

Improving Health Care Quality Through Health Information Technology for People With Intellectual Disability

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Organization:	University of Illinois at Chicago
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Summary: Caregivers and service providers who are responsible for the health of adults who have intellectual disabilities (ID) face numerous obstacles navigating a health care system that is not often organized to respond to and recognize the unique health needs of persons with ID. This may lead to higher rates of morbidity and poorer quality of life. Fragmentation of care is frequent, and additional supports are needed to improve the sharing of health information. To address the lack of continuity in care, a research team from the University of Illinois Chicago is collaborating with Special Olympics International in conjunction with HealthOne Global, a technology company, to adapt and test a personal health record (PHR) meant to meet the needs of people with ID. The PHR, known as the Personal Health Record for Adults with Intellectual Disabilities (PHR-ID), gives caregivers and health care providers access to longitudinal data on an individual with ID and provides alerts on action items in the individual's action plan.

The PHR-ID was built from the Special Olympics Healthy Athletes software database, which includes screening, demographic, and health history data. The first phase of the project was to gather input through focus groups and health care provider interviews to refine and finalize the PHR-ID content. Interviews with health care providers who specialize in the care of people with ID established requirements for the prototype system. Focus groups of adults with ID and their caregivers reviewed proposed interface design and discussed expectations of a PHR. During the second phase, a 3-month feasibility study was conducted to assess the usability, perceptions, and impact of the PHR-ID by caregivers and health care providers. The project will support the development of an infrastructure that provides guidance to caregivers and health care providers as they follow a customized critical care pathway for individuals with ID, thereby improving the coordination and quality of care.

Specific Aims:

- Adapt and refine an Internet-based PHR for adults with ID to share Special Olympics Healthy Athletes medical and health screening data with caregivers and health care providers. **(Achieved)**
- Conduct a feasibility study to examine the usability and user satisfaction of the PHR-ID in sharing electronic health information derived from the Special Olympics Healthy Athletes screening program with caregivers and health care providers. **(Achieved)**

2011 Activities: The pilot study of the PHR-ID concluded in 2011. A total of 39 families participated, and of those 16 viewed the PHR. As part of their participation in the pilot, families were asked to fill out the PHR-ID Usability Pre-Survey. At the conclusion of the pilot, an intervention study was initiated. Caregivers

responsible for adults and children with ID were asked to view the PHR-ID weekly. At the end of the study, parents were asked to talk to their son's or daughter's primary provider to review the PHR-ID together. The PHR-ID is available through a universal serial bus (USB) interface, allowing participants to bring this USB drive with them to visits with their son's or daughter's provider. Participants filled out the online PHR-ID Usability Post-Survey. The content of the survey was similar to the PHR-ID Usability Pre-Survey with a few additional questions regarding parents' or caregivers' acceptance of the PHR-ID, involvement of the Special Olympics athlete (son or daughter) in viewing the PHR-ID, and the experience of caregivers when they approached the health care provider to view the PHR-ID. A semi-structured interview guide was developed for interviewing caregivers who have completed the study. Interview questions are related to barriers and facilitators to PHR-ID use, home access to the PHR-ID, PHR-ID interface and usage, Internet use and clinical workflow patterns, and general feedback. These interviews will begin in 2012. In addition, caregivers will be asked to interact with the PHR-ID during the interview and to vocalize their thoughts and actions as they complete various activities.

As last self-reported in the AHRQ Research Reporting System, project progress and activities are mostly on track and project spending is roughly on target.

Preliminary Impact and Findings: Forty-one percent of participants viewed the PHR-ID in the pilot, with views ranging in number from one to nine. Preliminary analysis of the pilot phase data indicated the PHR-ID Usability Survey scales had good-to-moderate inter-item correlation. Additionally, one of the major PHR-ID Barrier Survey items endorsed by participants was, "I do not have time to use the PHR-ID." This comment supports the comments from families who were nonresponders about being too busy or overwhelmed to participate.

In the intervention phase, 35 percent of participants viewed the PHR-ID, with views ranging in number from one to four. Similar to the pilot phase, participants endorsed as one of the top three barriers, "I do not have time to use the PHR-ID." Two participants visited a health care provider and eight indicated interest in completing the optional semi-structured phone interview. A secondary finding was that the use of the USB drive as the data storage of the PHR was problematic for several reasons. For some families, it was not compatible with their home computer, and for clinicians, the USB created concerns about transfer of viruses if it was to be used on their office computers. The research team also learned the importance of engaging the patient through the PHR-ID by making it interactive.

Target Population: Persons with Disabilities*

Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

Business Goal: Knowledge Creation

* *This target population is one of AHRQ's priority populations.*