



A National Web Conference on Using Health IT to Improve Outcomes in Vulnerable and Disadvantaged Populations

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Moderator and Presenters Disclosures

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There are no financial, personal, or professional conflicts of interest to disclose for the speakers or myself.



Health IT-Enabled Telephone Counseling for Diabetes Self-Management Support in Diverse Populations

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Objectives

- Characterize the importance of health literacy as well as recent trends related to digital divide and their implications for health IT.
- Present diabetes self-management health IT intervention and its real-world implementation in diverse safety net setting(s).

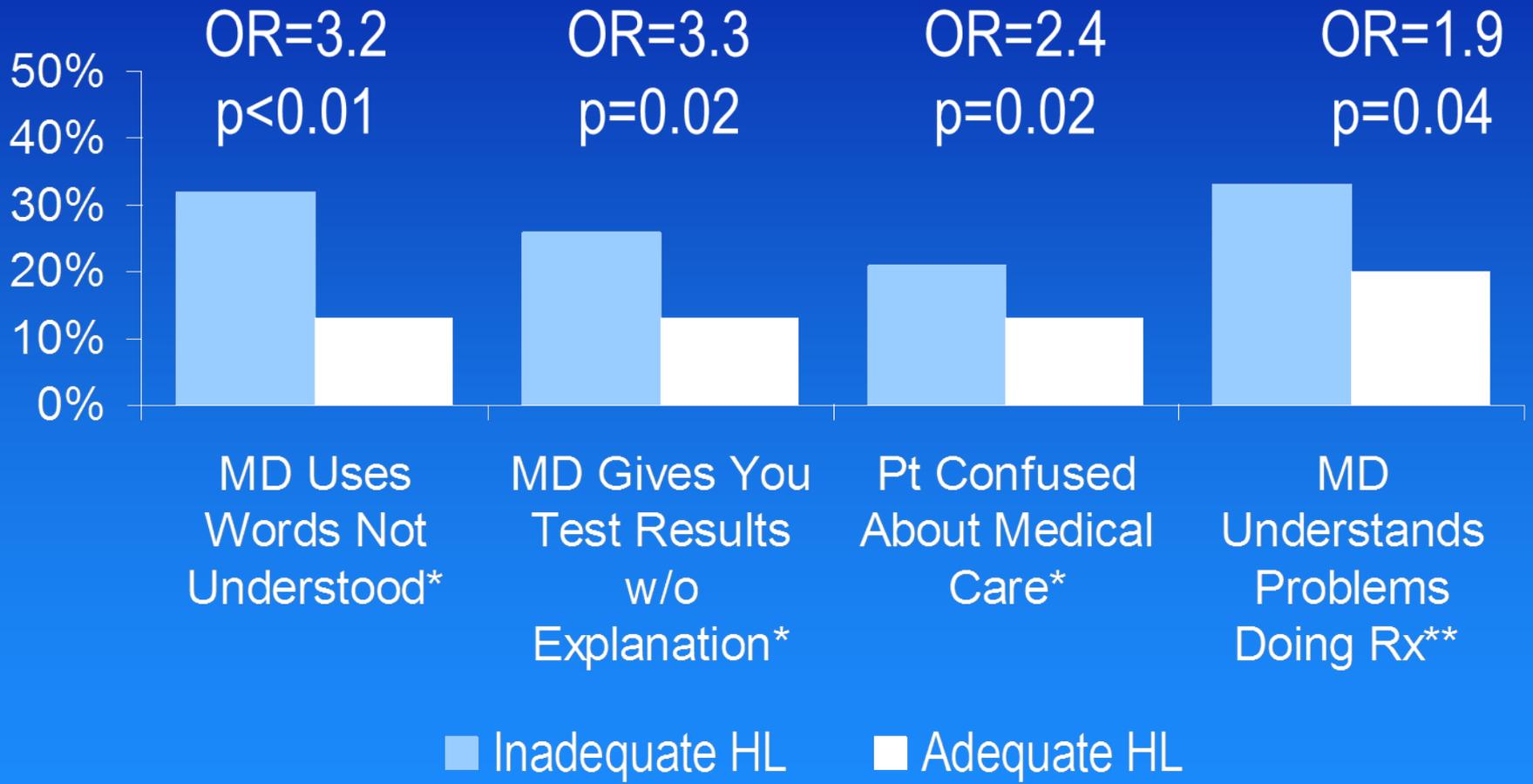


Limited Health Literacy (LHL)

- Health literacy: ability to read, comprehend, and act on written and numerical information received in health care settings
- Impact of limited health literacy on health outcomes:
 - Poorer knowledge of chronic conditions
 - Worse self-care
 - Higher utilization of services
 - Worse health outcomes
 - Poor glycemic control



LHL Associated with Poor Communication with Clinicians



* Usually / Always

** Never, Rarely, Sometimes

Schillinger PEC, 2004



What is a Digital Divide?

The digital divide refers to differences across demographic groups in access to and use of information technology, particularly computers and the Internet.

What type of digital divide do we have?

Mobile internet use, by demographics

% of American adults age 18+ within each group who go online wirelessly with a laptop or cell phone, as of August 2011

	% who go online wirelessly
All adults (age 18+)	63%
Men	67
Women	59
Age	
18-29	88
30-49	76
50-64	53
65+	21
Race/ethnicity	
White, Non-Hispanic	63*
Black, Non-Hispanic	62*
Hispanic (English- and Spanish-speaking)	63*
Household income	
Less than \$30,000/yr	50
\$30,000-\$49,999	64
\$50,000-\$74,999	75
\$75,000+	86
Educational attainment	
No high school diploma	36
High school grad	53
Some College	72
College +	82



Recent Shifts

- **2011 Population Survey—Pew Internet Project**

Internet broadband use in low-income and immigrant populations is up since 2008.

– Differences (US born and non-US born region)

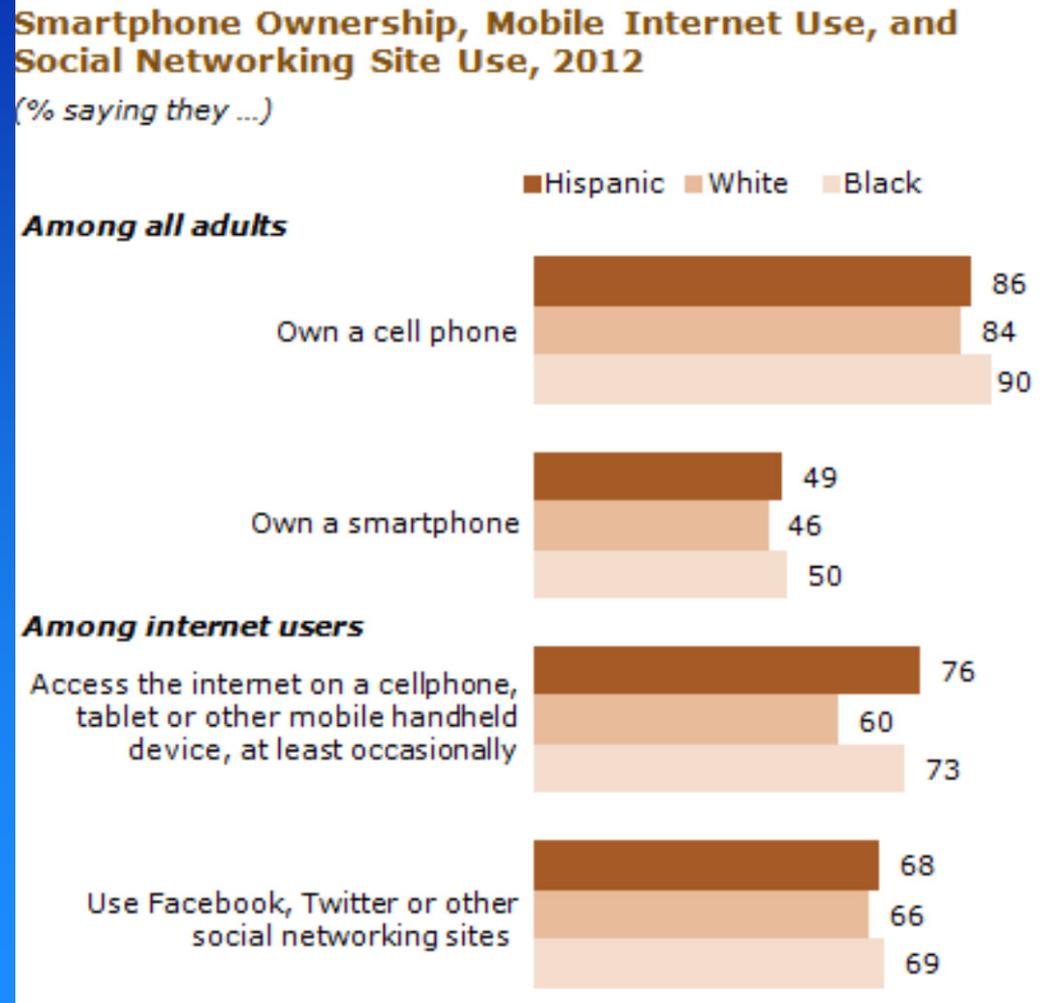
- **Safety Net Study (San Francisco, n=408)**

Majority of primary care patients currently use email, text messaging, and Internet—71% want to use these tools for communication with their providers; many don't have access.

