Towards an Open, Citizen-Centric Ecosystem for Data on Health and Engagement

Demo Presentation

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Abstract—In recent years, there has been a shift from hospital-centric to citizen-centric infrastructures for data management in health and healthcare. Various software vendors have built integrations between mainstream providers of health apps and wearables in order to give citizens more control over the health data that they generate. This presents ample opportunities for personalizing health and care. Unfortunately, smaller providers of health-related apps are typically overlooked while they do also generate precious data. Furthermore, it remains unclear how to perform large scale research on integrated health data under the constraints of privacy, security and openness. In this demo paper, we describe the partial realization of an infrastructure that aims to overcome these issues.

I. INTRODUCTION

A. From Hospital-Centric to Citizen-Centric

More than a decade ago, various scholars described a transition from provider-focused Electronic Health Records (EHRs) to patient-/citizen-centric Personal Health Records (PHRs) [1]. PHR system architectures have then been classified in provider-tethered and free-standing ones. Provider-tethered architectures involve hospital portals while free-standing PHRs have a hub-and-spoke architecture to integrate data from multiple hospitals with additional health data from pharmacies, consumer health devices and more. Free-standing PHR adoption has been challenged by various barriers, such as legacy legislation which favored the hospital-centric approaches. The Dutch ministry of health, wellbeing and sports has provided mid 2018 a 4 million Euro budget to boost PHR adoption and standardization via the MedMij program [2]. That program specifically promotes interoperability for data from: (1) home physicians, (2) hospitals, (3) pharmacies and (4) patient self measurements. Since a prior program (called VIPP) had already subsidized provider-tethered PHRs with significant grants for hospitals, MedMij can boost the the uptake of free-standing PHRs.

B. Potential & Limitations of Contemporary PHRs

In 2017, a network of small game enterprises recognized the need to collect health game data more systematically. Until then, such game data remained locked in isolated local storage of end-user devices. Among other problems, this complicated analyses on the effectiveness of such health games. Analyzing effectness was essential for two purposes: first, insurance companies and health authorities were demanding a form of evidence before reimbursing the games. Second, game developers aimed to make the gameplay more personalized by taking into account the player’s engagement and health effects over time. The game providers did not wish to handle the privacy and security challenges related to personal data collection themselves and recognized the potential of PHRs. More research was needed to align functionalities, Application Programmers Interfaces (APIs) and legal policies.

Therefore, a consortium was formed with expertise (1) on the technical and legal aspects of health privacy and security, (2) factors influencing game engagement and (3) factors influencing public health. This demo paper describes the outcomes and open challenges from the PHR infrastructure point of view. The next section describes our research methodology. Section III describes the results we can demonstrate so far. Section IV draws conclusions and outlines future work.

II. METHODOLOGY

Requirements for the infrastructure were derived by (1) reviewing the PHR literature, (2) reviewing the architecture and design characteristics of a sample of health games, (3) assessing the data privacy and security architecture of two Dutch PHRs, (4) designing an API extension, (5) developing an open source demonstrator of an integrated game, and (6) organizing a one-day connectathon for game developers.

III. RESULTS

A. Literature Review

Based on a PHR literature review, it was decided to strive for a citizen-centric PHR architecture, as proposed by the seminal work of Kaelber et al. [1]. Furthermore, we decided on using OAuth 2 and REST technologies for the interoperability, as proposed by Mandel et al. [3].

B. Health Game Evaluation

Supported by a large incubator of game studios⁴, we selected seven sample games for deriving integration requirements. The games involved a variety of data, ranging from EEG brainwave based concentration data, over (i.a. virtual-reality based) movement data to data on bedwetting. These games were evaluated against various criteria. Besides considering game maturity, games were categorized by target audience, I/O methods and distribution channels. Our largest emphasis was on evaluating the methods through which games realized (a) quantifiable health improvements and (b)

⁴See DutchGameGarden.nl
sustained user engagement. In particular, we checked which games were taking into account academic literature on both topics. We also checked the level of personalization and adaptation.

