In Memory of Kevin Robertson, PhD
Epidemiologic/Population Research Group:

What patient salient outcomes are most useful to gauge health related quality of life & prognosis?

Amy C. Justice MD PhD
Professor of Medicine and Public Health,
Yale University
VA Connecticut Healthcare System
Co-Authors

Matt Freiberg, Mike Silverberg, Keri Althoff, Kathy Anastos, Scott McClelland
Patient Salient Outcomes

- Reflect **quantity and/or quality** of life
- Commonly measured:
  - Mortality, hospitalization
  - HIV disease progression
  - Comorbid disease incidence, progression
- Less commonly measured, often patient reported:
  - Symptoms: pain, fatigue, sadness, nausea, diarrhea, etc.
  - Function: hearing, vision, mobility, cognition*, mental health*

*covered under Topic #2
Measurement Tools

• **Prognostic indexes** predict mortality, may predict hospitalization, falls, etc., e.g. Veterans Aging Cohort Study Index

• **Disease incidence/progression**, e.g. Framingham Risk Index or FRAX

• **Symptom** Indexes determine burden of bothersome symptoms, e.g. HIV Symptom Index

• **Health Related Quality of Life**, e.g. SF-12

• **Frailty**, e.g. Frailty Phenotype or Rockwood Score

• **Function**, e.g. timed walk, cognitive batteries, etc.
Three Major Measurement Issues

• Want to compare aging with and without HIV
  – Metrics need to be equally valid in both groups

• Validity may differ among important subgroups
  – Gender, race, age, and resource rich vs limited settings

• If using them as outcomes in research or care
  – Responsiveness to interventions is imperative
Key Research Questions:
Prognostic Indexes

• What are the most accurate and generalizable risk indices for mortality, hospitalization, and common comorbid diseases for those aging with HIV infection:
  – Do they demonstrate similar accuracy among subgroups?
  – Are they sufficiently responsive?
Key Research Questions: Patient Reported Outcomes

• What are the most valid & reproducible measures to study aging with HIV?
  – Do they demonstrate similar validity among subgroups?
  – Are they sufficiently responsive?
Key Research Questions: Cross Cutting Issues

• Is frailty a useful independent concept in the study of aging with HIV? Do appropriate measures of frailty differ from those aging without HIV?

• How can useful indices of prognosis, quality of life, and frailty be integrated into routine clinical care and research?