Building a Learning Healthcare System in North Norway

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Abstract

The Learning Healthcare System paradigm promises fast progression of knowledge extracted from health data into clinical practice for improving health for populations, personalizing care and minimizing costs (the Triple Aim). It is, however, less clear how these ideas should be adopted to address the challenges of healthcare worldwide. While challenges are global, the healthcare systems and their organization are highly country-dependent, thus requiring a customized development approach and tailored impact measures. This paper sketches high-level ideas of demonstrating the potential benefits of the learning healthcare in North Norway. The implementation serves as a pilot project for measuring the impact of the paradigm on healthcare delivery, patient outcome and estimating the consumption of resources for a large-scale (national) deployment.

Keywords: fragmented care, triple aim, data reuse, patient experience

Introduction

Observing the increasing pace of innovation in technology, industry and research, one may wonder, why and how healthcare remains so inertic and resistant to changes. Reports suggests a 17 years long timespan for implementing positive research results into clinical practice [1,2]. It is a surprisingly long time to take advantage of scientifically proven practices and interventions for improving patient care. Many changes are likely to occur during this time, which may affect the methods under adoption, minimize or even void the need of them in a rapidly changing context. Such considerations triggered a series of workshops organized by the Institute of Medicine (IOM) on reengineering the delivery of healthcare services to make them more efficient, adaptable and agile.

The Learning Healthcare System (LHS) concept was one of the formal products defined in the workshops to address the challenges in the current healthcare delivery [3]. The proposed paradigm describes processes within healthcare as a continuous cycle of clinical practice generating data for condensing and extracting knowledge, which, with minimal delays, are fed back to healthcare services to produce new data (Figure 1). The iterations of the cycle enable the healthcare to react rapidly to new knowledge, increase the adaptability to individual

needs and establish more accurate quality assurance procedures.

The promises of the LHS map well into the items of the triple aim for healthcare: "improving the individual experience of care; improving the health of populations; and reducing the per capita costs of care for populations" [4]. However, it is not clear how all three interdependent characteristics could be improved without compromising any of them. For instance, it may be easy to improve care and patient experience by investing in technology and human resources on the service provider side. However, managing costs in this scenario depends on the increased efficiency caused by the acquisitions. Finding an appropriate balance is not always possible.

The LHS concept has already been interpreted in several different ways aiming to achieve adaptable, patient centered and preventive healthcare services worldwide. The different approaches to the LHS often occur while deciding upon what data should be included (Figure 1). In a straightforward translation, data are referred to as information accumulated in the electronic health records (EHRs), reflecting the clinical side of patient health and treatment strategies. Regardless of the selected data collection and processing approach (centralized [5] or distributed [6]) it provides an information rich representation of "patient data shadow" [7].
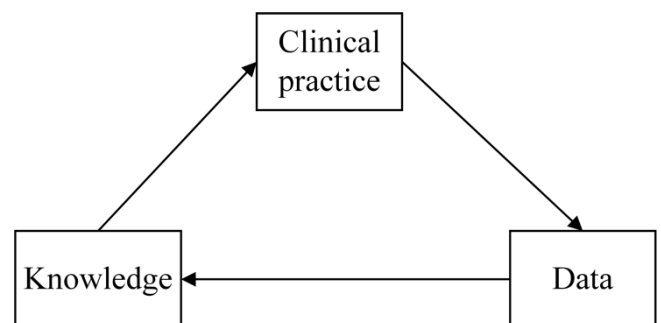

Figure 1- LHS cycle

Another approach to data within LHS is patient reported goals, outcomes and experiences. Such information provides an alternative view to the patient health and gives feedback on healthcare interventions [8]. It also helps identifying the gap between the medical and patient perspectives to health out-

comes, which is often overlooked by the current healthcare services [9].

This paper presents a vision to adopt the LHS practices in Norwegian healthcare context and demonstrate its feasibility and potential benefits in North Norway.

Materials and Methods

To demonstrate the potential of the LHS paradigm within the Norwegian healthcare system an infrastructure visualizing the different perspectives of health will be developed. It contrasts three representations of patient/population health status defined by:

1. Health data documented in EHRs across service providers (holistic view of treatment)
2. Patient reported health outcomes (patient profiles)
3. Clinical guidelines (Figure 2)

Health data

The fragmentation of healthcare data is one of the challenges in the project. It will be tackled through the Model, Extract, Transform and Load (METL) methodology for clinical data reuse [10]. The Model will be constructed from the archetypes defined in the Norwegian Clinical Knowledge Manager (CKM) in coordination with the openEHR international CKM. Extraction will be performed using distributed data processing and aggregation infrastructure provided by the SNOW project [11] enhanced by the techniques for privacy preserving computations [12]. SNOW platform is earning its momentum in Norway for health data extraction. It is already deployed at several healthcare institutions (general practices, microbiology laboratories) throughout Norway and expanding.

