

# **Improving Health Care Quality through Health IT for Persons with Intellectual Disabilities: A Final Report and Lessons Learned**

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## Abstract

**Purpose:** The University of Alabama at Birmingham (UAB), the University of Illinois at Chicago (UIC), and Special Olympics International (SOI) collaborated to examine the feasibility and the usability of internet-based Personal Health Records for adults with intellectual disabilities (PHR-ID). The PHR-ID provides electronic management of *Healthy Athletes* medical/health screening data collected at Special Olympics (SO) events.

**Scope:** There were two phases in this study. Phase I developed and refined the online PHR-ID conducted by the SOI under a subcontract from UIC/UAB, and Phase II determined the usability of the PHR-ID in sharing electronic health information with caregivers. During the 12-week intervention, online surveys and semi-structured interviews were employed pre- and post-intervention to examine caregiver usability of the web-based PHR-ID.

**Methods:** A pre-/post one group intervention design was employed in this study. Data collection involved a semi-structured interview and a secure password-protected website for completion of the online surveys (e.g., usability of the website by caregivers & primary care providers, barriers encountered using the website by caregivers, etc.).

**Results:** Although technical assistance was provided, participant use was limited due to low interest and compliance. We believe that PHRs may have the potential to improve patient-provider communication, the availability of health information, and the quality of care for adults with ID; however, further research is needed to improve usability and adoption of PHRs among caregivers, healthcare providers and adults with ID.

**Key Words:** intellectual disabilities, health information technology, electronic health records, health care

# Improving Health Care Quality through Health IT for Persons with Intellectual Disabilities: A Final Report and Lessons Learned

## PURPOSE

This study was designed to refine and develop the PHR-ID and to examine the feasibility and usability of the PHR-ID. The specific project aims were as follows:

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

## SCOPE

**Background.** People with intellectual disabilities (ID) experience poorer health and have less access to health care than the general population (Freedman & Chassler, 2004). For the more than six million individuals with intellectual disabilities living in the U.S. (U.S. Department of Health and Human Services, 2002), there is a significantly higher risk of poorly managed health care (Krahn & Drum, 2006; Lennox et al., 2004; Ouellette et al., 2004). Compared to the non-disabled population, people with intellectual disabilities are subject to poorer continuity of care and health maintenance, receiving fewer routine and preventive health services such as blood pressure checks and cholesterol and cancer screenings (Lennox et al., 2004; Rimmer, Braddock, & Fujiura, 1993; Rimmer & Yamaki, 2006; Sutherland, Couch, & Iacono, 2002).

Good medical care relies not only on an individual comprehending the need to seek appropriate medical advice, but also having the ability to furnish essential details on which a diagnosis is based, and understanding that he/she has to follow the advice obtained from the health care provider (Kerr et al., 2003). People with ID must rely on others including family caregivers, direct support staff and part-time employees (i.e., nurses) to ensure compliance of certain recommended treatments. As a person with ID transitions from home life— with a family member who may no longer be able to care for an older child or has passed away—to a residential setting such as a group home or other supported living facility (small apartment dwelling), there is often a lack of awareness among health care professionals that the individual may require certain health care services (Tyler & Bourguet, 1997). House managers, social

workers, nurses, family members, and others are often involved in the care of adults with ID, and transferring medical information from one provider to another often results in missing or inaccurate information (Mitchell, 1999). This creates substantial problems in maintaining current and accurate medical information on adults with ID (Kerr et al., 2003).

**Prevalence.** The high prevalence of chronic health conditions observed in people with intellectual disabilities including vision and hearing problems, syndrome-specific conditions (e.g., dementia in Down syndrome, communication disorders), seizures, behavioral disorders, falls, pain, constipation, obesity, osteoporosis, diabetes, high blood pressure, oral disease, and others, makes it extremely challenging for caregivers to manage their health across the lifespan. Obesity is not only related to adverse health consequences, such as type 2 diabetes, hypertension, cardiovascular disease, and early mortality, it is also associated with psychosocial problems and socioeconomic burden (Dixon, 2010; Finkelstein, DiBonaventura, Burgess, & Hale, 2010; Finkelstein, Fiebelkorn, & Wang, 2003). Several studies have reported that the prevalence rate of obesity among adults with ID ranges from 26.5% to 58.5% in the United States (Rimmer, 2006; Rimmer et al., 1993; Yamaki, 2005), which indicates that obesity is a significantly greater problem in this population than in the general population (de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012; Yamaki, 2005).

