Challenges and Opportunities in evolving TreC Personal Health Record Platform

Venet Osmani, Stefano Forti, Oscar Mayora
Fondazione Bruno Kessler
TrentinoSalute 4.0 Competence Center
Trento, Italy
{vosmani, forti, omayora} @fbk.eu

Diego Conforti
Autonomous Province of Trento
TrentinoSalute 4.0 Competence Center
Trento, Italy
diego.conforti@provincia.tn.it

ABSTRACT
Electronic Health Records (EHR) have been one of the factors in transforming healthcare and health management by providing electronic access to information recorded on paper charts. However, increasing interest of patients to be actively involved in the management of their condition and their health has necessitated evolution of EHRs so as to accommodate patients' role in the care loop. In response, Personal Health Records (PHR) have been developed that are patient-facing and provide the possibility to enrich EHRs data using data sources that have not been considered in the traditional healthcare, either due to unavailability or difficulty in acquiring data. An example of PHR is TreC platform, designed and validated by our research group. We provide an overview of TreC PHR, describe the challenges and provide an outlook on future opportunities.

Author Keywords
Personal Health Records, PHR, Electronic Health Records, EHR, Electronic Medical Records, EMR, TreC, Cartella Clinica del Cittadino.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

INTRODUCTION
Electronic Health Records have been one of the main drivers of transforming management of health and diseases. This transformation began with the requirement of having electronic access to information recorded on paper charts. Thus, digitalisation of this information began with the invention of Electronic Medical Records (EMR). However, EMR data remained at the premises where they were generated (such as physicians' office or a hospital) and did not follow the patient at a different treatment institution. In this regard the need to share data between institutions became necessary to follow the patients' history regardless of the place where the treatment took place. In response, Electronic Health Records (EHR) were developed that provide a broader view of the patient's care. EHRs, in addition to recording patient's care, can also share information with other care providers, such as specialists and laboratories. Therefore, EHR follow the patients not only across institutions, but also within the country and possibly across countries as well.

While EHRs addressed issues related to providing a broader view of patients' care, recently another requirement came into view, namely the potential to empower patients to be increasingly involved in the management of their condition and their overall health. The rise of personal trackers, connected health monitoring devices, better health education and improved standard of living have contributed to the active involvement of patients in managing their health. Healthcare institutions and associated actors are no longer the only stakeholders in this process. Patients not only wish to play an active role, but also be given an opportunity to provide valuable data and insights on the status of their health. This is the kind of data, continuous tracking of health parameters for example, that traditionally has not been considered in the care process, either due to unavailability or difficulty in acquiring. However, there is an increasing interest in using this type of data, in addition to traditional methods, because of the benefits in providing more accurate diagnosis and implementing preventative measures. As a result, Personal Health Records (PHR) were developed as a patient-facing data store that provide the possibility to empower patients in managing their health condition and enriching diagnosis and treatment using additional sources; these include objective sources, such as connected health trackers, wearable sensors and subjective sources, such as self-reporting of lifestyle parameters and physical and mental symptoms. This allows the patients to become generators of health data, especially longitudinal data that traditionally has been difficult or infeasible to acquire. At the same time, this results in improved knowledge of their condition, understanding of clinical management, follow lifestyle advice and become aware how their behaviour is influencing their health, as shown through findings in [1].

In this paper we draw from our experience in designing and validating TreC, a PHR platform in active use by Public Health Authority (APSS)[1] of the Autonomous Province of Trento in Northern Italy.

While there is no consensus regarding the definition of a PHR, in our view the most comprehensive definition, which is also aligned with our design aims, is given by the Markle Foundation. They define PHR as "…tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it [2].

OVERALL CONTEXT AND CHALLENGES

TreC ("three **C**" abbreviated from its Italian name **C**artella **C**linica del **C**ittadino, meaning Citizen's Medical Records) platform, designed and validated by our research group, is a PHR that enables the citizens to access, supplement, manage and share their health and wellbeing information. As of March 2017, TreC (both an early version and the updated version which is referred to in this paper) is in active use by more than 70.000 citizens, allowing consultation of test results, prescriptions, and refills.