Cell Phone Increases Among Latinos

Latinos and cell phones

- Similar to blacks and whites for smartphone ownership
- Latino Internet users more likely than white internet users to say they go online using a mobile device— 76% versus 60%



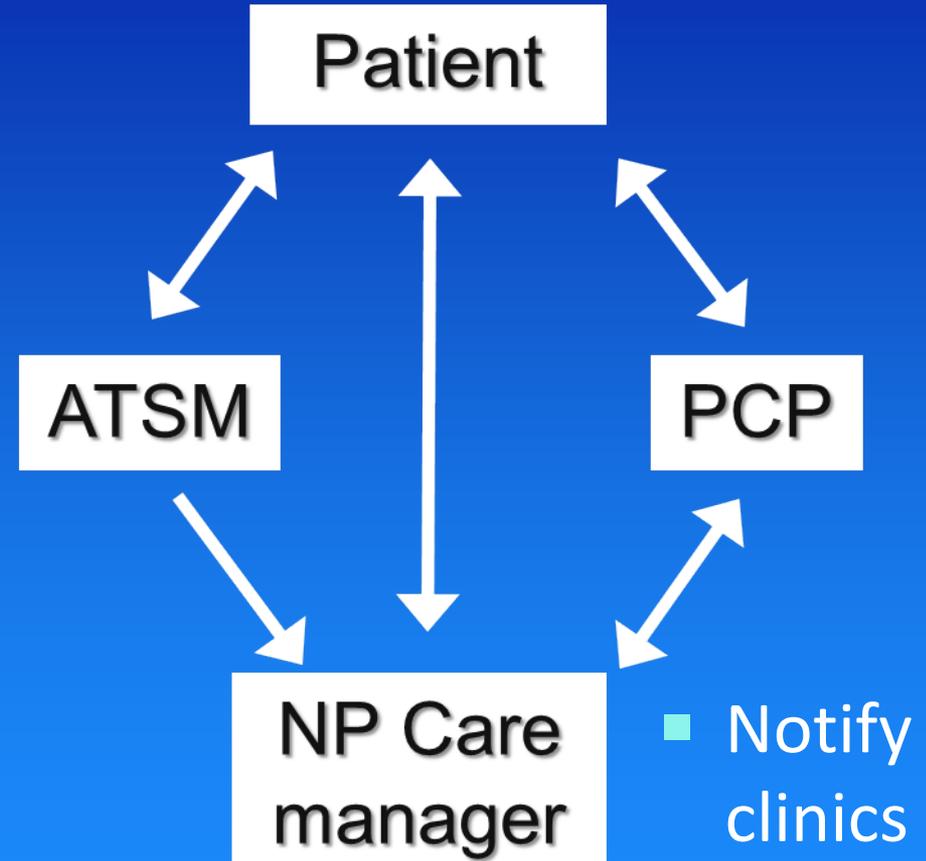


Telephones and Self-Management Support

- Self-management support improves behaviors, satisfaction, and outcomes
- Desired by patients with LHL and limited English proficiency*
- Automated telephone self-management support (ATSM)
 - 97% of adults in CA have phone
 - Relatively inexpensive and efficient
 - Control jargon, volume, pace, and language
 - Effective in diverse, low-income patients

ATSM and Improving Diabetes Efforts Across Language and Literacy

- Developed with users
- Preferred language
- Weekly surveillance
- Touch-tone response
- Tailored education
- Language-concordant care managers respond to out-of-range triggers





Intervention: ATSM + Health Coach

- 27-39 weeks of ATSM calls
- Health coach or nurse for follow-up calls
 - Tailored training and scripts

Question	Call Back Trigger	<u>Prosodie Education</u> (use to guide education during callback)	SMART Steps Scripts
<p><i>In the last 7 days, how many days did you MISS taking your DIABETES medications, even just one pill or shot? Was it 0 days, 1 day, 2 days, 3 days, 4 days, 5 days, 6 days, or 7 days? Press the number of days that you MISSED taking your</i></p>	<p>3-7</p>	<p><i>You might be going through something similar to Mrs. Jones. Mrs. Jones sometimes forgot to take all of her diabetes pills. She also stopped taking her pills when she felt good. After a few weeks she began to feel tired and sick and went to see her doctor. Her doctor was very worried about her</i></p>	<p><u>Nonjudgmental:</u> "Many patients take their medications differently from the way they are prescribed. It's important for me to understand how you're taking your medications." <u>Check accuracy:</u> "In this week's call, you answered that you missed your diabetes medications ___ days this week. Is that correct?" <u>Check understanding about diabetes meds:</u></p> <ul style="list-style-type: none"> • "What medications are you taking for diabetes now? Tell me their names. How much do you take? What they are for?" • "Do you have the bottles? Can you get them and read the name / instructions on them?" • "Are you taking a medication called ___? Tell me how you're taking it." • "I just want to check about ___ medication. Your health care team thinks you are taking ___ medication ___ times per day. That seems different from what you just said. Tell me more about that." <p><u>Check for barriers to adherence:</u></p> <ul style="list-style-type: none"> • "What side effects or problems do you have when you take ___?"

Health IT Can Promote Patient-Centered Diabetes Care (IDEALL)

- Randomized trial: ATSM, group visits, and usual care
- 339 patients with poorly controlled DM
 - 43% Spanish- and 11% Cantonese-speaking
- 94% completed ≥ 1 call \rightarrow 84% ≥ 1 action plan
- High PCP satisfaction
 - Perceived activated patients and higher quality of care
 - Overcoming barriers to LEP and medication management





IDEALL Implementation Process

1. Identify priority population/condition and objectives
2. Harness registry and network to identify population
3. Develop queries to solicit questions and concerns
4. Write and revise health education (cooperative process)
5. Pilot questions and health education responses with patients
6. Translate and adapt toward cultural appropriateness
7. Record and code
8. Design callback algorithm (scenarios) and trigger reports
9. Beta-test
10. Train clinical staff
11. Launch



Qualitative Themes

Awareness

“I became more aware of what I put in my system and that I need to do something greater than what I’ve been doing to lose more weight... (ATSM narratives) talked about a woman who lost weight... I liked that... I could walk in those shoes.”

Self-efficacy

“I had already made a moral promise that this week I would give 100%, that I would exercise and get sweaty, and I did it.”

Empowerment

“It elevated my self-esteem so that I could ‘get fired up’ and really respond because it was up to me to gain control of my diabetes. In other words, one needs to do their part.”



IDEALL Program Outcomes

- + Interpersonal communication with providers
- + Self-management behaviors (diet, exercise)
- + Functional status, fewer days confined to bed
- Primary care physicians very favorably disposed
- Participation rates were high across all levels and preferentially attracted Spanish-language speakers, uninsured, and Medicaid recipients
- Higher engagement among those with limited English proficiency and limited health literacy

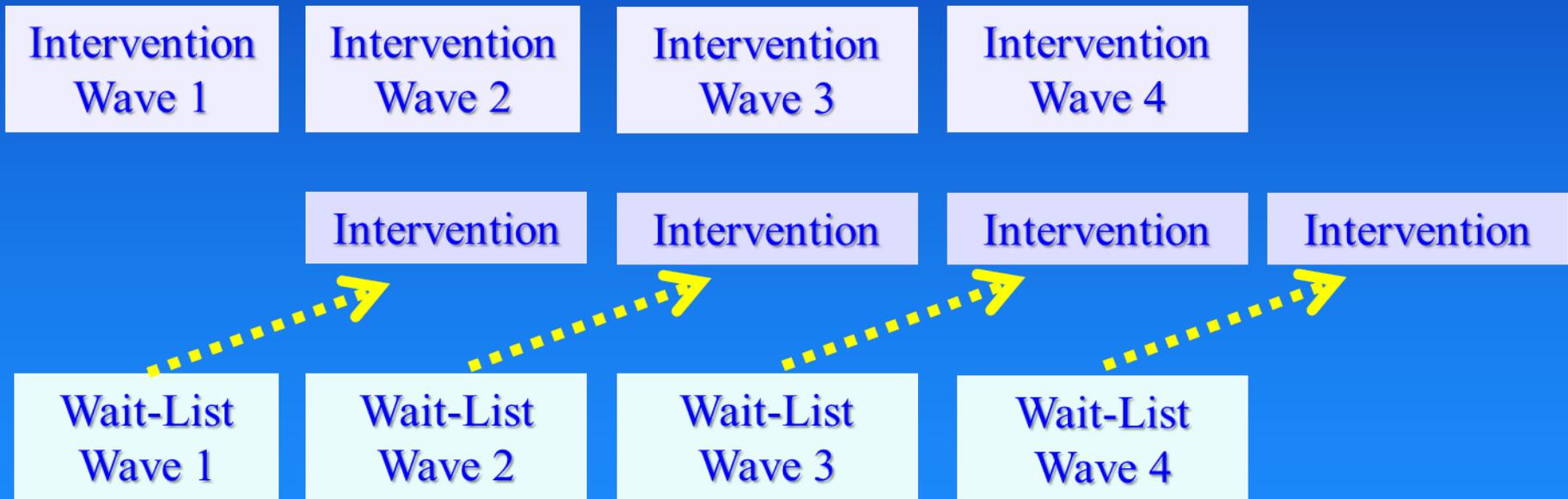
SMART Steps: Partnering to Put Research Into Practice

- San Francisco Health Plan (SFHP): nonprofit government-sponsored Medicaid managed-care plan
 - Linguistically diverse vulnerable population
 - SFHP recruitment for members from four clinics
 - SFHP implementation but electronic exchange with UCSF and clinic-based medical records
 - Evaluation by UCSF



Implementation of a Quasi-Experimental Study Design

- SFHP did not want control group; staggering better for staffing
- Wait list with 6-month crossover; recruiting in waves
- Real-world implementation: data integration, in-house coaches