**Context.** New health information technologies offer health care providers and caregivers the opportunity to reduce adverse events as well as costly and unnecessary health care expenditures resulting from misdiagnoses or undiagnosed illnesses (Blumenthal & Glaser, 2007). Despite the abundance of evidence that people with intellectual disabilities are receiving poorer quality health care and have substantially greater health disparities compared to the general population (Krahn & Drum, 2006; Ouellette-Kuntz, 2005; U.S. Department of Health and Human Services, 2007), there is currently no health IT system that addresses the unique health care needs of this population. Given the significantly greater health risks and poorer health status observed in adults with intellectual disabilities along with their unique needs which are associated with health care management across a variety of health care providers and settings, there is a growing need to identify effective strategies for tracking and monitoring the health of adults with ID. To address this problem, we tested the usability of a personal health record (PHR-ID) on a group of caregivers who had an adult son or daughter participating in the *Healthy Athletes* Special Olympics (SO) program.

**Settings.** SO staff assisted the research team in recruiting caregivers who had an adult son/daughter participating in the national, state or local SO games in 2010. The intervention, survey administration, and phone interviews were conducted in family caregivers' homes.

**Participants.** Seventy-six caregivers (Cohort 1, n=42; Cohort 2, n=34) who had an adult son or daughter with ID participating in the Special Olympics *Healthy Athletes* program volunteered and provided informed consent to participate in the study. The inclusion criteria

included: (a) an adult child with ID between the ages of 18 to 40 years; (b) home internet service; (c) a family member who could read and speak English (self-report).

Although 76 caregivers consented to participate in the study, 10 participants were excluded from the study because they did not receive their son's/daughter's PHR-ID from Health One Global within the allotted timeframe of the intervention. The remaining participants (N=66) who received a USB drive needed to access the PHR-ID on their adult child. Eleven percent of participants were 40 years and younger; 33% were 41 to 50 years; 39% fell between 50-60 years; and 17% of participants were over age 60. All participants were white and 94% were female. Fifty percent graduated high school, 39% graduated college, and 11% had some post-college or graduate school education.

Eighteen participants completed the online usability surveys and 24 participants completed the barriers surveys at post-intervention. Thirty-nine (59%) of the 66 caregivers did not open the PHR-ID. Twenty seven participants (41%) opened the PHR-ID at least once with a range of one to nine views. Fourteen participants (11 who used the PHR-ID, 3 who did not) were interviewed by phone at the end of study regarding their experience using or not using the PHR-ID (see Figure 1.)

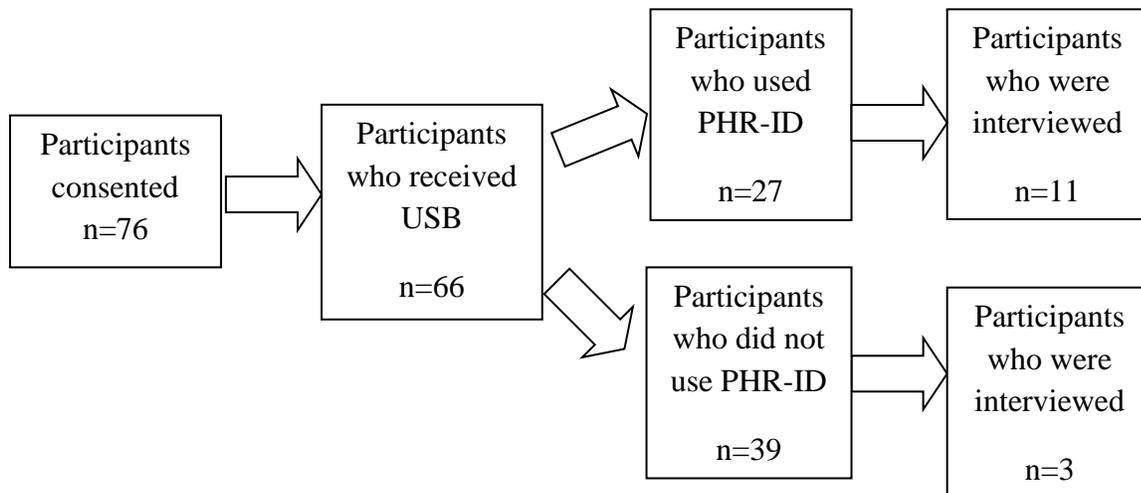


Figure 1. Flow chart of study participants

## METHODS

**Study Design.** We conducted a 12-week intervention to examine caregiver usability of the web-based PHR-ID. Informed consent was obtained prior to participation. After the consent process, caregivers received a password protected USB drive from Health One Global that allowed them access to the PHR-ID on a secure website. Following the 12-week intervention, participants completed online surveys on usability (including barriers to use) and perceived control over health information. A semi-structured telephone interview was also conducted at the