In the Autonomous Province of Trento healthcare is typically delivered through the public sector, provided by a local authority (APSS). In the past decade a significant effort has been made to build an electronic infrastructure targeted at primary and secondary care. Hospital and territorial systems have been implemented and general practitioners have access to their patients' files. In this context three key challenges were identified:

i) Providing personalised services

The first challenge was to provide services to the whole population. Healthy persons are often not included in telehealth projects as they do not require health services. However, in our approach healthy persons become an integral part of the system such that preventative measures can be taken before the need for hospitalisation arises. The main challenge in this respect was to enable all citizens to have **online access to their medical records** and to provide them with tools to **keep track of their clinical history.** This would establish a proactive loop between the patients, medical institutions, and their staff. The **actizen** (active citizen) that provides personal health information that otherwise would not be available in the clinical systems, such as information from personal health monitors, would enrich their health picture and allow for a personalised and targeted course of treatment. Moreover, the information accessible by TreC platform would allow clinicians in agreement with patients to better determine personalised treatment strategies accessible to them at different intervals on the care process.

[1] https://www.apss.tn.it

ii) Providing self-tracking tools for health promotion

The second challenge is to enable citizens to record observations of daily living. Keeping track of diet, physical activity, triggers, pain, symptoms and the like can be useful to better understand oneself or to achieve personal goals (increase physical activity or weight reduction for example). In this respect the main challenge is to provide citizens with tools and interfaces that are **intuitive**, allow for **fast and easy recording** of information and provide compelling **visualization** of their data. The use and configuration of such tools should be jointly agreed and defined by patients and clinicians in order to follow personalised treatment course according to the patient condition. This approach would further engage citizens to take active part in the management of their health and wellbeing through analysis and visualisation of their health data and become better actizens.

iii) Providing tools for the self-management of chronic diseases

The third challenge is to develop tools to support patients suffering from chronic illnesses. People with chronic disease need to monitor their condition on continuous basis, have frequent contact with their healthcare providers and often rely on some form of support from family or caregivers. The main challenge for this target group was the provision of monitoring tools that would not only enable **remote assistance and care**, but also **support the family and caregiver network**, thus consequently improving health outcomes.

ADDRESSING CHALLENGES THROUGH TREC PHR

With regards to addressing the challenges outlined above, an early version of TreC PHR has been implemented, deployed, and is in use since 2012.

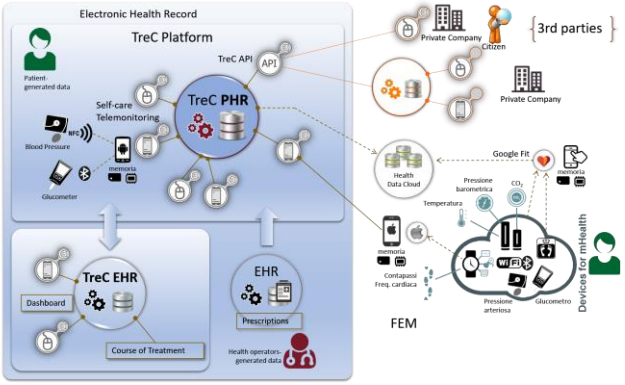

Figure 1 TreC Architecture and Services

Since then, an evolved version used for research purposes is being continuously developed. TreC design is characterised by an important conceptual feature. Rather than developing a health information hub, TreC has been designed as a "system of systems" with an extensible architecture, where sub-systems can be developed to provide additional and specific functionality, as shown in Figure 1. Authorisation

