Important Outcome Measurement Concepts

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Important Concepts

- Selecting the best outcome measure
  - Match construct of interest to measure
  - Examine psychometric properties of measures

- Measurement innovations
  - Patient reported outcome measures
  - Computerized adaptive tests

Selecting the Best Outcome Measure

- What construct do you intend to measure?
  - Conceptual framework: International Classification of Functioning Disability and Health (ICF)
How to measure this outcome?

- Examine the following:
  - How is the construct operationalized?
  - Is there the potential item bias?
  - Is the measure likely to capture change?
  - Should other types of outcomes be considered?

Psychometric Properties

- Ability to detect change
  - Minimal Detectable Change (MDC\textsubscript{90})
    - Identifies error associated with the measure – real change should exceed error
  - Standardized change scores assess the size of the difference between two means not confounded by sample size
    - Effect Size (ES)
      - change/standard deviation of baseline score
    - Standardized Response Mean (SRM)
      - change/standard deviation of change score

Sensitivity to Change vs. Responsiveness

- Sensitivity to change = the ability of an instrument to measure a change in state, may not be relevant or meaningful to the decision maker.
- Responsiveness = ability of an instrument to measure a meaningful or important change in a clinical state. A critical property of instruments designed to measure change and effectiveness of interventions.
Minimal Clinical Important Difference (MCID)

- Defines outcomes in terms of patient experience
- Can be used to track individual patient progress
- Can be used to compare outcomes internally and across sites/clinics to establish benchmarks
- Could be used for reimbursement
  - Examples
    - Patients not demonstrating sufficient change
    - Patients not ready for discharge – have not met MCID
- PROBLEM
  - Methods for calculating MCID are not standardized

Questions:
1.) What factors can affect MCID values?
2.) Describe issues you could have using an MCID established in a population that was at a lower functional level than your patients?
Why Patient-Reported Outcomes?

Capture perspective of persons served:
- Outcomes important to clinicians and administrators may not be important to persons served
- Unique and important view of impact of services provided
- Who knows best the impact your program has had?

What Can Be Measured?

- Specific domains of functioning (e.g., mobility, self-care, fatigue)
- Health status
- Well-being
- Quality of life
- Satisfaction

How Administered?

- Types
  - Paper & pencil forms
  - Computer Adaptive Tests (CATs)
  - Computer Survey
- Modes
  - Person or proxy
  - Phone interview
  - Web-based
  - Stand-alone computer
  - PDA
  - iPad
What Can Be Learned?

- Are people served doing better?
- Is one subgroup better/worse than others?
- Do changes in patient-reported outcomes match changes in other outcomes?
- If not, why?

Selecting Patient-Reported Outcome Measures

- Data collection methods:
  - Interview
  - Online survey
  - Local computer/kiosk survey
  - Paper survey
- Best measure to capture domain of interest

Target Instrument to Area(s) of Interest

- Conceptual framework for selecting appropriate measures
- Effects/impacts to assess
- How different domains could be affected by services provided
Examples: General Types of Patient-Reported Outcomes Measures

- **Generic**
  - Scores for specific domains (e.g., SF-36, PROMIS)
- **Post-acute care**
  - Scores for specific domains (e.g., AM-PAC)
- **Disease/condition specific**
  - NeuroQOL, Arthritis, Asthma
- **Adult/pediatric**
  - Late Life Function and Disability Index
  - Pediatric Evaluation of Disability Index

PROMIS Development

Patient-Reported Outcomes Measurement Information System (PROMIS):

- Initiative by the National Institutes of Health (NIH)
- 5-year cooperative group research program to develop, validate, and standardize item banks measuring patient-reported outcomes (PROs) across common medical conditions

