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:

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    Chair, NCDHR Deaf Health Community Committee
Steven Barnett MD
    Chair, NCDHR Research Committee
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    NCDHR Research Committee
Patrick Graybill MS HonLHD
    Past Chair, NCDHR Deaf Health Community Committee
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    NCDHR Deaf Health Community Committee
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    Director, National Center for Deaf Health Research

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Carolyn Lomeo 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 <u>a few</u> steps in the survey development process
- Describe survey interface (screen shots)

- You can see the actual survey after the presentation, near the NCDHR posters

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
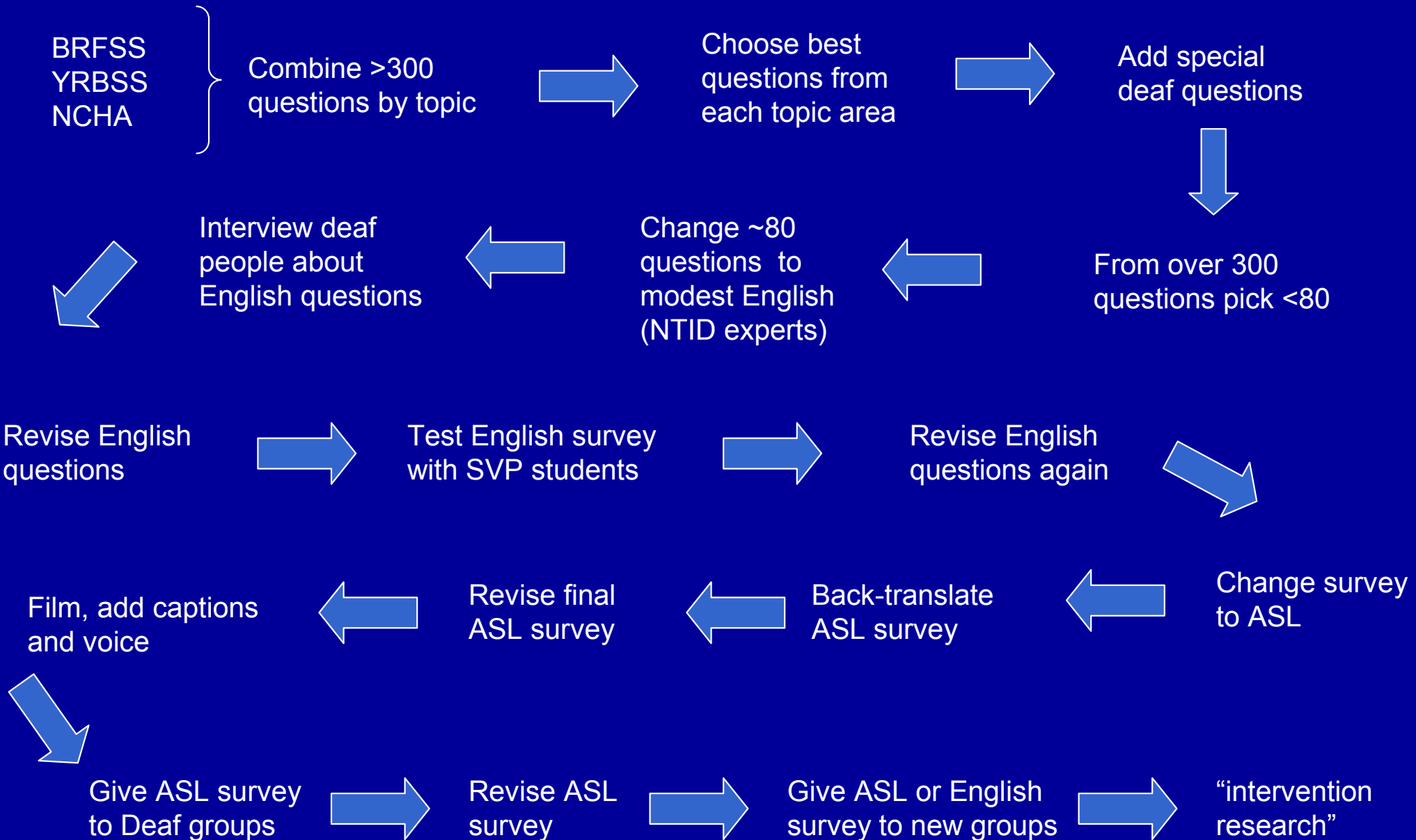- Less frequent physician visits than general population

