**Sharing Personal Health Data to Improve Treatment of Chronic Conditions**

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**Problem**

In the U.S. today, more than 40% of adults are suffering from two or more chronic medical conditions. Primary care practices are treating an increasing number of patients with multiple chronic conditions as the aging population continues to grow. This results in spending 71% of U.S. health care dollars on managing chronic conditions. While patients can appreciate the importance of managing their chronic conditions, they may be overwhelmed by the challenges of adhering to a complex medication regimen while trying to stick to good health habits like exercising and eating a healthy diet.

**Monitoring Chronic Conditions**

To improve monitoring and self-management of chronic conditions, patient-reported outcomes (PROs) can be recorded in real time between office visits. This information provides a more complete and accurate view of the patient’s current health status than self-reports based on patient recall during an office visit. With a better understanding of the patient’s current health situation, PROs help patients work with their physicians to monitor and better manage their chronic conditions.

**Open mHealth and IEEE P1752 Standard for Mobile Health Data**

Believing that no single app or device provides all the information for an individual’s health story, Open mHealth plans to make patient-generated data from disparate sources accessible and to provide an interoperability standard for harmonizing and helping to make sense of digital health data. A working group is currently developing the IEEE P1752 Standard for Mobile Health Data, with the scope and purpose described below. (Note: I recently joined the working group).

“Scope:  This standard will define specifications for a mobile health data applications programming interface (API) and standardized representations for mobile health data and metadata. Mobile health data encompasses personal health data collected from sensors and mobile applications.”

“Purpose: The purpose is to provide standard semantics to enable meaningful description, exchange, sharing, and use of mobile health data. Data and associated metadata will be sufficiently clear and complete to support analysis for a set of consumer health, biomedical research, and clinical care needs.”

**Protecting Personal Health Data**

Since each person’s health story includes data from different sources, each source of data needs to be identified as pertaining to a particular individual while protecting the individual’s Personal Information (PI), Personally Identifiable Information (PII), and Protected Heath Information (PHI).

Privacy standards and guidelines mentioned by the IEEE P1752 working group include:

* **HL7 FHIR (Fast Healthcare Interoperability Resources) Release 4** is a standard for exchanging healthcare information electronically. The standard includes a Security & Privacy module, which describes access control and authorization to protect a FHIR server, consent documenting the permissions a user has granted, and provenance and audit logging to record events that have been performed. However, the document states that “FHIR does not mandate a single technical approach to security and privacy; rather, the specification provides a set of building blocks that can be applied to create secure, private systems.”
* **The IEEE P7002 Data Privacy Process** standard defines requirements for a systems/software engineering process for privacy oriented considerations for organizations and projects developing and deploying products, systems, processes, and applications involving personal information.
* **The National Institute of Standards and Technology (NIST) Privacy Framework** helps organizations manage privacy risks from Personally Identifiable Information (PII) about individuals being collected, stored, used, and shared by an organization during the use of the organization’s products and services.
* **Xcertia mHealth App Privacy Guidelines** assess whether a mobile health app protects the user’s information, including Protected Health Information (PHI), Personal Information (PI), and Personally Identifiable Information (PII) in full compliance with all applicable laws, rules and regulations.

**Protecting Personal Health Data with Decentralized Digital Identity**

I would like to work with others to develop scenarios demonstrating how decentralized digital identity can help in protecting Personally Identifiable Information (PII), Personal Information (PI), and Protected Health Information (PHI) while facilitating sharing of personal health data in the context of Open mHealth and the IEEE P1752 Standard for Mobile Health Data.

**References**

HL7 FHIR Release 4 <https://www.hl7.org/fhir/overview.html>

HL7 FHIR Security and Privacy Module https://www.hl7.org/fhir/secpriv-module.html

IEEE P1752 Working Group <https://site.ieee.org/sagroups-1752/>

IEEE P7002 Data Privacy Process <https://standards.ieee.org/project/7002.html#Standard>

Improving the Management of Multiple Chronic Conditions with mPROVE <https://digital.ahrq.gov/ahrq-funded-projects/improving-management-multiple-chronic-conditions-mprove>

Mobile Devices and Health, Ida Sim, The New England Journal of Medicine, Sept. 5, 2019 <https://www.nejm.org/doi/full/10.1056/NEJMra1806949>

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