Technical infrastructure implications of the patient work framework

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In their response to our original paper, "Transforming Consumer Health Informatics through a Patient Work Framework: Connecting Patients to Context," Marceglia and colleagues propose an architecture that integrates the patient work framework into a higher-order framework linking consumer health informatics (CHI) applications and professional health information systems (designated by the authors as the health-Information Technology (IT) ecosystem).[1] The purpose of our letter is threefold. First, we detail how an expanded understanding of the patient work framework already conceptually encompasses the larger contexts in which CHI use must occur. Second, we assert that meaningful application of the patient work perspective yields implications not only for integration with professional health information systems but also with the larger information infrastructures within the community. Third, we propose modifications to Marceglia and colleagues' architecture to explicitly represent a "shared space" between CHI applications and professional health information systems; this space contains collaborative work and collaborative informatics.

Our original patient work framework was intended to serve as a foundation for CHI design by enabling the understanding of people, their daily contexts, and their daily activities. As such, we limited the scope of our discussion to the immediate home and community environments of the patient. We agree, however, with Marceglia and colleagues that a deeper understanding of the macrostructures encompassing patient work is required. This understanding is necessary not only for specifying constraints on the design outcome, but also for generating creative design alternatives. Larger macrostructures are included in the human factor engineering and social science theories that form the core of the patient work framework; consequently, they are already conceptually embedded.[2–4] These macrostructures include not only the larger technological infrastructure (including, but not limited to, the health-IT ecosystem specified by Marceglia and colleagues), but also the economic, regulatory, and policy landscapes. For example, awareness of insurance policies may lead designers to plan for a future in which CHI applications are covered entities. However, designers of applications for people with low socioeconomic status and less generous health insurance plans may need to pursue low-cost alternatives. Designing for populations that use older hardware or operating systems will similarly require technological challenges to be understood and addressed, such as the backward compatibility of mHealth applications and Short Message Service (SMS)-based alternatives. In the phase of conceptual design, the second step in our user-centered design process, integrating knowledge of these broader contexts is particularly salient.

Although we agree that the patient work framework can produce valuable insights into connecting CHI applications with professional health information systems, we assert that its technical implications are, in fact, much broader. As an investigational framework, patient work also illuminates numerous areas of connection to a more broadly conceptualized health-IT ecosystem that includes the information infrastructures of patients' homes and communities. To illustrate, we offer a few examples of design alternatives that build upon a recognition of this larger health-IT ecosystem. In the category "physical environment," neighborhood walkability scores and safety information, along with patient health and social network data, may inform the development of strategies for integrating therapeutic physical activity into patients' daily lives. Moreover, establishing a connection between patients and relevant environmental data may facilitate health management planning (e.g., providing a pollen count warning for patients with asthma triggered by seasonal allergies). Smart reminders may also help patients and their caregivers anticipate medication refills when medication usage is seasonally higher. Similarly, the analysis of data from the category "articulation work" may reveal transportation challenges, indicating that linking bus routes, schedules, and location data with patient reminders may assist with appointment-keeping. Long-term solutions may involve linking patients with data regarding insurers that provide transportation assistance or social media–facilitated informal transportation networks. This integrated approach moves beyond the vision of seamless exchange of patient health information to the