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
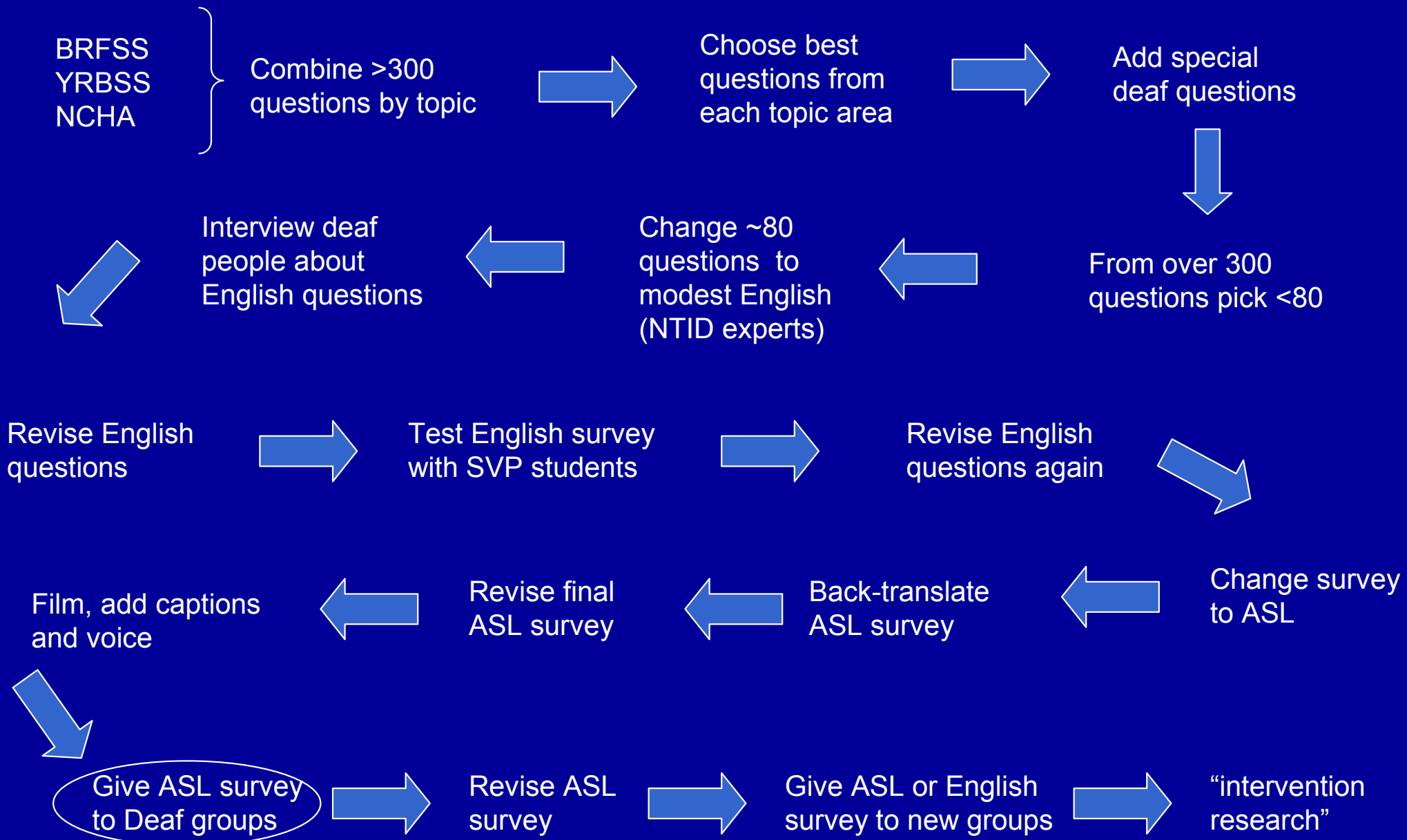