Chapter 54
A Case for Enterprise Interoperability in Healthcare IT: Personal Health Record Systems

Mustafa Yuksel
Software Research Development and Consultancy Ltd. (SRDC), Turkey & Middle East Technical University (METU), Turkey

Asuman Dogac
Software Research Development and Consultancy Ltd. (SRDC), Turkey

Cebrail Taskin
Argela Software and Informatics Technologies, Turkey

Anil Yalcinkaya
Argela Software and Informatics Technologies, Turkey

ABSTRACT
The PHR systems need to be integrated with a wide variety of healthcare IT systems including EHRs, electronic medical devices, and clinical decision support services to get their full benefit. It is not possible to sustain the integration of PHRs with other healthcare IT systems in a proprietary way; this integration has to be achieved by exploiting the promising interoperability standards and profiles. This chapter provides a survey and analysis of the interoperability standards and profiles that can be used to integrate PHRs with a variety of healthcare applications and medical data resources, including EHR systems to enable access of a patient to his own medical data generated by healthcare professionals; personal medical devices to obtain the patient’s instant physiological status; and the clinical decision support services for patient-physician shared decision making.

INTRODUCTION
The Personal Health Record (PHR) systems have evolved from Web pages where patients entered their own data manually to the systems giving patients access to their electronic health records (EHRs) from a healthcare provider. The latter is called a provider-tethered PHR system, and the data from a healthcare provider’s information system such as an EHR or a laboratory system is entered into the PHRs automatically via the data exchange interfaces established among these systems. There are also employer/payer portals providing patients access to claims data and more.

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recently third party PHR systems such as Microsoft HealthVault (http://www.healthvault.com) that provides a secure storage for PHR data together with data exchange interfaces so that third parties can develop applications to upload patient data from a specific system or source, for example, home health devices.

The intent of all of these systems is to give patients better access to their own healthcare data (Halamka et al., 2008). The PHR is defined as “a tool for collecting, tracking and sharing important, up-to-date information about an individual’s health or the health of someone in their care” (American Health Information Management Association et al., 2007, p. 1). It typically contains information about an individual’s diagnoses, medications, allergies, procedures, lab test results, immunization records and other personal health information. Many PHR systems also provide linkages to convenience tools such as requesting appointments, requesting prescription renewals, asking billing questions and communication tools to assist the patient in connecting with various healthcare professionals.

However, currently all this integration is achieved mostly in a proprietary way and in a fragmented fashion rather than using the standard interfaces. A recent survey investigating the major 48 PHR systems on the market discovered that almost none of the PHRs use existing medical standards for the storage and communication of their data (Helmer et al., 2011). Given the existing semantic and technical diversity of eHealth platforms, each integration effort with a new system will be an expensive process unless standard interfaces are used for data exchange.

In this chapter, we present a survey and analysis of interoperability standards to connect the PHR systems to healthcare applications and medical data resources including EHR systems, personal medical devices and clinical decision support services. Some of these standards are specifically developed for the PHR systems; some are general standards that can also be used in the PHR systems. Additionally, because PHR systems contain a summary of EHR data, some EHR standards directly apply. For the sake of completeness, we present an analysis of all these standards as they apply to the PHR systems.

The chapter is organized as follows: A motivating example based on a visionary scenario is presented in the next section. Then, a classification of the PHR interoperability standards is provided, which is followed by a section on the EHR-PHR interoperability content standards and profiles. The succeeding section classifies the terminology systems based on the underlying structure and the knowledge representation formalism which determine the way they express the semantics and hence help with the interoperability. After that, the medical device interoperability standards and profiles for importing medical device data to patient’s PHR are introduced. The standards relevant for clinical decision support services are covered in another section. Finally, the last section concludes the chapter.

A MOTIVATING EXAMPLE

Mr. Smith visits his general practitioner (GP) with the symptoms of pain in his joints. The results of laboratory tests as well as radiographs indicate rheumatoid arthritis with high risk of damage in the joints. The GP refers the patient to a rheumatologist in the local hospital.

The local hospital that Mr. Smith is referred to has a care management system for rheumatoid arthritis, which provides a care plan for shared decision making between the physician and the patient to help them monitor the progress jointly. The care plan is a workflow based on “National clinical guideline for management and treatment of rheumatoid arthritis in adults,” and it is processed and visualized through a clinical decision support service.