

New study evaluates community response to personally controlled health information

May 1 2009

A new paper published in the latest issue of the open access publication *Journal of Medical Internet Research* evaluates consumers' experiences with the Indivo personally controlled health record (PCHR) system - a system developed by researchers in the Children's Hospital Informatics Program (CHIP) more than a decade ago that has been adapted by PCHR providers including Dossia, Microsoft and Google. This is the first report to be published that investigates consumers' response to a platform PCHR and subsequent implications for policy and design.

The two-year study was conducted by CHIP researchers at a university-based health center, where Indivo was promoted to all members of the university community, including undergraduate and graduate students, faculty, staff, retirees and affiliates of the site and setting, regardless of a person's status as a patient of the health center. More than 300 people, ranging in age from 18 to 83, participated in the study via focus groups, interviews, usability testing or a full demonstration of Indivo and shared their experiences, feedback and suggestions with the study team.

"This research comes at an important time," said co-author Kenneth Mandl, MD, MPH, director of the Intelligent Health Laboratory within CHIP. "The Obama administration has made health information technology a priority and we have a unique window of opportunity now, before widespread adoption of PCHRs is realized, to do research - in this case, to see how people in a community access and interact with their health information independent of a clinician or administrator - and determine what changes need to be made and policies put in place, and

get it right."

Observations obtained during the course of the study suggest that issues of health and technology literacy, accessibility, privacy, autonomy, quality and accuracy, age, and social support within households and families are all variables relevant to the adoption and use of PCHRs. Broadly, researchers detected:

- A general feeling of disconnect between people and their health information
- A dramatic overestimation of the extent to which health information data are digitized and flowing in support of patient care
- A lack of awareness of the existence of PCHR technology
- High levels of interest in PCHRs once participants had exposure to one
- A perception that PCHR benefits outweigh their potential risks
- Differing opinions/appreciations between older/younger participants around the risks and opportunities associated with sharing [health information](#)
- A need for help understanding technical or clinical issues
- Concerns about quality, accuracy and locus of responsibility for maintaining records
- Uncertainty about appropriate and safe read/edit access policies

- Consumer demands of the technology that exceeded technical sophistication of current PCHR

The co-authors believe the resonance of the Indivo PCHR platform with study participants is an indication of the rapidity at which PCHR will be adopted once the technology has progressed further. In the meantime they advocate for continued evaluations of PCHR use and broader discussions about technical and policy approaches, including the development of clear guidelines, lines of responsibilities and methods of educational and technical assistance.

"As we progress toward large-scale adoption of PCHR, we need to proceed with a critical eye for how to advance the technology but also continuously assess the impact it is having on the existing landscape of health behaviors, knowledge, understanding and relationships," said Elissa Weitzman, ScD, MSc, lead author of the paper and also of CHIP. "When you drop a new technology like this into an already complex system of behaviors, knowledge and assumptions, we can expect it to create a ripple effect that will resonate out from an individual to their care providers and beyond."

Source: Children's Hospital Boston ([news](#) : [web](#))

Citation: New study evaluates community response to personally controlled health information (2009, May 1) retrieved 27 April 2024 from <https://medicalxpress.com/news/2009-05-response-personally-health.html>

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