

Holistic understanding of digital transformation of health care system as a point-of-departure for system requirements specification

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Abstract

The challenges regarding harmonised interoperable e-health services are enormous due to the complexity of the domain, comparatively high demands of privacy and security, implications of storing, sharing, and managing health data as well as unclear definitions and standards for patient's electronic health records. Therefore, the advantages of digitalisation are yet to reach the end user-patient, especially in the emergent regions where digital infrastructure is limited. The focus is on the north and northeast regions of Brazil, where a holistic understanding of the requirements for a digital transformation of the health care system is explored through the lens of an expert panel using a Delphi methodology, complemented by a comparison with related innovations in the digital health domain.

Keywords

Digital transformation, health care, system requirements, patient centrality

1. Introduction

For the healthcare domain, the complexity of the digital transformation process is high due to the high sensitivity of the health data and the privacy and security reservations concerning the domain [1]. Digital transformation of health units, including the processes

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for managing personal electronic medical records of the patient, can become an essential enabler for the efficient and effective provision of public health service. However, challenges are encountered in every step of the process of digital transformation due to the complexity and fragmentation of the legal, technical, semantic, and business demand and supply, which, oftentimes, are constrained by the policies and practices of the healthcare domain [1, 2]. The gap is growing constantly as contemporary literature pinpoints. The impact is even higher in emerging and rural regions, where the resources, funds and health service infrastructure are limited. While the typical digital platform solutions available today are also not created from a human-centred patient perspective [3], it is essential to understand the prerequisites for eHealth, prior to instrumenting solutions, through the lenses of answers to questions such as “what is required to make a patient’s journey more effortless and efficient”, “how a patient take a more active role in managing their healthcare”, “how can a patient mitigate treatment risks and lower his/her anxiety about illnesses and diseases”, and “how can the access to healthcare and interaction with healthcare professionals be improved”.

The project Electronic Identity-Enabled Standardized and Harmonized Health Record Management (eSHARE) therefore tries to understand the demands of the complex context of digital transformation of the health system through a feasibility pre-study [4]. Firstly, it aims to understand the context and local practices to elicit the requirements and obligations for patient-centricity, i.e. letting the experiences and contextual know-how of patients serve as the backbone for system design (cf. [3]), followed by an analysis of the impact that a patient-centric approach preserving privacy and security of patient data has on digital identification in the local healthcare delivery system and a harmonised standardised health records management. This paper presents the steps taken towards forming a minimum set of requirements for an electronic health record management system, based on the legal and ethical contexts together with national, regional, sectorial, and municipal healthcare regulations and policies. The selected emerging region in this work is the north and north-east regions of Brazil, where the technology infrastructure, the basic needs of the patients and the literacy levels of the citizens differ widely compared to the other regions of the country [5].

2. Study context

Brazil’s Unified Health System (Sistema Único de Saúde - SUS) is mandated to provide equal health services to all citizens, although regional finances and availability of professionals have created a huge gap in the quality-of-care provisioning across different states. The digital health strategy of Brazil predominantly aims at levelling up and leveraging efficient and effective care provision. However, the digital solutions provided by the federal government in support of the implementation are being pertained in diverse ways, due to the federal government structure. In addition to the national digital health strategy, which is the governing framework of digital transformation in the sector, operational strategies for implementation and uptake at the municipal level are needed. Such local strategies promote operational efficiency and effectiveness of the health service, transparency, inclusion, and patient mobility aiming for an increase in patient satisfaction, and patient

meetings, fostering preventive health initiatives while attracting qualified healthcare professionals [6].

Despite improvements in the healthcare infrastructure, a great gap in the dissemination of care facilities between rural and urban areas still exists [7]. Among other disparities, the distribution of care units, the number of healthcare professionals, the provision of medicine and special treatments including special care, as well as the technology maturity and literacy among users are a few to mention. There is also a heterogeneous application of digital tools in the current SUS, including an electronic health record system introduced by the federal government [7]. Therefore, it is essential to understand the current landscape and the services prior to proposing digital solutions for municipal healthcare services [3].