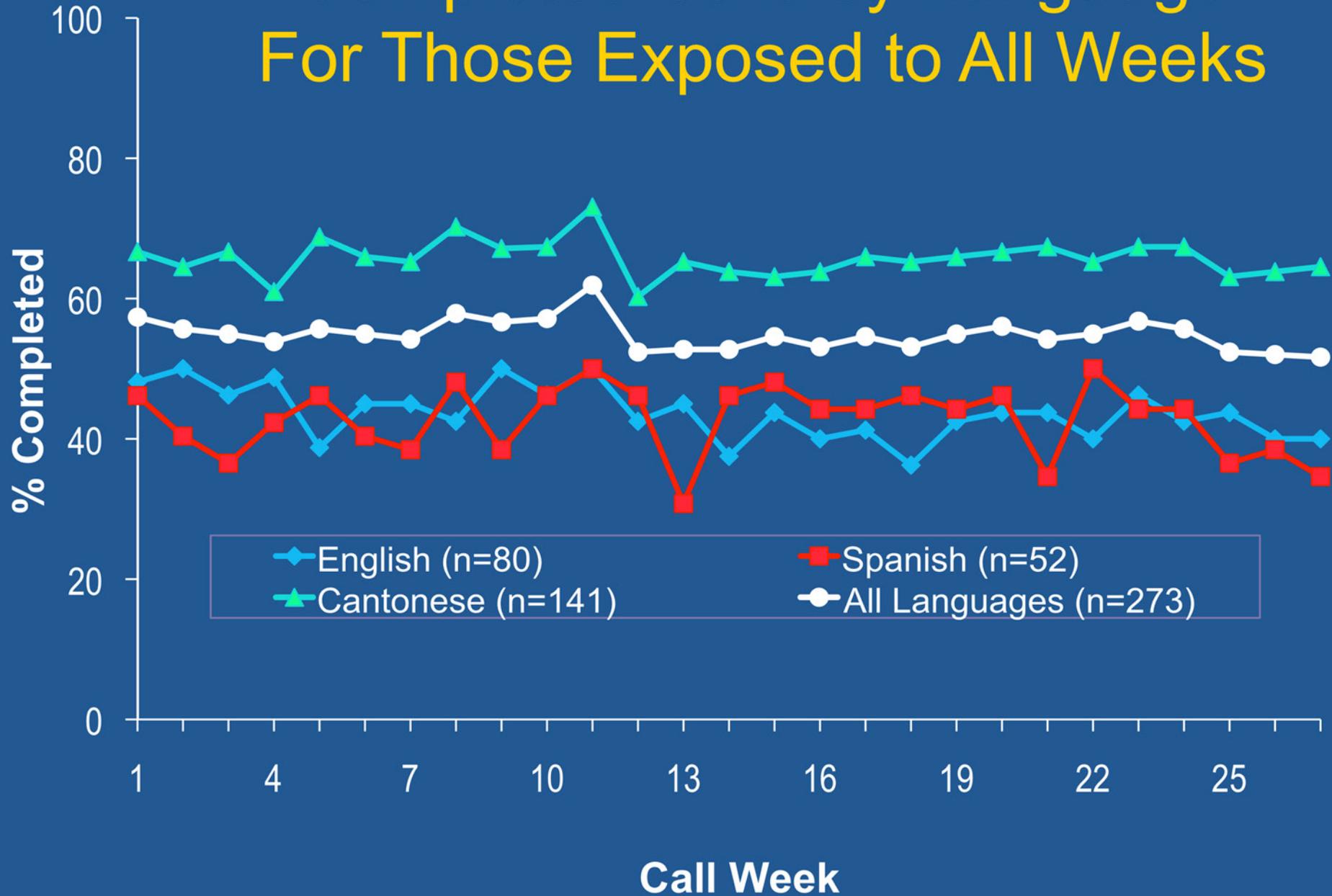




Participants With 6-Month Follow-up (n=249)

Characteristic	Intervention (n=125)	Wait-List (n=124)
Age in years, mean (SD)	56.6 (7.9)	54.9 (8.6)
Women	77%	72%
Latino	26%	20%
Black / African-American	6%	10%
Asian / Pacific Islander	60%	62%
White / Caucasian	6%	7%
Born Outside the U.S.	86%	85%
Cantonese-speaking	54%	55%
Spanish-speaking	20%	19%
8 th grade education or less	39%	47%
Limited health literacy	47%	40%
Income ≤ \$20,000 / Yr	61%	60%
Hgb A1c >8.0%	30%	24%

Completed Calls by Language For Those Exposed to All Weeks





Change in Quality of Life at 6 Months

	Adjusted* Difference (95% CI)	Standardized Effect Size*	p-value
Physical Component SF-12	2.0 (0.1,3.9)	0.25	0.04
Mental Component SF-12	1.3 (-1.0,3.6)	0.14	0.26

*Controlling for baseline value; effects greater for Spanish speakers



Change in Self-Care at 6 Months

	Adjusted* Difference (95% CI)	Standardized Effect Size*	p- value
Overall Self-Care	0.2 (0.1, 0.04)	0.29	<0.01
Glucose Monitoring	0.7 (0.2, 1.3)	0.30	<0.01
Foot Care	0.6 (0.2, 0.9)	0.32	<0.01
Medication Adherence	0.0 (-0.2, 0.2)	0.02	0.82

*Controlling for baseline value; effects greater for LHL patients



Implementation/Fidelity Outcomes

- Health system integration fidelity was high for electronic exchanges, identification of eligible patients, reporting on call-level responses
- Coaching callbacks generally delivered per protocol (based on check-off reports) with some variation by topic of ATSM/medication triggers, and by language



Successful Implementation Strategies

- Partnering with LHL / LEP patients:
 - Bicultural and bilingual content
 - Unmet need for language-concordant support
- Practice-based research:
 - Innovate and create from within
 - Invest in the safety net providers
 - Partnership with Medicaid managed care plan
 - Population-based implementation
 - Long-term relationships



New Directions

- Scope: develop new content for health promotion across health conditions, postpartum women with past gestational diabetes—prevention
- Platform: mHealth beyond telephone outreach
- Linkages to patient-centered medical home, community programs such as WIC
- Reach and sustainability:
 - Within our health system
 - Medicaid and other insurers



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Creating Tailored, Influenza Vaccination Alerts in the Electronic Health Record for a Low-Income, Pediatric Population

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Influenza Vaccination

- Universally recommended: children and adults ≥ 6 months old
- Young children have higher infection rates, morbidity
- Recommendation begin vaccination when vaccine is available and continue through early spring



Influenza Vaccination

- Low vaccination coverage nationally
 - 51.5% of 6-month to 17-year-olds
 - 33.7% (13 to 17 years); 74.6% (6 to 24 months)
- Missed opportunities for vaccination
 - In recent study of children who needed two doses in a given season, 36.3% had at least one missed opportunity for second dose.



Influenza Vaccination

- Electronic health record (EHR) use common
 - 2012 National Ambulatory Medical Care Survey: 72% office-based doctors have adopted an EHR
- Vaccine alerts in EHR promising results for influenza vaccination esp. in low-income, urban clinics
 - Need to be part of workflow

(Fiks et al., *Pediatrics* 2009)



Influenza Vaccination

- Goal: Create a pediatric influenza vaccination alert in the EHR based on provider and parent preferences



Setting

- Academic medical center in underserved community
 - Primarily Latino, Medicaid/SCHIP
- Hospital and network of affiliated pediatric ambulatory clinics (n=4)



Setting

- Hospital immunization registry synchronizes data with New York Citywide Immunization Registry (CIR)
 - Vaccination data are available for our patients for vaccines administered anywhere in NYC reported to CIR



Focus Groups: Providers

- Four focus groups with providers (n=21); five individual interviews
- Several barriers to influenza vaccine delivery:
 - Remembering to vaccinate during sick visits
 - Need to review multiple sources of immunization information
 - Time shortages
 - Inadequate staffing

(Birmingham et al., *Prev Med* 2011)



Focus Groups: Providers

Desired alert characteristics

1. Alerting providers early in the visit
2. Accurately determining patients' vaccination status: merging multiple sources of immunization information
3. Facilitating vaccine ordering
4. Generating appropriate documentation in the EHR when vaccines were refused or not given for other reason



Focus Groups: Providers

Potential concerns

1. Reliability and accuracy of alert
 - Want to see immunization dates
2. Workflow interruptions
3. Forced actions



Focus Groups: Parents

21 parents:

Interested in

1. Their child's risk for influenza
2. Side effects and safety of the vaccine
3. Effectiveness of the vaccine
4. Timing of vaccine
 - Developed talking points used in alert



Alert Development

- Designed reminder within Eclipsys SCM Ambulatory application
- Fires with note opening
 - No forced action



Alert Development

- Retrieves immunization information, via a Web service, from hospital immunization registry
 - Synchronized with the New York City's Department of Health CIR
- Graphical user interface (GUI) designed, evaluated and revised to reflect feedback from our provider's supervisory panel
 - Beta testers



Alert Development

GUI

- Alerts provider to patient's influenza immunization status (using up-to-date rules)
- Providers can order influenza vaccine
- Documents why a vaccine was not given
- Allows access to important clinical information, e.g., allergies and immunization history



Alert Development

- End-to-end data transfer mechanism between alert and Eclipsys SCM Ambulatory application via Eclipsys' medical logic modules (MLM)
 - Allows users to pass information back to Eclipsys and paste into the provider's note

Test, First; 1234567; 12/1/1995; 15y0m

Flu Vaccine Status: NOT UP TO DATE

Most Recent Seasonal Flu Vaccines: H1N1 Vaccine:

03/07/2010 01/03/2008 10/03/2006 03/07/2010

Would you like to order the flu vaccine today?

