

1. This document was created to support maximum accessibility for all learners. If you would like to print a hard copy of this document, please follow the general instructions below to print multiple slides on a single page or in black and white.
2. This handout is for reference only. Non-essential images have been removed for your convenience. Any links included in the handout are current at the time of the live webinar, but are subject to change and may not be current at a later date.
3. Copyright: Images used in this course are used in compliance with copyright laws and where required, permission has been secured to use the images in this course. All use of these images outside of this course may be in violation of copyright laws and is strictly prohibited.
4. Social Workers: For additional information regarding standards and indicators for cultural competence, please review the NASW resource: [Standards and Indicators for Cultural Competence in Social Work Practice](#)
5. Need Help? Select the “Help” option in the member dashboard to access FAQs or contact us.

## How to print Handouts

### On a Mac

- Open PDF in Preview
- Click File
- Click Print
- Click dropdown menu on the right “preview”
- Click layout
- Choose # of pages per sheet from dropdown menu
- Checkmark Black & White if wanted.

### On a PC

- Open PDF
- Click Print
- Choose # of pages per sheet from dropdown menu
- Choose Black and White from “Color” dropdown

*No part of the materials available through the continued.com site may be copied, photocopied, reproduced, translated or reduced to any electronic medium or machine-readable form, in whole or in part, without prior written consent of continued.com, LLC. Any other reproduction in any form without such written permission is prohibited. All materials contained on this site are protected by United States copyright law and may not be reproduced, distributed, transmitted, displayed, published or broadcast without the prior written permission of continued.com, LLC. Users must not access or use for any commercial purposes any part of the site or any services or materials available through the site.*

A solid red square is located in the bottom left corner of the page.



AMERICAN COCHLEAR IMPLANT ALLIANCE

# Utility of the New CI Quality of Life Instruments to Personalize and Improve CI Care, in partnership with American Cochlear Implant Alliance

Ted McRackan, MD MSCR

Associate Professor, Medical University of South Carolina  
Medical Director, Cochlear Implant Program



# Ted McRackan, MD, MSCR

Dr. Teddy McRackan, MD MSCR is a fellowship trained neurotologist with a research career focused on a better understanding of the communication, health, social, and economic benefits of cochlear implantation in adults with hearing loss and the development of patient-centered interventions with a long-term goal of improving cochlear implant (CI) functional outcomes. To date, his research program has been supported by the National Institute on Deafness and Other Communication Disorders, National Center for Advancing Translational Sciences, American Cochlear Implant Alliance, and the Doris Duke Foundation. In May 2022, he received the Triological Society's Harold Mosher Award for Outstanding Clinical Research for his work developing and implementing the Cochlear Implant Quality of Life (CIQOL) instruments. His research interests have been informed by his experiences in basic, translational, and clinical outcomes research, and as a surgeon-scientist. He has published over 100 manuscripts and book chapters and has edited a comprehensive Neurotology textbook. In addition, he maintains a very active clinical practice and serves as the Medical Director of the MUSC Cochlear Implant Program and Director of the MUSC Skull Base Center.

# Five Part Series on Adult Assessments in Hearing Healthcare

- Adult Assessments: Working Across the Continuum
- Roles of Audiologists and Dispensers Working with Hearing Aid Users on CI Candidacy
- Utility of the New CI Quality of Life Instruments to Personalize and Improve CI Care
- Adult Perceptions of Hearing Status and Options: Professionals Facilitating a Life-Long Hearing Journey
- Optimizing Outcomes in Hearing Technology: Hearing Aids and Implantable Devices



# Why another organization in hearing health?

- Membership organization focused on cochlear implantation and access to care
- Members are audiologists, physicians, speech pathologists, educators and others on CI teams + consumers/parents, advocates, hearing aid specialists
- Website designed for those in and out of CI
- Highly collaborative with other organizations

Welcome your involvement!

[www.acialliance.org](http://www.acialliance.org)

<https://www.facebook.com/ACIALLIANCE.ORG/>

Twitter@acialliance



# American Cochlear Implant Alliance

- Mission: Advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness
- Address factors contributing to underutilization of cochlear implants
- Improve awareness regarding candidacy and outcomes

# New Cochlear Implant Quality of Life Instruments to Personalize and Improve CI Care

Ted McRackan, MD MSCR

Associate Professor, Medical University of South Carolina

Medical Director, Cochlear Implant Program

# Disclosure

- **Presenter Disclosure:** Financial: Ted McRackan is employed by the Medical University of South Carolina. He received an honorarium for this presentation. He receives funding from American Cochlear Implant Alliance and NIH/NIDCD: K23DC016911. Non-financial: Ted McRackan serves on the advisory board for Envoy Medical and is an educational consultant for Stryker Corporation.
- **Content Disclosure:** This learning event does not focus exclusively on any specific product or service.
- **Sponsor Disclosure:** This course is presented by AudiologyOnline in partnership with the American Cochlear Implant Alliance.

# Learning Outcomes

After this course, participants will be able to:

- Describe the background of the CIQOL instrument development.
- Explain how the CIQOL instruments can be used during CI evaluations.
- Explain how the CIQOL instruments can enhance post-CI monitoring and direct patient care.



# Rapid Expansion



- FDA approval 1984
- ~1 Million CI performed
- >125% increase in past 10 years
- Incredible technological advances



## What hasn't changed?

How we determine candidacy  
How we measure outcomes  
How we direct patient care

# Current Standard

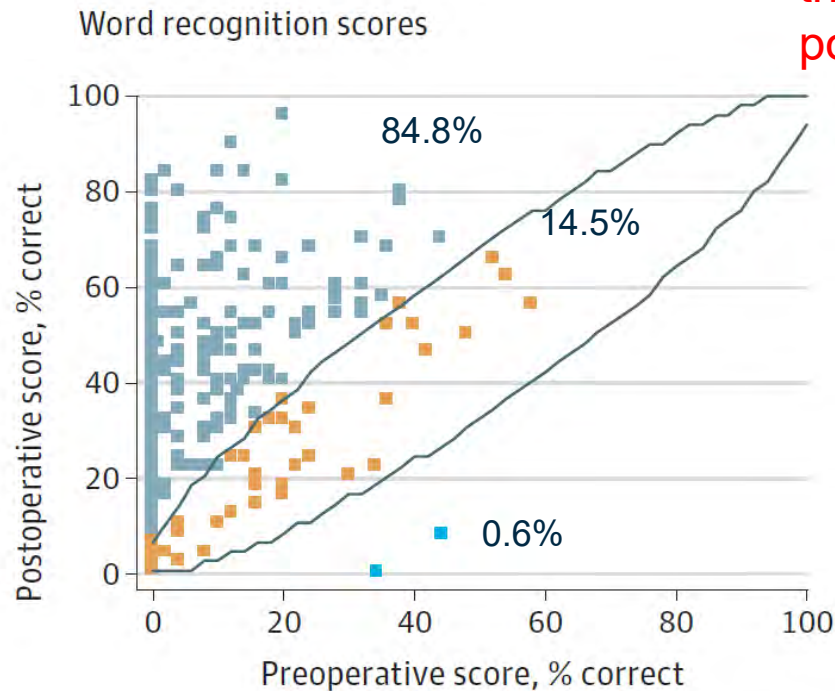
## Speech Recognition Testing



|                    | <u>Pre-op (SD)</u>   |   | <u>12mo post-CI(SD)</u> |
|--------------------|----------------------|---|-------------------------|
| Words in quiet     | 12.8% ( $\pm 15.8$ ) | → | 59.5% ( $\pm 22.2$ )    |
| Sentences in quiet | 20.2% ( $\pm 20.3$ ) | → | 79.6% ( $\pm 23.8$ )    |
| Sentences in noise | 21.6% ( $\pm 19.2$ ) | → | 57.5% ( $\pm 25.1$ )    |

# Current Standard

## Speech Recognition Testing

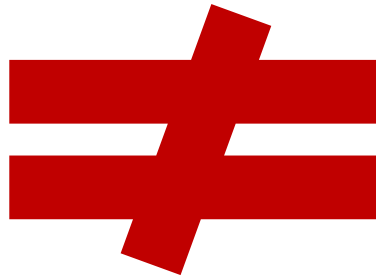


What does this mean regarding real-world functional ability?

How can you use these data to counsel potential CI users?

# Current Standard

Speech  
Recognition  
Testing

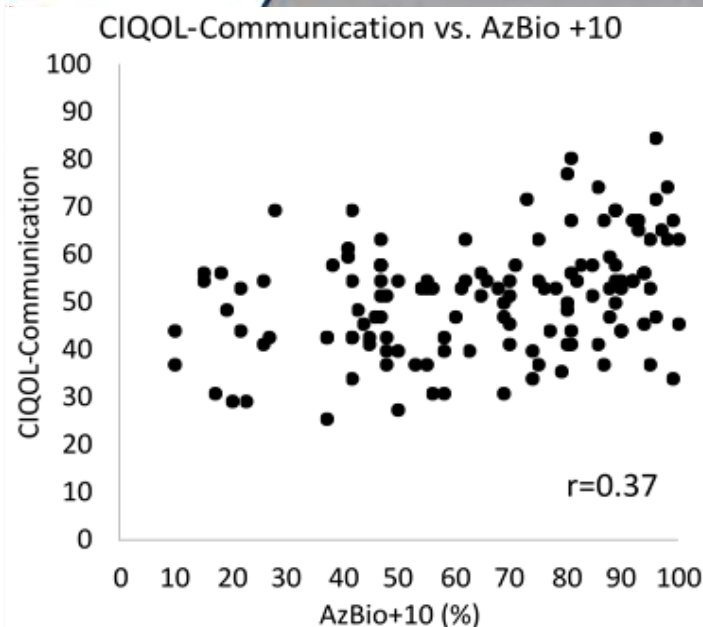
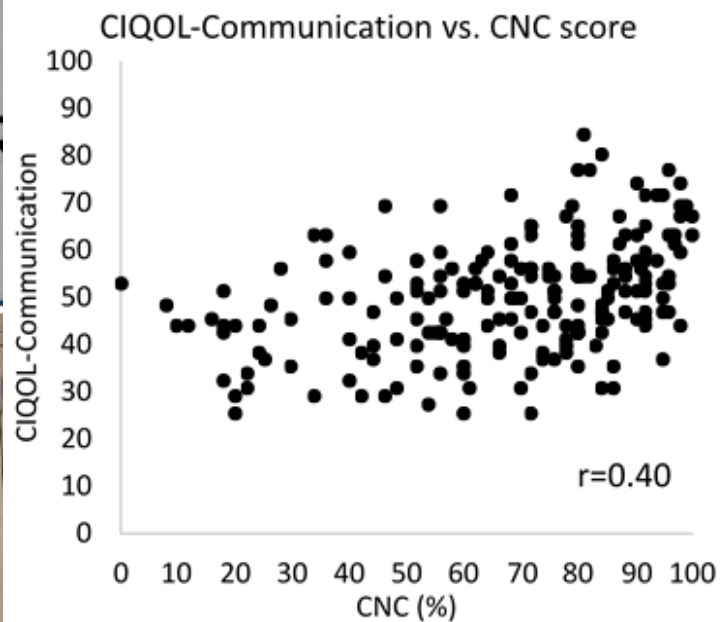


Real-world  
communication  
abilities



# Current Standard

HINT



# Current Standard



- Speech recognition only accounts for 4-16% of variance in patient self-reported communication ability
- Even lower in multivariable regression models ( $\beta=0.0$  (0.0-0.1))

# Current Standard



Are we valuing what we measure, rather than measuring what patients' value?

