthcare through an ecosystem for structured terminologies, ontologies and codes [11].

Currently there are several ongoing initiatives in Norway that aims to improve patient information access, end-user experiences, patient safety, data quality, and improved data reuse: 1) three out of four regional specialist healthcare authorities are consolidating their databases, modernizing and implementing next-generation EHRs [2,10, 12] 2) a fourth specialist healthcare region is implementing a shared EHR for the hospital and municipalities [13]. 3) a process for implementing a shared EHR for the whole primary care sector (Akson) [13]. The Akson project is the focus area for this paper. Akson will include the Akson EHR for primary care and a national platform for healthcare interoperability. The goal is 100% participation from the municipal health and care service, including GPs, total semantic interoperability [13], and improved information access.

Enabling information exchange in healthcare demands for a platform able to exchange data on numerous standards with an extensive overview of the data exchanged on the platform. We participated in the work with Akson and through qualitative research including interviews we found that the project could benefit from other similar infrastructure processes we have followed in Norwegian healthcare over the last years. First, a national process of defining and designing clinical archetype standards (information models) for an EHR. Second, a regional process to improve data exchange between the EHR system and a national quality registry. The aim of the paper is to outline some lessons learned from these previous processes, for Akson and similar large-scale projects. We focus on the following issues: 1) Interoperability; the possibility to exchange data seamlessly within and across healthcare levels. 2) Governance; establishing national and regional governance organizations. Hence, we ask the following research question: *Which experiences from previous large-scale infrastructure processes should be considered when establishing a national digitalization platform for sharing data?*

Methods

This is a qualitative evaluation study addressing two large-scale infrastructure process in Norway. We have contributed to defining the concept of Akson through meetings with the directorate for e-health, and other national governance organizations, participating in the national media debates, document studies and interviewing different actors to gain an understanding of the ongoing process.

Experiences from the national archetype work and the regional work of combining registry data and the EHR was conducted between 2014-2020 through open-ended interviews, document studies and observations. For more details see for instance [2, 4]. The first and second author participated in the processes 50% as researchers and 50% as employees in the regional governance organization. To ensure that the data was not biased by their insider roles, it was discussed in detail with the third and fourth authors and vice versa since the two last authors were the ones participating in the conceptualizing of Akson. Data was analyzed inspired by systematic text condensation by Malterud

Results

Akson - The process for implementing a shared EHR for the whole primary care sector

In a 2015 the Norwegian directorate for e-health ordered an investigation related to the current status of the EHRs and interoperability in Norway. This resulted in defining complex and multifaceted challenges for the primary care sector, and concluded that it would not be feasible to continue the status quo characterized by a multitude of non-operable and siloed EHR applications [13], they defined requirements for a new solution, [14], and in 2018, they recommended a national digitalization platform, and a joint national EHR for municipalities [15] as the preferable option.

The concept named Akson, will communicate with other digital solutions throughout the Norwegian healthcare system. The aim is total semantic interoperability [15] to reduce the risk of mistakes being made in the health service, through improved information access. This is estimated to provide 3.7 billion in socio-economic gains [15]. The Akson Digitalization platform will consist mainly of national e-health services (e.g. a Core journal, The patients medication list, electronic prescription), health information exchange capabilities and data storage, shared services for identification, and several infrastructure components (e.g. clinical codes and terminologies) to obtain semantic interoperability. Many of these services and components are already in use/partly in use, and the interoperability platform can therefore be considered a continuation of ongoing large-scale infrastructure efforts.

44 municipalities and 200 health workers have been closely involved in the pre-procurement phase, [15]. 185 of 291 relevant municipalities have supported the further work by signing a non-binding declaration. The plan is to implement Akson EHR between 2025-2030 in municipalities and for 60% of GPs by 2033. It is estimated that more than 150 000 health workers in the municipalities will use the system [8]. The total costs of the project is estimated at NOK 22 billion. The municipalities are expected to pay most of this cost themselves.

Large-scale infrastructuring processes like Akson is challenging to conduct, and the pitfalls for failing are many, hence it is useful to look to other similar processes in Norwegian healthcare to reduce the number of challenges along the way. Two of the most important areas to focus on is how to govern the digitalization platform at different healthcare levels and how to reuse healthcare information within and across healthcare institutions.

