

Independent Decision Support at the Point of Care with HIE of One and NOSH

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Executive Summary

Decision support information, such as presenting the cost of a pharmaceutical or lab test, the out-of pocket expense of a referral, or the most likely differential diagnoses, is rarely available to patients at the point of care when questions and changes are most effectively considered. Even physicians, with access to sophisticated health IT at the point of care, often lack independent and unbiased cost and quality information when such information conflicts with the business imperatives of the institution that supplies their electronic health record (EHR). The lack of independent decision support information limits the opportunities for innovation and practice reform and delays the improved outcomes promised for Meaningful Use Stage 3.

The proposed solution provides decision support information formatted separately for both the physician and the patient during and after engagement at the point of care. By using the HEART specifications for data exchange, HIE of One (Health Information Exchange of One) and NOSH (New Open Source Health) are able to provide decision support independently of the EHR that is being used by the clinician. A HEART-compliant EHR is accessed in near-real time even as the clinician enters an order or writes a prescription. New information is transferred under the control of HIE of One to a patient-centered health record (NOSH) where it can be integrated and used to query any decision support services selected by either the patient or her caregivers. Results of the decision support inquiries are presented separately to the patient and to authorized clinicians via Text message notification with secure links to the information in NOSH.

Illustrating a great feature of the HEART approach, the solution targets providers and patients independently as well as together. Although physician “prescription” is our primary business model, a patient can install HIE of One and manage HEART access themselves. A physician can also install NOSH as a practice management system for his/her coverage group and use HEART patient-directed interoperability to automatically access various EHRs for patient care.

Early adopters will be patients with high-deductible health plans and physicians eager to help reduce their cost. Another group of early adopters will be adult caregivers of elderly patients who often manage medical encounters at a distance by asking the elder’s

physician to communicate via cell phone during their encounter. The remote caregiver and the physician will use HIE of One as variant on telemedicine where the patient is actually local with the physician but the decision maker is remote. In this use-case, the solution can avoid the interruption of a live phone call during the encounter.

The HIE of One and NOSH solution solves cost and consent problems by putting decision support at the point of care under the control of patients and physicians without the cost, delay, and potential conflict of interest of integration with the institutional EHR.

The HIE of One and NOSH Solution

The methods used to develop our decision support solution are decentralization and separation of user authentication from user credentialing. Decentralization is key to a patient-centered approach. By giving each patient their own HEART-standard EHR, we ensure that any decision support service can be prescribed by their caregivers regardless of what EHRs and how many different institutions are involved.

The separation of user authentication from user credentialing is essential to decentralization. It enables standards-based single sign-on for increased cybersecurity and workflow efficiency when providers access the patient-centered EHR. It is our hypothesis that single sign-on has not seen significant adoption in healthcare because identity and credentials are typically bound together at the hospital level. We use OpenID Connect and blockchain user authentication standards to separate credentialing from access to any patient's personal health information (PHI).

The proposed solution utilizes all of the HEART implementation specifications including OAuth2, OpenID Connect, and UMA to synchronize a patient's various EHRs into a patient-centered EHR that, thanks to HEART, can be updated without patient intervention and without interrupting a physician's workflow. Beyond synchronization, we used HEART to demonstrate a seamless transition between a physician's practice management system and a patient-centered health record without even one extra click.

Our deliverables consist of a combined installer for one patient's UMA Authorization Server (HIE of One) and patient-centered EHR (NOSH); a user authentication app that allows fingerprint-secured single sign-on to any OpenID Connect EHR, a hosting referral service, and, in the future, a home health record appliance as an alternative to a monthly hosting bill. All of the components of our solution that touch PHI or access decision support services are already open source software under the GPL v3 license.

A clear benefit of our patient-centered architecture, HIE of One, PBC does not see or store PHI or authenticate users and therefore we do not create a “honeypot” for hackers to breach multiple patients at once. Our solution is HIPAA-compliant when it is operated on a HIPAA-compliant host such as the one HIE of One recommends and resells.

Financial Overview

HIE of One and NOSH are being developed on an open source software business model where development support is a combination of volunteer contributions, charitable donations, and investment by strategic interests that seek access to physicians and patients uncensored by institutional EHRs. Our open source model has long-term impact as it encourages the deep adoption of standards including HEART.

The current versions of NOSH and HIE of One code are the work of volunteer developers, primarily Michael Chen, MD, a practicing family physician. To ease support, the solution will integrate the FreedomBox project of the Free Software Foundation.

This project is endorsed by the Patient Privacy Rights Foundation of Austin, Texas where Adrian Gropper, MD serves as volunteer CTO. HIE of One is likely to be a fundraising initiative for PPR and will benefit from development support as a result.