Yes **No** Pre-ordered More Info

Synchronized with CIR?: Yes. (Facility: Rangel Pediatrics-904)

Order Vaccination

Age Appropriate Flu Vaccinations: 36 months or more

0.5ml Influenza Virus Vaccine Injectable (>3 Years Old)
 0.2ml Influenza Virus Vaccine Intranasal ("FluMist")

FluMist: please review PMH and see precautions below

***Use of FluMist:**

FluMist is approved for use only in HEALTHY people 2-49 years of age who are not pregnant.

The following patients should NOT receive FLUMIST:

- Children < 5 years old with a history of **recurrent wheezing.**
- People with a medical condition that places them at high risk for complications from influenza, including those with **chronic heart or lung disease**, such as **asthma or reactive airways disease**; people with

Special Considerations

- FluMist can be administered simultaneously with another live vaccine (e.g. MMR, varicella), but if not given at the same time. ACIP recommends waiting four weeks before administering the second live

Submit **Cancel**

Do not order vaccination

Reason for not ordering

Patient: **Test, First**

MRN: **1234567**

Patient Ill
 Parent deferred today
 Parent refused
 Unaccompanied Adolescent
 Vaccine not available
 Vaccine received or planned for elsewhere
(please update record)
 Other

Submit



Assessment/Plan:

∴
Plan Flu vaccine was ordered ("Influenza Virus Vaccine Inj >3 Years Old").

Assessment/Plan:

∴
Plan Flu vaccine not ordered: Patient Ill.

Test, First; 1234567; 12/1/1995; 15y0m

Flu Vaccine Status: **NOT UP TO DATE**

Most Recent Seasonal Flu Vaccines: H1N1 Vaccine:

03/07/2010 01/03/2008 10/03/2006 03/07/2010

Would you like to order the flu vaccine today?

Synchronized with CIR?: Yes. (Facility: Rangel Pediatrics-904)

More Information [X]

FLU VACCINE: NOT UP TO DATE

Patient Info

Name: Test, First2
MRN: 1234568
DOB: 11/1/1995

ALLERGIES:
No Known Allergies

Significant History

- * Diabetes Type II
- * MYOPIA
- * ASTIGMATISM NOS

Seasonal Flu and H1N1 Vaccine History

Influenza: 5/10/2010
Influenza: 4/29/2010
H1N1-09 Inj.: 4/27/2010
Influenza (unspecified): 9/23/2009

Order

Do Not Order

Parent Talking Points

- [Is the flu serious?](#)
- [Does the flu shot cause the flu?](#)
- [Will my child still get sick this Winter if I get the shot?](#)
- [What are the side effects of the vaccine?](#)
- [Why does my child need 2 shots?](#)
- [Why does my child need a flu shot every year?](#)
- [Aren't there other ways to protect my child against the flu?](#)

Close

Talking Points

Talking Point: *Is the flu serious?*

English/Spanish English only Spanish only

A-

A+

Is the flu serious?

- The flu is a serious, contagious illness.
- The flu is a major reason that children miss school every year, and parents miss work to stay home and care for them.
- Last year, 272 children died from influenza-related illness.
 - This is >3X the number who died in 2006-2007. (see graph below)
- Each year ~200,000 people in the U.S. are hospitalized and 36,000 people die from flu.
- ~20,000 children < 5 are hospitalized with flu-related illness every year.
- **Getting the vaccine is the best protection against this disease.**

¿Es la gripe una enfermedad seria?

- La gripe es una enfermedad seria y contagiosa.

Note Closing Warning [X]

Warning:

 A decision regarding Flu vaccination has not yet been recorded.
How would you like to proceed before this note is closed?

Order Now **Do Not Order** **More Info** **Defer**



Test, Sam; 3456789; 12/1/2000; 10y1m

Flu Vaccine Status: **UP TO DATE for 2010-2011 Season**

Most Recent Seasonal Flu Vaccines:	H1N1 Vaccines:
09/02/2010	None

More Info

Synchronized with CIR?: Yes (Washington Hgts Pediatrics-862)

F Test, Second; 1245678; 4/1/2009; 1y6m

Flu Vaccine Status: Up To Date: Next shot due 11/04/2010

Most Recent Seasonal Flu Vaccines: 10/07/2010 01/02/2010 11/30/2009	H1N1 Vaccines: None
---	-------------------------------

English
 Spanish

Print Next Shot Due Date **More Information**

Synchronized with CIR?: Yes (Audubon Peds Primary Care-836)

F Test, Child; 456789; 1/1/2006; 15y0m

Flu Vaccine Status: **NOT UP TO DATE**

Patient has a Documented Egg Allergy

Egg allergy and flu vaccine **More Patient Information**

Facility: Broadway Clinic Peds-405)



Training

- Created training tools
 - User manual
 - PowerPoint
 - Quick reference guide
- On-site training



Lessons Learned

- Involve users early
 - Although no forced action: providers did act
- Make alert smart and tailored
- Don't interfere with workflow
 - Important for us not to delay note opening
- Open to changes
 - Green alert now disappears



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- New York Presbyterian Hospital EzVac Immunization Information System
- New York Presbyterian Hospital Ambulatory Care Network



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Usability of a Personal Health Record for Monitoring the Health of Adults with Intellectual Disability

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Background

- People with intellectual disabilities (ID) experience poorer health and have less access to health care than the general population.
- Transferring medical information of adults with ID from one provider to another often results in missing or inaccurate information, creating problems in maintaining current and accurate medical information.
- People with ID often have poor health behavior habits.

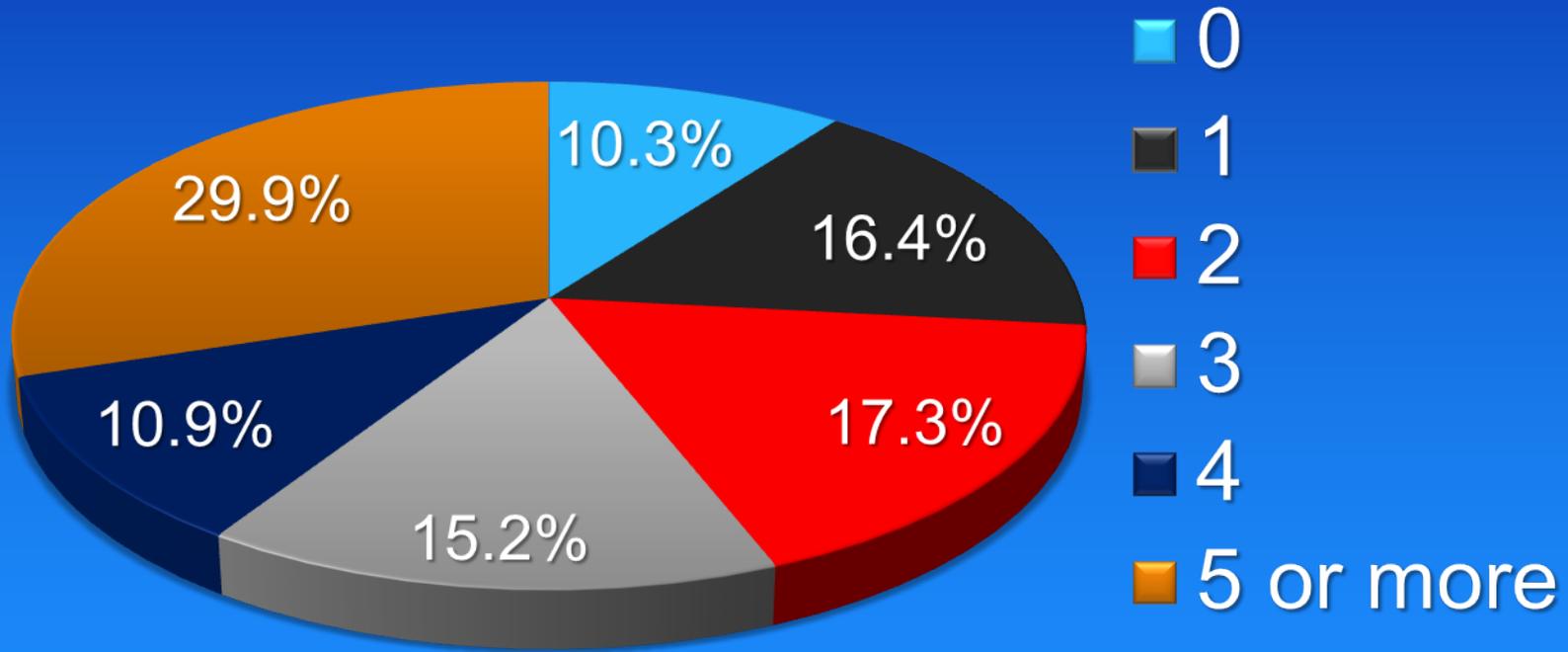
Freedman & Chassler, 2004; Krahn & Drum, 2006; Lennox et al., 2004; Ouellette et al., 2004; Mitchell, 1999; Kerr et al., 2003