Adapted from Mitch Resnick

# Cochlear implant evaluation:



# Patient-reported outcome measures (PROMs)

- Instruments that capture a patient's perspective about their overall health or treatment
- Direct assessment of how a disease or intervention impacts functional abilities in real-world settings
- Not all PROMs measure quality of life



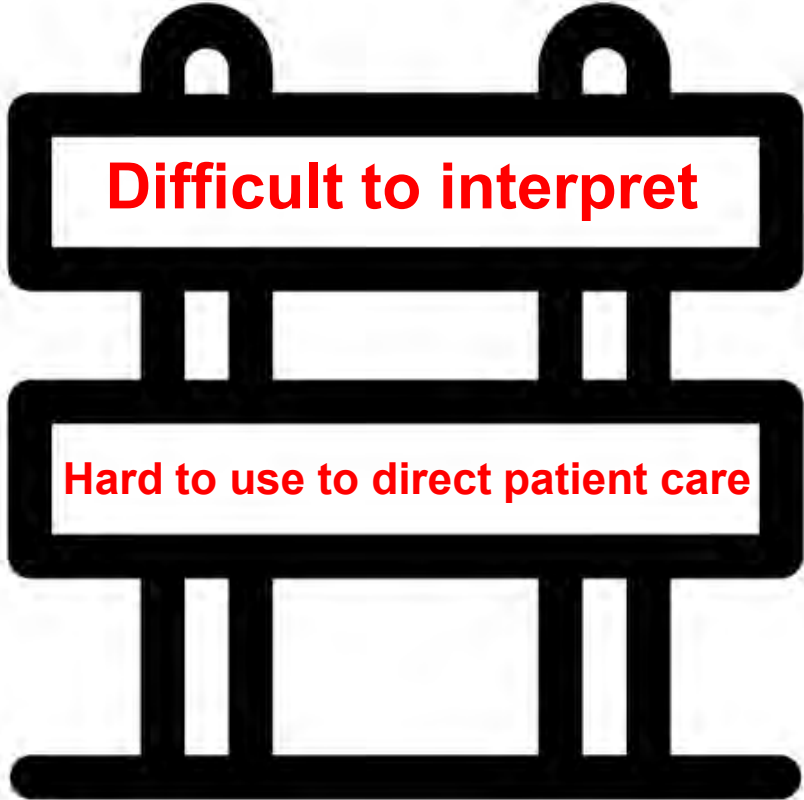
# Patient-reported outcome measures (PROMs)



- Important because:
  - Independent assessment of the patient's condition
    - Removes clinician's bias
- Can efficiently measure multiple constructs
- Regulatory standpoint:
  - Now required for FDA trials
  - Part of CMS Meaningful Measures Framework



# Why are PROMs not used more for CI care?



**Difficult to interpret**

**Hard to use to direct patient care**

# Why are PROMs not used more for CI care?

**CIQOL  
Development**



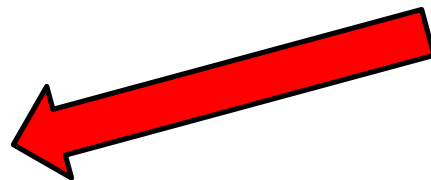
**CIQOL  
Implementation**

# Cochlear Implant QOL (CIQOL) Instruments



- Developed using rigorous development standards
- **No previous patient-reported outcome measure (PROM) has been validated in hearing loss or CI users that meets current standards**

MENTION RESEARCH WEBSITE



<https://education.musc.edu/ciqol>

Qualitative



Quantitative

Mixed methods research design  
development and validation



## Qualitative



## Quantitative

- CI user focus groups
- Cognitive interviews



- Established face and content validity



**Ensures outcomes are reported within a meaningful patient-centered framework**



# Qualitative



# Quantitative



- Columbia University
- Duke University
- Eastern Virginia Medical School
- Georgetown
- House Ear Clinic
- Johns Hopkins University
- Kaiser Health Los Angeles
- Kaiser Health San Diego
- Loyola University
- Mass Eye and Ear Infirmary
- Mayo Clinic Rochester
- MUSC
- New York Eye and Ear Infirmary
- Ohio State University
- Oregon Health Sciences University
- Rush Medical Center
- Stanford University
- Summit Medical Group

- SUNY Downstate
- University of Arkansas
- University of Cincinnati
- University of Colorado
- University of Maryland
- University of Miami
- University of Pennsylvania
- University of Utah
- University of South Carolina
- University of Texas Southwestern
- Vanderbilt University
- Virginia Mason Seattle
- University of Miami
- Washington University
- Advanced Bionics
- Cochlear Corporation
- MED-EL

- Psychometric analyses:
  - Confirmatory factor analyses
  - Item response theory
- Recruited 371 CI users from 30 CI centers



<https://education.musc.edu/ciqol>

**Qualitative**



**Quantitative**

**CIQOL Item Pool**  
**(101 items in 7 domains)**



- Psychometric testing

**CIQOL Item Bank**



Qualitative



Quantitative

## Psychometric testing

- Transition to quantitative methodologies
- Item Response Theory (IRT) is the modern standard
- Several advantages over classical test theory (CTT):



<https://education.musc.edu/ciqol>

Qualitative



Quantitative

## Psychometric testing

- Transition to quantitative methodologies
- Item Response Theory (IRT) is the modern standard
- Several advantages over classical test theory (CTT):



- Focuses on test-level psychometrics
- Major barrier to interpretation
    - Scores are ordinal



Qualitative



Quantitative

## Psychometric testing

- Transition to quantitative methodologies
- Item Response Theory (IRT) is the modern standard
- Several advantages over classical test theory (CTT):



**Qualitative**



**Quantitative**

**CIQOL Item Pool**  
**(101 items in 7 domains)**



- n=371
- Psychometric analyses

**CIQOL Item Bank**  
**(81 items in 6 domains)**



**Qualitative**



**Quantitative**

**CIQOL Item Bank  
(81 items in 6 domains)**



- IRT and CFA to select highly discriminative items with coverage of ability continuum

**CIQOL-35 Profile Instrument  
(35 items in 6 domains)**



Qualitative



Quantitative

## CIQOL-35 Profile Instrument (35 items in 6 domains)

### Validation study

- Independent population (n=334) enrolled through consortium
- Compared psychometric properties to:
  - Nijmegen Cochlear Implant Questionnaire (NCIQ)
  - Health Utilities Index-3 (HUI-3)
- More psychometrically sound and comprehensive than legacy measures for assessing QOL in adult cochlear implant users
  - Highly reliable



HINT

## Cochlear Implant Quality of Life-35 Profile

Name: \_\_\_\_\_ Date: \_\_\_\_\_

INSTRUCTIONS: Think about your daily life with your cochlear implant (and/or hearing aid, if you also use one). Answer how often each of the following statements applies to your feelings and experiences. Answer how often each statement applies even if you don't use cochlear implants or hearing aids.

|                                                                                                                | Never         | Rarely | Sometimes | Often | Always |
|----------------------------------------------------------------------------------------------------------------|---------------|--------|-----------|-------|--------|
| 1. I am able to have a conversation in a quiet place without asking the other person to repeat themselves      | Communication |        |           |       |        |
| 2. Other people's voices sound clear and natural to me                                                         |               |        |           |       |        |
| 3. I am able to have a conversation with a group of three or more people                                       |               |        |           |       |        |
| 4. I am able to have a conversation without asking the other person to repeat themselves                       |               |        |           |       |        |
| 5. I can hear and understand without looking at the person speaking                                            |               |        |           |       |        |
| 6. I have to ask a lot of questions about what is being said in a conversation                                 |               |        |           |       |        |
| 7. I can understand a conversation in a crowded environment (restaurant, party, etc.)                          |               |        |           |       |        |
| 8. I am able to have a conversation with someone in a noisy place without asking them to repeat themselves     |               |        |           |       |        |
| 9. I can understand strangers without lip-reading in a noisy place                                             |               |        |           |       |        |
| 10. I can follow the conversation in a group of five people in a crowded restaurant when I cannot see everyone |               |        |           |       |        |
| 11. I feel comfortable being myself                                                                            | Emotional     |        |           |       |        |
| 12. My hearing loss makes me feel inadequate                                                                   |               |        |           |       |        |
| 13. My hearing loss makes me irritable                                                                         |               |        |           |       |        |
| 14. I keep quiet in a conversation to avoid saying the wrong thing                                             |               |        |           |       |        |
| 15. I become frustrated when I cannot follow a conversation                                                    |               |        |           |       |        |

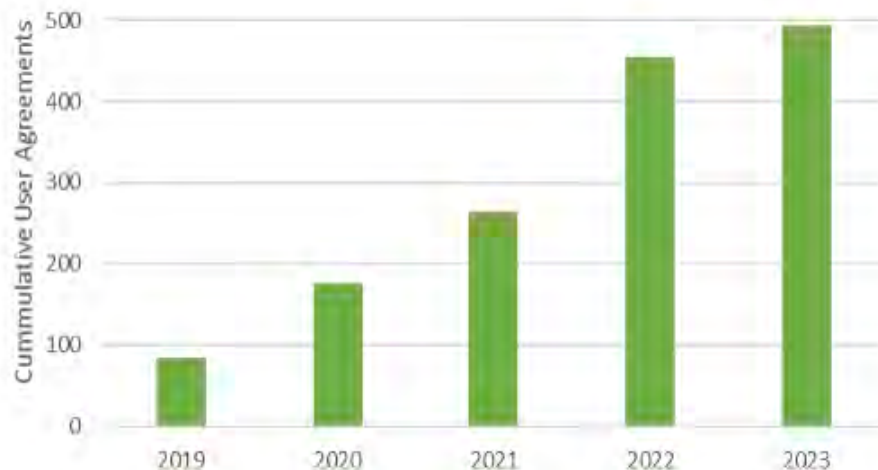
|                                                                                           | Never            | Rarely | Sometimes | Often | Always |
|-------------------------------------------------------------------------------------------|------------------|--------|-----------|-------|--------|
| 16. My hearing loss prevents me from listening to TV or radio                             | Entertainment    |        |           |       |        |
| 17. I am able to enjoy listening to the radio and TV                                      |                  |        |           |       |        |
| 18. I am able to enjoy music                                                              |                  |        |           |       |        |
| 19. I can recognize certain melodies in music                                             |                  |        |           |       |        |
| 20. Music sounds clear and natural to me                                                  | Environment      |        |           |       |        |
| 21. Everyday sounds (birds chirping, rain, car horns, etc.) are clear to me               |                  |        |           |       |        |
| 22. Everyday sounds (microwave, birds chirping, rain, car horn) sound natural to me       |                  |        |           |       |        |
| 23. I am able to distinguish sounds in nature                                             |                  |        |           |       |        |
| 24. I am able to hear cars approaching in traffic                                         |                  |        |           |       |        |
| 25. I can hear someone approaching from behind                                            | Listening Effort |        |           |       |        |
| 26. I am able to follow a conversation with minimal effort                                |                  |        |           |       |        |
| 27. I am able to ignore competing sounds and focus on the person who is speaking          |                  |        |           |       |        |
| 28. I can easily have a conversation in a noisy place (restaurant, party, store)          |                  |        |           |       |        |
| 29. I have to concentrate when having a conversation                                      |                  |        |           |       |        |
| 30. I have to concentrate when having a conversation with strangers when in a noisy place |                  |        |           |       |        |
| 31. If I am interested, I will join family or friends for a social event                  | Social           |        |           |       |        |
| 32. I have the confidence to socialize                                                    |                  |        |           |       |        |
| 33. I avoid socializing with friends, relatives, or neighbors due to my hearing loss      |                  |        |           |       |        |
| 34. I avoid social situations due to my hearing loss                                      |                  |        |           |       |        |
| 35. I feel left out when I am with a group of people due to my hearing loss               |                  |        |           |       |        |

Qualitative



Quantitative

## CIQOL Instruments



- ~ 500 user agreements
- Has undergone cross-cultural adaptation and translation into Hebrew, German, French, Mandarin, and Arabic
  - 4 additional languages in process



**Qualitative**



**Quantitative**

**CIQOL-35 Profile Instrument**



- IRT/CFA used to select highly discriminative items with coverage of ability continuum

