Adapting the Behavioral Risk Factor Surveillance System (BRFSS) to survey deaf sign language users

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Introduction

Telephone surveys, including the Behavioral Risk Factor Surveillance System (BRFSS), are inaccessible to deaf people.

Many adults deaf since birth or childhood use American Sign Language (ASL), which is different from English and has no written form.

For complex reasons, many deaf adults have low English literacy.

The mission of the CDC-funded Rochester Prevention Research Center: National Center for Deaf Health Research (NCDHR) is health promotion and disease prevention with deaf people and their families through community-based participatory research (CBPR).

The lack of health research data limits the community's ability to identify and address health priorities.

An initial NCDHR research project is to adapt the BRFSS for use with deaf adult ASL-users in order to collect baseline data on health & health risks.

Methods

To create an accessible survey, we:

(a) translated the English BRFSS items into sign language (and back-translated),

(b) adapted the English for captions,

(c) added deaf-specific items,

(d) worked with community partners to prioritize topics,

(e) designed the computer-based survey interface,

(f) developed a dictionary to address fund-of-information deficits,

(g) conducted in-depth individual cognitive interviews to evaluate the survey,

(h) developed recruitment strategies for further field-testing

(i) administered the survey to two samples: one local to Rochester, NY (n=302) and one national (n=215).

The research was approved by the University of Rochester Research Subjects Review Board.

Translation/Adaptation

In addition to translation, we adapted some items to preserve clarity. An adaptation example:

English

What is the highest grade or level of school that you have completed?

__ 8th grade or less

__ Some high school, but did not graduate

__ High school graduate or GED

__ Some college or 2-year degree

__ 4-year college graduate

__ More than 4-year college degree

ASL format

Did you graduate high school or get your GED?

-If Yes: After high school, did you go to college?

--If Yes: What degree to you have?

-If No: Did you go to high school?

--If No: Did you finish 8th grade?

---If No: Did you finish Kindergarten?

-If Don't know: Did you go to high school?

--If No: Did you finish 8th grade?

---If No: Did you finish Kindergarten?

Instrument

We developed a survey that worked on a touch-screen computer kiosk. We designed the survey to be accessible to a broad segment of the population. We tested the survey design with members of the deaf community, and adjusted the design based on feedback.
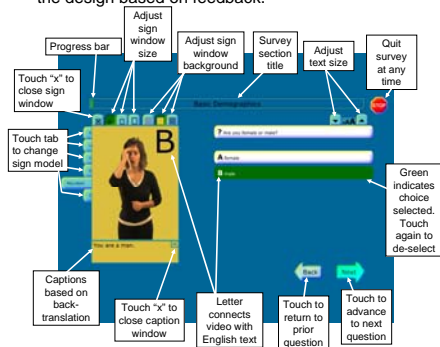
Data Collection

We administered the NCDHR Deaf Health Survey in Rochester to 302 non-institutionalized adults from March to September 2008. Approximately half took the survey at the NCDHR office, either by appointment or as a walk-in. Others took the survey at community sites, such as the Rochester Recreation Club for the Deaf (RRCD), often during a community event. For a few individuals with limited transportation, NCDHR staff brought the survey to their home.

We also administered the NCDHR Deaf Health Survey to 215 of the more than 700 adults who attended the 40th Anniversary Reunion of the National Technical Institute for the Deaf (NTID) in Rochester June 26-28, 2008.

Demographics

Below are demographics for the first 283 adults from the Rochester Metropolitan Statistical Area (MSA) who took the survey.

Age range.....................	18 - 88
Age mean	46yo
Female	50.4%
Married	48.9%
Hispanic/Latino	2.6%
Race	
White	85.6%
Black/African-American	4.9%
Asian	2.7%
American Indian	1.1%
Other/Multi-racial	5.7%
Education (highest level)	
Some HS	5.3%
HS grad	11.5%
Some college	11.8%
Two-yr degree	22.9%
Four-yr degree	20.6%
Graduate degree	27.9%

Deaf Demographics

Deaf parent or sibling	29.3%
Usher syndrome	2.2%
Education (type attended)	
Only deaf schools	43.5%
Never a deaf school	20.8%
Deaf school & other	35.8%
Age-at-onset of deafness	
Birth	70.2%
< 1yo	9.5%
1 - 7yo	14.9%
Don't know	4.2%

Geography

Home ZIP code of Rochester MSA survey participants

	= 0 surveys
	= 1 – 5
	= 6 – 10
	= 11 – 20
	> 20
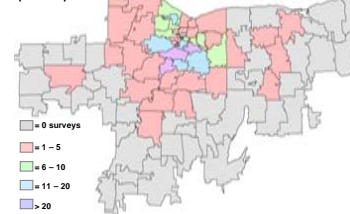
Discussion

Even with collaboration, recruitment challenges remain in reaching certain groups (race, education level, geography)

Informed consent in health research has not been studied with deaf ASL-users. Discussions amongst community members, researchers & members of the Institutional Review Board (IRB) helped develop relationships & protect participants

Traveling to take a survey at a kiosk location is fundamentally different than taking a survey at home via telephone

The Rochester deaf community is not representative of other US deaf communities. It is likely that findings from the Rochester Deaf Health Survey will underestimate health disparities experienced by deaf people

Conclusions

Community-based participatory research (CBPR) is essential for adapting surveys. Our computer-based BRFSS enhances access to a difficult-to-reach understudied health disparity population. Ongoing research will continue to develop accessible surveys. Future research will use survey data to collaboratively identify health priorities and develop & evaluate linguistically & culturally appropriate health promotion interventions.

Acknowledgments

Contact

NCDHR   http://www.urmc.edu/ncdhr