3. Method

As described in the preceding section, an exploratory case study strategy is pursued to understand the prerequisites for requirements elicitation within the context. The case itself premises the features of an emerging region, where its current landscape of health service, legal and strategic demands play a pivotal role in discerning and outlining the essential prerequisites crucial for executing a successful digital health transformation. It intends to function as a guiding baseline, systematically identifying the specific needs, technological aspects, infrastructural demands, and potential challenges unique to the region, thereby paving the way for an effective implementation strategy tailored to its distinctive context.

3.1. The context and unit of analysis

General aspects characterising the territorial context of Brazilian healthcare were explored before setting up the empirical approach within specific regions in the north and northeast (states of Maranhão and Para). While responsibilities are governed centrally by the federal government, some are by the region (State), and the main operational unit is by the municipality [8]. Therefore, the unit of analysis in this study is a municipality in the selected region. Maranhão is divided into 217 municipalities and Para in 144 municipalities, but it is larger and more populous. The eSHARE project works with a consortium of 26 municipalities (CIM) from both states, collaborating on addressing common issues affecting their region.

Basic Health Units (Unidades Básicas de Saúde – UBS) form the foundation of primary care, which provides preventive care, vaccinations, basic treatments, and health promotion services to their communities. Each municipality typically has several UBS scattered across its territory. An example is Family Care, which assigns multidisciplinary teams, such as community health agents (ACS) and other professionals, to specific neighbourhoods, villages, or regions, to provide more comprehensive and continuous care. Municipalities may also specialise in outpatient clinics or centres for specific services, such as mental health support, physical therapy, and other treatments. The hospitals and emergency care units are typically located in the largest municipalities in the region (Unidades de Pronto Atendimento - UPA), which manage more complex cases and emergencies. Each municipality has a Health Secretariat responsible for overseeing and coordinating health policies, it manages budget allocation, resource distribution, and implementation of

initiatives within its jurisdiction. The operational framework of the health sector within the municipalities is oriented, by design, towards ensuring universal access to healthcare services. Therefore, the requirement elicitation processes in this study are part of a focus on the electronic health record (EHR) for primary and secondary care.

Four stakeholder groups were identified to systematically capture the current landscape of healthcare provisions: patients (who require continuous visits for health service); healthcare professionals, such as doctors, nurses, and support staff in healthcare units; leadership in municipalities (head of healthcare) and heads of information technology from the municipalities in the selected regions. Patients were not directly included in the respondent group, due to heterogeneity of their knowledge level in the area, which might have led to difficulties in comprehension and a lack of awareness of patient rights in the context of digital transformation. However, representatives from one patient organisation were included.

3.2. Application of method

A multi-method approach to engage expert groups consisting of health care professionals active in the context of the case was adopted, complemented by a comparative study against previously identified requirements for the health care domain. Similarly, Ref. [9] used a questionnaire as their primary method in addition to document analysis, system analysis, interviews, and observation as qualitative multimethod approaches to study healthcare record records management in a study conducted in South Africa. The approach involved two stages. Stage one included discussion sessions conducted with health research experts, healthcare professionals (HCP), and the eSHARE project partners, to understand the current situation and problems affecting the provision of healthcare services. The results of these discussions were captured using a MIRO board as shown subsequently. Stage two focused on prioritised requirements, selected by comparing the results from the discussion session against literature and previously identified requirements, especially the Australian platform “My Health Record Australia” [10] which is promoted as a world benchmark for good practice in EHR systems.

3.3. Expert group discussions

The methodological base for the expert group discussions followed a Delphi approach, [7]. The panel took place several times with four respondents and one discussant. Iterative meetings allowed respondents more opportunities to gather the perspectives of patients, HCPs, and system/technology administrators about the situation of the current healthcare system and pinpoint their needs and demands for implementing an EHR system. Privacy-related requirements were elicited based on the privacy taxonomy [11] and privacy by design [12], ethical concerns-driven requirements [13], and security-related requirements [14].

