

Working Collaboratively for the First Community-based Comprehensive Health Survey of a US Deaf Community

Rochester Prevention Research Center:
National Center for Deaf Health Research
University of Rochester

Presenters:

Julia Aggas MS

Chair, NCDHR Deaf Health Community Committee

Steven Barnett MD

Chair, NCDHR Research Committee

Tamala David MPA MS FNP, ASPH/PRC Fellow

NCDHR Research Committee

Patrick Graybill MS HonLHD

Past Chair, NCDHR Deaf Health Community Committee

John Patrick Sullivan LCSW-R

NCDHR Deaf Health Community Committee

Thomas A Pearson MD PhD MPH

Director, National Center for Deaf Health Research

Kim Kelstone CI/CT

Annette Quiroga CI/CT



Communication Rules

- Turn-taking – the interpreters can only interpret for one speaker at a time
- Wait for the delay
- Be aware of others -- deaf people use different cues (visual rather than auditory) to indicate they want to make a comment

Take Home Messages

- ASL is not English
- Deaf sign language users comprise understudied disparity populations
- Community-based participatory research is essential to the survey adaptation process

Outline

- Background
- Review a few steps in the survey development process
- Describe survey interface (screen shots)
- You can see and try a demo survey after the presentation

Are you currently taking medications?

Sign Language

- American Sign Language (ASL)
 - Different from English
- English-based signing
- Not measured by census/surveys

Deaf people who use ASL

- Usually adults deaf since birth or childhood
- Late-deafened adults very different
- “Rubella bulge”

Why Deaf people?

- HP2010 objectives
- Disparities in access to research
 - Modality
 - Language
 - Literacy
- Disparities in health & healthcare

Rochester NY

- Many sign language users
- Rochester Deaf Health Task Force
- Rochester Prevention Research Center:
National Center for Deaf Health Research
 - health promotion & disease prevention with deaf ASL-users and their families
 - Local & national connections
 - Core project is to create an accessible survey to collect data

Social similarities

ASL-users & other language minorities

- Use of a non-English language
- Socialize & partner/marry within community
- Cultural norms different than those of the majority community
- Children often become bicultural/bilingual

Opportunity similarities

ASL-users & other language minorities

- Many have lower education level, income, & literacy than the general population
- Often encounter prejudices that limit opportunities
- Often have limited access to English language-based information

Healthcare similarities

ASL-users & other language minorities

- Infrequently encounter a doctor from their own cultural group
- Often experience language differences as barrier to good healthcare
- Often experience cultural insensitivity as barrier to good healthcare
- Often have limited health knowledge
- Poorer health status than general population
- Less frequent physician visits than general population