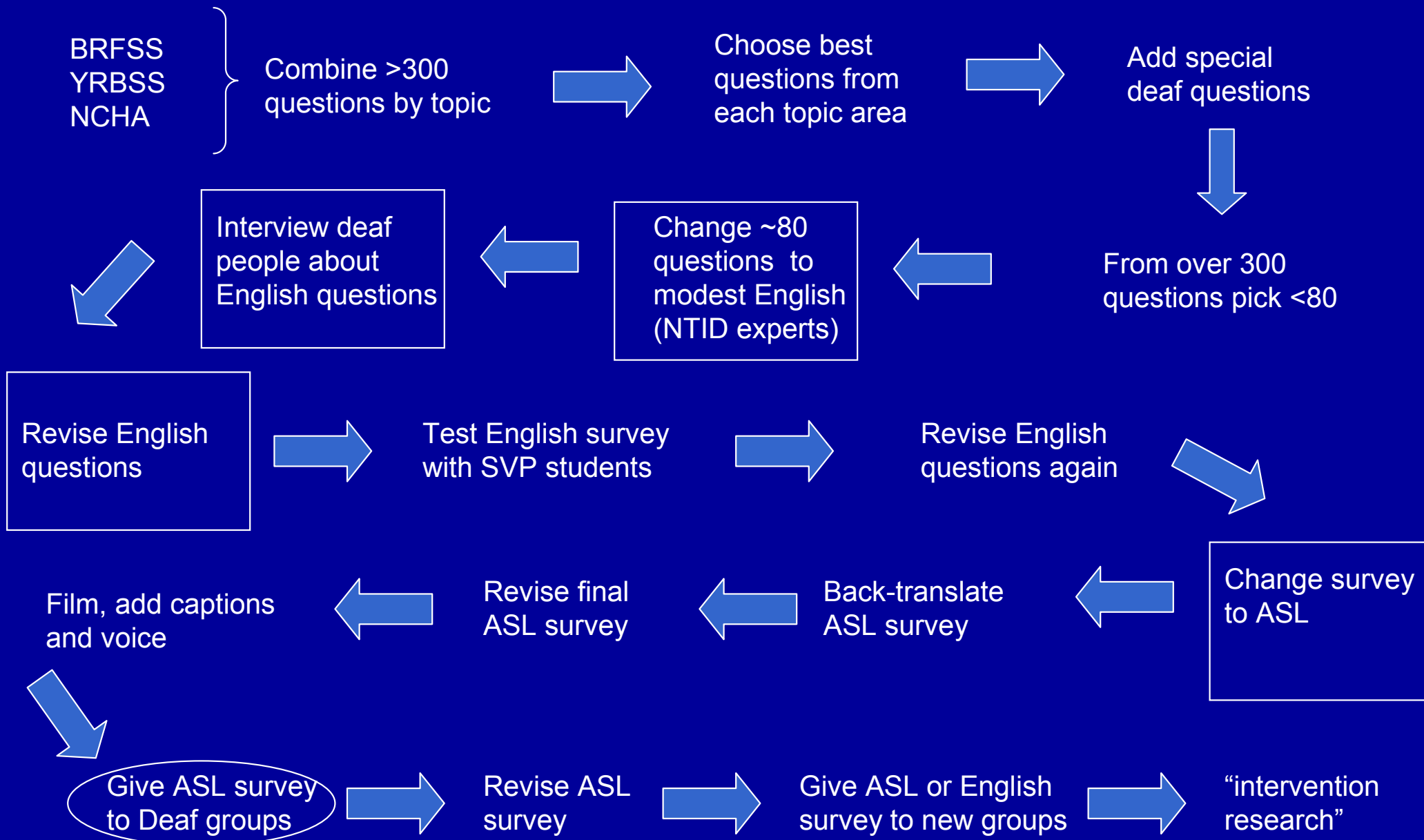- Americans with Disabilities Act applies to deaf people