3.4. Ethical aspects

The healthcare domain resides in one of the most sensitive data in public service where utmost care should be taken when collecting and managing information of patients. We

have not measured or taken any sensitive or personal data from any participants involved in data collection. This article addresses ethical concerns outlined in [10], from data collection to publication. For instance, informed consent was obtained from participants before data collection. We informed participants about anonymity and the study's purpose. Consequently, all participant data collected for this research is fully anonymised.

4. Results and discussion

4.1. Discussion sessions

Expert discussions provided a holistic perspective on the needs related to the EHR systems, pointing out varying levels of requirements granularity. The discussion sessions were held in an informal setting and three rounds until no new knowledge appeared. The collaboration with expert panels was facilitated by the MIRO platform [15], explicating the distinct perspectives on the requirements of patients, doctors, and, to a lesser extent, IT administrators (see Fig. 1, accessible through [16]).

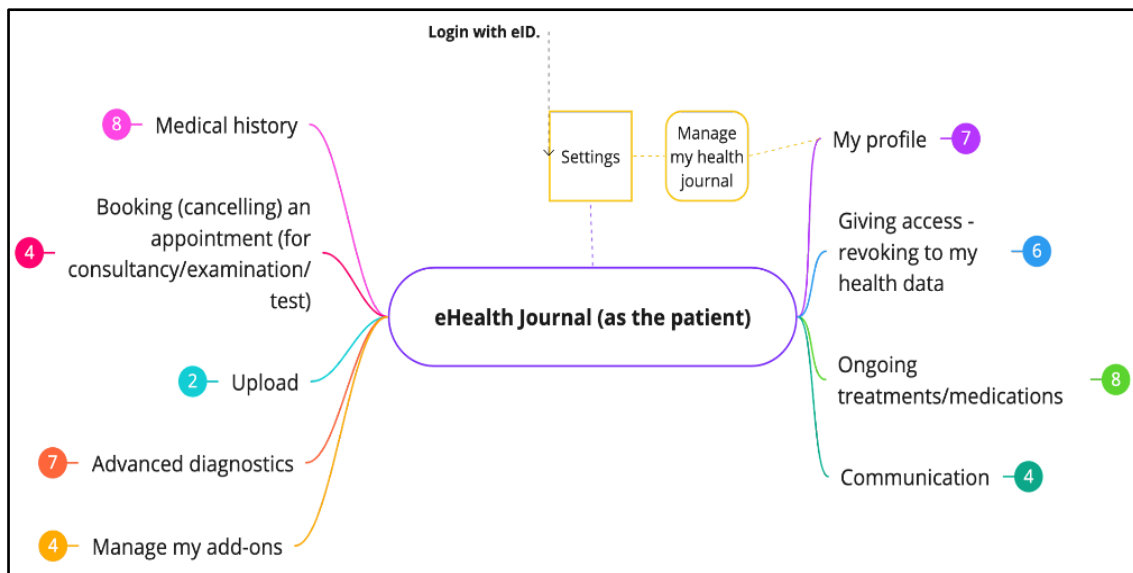


Figure 1: High-level requirement set collected in expert discussions.

4.2. Comparing with literature

Ermakova et al. [17] were used as a basis to enrich security requirements, and [14] and [13] for privacy requirements. Hence, the principle of privacy by design has been integrated as a foundational element of a patient-centric EHR system and a necessity to comply with stringent data protection regulations affecting the digital healthcare landscape. Ethical standards and compliance with existing personal data protection laws are expected as a default practice by users. The “Privacy by Default” aspect is added since it adds an extra layer of pressure for the solution designers with a legal binding to put data safety in the first place while creating the system [14]. It is also advised that the default settings for the use of cookies should only encompass consent elements deemed essential, rendering any opt-

out consent options invalid. Additionally, the system must guarantee that personal information is accessible solely to authorised individuals. Requirements were matched and proposed in Table 1. Note that only the EHR System requirements are presented here.