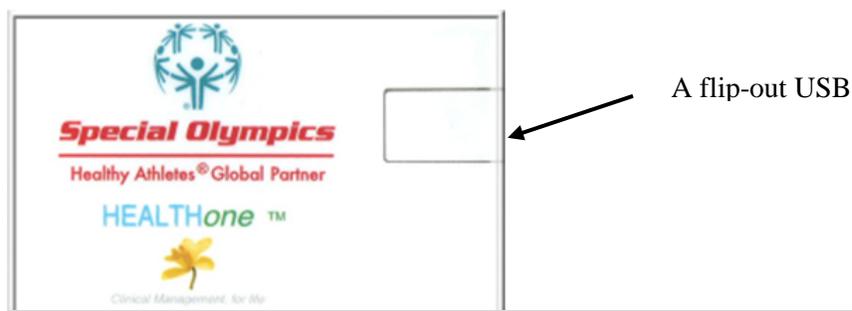
end of the intervention with a subset of caregivers (n= 14) to obtain more in-depth qualitative information on the usability of the PHR-ID.

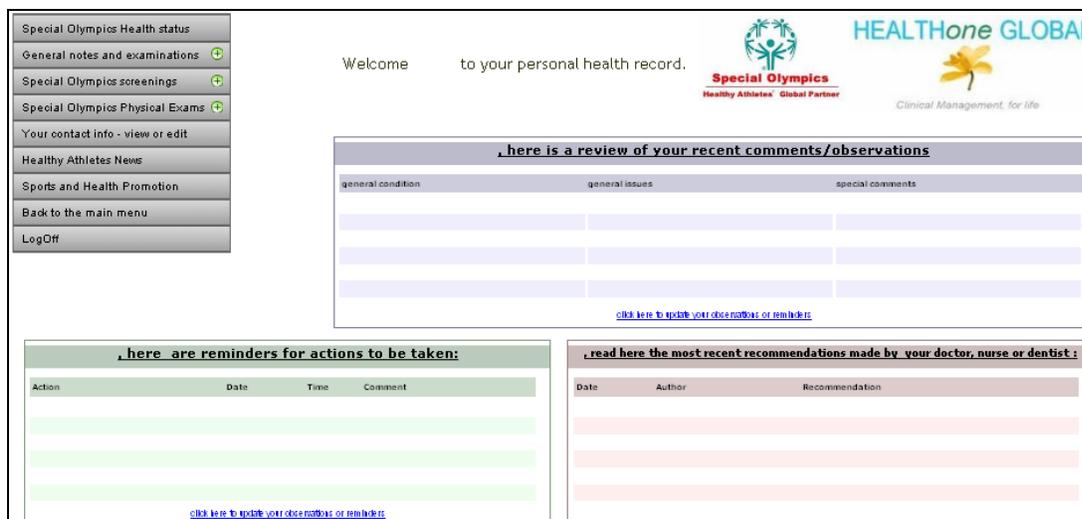
**Data Sources/Collection.** Data collection for the study results presented in this report are from: 1) baseline - start of the project period (pre-PHR-ID implementation), and 2) at the 12 week mark (post-implementation). We analyzed data using mixed methods (quantitative and qualitative). For quantitative analyses (i.e., those related to our 12-week post-intervention survey data), the major outcomes that were analyzed were user experience and usability. Descriptive statistics (e.g., means, medians, standard deviations, ranges, and proportions) were obtained for all study variables.

Qualitative analyses were conducted on the semi-structured phone interviews administered to a select number of caregivers. The interviews were transcribed and analyzed by coding responses to each question in an Excel file. All transcripts were read initially to discern if a more structured thematic approach to the analyses could be conducted. After a second review, codes were developed for each question and an Excel file was created to aggregate categorical responses for each caregiver. The results were tabulated as frequencies and percentages and presented with direct quotes.