Games varied in their level of maturity and the data to be integrated. However, none of the games was collecting health data systematically for big data analyses. In this context, various game providers wanted to delegate to a PHR hub the responsibility of controlling sensitive health data.

C. PHR Evaluation

Two Dutch vendors of PHR technology were assessed in terms of platform architecture and privacy/security measures. Selfcare was selected as the most promising free-standing PHR to extend the state-of-the-art. At its functional core, Selfcare provides charts of a variety of health parameters, ranging from steps, over heart rate to blood sugar levels. The platform provides integrations to wearables and scales from a variety of vendors and puts end-users in control of the data they generate:

- an OAuth 2 protected REST API lets third party apps retrieve longitudinal health data after user consent;
- a sharing dashboard enables end-users to share time-series views with trusted contacts (physicians or others).

Selfcare is also being integrated with physician information systems via MedMij funding [2].

D. API Review and Extension

From the API point of view, Selfcare unfortunately did not yet enable third parties to contribute additional data integrations. That lack of openness hampered scalability of the ecosystem. Specifically, only employees or subcontractors of the PHR provider could contribute new integrations. Therefore, we designed an API extension which enables third parties to store sensitive data in Selfcare, after user consent. The API supports any type of data, as game developers aimed to store quite complex engagement-related data (e.g., how do users interact with certain types of avatars, etc.) To the best of our knowledge, no other PHR API supports storing arbitrary types of data. For the extended Selfcare API, two kinds of data can be stored by third party software:

1) numeric data, which can be displayed on charts accessible to the end user and his/her trusted contacts,
2) complex data (e.g., full game session data including details that cannot be visualized to end-users).

E. Open Source Demonstrator

To demonstrate to health app developers how to integrate their data into the citizen-centric PHR, we developed an open source demonstrator: see https://github.com/pvgorp/RockPaperScissors-SelfcareEngage. The demonstrator involves a command-line implementation of the game Rock-Paper-Scissors. The demonstrator clarifies the five technical steps involved in using the API:

1) Retrieve from the API a Selfcare user-specific URL;
2) Load from that URL a page with a privacy policy and consent controls for integration-specific data items;
3) Get from the PHR a user-specific access token for securing the network communication to the PHR;
4) Storing time-stamped health data to the PHR;
5) Retrieving time-stamped health data back from the PHR.

Steps 1-3 are for initialization only. Step 5 comes in two flavors: one for primitive numeric data and one for complex data. The demonstrator will be shown live during ICT.Open’19.

F. Connectathon with Health Game Developers

From the diverse pool of games discussed in Section III-B, we decided to integrate one game related to dietary education and another game related to promoting physical activities: Digest Inn and Hello Yoop. Inspired by events like https://connectathon.ihe-europe.net/, we organized a session in which we supported the developers of these games in (1) deciding which data to store in the PHR and (2) replicating the steps of our open source demonstrator.

IV. Conclusions and Future Work

In this demonstrator paper, we have described how we advanced the state-of-the-art in personal health data infrastructures by enabling the developers of health games to store data in a citizen-centric PHR. Two commercial providers of games have already connected to the PHR for which we designed an API extension. Thanks to existing PHR functionality, patients can grant trusted parties to monitor (potentially a subset of) their integrated PHR data. Furthermore, this novel ecosystem supports our aim to analyze via machine learning (1) when certain types of users respond to specific types of motivational strategies and (2) which game strategies have optimal effects on health outcomes (as measured by devices already connected to the PHR).

Our ongoing work relates to GDPR-compliant work- and data-flows which enable knowledge institutes to perform studies on integrated PHR data. The resulting Selfcare “Research Module” will also be demonstrated at ICT.Open’19.

Our future work involves novel approaches to data anonymization to support open data initiatives even under strong confidentiality constraints.

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REFERENCES

