Guest Editors’ Introduction

Contemporary Web-based architectures can help us address the technological and architectural challenges inherent to modern personal health record (PHR) systems. Current research in the area of healthcare informatics has focused on incorporating Web-based technology for PHR systems’ primary functions. This special issue presents work in this area of research. First, however, let’s look at how PHR systems are defined, examine some of their benefits, and examine possible barriers to their widespread adoption.

PHR Systems Defined
A summary of an American Medical Informatics Association (AMIA) College of Medical Informatics Symposium presents the following accepted definition for a PHR:

An electronic application through which individuals can access, manage, and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.1

PHRs let individuals monitor and share their healthcare information with healthcare providers as well as third-party health and wellness providers, such as applications for healthy living and weight management. The acronym PHR is often used interchangeably with PCHR (Personally Controlled Health Record), and the definition just given applies to both. The use of technology to let individuals share healthcare information makes PHRs an important aspect in how patients and providers manage care in the future. Whereas only healthcare providers can keep and maintain electronic health records (EHRs), PHR record systems are controlled by the patient. For example, Google and Microsoft each offer their own healthcare platforms (Google Health [www.google.com/health/] and Microsoft HealthVault [www.healthvault.com], respectively) that let users self-manage certain aspects of care.

PHR platforms could radically move the locus of control over health information to the patient (consumer).
Kenneth Mandl and Isaac Kohane have described the provision in these PHRs that lets patients control “what they can do with their health information and who they can share the information with” as a “tectonic shift in the health information economy.” PHR systems are in contrast to the traditional clinician’s record of patient encounter-related information managed within a healthcare institution. Consequently, they’re a disruptive innovation that inverts the status quo of healthcare information flow in that they’re created by and reside with patients who grant permissions for their use to institutions, clinicians, researchers, public health agencies, and other consumers of medical information.

Ubiquitous PHR System Use
PHR systems are emerging as a common component within the healthcare information ecosystem. One recent study reports the estimated number of people in the US with access to PHR systems as 70 million; 50 million of these are patients who have healthcare providers with EHRs that include a tethered PHR component. Most of these systems are Web-based.

Most of the major players in the US healthcare system have recognized PHR systems as an important component. In particular, the Department of Health and Human Services (HHS), the National Coordinator for Health Information Technology (HIT), and the Centers for Medicare and Medicaid Services (CMS) have all identified PHRs as a top priority for healthcare going forward.

PHR Benefits
PHR systems help develop closer interactions with patients to improve patient satisfaction and efficiency in the provision of care. They also empower patients to better participate in their own care and improve the management of chronic illnesses. In addition, such systems are (in some cases) better suited to facilitate the flow of information than those that rely on inter-institutional data-sharing agreements.

Two areas in which PHR systems have the greatest recognized potential are for patients with long-term conditions and for leveraging the mobile and remote submission of patient data to facilitate patient monitoring and decision support. The use of Web-based portals accessible outside the primary care context facilitates such interactions.

Patients can also anticipate benefits from PHR systems. Claudia Pagliari and her colleagues have gathered a reasonable amount of information regarding the functions most patients expect from such systems. Patients are interested in better access to their EHR data, tracking test results and medications, and having medical offices that use the Web and email to facilitate patient-initiated appointment scheduling and communication with primary care physicians.

Intuitively, a major benefit to a patient having his or her medical information in such a system would be that authorized medical professionals and other trusted parties or agents could access it from anywhere. Indeed, such a repository of patient data should be as easy to interface with — but no less secure than — bank accounts via ATMs, which we can now access anywhere in the US or most of the world.

PHR Disruption: Implementation, Opportunities, and Challenges
The Internet and the Web are continually evolving from earlier closed systems that served authored content via Web pages to open systems that allow for content creation and data sharing. A significant fallout of this evolution (popularly defined as Web 2.0) has been the emergence of data as a critical entity in the Internet ecosystem. PHRs’ arrival does to healthcare data what Google Maps did to mapping data. Just as Google Maps provided a systematic way to access geological information that has been traditionally owned and copyrighted by mapping service providers such as NavTeq and TeleNav, PHRs enable users to access healthcare information that has been traditionally siloed with healthcare providers.