**CIQOL-10 Global Instrument**



# Development complete...now what



**CIQOL  
Development**



**Widespread  
clinical  
implementation**

**CIQOL  
Development**

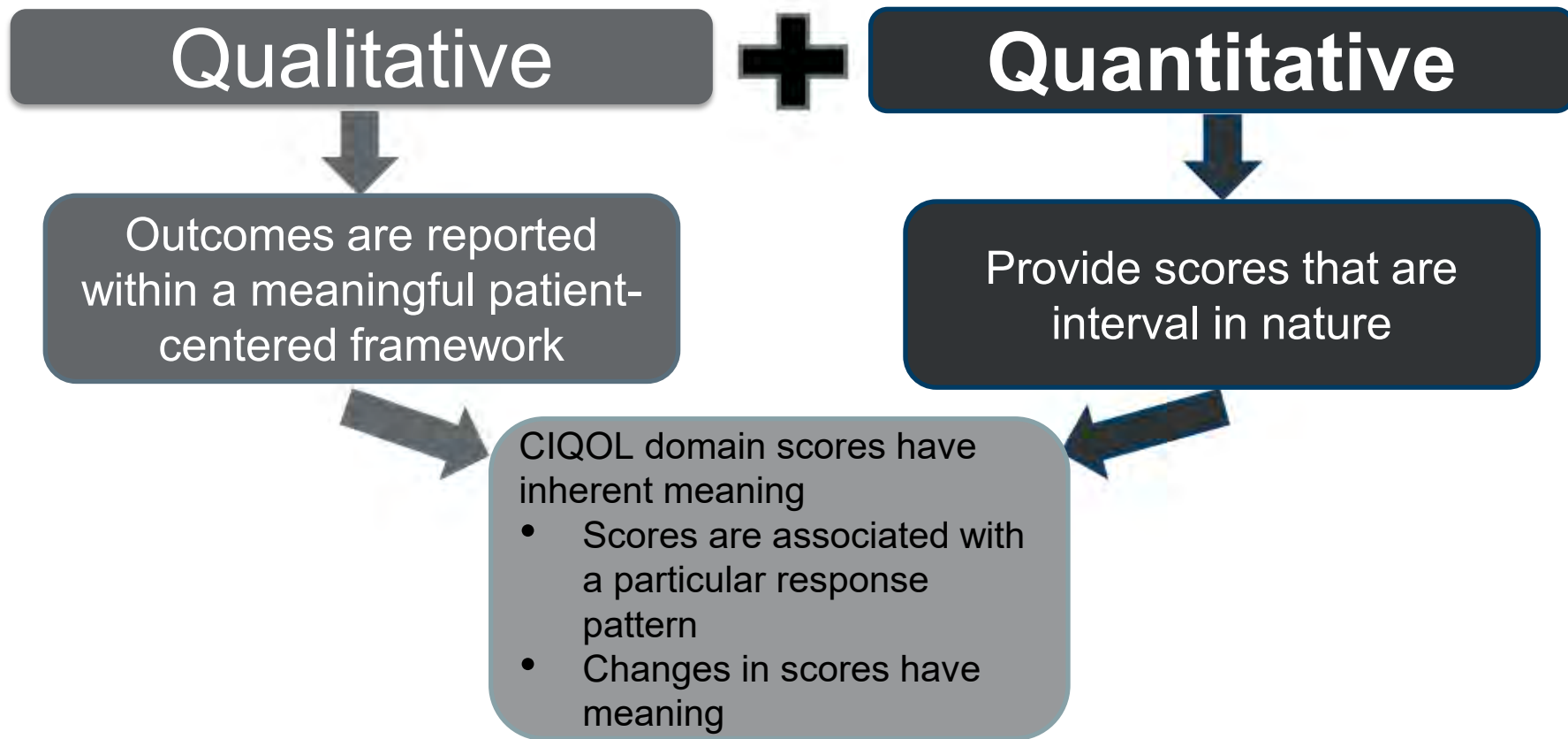


**Widespread  
clinical  
implementation**

**Score  
interpretation**

# Development complete...now what

- Rigorous mixed method approach helps overcome common problems with PROMs





# Functional Staging Systems

- Enhance the interpretability of PROM scores
  - Provide detailed descriptions of patient-reported abilities via clinical vignettes
  - Maintain psychometrically derived (item response theory; IRT) hierarchy of quantitative scores
- Used in other health care settings

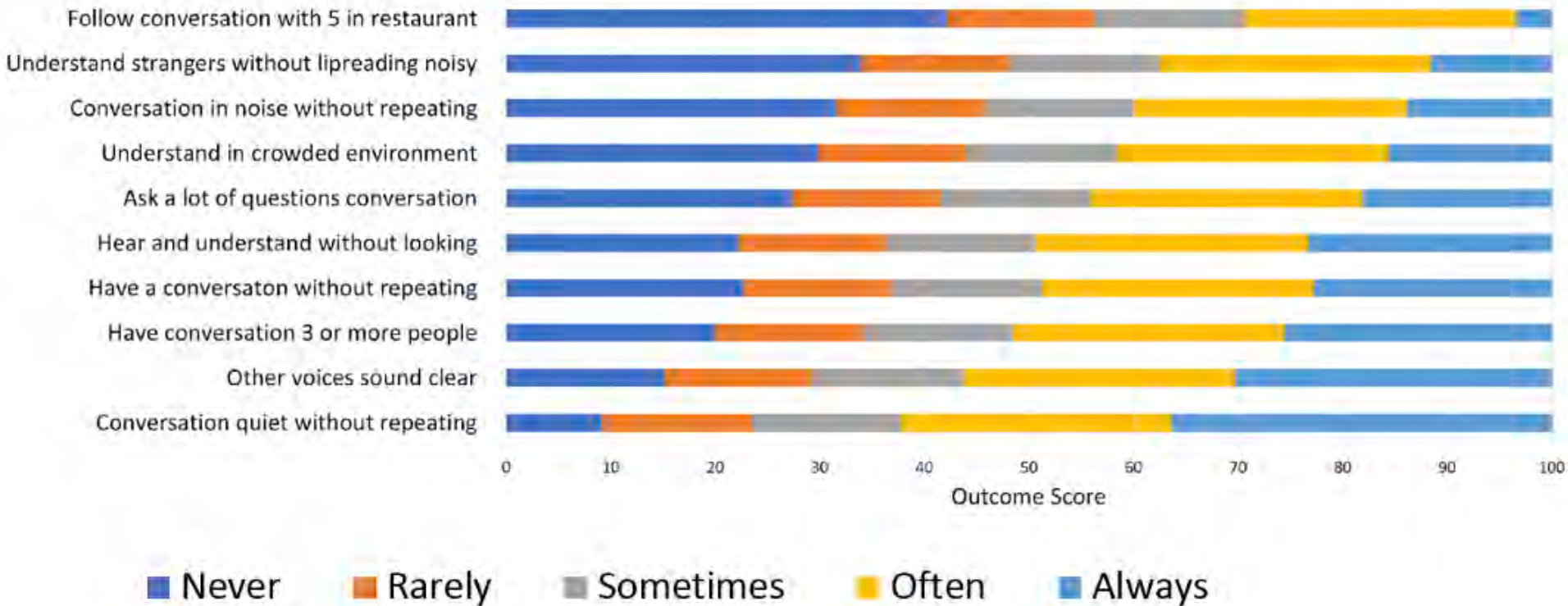


# CIQOL-Communication example

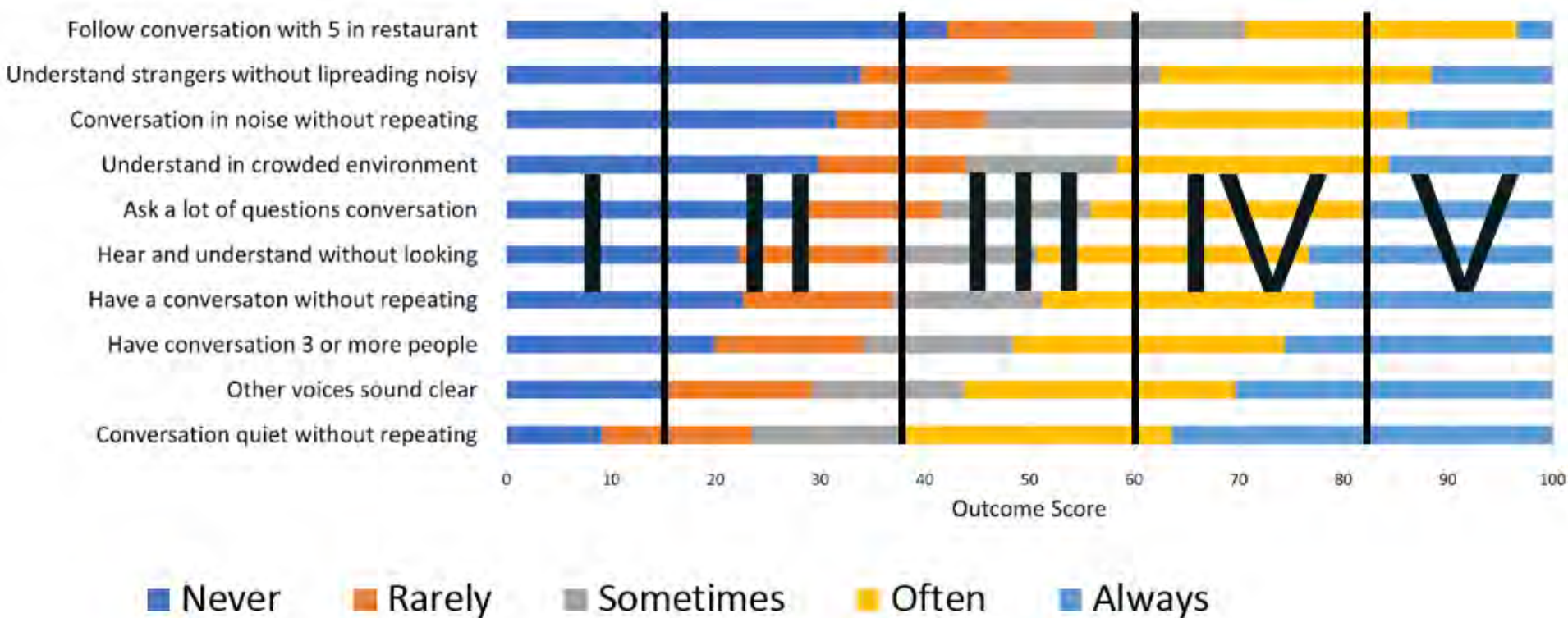
- n=705 adult CI users from 30 centers (≥12-month CI experience)
- Item response theory analyses used to:
  - Determine number of functional stages for each domain
  - Determine abilities associated with domain outcome score (0-100)



# CIQOL-Communication example



# CIQOL-Communication Functional Staging System



- IRT analyses and expert opinion to identify cut-scores that separate stages
- Develop clinical vignettes

n=705

Frequency

150  
125  
100  
75  
50  
25  
0

Follow conversation with 5 in restaurant

Understand strangers without lipreading noisy

Conversation in noise without repeating

Understand in crowded environment

Ask a lot of questions conversation

Hear and understand without looking

Have a conversaton without repeating

Have conversation 3 or more people

Other voices sound clear

Conversation quiet without repeating

0

10

20

30

40

50

60

70

80

90

100

Outcome Score

■ Never

■ Rarely

■ Sometimes

■ Often

■ Always

# CIQOL-Communication Functional Staging System

I (0.4%):

- Unable to have a conversation in any listening environment

V (1.4%):

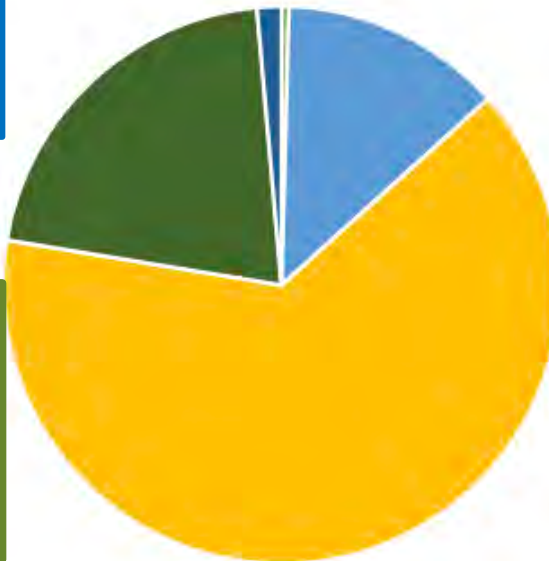
- Able to have a conversation in all listening environments with essentially no lip-reading

II (12.9%):

- Can sometimes have a conversation in quiet environments
- Need people to repeat themselves to understand conversation in quiet environments

IV (20.0%):

- Able to have a conversation in small groups in quiet
- Can sometimes have a conversation in noisy environments without lip reading



III (64.3%):

- Sometimes able to have a conversation in small group in quiet
- Has difficulty understanding, even with lip reading, in noisy environments

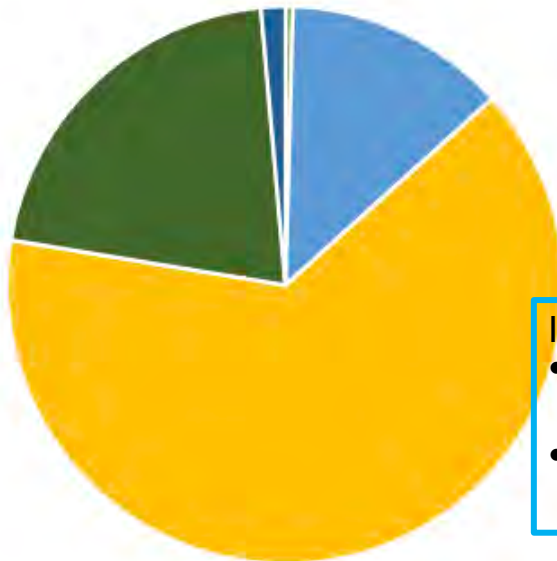
# CIQOL-Communication Functional Staging System

## III (23.1%):

- Usually able to enjoy music
- Music usually sounds clear and natural
- Hearing loss does not prevent them from listening to TV or radio

