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The Personal Health Library: A Single Point of Secure Access to Patient Digital Health Information

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Abstract. Traditionally, health data management has been EMR-based and mostly handled by health care providers. Mechanisms are needed to give patients more control over their health conditions. Personal Health Libraries (PHLs) provide a single point of secure access to patients' digital health information that can help empower patients to make better-informed decisions about their health care. This paper reports a work-in-progress on leveraging tools and methods from artificial intelligence and knowledge representation to build a private, decentralized PHL that supports interoperability and, ultimately, true care integration. We demonstrate how a social application querying such a decentralized PHL can deliver a tailored push notification intervention focused on improving self-care behaviors in diabetic adults from medically underserved communities.

Keywords. Personal health library, digital health, privacy, interoperability.

1. Introduction

Currently, patients receive important digital health information in multiple settings and through different communication modalities. Emerging evidence indicates that patients are frustrated by the lack of EMR interoperability among these fragmented systems and platforms [3-8] and want to have an active role in managing their data [1, 2]. Improved interoperability and support for patient-provider communication has the potential to improve patient satisfaction and, evidence suggests, could even help detect and prevent medical errors [8]. Table 1 summarizes some critical requirements of PHL from the patient perspective identified in the literature [1-8]. In digital health management, a health state is a digital representation of the state of someone's health at a point in time, including their medications, test results, exercises, diets, insurance claims, vaccines, allergies, appointments, and their outcomes. Such data come from diverse sources, including health care organizations, government agencies, and clinicians. It can also include digital health information from mass media and social networks. Health data also comes in different formats, including EMRs, family histories and genealogies, data streams from activity trackers, personal genome sequences, articles, videos, and public datasets. Health states change over time as data is acquired through ongoing health-

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related processes and events embedded within those processes. A health-related intervention is a process, which could either be therapeutic or preventive. For instance, an intervention for self-management of chronic diseases (e.g. diabetes) focused on promoting health behavior change to improve clinical outcomes is an example of a preventive intervention. In this paper, we describe a strategic implementation plan for a social application querying a decentralized PHL that can deliver a tailored push notification intervention focused on improving self-care behaviors in diabetic adults from underserved communities.

Table 1. Patient requirements (Req.) for a PHL.

Req.	Description
Construction and Management (PODs)	
R1.1 R1.2 R1.3	A mechanism to construct a PHL by bringing their data together in a trustworthy, usable, and useful library by gathering different types of knowledge into a single resource.
R2	Ability to manage the PHL by adding, editing, or removing resources
Access Management and Privacy (PODs)	
R3.1 R3.2	Ability to decide what types of data should be kept, and who has access to that data
Knowledge Acquisition and Aggregation	
R4.1 R4.2	Ability to seek health information from constantly changing public sources, enriched with new streams and types of data
R5	Ability to decide what types of data is important enough to collect, manage, and share
R6	Ability to participate by sharing their data with citizen science and research initiatives
Usage (Applications)	
R7.1 R7.2	Ability to search through the PHL using intelligent mapping for vocabulary used to describe resources in their profile.
R8	Ability to annotate their own results from participating in clinical trials to look for patterns
R9	Ability to receive alerts about new information related to topics covered in the PHL
R10	Ability to play an active role in staying healthy by monitoring their progress
R12	Ability to find and use information including text summarization, knowledge mapping.
R13	Ability to get digital assistance: personalized alerts, literacy aids, translations.

2. Method

We provide a solution for constructing and using a Personal Health Library (PHL) inspired by the Social Linked Data (Solid) framework [9]. Solid builds on the future vision of the decentralized Web by providing an infrastructure for separating data from applications that process that data. It provides users with true ownership of their data by storing it among several Personal Online Data stores (PODs) hosted wherever they desire, and selectively authenticating applications to access and process specific resources within those PODs. The proposed Solid-based PHL manages distributed data storage in several PODs and enables interoperability between applications by reusing standard protocols, formats, and vocabularies, and by providing a common access RESTful API. Table 2 shows the main features supported by the proposed Solid-based framework.

Table 2. Features supported by the proposed Solid-based framework.