**Interventions.** Participants received a *User Guide* prior to the intervention with instructions on how to access and use the PHR-ID along with a special USB card (Figure 2) required for PHR-ID access. After logging in to the PHR-ID (see Figure 2 for screen capture), caregivers were able to view the following items: (a) adult child’s health status (including the Special Olympics physical exam), (b) General notes and examinations related to observations made by the adult child’s doctor, dentist, nurse, or caregivers, (c) *Healthy Athletes* screenings results (e.g., vision, hearing, oral care, and fitness), (d) *Healthy Athletes* News, and (e) Sports and Health Promotion. In the Sports and Health Promotion section, caregivers could enter information on daily food intake (e.g., fruits, soft drinks, juice, milk), body hygiene (i.e., frequency of tooth brushing, showers, bathing), and physiological measures (i.e., heart rate, blood pressure, and weight) as well as update a Special Olympics training log and a physical activity log. In addition, the PHR-ID included areas where recommendations for referrals could be made based on HAS screening data from SO events (e.g., recommend referral for ophthalmologist based on abnormal eye exam conducted at SO games).

Figure 2. USB Card and PHR-ID Page





We conducted an evaluation of the User Guide (n=26) prior to the intervention to determine if the guide was useful in explaining how to access and use the PHR-ID. Participants reported that the guide was useful (92.3%), easy to understand (88.5%), and answered all of their questions related to using the PHR-ID (91.7%).

Participants were asked to view the PHR-ID monthly over the course of 12 weeks. After the caregiver accessed his/her PHR-ID account online to view the screening data, if their son/daughter had a referral note, the caregiver was encouraged to make arrangements for their son/daughter to visit the relevant healthcare provider. A research staff offering technical assistance for using the PHR-ID was available via email and a toll-free phone. Health One Global provided electronic reports indicating which participants logged in to view their adult child’s PHR-ID. Whenever a caregiver did not open the PHR-ID for more than two weeks, an e-mail request was sent reminding them to log in to the PHR-ID and view their child’s record. If there was still no response, a follow up phone call was made to determine if there were any problems accessing the PHR-ID.

At the end of the intervention, participants were asked to complete an online usability survey. Caregivers were also invited to participate in a post-intervention process evaluation conducted by telephone. The purpose of the process evaluation was to gain more in-depth knowledge of the participants’ experiences with the PHR-ID regarding: (1) entering data into the system, (2) sharing or using the PHR-ID, (3) usage barriers, and (4) usage benefits. Individuals who agreed to the evaluation were contacted after they completed the online survey and verbal consent was obtained at the time of the evaluation. A research assistant conducted all the interviews, following a semi-structured guide and audio-recording the conversation for transcription.

**Measures.** Quantitative and qualitative measures were employed in this usability study. All outcome measures were collected after the 12-week intervention exposure period.

Demographic data, including age, gender, race/ethnicity, income, education, and frequency of record view, were also collected on each caregiver. All survey data were collected through online questionnaires.

***Barriers to Using PHR-ID.*** Questions associated with barriers to using the PHR-ID included four positive items and six negative items (see Table 1). Ratings were based on a 5-point Likert scale from “1” Strongly Disagree to “5” Strongly Agree. An open-ended question on what they liked and disliked about the PHR-ID was included at the end of the survey.

***Usability.*** Usability was assessed with a modification of items from the System Usability Scale (Brook, 1996). Eight online questions included four positive and four negative statements. Ratings were based on a 5-point Likert scale from “1” Strongly Disagree to “5” Strongly Agree. The reliability for the scale was .77.

***Perceived Control.*** Caregiver-perceived control of their son or daughter’s health data was assessed using a modification of items from the perceived control scale (Menon, 2002). The survey included nine questions related to: accessing the health record, getting needed support, the record’s usefulness to doctors or other health care providers, influence on the health care provider to use the record, and helping to make decisions concerning the person’s health (see Table 2 for the complete set of questions). Responses were on a 5-point Likert scale from “1” Strongly Disagree to “5” Strongly Agree. The reliability for the scale was .71 .

***Technical Assistance.*** Data were recorded regarding participant requests for assistance by frequency and the solutions that were provide to resolve problems.

**Limitations.** There were at least two general concerns regarding participation retention and compliance. While a number of participants expressed interest in the concept of PHRs for persons with ID, the actual time and effort directed toward accessing the record, solving technical problems, and exploring the records’ features was limited. Of the 66 family members who originally agreed to participate in the study, only 27 (41%) opened the PHR-ID at least once; the rest (59%) never opened the record.