## I (17.7%):

- Usually unable to enjoy music
- Unable to recognize melodies in music

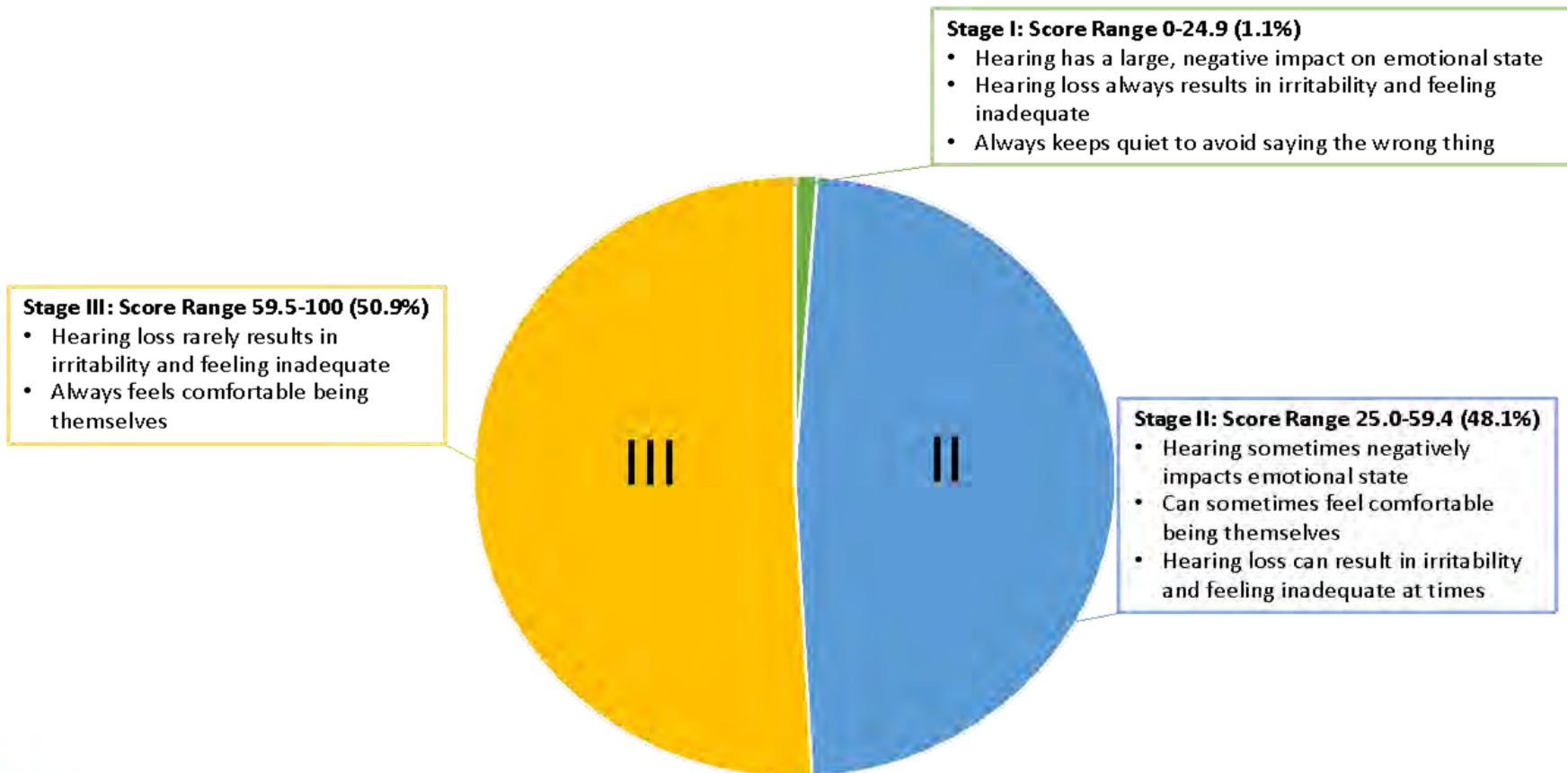


## II (59.1%):

- Hearing loss may prevent them from listening to TV or Radio
- Music does not always sound clear and natural

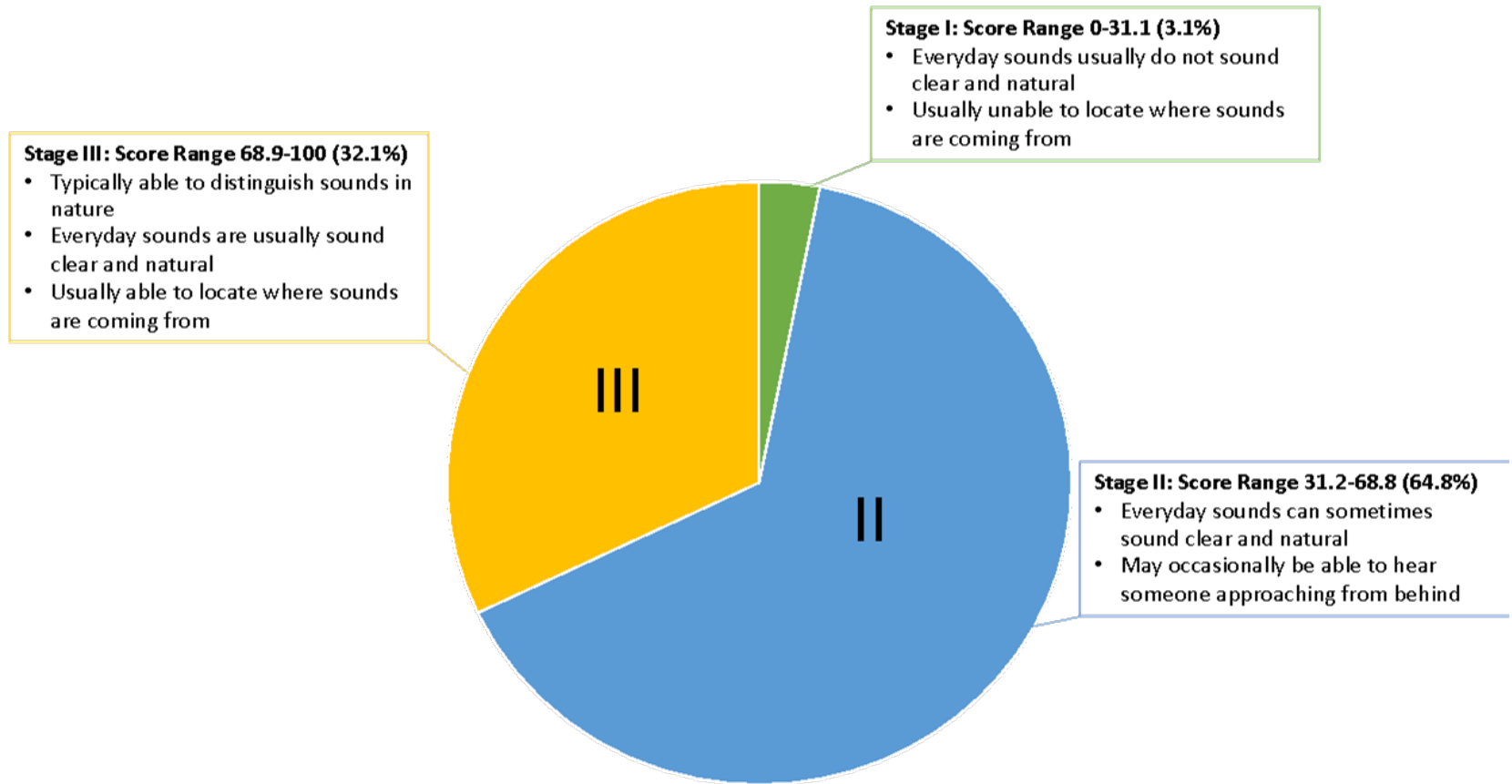
# CIQOL-Communication Functional Staging System

## Emotional



# CIQOL-Communication Functional Staging System

## Environment



# CIQOL-Communication Functional Staging System

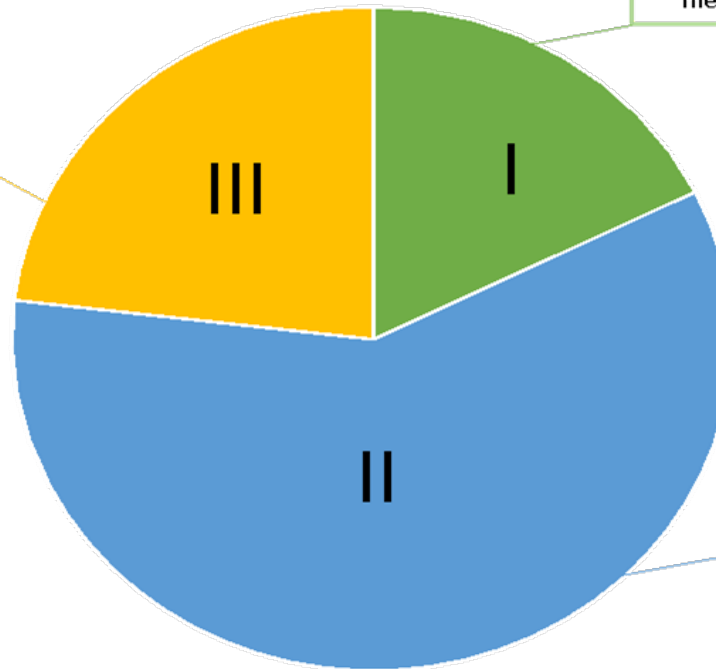
## Entertainment

### Stage III: Score Range 69.1-100 (23.1%)

- Usually able to enjoy music
- Music usually sounds clear and natural
- Hearing loss usually does not prevent them from listening to TV or radio

### Stage I: Score Range 0-34.2 (17.7%)

- Usually unable to enjoy music
- Usually unable to recognize melodies in music



### Stage II: Score Range 34.3-69.0 (59.1%)

- Hearing loss may prevent them from listening to TV or Radio
- Music does not always sound clear and natural

# CIQOL-Communication Functional Staging System

## Listening Effort

### Stage III: Score Range 67.9-100 (5.8%)

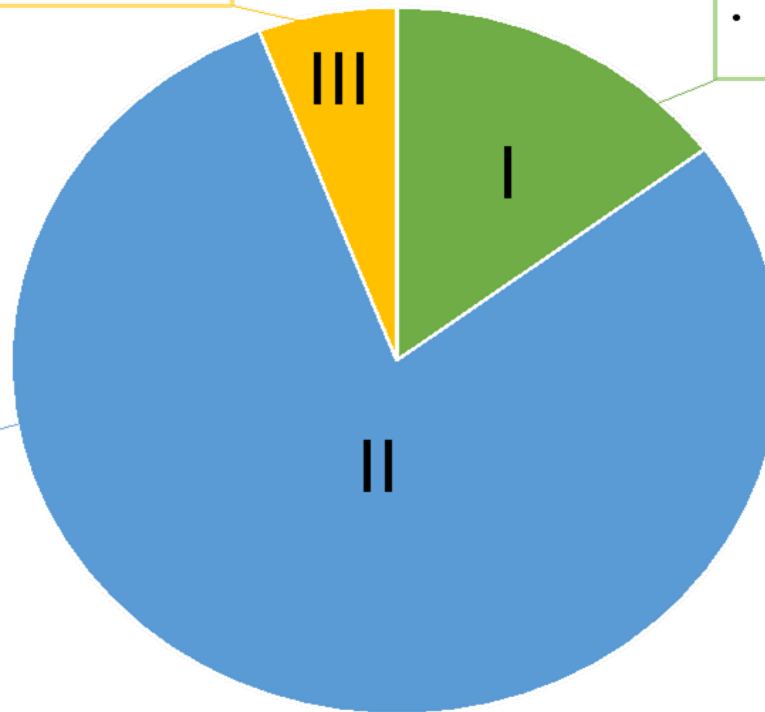
- Able to have a conversation in any environment without concentrating
- Usually able to focus on the person speaking and ignore competing sounds

### Stage I: Score Range 0-27.1 (14.8%)

- Takes great effort and concentration to follow or participate in a conversation in any listening environment
- Unable to ignore competing sounds and focus on person speaking

