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Apple Health Records

Kevin Schulman
Magda Rosenmöller

Julia Rivera was in good health one sunny day in Palo Alto, California, cycling to visit friends at the expansive Stanford University campus. With beautiful views of the mountains and palm trees, she found herself distracted and crashed, fracturing her leg. She was taken to the emergency room at Stanford Hospital. She was told she needed surgery to repair her leg and would require hardware implanted to help the fracture heal. She agreed to the surgery, and everything proceeded smoothly.

During her stay, she noticed that the hospital had an electronic medical record system. She was curious about the system and was told that the physicians and nurses used it to document all of care they gave, including the details of her surgical implants (such as the manufacturer's name, hardware type, and serial number).

After being discharged, she was able to log into the patient portal to access her records. Since she lived out of town, she wanted to share her records with her own physician back home. The Stanford portal was connected to the Apple Health Records application on her smartphone. This was a novel way to share her information. Rivera was excited to have electronic access to her data and wondered how this new technology could change health care in the future.

Connectivity and Personal Health Records[1]

The conceptual appeal of an electronic health record (EHR) is intuitively simple. It is about having all of your past data available to help make important medical decisions, such as which medications to take (avoiding exposure to medications to which you have an allergy or that have

[1] Adapted from Kevin A. Schulman and Barak D. Richman, "The Failure and Promise of Health Information Technology: Towards a Personal Healthcare Architecture," New York: Oxford University Press, forthcoming.

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been ineffective before), what treatments and tests are not required because you have received them already for your medical condition (in order to prevent duplication of services), and which physicians or hospitals to see (the lowest-cost and highest-quality providers for your condition). For the purposes of this case, this notion of having data available to help inform clinical decisions can be considered the primary use case for health information technology.

Data architecture is a critical element for understanding how we can implement this use case successfully. Most electronic health record systems are designed around the medical provider (the physician or hospital). Thus, if you see multiple different providers, you will have multiple health records.

The concept of interoperable electronic health record systems is a question of whether and how these data can be shared. How they are shared could include documents—using the Continuity of Care Document (CCD) specification, for example—that are not fully computable but have some structure beyond free text or the true electronic data transfer of individual data items that can be computed.

The current provider-centered architecture leads to data fragmentation, and people can never have the assurance that they have access to all of their medical data at a time when critical medical decisions are being made.

An alternative form of data architecture is emerging to support the primary use case: a personal health record (PHR). A PHR system is as simple as it sounds. It is a health record where the data and services are designed around the needs and activities of the individual. Moreover, it is not a novel idea. In many emerging-market countries, patients have small notebooks that have their medical history. They take their notebooks with them when visiting their physicians, the physicians update the information in the notebooks, and the patients takes them back home for safekeeping. A PHR system requires no greater technological capability than a typical EHR. However, it is revolutionary because it is constructed around a different architecture, organizing patient data with each patient as an individual in mind.

Several countries have managed to pursue a PHR architecture. In France, health insurance cards come with an embedded "shared medical file" ("dossier médical partagé" or DMP) controlled by the patient. ("DMP" was previously an abbreviation for "dossier médical personnel" or "personal medical file.")[2] In Singapore, the slogan of "One Patient, One Health Record" has been adopted.[3]

The Eastern European country Estonia, located on the Baltic Sea, has taken a unique approach to the concept of personal health records. At a national level, Estonia has created an architecture for personal health records using blockchain technology. Patients have access to their records through a portal and an electronic identification card. Rather than there being a single national database, personal data are aggregated when a query is made.

The e-Estonia website has described the Electronic Health Record system as follows:

> Functioning very much like a centralized, national database, the e-Health Record actually retrieves data as necessary from various providers, who may be using different systems, and presents it in a standard format via the e-Patient portal. A powerful tool for doctors that allows

[2] "En quoi consiste le dossier médical personnel (DMP)?" Service-Public.fr, updated August 21, 2017, accessed June 28, 2018, https://www.moh.gov.sg/docs/librariesprovider5/resources-statistics/educational-resources/english-brochure-(final).jpg.