HIE of One, the Public Benefits Corporation (B-corp) is working through foundations and standards organizations like the World Wide Web Consortium (W3C) to attract strategic investors such as health plans, pharmaceutical, and medical device companies that would benefit from enhanced access to the physician-patient relationship.

Operating revenues for HIE of One and NOSH will flow through HIE of One, PBC as payment for software hosting, directory, end-user support, and privacy registry services. Consistent with open source and a public benefits corporation charter, these services will be offered on a non-exclusive basis but protected by copyright and trademark.

We project a \$2 Million investment will be needed to bring the initial solution to market. This money will mostly be spent on industrial design of the user interfaces and user experience, HIPAA Compliance, and public relations efforts to drive adoption.

Development Plan and Timeline

The first version of HIE of One and NOSH was demonstrated as a proof-of-concept to HEART in February 2016. We added the capability of decision support via an interface

to the GoodRx API that provides a text message to the patient with linked price alternatives at various pharmacies in March 2016 (See slides for demo screens).

A second version of HIE of One and NOSH is available as of August 2016. It has a much simpler user experience and has reduced the cost of hosting the solution by 1/8. We are at our near-term goal of \$10 / patient / month hosted or \$100 for a home appliance. This version is primarily intended to demonstrate the HEART user experience to the HEART workgroup as we continue work on the profiles. It will also help solicit foundation and strategic sponsor support for the beta phases to follow.

The third phase of development will move from a proof-of-concept to actual patient beta in a hosted environment. This will add Bitcoin-level high security and HIPAA compliance via a secure mobile app that will control encryption of all data and sharing protocols. An application partner has agreed to provide the open source security and authentication app for the beta release. The patient beta release is planned for January 2017. A public beta release, including a public website and paid support is planned for May 2017.

Success Metrics

The metrics of open source projects and B-corporations like HIE of One are based on adoption and public benefit. Our primary metric will be the size of the user community in general and HIE of One, PBC revenues for hosting referrals, appliances, and support.

Risks, Mitigations and Security Constraints

The principal risk, given that much of the code already exists (a version of NOSH has been in clinical use since 2010), is delay in support of the HEART profiles by EHRs. We are mitigating this risk by keeping operating expenses to a minimum.

In parallel, we also have the opportunity to promote the HEART-compliant NOSH EHR to direct medicine and telemedicine physicians rather than wait for HEART implementation by the EHR vendors. This will grow our user community and promote patient-directed health information exchange based on HEART.

HIE of One and NOSH are a decentralized design that does not create a “honeypot” of personal health information as it grows. Each patient and each physician practice is a separate instance and breach of one HIE of One is a breach of one. The open source code does not depend on security by obscurity and leverages the transparency and community attention that makes open source the rule in high security projects. Our open

source business model and technology have demonstrated success in the majority of security-intensive markets.

Participants

Adrian Gropper, MD is CEO of HIE of One, PBC and CTO of Patient Privacy Rights. He is a co-founder of the HEART workgroup and a well-known advocate for patient-centered longitudinal health records and patient-directed health information exchange. He is an experienced serial entrepreneur in medical devices including two IPOs. He holds an engineering degree from MIT and an MD from Harvard Medical School.

Michael Chen, MD is the founder and lead developer of NOSH and CTO of HIE of One. He is a board-certified family physician who currently has an active DPC (Direct Primary Care) practice in Vancouver, Washington with Paladina Health as well as working at an urgent care center in Portland, Oregon for the Portland Clinic. He has experience in developing web-based medical applications with an intuitive user interface for clinical workflows and an interest in patient safety and patient-directed health information exchange. His MD is from the University of Missouri-Columbia School of Medicine.

J Randolph Bak, MD JD is COO and the Privacy and Security officer of HIE of One. A practicing pediatrician, he is also a consultant in health policy, information systems, reimbursement, and health insurance. His MD is from Temple University School of Medicine and his JD is from the University of Washington School of Law.

Additional participants in the project include Microsoft Azure as HIPAA-compliant hosting provider and Consensys uPort as supplier of the secure user authentication app. These have already announced their intent to work together to create a secure hosting environment. In addition, Patient Privacy Rights Foundation is a supporter and will act as registrar for our privacy policies and our initial decision support partners.

Conclusion

Meaningful health reform requires practice reform and that is currently hampered by implementation delay and strategic manipulation of information technology at the point of care. This challenge is clearest when it comes to decision support information for physicians and patients. HEART is the key to patient-directed exchange at a national scale. HIE of One leverages the HEART standards to enable independent decision support at the point of care that is essential for practice reform and improved outcomes. Physicians can adopt our patient engagement solution incrementally, patient by patient.