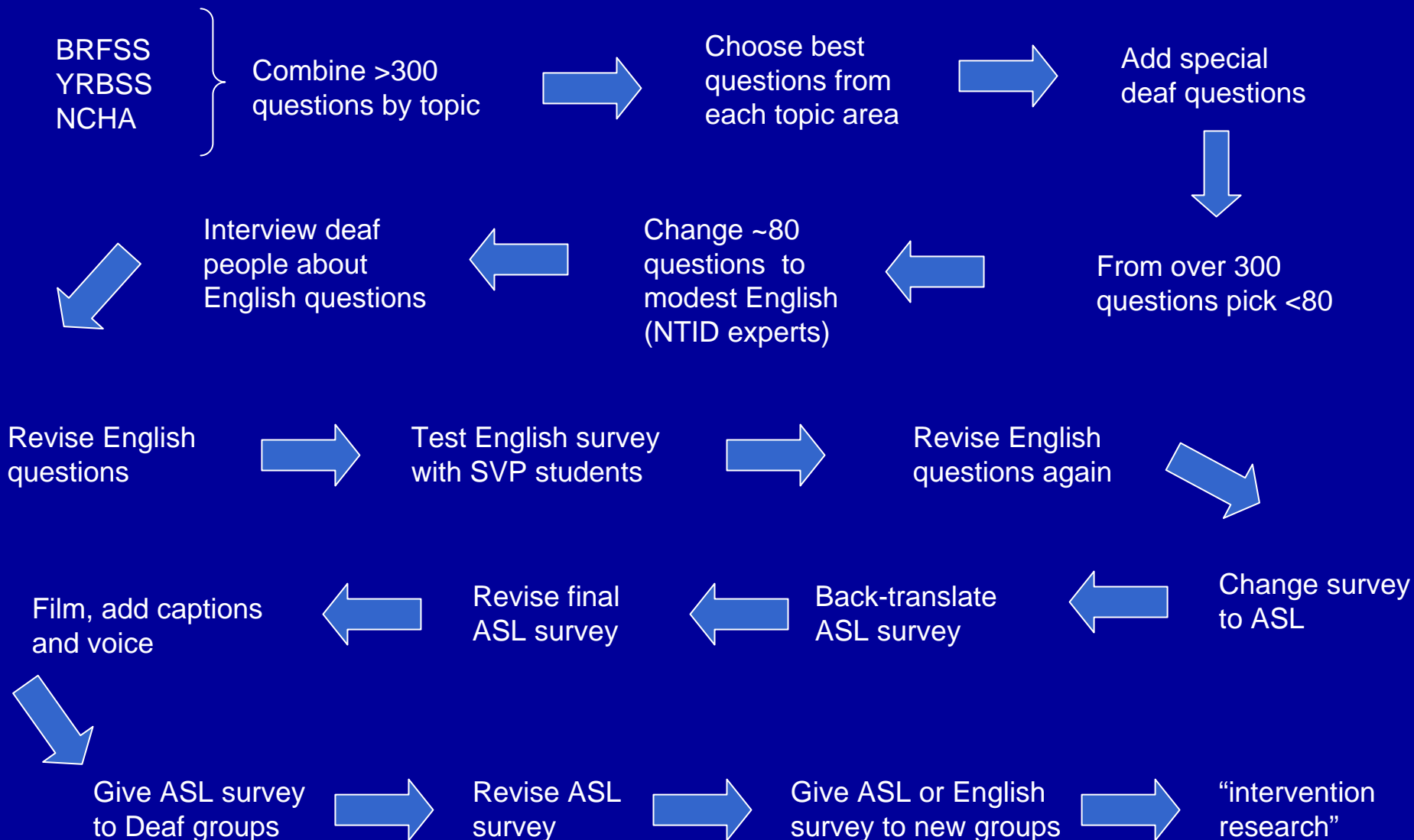
Differences

ASL-users & other language minorities

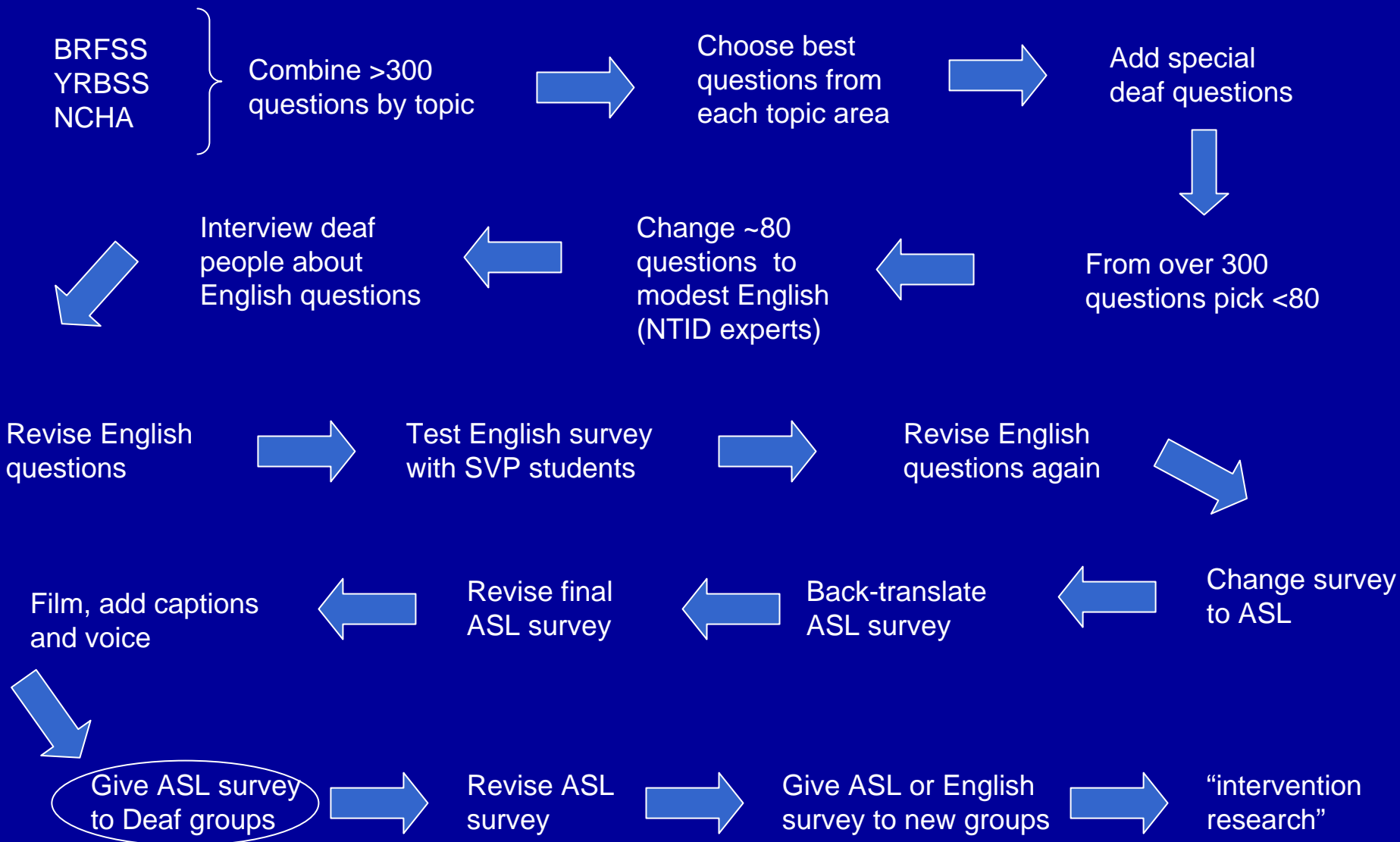
- Deaf culture often transmitted from peers (horizontally) rather than from parents (vertically)
- Doctors/researchers often expect deaf people to have fluency in written English
- Doctors/researchers often expect deaf people to speechread English
- Americans with Disabilities Act applies to deaf people