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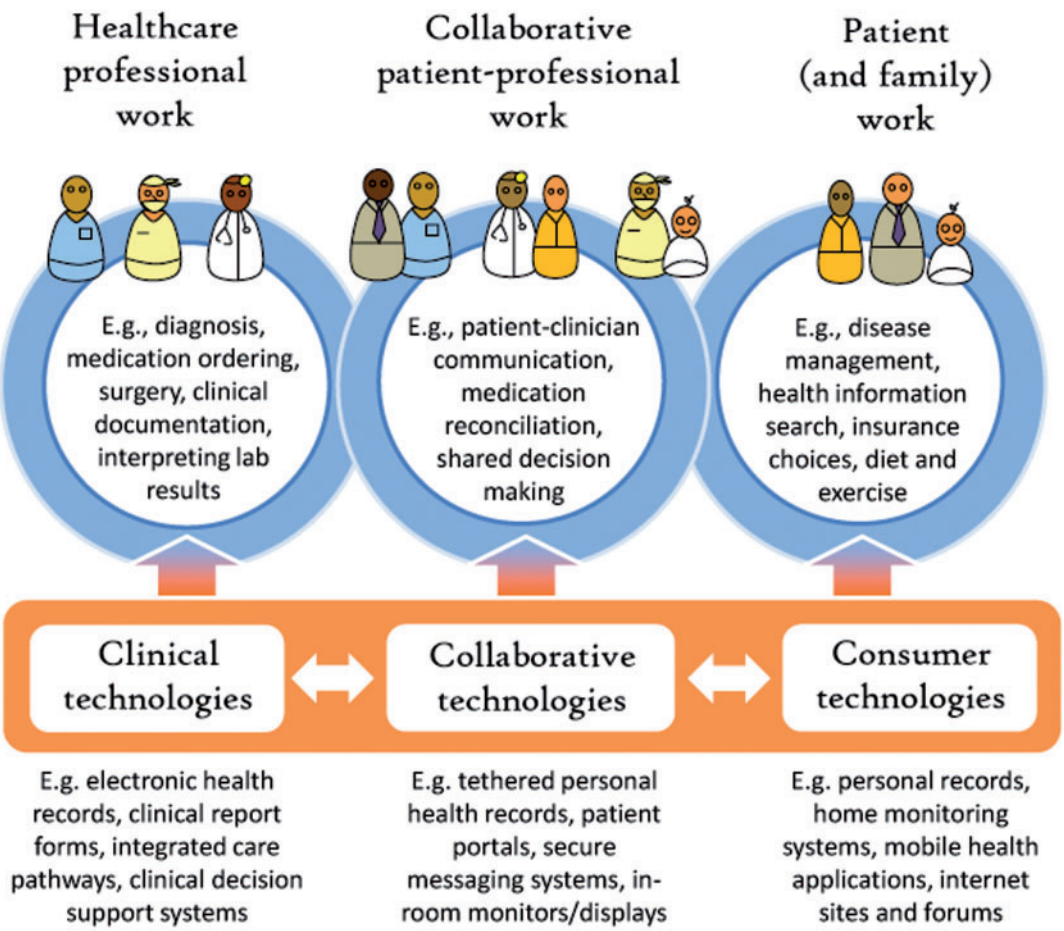
Figure 1: Three forms of work activity performed by professionals, patients, and families, and corresponding technologies (adapted from Holden *et al.* 2013[2] and Marceglia *et al.* 2014[1]).



seamless exchange of all information that, from the perspective of social determinants of health, shapes patient outcomes.[5] Thus, technical architectures to support patient work may be infinitely more complex than those that facilitate data exchange between CHI applications and professional health information systems, despite the importance of efforts in that direction.

The architecture proposed by Marceglia and colleagues creates a clear distinction between CHI applications and professional health information systems. However, we assert that patient and health care provider work are often jointly constructed and performed (e.g., patient-clinician communication/secure messaging, medication reconciliation, family-centered pediatric rounds, and cancer treatment planning). The clinical encounter is often grounded in patient narratives that relate the experience of self-management in the home. Similarly, patients' self-management practices in the home are often influenced by discussions with providers in clinical settings. Patients' health management practices in the home may also involve the presence of health professionals such as physical therapists, social workers, and home care nurses. Consequently, we contend that the proposed architecture should be expanded to contain a middle space for collaborative professional-patient work[2] and informatics solutions (see Figure 1). Collaborative informatics solutions include tethered personal health records, which enable the sharing of both clinic-generated data with patients and patient-generated data with health care providers. We believe that this amendment to Marceglia and colleagues' approach may yield promising directions for system design, focusing on the interconnectedness of and interactions between both sets of work systems. Informatics tools based on such an understanding would promote interoperability not only at the technological and semantic levels but also at the level of work processes.

Achieving the full vision of informatics-supported patient engagement will require understanding and designing solutions that integrate with the numerous macrostructures within which patient work is performed. It will require creating CHI applications that communicate not only with professional health information systems but also with the larger information infrastructures of the community. Finally, it will further necessitate creating informatics

solutions that recognize the collaborative nature of work that ultimately maintains and improves health.

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