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

- Patients' subjective experiences of illness may shape their response to HRQOL items
  - In response to general questions re: health status or quality of life, patients may describe the effects of those conditions that are most immediately bothersome (e.g., arthritis) while omitting chronic conditions that are under control (e.g., diabetes)

- Cultural factors such as stoicism or sensitivity to pain may affect patients' responses to PCO measures of pain, depression
  - Low health literacy may exacerbate these tendencies

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

- We found little familiarity with Likert scales in low-literate Vietnamese patients (and less educated Russian-speaking patients)

- We use face-to-face, orally administered web-based surveys with medically underserved patients at a FQCHC.
  - Bilingual/bicultural research assistants ask questions and enter patients' responses into the web survey. They explain question formats and topics patients are not familiar with.

What approaches would you recommend in the future?

- Use open ended survey questions to collect information of greatest concern to patients.

- HRQOL instruments should include specific items addressing medication use.
  - Some patients may feel sicker when they are prescribed medication for their asymptomatic chronic illness
  - Ask patients directly about what concerns they may have about their chronic disease medication. Concerns about medication are negatively associated with adherence.

What additional research is needed in this area?

- How valid are Likert responses in populations with limited previous exposure to them?

- PCOMs must account for culturally variable illness constructs such as depression, anxiety or *nervios*