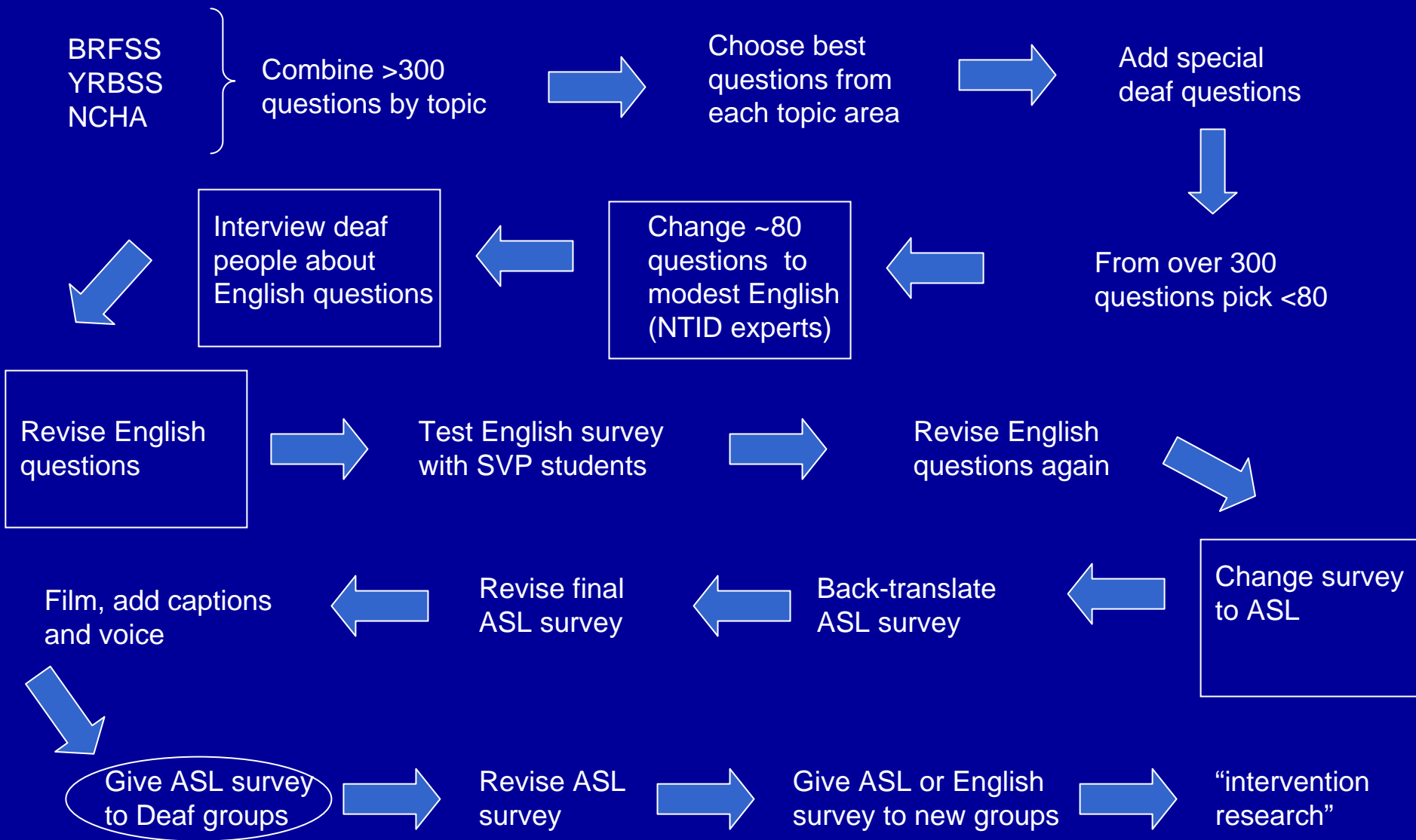
Core Project Steps



Core Project Steps



Core Project Steps



Adapt English

- Linguists reviewed original English
 - “Do you wear a helmet when you ride a motorcycle?” changed to “When you ride a motorcycle, do you wear a helmet?” [from NCHA]
- In-depth individual cognitive interviews
 - “... blood cholesterol tested ...” [from BRFSS]

Dictionary

- Addresses fund of information
- Similar in function to BRFSS explanations
 - Mammogram
- Consistent with purpose
 - Compare with other groups
 - Compare pre- & post- intervention



Translations

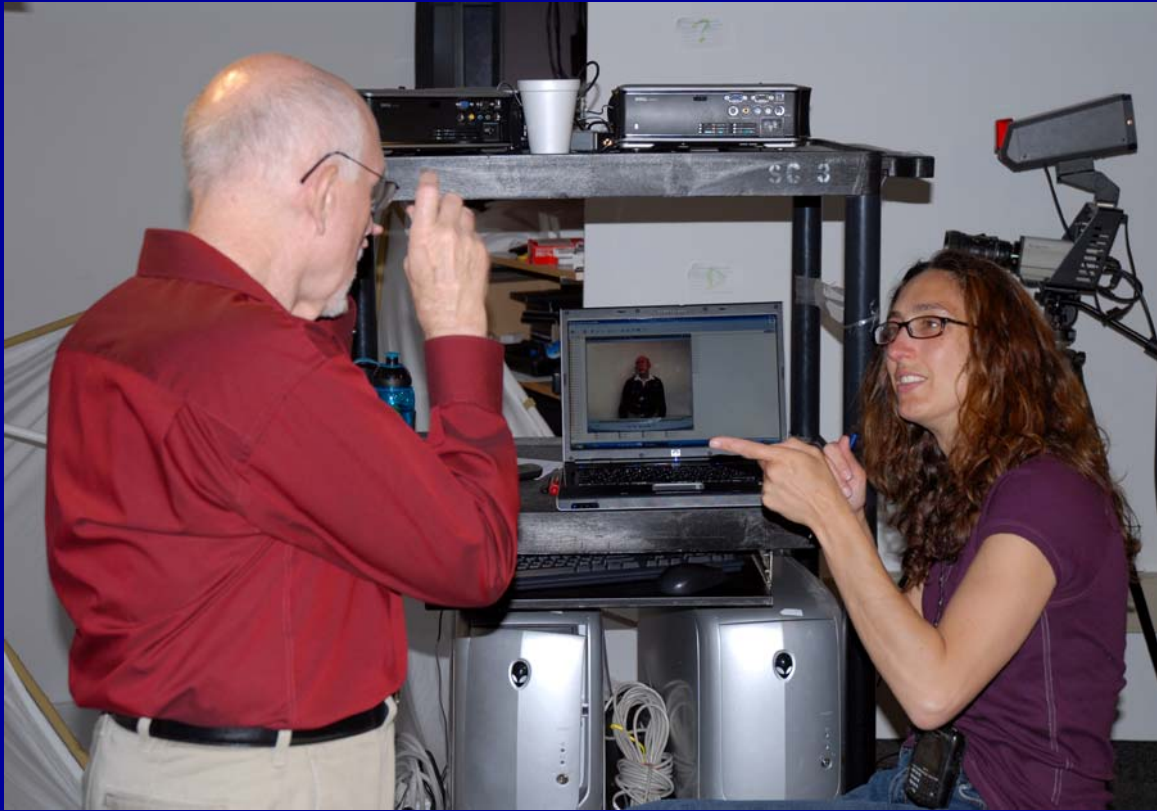
- Bilingual fluent community members & researchers
- Two teams
 - ASL
 - English-based sign
- Script video-recorded
- Independent back-translations
- Sometimes further decisions made in the studio