and access to data is one example. TreC contains health data that is accessible only to the authorised citizens and when necessary shared in the network of care. Citizens are in control of their information and authorise sharing of their data, such as to prevent access to unnecessary information from other stakeholders in the care process. For example, an orthopaedic surgeon might not need the patients' mental history. A number of other systems have been implemented and are running on the current TreC platform, including i) The *TreC Registry* which allows centralised management of configuration of apps, both web and mobile for each user. Users can manage the configuration themselves or doctors can change the configuration, for example to enable or disable specific functionality of applications on patient's remote devices. TreC registry, is used to implement the concept of "Prescription-based Health Apps" described in [3]; ii) Alarms and messages sub-system automatically analyses the patient clinical data reported by the physician in one hand and data provided by medical devices system in another to understand potential risks to patients' health based on predetermined parameters; iii) Medical devices sub-system allows integration with data provided by various medical devices. Currently, the system interfaces with a glucometer that is being used in a diabetes type 1 trial [4]. The data is shared with the medical specialist and allows the patient to visualise changes and trends of their glucose levels in order to better manage the condition; and

Figure 2 TreC PHR data integration

iv) Commercial devices subsystem provides an interface with the various personal trackers currently on the market. This includes integration with products from Jawbone, Withings and Misfit. Additionally, TreC platform allows for interfacing with the Electronic Health Records, access to and by pharmacies and access to other services provided by the public administration, such as nursing homes. Figure 2 provides a graphical representation of the TreC PHR data integration platform.

The development and deployment of the TreC research version has given rise to a health living lab. Living Labs are research and innovation environments in which end-users are empowered with ICT solutions and services in real-life conditions. Living Labs allow for the tailoring of technical solution through context research but also to discover and co-create with the cooperation of end-users. Evaluating and testing technologies in a real-life context allows to elicit institutional and organizational complexities of provisioning of health and wellbeing services and respond to them before moving to large scale provisioning of these services to the public.

Through TreC architecture, external services can be provided by third parties. For example, software services can provide a geo-fence that would warn allergy sufferers of pollen concentration, or even development of hardware equipment such as continuous glucometer with automatic provisioning of data to TreC.

TREC AT THE BENEFIT OF THE CITIZENS

Considering the functionality described above, TreC is being actively used by a large number of citizens, both healthy and affected by chronic diseases. In this section we highlight a few use cases where citizens take an active role in managing their health and wellbeing.

TreC is being actively used in a study regarding the management of type 1 diabetes. The Diab-PHR project has been running from 2010 [5] and explores the use of an electronic log-book for paediatric patients to keep track of their glycemic control and allow remote monitoring by the physicians. The glucometer automatically sends blood glucose level data to TreC, where it can be visualised and shared with the physicians. Interviews conducted with a selection of 12 patients (6 female, 6 male, age 4-20 years, average 12) have revealed that the PHR was effective as an instrument to support personal diabetes management, while allowing the patients to integrate their own knowledge in the management of their condition. Along the same line, another study that ran in 2014, enrolled 15 youths from four to eight years of age (average 8), diagnosed with Type I diabetes [4]. The study highlighted the complexities of information sharing among patients and doctors, specifically challenges in interpreting patient data considering wider context, such as lifestyle habits including nutrition and exercise. This study also highlighted the "personal" in PHR, since no subject involved in the clinical study used all the functions provided. At the same time, no subject used only a single functionality, based on the analysis of log data. This finding is in line with the "system of systems" design of TreC that makes it possible to pursue a design strategy aimed not at identifying a few features universally used, but rather at offering a wider set of options which can then be selected by the users in accordance to their needs.

TreC has also been used in an oncology practice to develop a safe therapy mobile (STM) system for the safe delivery of intravenous chemotherapy in clinical setting. This platform is also being used for patients receiving oral chemotherapy at home to manage toxicity and improve adherence [6]. The system was tested with 59 patients and used to administer a total of 176 treatments. The impact of introducing the system on the hospital workflow was also tested. This was carried out by measuring the duration of the entire administration process in a few patients who received the same chemotherapy regimen before and after the system was introduced into routine practice. Though sixty percent of nurses expressed that us of the TreC platform slowed down their work, the measured duration of chemotherapy administration before and after system implementation did not change significantly. The two use cases described above and their results demonstrate the use of TreC in real-life setting and the benefits it brings to the citizens.

