Chapter 6
An Approach to Participative Personal Health Record System Development

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ABSTRACT

Healthcare delivery is undergoing radical change in an attempt to meet increasing demands in the face of rising costs. Among the most intriguing concepts in this effort is shifting the focus of care management to patients by means of Personal Health Record (PHR) systems which can integrate care delivery across the continuum of services and also coordinate care across all settings. However, a number of organizational and behavioral issues can delay PHR adoption. This chapter presents a general approach to breaking down barriers that exist at the level of individual healthcare professionals and consumers. According to this approach, user participation in PHR system development is considered essential for achieving systems implementation success. Realizing a participative PHR system development, where users are full members of the development team, requires not only choosing an appropriate methodology but also organizing the participation process in a way that is tailored to the particular situation in order to achieve the desired results.

INTRODUCTION

Throughout their lives, individuals receive care in various healthcare organizations. This results in patient health data being scattered around disparate and geographically dispersed information systems hosted by different healthcare providers (Koufi and Vassilacopoulos, 2008; Tang, Ash, Bates, Overhage and Sands, 2006). The lack of interoperability among these systems impedes optimal care as it leads to unavailability of important information

regarding patient health status when this is mostly needed (e.g. in case of an emergency).

Recently there has been a remarkable upsurge in activity surrounding the adoption of Personal Health Record (PHR) systems for patients (Tang, Ash, Bates, Overhage and Sands, 2006). A PHR is a consumer-centric approach to making comprehensive electronic health records (EHRs) available at the point of care while protecting patient privacy (Lauer, 2009). Unlike traditional EHRs which are based on the 'fetch and show' model, PHRs' architectures are based on the fundamental assumptions that the complete records are held on a central repository and that each patient retains authority over access to any portion of his/her record (Lauer, 2009; Wiljer, Urowitz, Apatu, DeLenardo, Eysenbach, Harth, Pai, Leonard, 2008). In essence, a PHR is a health record bank account which operates much like a checking account (Yasnoff, 2008). Instead of depositing money, healthcare providers deposit copies of the patients' new records after each care episode (which they must do at the patient's request under the Health Insurance Portability & Accountability Act, or HIPAA) (Yasnoff, 2008). Thus, an entire class of interoperability is eliminated since the system of storing and retrieving essential patient data is no longer fragmented. Hence, quality and safety of patient care is enhanced by providing patients and health professionals with relevant and timely information while ensuring protection and confidentiality of personal data.

Providing patients with access to their electronic health records offers great promise to improve patient health and satisfaction with their care, as well as to improve professional and organizational approaches to health care (Wiljer, Urowitz, Apatu, DeLenardo, Eysenbach, Harth, Pai and Leonard, 2008). In particular, much potential can be realized if cooperation among disparate healthcare organizations is expressed in terms of cross-organizational healthcare processes, where information support is provided by means of PHR systems. Under this process-oriented, patient-centric model, health systems can integrate care delivery across the continuum of services, from prevention to follow-up, and coordinate care across all settings. Thus, healthcare processes are supported in a more direct way, since tasks to be performed are actively delivered to the right persons at the right time with the necessary information and the application functions needed (Reichert & Dadam, 1998). Workflow technology provides an appropriate infrastructure to realize process-oriented PHR systems. It allows modeling the control and data flow within healthcare processes separately from the implementation of the application programs (Malamateniou & Vassilacopoulos, 2002). It supports the controlled exchange of information between them, it provides worklists to users and it invokes the application programs associated with work items from these lists.

Although many benefits have been identified, there are many questions about best practices for the implementation of PHR systems (Wiljer, Urowitz, Apatu, DeLenardo, Eysenbach, Harth, Pai and Leonard, 2008). As with EHR, a number of impediments to PHR adoption has been identified which is not limited to technical ones. In addition to the economic and technical challenges, organizational and behavioral issues can delay PHR adoption. Barriers exist both at the environmental level and at the level of individual consumers and healthcare professionals (Tang, Ash, Bates, Overhage and Sands, 2006). With regard to consumers, individual-level barriers are due to the concerns consistently ranked by them about security and privacy of PHR information (e.g. health, financial). Moreover, the development of a workflow-based PHR system poses problems not encountered in conventional information systems. It requires taking a horizontal, process-oriented view of each healthcare organization and undertaking the system's development process within the context of a process engineering life-cycle (Walter & Herrmann, 1998). This may provoke greater resistance from healthcare professionals as it involves making larger financial, sociocul-

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