ASL Translation

- 6 team members
 - 3 from DHCC
 - 3 from NCDHR Research Committee
- Decision examples
 - Include question stem in response
 - Education level question -> 11 items

EBS Transliteration

- 4 team members
 - 1 from DHCC
 - 1 from NCDHR Research Committee
 - 2 from community
- Task to match English source and ASL translation
- Decision examples
 - Voice track



Interface design

- Accessible for broad range of education levels
- Strong feedback from the community about confidentiality
- Survey collects a lot of data



CC



CC



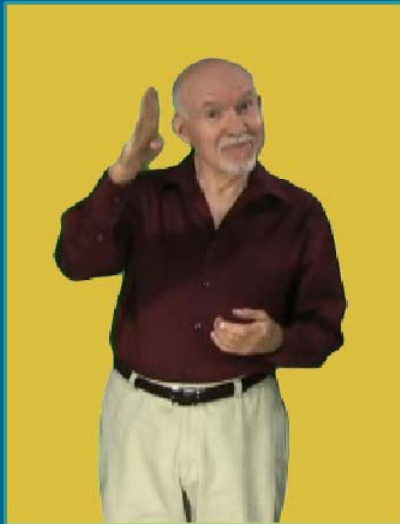
CC



CC



CC



CC

My name is Patrick. You can touch on the other signers. You can pick a different signer at any time. When you are done. Touch next.



Introduction



i

MaryBeth

As the survey progresses sometime you may see an 'i' inside a circle appear.

During the survey questions, sometimes you will see that the letter 'i' with a circle around it will appear. Touching the 'i' will open a dictionary. You may see a word or sign that is unfamiliar. In this example we use the word 'cholesterol'. Touch the 'i' and a panel with the word being defined will slide out from the right. A sign explanation of the word will be given and then the English text version will appear. To close the dictionary, touch the box with the X in the top right corner.

i Cholesterol

A Example Answer 1

B Example Answer 2

C Example Answer 3




Basic Demographics



Navigation icons: [Close] [Home] [Back] [Forward] [Search] [Refresh] [Zoom]