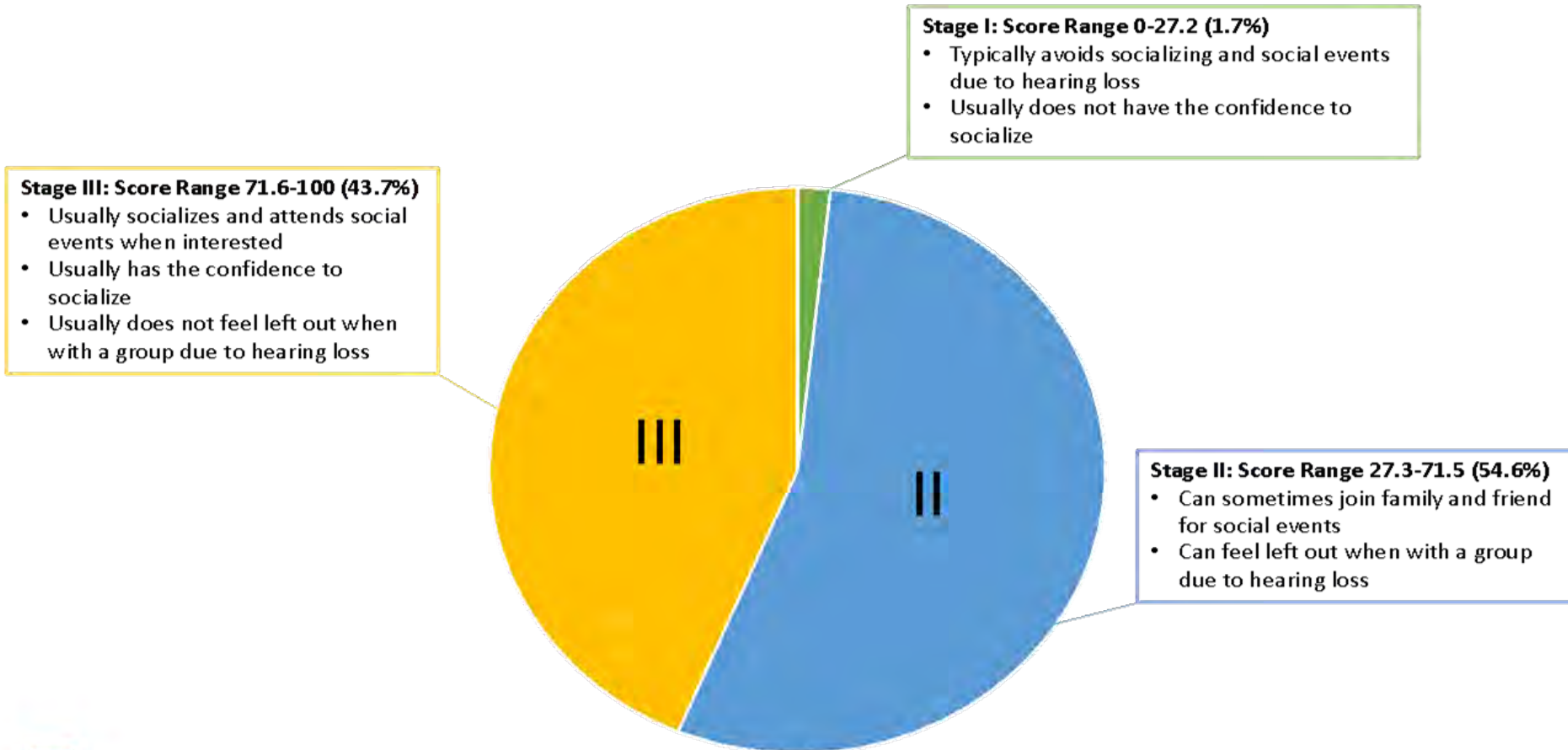
### Stage II: Score Range 27.2-67.8 (79.4%)

- Can sometimes follow a conversation with minimal effort
- Amount of concentration needed to participate in a conversation depends on the listening environment



# CIQOL-Communication Functional Staging System

## Social





# CIQOL Functional Staging System

- Novel application of IRT-based psychometrics to provide real-world understanding of functional abilities of adult CI users
- Increased abilities associated with each stage are logical (?obvious), but first evidence-based understanding of the abilities that define low vs. high CI performance



**CIQOL  
Development**



**Score  
interpretation**



**Pre-CI  
Counseling**



**Widespread  
clinical  
implementation**

# Pre-CI counseling

- Current standard:



General  
conversations  
about patients'  
expectation



Clinician's personal  
experience with CI  
users



# CIQOL-Expectations

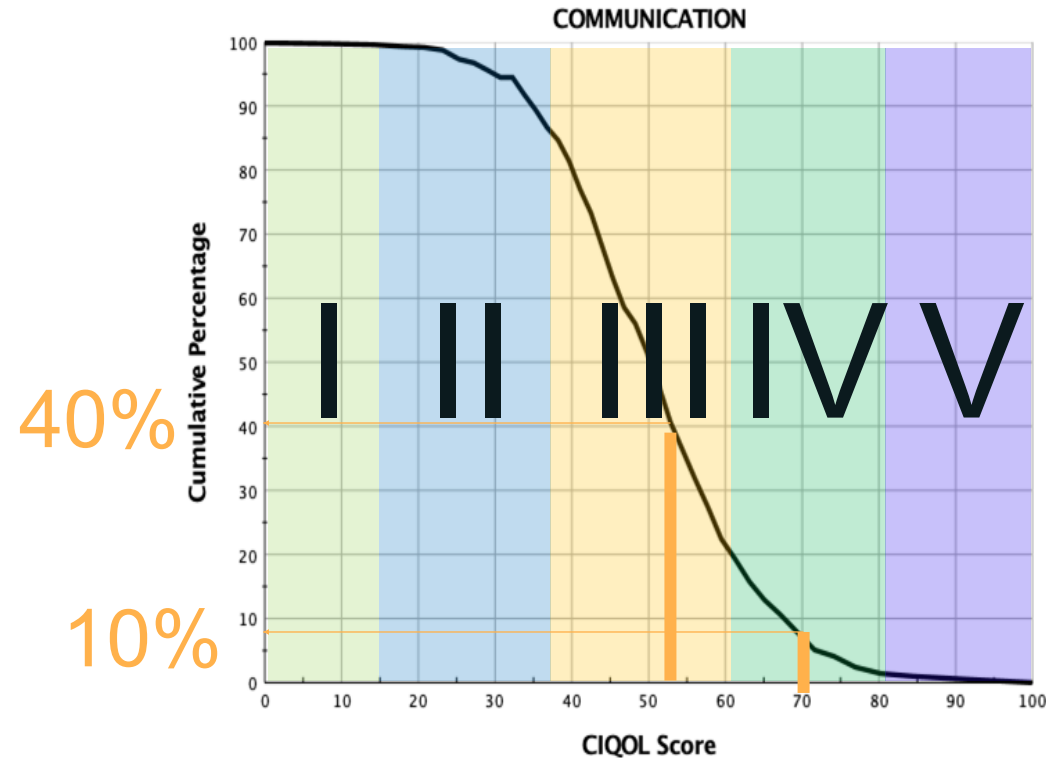
McRackan, T. R., Hand, B. N., Chidarala, S., & Dubno, J. R. (2022). Understanding patient expectations before implantation using the cochlear implant quality of life–expectations instrument. *JAMA Otolaryngology–Head & Neck Surgery*, 148(9), 870-878.

- Using CIQOL framework, validated an instrument that measures pre-CI patient expectations
  - Corresponds to CIQOL-35 Profile



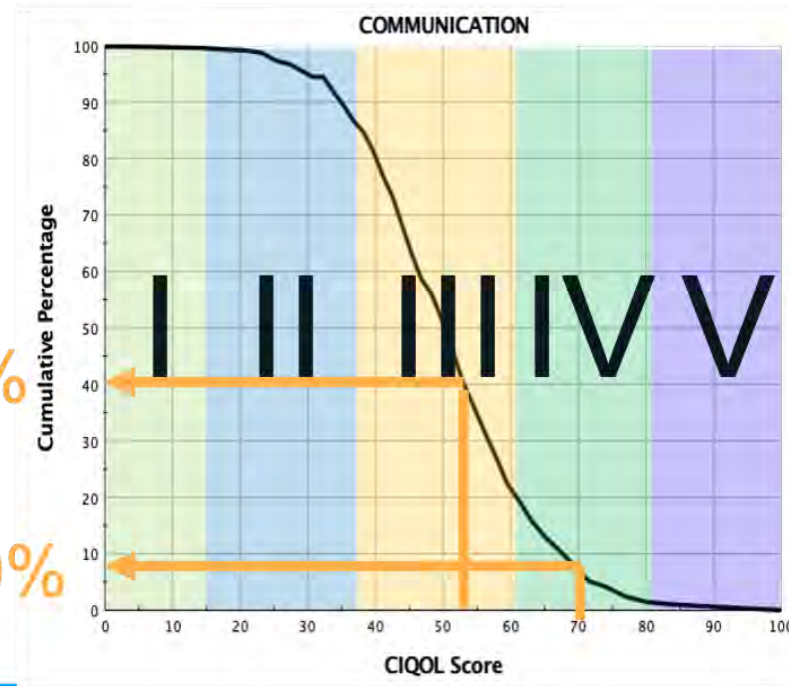
# CIQOL-Expectations

- Goals:
  - Enhance clinicians' understanding of patients' expectations
  - Improve patient's understanding of likely outcomes



# CIQOL-Expectations

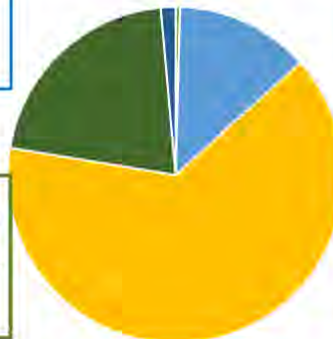
- Goals:
  - Enhance clinicians' understanding of patients' expectations
  - Improve patient's understanding of likely outcomes



I (0.4%):  
 • Unable to have a conversation in any listening environment

V (1.4%):  
 • Able to have a conversation in all listening environments with essentially no lip-reading

IV (20.0%):  
 • Able to have a conversation in small groups in quiet  
 • Can sometimes have a conversation in noisy environments without lip reading

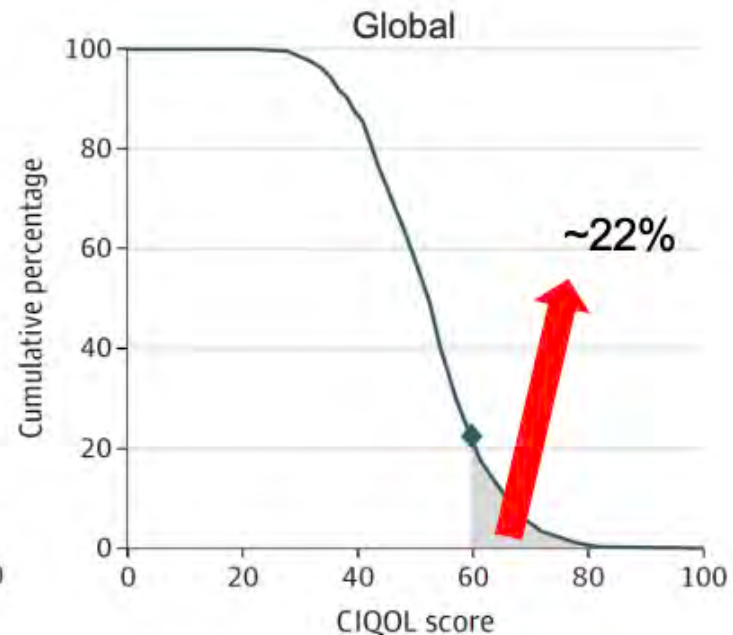
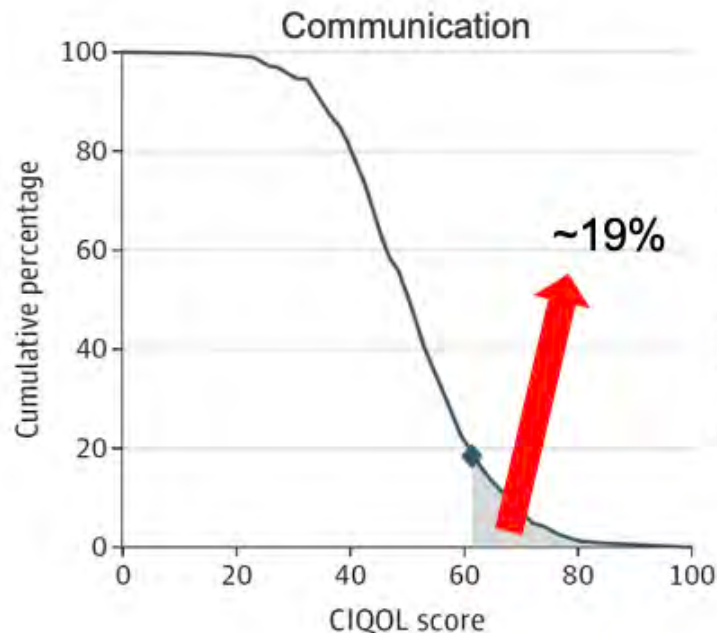


II (12.9%):  
 • Can sometimes have a conversation in quiet environments  
 • Need people to repeat themselves to understand conversation in quiet environments  
 • Usually unable to have a conversation in noisy environments