Table 1
Requirements for EHR Journal compliant with security and privacy

Macro Area	Requirements over Data and Information (Security)	Requirements EHR (Journal)
Data Confidentiality	<ul style="list-style-type: none"> Confidentiality Anonymity 	<ul style="list-style-type: none"> Secure authentication via trusted electronic ID (eID)
Access Control	<ul style="list-style-type: none"> Control of access rights Revocation of access rights Fine-grained access control (i.e. use of data that is only necessary and permitted) Access to patient data in emergencies Unlinkability (i.e. medical actions and identities are hidden from unauthorized users) 	<ul style="list-style-type: none"> Enable patients to set access control (revoke, grant, deny, etc.) of their health records after reviewing and accepting access policy rights Enable doctors to write, edit, and update the medical records of their patients only if they are granted access to Enable patients to decide which healthcare provider organization can view or update their health record or documents Enable healthcare workers to supersede restrictions to access to documents in case of emergency (e.g. accepting policy regarding the protection of patient privacy)
Data Ownership & Integrity (Ownership)	<ul style="list-style-type: none"> Ownership of medical data Integrity of patients' personal information 	<ul style="list-style-type: none"> Patients can mark some health record as personal/sensitive (optional) Default access to patients' records is only accessible for registered healthcare provider organizations
Security & Compliance (Actions on data)	<ul style="list-style-type: none"> Detection and prevention of security violations Non-repudiation Authenticity and authentication Auditability 	<ul style="list-style-type: none"> Notify patients when their health records or documents are viewed, updated, created, removed or reinstated Notify patients when the emergency access function is invoked by healthcare providers Notify patients when their primary doctor/healthcare provider is changed
Data Availability & Management (Storage)	<ul style="list-style-type: none"> Archiving should be facilitated. Fault tolerance Provide non-stale or up-to-date data Storage should last for many years 	<ul style="list-style-type: none"> Log health record access for transparency and accountability. Enable patients' to limit sharing time of documents via short-time access code (e.g. healthcare provider must be supplied with the code to access to documents for the ongoing medication) The system shall activate the eID authentication when healthcare provider demands access to restricted documents.

		<ul style="list-style-type: none"> Allows access emergency functions (e.g. policy should include conditions for allowing access documents/information)
System Performance (System)	<ul style="list-style-type: none"> Scalability Usability Efficiency 	<ul style="list-style-type: none"> Should allow add-ons integration for patients' management (e.g. connecting with other health apps and importing/exporting data; manage subscriptions for integrating care) Should facilitate communication between - Patient to doctor (1-1); Patients to health forums (1-many); share news for patients (1-many); direct messaging (e.g. legal compliance)

5. Concluding remarks and further work

This paper instrumented an approach to understanding in a holistic perspective of a digital transformation of primary and secondary health care systems from a patient-centric perspective. A preliminary requirement list was aggregated through discussion sessions with experts and triangulated by desk research with the intention to be further trimmed down through the lenses of healthcare stakeholders, commenting on the challenges of day-to-day operations. It is evident that from the two exercises reported on in this paper alone, the resulting requirement set remains too broad to tackle the development of a minimum viable solution. Hence, we proceeded to distil these requirements into targeted use cases from primary and secondary care as a crucial step to identify core functionalities that directly address the more critical needs in the health care system.

The set of use cases can be used to elaborate the requirement set for each case and lay the ground for a patient-centric minimum viable solution for an electronic journal system in the context of northern Brazil. Further work includes stipulating a tangible minimum requirement set, identified through a series of participatory workshops using concrete patient use cases as a backdrop for revealing the necessary information flow between the actors involved in regular health care visits.

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