The national work with archetype standards – complex standards demands for complex governance

Standardization in healthcare has often proven difficult to accomplish because structuring of the EHR content often translates into the need for standardization of clinical practices. This calls for flexible standards that comply to multiple requirements [2]. In this regard the openEHR platform seems promising as it includes different purposes like interoperability, clinical content and patient pathways. This is an important difference from traditional proprietary systems where information models are integrated and controlled by the vendor. The archetype standards in the EHR system can be conceptualized as 'interoperability standards', which support sharing and reuse of information within and between EPR systems in different organizations, heterogeneous users, and different stakeholders [2]. Accordingly, the openEHR clinical information models are designed as 'meta-standards' independent of use context, which make it possible to support clinical work processes as well as reuse of data for 'secondary' purposes.

The openEHR's archetypes are clinical information models defined as maximum dataset standards which represent a description of all information a clinician might need, its sub-elements, and a technical well-defined data model [3]. For example, a blood pressure archetype represents a description of all the information a clinician needs regarding this concept. For instance, diastolic and systolic, cuff size, 24-hour BP etc. National archetypes in Norway are designed in accordance with the design principles from the openEHR community [16]. They are published both nationally and internationally so that they can be reused across different openEHR conformant EPR systems. Establishing the national archetype governance and agreeing on the modelling of the archetype standards was a complex process due to several reasons: 1) The openEHR approach is supposed to put that healthcare personnel in 'the driver's seat' of the standardization processes [3], and the extended use-contexts of the archetypes call for governance routines to ensure that interoperability is obtained across different organizations and user-needs. One representative from the regional archetype project stated “semantics of clinical concepts is very difficult to deal with it. You actually need to have health professionals with clinical expertise to be able to get good answers”. Hence including enough semantics to the standards was challenging and demanded for including clinicians in the work with evaluating and quality approving the standards. 2) The standards demand for both technical and clinical competence as well as extensive knowledge on the openEHR architecture, hence a group of expert users had to be trained. 3) It was complex to decide on modelling of the standards; should they be generic to fit as many clinical requirements and be as interoperable as possible, and at the same time become large and complex? Or rather be simpler and more specific, to fit detailed requirements in EHR systems and local settings, and compromise on the interoperability. 4) Establishing regional and national archetype governance organization was a time-consuming process. The national archetype governance was established in 2014 and they used more than a year to publish the first archetype. First, they had to recruit regional resources to work in the national governance, educate expert users, define modelling patterns for the standards, and establish a collaboration with the international openEHR organization. They also had to define a quality assurance process, and recruit clinicians to participate in validating the standards. A regional archetype governance organizations were challenging to establish, however it was crucial to increase the regional competence on archetypes both for the Health Authorities that made decisions, as well as for the healthcare personnel, and governance personnel that should work with and maintain the standards.

The regional work with combining EHR and registry data – the challenge of reusing data for different purposes

When connecting different systems, it is important to consider how to make data reuse possible. Today, the documentation of treatment and care in the EHR is mainly free-text descriptions recorded retrospectively. This influences the present way of exchanging data for secondary purposes like reporting to a national quality registry. Today the surgeons look up relevant information from different journal documents in the EHR and fill out a paper- based form. Then a nurse or secretary fill the information into, a web-based registry portal [17]. In November 2018, a collaboration between the North Norwegian Health region, and the National spine registry (NORSpine) was established. The aim was to design an electronic form to implement in the EHR system, to enable automatically exchange of clinical data within the EHR, and from the EHR to the registry. This would generate a more efficient process of registering and exchanging data with less double registration and risk of data errors [4].

Structuring the NORspine form was the first time a health region in Norway tried to structure clinical EHR information themselves, with the aim of reusing information for a secondary purpose. The aim was to establish a national standard for how to conduct such process. However, reuse of data is complex and challenging. Some examples of this relates to the following: 1) Reuse of data demands for information models that provides metadata to ensure that the right variable is reused at the right place. Including context makes it possible to identify where the information comes from and how the information was used. For instance, a patient may have had two different surgeries in the same submission period, then it is important that the values reused for the spine surgery form is the ones actually coming from the spine surgery. 2) Reuse of information from primary to secondary purpose addresses the need for different granulation levels of the archetypes. For example, the variable ‘other endocrine diseases’ used in the register form, covers all kind of endocrine diseases, except from diabetes. However, in clinical practice, ‘other endocrine diseases’ is too generic to use when documenting treatment and care. The different granulation levels complicate the potential for automatically reusing information about endocrine diseases into the registry form since all possible endocrine diseases must be mapped to the variable “other endocrine diseases in the registry form, which is complex to do. 3) Using and reusing archetypes demands for an extensive archetype governance organization at a regional level that can make decisions like when to use national and when to use regional system specific archetypes. It is recommended to use national approved archetypes to ensure semantic interoperability of clinical information. National approved archetypes are complex standards that demand for extensive adjustments when using them, to comply with specific contextual requirements, e.g., the registry form. Using local archetypes is less complex since they are often designed to fit specific requirements of the EHR system. These standards designed for specific purposes are not very reusable for different settings.

