LESSONS LEARNED FROM MEASURING WHAT MATTERS

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Why Measure?

- Discriminate (screening measures)
- Evaluate
- Predict


- Understand and to fix  (Lord Kelvin)
- (Can’t understand what you cannot measure, and you cannot fix what you cannot understand)
What matters?

Kerr White and the 5 D’s

- Death
- Disease
- Discomfort
- Disability
- Dissatisfaction
- (Destitution)

What matters?  To whom?

Outcomes

- Mortality
- Morbidity
- Disability
- Satisfaction
- Cost
- QOL

Stakeholders

- Patient / person / client
- Clinician
- Family
- Society
What’s Canada got to do with this?

- Long history of measurement
- Strong roots in measures for rehabilitation
- Disease-specific measures primarily
- Single public payer for health care may be impetus for evaluating outcomes
Canadian eh!

- McGill Pain Scale (1971)
- Spitzer index (1981)
- Self rated health (1982)
- WOMAC (1982)
- 6MWT (1985)
- RNL (1987)

- Chronic Respiratory Disease Questionnaire-CRQ (1987)
- SMAF (1988)
- IBDQ (1989)

PRO Non-PRO Proxy/Clinician
Canadian eh!

- COPM (1991)
- GAS (1968/1992)
- TEMPA (1993)
- CMSA (1994)
- Fatigue Impact Scale (1994)
- Disability Assessment in Dementia (1994)
- Pain Catastrophizing Scale (1995)
- Activities Balance Confidence (ABC) (1995)

- HUI (1996)
- Toronto Extremity Salvage Score (TESS) (1996)
- DASH (1996)
- Quebec Back Pain Disability Scale (1996)
- MHAVIE (1996)
- McGill QOL (1997)
- STREAM (1999)
- LEFS (1999)

PRO Non-PRO Proxy/Clinician
Canadian eh!

- MQE (2002)
- PBSI (2003)
- MOCA (2005)
- Early Physical Function Post-Stroke (EPF-3d) (2009)
- Manitoba IBD Index (2009)
- Functional Recovery Stroke (F3m) (2009)
- GDS-Stroke (2010)
- Stroke Arm Ladder (2011)
- PBMSI (2013)
- B-CAM (2013)

PRO, Non-PRO Both
LESSONS LEARNED IN DEVELOPING 37 MEASURES
New and Old Terminology

- **PRO**
  - “any report of the status of a patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else.”

- **Non-PRO - ClinRO**
  - **Physical Performance**
    - Directly measured (6MWT, Barthel Index)
    - Self-reported (Barthel Index)
    - Proxy-reported (Barthel Index)
  - **Physical exam**
    - Clinician assessed (APGAR)

- **Non-PRO - ObsRO**
  - Behaviour
Measures can contain elements of PRO and Non-PRO

- Source of information on the construct is irrelevant to the measurement of the construct
- Measures of physical function and cognition can easily combine PRO and Non-PRO items and introduce flexibility in measurement
  - Early Physical Function Post-Stroke (EPF-3d)
  - Functional Recovery Stroke (F3m)
  - Stroke Arm Ladder
  - B-CAM
**Response shift: Physical Function**

<table>
<thead>
<tr>
<th>Construct</th>
<th>RS Potential</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-PRO</strong></td>
<td></td>
</tr>
<tr>
<td>Performance</td>
<td>NO</td>
</tr>
<tr>
<td>Units (m., m/sec, etc.) limitation, need for assistance/supervision</td>
<td>NO</td>
</tr>
<tr>
<td>Self-reported</td>
<td>NO</td>
</tr>
<tr>
<td>Limitation</td>
<td></td>
</tr>
<tr>
<td>Observer reported</td>
<td>NO</td>
</tr>
<tr>
<td>Limitation</td>
<td></td>
</tr>
<tr>
<td><strong>PRO</strong></td>
<td>YES</td>
</tr>
<tr>
<td>Difficulty</td>
<td></td>
</tr>
</tbody>
</table>