Two limitations emerged regarding the USB card and PHR system. First, while the USB card offered a potential means to “control” access, there were difficulties in using the USB card (e.g., some providers’ staff did not trust it with their computers out of concern for viruses). Furthermore, capacity to synchronize PHR-ID information with other electronic health records is limited. Providers cannot easily ensure PHR-ID information entered by caregivers or athletes and HAS screening data will be incorporated into a patient’s electronic record (and vice versa).

## **RESULTS**

**Principal Findings.** Table 1 presents the data on participants who viewed the PHR-ID at least once and completed the barriers survey (n=24). For the four positive statements, 75% of

caregivers strongly or agreed on the statement “Most of the time, I found it easy to get to all sections of the PHR-ID”, followed by “I am very comfortable using the PHR-ID” (66.6%), “I feel comfortable approaching my doctor about using the PHR-ID” (41.7%), and “This record could be used by the person I am caring for with minimal assistance from me” (37.5%). For the six negative statements, 37.5% of caregivers strongly agreed or agreed on the statement “The person I am providing care for is not involved when I view the PHR-ID”, followed by “I do not have time to use the PHR-ID” (25%), “I could have used more technical support along the way to help me use the PHR-ID” (16.7%), and “My computer is not handling the PHR-ID well while I am using it” (16.7%). Less than 5% of caregivers strongly agreed or agreed with the negative statement, “Entering information into the PHR-ID takes too long”, or “The language in the PHR-ID is too difficult to understand”.

Table 1. Barriers to use PHR-ID

Barriers to use PHR-ID statements	n	<u>Strongly disagree/ Disagree</u> n (%)	<u>Neither</u> n (%)	<u>Agree/ Strongly agree</u> n (%)	Mean (SD)
I am very comfortable using the PHR-ID	24	3 (12.5)	5 (20.8)	16 (66.6)	3.75 (.94)
Most of the time, I found it easy to get to all sections of the PHR-ID	24	3 (12.5)	3 (12.5)	18 (75.0)	3.71 (.96)
This record could be used by the person I am caring for with minimal assistance from me	24	10 (41.7)	5(20.8)	9 (37.5)	3.00 (1.10)
I feel comfortable approaching my doctor about using the PHR-ID	24	4 (16.7)	10 (41.7)	10 (41.7)	3.33 (1.01)
I do not have time to use the PHR-ID	24	10 (41.7)	8 (33.3)	6 (25.0)	2.71 (1.00)
I could have used more technical support along the way to help me use the PHR-ID	24	12 (50.0)	8 (33.3)	4 (16.7)	2.58 (.88)
My computer is not handling the PHR-ID well while I am using it	24	16 (66.7)	4 (16.7)	4 (16.7)	2.50 (1.18)
The person I am providing care for is not involved when I view the PHR-ID	24	12 (50.0)	3 (12.5)	9 (37.5)	2.83 (1.24)
Entering information into the PHR-ID takes too long	23	14 (60.8)	8 (34.8)	1 (4.3)	2.30 (.77)
The language in the PHR-ID is too difficult to understand	24	16 (66.7)	7 (29.2)	1 ( 4.2)	2.25 (.74)

Note. 1 = Strongly disagree, 2 = Disagree, 3= Neither agree or disagree, 4 = Agree, 5 = Strongly agree. Negative statements are in grey.

Table 2 presents percentages of agreement on usability statements. Over 83% (15) of participants liked using the PHR-ID and agreed that the various features worked well together. Participants felt that the PHR-ID was easy to learn (78%) and use (72%). Twenty-two percent of participants had a negative experience using the PHR-ID. Twenty-two percent needed technical support, 17% felt that the PHR-ID was unnecessarily complex, 12% felt that the information in the PHR was not consistent throughout the record, and 11% thought it was very awkward to use.