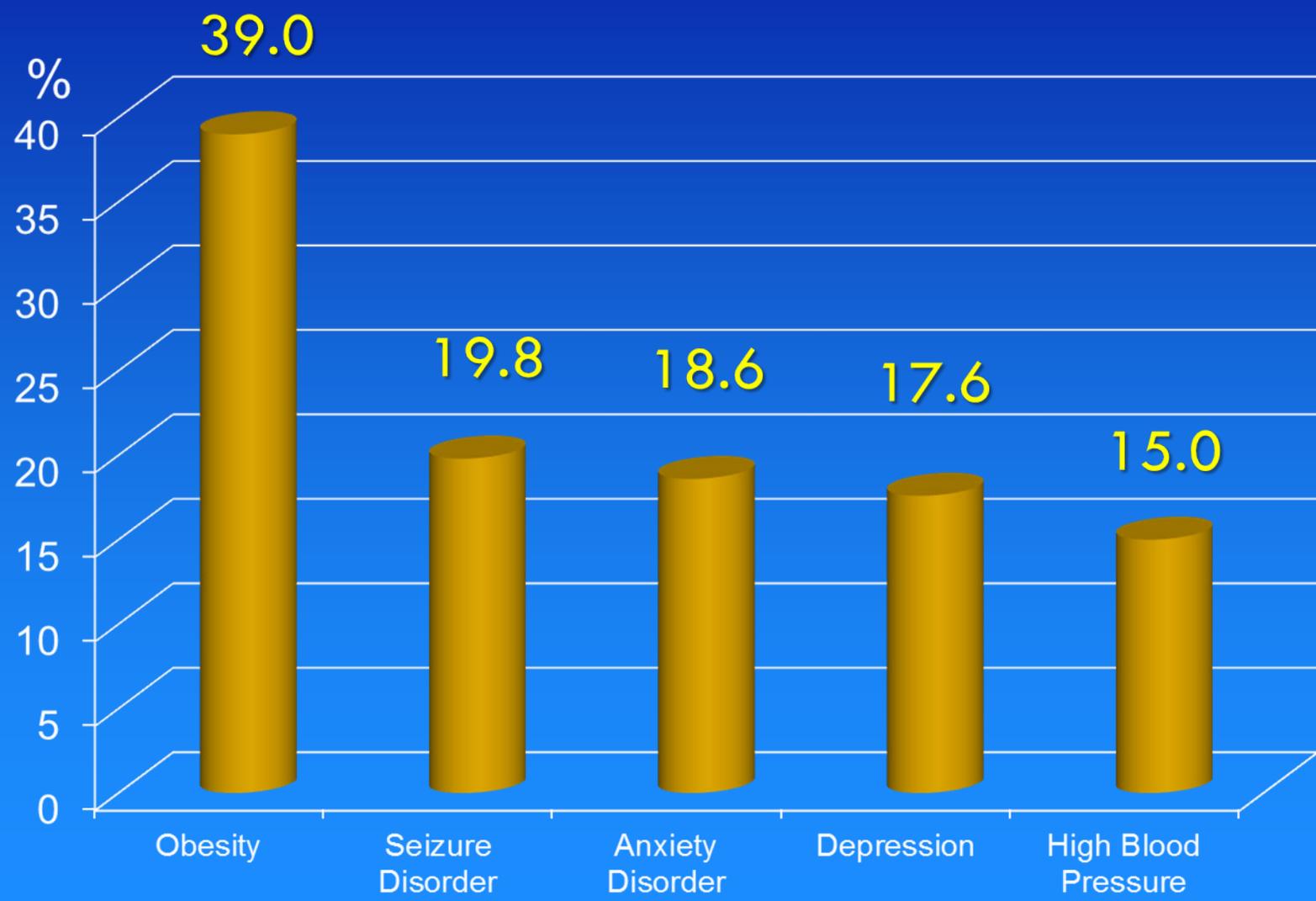
Background

- In the United States there is a significantly higher risk of poorly managed health care.
- Currently, there is no health IT system that addresses the unique health care needs of the ID population.
- There is a growing need to identify effective strategies for tracking and monitoring the health of adults with ID.

Percent of Participants with Chronic Health Conditions (N=938)



Prevalence of Top Five Chronic Health Conditions Among Adults with ID (N=938)

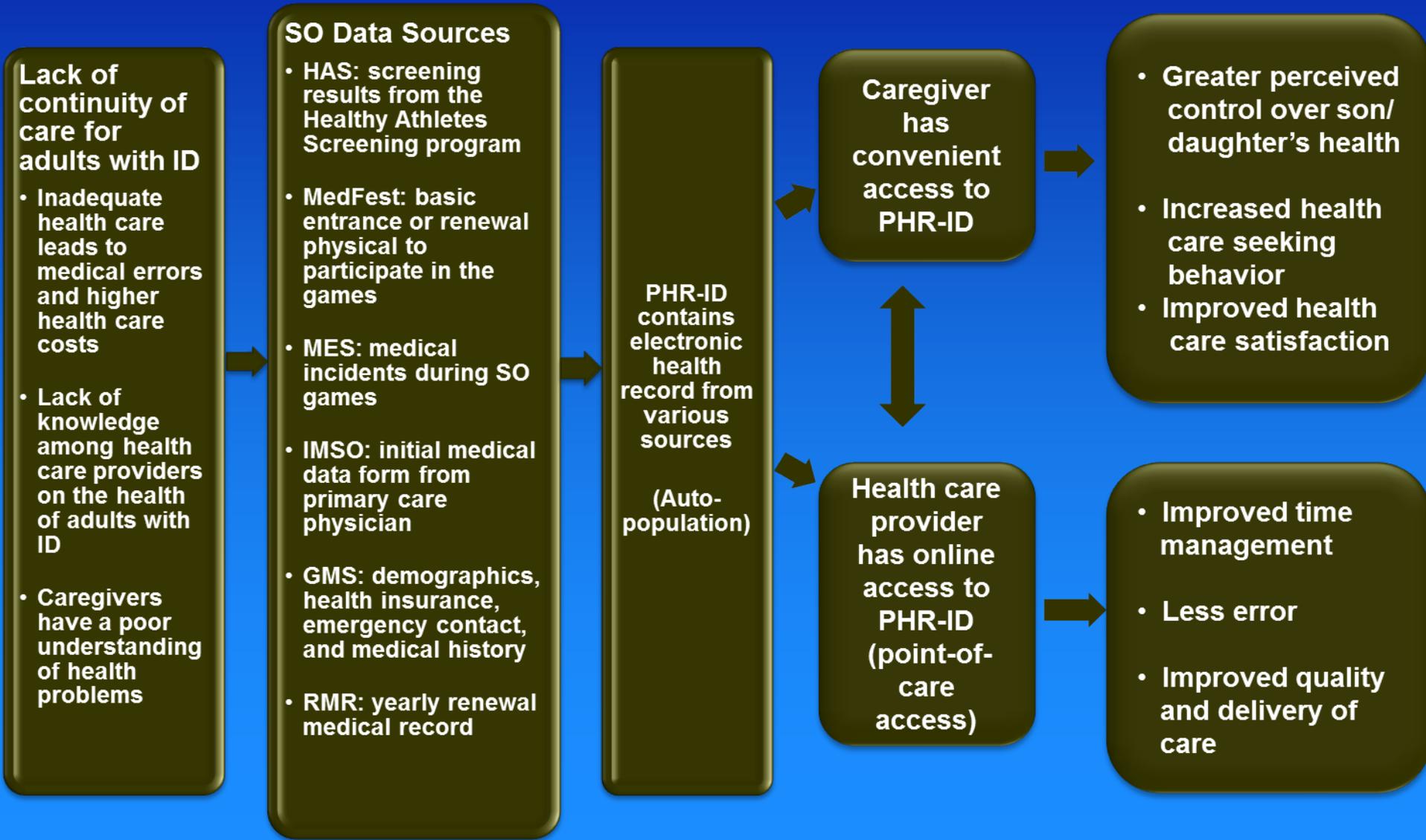




Research Questions

1. What is the user experience of a personal health record for adults with ID?
2. How much perceived control did the caregiver have over the health data of the adult with ID?
3. What are the barriers in using a personal health record for adults with ID?

Conceptual Framework

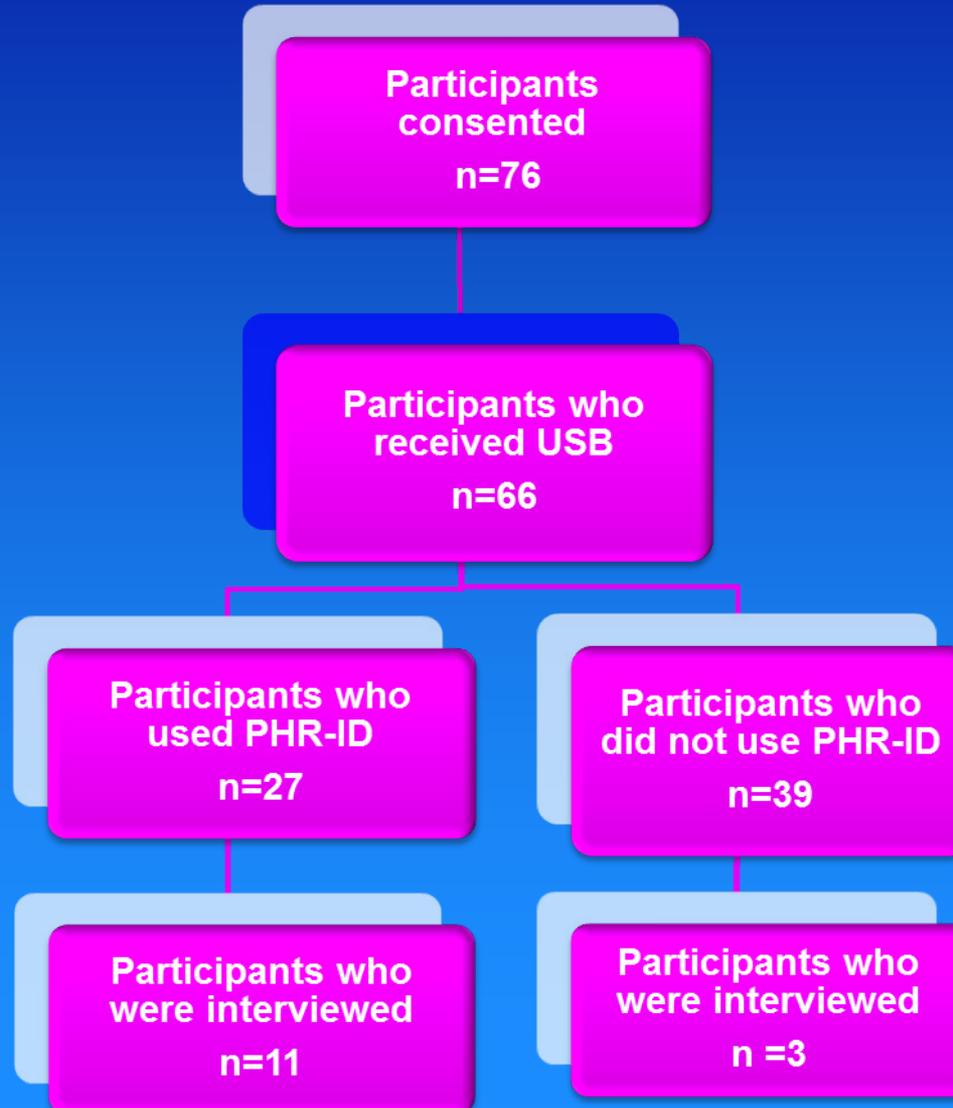




Participants

- Inclusion criteria
 - Adult child with ID from 18 to 40 years old
 - Home Internet service
 - Family member could read and speak English (self-report)
- The research team and Special Olympics (SO) staff recruited caregivers who had an adult son/daughter participating in the national, state, or local SO games in 2010.