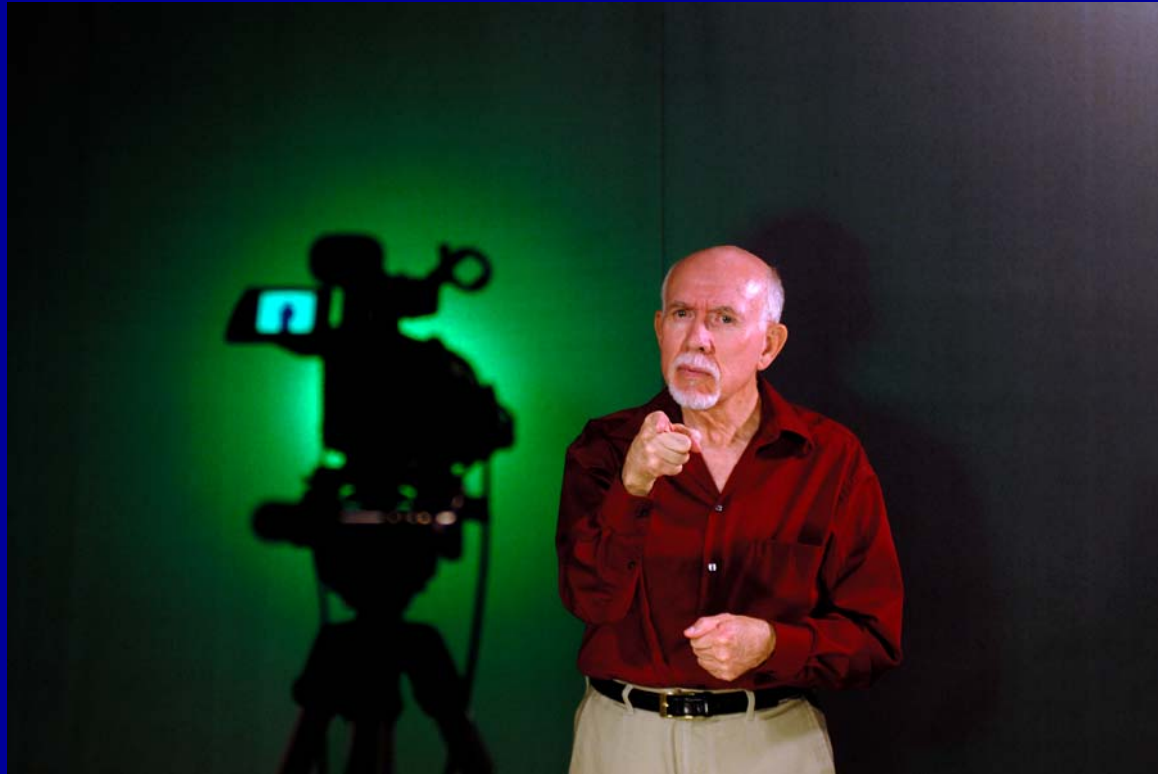
Vertical menu: R, Li, P, G, MaryBeth, D



You are a man. [Close]

- AAA [Close] [Zoom]
- ? Are you female or male?
 - A female
 - B male**





Survey Experience

Early data collection

Summary of data collected 2/29 – 3/17 2008

- 115 surveys
 - 58% at NCDHR
 - Community locations include
 - Deaf club
 - Apt complex with many deaf residents
 - U of R department with many deaf faculty/staff
- 40 exit interviews

Exit Interviews

Early data collection

- A lot of positive feedback
- Concerns about the survey length
- Some discomfort with some topics
 - violence, mental health, alcohol
- No questions should be dropped
- Suggestions for future topics



Demographics

Early data collection

Men	50.5%
Age (median)	50 yo
Age (range)	18 - 77
Hispanic	2.9%
White	92.1%
Married	52.9%

