# Patient-reported outcomes in serious illness: What’s missing?

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# Rapid growth in availability and use of patient-reported outcomes (PROs) in research and clinical care

- Increasing recognition that allowing patients to voice their own needs and experiences makes care better

- Patient reports are also increasingly used to inform research agendas and assess efficacy of health care interventions

- But the current state of the science includes important gaps
  - Available PROs cover select domains
  - And are appropriate for select populations

# Patient-reported outcomes

- Robust, well-validated PROs are available in several important domains
  - Symptoms
  - Physical function
  - Quality of life
- PRO-CTCAE covers discrete symptoms, including frequency, severity, and interference to facilitate symptom management
- PROMIS covers symptoms and broader domains such as function and quality of life
- Both have versions available for patients across the lifespan, including proxy report for the youngest patients and pediatric self-report starting around age 7-8

# What’s missing?

- Step back to think about the fundamental questions in the field

# Serious illness care questions

- How do patients with serious illness come to understand and accept their conditions?
- How should we talk about these issues with patients?
- What are patient priorities for care and treatment?
- What do patients want to experience and achieve in life?
- How do priorities translate into decisions?
- How well do decisions reflect personal priorities, goals, and values?

# Serious illness care questions

- We have very few tools to measure these fundamental issues

# Issues that need to be measured

- Communication processes and outcomes
- Patient preferences, goals, values
- Decisions
- Goal concordance of care

# Serious illness care questions

- Where measures exist, they are often not:
  - Validated
  - Culturally adapted
  - Tested for responsiveness to change
  - Adapted across the life span

# Why it matters

- A lack of robust, validated measures that can be used to understand patient goals and values is a significant limitation to progress in the field
- Challenges development of interventions, attainment of funding, testing of intervention efficacy, and comparison across studies
- Limits the extent to which the patient voice is heard in work in palliative care
    - (which is contrary to the reason most of us are in the field)

# Important to make sure that all voices are considered

- Children and adolescents
- Individuals with limited literacy
- Individuals with limited English proficiency
- Individuals who require proxy report due to age, cognitive disability, critical illness
  - What is the process for optimizing proxy report when needed?

# Recommendations

- Identify domains of key importance for measure development
- Convene working groups to review and assess available measures in each domain
    - Where appropriate measures exist, engage in refinement and testing
    - Where measures are absent, prioritize development as a fundamental need for the field

# Recommendations

- Enhance funding opportunities for psychometric work
- Incentivize inclusion of “quieter voices”
- Ensure that patients and caregivers are involved in every step
  - Including prioritization of needed domains
- Ultimate goal: set of robust measures that are recommended for use