[3] "One Patient, One Health Record," National Electronic Health Record, Ministry of Health, Singapore, 2014, last viewed October, 22, 2019, https://www.moh.gov.sg/docs/librariesprovider5/resources-statistics/educational-resources/english-brochure-(final).jpg.

> them to access a patient's records easily from a single electronic file, doctors can read test results as they are entered, including image files such as X-rays even from remote hospitals.
>
> For assuring the integrity of retrieved electronic medical records as well as system access logs, the KSI [Keyless Signature Infrastructure] blockchain technology is being used.[4]

Estonia's system covers 99% of the population. The government also uses the system to produce national health statistics and other system-level reporting.

Similarly, Costa Rica won a 2019 United Nations Public Service Award for the development of its national personal health record system, the Single Digital Health File (Expediente Digital Único en Salud, or Edus).[5] Through the Edus smartphone app, a patient is promised the following advantages:

> You will have access to consult and update your personal data and upcoming and previous medical appointments, as well as request or cancel your appointments and those of your dependents in the assigned health establishment, validation of rights, prescribed medications, diagnoses and allergies, among other data. Additionally, you will be able to verify your medical care rights and have access to the help section.[6]

There is actually a long list of firms that have tried to develop personal health records in the United States in the past. There have been Microsoft with its HealthVault,[7] Google Health,[8] and the Dossia Consortium involving Intel and Walmart.[9] However, most of these firms entered the market before health data were digital, so often the models were based on patients having to load data manually into their record.

In 2009, the US government put massive investment into electronic health record systems for hospitals and physicians through the Health Information Technology for Economic and Clinical Health Act (HITECH Act). This legislation was a significant setback to a PHR strategy in the United States since the rules implementing the legislation encouraged EHR systems to be built on top of provider-based frameworks that were often incompatible with a PHR architecture.

Almost a decade later, the original HITECH architects expressed an interest in PHR frameworks. David Blumenthal, formerly the national coordinator for health information technology under President Barack Obama, was sponsoring the Digital Health Advisor app initiative at the Commonwealth Fund.[10] Aneesh Chopra, former chief technology officer of the United States, touted Apple's development of a personal health record as a "game-changer." In a jointly written

[4] "E-Health Records." E-Estonia. Last modified June 1, 2017. https://e-estonia.com/solutions/healthcare/e-%20health-record/.

[5] "Naciones Unidas Premió Al Expediente Digital De La CCSS." Presidencia De La República De Costa Rica. Last modified May 21, 2019. https://presidencia.go.cr/comunicados/2019/05/naciones-unidas-premio-al-expediente-digital-de-la-ccss/.

[6] Caja Costarricense de Seguro Social. "EDUS - Apps on Google Play." Google Play. Accessed April 14, 2020. https://play.google.com/store/apps/details?id=com.ccss.expedienteunico&hl=en_US.

[7] "Microsoft Launches HealthVault - Platform for the People." Healthcare IT News. Last modified December 27, 2008. https://www.healthcareitnews.com/news/microsoft-launches-healthvault-platform-people.

[8] "Cleveland Clinic Teams with Google in Online Health Record Pilot - MM&M - Medical Marketing and Media." MM&M - Medical Marketing and Media. Last modified February 21, 2008. https://www.mmm-online.com/home/channel/cleveland-clinic-teams-with-google-in-online-health-record-pilot/.

[9] "About Us: A Passion for Personal and Population Health," Dossia Consortium, accessed June 28, 2018, http://dossia.org/about-us.html.

[10] "Envisioning a Digital Health Advisor", The Commonwealth Fund, accessed November 10, 2019, https://www.commonwealthfund.org/blog/2016/envisioning-digital-health-advisor