PROMIS Features

- PROMIS instruments measure concepts such as:
  - Pain
  - Fatigue
  - Physical function
  - Depression
  - Anxiety
  - Social function
- Item banks (collections of questions measuring same concepts):
  - Administer in short forms
  - Evaluate using computerized adaptive testing
- Efficient:
  - Short forms require 4–10 items
  - Computerized adaptive testing require 3–7 items for more precise scores
- Available for children and adults
<table>
<thead>
<tr>
<th>PROMIS Physical Health Banks</th>
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<tbody>
<tr>
<td><strong>Adult</strong></td>
<td><strong>Pediatric</strong></td>
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<td>Pain behavior</td>
<td>Pain behavior</td>
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<td>Pain interference</td>
<td>Pain interference</td>
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<td>Fatigue</td>
<td>Fatigue</td>
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<td>Pain intensity</td>
<td>Upper extremity function</td>
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<td>Physical function</td>
<td>Mobility</td>
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<td>Sleep disturbance</td>
<td>Asthma impact</td>
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<td>Sleep-related impairment</td>
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<th>PROMIS Mental Health Banks</th>
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<td><strong>Adult</strong></td>
<td><strong>Pediatric</strong></td>
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<td>Anxiety</td>
<td>Anxiety</td>
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<td>Depression</td>
<td>Depression</td>
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<td>Anger</td>
<td>Anger</td>
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<td>Illness impact negative</td>
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<td>Illness impact positive</td>
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<td>Applied cognition—concerns</td>
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<td>Applied cognition—abilities</td>
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<tr>
<td><strong>Adult</strong></td>
<td><strong>Pediatric</strong></td>
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<tr>
<td>Ability to participate in roles &amp; activities</td>
<td>Peer relationships</td>
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<td>Satisfaction with roles &amp; activities</td>
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<tr>
<td>Companionhip</td>
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<td>Emotional support</td>
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<td>Informational support</td>
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<td>Instrumental support</td>
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<td>Social isolation</td>
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Assessment Center

- PROMIS Computerized Adaptive Tests (CATs) available for different domains
- PROMIS measure can be downloaded for paper administration
- Short-form versions available for most dimensions

Example: Short-Form Version: Fatigue

Fatigue - Short Form 7a

Please respond to each question by marking one box per row.
In the past 7 days...

- How often did you feel tired?..............
- How often did you experience extreme exhaustion?
- How often did you run out of energy?........

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
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Coming Soon....

NeuroQOL:
- Measures for persons with neurologic impairments.
Computerized Adaptive Tests (CATs)
- Overcome limitations of standard ‘fixed’ forms
- Based on large calibrated item banks comprised of items to assess a range of a given trait (e.g., mobility, depression)
- All scores are on the same metric, even though different items are administered

Computer Adaptive Tests (CATs)
- Computer program selects items that match an individual’s ability level:
- Based on large bank of calibrated items scaled on single dimension
- Responses to items used to select next item
- Yields precise estimates of ability with a few well-selected items
Advantages of CATs

- Items match each person’s ability
- Increases measurement breadth
  - Minimizes floor and ceiling effects
- More precise estimate with few items
  - Often 6-10 well-selected items
- Can filter irrelevant or offensive items

[Diagram of COMPUTERIZED ADAPTIVE TESTING]

(AM-PAC™) CAT

- Activity Measure for Post-Acute Care™
- Can be used to assess function across the continuum of care
  - Inpatient
  - Outpatient
  - Home
- Measures function in three domains
  - Basic mobility
  - Daily activities
  - Applied cognitive
(AM-PAC™) CAT

Application
- Functional assessment in adults with wide range of diagnoses and functional abilities

Use for
- Quality improvement
- Outcomes monitoring
- Research activities in:
  - Inpatient and outpatient rehabilitation
  - Home care, nursing homes and long-term acute care settings

LLFDI™
Late-Life Function and Disability Index™

- Assesses and responds to meaningful change in two distinct outcomes:
  - Function (ability to perform discrete actions or activities)
    - 32-item function component
  - Disability (performance of socially-defined life tasks)
    - 16-item disability component

- Appropriate for community-dwelling older adults

PEDI™ CAT

Pediatric Evaluation of Disability Inventory™

- Descriptive measure of child’s current functional performance
- Tracks changes over time
- Measures capability and performance of functional activities in three content domains:
  - Self-care
  - Mobility
  - Social function

- Comprehensive clinical assessment of:
  - Key functional capabilities and performance
  - Children between six months and seven years
  - Can be used to evaluate older children with functional abilities less than expected of 7-year-old child without disabilities
SF-36v2® Health Survey
- Provides scores for eight health domains:
  - Physical health
  - Role—physical health
  - Bodily pain
  - General health
  - Vitality
  - Social functioning
  - Role—emotional
  - Mental health
- Component scores:
  - Physical component summary (PCS)
  - Mental component summary (MCS) scores.
- Administer online or via paper and pencil

Considerations
- Feasibility in your setting?
- Data collection and management strategies
- Merging with other clinical and demographic data
- Planning baseline and follow-up data collection
- Accounting for differences based on diagnosis and severity?
- How will you use this information?

Demonstration
- http://www.nihpromis.org/