Transformation techniques will be applied to make the extracted data compliant with the archetypes defined in the Model stage [13]. The transformed data will be loaded into an openEHR database that facilitates queries in the Archetype Query Language (AQL) [14]. These queries are executed over the archetypes and detach data from the original proprietary schemas. Information retrieved through AQL will be afterwards merged with the patient reported outcomes.

Patient outcomes

The available reference models and ontologies will be considered to determine the most appropriate structure for patient profiles. The usability of visualized and tailored parameters will be evaluated by the healthcare professionals from primary, secondary and homecare to maximize their knowledge about a certain case.

Patient perspectives will be collected through manual feedback mechanisms adapted to the medical condition. Patterns and trends discovered by the visualization tool will be qualitatively evaluated by the stakeholders before they are made available to the healthcare professionals outside the project. A quantitative evaluation will follow every iteration of the LHS (Figure 1) to assess the impact of the paradigm on patient outcomes and health services delivery. Results will form estimates for adoption of the LHS in a national scale.

Clinical guidelines

Computerized clinical guidelines will represent a formal perspective of the treatment. Applicable guidelines will be visualized together with health data and patient outcomes (Figure 2).
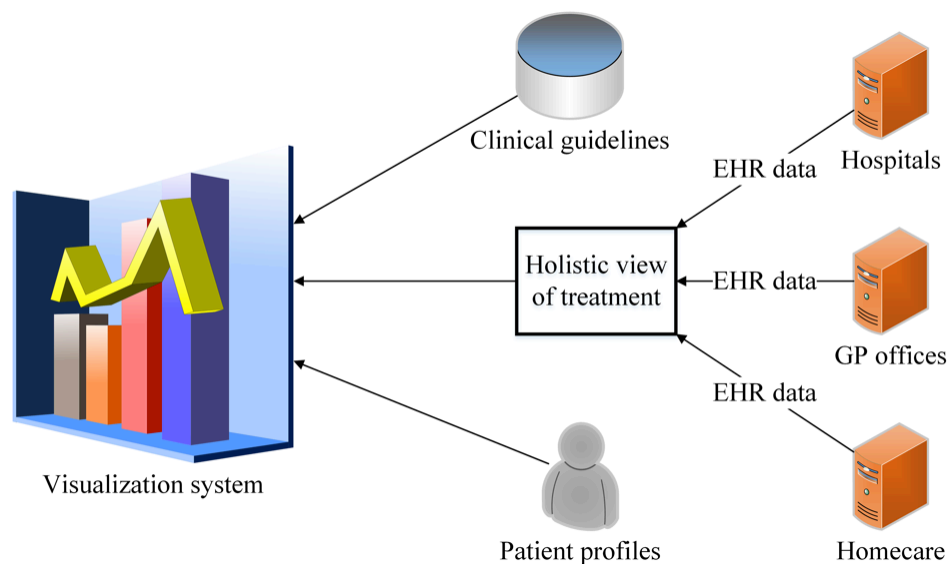

Figure 2- Data sources

Results

This paper demonstrates an interpretation of IOM's ideas on transforming the healthcare services into patient-centered and adaptable LHS. We aim to develop a tool for healthcare professionals enabling them to observe a holistic view of patient treatment for better coordination of care. Instead of introducing changes to healthcare delivery top-to-bottom, an opposite approach of healthcare specialists triggering changes based on provided information is prioritized.

While keeping the transition between clinical practice, data and knowledge (Figure 1) in mind, major attention is paid to data collection, making sure the fragmented patient information is as complete as possible. Such information is often distributed among service providers within the healthcare system. If we take a complex elderly patient, having multiple long-term conditions as an example, he/she is likely to be continuously treated by GP, hospital doctors and homecare (Figure 2). Data sharing between these service providers is often limited to discharge letters, summarizing the intervention. However, a complete overview of care the patient is receiving is not available at any institution.

To create a comprehensive representation of clinical patient care, three data sources are linked into a holistic view of the treatment (Figure 2). Properly visualized this view alone could potentially contribute to better care coordination between the providers by delivering a detailed insight into patient pathway, treatment history throughout the evolving long-term condition.

In addition to the clinical representation of health, patient-reported health profiles are established and continuously updated by the patients themselves. They reveal how clinical treatment corresponds to the health-related goals and expectations. These two perspectives of health (clinical and patient-reported), supplemented by the applicable clinical guidelines are visualized and contrasted, providing healthcare professionals with a comprehensive view of care process. Such representation is a starting point for finding a compromise between the three perspectives to tailor the care plans according to the expectations of the patient (Figure 3). The complexity of such visualization in real life may limit its usability, the number of dimensions describing health status of a complex patient over time may become difficult to administer. A balance between too simplistic (missing important indicators of healthcare status changes) and too complex (hindering the usability) needs to be found.

