Deaf People and Healthcare: Adapting CAHPS® to be Accessible for Sign Language Users

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Outline

• Background
• Work before my K
• Work during my K
• My research
• Implications
Career Development

• Goal:
  To be a leading expert & independent researcher on the topic of health and healthcare with deaf people and their families

• Project:
  To adapt CAHPS® in order to collect data in sign language on healthcare experiences
Why Deaf people?

• Cross-language/cross-cultural issues
• Frequently overlooked minority population
  – Healthcare
  – Health-related research
• Family dynamics
• Environmental aspects of “disability”
• Highlights & challenges my assumptions
Healthcare Issues

• Language
• Literacy
• Fluency
• Fund of information
• Mistrust
• Family
Research Issues

- Language
- Literacy
- Fluency
- Fund of information
- Mistrust
- Family

- Modality
- Continuum
- IRB
- Prior survey experience
Before my K08

- Patient care (mostly deaf-related)
- Teaching (sometimes deaf-related)
- Research (sometimes deaf-related)
During my K08

- Patient care (mostly deaf-related)
- Teaching (often deaf-related)
- Research (mostly deaf-related)

- Dedicated time for career development
  - Mentors
  - Formal coursework/teaching
  - NCDHR
- Flexibility
Research

- Modality
- Translation
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.
Basic Demographics

Are you female or male?

A female
B male

You are a man.
Translation

• What is the highest grade or level of school that you have completed?
  • 1☐ 8th grade or less
  • 2☐ Some high school, but did not graduate
  • 3☐ High school graduate or GED
  • 4☐ Some college or 2-year degree
  • 5☐ 4-year college graduate
  • 6☐ More than 4-year college degree
Translation

• Did you graduate high school or get your GED?
  – If Yes: After high school, did you go to college?
    • If Yes: What degree do 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?
Translation

In the last 12 months, did you phone this doctor’s office with a medical question during regular office hours?
Implications

• Feedback to clinicians/systems
• Feedback to patients/families
• Feedback to public health & policy-makers
• Survey design
Take Home Messages

• Career Development Awards are great
• Deaf sign language users comprise understudied disparity populations
• Community participatory research is essential to the survey adaptation process
Questions?

Feedback?
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