Appendix: Content Summaries of Selected Best Papers for the IMIA Yearbook 2018, Section Health Information Management

Roehrs A, da Costa CA, da Rosa Righi R
OmniPHR: A distributed architecture model to integrate personal health records
J Biomed Inform 2017 Jul;71:70-81

The authors discuss a distributed architecture model, called OmniPHR, to integrate personal health records (PHRs). The authors' research goal is to answer how to have a single view of a PHR that is up-to-date and interoperable for patients and providers. The proposed model focuses on a distributed approach where patients can maintain a unified view of their health history, from any device anywhere. The approach recognizes current challenges since patients' health data are collected throughout their lives, across the care continuum, and come from multiple and diverse sources, including clinicians, laboratories, clinics or hospitals, and data from sensors that monitor the patients' health. The article summarizes the main concepts, challenges, and models that support the authors' proposal; explains the most significant related work; presents the foundational technologies for model development; details the architecture model; provides the evaluation and methodology of the study; summarizes the results and discusses the impacts, limitations, and future directions; and presents the conclusions of their work.

Setting the stage for their proposal of a computer architecture model for PHRs based on a distributed P2P (peer-to-peer) network system, the authors apply the International Organization for Standardization's (ISO) Technical Committee (TC) 14639 (Health informatics – Capacity-based eHealth architecture roadmap – Part 2: Architectural components and maturity model) definitions for EHRs and PHRs. The authors include discussions about the limitations and the challenges of EHRs and PHRs. A summary of other models described in the literature is also included. The authors discuss the technologies that complete their proposed solution and how they are interconnected with the proposed model. These technologies include: Blockchain, Routing Overlay, openEHR standard, Chord algorithm, and Publish-Subscribe systems. Following the discussion of the model and technologies, the authors provide an additional description of the model's purpose (to allow a unified view of health records which are distributed in several health organizations) and they address the challenges regarding a distributed architecture that is scalable, elastic, and interoperable.

The next section of the paper focuses on the modules and components of OmniPHR design and includes descriptions of each. The authors describe the use of the modeling and profiling methodology to evaluate mobile applications. Their goal is to describe and evaluate scenarios of use where OmniPHR can be applied. The authors also describe and depict the mathematical systems analysis that was undertaken and then provide an extensive discussion of the findings and results. Limitations of the model are described and the authors identify challenges and opportunities. For example, one key challenge for the model is the need to verify the identity and authenticity of the data informants (sources). The need to assure data validity, chain of trust, and security and privacy are also discussed and the need for further testing for security and privacy is noted.

Klein DM, Pham K, Samy L, Bluth A, Nazi KM, Witry M, Klutts JS, Grant KM, Gundlapalli AV, Kochersberger G, Pfeiffer L, Romero S, Vetter B, Turvey CL
The veteran-initiated electronic care coordination: a multisite initiative to promote and evaluate consumer-mediated health information exchange
Telemed J E Health 2017 Apr;23(4):264-27

This pilot study examines the potential of consumer-mediated health information exchange, which gives patients access and control of their health data for promoting continuity of care. Although veterans receive most of their care at the Veterans' Affairs (VA) facilities, many veterans, referred to as 'dual use', receive some care outside the VA. The VA Office of Rural Health and the Health and Human Services Office of the National Coordinator for Health IT partnered to promote the use of My HealtheVet's Blue Button capability to facilitate transfer of VA health information to non-VA providers to improve care coordination for rural dual-use veterans. The VA launched the Blue Button feature in My HealtheVet, the VA's patient portal, in August 2010. In 2013, a Continuity of Care Document (CCD) in standardized format became available. The VA CCD includes essential information (allergies, medications, diagnoses, immunizations, recent lab results, vital signs, history of procedures, and encounters) from the VA's electronic health record (EHR) that is accessible via the Blue Button.

In this study, VA facilities and rural community healthcare organizations collaborated to develop optimal processes for information exchange. The researchers also engaged and trained veterans in health information sharing (i.e., how to use the Blue Button). The project developed methods for evaluating patient and provider impact of this sharing. The goals of the project were to: (1) train dual-use rural veterans to use the VA's My HealtheVet Blue Button capabilities to promote consumer-mediated HIE of their VA CCD with their non-VA care providers, and (2) evaluate if the availability of VA information at a community clinical encounter impacted the care received.

The authors provided details about how these processes were undertaken and accomplished. Approaches and methods available for veterans to share data with non-VA providers varied and veterans were trained in these processes. Veterans were asked to complete a brief questionnaire after training to evaluate their experiences. Non-VA ("community") providers were also asked to complete a questionnaire to help assess provider satisfaction with the CCD and whether the provider believed the CCD had an impact on the care provided. Detailed analyses were conducted in the following areas: patient characteristics and perceptions of provider communication; patient training evaluation; and data sharing at community non-VA provider visits. Study limitations (such as site variation for patient engagement/training; lack of a comparison

group; and potential for participant selection bias (veterans' level of interest in health and technology) were described.

The authors conclude that the pilot demonstrated the feasibility and value of patient access to a standard CCD to facilitate information sharing between VA and non-VA providers. With brief training, veterans were able to generate their CCD in My HealtheVet, share it with non-VA providers, and benefit from improved communication about medications and reduced laboratory test duplication. Thus, the authors found that there is patient and provider support for consumer-mediated HIE and they noted that this type of HIE requires outreach and targeted education.

