

My Care Pathways – Creating Open Innovation in Healthcare

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Abstract

In this paper we describe initial results from the Swedish innovation project "My Care Pathways" which envisions enabling citizens to track their own health by providing them with online access to their historical, current and prospective future events. We describe an information infrastructure and its base services as well as the use of this solution as an open source platform for open innovation in healthcare. This will facilitate the development of end-user e-services for citizens. We have technically enabled the information infrastructure in close collaboration with decision makers in three Swedish health care regions, and system vendors as well as with National eHealth projects. Close collaboration between heterogeneous actors made implementation in real practice possible. However, a number of challenges, mainly related to legal and business issues, persist when implementing our results. Future work should therefore target the development of business models for sustainable provision of end-user e-services in a public health care system such as the Swedish one. Also, a legal analysis of the development of third party provider (non-healthcare based) personal health data e-services should be done.

Keywords:

Consumer informatics, information infrastructure, eHealth, Patient empowerment, Personal health informatics.

Introduction

Patient-centered or citizen-centered care describes a shift from organization to patient-centric provision of healthcare as this will strengthen the role of patients and family caregivers. Today a growing number of patients are no longer content to be passive recipients of care. They want shared decision making, active participation in healthcare processes, and access to their own health data. These patients and citizens are increasingly requesting access to and control over their health information.

For example, online access to their electronic health records (EHRs) or taking active control of their own healthcare needs through increased health and wellness activities, self-monitoring of health-related issues, and active use of Internet-based education and support groups. eHealth is often suggested as having the potential to revolutionize the way health care and prevention is provided, shifting the power and responsibility from healthcare professionals to patients and citizens.

However, healthcare organizations are having a difficult time in keeping up with this development, and current health information systems such as electronic health records (EHRs) are not designed to meet these new demands. To support healthcare organizations, the United States National eHealth Collaborative recently released a Patient Engagement Framework to guide them in developing and strengthening their patient engagement strategies through the use of eHealth tools and resources. The framework identifies 5 stages to patient engagement (1) inform me, (2) engage me, (3) empower me, (4) partner with me, and (5) support my e-community [1].

Within the field of eHealth and personal health informatics focus is on patients' information systems. The Personal Health Record (PHR) has therefore been recognized as a central concept of these systems. In 2005, the International Standardization Organization (ISO) defined the key features of the PHR to be that "it is under the control of the subject of care and that the information it contains is at least partly entered by the subject (consumer, patient)" [2]. Many different forms of PHRs can be used with different levels of integration with clinical health records: "(a) a self-contained electronic health record (EHR), maintained and controlled by the patient/consumer, (b) a self-contained EHR, maintained and controlled by a third party such as a web service provider, (c) a component of an integrated care EHR maintained by a health provider (e.g. general practitioner) and controlled at least partially (i.e. the PHR component as a minimum) by the patient/consumer, or (d) a component of an integrated EHR but maintained and controlled by the patient/consumer" [2]. Examples of different types of PHRs and recent developments in the area are de-

¹ Project leader

² Track leader - research

³ Track leader – care processes

⁴ Track leader – technology/infrastructure

⁵ Track leader – technology/service integration

scribed in [3]. Opinions on whether the PHR should be self-contained or integrated diverge. Many authors, however, found that PHRs are not likely to fully support improvements in patient health outcomes if they are not integrated with EHRs [3–6].

Nevertheless, although some solutions offer ways for information exchange between the PHR and clinical information systems, there is currently no real re-architecting of health care services around the patient [7]. Few solutions have been designed as decision support tools for patients. PHRs therefore mostly represent a snapshot of the provider's EHR without redesign! [8]. In order to provide inter-organizational continuity and safety for citizens with long-term need for care, it is important to provide both involved care providers and receivers with an overview of the entire patient care process, and appropriate and usable support for active collaboration and continuity of care. Information and communication technology (ICT) in the form of health, social, and consumer informatics can be a crucial tool for enabling this shift in focus. This will allow long-term care to be truly citizen-centered rather than organization or provider-centered. However it will require novel and integrated solutions built upon open and secured platforms that give patients control over their health-related information and bridge the gap between clinical and personal health informatics.

Vision

Our vision is to enable citizens to track their health by providing them with online access to historical, current and prospective future events of their personal care pathways. In this context, we define "personal care pathway" as the chain of a patient's past health events in combination with a prospective possible critical path of future events. We further believe that an open platform for eHealth innovation is necessary to enable developers outside the traditional health IT sector to contribute with novel ideas and individualized solutions.

Objectives

To create new mobile citizen e-services that allow patients to follow, own and manage their care process related information. We aim to adapt and further develop the Swedish National platform for citizen e-services and to provide a freely available software development kit (SDK) for developing new e-services based on National health informatics standards. We also aim to describe the challenges that still face health informatics research and practice in achieving our vision.