Table 2. Distribution of Usability Statements after Intervention

Usability statement	n	<u>Strongly disagree/ Disagree</u> n (%)	<u>Neither</u> n (%)	<u>Agree/ Strongly agree</u> n (%)	Mean (SD)
I would like to use the PHR	18	--	3 (16.7)	15 (83.4)	4.00 (.59)
The PHR is unnecessarily complex	18	13 (72.3)	2 (11.1)	3 (16.7)	2.39 (.85)
The PHR is easy to use	18	3 (16.7)	2 (11.1)	13 (72.3)	3.61 (1.04)
I will need the support of a technical person to be able to use the PHR	18	12 (66.7)	2 (11.1)	4 (22.2)	2.56 (1.04)
The various features in the PHR work well together	18	--	3 (16.7)	15 (83.4)	4.00 (.59)
The information found in the PHR was not consistent throughout the record	17	13 (76.4)	2 (11.8)	2 (11.8)	2.18 (.88)
Most people will learn to use the PHR very quickly	18	1 (5.6)	3 (16.7)	14 (77.8)	3.94 (.80)
The PHR is very awkward to use	18	12 (66.7)	4 (22.2)	2 (11.2)	2.33 (1.03)

Note. 1 = Strongly disagree, 2 = Disagree, 3= Neither agree or disagree, 4 = Agree, 5 = Strongly agree. Negative statements are in grey.

Table 3 shows the results for perceived control. Perceived control was measured to examine caregivers' beliefs about their ability to control their adult child's associated health conditions. The majority of caregivers appreciated having access to the health record of their adult child (88%) and felt positive about being able to get the support they needed to help their child (82%). Many also liked the aspect of being involved in the decision making process

regarding their son's or daughter's health (82%). Almost 60% of caregivers thought the health care provider of the person they were caring for would find the PHR-ID useful, felt very confident using the PHR-ID, intended to use the PHR to manage their adult child's health, and wanted to continue using it. Over 50% felt that they could encourage health care providers to use the PHR-ID. Forty-four percent of participants felt that they needed to learn more before they could use the PHR (see Table 3).

Table 3. Percentage of Perceived Control Statements after Intervention

Perceived control statement	n	<u>Strongly disagree</u> <u>/disagree</u> n (%)	<u>Neither</u> n (%)	<u>Strongly agree/agree</u> n (%)	Mean (SD)
I like having access to the health record of the person I am caring for	17	0	2 (11.8)	15 (88.2)	4.24 (.66)
I can get the support I need to help the person I am caring for with their health	17	1 (5.9)	2 (11.8)	14 (82.3)	4.00 (.79)
I think the doctor or other health care provider of the person I am caring for will find the PHR useful	17	0	7 (38.9)	10 (58.8)	3.76 (.75)
I can influence the physician or other health service provider to use the PHR	17	1 (5.9)	7 (41.2)	9 (53.0)	3.53 (.94)
I am able to help make decisions concerning the health of the person I am caring for	17	0	3 (17.6)	14 (82.3)	4.06 (.66)
I feel very confident using the PHR	17	5 (29.4)	2 (11.8)	10 (58.8)	3.29 (1.11)
I need to learn a lot of things before I can use the PHR	16	6 (37.5)	3 (18.8)	7 (43.8)	3.00 (1.21)
I intend to use the PHR to manage the health of the person I am caring for	17	2 (11.8)	5 (29.4)	10 (58.9)	3.53 (1.01)
I want to continue using the PHR rather than stop using it	17	2 (11.8)	5 (29.4)	10 (58.9)	3.53 (1.01)

Note. 1 = Strongly disagree, 2 = Disagree, 3= Neither agree or disagree, 4 = Agree, 5 = Strongly agree. The negative statement is in grey shading.

**Results of Qualitative Interviews.** At the end of the intervention, 11 out of 27 (41%) caregivers who reported viewing the PHR-ID at least one time and 3 out of 39 (8%) caregivers who reported never viewing it were contacted and administered a phone-based interview. Of the 11 participants who opened the PHR-ID, seven felt that they needed additional training in using

the USB port and/or navigating the system. Eight participants felt that the instructions were not detailed enough to comfortably access their adult child's PHR-ID, or reported that they had little to no prior experience using a USB port.

***Experiences Entering Data into PHR-ID.*** Six participants entered information regarding their adult child's diet, physical activity, and/or other health habits. Five caregivers successfully entered health data (e.g., blood pressure, medication) into the PHR-ID; one caregiver attempted to enter data but had difficulty navigating to the correct location. Another caregiver reported that she was hesitant about entering medical data into the PHR-ID because she was unfamiliar with some of the terminology. She expressed a willingness to enter health data had she understood the terminology better. A common issue expressed by almost half of the participants was difficulty navigating the system. It seemed that they most often wanted to locate something specifically, but could not get to that section of the PHR-ID.

Data entry by the adult child with ID was limited to only one caregiver who reported that her two sons, both with ID, successfully entered diet and physical activity data on their own. Six caregivers reported that their child watched as information was entered into the PHR-ID and one caregiver attempted to share the process of entering data with their child, but had difficulty using the system.