III (64.3%):  
 • Sometimes able to have a conversation in small group in quiet  
 • Has great difficulty understanding, even with lip reading, in noisy environments

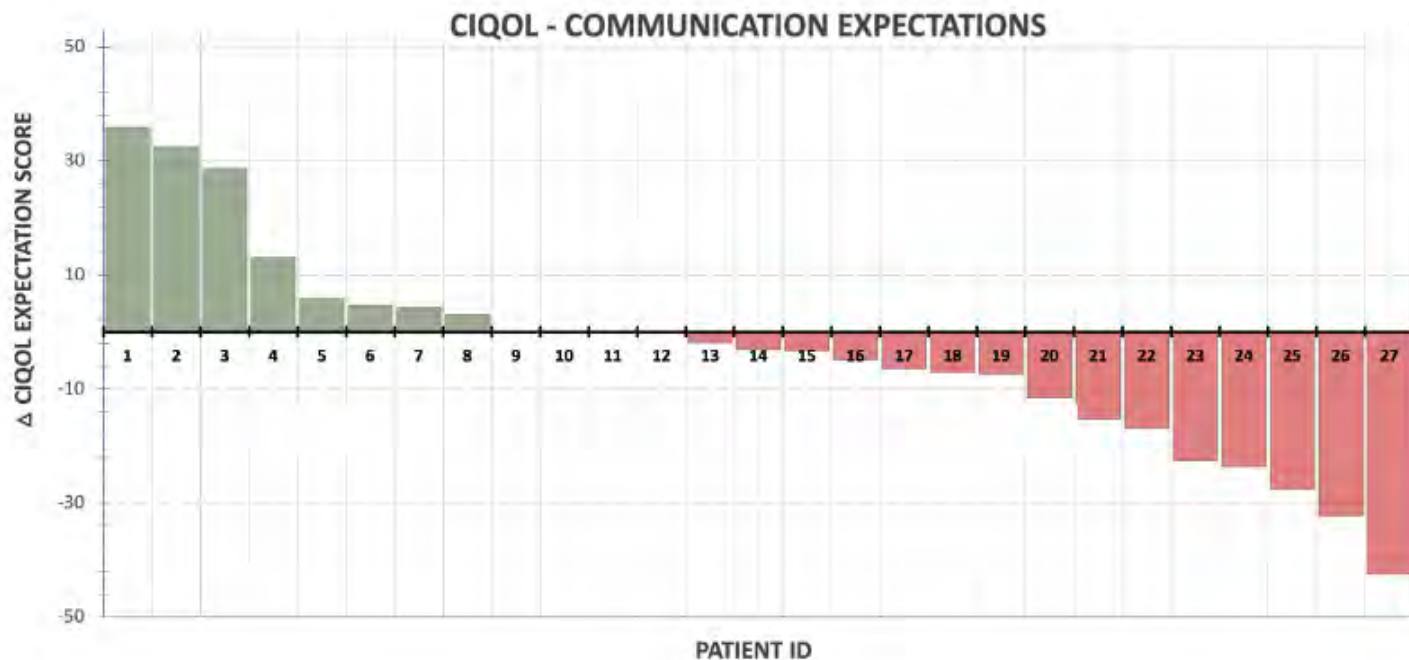
# CIQOL-Expectations

- Why important?
  - Patient expectations > likely outcomes



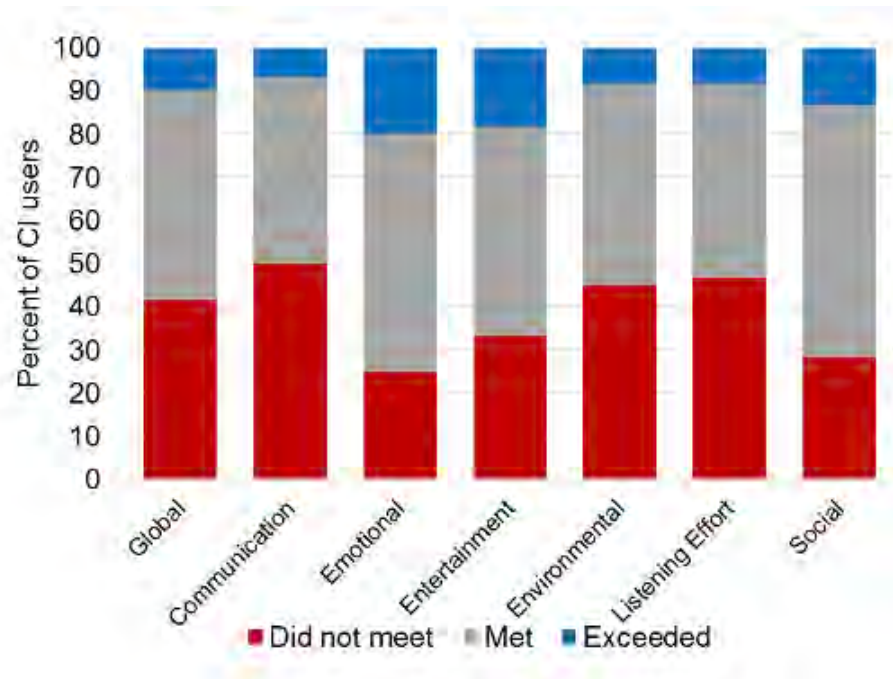
# CIQOL-Expectations

- Why important?
  - Expectations appear to be modifiable



# CIQOL-Expectations

- Why important?
  - % of CI users that meet or exceed their personal pre-CI expectations?



# CIQOL-Expectations

- Why important?
  - % of CI users that meet or exceed their personal pre-CI expectations?

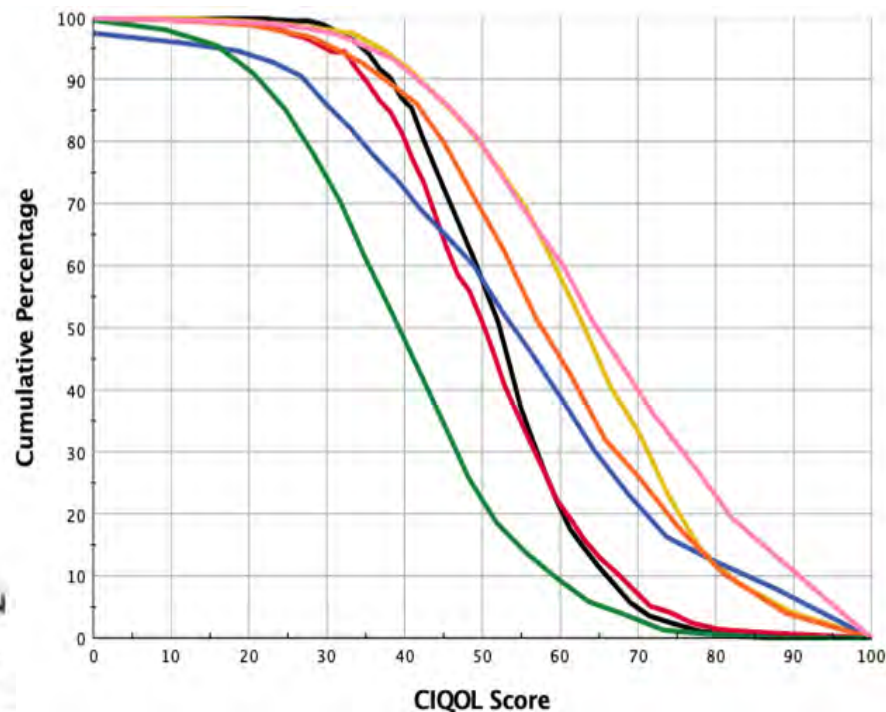


# Pre-CI counseling

Baseline (pre-CI)  
CIQOL scores

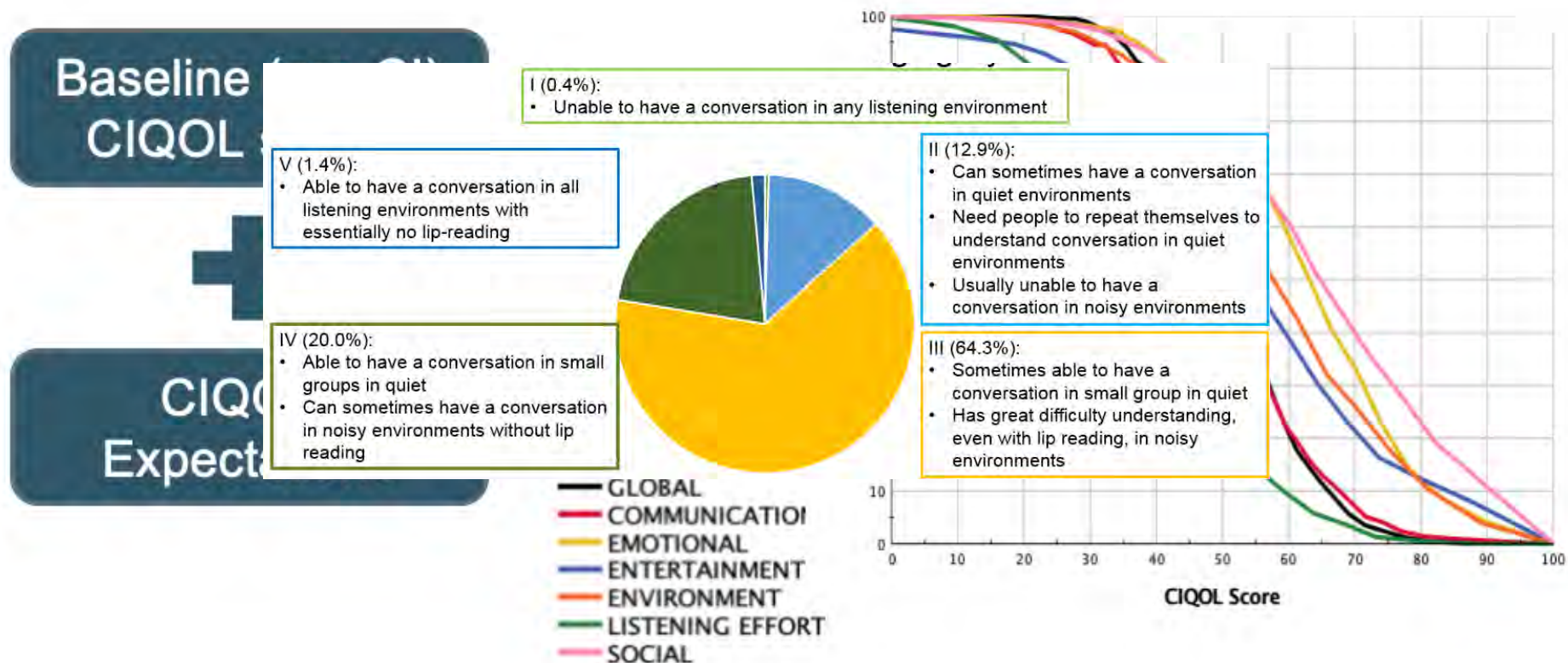


CIQOL-  
Expectations





# Pre-CI counseling



# Pre-CI counseling

**Cochlear Implant Quality of Life-35 Profile**  
Page 1 of 2

**IMUSC Health**  
IMMUNOSCIENCE

**Adult Cochlear Implant Expectations Questionnaire**  
Page 1 of 2

Patient: Jonathan L. A. Hinton

Date: 11-2-2015

Version: 1.0

**INSTRUCTIONS:** Think about your daily life with your cochlear implant (and/or hearing aid, if you also use one). Answer how often each of the following statements applies to your feeling. Answer how often each statement applies even if you don't use cochlear implants.

**INSTRUCTIONS:** Answer each of the following statements regarding how you expect to perform with your cochlear implant (and hearing aid, if you also use one).

