

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

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<b>Organization:</b>	University of Illinois at Chicago
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**Summary:** Caregivers and service providers who are responsible for the health of adults with 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 these individuals. Fragmentation of care is frequent, and additional support to improve the sharing of health information is needed. These shortcomings may lead to higher rates of morbidity and poorer quality of life for people with ID. A research team from the University of Illinois at Chicago collaborated with Special Olympics International in conjunction with HealthOne Global, a technology company, to adapt and test a personal health record (PHR) to improve the continuity of care for this community. 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 and generates notifications about patient action plan items.

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 this group established requirements for the prototype system. Adults with ID and their caregivers reviewed proposed interface design and discussed expectations of a PHR in focus groups. During the second phase, a 3-month feasibility study was conducted to assess caregivers' and health care providers' perceptions about the usability and impact of the PHR-ID. 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.

### 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)**

**2012 Activities:** The intervention study of the PHR-ID concluded in 2012. The PHR-ID was available through a USB (universal serial bus) interface, allowing participants to bring this drive to visits with their adult child's provider. Of the total 77 participants, 67 participants received a USB drive, and 27 viewed the PHR through the USB. Twenty-seven completed a pre-test from the intervention and 26 completed a

post-test. Forty-two completed a mid-point barriers survey. Caregivers responsible for adults with ID were asked to view the PHR-ID weekly. At the end of the study, parents were asked to talk to their adult child's primary provider to review the PHR-ID together. At the conclusion of the study, participants completed the online PHR-ID usability post-survey, which assessed their overall experience. The content of the survey included several questions about parents' or caregivers' acceptance and use of the PHR, the involvement of the Special Olympics athlete (son or daughter) in viewing it, and the caregivers' experience when they approached the health care provider to view it and discuss their adult child's health. Interviews with families who completed the study were conducted at the conclusion of the intervention using a semi-structured interview guide. Questions 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. In addition, caregivers were asked to interact with the PHR-ID during the interview and to vocalize their thoughts and actions as they completed various activities.

As last self-reported in the AHRQ Research Reporting System, project progress was completely on track and budget spending was on target. The project ended in May 2012.

**Impact and Findings:** The primary finding in both phases of the project was that participants did not have enough time to use the PHR. Forty-one percent of participants viewed the PHR-ID in the pilot, with number of views ranging from one to nine. One of the major PHR-ID Barrier Survey items endorsed by participants was "I do not have time to use the PHR-ID." In the intervention phase, 35 percent of participants viewed the PHR-ID, with number of views ranging from one to four. Participants found it difficult to find time to engage with their provider on the PHR, and only two visited a health care provider with the PHR-ID.

The secondary finding was related to the use of the USB drive. The drive presented several problems for participants, including lack of home computer compatibility, clinician concern about the possible transfer of viruses to office computers, and provider concern about the integrity and safety of the information on the drive. In addition, clinicians had a number of questions about the drives, including interoperability with their systems, notification of items patients were tracking in the PHR, and Health Information Portability and Accountability Act compliance. Providers also had questions about how the PHR would change their interaction with the patient during the visit. In addition, they reported that they would like a print-out of the information in the PHR.

Providers also worried about the trustworthiness and reliability of data put in the record by the family and patient. Despite these concerns, providers viewed the availability of the Healthy Athletes data from Special Olympics positively, trusted and valued the data, and were willing to refer based on the Healthy Athletes screening data. They liked the idea of centralized information that included health promotion as well as specialty care. The research team also learned the importance of engaging patients through the PHR-ID by making it interactive.

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**Target Population:** Adults, 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

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