Flowchart of Study Participants





Personal Health Record (PHR-ID)

- Designed by HEALTH One Global (UK)
- Autopopulated with personal health information from several data sources
- For this study, we focused on training caregivers to:
 - Navigate various sections of health data (e.g., medical history, Special Olympics health screening results)
 - Input their adult child's dietary intake, physical activity, body hygiene
 - Foster Special Olympics sport participation
 - Access PHR-ID via USB card. Caregivers could log in to a secure Web site to view their adult child's health information, and they were also provided with a special USB card required for PHR-ID access.



Personal Health Record (PHR-ID)

- After logging in to the PHR-ID, caregivers could view the following items:
 - Adult child's health status, which included the Special Olympics physical exam
 - General notes and examinations related to the observations made by the adult child's doctor, dentist, nurse, or the caregivers' own observations
 - Healthy Athletes screenings results (e.g., vision, hearing, oral care, and fitness)
 - Healthy Athletes News
 - Sports and health promotion

USB Card and Personal Health Record Page



A flip-out USB connector

- Special Olympics Health status
- General notes and examinations (+)
- Special Olympics screenings (+)
- Special Olympics Physical Exams (+)
- Your contact info - view or edit
- Healthy Athletes News
- Sports and Health Promotion
- Back to the main menu
- LogOff

Welcome to your personal health record.



here is a review of your recent comments/observations

general condition	general issues	special comments

[click here to update your observations or reminders](#)

here are reminders for actions to be taken:

Action	Date	Time	Comment

[click here to update your observations or reminders](#)

read here the most recent recommendations made by your doctor, nurse or dentist :

Date	Author	Recommendation



Design

- 12-week intervention to examine caregiver usability of the Web-based PHR-ID
- Following the intervention, participants completed online surveys on
 - Usability (including barriers to use) and
 - Perceived control over health information
- Semi-structured telephone interview conducted at the end of the intervention with a subset of caregivers (n=14)



Procedures

- Participants received a user guide prior to the intervention with instructions on how to access and use the PHR-ID.
 - Evaluation: Participants reported that the Guide was useful (92.3%), easy to understand (88.5%), and answered all of their questions related to using the PHD-ID (91.7%)
- Participants were asked to view the PHR-ID at least monthly over the course of 12 weeks.
- Research staff person was available via a toll-free phone number or email for technical assistance.
- Electronic reports were provided by Health One Global indicating which participants logged in to view their child's 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



Quantitative Measures

Barriers to using PHR-ID

- Four (4) positive items (participants' comments)
 - I am very comfortable using the PHR-ID.
 - Most of the time, I found it easy to get to all sections of the PHR-ID.
 - This record could be used by the person I am caring for with minimal assistance from me.
 - I feel comfortable approaching my doctor about using the PHR-ID.
- Six (6) negative items (participants' comments)
 - I do not have the time to use the PHR-ID.
 - I could have used more technical support to help me use the PHR-ID.
 - My computer is not handling the PHR-ID well while I am using it.
 - The person I am providing care for is not involved when I view the PHR-ID.
 - Entering information into the PHR-ID takes too long.
 - The language in the PHR-ID is too difficult to understand.
- 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.



Quantitative Measures

Usability

- Usability was assessed with a modification of items from the System Usability Scale (Brook, 1996).
- Four (4) positive items (participants' comments)
 - I would like to use the PHR-ID.
 - The PHR-ID is easy to use.
 - The various features in the PHR-ID work well together.
 - Most people will learn to use the PHR-ID very quickly.
- Four (4) negative items (participants' comments)
 - The PHR-ID is unnecessarily complex.
 - I will need the support of a technical person to be able to use the PHR-ID.
 - The information found in the PHR-ID was not consistent throughout the record.
 - The PHR-ID is very awkward to use.
- Ratings were based on a 5-point Likert scale from “1” strongly disagree to “5” strongly agree.



Quantitative Measures

Perceived control

- Perceived control was assessed using a modification of items from the perceived control scale (Menon, 2002).
- Eight (8) positive items (participants' comments)
 - I like having access to the health record of the person I am caring for.
 - I can get the support I need to help the person I am caring for with their health.
 - I think the doctor or other health care provider of the person I am caring for will find the PHR-ID useful.
 - I can influence the physician or other health service provider to use the PHR-ID.
 - I can help make decisions concerning the health of the person I am caring for.
 - I feel very confident using the PHR-ID.
 - I intend to use the PHR-ID to manage the health of the person I am caring for.
 - I want to continue using the PHR-ID rather than stop using it.
- One (1) negative item (participants' comments)
 - I need to learn a lot of things before I can use the PHR-ID.
- Ratings were based on a 5-point Likert scale from “1” strongly disagree to “5” strongly agree.



Quantitative Measures

- Technical assistance
 - Data were recorded regarding participant requests for assistance by frequency and solutions to resolving problems.



Data Analysis

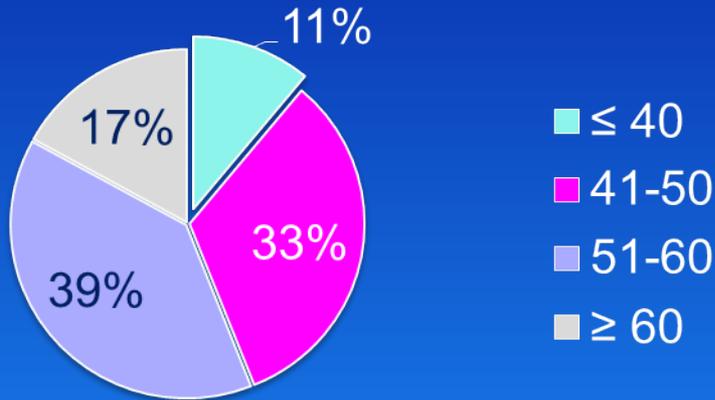
- Quantitative
 - Outcomes: user experience and usability
 - Descriptive statistics: means, medians, standard deviations, ranges, and proportions
- Qualitative
 - Semi-structured interviews over the telephone
 - Interviews were transcribed and analyzed by coding responses to each question
 - Frequencies and percentages
 - Content analysis



Results

Demographics (N=66)

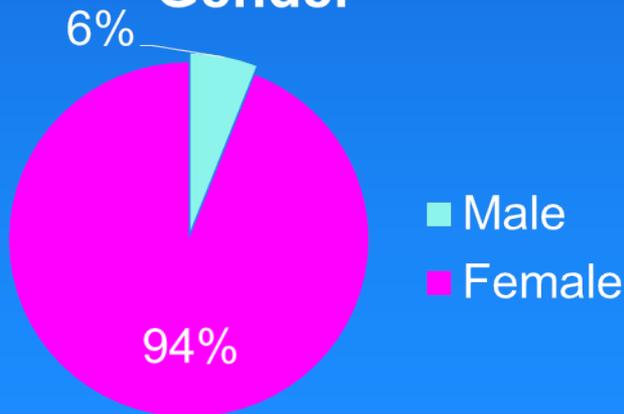
Age



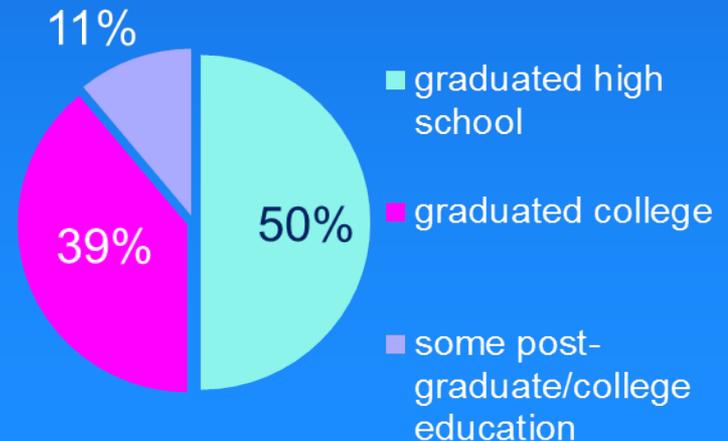
Race



Gender



Education





PHR-ID Usage (N=66)

- 27 (41%) participants viewed the PHR-ID
- 18 participants completed the online usability surveys
- 24 participants completed the barriers survey
- 14 participants participated in the interviews by phone
 - 11 participants used PHR-ID
 - 3 participants did not use PHR-ID



Barriers to Use of PHR-ID (N=24)

Barriers to use of PHR-ID	N	Strongly disagree/ Disagree n (%)	Neither n (%)	Agree/ Strongly agree 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 in blue shading.



