

How does health literacy impact the collection and interpretation of patient reported data/patient reported outcomes?

- Much of patient reported outcome measures focus on symptoms
- May be associated with accuracy of symptom attribution
 - Cognitive/memory symptoms may be confused with symptoms of depression

What approaches are used to collect patient reported data? How might these approaches be impacted by patient/family health literacy?

- We use Audio-Computer Administered Survey Instruments (A-CASI)
 - Allow for a human voice to read questions/possible responses aloud
 - Maintains privacy for sensitive information
 - Comfort with computers/technology can be a limitation

Are there optimal approaches/ tools for collecting patient reported data for patients with lower literacy?

- A-CASI approaches can reduce limitations imposed by reading difficulty
- Cognitive interviewing techniques (engaging participants to describe how they interpreted a question and the context from which they gave their answer) may aid obtaining valid information

What approaches would you recommend in the future?

- Field test questionnaires and data collection methods *before* enrollment
 - Use cognitive interview techniques
- Multiple approaches/types of data collection may be necessary (e.g., objective and subjective measures, qualitative measures)

What additional research is needed in this area?

- Validation of PROMIS measures among persons with low health literacy