Clinical guidelines represent control measures in the visualization with regards to the provided (holistic view of treatment) and perceived (patient profiles) care (Figure 3). They define standard path for a patient profile and enables deviation detection. From patient point of view they work as control mechanisms ensuring the compliance of the delivered treatment and recommendations, while from a society scale, they reveal population specific trends.
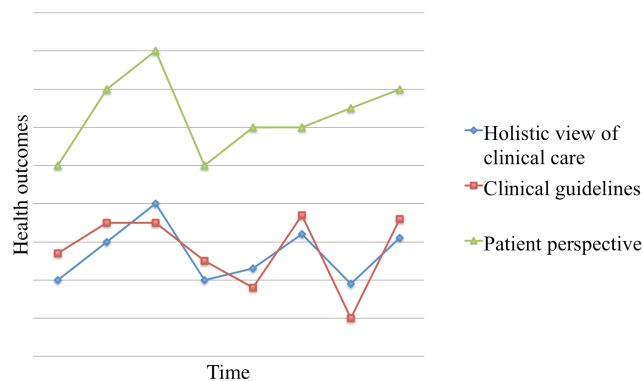

Figure 3- Simplistic visualization of health perspectives

Discussion

Minimizing the fragmentation of healthcare services is a hot research topic worldwide. It is defined as a major research and development direction by the Norwegian government in a long-term strategy for healthcare "one citizen – one electronic health record" (norw. "En innbygger – en journal") [16]. This initiative addresses numerous challenges related to insufficiency of the current IT infrastructure to support seamless data sharing between healthcare services in a national scale, patient inclusion into clinical decision making process, increasing the development of e-health technologies and establishing quality assurance procedures [17].

The LHS paradigm aligns well with the aforementioned strategies. It is, however, less clear how the aims of the discussed initiatives could be reached. An optimal recipe does not seem to exist and much research is required to define it. Looking at the future, additional challenges regarding the compatibility of national LHS instances in an international context are likely to occur. However, it may be too early to speak about international scale, considering that reports on much smaller LHS are only appearing in the literature and their impact on healthcare service delivery and patient outcome is still explored in a limited manner.

A national LHS is a big goal from both technological and social perspectives. It will take time and effort until such system is in place. It involves numerous decisions in selecting sufficient technologies to support the evolving LHS. The initiative to demonstrate the capabilities and impact of the paradigm in North Norway contributes to the overall understanding of how LHS ideas could be implemented in practice and how they are perceived by the healthcare professionals. It serves as a demonstrator project evaluating the impact of adopting LHS paradigm in a national scale and providing initial estimates on the required resources.

From a pragmatic perspective, Norwegian healthcare provides an advanced context for adopting the LHS. Many bits of the system are already in place: the coverage and active use of EHRs exceeded 90% of healthcare service providers in 2010 [16], making the majority of health data available in electronic form. Automated clinical guidelines and their impact on the process of care has already been investigated in numerous research initiatives that demonstrate positive achievements [18,19]. Comprehensive patient profiles for collecting patient

reported measures have so far been researched in a limited manner, making them the least explored part of the proposed LHS.

Evaluation of impact on healthcare services delivery, patient outcome and experience is a complex matter, raising philosophical questions. How can a perfect care be defined? Is it adherence to clinical guidelines? Improved vital signals? Or a satisfied patient? These three goals are sometimes located in different planes and cannot be maximized at the same time, complicating the impact measures. Considering that healthcare is supposed to serve the patient, self-reported measures could be fundamental for assessing the impact of the LHS.

Threats to success

Operationalizing the ideas of the LHS is not only a technological but also an organizational challenge. It requires a wide scale deployment of data processing infrastructure across the providers of healthcare services to achieve its goals. Limiting the scope to North Norway isolates the deployment in a single health region, however still remains challenging due to the organization of the providers. For instance, GP offices function as private entities, coordinating technology-related decisions, such as selection of EHR platforms, themselves. Despite the technological incompatibilities, organizational barriers need to be crossed to recruit the offices into the research activities. The payback for the GP is often insufficient for attracting their attention and, therefore, is slowing down the deployment.

Recruiting patients with complex conditions is another challenge. Elderly individuals circling in health services are the targets for demonstrating the validity of the LHS concept. Their input shapes the self-reported perspective of health – one of the data sources of the LHS. Technological literacy may become a bottleneck in this patient group, limiting the collection of data. Long-lasting inclusion in the LHS may also become challenging if direct payback for the patient is not visible.

Conclusion

It is not easy to estimate the impact of making the healthcare services fully aware of the interventions they are providing with regards to the clinical guidelines and patient perspective. However, it is an incentive to trigger changes in service delivery and learning from practice in a more rapid manner than it is done now. Moreover, it is also an attempt to personalize healthcare services paying more attention to the preferences and goals of the patients.

The LHS is an iterative process; its impact is not easy to measure. This paper presented high-level plans for establishing a LHS demonstrator in North Norway to estimate the adoption of the paradigm in a national scale.

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