F_n	Description
F1	*Agents*: Solid defines standard vocabulary to describe the different entities that contribute to a user's profile as Agents of different types (Person, Organization, Device, etc.)
F2	*WebID*: Each agent has a unique WebID, which links to a public RDF-based profile document that may link to other extended profiles. Extended profiles represent different user's application profiles.
F3	*Web of Trust*: Extended profiles can be used to build a Web of trust using the FOAF vocabulary by allowing agents to link their profiles in a public or protected way.
F4	*Web of Resources*: Whether it is a person, an inbox, a document, an image, a notification, or a relationship, everything within a profile is represented as a resource.
F5	*Hierarchical resource representation*: Resources can be organized hierarchically in containers (directories), which allows for fine-grained access control lists (ACL). Solid uses the WAC Ontology.
F6	*Resource Management*: RDF, the model driving the Linked Data Platform (LDP), follows REST principles of identifying resources by URIs. Users manage resources via HTTP operations on their URIs. SPARQL endpoints enable complex multi-pod data retrieval via link-following SPARQL.
F7	*Linkability*: Resources stored in different PODs are represented following LDP recommendations. LDP enables agents to dereference resource URLs to reach a resource from another. Links within LDP are typed, which enables agents to explicitly state how their linked resources are related.
F8	*Live Notifications*: are implemented following the W3C LDN protocol and *ActivityStream Vocabulary* and enable users to interact with content on each other's PODs and enable content owners to receive notifications in the appropriate *inbox*.
F9	*Portability and Interoperability:* The framework has a standard API that makes it easy for developers to write applications that allow users to use the same data in different applications instead of locking it inside different application data repositories
F10	*Security: Authentication*: The framework provides decentralized authentication, a global id space, and a global single sign-on through WebIDs. User has to register with an identity provider (their POD provider). The provider stores the users' WebID profile document associated with a cryptographic key.
F11	*Privacy:* Access Control Lists (ACL). Solid uses the WAC Ontology to define read, write, edit, etc. permissions on resources. Since resources are hierarchical this allows for fine-grained access control. A patient can grant fine-grained access permissions to the different agents, ranging from a single person or a group to everyone. The patient can also have a list of trusted applications and control their access to the different resources in his/her POD.

3. Results

To showcase the proposed Solid-based PHL in action, we focus on one application scenario, featuring a preventive intervention from the chronic disease self-management domain:

Bob is an African American adult with diabetes equipped with a smart-phone that collects physiological data (e.g. step counts) in real-time. The social application on his smartphone queries his decentralized PHL to deliver tailored push notifications to support behavior change related to chronic disease self-care. Depending on sensor readings and other information in his PHL, the app provides personalized and tailored recommendations for healthy eating, physical activity, medication taking, and/or visiting healthcare providers. Alice is a cancer patient who is part of Bob's social network and Mary is his primary care physician.

We leverage the Solid infrastructure and the relevant linked data principles to assist Bob in constructing and managing his PHL as well as interacting with other collaborators in his health and social networks, through the Solid ecosystem.

First, Bob generates unique WebID to securely login to his profile document (Table 2, F2, F10), sets up his PODs, and keeps a list of vCard URIs of trusted (Table2, F3) agents and applications in his extended profile. He adds Alice and Mary as Person agents and he adds the monitoring app and his smartphone as *device* and *software* agents, respectively (Table2, F1). Bob is interested in *gathering* the latest blog posts about diabetes from a blogging app. He adds the app under the trusted apps section of his profile document. He grants each of the above agents a fine-grained access permis-sion to the corresponding containers under his POD with the proper access mode (Table2, F11). He can set up a chatting *channel* of type LongChat about Diabetes as a resource under the Diabetes folder under his public folder (Table2, F4,F5,F6).

Alice and Mary can *subscribe* to the channel using their WebIDs and have message *notifications* pushed to their inboxes as resources with unique URIs and they can *collaborate* on assessing each other's messages. Bob can also *share* blog posts that he receives from the blogging app to Alice's inbox. Alice gets a notification in her inbox of the blog post (Table2, F8). She has several options to *interact* with the document, including replying to Bob, adding *annotations* to robustify links in the document by linking them to other concepts or sources of knowledge, and save either a copy of that document to her POD or a link to Bob's copy.

Resources generated by each of the three users is stored in their corresponding PODs, but can be linked to each other (Table2, F7). For example, message notifications get pushed by the messaging POD to the inboxes of the users who subscribed to the messaging app as resources with unique URIs. Assuming a message stored in Bob's profile is identified by https://bob.solid/messages/diabetes/1234, then Alice's comment at https://alice.solid/comments/36756 links back to Bob's message by the *hasTarget* Link Type defined in the Web Annotation Ontology (www.w3.org/ns/oa).

4. Discussion and Future Work

This paper has shown how a social application querying such a decentralized PHL can securely access, exchange, and use PHLs and deliver personalized and tailored push notifications to support chronic disease self-care. In this paper we employed a Solid-based framework to assist users in constructing their PHL by gathering different types of data, information, and knowledge into a single searchable resource. While there has been some effort to build similar systems, the novelty of the proposed approach lies in i) providing a decentralized, yet linked architecture; ii) supporting interoperability, portability, knowledge mapping, and reasoning by following protocol, format, and vocabulary standards; iii) building trust with patients by facilitating true ownership over their data, and appropriate reporting; and (4) giving them a fine-grained access control mechanisms.

Future work will focus on further implementation of an end-to-end framework of intelligent recommendation and digital assistance tools, including text summarization, knowledge mapping, and personalized resource suggestions. In achieving this goal, we will incorporate AI techniques and knowledge representation methods that have been successfully used in our previous works [10, 11, 12]. Other ongoing tasks will include setting up a clinical trial of the social application and recruiting participants to fully evaluate the application.

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