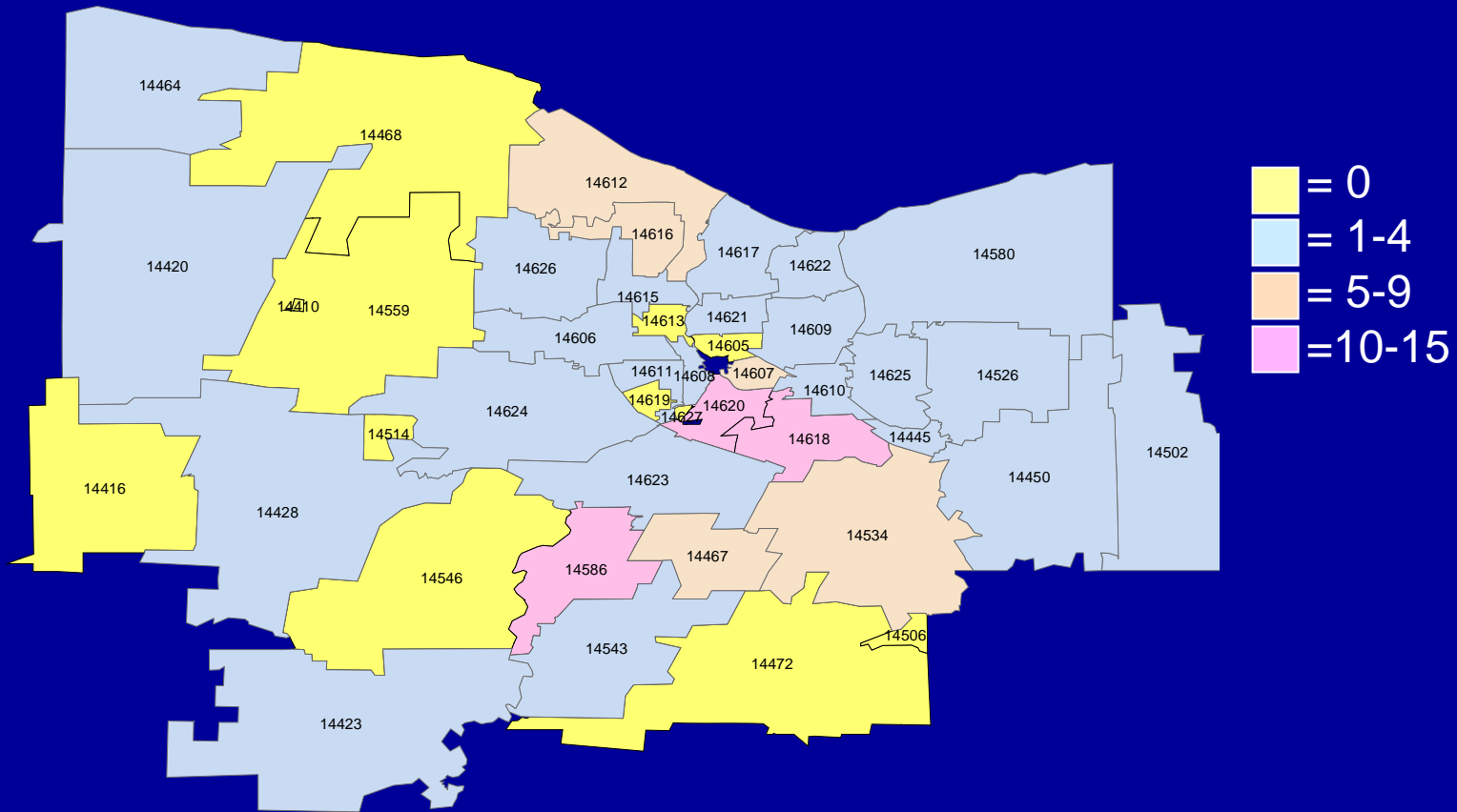
Demographics

Early data collection

Health = fair or poor	4.4%
Education	
Graduate degree	32.0%
College 4yr degree	16.5%
Some college	34.0%
HS graduate	13.6%
< HS	3.9%

Geographic distribution

Early data collection



Deaf demographics

Early data collection

Deaf parent or sibling	31.4%
Age became deaf	
Birth	70.9%
< 1 year	13.6%
1 – 6 years	10.7%
don't know	4.9%