Usability Statements Post-Intervention (N=18)

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 in blue shading.

Percentage of Perceived Control Statements After Intervention (N=17)

Perceived control statement	N	<u>Strongly disagree/ 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. Negative statement in blue shading.



Technical Assistance Requested (N=17)

Technical Assistance	N
USB drives became corrupted when inserted into the participant's computer.	7
Different operating systems and computer types required the PHR-ID to be adapted.	6
Participants could not access the login screen.	3
USB extension cable was needed to plug the USB into the back recess panel of the participant's computer.	1
Computer repeatedly shut down when the USB drive was inserted.	1

Six technical assistance requests were able to be resolved, and three participants either withdrew from the study or were unable to be reached after making a technical assistance request.



Qualitative Analyses (N=14)

- A total of 14 participants participated in interviews by phone
 - Eleven participants used the PHR-ID.
 - Three participants did not use PHR-ID.
- Of the 11 participants who used PHR-ID:
 - Seven felt they needed additional training in using the USB port.
 - Eight felt the instructions were not detailed enough.
- Experiences entering data into PHR-ID:
 - Six caregivers entered health information regarding their adult child.
 - Five caregivers entered health data.
 - One caregiver attempted to enter the health data but had difficulty.
 - One caregiver was hesitant to enter the data because she was unfamiliar with some terminology.
 - Half the participants had difficulty navigating the system.
 - Two adults with ID entered the data on their own.
 - Six caregivers reported that their children watched as information was entered.
 - One caregiver attempted to share the process with the child.



Qualitative Analyses (N=14)

- Sharing PHR-ID with provider
 - Two members who completed the study shared the PHR-ID with their adult child's physician or dentist.
 - Both members experienced less-than-receptive physicians.
- Additional comments regarding PHR-ID:
 - Two participants preferred to use Apple computers that were not compatible with the PHR-ID.
 - Four participants mentioned that they would have preferred a Web-based portal for keeping the PHR.
 - Six did not like the USB.
 - One felt that access would be limited without Web access because she relied heavily upon smartphones.
 - One caregiver expressed concern about 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.



Discussion and Conclusion

- There was low usage and interest in accessing the current structure of the PHR-ID among family members who had an adult with ID.
- Time and effort to access the record, solve technical problems, and explore the records' features were limited.
- Out of 66 family members who originally agreed to participate in the study, only 27 (41%) opened the PHR-ID one or more times, and 59% never opened the record.
- There was minimal incentive or need to access the PHR-ID as the adult with ID did not have any significant health issues.
- Despite technical challenges, potential advantages identified were:
 - Increasing the involvement of a person with ID in his/her own health care
 - Coordinating health information among various providers
 - Developing a structured and permanent record of health information
 - Having the ability to track health behaviors



Recommendations

- With more training on the use of the system, health care locus of control can be shifted to family members and people with ID.
- PHRs may be more effective when shared with providers.
- PHR-ID offers greater potential if it can directly involve persons with ID.
- Visual information (pictures, video, and other media) will help young adults with ID interact with personal health information and potentially offer an educational venue.
- Mobile technologies would further advance the capabilities of the PHR, particularly with respect to health screenings such as immunizations and follow-up provider visits.
- Patient portals that connect health consumers with their providers' electronic medical records may serve as an alternative.

Tailored Lifestyle Weight Management Program for Adults with ID: Personal Health Promotion Record (PHPR-ID)

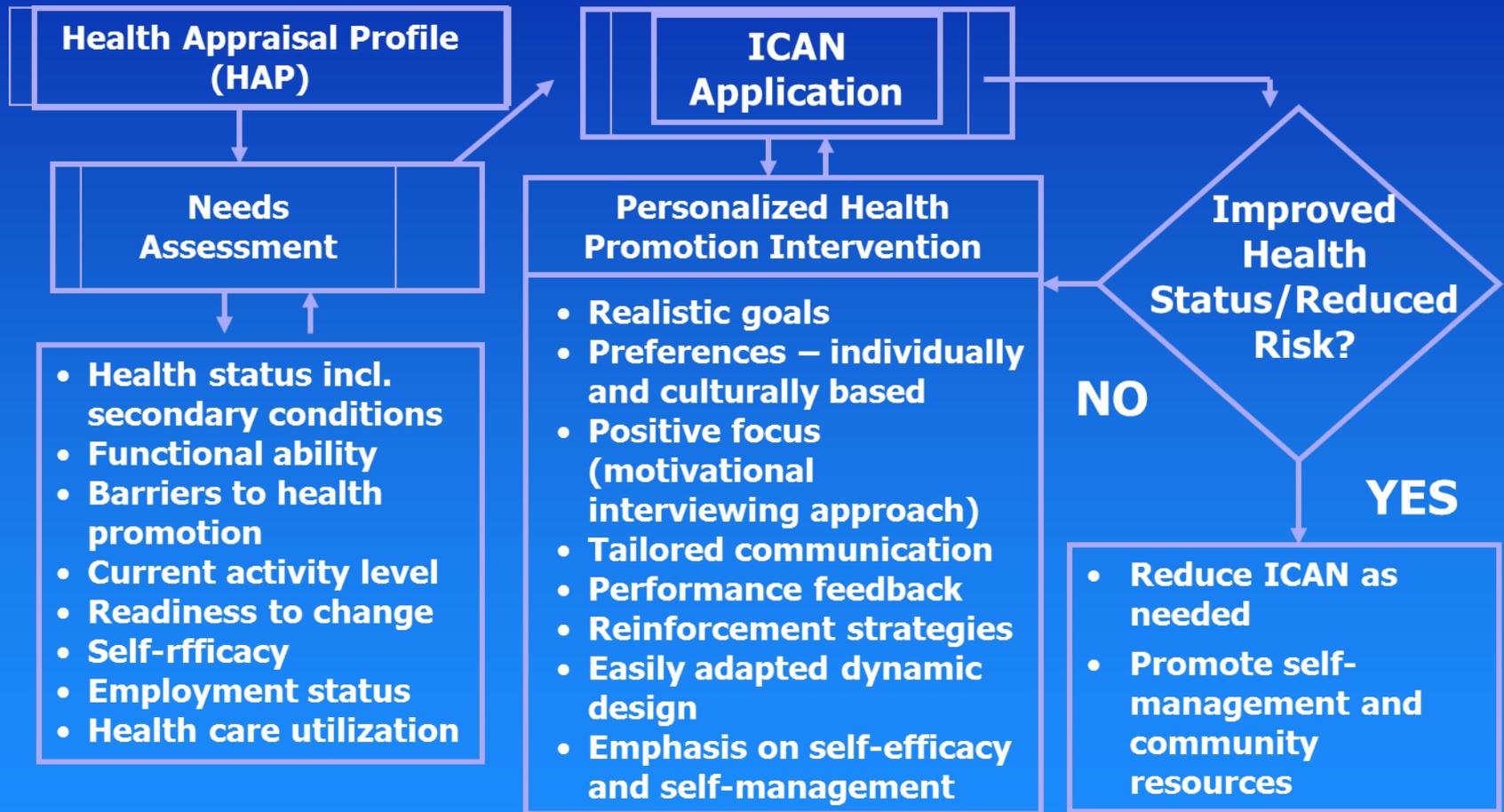




POWERS

Personalized Online Weight and Exercise
Response System (**POWERS**)

POWERS



POWERS



Nearby Subway Locations

https://maps.google.com/maps?q=subway&ll=41.901143,-87.689996&sspn=0.009742,0.015407&near=2511+W+Cortez+St,+Chicago,+IL+60622&geocode=CSkSwi7Oh2f5FdpXfwdCfXf-im

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subway loc: 2511 W Cortez St, Chicago, IL 60622

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- A Subway** ▼

1129 N Western Ave, Chicago, IL 0.2 mi NE
 (773) 276-2383 · [subway.com](#)
 3 reviews \$
 "Step up to the counter and pick your fixings; this international chain ..." - gayot.com
- B Subway** ▼

