Choosing Patient-reported Outcomes and Measurement Methods

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Continuum of Kidney Disease (KD) and General Health Measures

**Clinical Markers**

1. eGFR

**Specific Symptoms**

2. Kidney Symptoms: To what extent were you bothered by?
   - Muscle soreness
   - Cramps
   - Itchy skin
   - Lack of appetite

**KD-specific Impact**

3. How often did your kidney disease limit your usual activities or enjoyment of everyday life?
   - Very often
   - Often
   - Rarely
   - Never

**General Health**

4. How often did your health limit your usual activities or enjoyment of everyday life?
   - Very often
   - Often
   - Rarely
   - Never

**References:**
- Wilson and Cleary, *JAMA*, 1995
- Ware, Richardson, Meyer & Gandek, *JASN*, 2019

Health-related QOL
Advantages of Disease-specific and General QOL Measures

Specific:
- More responsive
- More clinically actionable

General:
- Compare diseases & treatments
- Capture comorbid conditions

Kidney Symptoms
To what extent were you bothered by?
- Muscle soreness
- Cramps
- Itchy skin
- Lack of appetite

KD-specific Impact
How often did your kidney disease limit your usual activities or enjoyment of everyday life?
- Very often
- Often
- Rarely
- Never

General Health
How often did your health limit your usual activities or enjoyment of everyday life?
- Very often
- Often
- Rarely
- Never

Clinical Markers
Specific Symptoms
Disease-specific QOL Impact
General QOL Impact
New Approaches to Disease-specific and General QOL Measures

**QOL Disease Impact Scale (QDIS)**

- **Clinical Markers**
- **Specific Symptoms**
  - Kidney Symptoms
    - To what extent were you bothered by?
      - Muscle soreness
      - Cramps
      - Itchy skin
      - Lack of appetite
- **KD-specific Impact**
  - How often did your kidney disease limit your usual activities or enjoyment of everyday life?
    - Very often
    - Often
    - Rarely
    - Never

**QOL General (QGEN)**

- **General Health**
  - How often did your health limit your usual activities or enjoyment of everyday life?
    - Very often
    - Often
    - Rarely
    - Never
General and Disease-specific QOL Are the Best Healthcare Predictors

Predictive Validity

Health-Related QOL

Disease-specific QOL Impact

General QOL Impact

Costs of health care
Job loss
Response to treatment
Return to work
Work productivity
Future health
Mortality