Core Project Steps

BRFSS
YRBSS
NCHA
→ Combine >300 questions by topic → Choose best questions from each topic area → Add special deaf questions

↓

Interview deaf people about English questions ← Change ~80 questions to modest English (NTID experts) ← From over 300 questions pick <80

↓

Revise English questions → Test English survey with SVP students → Revise English questions again ↘

Film, add captions and voice ← Revise final ASL survey ← Back-translate ASL survey ← Change survey to ASL

↓

Give ASL survey to Deaf groups → Revise ASL survey → Give ASL or English survey to new groups → "intervention research"

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Give ASL or English survey to new groups

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"intervention research"

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

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.

Next

STOP

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.

ⓘ **Cholesterol**

A Example Answer 1

B Example Answer 2

C Example Answer 3

MaryBeth

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

Back   Next

STOP

B

You are a man.

? Are you female or male?

A female

B male

MaryBeth

Back

Next
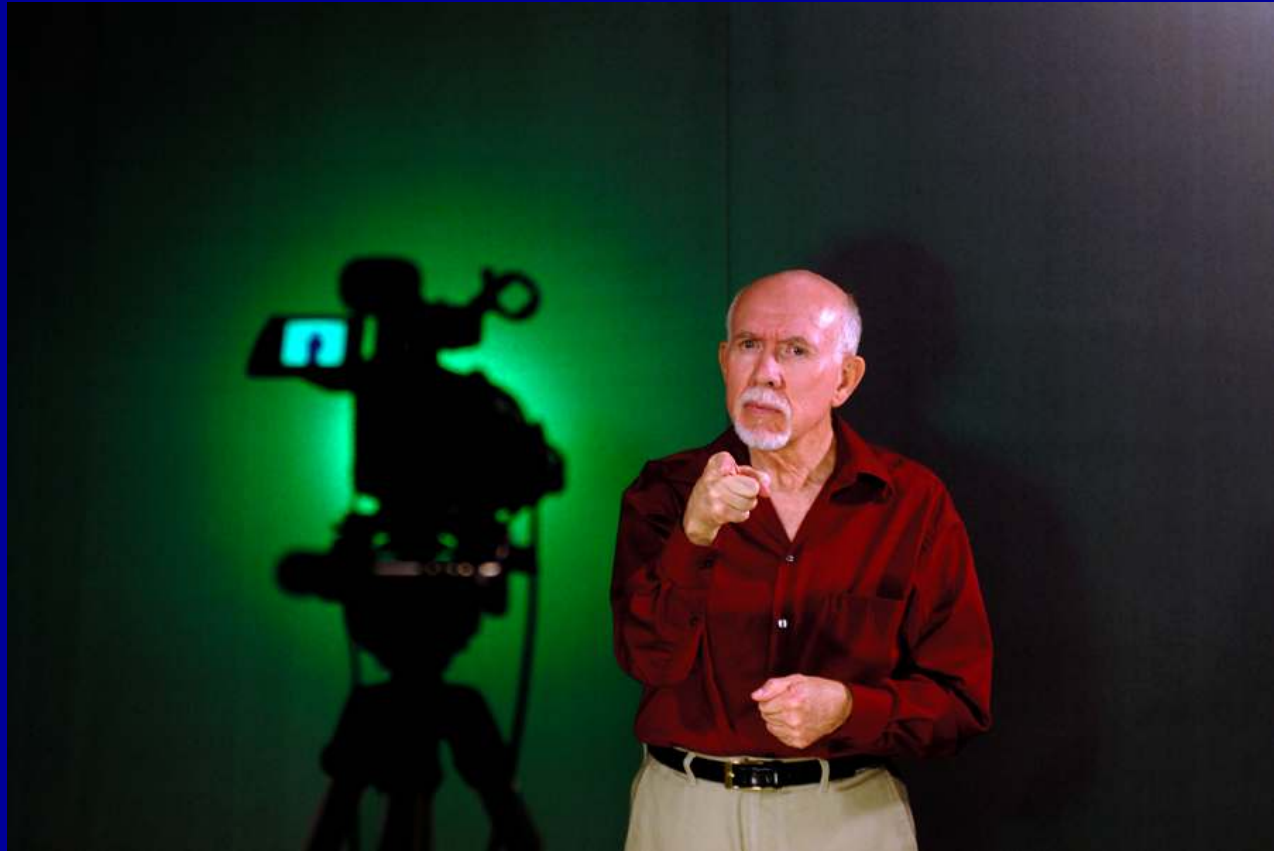
Survey Experience
Early data collection