Materials and Methods

The work presented in this study is performed within the Swedish research project "My Care Pathways" [9].

Project management

The project adheres to the Triple Helix model [10] and is based on a network of partners from academia, industry and public sector. The project is collaboration between three different Swedish healthcare regions, three universities, several industrial partners and three patient organizations. Representatives of each sector (including patient organizations) are part of the project's steering committee. Headed by Stockholm County Council (SCC), responsibility for different parts (i.e. research, care processes, technology/infrastructure, and technology/service integration) is delegated to different track lead-

ers. SCC is also the owner of the project results and promises to make them available at a national level (cf discussion of business model and results).

Socio-technical framework

We applied an information infrastructure socio-technical framework as this is designed to support a range of activities: it is a technology built as a layer on another technology, and integrated with other systems and infrastructures into unlimited networks. Furthermore, it is shared by and open to larger communities of practices including heterogeneous entities such as patients, medical staff, researchers, technological components, organizations, and institutions [11]. It links different human actors and systems together over distances that span a number of activities and objectives. Another difference between isolated health information systems and information infrastructures is that the latter are developed and changed by several independent actors without any explicit coordination [12]. This means that it rapidly changes its features and functionalities over time as opposed to traditional health information systems that have a slower evolutionary curve. The Internet is an example of an information infrastructure. An important aspect of an information infrastructure is that it is built on both social and technical standards, and is developed over a long time.

Design methods

Design of end-user e-services is based on co-production between patients, healthcare, industry and research. In the initial stages of the project, three patient groups are involved in the e-service design; stroke, lung cancer and hip surgery patients. A series of focus group meetings were performed with each patient group for needs and requirements analysis. Two meetings with 4–5 patients in each group were performed as well as initial test sessions with early prototypes.

Technical pre-requisites

The project is based on a secure national service platform with defined service contracts for different data sets that are made available through Application Programming Interfaces (APIs). These data sets are gathered from the current electronic health records (EHRs) used in the three test regions. This integration is a precondition for the availability of the My Care Pathways service and Swedish County Councils have signed an agreement to make their patient related information available. My Care Pathways is built upon several already existing e-infrastructures, that is, local EHR systems, the Swedish National integration platform, the National secure service platform and the Swedish National platform for citizen e-services. Subsequently, available service contracts/interfaces include data about patients' contacts with healthcare, status of electronic requests, contact information of health and social care providers, appointment scheduling and national patient surveys. We added a number of infrastructure e-services as parts of this national platform during the project (hereinafter called *basic services*) and made them publicly available.

An important aim of the project is to enable innovative service design allowing new actors to enter the healthcare market and collaborate with healthcare and patients to develop eHealth services. A Software Developer Kit (SDK) is therefore implemented containing a number of APIs which provide online services for software developers. This allows them to design applications that are interoperable with current health information systems through the platform.

We therefore enable open innovation; that is healthcare providers; patient organizations, entrepreneurs etc. can build their own end-user services in the form of mobile “APPs” by reusing basic services and the SDK.

Results

We will describe the results achieved so far within “My Care Pathways” from different perspectives. Firstly, we will describe the results of our collaborative work with the different patient groups in the form of needs analysis and proposed end-user e-services. We will also give an overview of the technical platform and its basic services that allow the development of new end-user e-services. Finally we will discuss some of the major challenges that need to be solved when developing and implementing these solutions.

Patient needs and proposed end-user e-services

Performing needs and requirements analyses with distinct patient groups aimed to elicit specific requirements for each group but also to be able to generalize information needs and functions that all groups have in common. We identified a number of potential e-services that all patient groups share (Table 1).

Table 1 – Potential e-services and their descriptions

e-Service	Description
My Calendar	A service to keep track of care-related or personal appointments and get reminders about appointments and encounters
My Medicine	A service to keep an overview of the list of earlier and current drug prescriptions, to get information about drugs (e.g. contraindications) and prescriptions (e.g. retrieval date, reminders about renewal) as well as instructions for administration
My Diary	A service to enter personal notes, keep track of the personal health condition (e.g. problems, self-rehab activities, self-monitoring of medical data and life style factors), and to share that data with care givers
My Care Providers	A service to manage contact data about physicians, institutions involved in the care process (e.g. hospital department, rehabilitation clinic), the stroke team, and nurses. Additionally, the service contains dates of stays at different institutions and other measures to compare and choose between different health care providers.
My Health Information	A service providing an overview of the patient's diagnoses, treatments, patient history, and laboratory results in an understandable way.
My Information flows	This service represents an excerpt of the patient record concerning the flow of documents and information between different care givers (e.g. discharge summary).
My Referrals	Sub-service within My Information flows that enables the patient to keep track of referrals between different health care providers
My Aids	A service containing information about the available and technical and cognitive aids
My Rights	A service helping to clarify the patient's rights in terms of care choice and guarantees

