Guest Editorial

Project HealthDesign: Advancing the vision of consumer–clinician–computer collaborations

The plea for personal health records (PHRs) has begun to rival the call for electronic health records in national visibility. Activity within the American Medical Informatics Association [1] and the Office of the National Coordinator for Health Information Technology (http://www.hhs.gov/healthit/ahic_ce_archive.html), along with statements by such notable groups as the Markle Foundation [2], the eHealth Initiative [3], the Institute of Medicine [4], and the Robert Wood Johnson Foundation (RWJF), embrace an evolving interdigititation between electronic health records and tools that engage patients and families in health care. Spurred on by the challenge to rethink the power and potential of personal health records, the RWJF grantees of the initial round of what is known as Project HealthDesign present their work through the papers in this supplement.

There are various definitions of PHRs, each of which emphasizes different aspects of what is meant by personal, health, and record. A discussion of these differences is beyond the scope of this supplement; rather, we will rely upon the definition of PHRs promoted by the Markle Foundation, which defines a PHR as 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” [3]. Such products are rapidly increasing, with estimates noting as many as 200 different PHR applications available today [5]. Varying approaches to ensure that the record be patient-controlled are underway, ranging from universal serial bus devices to more sophisticated and robust models of the data that embed access and authorization rights into the metadata of the record [6,7]. Hospitals and clinics also have begun to explore the institutional rules that allow PHRs to be adopted [8].

Products in the current market place claiming to be PHRs arise from technically distinct approaches and largely are based on idiosyncratic perceptions of essential design requirements that are typically provider-centric. However, these visions for PHR development often lack the association with specific use cases. How will these technical approaches scale to meet the demands of a child being cared for in multiple care settings? How well do these approaches align with the types of data and monitoring of an adult with diabetes? What can we learn about health behavior modifications of bi-directional real-time information sharing, while Dr. Fonda’s paper characterizes a surprising finding about patient acceptance of user-triggered versus automatic data collection.

In addition to these immediate concerns, there is the reality of Moore’s Law [9] and the rapid advancement of health information technology that technical progress will enable in the next decade. In addition to their impact on the armamentarium for clinicians, it is likely that devices in development or in limited use outside of the medical domain will transform the evolution of consumer-facing technologies. Recognizing these challenges, Project HealthDesign embraced a modular approach to design, focusing on the human engagement side of the PHR puzzle but also deriving functional requirements common to all applications.

It is in the spirit of this reality that the Robert Wood Johnson Foundation created its Pioneer Portfolio and launched Project HealthDesign as one of its key initiatives. This initiative, which began in 2006, was created to “stimulate innovation in personal health information technology” [10]. After an extremely competitive application process, nine teams were awarded funding to create a user-refined vision and prototype to demonstrate how personal health information technology can solve real problems that patients experience today. These projects encompassed a wide range of medical specialties, patient-care settings, and patient demographics. Each project team worked both independently and cooperatively with other teams to refine visions, to develop common tools, and to present their findings.

Dr. Brennan begins this supplement with an overview of Project HealthDesign [11]. As readers of this supplement will quickly discern, the lessons from these projects transcend the relatively narrow domains in which each team concentrated its efforts. For example, the projects led by Dr. Esserman [12] in the area of care plan development, and by Dr. Chira [13] in a project on the Quality of Life Timeline, both propose transformative models for sharing information and creating new knowledge derived from unconventional data types and information presentations.

Drs. Ferguson [14] and Fonda [15] both assembled teams that addressed the challenges of next-generation data-entry modalities. Dr. Ferguson’s article focuses in particular on the privacy implications of bi-directional real-time information sharing, while Dr. Fonda’s paper characterizes a surprising finding about patient acceptance of user-triggered versus automatic data collection.

Projects by Ross [16], Johnson [17], Luckmann [18], Ralston [19], and Massoudi [20] have focused on data input and output using mobile technologies in the hands of geriatric patients, children, adults with chronic illness, and adults with a desire to modify their health behaviors. Each project has uncovered important insights about the need for, and attitude toward, tailored feedback in the absence of human–human discussion, and the special user interface demands that many of these tasks place on mobile technology platforms. Almost all of the projects described in this supplement have relied on data stored in a common repository. Although this idea has now become commonplace, it was a fairly radical notion three years ago when these prototypes were first being conceived. Dr. Sujansky and his team of developers [21] describe the nuances of this kind of approach to a “common platform” and present some recommendations for vendors building these tools today.
Any set of projects combining the needs of patients with next-generation technology can be expected to inform us about new ethical, legal, and social issues that these ideas raise. Dr. Cushman and his team [22] provide us with an overview of those concerns, many of which were deemed critical to the evolution of the proposed projects.

Collectively, as the discussion above demonstrates, this supplement and its appendices provide a thorough summary of lessons from the first three years of Project HealthDesign. As was the case with every other aspect of this Project, each team has participated actively in the construction of this summary by contributing as authors, reviewers, and even supplement format designers! We thank The Robert Wood Johnson Foundation, the California Health Care Foundation, the editorial staff of the *Journal of Biomedical Informatics*, and the tireless efforts of our colleagues and patients who have made this supplement possible. For more information on Project HealthDesign, see [www.projecthealthdesign.org](http://www.projecthealthdesign.org).

**Conflict of interest**

The author declares no conflicts of interest related to the contents of this editorial.

**References**


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