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
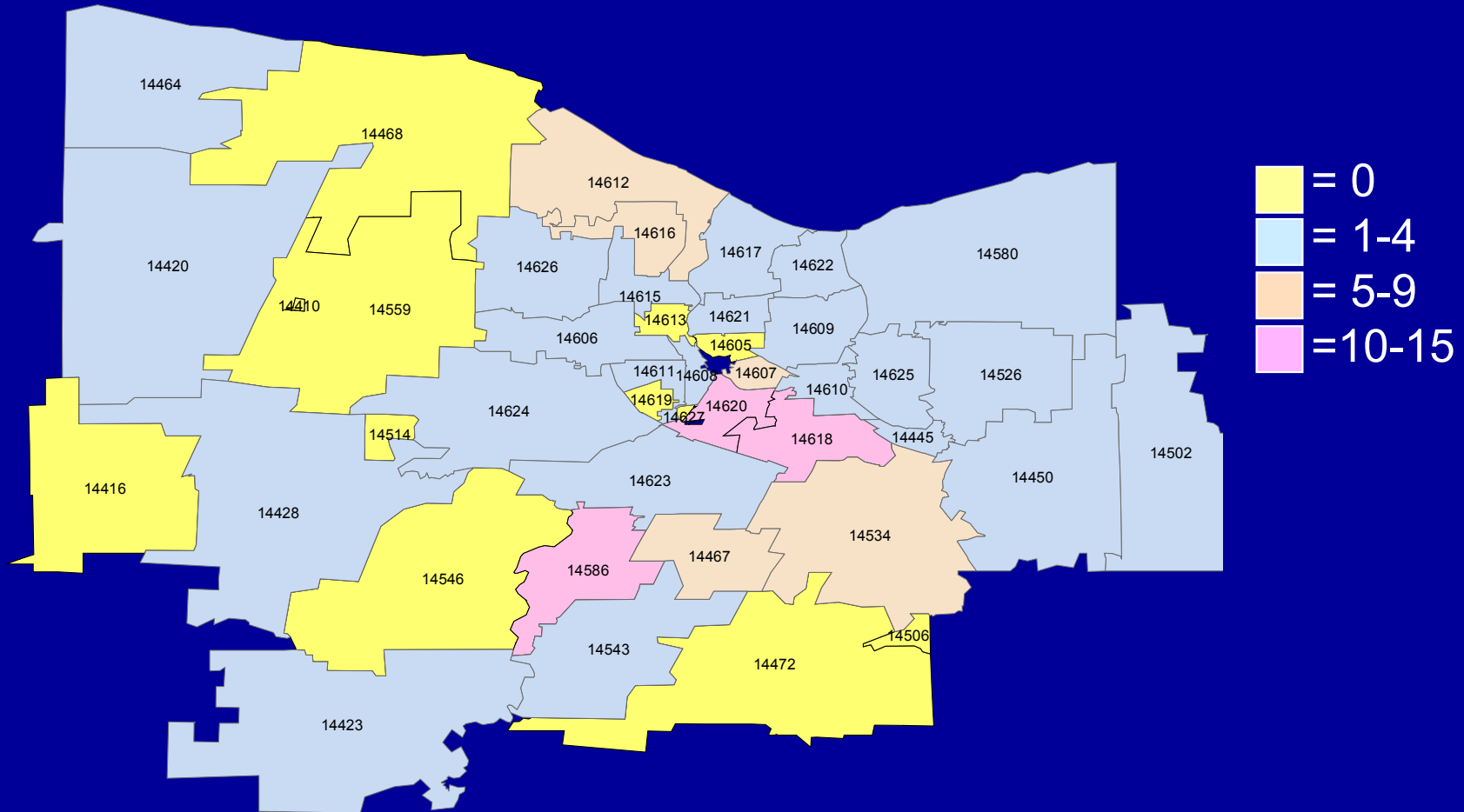
Deaf demographics
Early data collection