We also found that a large part of patients' information needs relates to administrative functions such as being able to track a referral rather than clinical data and being able to access for example the EHR. Most of these functions fall into the first two categories of the Patient Engagement Framework; *inform me*, and *engage me*. The later stages; *empower me* and *partner with me*, were discussed in terms of their support for self-care (e.g. instructions for administering medications or performing rehabilitation exercises), and communication with healthcare professionals (e.g. using images/video to get support during follow-up) and keeping a self-monitoring diary and communicating relevant parts of this with healthcare professionals. The

final stage of the Patient Engagement Framework, *support my e-community*, was not addressed by the participants in our focus groups. We hypothesize that progression in the framework may be an incremental process for not only care providers, but also for patients, and until the initial stages are sufficiently supported there will be limited request for the later ones.

A first demo e-service, “My Referrals” was implemented using the platform and was tested by 20 patients at five different healthcare centers in Stockholm. A user interface of the service is shown in Figure 1. The e-service is accessible through the web, Ipad and smart phone. It is a national citizen service free for all Swedish citizens, and is now in the process of being launched at a national level. Whereas ownership of the My Referrals e-service will reside with Stockholm County Council, management and support will be handled nationally through the National platform for citizen e-services and financed by participating care providers.

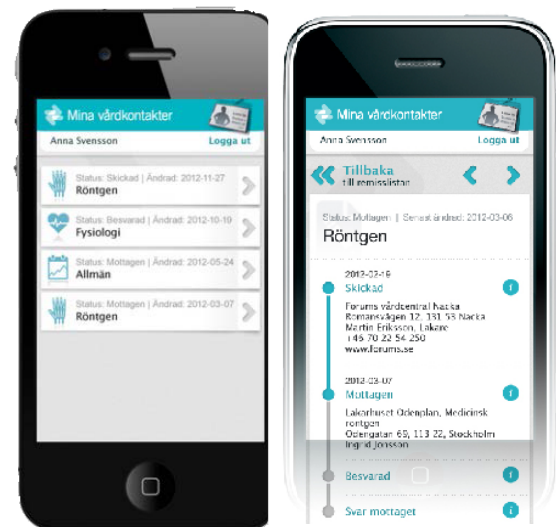


Figure 1- draft GUI of the e-service My Referrals (in Swedish)

The characteristics of the care process for each patient group vary over time and patients' needs for information support differ at different stages. For instance patients waiting for hip surgeries were more interested in getting an overview of the entire process as planned while lung cancer patients were mainly interested in getting fast feedback about different referral services during the staging process following the initial diagnosis. Stroke patients participating in our focus groups perceived that they often lose contact with healthcare professionals after hospital discharge and requested services that support patients in making informed choices of care providers for homecare and social services. In addition they wanted individualized guidance in the rules and regulations that govern access to rehabilitation, homecare and social services [13].

Information infrastructure in place

We created an open service platform (figure 2) that allows the market to compete in Health 2.0 services and enrich patient empowerment by giving patients control of which APPs operate on their personal health data. This also allows patients to combine private data with healthcare data and open data.

Basic services of the platform include the following services: Security service, Template service, Resource state service, Integration service.

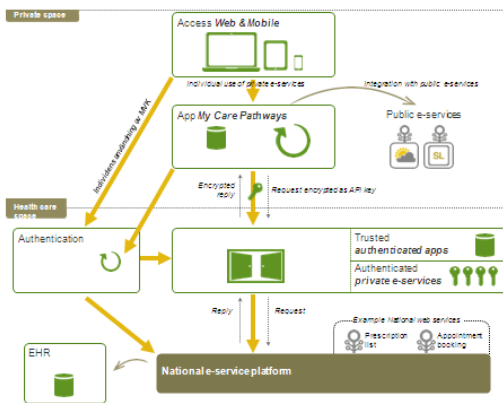


Figure 2- Overview of My Care Pathways' Secure Information infrastructure

Security service

API Gateway is a security service that allows Health 2.0 companies to build apps that interact with patients EHRs across Swedish healthcare providers. The API Gateway is an open source project. The gateway is built around RESTful [14] and OAuth 2.0 API architecture and security [15]. As a result, the patient has the power to select Health 2.0 APPs created by third parties and (through OAuth 2.0) grant APPs to interact with healthcare data that is integrated from regional EHRs through the platform. Currently the following information assets are integrated through standardized HL7 APIs (based on HL7 v3 Green CDA 2) into the information infrastructure: all patient contact information, request status (referrals, lab orders), diagnosis, radiology images, scheduling of care visits, prescribed medication, and preferred-care-provider preferences.