A defining concept in Web 2.0 evolution is that of rich Internet applications, which bring data from multiple sources together in ways such that the whole is greater than the sum of its parts. The arrival of the Google Maps API heralded a slew of innovative mashups that demonstrated the value and utility of this new breed of applications. PHRs are beginning to have a similar impact by enabling third-party application developers to create rich Internet healthcare applications. Lastly and most importantly, PHRs have created a way for users to access their healthcare information anywhere and at any time.
The central goal of PHR platforms such as Google Health, Microsoft HealthVault, and Dossia Indivo (http://indivohealth.org) is to let patients use their health information for better self-management via the applications and services built on these platforms. Third-party applications such as Livestrong (http://livestrong.com) and TrialX (http://trialx.com) re-use the data within a patient’s PHR (with due patient consent and with required measures to protect patient privacy) and provide personalized and useful services. For example, patients can connect with Livestrong from within Google Health and get personalized recommendations to meet their fitness goals.

In addition, the PHR model can have a potentially dramatic effect on addressing the current roadblocks that exist in utilizing medical records for research purposes, as patients can now give their consent to third-party application providers such as TrialX, a clinical-trial matching service. TrialX uses the wealth of available information in PHRs to intelligently help patients with medication conditions to find trials, taking into account such trials’ complex requirements, like inclusion and exclusion criteria.

In this Issue
The three articles in this special issue address some of the challenges and opportunities PHR systems present.

“Beyond Health Tracking: A Personal Health and Lifestyle Platform,” by Florian Daniel and his colleagues, discusses a platform that lets users maintain their own personal health and lifestyle record (PHLR) and use it for personalizing health and lifestyle habits. A PHLR integrates lifestyle information with the health information contained in a PHR. The authors present a computational model to represent and use the lifestyle information. The PHL platform they discuss uses the PHLR to offer a training plan based on a user’s current physical and health conditions, and supports progress monitoring.

“Creating a Virtual Personal Health Record Using Mashups,” by Ronan Fox, James Cooley, and Manfred Hauswirth, addresses the challenges arising today due to the centralized nature of current PHR systems in environments that are heterogeneous and require personalization and distributed collaboration. The article cites telehealth services as an example of such an environment and proposes using trusted online social networks as a way to deliver such services. These networks use a virtual PHR approach based on integrating data from various sources on the Web using mashups. The authors present Sqwelch, a system that lets caregivers create mashups that reflect the personalized nature of the care being provided, while giving users privacy control.

Sharing and proper information use is an important aspect of modern electronic healthcare systems. E-health technologies provide efficient and effective ways of sharing medical information but give rise to various issues. Information security and patient privacy are key impediments that hinder the secure sharing of PHR systems. “Sharing with Care: An Information Accountability Perspective,” by Randike Gajanayake, Renato Iannella, and Tony Sahama, investigates the role of information accountability when health information is shared through electronic media among healthcare participants and other agents.

The articles in this special issue demonstrate not only the technical issues but the progress being made in implementing such platforms. PHRs are important for healthcare providers as well as consumers. Having access to a patient’s entire history on an electronic record will both improve healthcare and lower costs. Providing patient-controlled PHRs will likely enable a new industry in which cloud-like companies compete to offer secure records to individuals, much like backup and security systems for PCs today. Indeed, PHRs are a major near-term Internet application.

References
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Infrastructures for Online Social Networking Services (May/June 2012)

Final submissions due 1 September 2011

Please email the guest editors a brief description of the article you plan to submit by 15 August 2011

Guest Editors: Anwitaman Datta, Marios D. Dikaiakos, Seif Haridi, and Liviu Iftode (ic3_2012@computer.org)

The proliferation of rich social media, online communities, and collectively produced knowledge resources has accelerated the convergence of technological and social networks, resulting in a dynamic ecosystem of online social networking (OSN) services, environments, and applications. OSN sites’ success is reshaping the Internet’s structure, design, and utility. It’s also creating numerous challenges and opportunities for the development, deployment, management, and operation of scalable, secure, interoperable OSN infrastructures that can sustain a cycle of innovative application development, improved end-user experience, high-quality service provision, privacy protection, and a healthy market expansion.

This special issue seeks recent research results in systems, software, and services that provide novel ubiquitous, scalable, secure, and trustworthy OSN infrastructures. Topics of interest include

- architectures, algorithms, and protocols for scalable and trustworthy OSN infrastructures;
- infrastructure support for security and privacy;
- software platforms for social-networking-centric applications and services;
- storage systems and data management issues;
- infrastructures for mining OSN data and social interactions, and measuring and monitoring social networks and activities;
- OSN infrastructures for mobile devices, vehicular networks, and location-based services;
- innovative OSN-centric applications and services; and
- adaptivity and self-management in OSN infrastructures and services.

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