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

Survey time
Early data collection
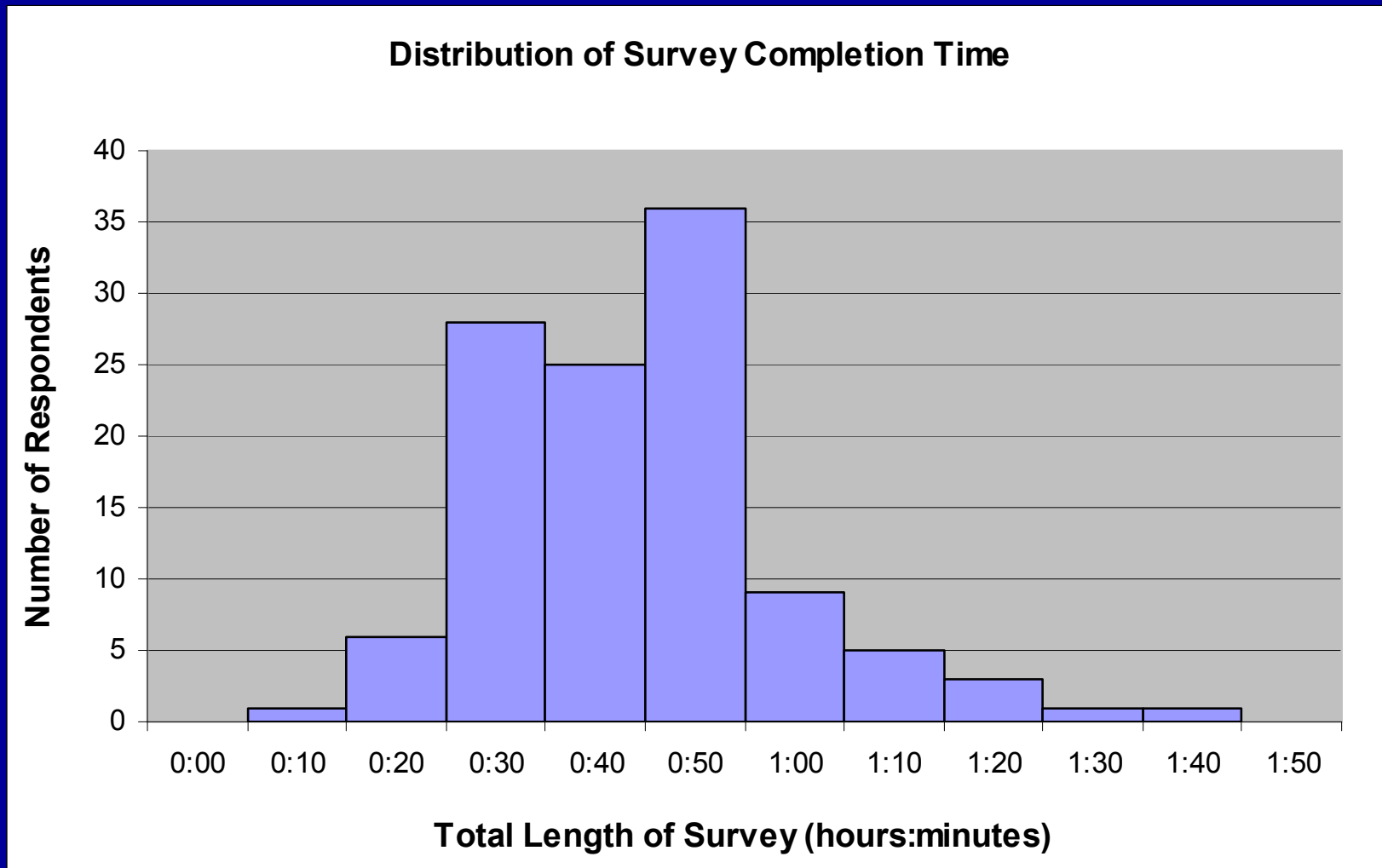
Distribution of Survey Completion Time

Take Home Messages

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Questions?

Feedback?

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