Template service

Template service is a generic service for the development of structured forms and templates to be part of an end-user e-service. For example it is used for the registration of patient information prior to a planned visit.

Resource state service

The resource state service is a basic service that tracks patient-related conditions in all the databases that are connected to the information infrastructure (currently there are three different EHR systems). The resource state service is used in the e-Referral service to track the existence of, and status of referrals for a specific patient.

Integration service

The integration service guarantees the mapping of existing legacy databases (e.g. from EHR systems) to National service standards.

Software Development Kit (SDK)

The Software Development Kit (SDK) [16] is a set of application services that facilitate and encourage the development of new citizen, care or research services. These offer developers a set of techniques and tools through which new services can be created currently based on open data and successively on

different categories of personal data. SDK is freely available to developers, healthcare providers and other stakeholders, and is continuously updated as more API interfaces are developed, (i.e. opening up the information stored in EHR systems in a secured way for innovation).

Identified Challenges and proposed solutions

Throughout the project, major challenges that are currently inhibiting the development of solutions that bridge the gap between clinical information systems and patient information systems were identified and analyzed. We present some of the main challenges that need further exploration to ensure that the final results of the project are robust and sustainable as well as some of our current solutions.

Business-model issues

The project results are owned by Stockholm County Council and made accessible through the Swedish National platform for citizen e-services because of an agreement between Stockholm County Council and the organization running the National platform. Each county council in Sweden using the My Care Pathways service will pay a yearly fee to this organization which will decide on, order, and pay for new developments and larger modifications. The My Care Pathways service is free of charge for Swedish citizens and is nationally available. In Sweden both public and privately operated healthcare services are government-funded. New innovative apps for Android and iOS platforms can be fully integrated with My Care Pathways. It is the patient that decides on additional services and gadgets that are required to link to My Care Pathways. As long as these new services are provided through healthcare they will be provided free of charge to patients. When developed through commercial participants they could also be patient paid services.

Further, services such as My Care Pathways stimulate the translation from physical to virtual healthcare appointments. This calls for new payment models supporting virtual healthcare work. The first payment model for virtual healthcare activities is implemented in Stockholm County Council 2013. This could, for instance, be the physical patient appointment prior to a hip surgery being replaced by the patient's registration on electronic forms and the medical staffs follow up of those electronic forms.

Legal issues

Patient access to their clinical data remains a key challenge. In Sweden, legislations have been revised to ensure patients' right to online access to their electronic health records. However, there are still issues with privacy and patient control of information that are hampering the implementation and widespread use of health informatics in the intersections between health and self-care. An analysis of the legal aspects related to patients' access to and use of personal health data, is currently ongoing [17]. Some decisions in this regard, have recently been taken that the project can build upon.

Interoperability issues

Although the platform is based on standards for information sharing and open interfaces, there remain issues to be resolved. One open challenge is the use of standardized terminologies in health and social care. Standardization efforts currently undertaken in health informatics have yet to incorporate social care and citizen perspectives and these are issues that will need to be further explored.

User interface issues

Designing usable ICT for senior citizens, stroke patients or other users with physical and/or cognitive impairments is a recognized challenge. Designing services that are useful for all disabilities is difficult. By providing an open platform, we believe that the market for specialized solutions addressing specific physical and/or cognitive disabilities will thrive, because they will provide access to a greater number of individuals.

Organizational issues

ICT solutions that address the intersections between different organizations will inevitably affect the roles, relationships and responsibilities for different stakeholders. As patients are given access to their health information and new services enable them to track their own care processes, the relationship between care professionals and patients will change. This can be both threatening and disruptive, and healthcare professionals' fears and apprehensions need to be acknowledged and discussed. In this project we tried to find solutions that fit both situations. For example, the eReferral service was initially designed for patients and is now being modified to make it available in a version adapted to healthcare professionals.

Discussion and conclusions

The new open source approach marks the beginning of a change from system to information infrastructure; from local to enterprise IT supported processes, from closed to open innovation and from a context where knowledge was power to a stage where cooperation is power. The challenges are to develop useful and secure services for different healthcare communities related to the information infrastructure. It involves continuous negotiation with relevant groups concerning how they should collaborate in a patient care process. This includes the patient, healthcare providers, researchers and global healthcare experts. This information infrastructure is just a starting point for a novel and limitless App service development, including limitless healthcare related actors and activities.

We have enabled this open innovation infrastructure technically. Further, close collaboration with decision makers in three health care regions as well as with National eHealth projects makes implementation in real practice possible. However, a number of challenges, related to both legal, business, interoperability, user interface and organizational issues, persist when implementing our results.

Future work will therefore target the further development of business models for sustainable provision of end user e-services in a public health care system such as the one in Sweden and a legal analysis of the development of third party provider (non-healthcare based) of personal data e-services.

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