The governance organization also needs to have control over archetypes, templates and forms implemented in the EHR, and the queries dependencies and calculations within and between the variables, accompanying an overview of where they are used both within the EHR and for secondary purposes. Such overview is important since changing an archetype or a query has consequences wherever it is used, both in forms and in the clinical documentation process in the EHR. The same change needs to be conducted everywhere the standard is used to ensure further interoperability.

Discussion

From the cases described, we like to present lessons learned with importance for the Akson digitalization platform. The first relates to organizing and governing the platform at different levels of the healthcare organizations. In order to alleviate some of the challenges related to having each individual municipality govern their local HIT, Akson intends to centralize the process of procurement, management and governance. Ideally, centralization of these processes can provide municipalities with more impact in relations with vendors, as the collective negotiation power can give more leverage. This is important, as their ability to receive support, upgrades and implementation of system changes previously has been low. However, this benefit is dependent on high degree of support and adaptation of Akson amongst the municipalities, and the degree of endorsement Akson will receive. It is challenging to get more than 200 municipalities to connect to the digitalization platform, especially the GPs since the Norwegian medical association has been sceptical to Akson. Also, with an ecosystem of different vendors with a set of common standards for interoperability the digitalization platform will have to solve severe governance issues to obtain the semantics of information.

The governance of archetypes was difficult to obtain on a national level. Establishing local governance organizations and prioritize time and resources to participate in the consensus and organizational national work was even more challenging. There is a risk that Akson will experience some of the same challenge. The municipalities are very different in size, from Utsira with 198 inhabitants to Oslo with 1019513. This means that their capacity to participate in a national governance varies extensively. That generates a risk that the larges municipalities will be the ones contributing most and making most of the decisions. Another important dilemma will be how to make decisions in such an infrastructure. In Akson potentially 291 municipalities will be included in the platform, including nursing homes, GPs, public health nurses, physical therapists, emergency rooms and so on with different interests. How many of the municipalities have to agree for a decision to be valid? Is it even possible for 291 municipalities with different interest both within and amongst them to agree on national standards? Based on this it becomes important to take time to define common standards for the national governance of such a platform, including how to organize it to make sure that all the municipalities and different instances feel included and part of the decision process, without making it too complex to handle.

In Norwegian healthcare there has been no requirements for how the information models for such systems should be designed or how to exchange information between them. Hence, there are numerous standards and limited interoperability. The Akson digitalization platform needs to be a mapping device for a number of systems with different information models. Exchanging information through the platform demands for the use of an interoperability standard that all the different information models are mapped to. Lessons learned is that it takes time and effort to establish generic standards to fit rich semantic standards as for instance the archetype standard, and. there is a need for biomedical terminologies for the exchanging and reuse of data to be understandable.

The Norwegian directorate for e-health has defined HL7 FHIR as the national standard for exchanging healthcare data. The national work with FHIR standards has just started. This demands for establishing national HL7 FHIR profiles that for instance mirror the content of an openEHR archetype as well as a national and regional governance organization to face similar tasks and challenges described for the work with archetypes and structured forms addressed in our previous work illustrated as examples in this paper. In the North Norwegian health region, they have worked with establishing FHIR standards for vital information like blood pressure, weight, respiration to be exchanged between systems. Learning from the work with archetypes it is important to free up time and money for clinicians to participate in such quality work, in the archetype work after 2 years they had not been able to include clinicians from all medical specialties in Norway. Once you get to the actual clinical information, the information developers struggle. They depend on the clinicians to be able to make information models suitable for high quality semantic interoperability in healthcare.

Conclusion

Summarizing the findings:

1) It is important to establish governance organizations at different healthcare levels. It takes time and effort to establish generic standards to fit the semantic richness of healthcare processes. Involving clinicians in the work demands for healthcare organizations and health trusts to free up their time to do so. In the archetype work they had to participate in their free time in addition to full time work, this is demanding even for those interesting in participating.

2) In the design of Akson two important lessons can be learned from this work. The first that reuse of data is more complex than expected. The Akson digitalization platform will consist of several different systems with different information models. It is important both to ensure that the right data is reused, and that the data is reused at a suitable granulation level for the purpose it is used. Exchanging data for such a platform will demand the use of an exchange standard that all the different systems can connect to.

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Address for correspondence

Gro-Hilde Severinsen

Preferred method of contact: Gro-Hilde Severinsen@ehealthresearch.no