

National Center for Deaf Health Research (NCDHR) Deaf Health Survey: Using Technology for Health Surveillance and Health Promotion with Deaf Communities

Vincent Samar¹, Steven Barnett², Elouise Oyzon³, Heidi Thompson², NCDHR Research Committee, Deaf Health Community Committee, Michael Delaney³, ITX Corp⁴



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¹National Technical Institute for the Deaf ²University of Rochester ³Rochester Institute of Technology ⁴Trusted Technology Partner for RIT

Abstract

The National Center for Deaf Health Research (NCDHR) is one of 33 Prevention Research Centers funded by the Centers for Disease Control and Prevention. NCDHR's goal is health promotion and disease prevention with deaf people and their families through community-based participatory research. Researchers and Information Technology experts at the National Technical Institute for the Deaf (NTID) and the Rochester Institute of Technology (RIT) collaborated with researchers and deaf community members at NCDHR and with Rochester-based software developers to create a computerized health surveillance survey for use with deaf communities. An innovative touch screen user interface is used to deliver the survey in ASL or English-based signing. The interface and survey were evaluated in usability studies and cognitive interviews. The interface permits the survey respondent to audition and select a preferred signer to administer the items, and to continuously control the survey's appearance and performance. The interface can branch to different items and health themes based on respondent-supplied information such as gender, age, and health behaviors.

Deaf communities are largely overlooked in national health surveillance due to the inaccessibility of telephone surveys used by public health agencies. Therefore, health disparities between these communities and the general community are not currently addressed by public health policy. The NCDHR Deaf Health Survey offers the first opportunity to obtain local and national health surveillance of deaf communities using a linguistically and culturally valid survey instrument. Health data collected with this instrument will help to define specific health needs of deaf communities and to design effective future health promotion efforts to address those needs.

Deaf Health Community Committee



NCDHR Research Committee



Deaf Health Survey

- A computerized, Interactive Health Survey Accessible in American Sign Language (ASL) and English Based Signing
- 98 Health and Demographic Questions based on National Health Surveys and Deaf Population Characteristics
- Computer Interface and Survey Items were Evaluated in Extensive Usability Studies and Cognitive Interviews with Deaf Community Members
- Survey Topics
 - Demographics (age, gender, etc.)
 - Health Status
 - Health Care Access
 - Preventive Services Use
 - Women's Health
 - Vision
 - Diabetes
 - Blood Pressure and Cholesterol
 - Cardiovascular Disease Prevalence
 - Weight and Weight Control
 - Tobacco and Alcohol Use
 - Safety
 - Sexual Behavior
 - Interpersonal Violence
 - Mental Health
 - Suicide
 - Learning Disability/ADHD
 - Hearing Level and Communication

Deaf Health Survey Translation Teams

- ASL Team
- Robert Pollard
 - Robyn Dean
 - Elizabeth Finigan
 - Betsy McDonald (Back Translator)
 - Patrick Graybill
 - Julianna Aggas
 - Susan Demers
- English Based Signing Team
- Patrick Sullivan
 - Katherine Schmitz
 - Karen Finch
 - Aaron Kelstone (Back Translator)
 - Barbara Ray Holcomb (Back Translator)

NCDHR Goals

- Deaf Communities Partner with Researchers
- Learn about Deaf Health Issues
- Conduct Research with Deaf People
- Empower Deaf People to Become Better Informed in Healthcare
- Improve Health and Healthcare with Deaf People and their Families
- Encourage Deaf People to Choose Research Jobs
- Teach Students, Doctors, Nurses, Researchers about Deaf Health
- Mentor New Deaf and Hearing Researchers to Work with Deaf Communities

NTID Partnership with NCDHR



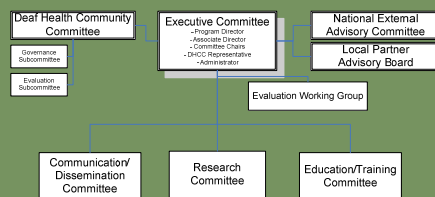
Interface and Sample Item



How Will the Deaf Health Survey Help Deaf Communities?

- Will Provide the First Linguistically and Culturally Accessible Health Survey to Deaf People
- Will Identify Health Disparities
- Will Identify Health Needs
- Will Help Set Priorities for Health Promotion and Disease Prevention
- Will Help Obtain Funds for New Services and Programs
- Will Create Public Health Research Jobs for Deaf People
- Will Provide Clinicians with Better Information for Working with Deaf people and their Families

National Center for Deaf Health Research (NCDHR) Organizational Chart



Health Data

	White Americans	African Americans	Deaf Americans
Cancer	193.9 per 100,000	243.1 per 100,000	No data
Diabetes	23.0 per 100,000	49.2 per 100,000	No data
Infant Mortality	5.7 per 1,000 live births	13.3 per 1,000 live births	No data
Adult Immunization	70.2 %	52%	No data

Source: www.cdc.gov

Interactive Features of the Deaf Health Survey

- Allows Choice of Six Signers to Present the Survey
- Allows Choice of ASL or English-Based Signing
- Allows Choice for Captions in English
- Permits User Control of Survey Appearance
 - Size of Signer Video
 - Size of Text
 - Color of Background
- Provides Dictionary for Medical Terms
- Can Branch to Different Items and Health Themes Based on Respondent-Supplied Information such as Gender, Age, and Health Behaviors.
- Touch Screen Access
- Guided Instructions in ASL, English-Based Signing, Text

Future Directions

- Administer the Deaf Health Survey with NTID Alumni and Others During the NTID 40th Reunion Weekend
- Adapt the Deaf Health Survey for Use with College Students to Learn About the Health of Deaf, Hard-of-hearing and Hearing College Students
- Adapt the Deaf Health Survey for Use with High School Students to Learn About the Health of Deaf and Hard-of-hearing Adolescents and Young Adults
- Use the Survey Data to Develop Health Promotion Interventions Targeting College Students, College Graduates, High School Students, Families with Deaf Children, and Others
- Continue to Explore Enhancements to the Survey Design and Delivery System