

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

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Organization:	University of Illinois at Chicago
Mechanism:	PAR: HS08-269: Exploratory and Developmental Grant to Improve Health Care Quality Through Health Information Technology (R21)
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Project Period:	June 2010– May 2012
AHRQ Funding Amount:	\$300,000
Summary Status as of:	December 2010

Target Population: Persons with Disabilities*

Summary: Adults who have intellectual disabilities (ID) face obstacles navigating the health care system that may lead to higher morbidity. 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, this project is adapting and testing 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), will build upon ongoing work by Special Olympics International in conjunction with HealthOne Global. The PHR-ID will give caregivers and health care providers access to longitudinal data on an individual with ID and will provide alerts on action items in the individual's action plan.

The PHR-ID will be built from the Special Olympics Healthy Athletes software database, which includes screening, demographic, and health history data. The first phase of the project will 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 will establish requirements for the prototype system. Focus groups of adults with ID and their caregivers will review the proposed interface design and discuss expectations of a PHR. During the second phase, a 3-month feasibility study will be 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. **(Ongoing)**
- 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. **(Ongoing)**

2010 Activities: During the first phase of the project, the team conducted focus groups with health care providers, caregivers, and others to inform the final development stages of the PHR-ID content for persons with intellectual disabilities. The PHR-ID was completed and 39 participants were recruited

for the pilot study. In November 2010, participants were mailed a USB drive to access the PHR-ID, an introductory letter about the study, and the user guide on how to use the PHR-ID, which included a link to the online baseline survey. The user guide was developed through feedback from the University of Illinois at Chicago research team and Special Olympics International to improve the clarity of instructions for caregivers. The user guide was made into a video format and posted on YouTube on the Special Olympics channel.

The study design includes security measures to protect the Special Olympics athletes' health information. Therefore, a separate e-mail was sent to each participant with the password needed to access the PHR-ID. The study team created a Google Group to maintain communication with participants and to provide them with easy access to documents. Participants were added as members of the group but, to preserve confidentiality, cannot see addresses of other members. Periodic e-mails and a newsletter have been sent to promote interest in the study and increase retention. The PHR-ID is important because it allows the progress of the patient to be viewed longitudinally. However, over the short study period of 12 weeks, it is difficult to engage families who may have a longer time frame for use. To address this, the project is encouraging use of the PHR-ID as an active record, for example, to record nutritional intake.

Preliminary content analysis of the focus group notes was conducted in November 2010 and used to construct the online barriers survey. Questions in the survey 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. In addition, parents and 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.

Grantee's Most Recent Self-Reported Quarterly Status (as of December 2010): Progress is completely on track as the team is meeting 100 percent of the milestones. Project spending is roughly on target.

Preliminary Impact and Findings: This project has no findings to date

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

* *AHRQ Priority Population*