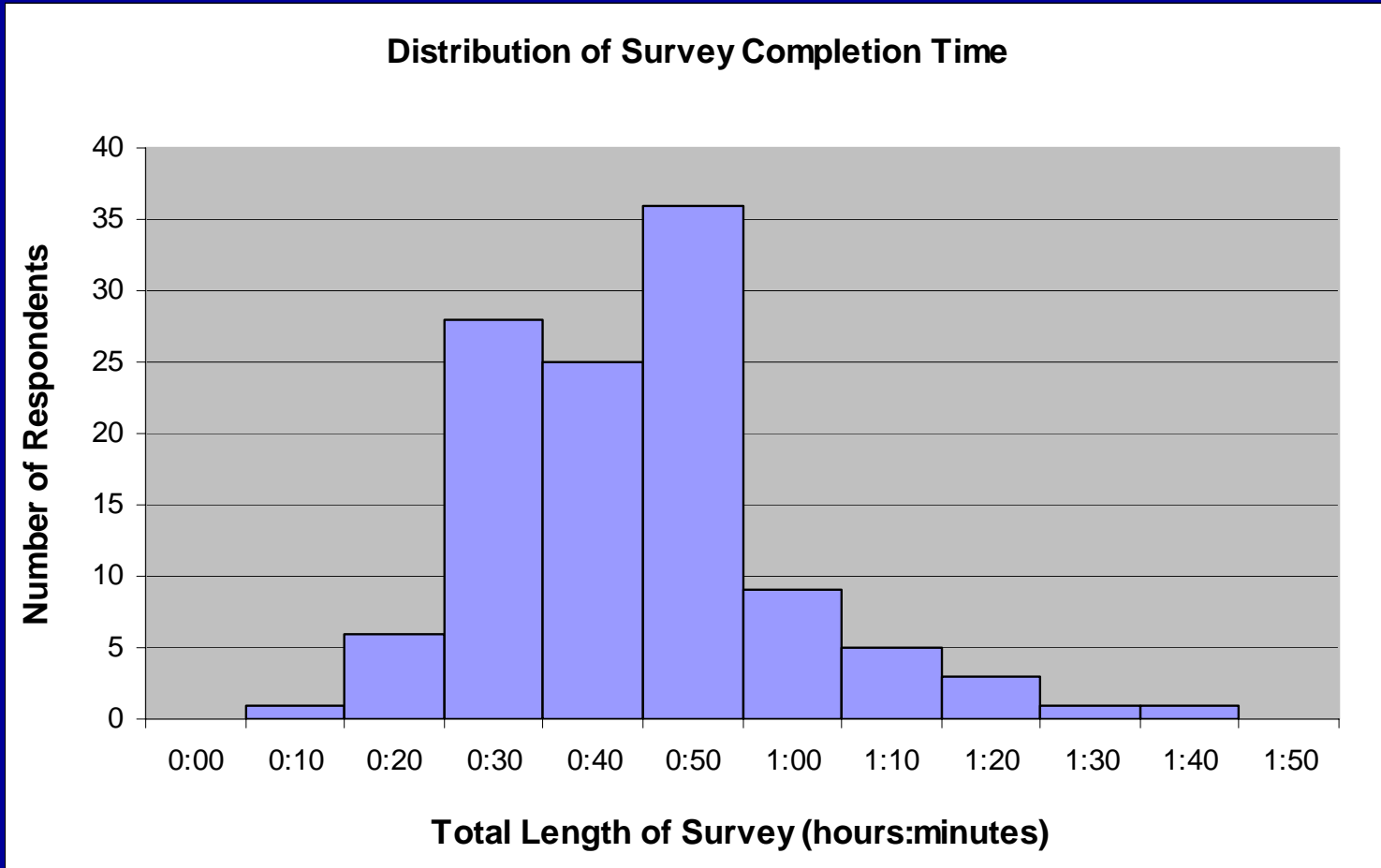
Survey time

Early data collection

	Mean \pm SD
Consent	5:51 \pm 0:54
Instructions	6:18 \pm 3:15
Survey	27:06 \pm 13:21

Survey time

Early data collection





Take Home Messages

- ASL is not English
- Deaf sign language users comprise understudied disparity populations
- Community-based participatory research is essential to the survey adaptation process

Questions?

Feedback?

NCDHR is supported by Cooperative Agreement Number U48 DP000031 from CDC. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the CDC.

This presentation briefly discusses a project made possible through a Cooperative Agreement between the Center for Disease Control and Prevention (CDC) and the Association of Teachers of Preventive Medicine (ATPM), award number TS-0817. The presentation content is the responsibility of the author and does not necessarily reflect the official views of the CDC or ATPM.

Tamala David is supported by Association of Schools of Public Health CDC Prevention Research Center (ASPH/CDC/PRC) Minority Fellowship Program.

Steven Barnett is supported by grant K08 HS15700 from the Agency for Healthcare Research and Quality.

Thank you to everyone who has worked with NCDHR.

National Center for Deaf Health Research
Rochester Prevention Research Center



University of Rochester

PO Box 278990

Rochester, NY 14627-8990

ncdhr@urmc.rochester.edu

(585) 276-2122 VP

(585) 424-1469 FAX

(585) 758-7804 TTY

(Voice calls: dial 711 to reach Relay Service)

www.urmc.edu/ncdhr

Presented during the 2008 Summer in the City Series, sponsored by the
Center for Community Health, University of Rochester Medical
Center (June 17, 2008)