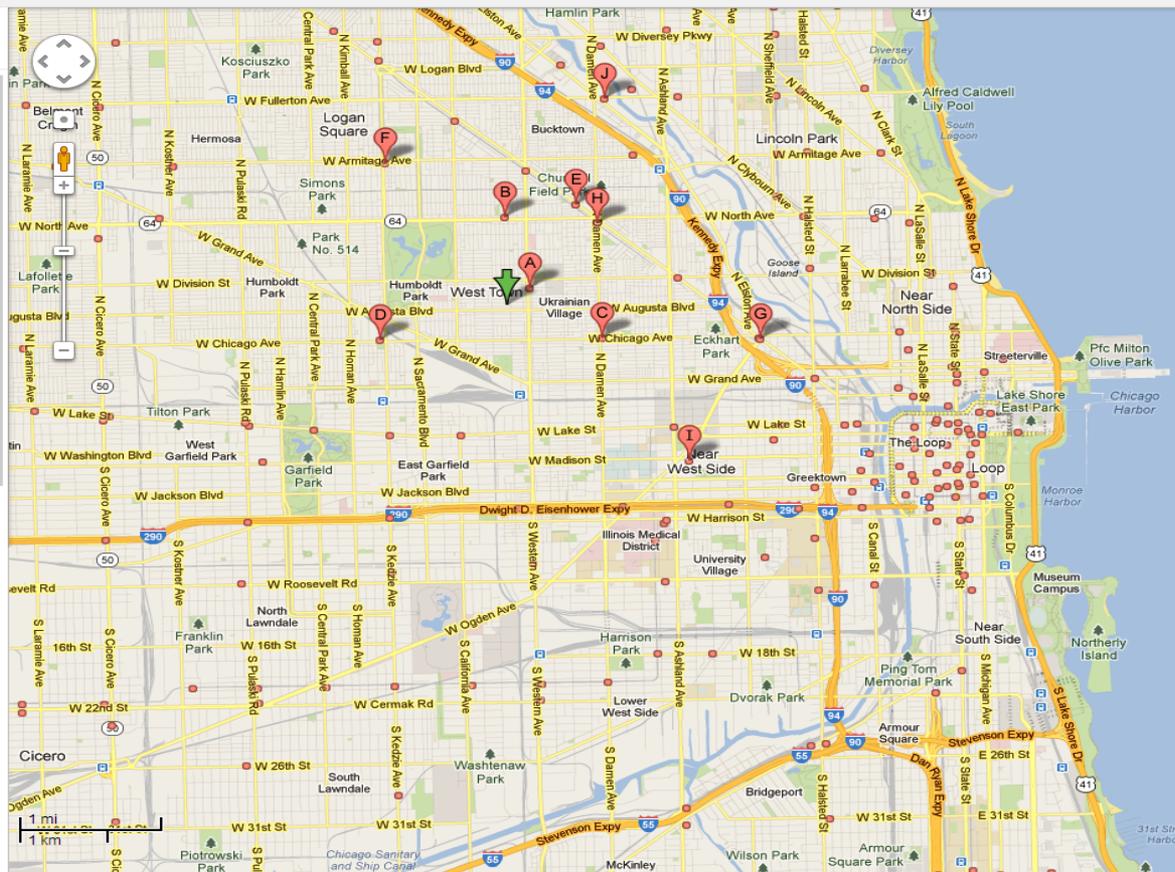
2512 W North Ave, Chicago, IL 0.7 mi N
 (773) 227-8276 · [subway.com](#)
 6 reviews \$
 "If you don't like serving people please get out of the service industry." -
- C SUBWAY** ▼

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 (773) 276-4048 · [subway.com](#)
 \$
 "Step up to the counter and pick your fixings; this international chain ..." - gayot.com
- D Subway** ▼

800 N Kedzie Ave #301, Chicago, IL 0.9 mi W
 Chicago Kedzie Plaza
 (773) 265-1567 · [subway.com](#)
 \$
 "Step up to the counter and pick your fixings; this international chain ..." - gayot.com
- E Subway** ▼

1704 N Milwaukee Ave, Chicago, IL 1.0 mi NE
 (773) 772-4630 · [subway.com](#)
 4 reviews \$
 "I asked for a toasted sub, she did toast it but waited 5 minutes until ..." -
- F Subway** ▼

3129 W Armitage Ave, Chicago, IL 1.5 mi NW
 (773) 252-7827 · [subway.com](#)
 4 reviews \$



POWERS

POWERS by Lakeshore – A Personalized Online Weight and Exercise Response System

HEALTH ASSESSMENT



Preferred Call-in Number: **312-555-1212** Next Scheduled Call: **4/1/2012 @1PM**

- [View Completed Calls](#)
- [Schedule a Call](#)

Demographics +

Participant: Jane Doe
 Location: Chicago, IL
 Age: 15 DOB: 4-13-1997
 Height: 5' 2"
 Weight: 137 lbs BMI: 25.1
 Home Phone: 312-555-1219
 Work Phone: 312-555-2239
 Cell Phone: 312-555-9999
 Email: jdoe9512@gmail.com

Disability & Function +

Primary Disability: Spina Bifida
 Secondary Condition: Obesity, Fatigue
 Associated Conditions: Meningomyelocele, Scoliosis, incontinence
 Chronic Conditions: Anxiety, Asthma
 Assistive Devices: Manual Wheelchair

Chronic Health +

Physical Activity +

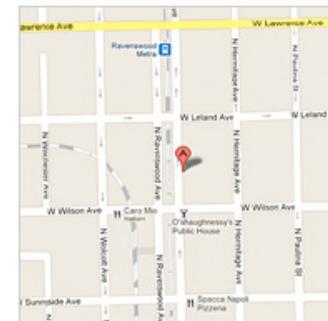
Physical Activity Barriers +

Nutrition & Weight +

[Advanced Search](#)

Physical Activity + Nutrition + Behavior + All + Notes +

Objective	Strategies	Status
+ Increase physical activity to 30 minutes a day.	Perform the cardio section of the NCPAD exercise video developed for youth with spina bifida for 10 minutes. Lorem ipsum dolor sit amet unum loremwinger dopet sit.	Complete Active
+ Perform light stretching activities before endurance exercise (ie, Wii boxing and wheeling around block) to improve range of motion in lower extremities and reduce effects of spasticity during activity.	Place a chair that is the same height of the child's wheelchair in front of child and extend one leg at a time onto the chair to stretch hamstrings and calves. Hold each stretch for 15 sections (see sample video in coaching corner). Lorem ipsum dolor sit amet unum loremwinger dopet sit.	Complete Active
+ Improve peak flow	Teach child how to use diaphragmatic breathing (belly breathing) by taking deep breaths into abdomen and blowing out air through pursed lips (see sample video clip of technique in coaching corner). Perform for five minutes daily before wheeling around the block.	Active
+ Another physical objective goes here.	Another physical strategy goes here.	Active
+ Add new		



Daily Goal Evaluation

Enter/Edit Values

Fruit and Vegetable Consumption 80%



Calorie Goal 1400



Accumulated Physical Activity 90%



Steps 5000



Physical Activity 75%



Personalized Online Weight and Exercise Response System (POWERS)

Accessible Community Features

+ SUBMIT A REPORT

HOME

REPORTS

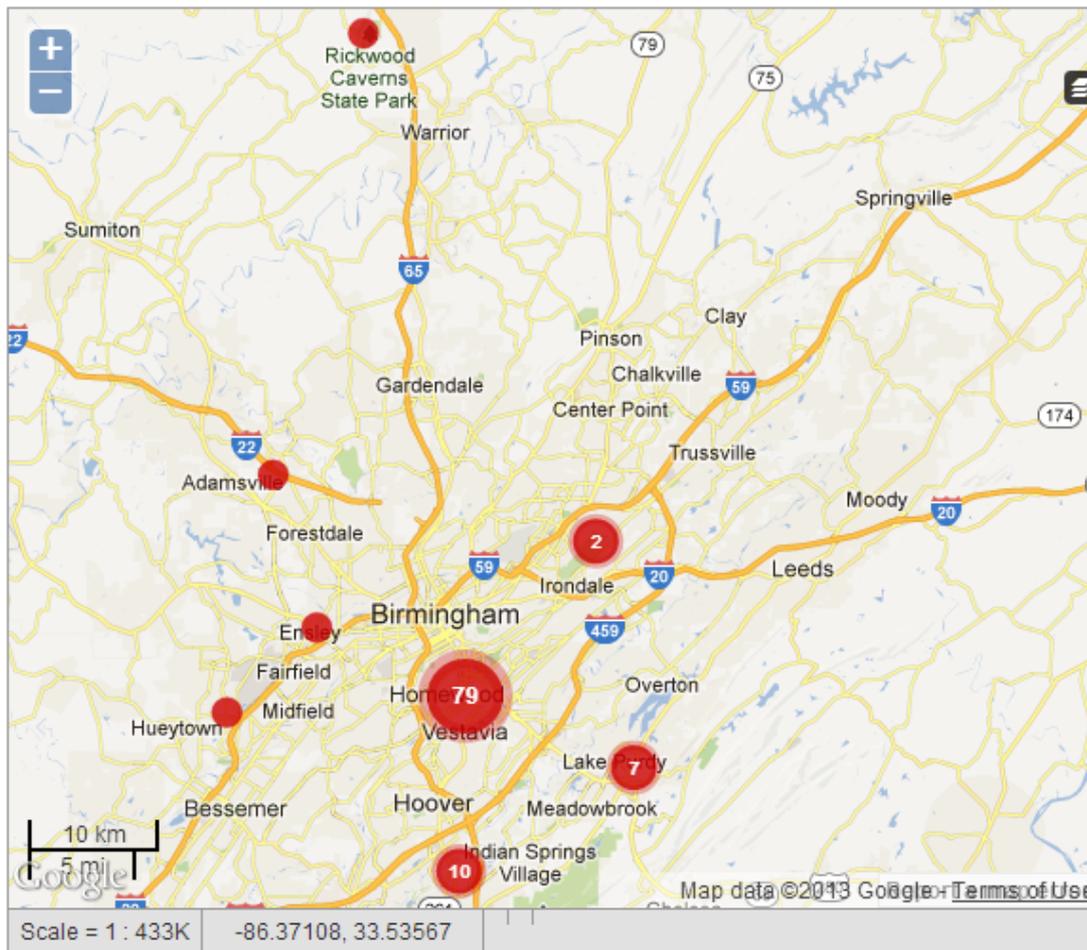
SUBMIT A REPORT

GET ALERTS



FILTERS → ALL NEWS PICTURES VIDEO

↓ CATEGORY FILTER [HIDE]



ALL CATEGORIES

ADVENTURE PROGRAMS

SOCCER

BIKING

AEROBICS

VARIOUS SPORTS

HOCKEY

WATER
AEROBICS/EXERCISE

ATHLETICS/ TRACK & FIELD

TABLE TENNIS

FISHING

BOCCIA

HIKING



Contact Information

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UAB-Lakeshore Research Collaborative



Q & A

Please submit your questions by using the Q&A box to the right of the screen.



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Participants must complete an online evaluation in order to obtain a CE certificate.

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