Boockvar KS, Ho W, Pruskowski J, DiPalo KE, Wong JJ, Patel J, Nebeker JR, Kaushal R, Hung W

Effect of health information exchange on recognition of medication discrepancies is interrupted when data charges are introduced: results of a cluster-randomized controlled trial

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The authors explored the effect of health information exchange (HIE) on medication prescribing for hospital inpatients in a Veterans Administration hospital in a cluster-randomized controlled trial and examined the prescribing effect of availability of information from a large pharmacy insurance plan in a natural experiment. They recognized that a key step in medication reconciliation is information-gathering from various sources such as patients, family members, providers' offices, health care facilities, pharmacies, and prescription coverage plans and postulated that [regional] HIEs could improve medication safety by facilitating reconciliation of medication information from multiple sources at the time of patient care. The researchers hypothesized that HIE would raise the impact of medication reconciliation for hospitalized veterans who utilize VA and non-VA services on discrepancies between preadmission and inpatient medication regimens (primary outcome) and reduction of ADEs (secondary outcome). Patients were assigned to intervention or control groups according to the hospital unit(s) to which they were admitted.

The study describes the methodology, protocols, and quality controls in detail. For patients assigned to the intervention group (HIE-enhanced medication reconciliation), an intervention pharmacist conducted HIE-enhanced medication reconciliation, following a structured protocol. For patients assigned to usual care, the intervention pharmacist performed the structured medication reconciliation protocol but without access to the information available from HIE. The study defined medication discrepancies as differences between a patient's prehospital medication list and the medications received in the hospital. The discrepancies were initially identified and recorded by the unblinded intervention pharmacist at the time of admission medication reconciliation. The unit of observation was hospitalization episode. For each study group, descriptive statistics were used to describe patient and hospitalization characteristics, time from hospital admission to medication reconciliation, and house staff rectification of medication discrepancies.

Results indicated that there were no significant differences between intervention and control groups in baseline characteristics. The mean time from hospital admission to medication reconciliation in both intervention and control groups was the same. The researchers also found that there were no differences between intervention and control groups in numbers of verbal or co-signature alerts that the intervention pharmacist provided to physicians. However, patients who received HIE-enhanced medication reconciliation with pharmacy insurance data available had greater risk-weighted medication discrepancies identified than those who received usual care. There were no differences in ADEs between those assigned to HIE-enhanced medication reconciliation and those assigned to usual care, or between those who received HIE-enhanced medication reconciliation with pharmacy insurance plan data available and those who received usual care.

Study limitations were described and include: low house staff responsiveness to medication discrepancy information; delayed mean time from hospital admission to the intervention pharmacist's medication reconciliation; and low level of medication information in the HIE. The authors noted a strength of their study was that they tested the effect of HIE in potentially high-impact circumstances (medication prescribing at the time of hospital admission) and did not depend on voluntary HIE access by the user (the intervention pharmacist was obligated to access HIE for all intervention patients). The authors conclude that HIE may improve outcomes of medication reconciliation. However, the authors raise concerns related to potentially harmful consequences of charging for access to information (in this case payment data) and related to information blocking practices.

Downing NL, Adler-Milstein J, Palma JP, Lane S, Eisenberg M, Sharp C; Northern California HIE Collaborative, Longhurst CA

Health information exchange policies of 11 diverse health systems and the associated impact on volume of exchange

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Focusing on health information exchange (HIE) across 11 health systems that all used the same electronic health record, the authors conducted a retrospective time series analysis of the effect on the monthly volume of clinical summaries exchanged of automatic querying and different processes for patient consent. The consent processes included using the general consent for treatment to cover the consent for HIE vs. requesting specific consent for each individual need for HIE. The researchers did not assess degree of use or usefulness of the information exchanged (care summaries), organizational decision-making processes, or generalizability to other vendors.

Given the policy levers and financial incentives available to providers, a variety of approaches to health information exchange (including community-based exchange networks, enterprise-based exchange networks, and electronic health record (EHR) vendor-based platforms) have been implemented. While each approach reflects various technological solutions, there are

also operational, logistical, and management processes, and decisions that are embedded within each exchange. The study objective was to examine the relationship between electronic exchanges of patient health information across organizations and organizational HIE policy decisions.

The researchers looked at data on organization-level HIE policy decisions and their impact on HIE volume from a diverse set of health care systems using the same EHR-based HIE platform. The focus of the policies was on whether to automatically search for information from other organizations whenever a patient with data in those organizations presented for care, and whether to require HIE-specific patient consent. Their research questions were: 1) What proportion of organizations chose to engage in automatic querying and what is the associated impact on the volume of clinical summary exchange? 2) When automatic querying is enabled, what proportion of patient linkages are established automatically (representing information at another institution that the provider did not know to seek) vs. manually requesting the information (representing information the provider knew to seek)? and (3) What proportion of organizations chose not to require specific patient consent for HIE and what is the associated impact on the volume of clinical summary exchange?

The study covered a 2-year period from January 1, 2013, through February 28, 2015, and included linkages made and clinical summaries transferred across all clinical settings within each institution (such as outpatient clinics or other settings, emergency departments, and inpatient stays). Study limitations included: the inability to normalize exchange volume to account for the volume of patient care; inability to determine the extent to which clinical summaries were used for patient care; lack of information on how providers decided to implement their approach (auto-query or consent); and inclusion of only institutions using a single vendor-based HIE platform.

The authors found that automatic querying and not requiring specific consent for HIE for each individual care episode appeared to substantially increase exchange volume. They conclude that these organizational HIE policy decisions impact the volume of exchange, and ultimately the information available to providers to support optimal care.