**PATIENT IDENTIFICATION LABEL**

Patient Name: Jonathan A. Hinton  
 VRN: 5534333

|                                                                                                                   | Never | Rarely | Sometimes | Often | Always |
|-------------------------------------------------------------------------------------------------------------------|-------|--------|-----------|-------|--------|
| 1. I am able to have a conversation in a quiet place without asking the other person to repeat themselves.        |       |        |           |       | ✓      |
| 2. Other people's voices sound clear and natural to me.                                                           |       |        |           |       | ✓      |
| 3. I am able to have a conversation with a group of three or more people.                                         |       | ✓      |           |       | ✓      |
| 4. I am able to have a conversation without asking the other person to repeat themselves.                         |       |        |           | ✓     |        |
| 5. I can hear and understand without looking at the person speaking.                                              |       | ✓      |           |       | ✓      |
| 6. I have to ask a lot of questions about what is being said in a conversation.                                   |       |        |           | ✓     |        |
| 7. I can understand a conversation in a crowded environment (restaurant, party, etc.)                             |       | ✓      |           |       | ✓      |
| 8. I am able to have a conversation with someone in a noisy place without asking them to repeat themselves.       |       | ✓      |           |       | ✓      |
| 9. I can understand strangers without lip-reading in a noisy place.                                               |       | ✓      |           |       | ✓      |
| 10. I can follow the conversation in a group of five people in a crowded restaurant when I cannot see everyone.   |       | ✓      |           |       | ✓      |
| 11. I feel comfortable being myself.                                                                              |       |        | ✓         |       | ✓      |
| 12. My hearing loss makes me feel inadequate.                                                                     |       |        |           | ✓     |        |
| 13. My hearing loss makes me introvert.                                                                           |       |        |           | ✓     |        |
| 14. I keep quiet in a conversation to avoid saying the wrong thing.                                               |       |        |           | ✓     |        |
| 15. I become frustrated when I cannot follow a conversation.                                                      |       |        |           | ✓     |        |
| 16. I will be able to have a conversation in a quiet place without asking the other person to repeat themselves.  |       |        |           |       | ✓      |
| 17. Other people's voices will sound clear and natural to me.                                                     |       |        |           |       | ✓      |
| 18. I will be able to have a conversation with a group of three or more people.                                   |       |        |           |       | ✓      |
| 19. I will be able to have a conversation without asking the other person to repeat themselves.                   |       |        |           | ✓     |        |
| 20. I will be able to hear and understand without looking at the person speaking.                                 |       |        |           | ✓     |        |
| 21. I will have to ask a lot of questions about what is being said in a conversation.                             |       |        |           | ✓     |        |
| 22. I will understand a conversation in a crowded environment (restaurant, party, etc.).                          |       |        |           | ✓     |        |
| 23. I will be able to have a conversation with someone in a noisy place without asking them to repeat themselves. |       |        |           | ✓     |        |
| 24. I will understand strangers without lip-reading in a noisy place.                                             |       |        |           | ✓     |        |
| 25. I will follow the conversation in a group of five people in a crowded restaurant when I cannot see everyone.  |       |        |           | ✓     |        |
| 26. I will feel comfortable being myself.                                                                         |       |        |           |       | ✓      |
| 27. My hearing loss will make me feel inadequate.                                                                 |       |        |           | ✓     |        |
| 28. My hearing loss will make me introvert.                                                                       |       |        |           | ✓     |        |
| 29. I will keep quiet in a conversation to avoid saying the wrong thing.                                          |       |        |           | ✓     |        |
| 30. I will become frustrated when I cannot follow a conversation.                                                 |       |        |           | ✓     |        |
| 31. My hearing loss will prevent me from listening to TV or radio.                                                |       |        |           | ✓     |        |
| 32. I can easily have a conversation in a noisy place (restaurant, party, store).                                 |       |        | ✓         |       |        |
| 33. I have to concentrate when having a conversation.                                                             |       |        |           | ✓     |        |
| 34. I have to concentrate when having a conversation with strangers when in a noisy place.                        |       |        |           | ✓     |        |
| 35. If I am interested, I will join family or friends for a social event.                                         |       |        |           | ✓     |        |
| 36. I have the confidence to socialize.                                                                           |       |        |           |       | ✓      |
| 37. I avoid socializing with friends, relatives, or neighbors due to my hearing loss.                             |       |        |           | ✓     |        |
| 38. I avoid social situations due to my hearing loss.                                                             |       |        |           | ✓     |        |
| 39. I feel left out when I am with a group of people due to my hearing loss.                                      |       |        |           | ✓     |        |
| 40. I will be able to have a conversation in a noisy place (restaurant, party, store).                            |       |        |           |       | ✓      |
| 41. I will have to concentrate when having a conversation.                                                        |       |        |           | ✓     |        |
| 42. I will have to concentrate when having a conversation with strangers when in a noisy place.                   |       |        |           | ✓     |        |
| 43. If I am interested, I will join family or friends for a social event.                                         |       |        |           | ✓     |        |
| 44. I have the confidence to socialize.                                                                           |       |        |           |       | ✓      |
| 45. I avoid socializing with friends, relatives, or neighbors due to my hearing loss.                             |       |        |           | ✓     |        |
| 46. I avoid social situations due to my hearing loss.                                                             |       |        |           | ✓     |        |
| 47. I feel left out when I am with a group of people due to my hearing loss.                                      |       |        |           | ✓     |        |

Version: 1.0

**PATIENT IDENTIFICATION LABEL**

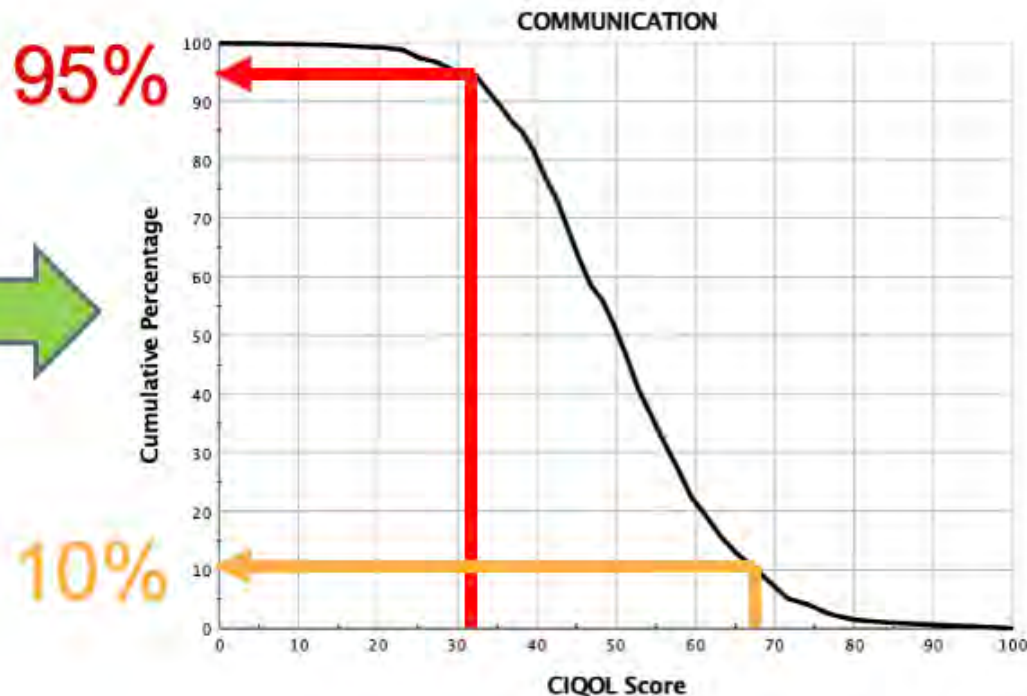
Patient Name: Jonathan A. Hinton  
 VRN: 5534333

