# Gaps and Opportunities for Patient and Caregiver Reported Outcomes

Antonia V. Bennett, PhD
Department of Health Policy and Management

NASEM Serious Illness Care Research – Session 3
November 2-3, 2023

Gillings School of Global Public Health
Department of Health Policy and Management

THE UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL

# Disclosures

- Potential conflicts of interest: None

# 1. Valid and reliable measurement tools are crucial to productive science but often lacking

- Many instruments were developed in a prior era and the measurement properties are often poor or unknown
- *"Responsiveness to change"* is often not assessed in validation but is a key characteristics
- Many instruments were developed in predominantly white, middle class samples. The content of the instrument may not be entirely relevant to many other groups in the U.S. – key content may be lacking.

PATIENT AND CAREGIVER REPORTED OUTCOMES

# 2. Research investment in instrument development in the past 10-15 years has been limited, following substantial investment in NIH PROMIS

PATIENT AND CAREGIVER REPORTED OUTCOMES

# 3. Serious illness care research, especially at end-of-life, requires conceptually specific and nuanced instruments on many topics, e.g., spiritual concerns, quality of hospice care, caregiver distress

PATIENT AND CAREGIVER REPORTED OUTCOMES

# 4. Financial hardship is a major issue for most patients and families

- Rapidly growing area of research and policy interest across disease conditions, especially cancer and Alzheimer’s disease
- Many gaps in existing instruments for measuring financial hardship
- Impact on patients and families of health care costs and caregiving

# 5. Data collection options are improving over time

- Systems for capturing information, e.g., EHR patient portals, text message, apps, and smartphones
- People's ability and willingness to provide data for clinical care and research
  - The proportion of U.S. adults age 65+ who say they own a smartphone has grown from 13% to 61% in the past 10 years. (Pew Research Center)
  - However, smartphone use highly correlated with socioeconomic characteristics
  - Among U.S. adults age 50-64, currently 83% own a smartphone

PATIENT AND CAREGIVER REPORTED OUTCOMES

# Summary

- Informative research studies require high quality outcome measures
  - Valid and reliable measures
  - Unique experiences of cultural and socioeconomic groups within the U.S.
- Serious illness care research includes many topics for which high quality outcome measures are lacking
  - Financial hardship of patients and families
- Evolving landscape for data collection