OPPORTUNITIES FOR OTHER STAKEHOLDERS

To summarise, the benefits the TreC platform awards our citizens, the ecosystem of personal devices and the TreC platform enables online access to health care services, provides parameters of their health and well-being, receives feedback and suggestions (such as through a virtual coach) and communicates and shares this personal information with the health professionals in the context of prevention, treatment and self-care or remote monitoring.

Health professionals have the opportunity to prescribe certified apps, personalised and adapted to the particulars of the patient and their condition such as the functionality of pertinent reminders: weight measurements, glucose measurements for example; definition of remote monitoring period of interest and viewing of patient data in real-time so as to enable prompt assessment.

Health care facilities can enable remote care models, customised to the individual patients requirements, enable online screening campaigns and perform multi-site clinical trials based on upcoming technologies integrated with data generated by the patients.

Public Administration (such as Ministry of Health or Health Departments) through the TreC services, can implement a citizen-centred health system, where the citizen decides how to share their health information, with which third parties and in which health facilities, allowing active involvement of citizens in the healthcare decision process.

Research and innovation - the platform will provide the technological infrastructure to perform multi-center clinical trials and allow to perform research and innovation at local and national level and in the field of innovative next-generation health services, such as telehealth for the management of chronically ill using also data generated by the patients. In addition, the use of machine learning technologies can provide predictive models for particular diseases and guide the cure process.

In a wider context, as noted by [7] governments, healthcare providers and medical insurers promote uptake of PHRs with broadly the same message; namely, that patients who engage with their own healthcare secure better health outcomes and incur lower costs. A PHR centralises important medical information, ensures against data loss and medical errors, facilitates user convenience (such as ordering repeat prescriptions), and enables patients to make better lifestyle choices. The benefits are tangible for those living with chronic conditions or disability, or those living in remote areas without easy access to primary care services.

ACKNOWLEDGEMENTS

We would like to acknowledge the contribution of the following people: Stefano Cavallari, Luca Vettoretto, Barbara Purin, Marco Dianti, Flavio Berloffa, Claudio Eccher and Enrico Piras. Ideas presented in this paper served as an input for FIWARE Mexico project (id: 723088), funded by European Commission's Horizon 2020 Programme.

REFERENCES

[1] C. Pagliari, T. Shand, and B. Fisher, "Embedding online patient record access in UK primary care: a survey of stakeholder experiences," *JRSM Short Rep.*, vol. 3, no. 5, pp. 34–34, 2012.

[2] Working Group on Policies for Electronic Information Sharing Between Doctors and Patients, "Connecting Americans to Their Healthcare: Final Report - Working Group on Policies for Electronic Information Sharing Between Doctors and Patients," 2004.

[3] V. Osmani, O. Mayora, and S. Forti, "Enabling Prescription-based Health Apps," in *Submitted to Pervasive Health 2017 Workshop proceedings*, 2017.

[4] F. Miele, C. Eccher, and E. M. Piras, "Using a Mobile App to Manage Type 1 Diabetes: The Case of TreC Diabetes," *Proc. 5th Int. Conf. Digit. Heal. 2015. ACM, 2015.*, pp. 113–114, 2015.

[5] E. M. Piras and A. Zanutto, "'One day it will be you who tells us doctors what to do!'. Exploring the 'Personal' of PHR in paediatric diabetes management," *Inf. Technol. People*, vol. 27, no. 4, pp. 421–439, 2014.

[6] E. Galligioni *et al.*, "Integrating mHealth in oncology: Experience in the province of trento," *J. Med. Internet Res.*, vol. 17, no. 5, May 2015.

[7] J. Cruickshank, C. Packman, and J. Paxman, *Personal Health Records: Putting Patients in Control?* 2020health. org, 2012.