***Sharing of PHR-ID with Provider.*** Parents who consented to participate in the study also agreed to share the PHR-ID with their adult child's physician or dentist. Only two of the 27 family members who completed the study (7%) shared the PHR-ID with their adult child's physician or dentist. Unfortunately, both of those experiences were met with less than receptive physicians. In one case, the physician reportedly expressed concern that plugging in the USB might spread a virus to the office computer. The family member noted that she struggled explaining to the physician exactly what information was on the USB and why it might be helpful. A second participant took the PHR-ID to both her adult child's physician and dentist. The physician refused to open the PHR-ID, but the dentist was receptive to opening the record, reading over the information and entering additional data about the patient into the PHR-ID. Several participants indicated that they did not take the PHR-ID to the physician or dentist because their adult child did not need to see the physician or dentist during the study intervention period. One participant noted that she did not see any benefit to sharing the PHR-ID with her adult child's physician or dentist. Another parent expressed concern that the USB was of no use to her child's physician because the office kept paper records and there was no computer in the clinic rooms. Another participant admitted that she was uncomfortable with the idea of taking the USB to the physician

***Additional Comments Regarding PHR-ID.*** Additional comments provided insight into participants' experiences with the PHR-ID. Two participants preferred to use Apple computers which are not compatible with the PHR-ID, four participants mentioned that they would have preferred a web-based portal for keeping the PHR, and six did not like the USB. One felt that

access would be limited without web-access because she relied heavily upon smart phones. A caregiver expressed concern related to backing up the information on the USB. Another caregiver, who was very concerned about her child's weight gain, found the diet information to be too general and indicated that she would have preferred to have the option of distinguishing between different types of milk and being able to indicate whether vegetables were fresh, canned, or frozen, not simply the number of servings.

**Outcomes.** Despite technical challenges in implementation and use, a number of potential advantages were identified by a small proportion of users in making health information accessible and interactive. These include increasing the involvement of a person with ID in his/her own healthcare, coordination of health information between various providers, a structured and permanent record of health information, and ability to track health behaviors.

**Discussion.** This is the first study that has been conducted to describe caregiver usability of a personal health record in adult children with ID. Personal health records are consumer-centric tools that can strengthen consumers' ability to actively manage their own health and health care. Our findings showed great interest among family members in using the PHR-ID at the outset of the study but once family members attempted to retrieve the record, the typical barriers associated with using PHRs (Lober et al., 2006; Tang, Ash, Bates, Overhage, & Sands, 2006) became evident (i.e., low interest, knowledge, and technical skills). This study revealed the level of technological literacy and training needed for caregivers and adults with ID to implement health information technology as an aid in managing their health and improving the continuity of health care.

**Significance.** Family members/caregivers who actively used the PHR-ID in the Pilot Phase indicated the PHR-ID is helpful in organizing health information, tracking progress towards health goals (i.e. tracking weight loss, physical activity, and fruit and vegetable consumption), and sharing health information with a healthcare provider. This feedback lends support for the conceptual model that when family members/caregivers experience greater perceived control over the SO athlete's health, healthcare-seeking behavior and healthcare satisfaction also increases. The PHR-ID also allows family members/caregivers to keep track of accurate and current health information so that the SO athlete can receive better healthcare.

**Implications.** There are a number of implications learned overall from the PHR-ID project. First, giving caregivers more control in the decision-making and planning processes of their adult child's health may allow them to become more active in their care and prompt them to communicate with the appropriate doctor or specialist when necessary. Sharing self-reported and external health-related data may encourage caregivers and persons with ID to become more active and participatory during healthcare encounters.

**Conclusions.** The PHR-ID has the potential to improve quality of care among persons with intellectual disabilities. To realize this potential, additional research should be conducted on

the adoption of internet PHR-IDs, attitudes toward PHRs, privacy and security concerns, and information collection and sharing functionality. A PHR specifically designed and tested with caregivers and persons with ID will have the greatest chance for sustainability. Future PHR-ID efforts will support knowledge and behavioral promotion through online consumer health information and allow for information sharing with providers (Gerber & Eiser, 2001). Furthermore, successful PHRs may overcome healthcare fragmentation and improve the utilization of preventive services, ultimately improving the health of those with intellectual disabilities.

## **PUBLICATION/PRODUCT**

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