# Pre-CI counseling

Baseline (pre-CI)  
CIQOL scores



CIQOL-  
Expectations

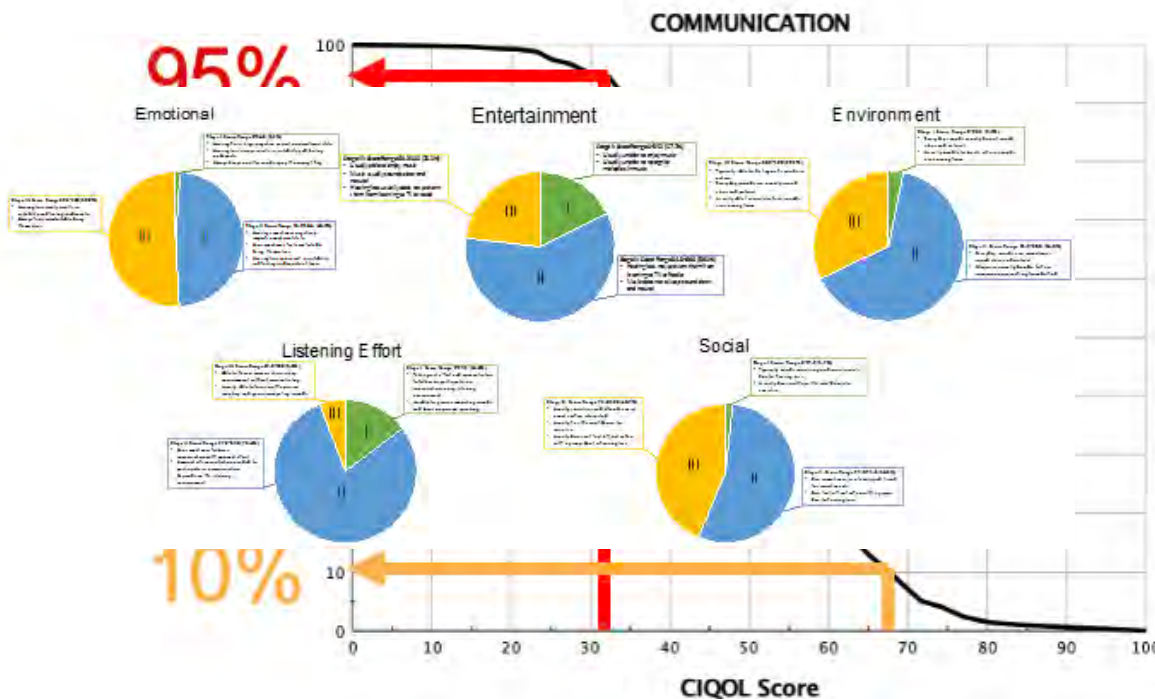


# Pre-CI counseling

Baseline (pre-CI)  
CIQOL scores



CIQOL-  
Expectations



**CIQOL  
Development**



**Score  
interpretation**



**Pre-CI  
Counseling**



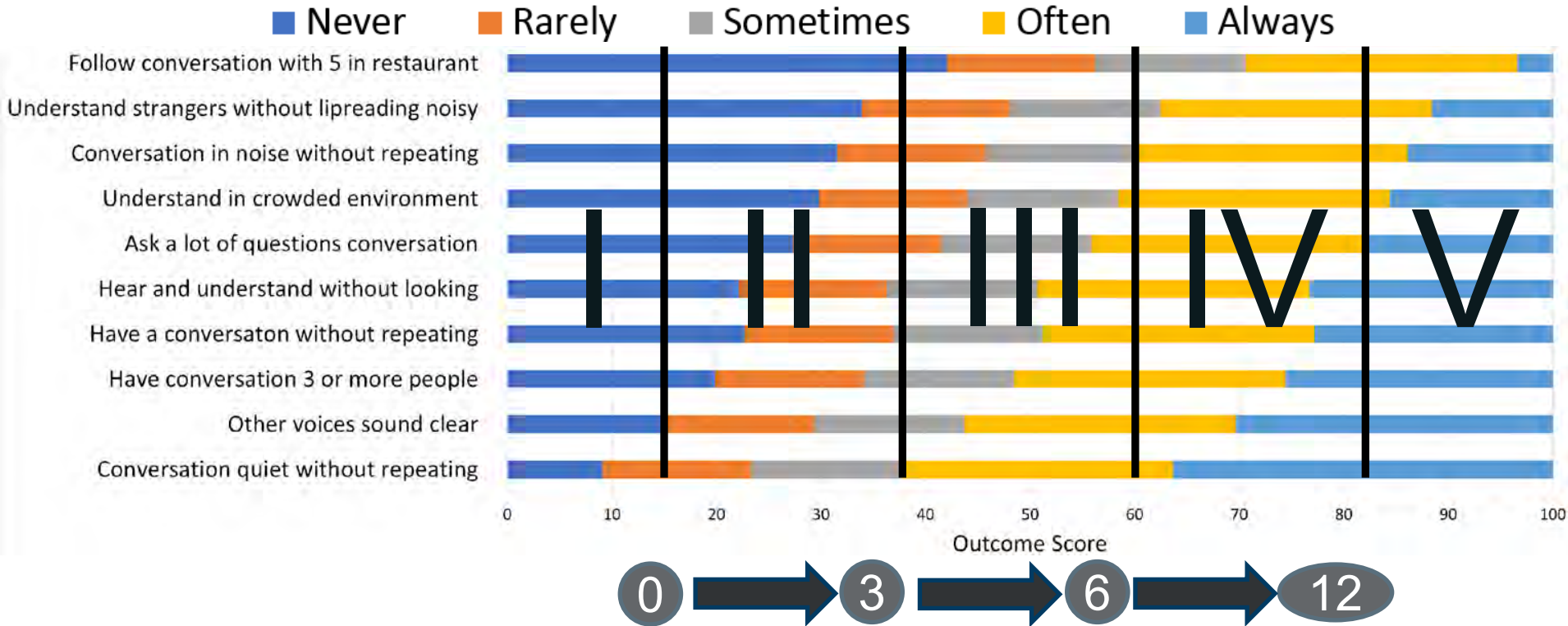
**Post-CI  
Monitoring**

**Widespread  
clinical  
implementation**

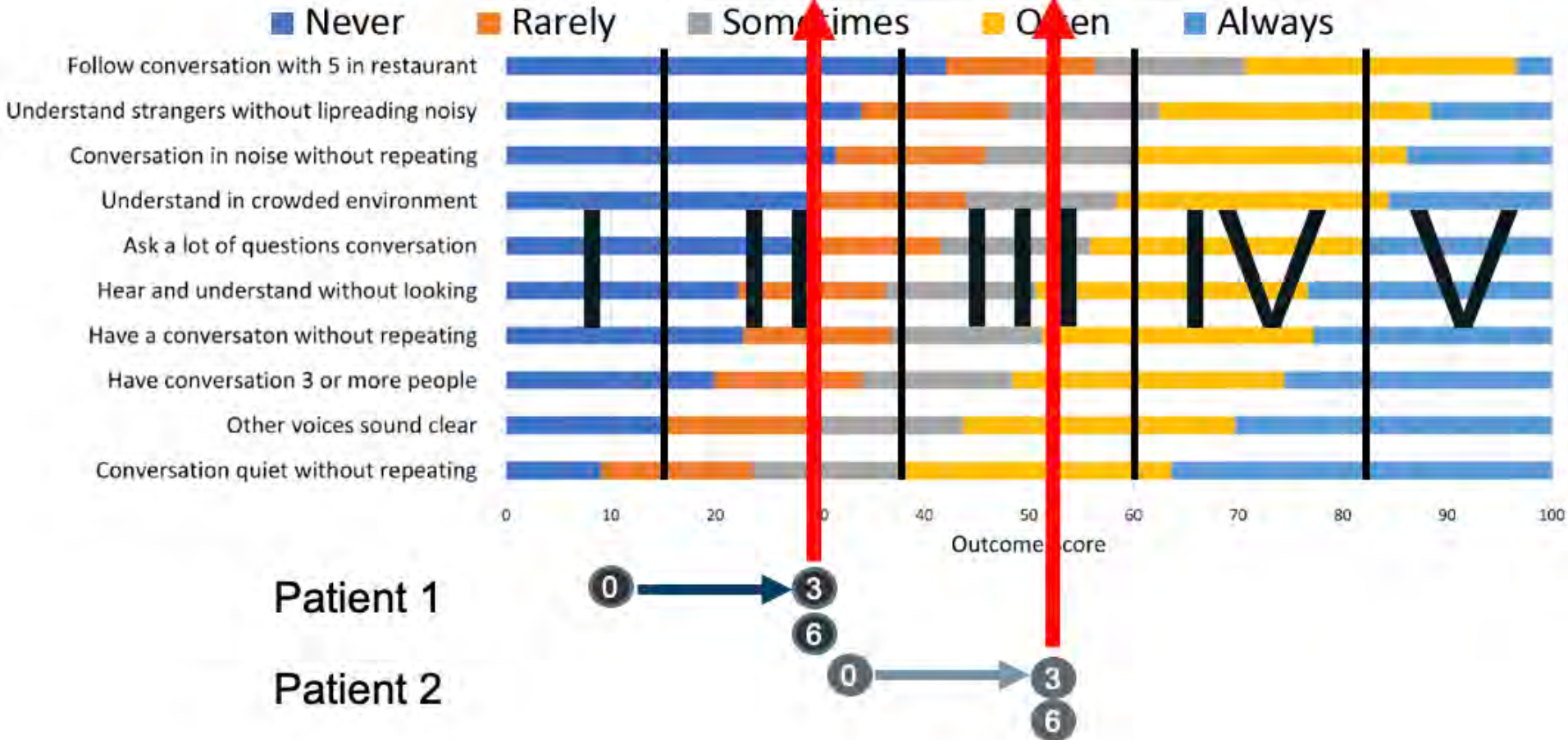
# Understanding meaningful score improvement

- Essential to be able to determine if improvement is clinically significant and beyond measurement error
- Have determined conditional minimal detectable change values (cMDC) values for CIQOL score

# Monitoring post-CI activation progress: Communication



## Precision medicine



# Monitoring post-CI activation progress

- Implementation of the CIQOL-35 Profile and functional staging system have the potential to enhance our:
  - Understanding the barriers/problems that each individual patient is facing
  - Personalize rehabilitation strategies based on individual CI user's ability threshold
    - Need to develop new interventions?
- **Reminder: CIQOL-35 Profile and functional staging system measure outcomes/progress in 5 additional domains**
  - **Capacity to comprehensively monitor patient progress after CI activation**
    - **Non-communication related interventions**

**CIQOL  
Development**



**Score  
interpretation**

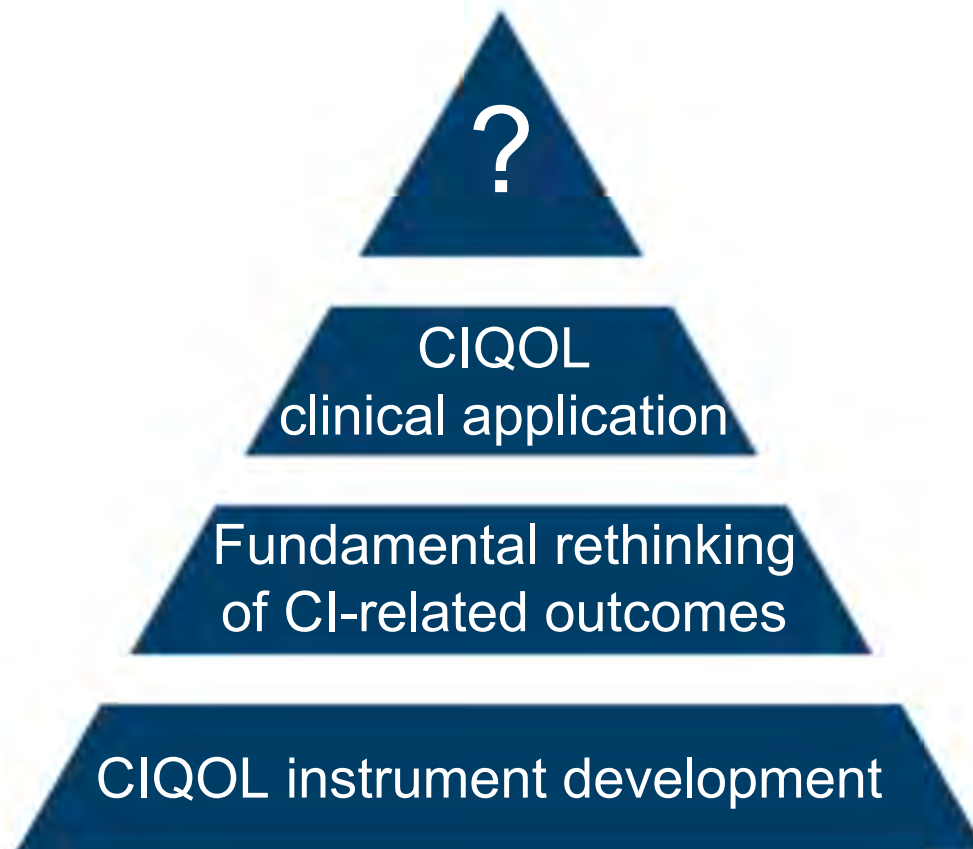


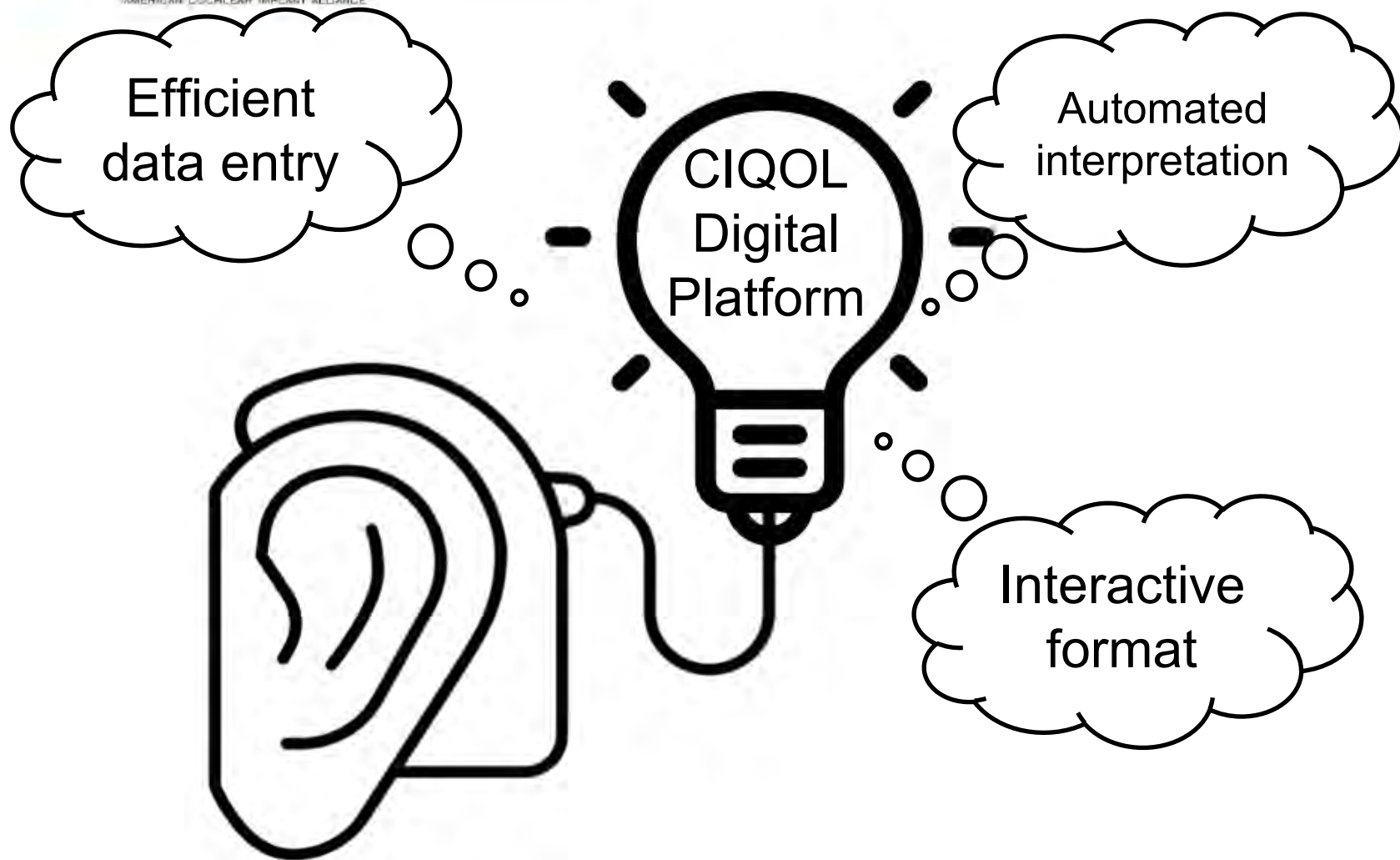
**Pre-CI  
Counseling**



**Post-CI  
Monitoring**

**Widespread  
clinical  
implementation**





# Acknowledgements:



## >900 unique research participants

- Judy R. Dubno
- Craig Velozo
- Brittany Hand

## Adult CI team



- Kara Leyzac
- Rob Labadie
- Paul Lambert
- Ted Meyer
- Habib Rizk
- Liz Camposeo
- Kaylene King
- Amy Noxon
- Meghan Carter



- CIQOL Development Consortium



- Columbia University
- Duke University
- Eastern Virginia Medical School
- Georgetown
- House Ear Clinic
- Johns Hopkins University
- Kaiser Health Los Angeles
- Kaiser Health San Diego
- Loyola University
- Mass Eye and Ear Infirmary
- Mayo Clinic Rochester
- MUSC
- New York Eye and Ear Infirmary
- Ohio State University
- Oregon Health Sciences University
- Rush Medical Center
- Stanford University
- Summit Medical Group

- SUNY Downstate
- University of Arkansas
- University of Cincinnati
- University of Colorado
- University of Maryland
- University of Miami
- University of Pennsylvania
- University of Utah
- University of South Carolina
- University of Texas Southwestern
- Vanderbilt University
- Virginia Mason Seattle
- University of Miami
- Washington University
- Advanced Bionics
- Cochlear Corporation
- MED-EL



# Questions

[mcrackan@musc.edu](mailto:mcrackan@musc.edu)



<https://education.musc.edu/CIQOL>