CANADA EARLY ADOPTER OF WHO INTERNATIONAL CLASSIFICATION OF FUNCTION (ICF)
The biopsychosocial model of functioning and disability

Health condition (disease, trauma)

Body function and body structure

Activity

Participation

Environmental factors

Personal factors

Contextual factors
Body function / Impairments

- Body functions are physiological functions of body systems, including psychological functions.
- Impairments defined in terms of problems with.
- PRO level impairments are synonymous with symptoms.
Activity / Activity Limitation

- Activities that are normal for any person
- Limitation is defined in terms of:
  - Capacity (what they can do): ClinRO / ObsRO
    - Includes concept of assistance or supervision
    - PRO: overestimates capacity
  - Performance (what they do do): ClinRO/ObsRO
    - Includes concept of assistance or supervision
    - PRO: overestimates performance
  - Difficulty: PRO
    - Susceptible to response shift
- MEASURE CAN DO, DOES DO, & DIFFICULTY
Participation / Participation restrictions

- Takes societal point of view on roles
  - interpersonal relationships, major life areas (education, work, and economic life), and community, social and civic life

- Specifics defined by the person
  - Eg. Work is societal perspective but person defines their particular job

- Performance
  - Frequency, duration
  - Satisfaction with
  - Productivity (work)
ICF provides an international common language and universal conceptual framework for describing functioning, disability and health.
The biopsychosocial model of functioning and disability

Health condition (disease, trauma)

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Indicates WHAT Not HOW to measure
Lessons Learned

- ICF components need different:
  - Conceptual approaches (models)
  - Therefore different types of measures

- Impairments – Symptoms
  - Frequency, Duration, Intensity, Impact
  - First 3 may be formative
  - Impact may be reflective/may be formative

- Do not easily go together in one measure
Lessons Learned

**Activity**
- Likely reflective – true latent – model
- Fix the construct, the items will change
- Hierarchical by definition
- People move up and down the “ladder”
- Suitable for Rasch/IRT approaches to creating total scores

**Participation**
- Likely formative – composite measure
- Items form the construct
- A count of the number of family and societal roles the person takes on is a good representation of participation
- Not suitable for Rasch/IRT
Not everything can be added up
ICF ~ Content Validity

Health Status Measures

Mapping

WESTERN ONTARIO AND MCMASTER UNIVERSITIES Osteoarthritis Index (WOMAC)

NTROTTINGHAM Health Profile

SF-36

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.
Do generic utility measures capture what is important to the quality of life of people with multiple sclerosis?
## What matters - To whom

<table>
<thead>
<tr>
<th>Patient</th>
<th>Clinician</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morbidity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence and severity of diseases</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impairments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms (what, frequency, duration, intensity, impact)</td>
<td>Physiological function cells, tissues, organs or markers there of; macro and micro structure of cells, tissues, organs</td>
<td>Behaviour (what, frequency, duration, bother, impact on family/caregivers)</td>
</tr>
</tbody>
</table>
What matters - To whom

<table>
<thead>
<tr>
<th>Activity Limitations (mobility, self-care)</th>
<th>Patient</th>
<th>Clinician</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with Difficulty with Priority</td>
<td></td>
<td>Capacity to</td>
<td>Capacity to Performance in</td>
</tr>
<tr>
<td>Importance of Priority</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## What matters - To whom

<table>
<thead>
<tr>
<th>Patient</th>
<th>Clinician</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participation restrictions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What</td>
<td>What</td>
<td>What</td>
</tr>
<tr>
<td>Frequency and duration</td>
<td>Frequency and duration</td>
<td>Frequency and duration</td>
</tr>
<tr>
<td>Satisfaction with</td>
<td></td>
<td></td>
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<tr>
<td>Difficulty with</td>
<td>Performance</td>
<td></td>
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<tr>
<td>Importance of</td>
<td></td>
<td></td>
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<tr>
<td>Priority</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived health</td>
<td>Health status</td>
<td>No data (both?)</td>
</tr>
</tbody>
</table>
# What matters - To whom

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<thead>
<tr>
<th>Patient</th>
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<th>Family</th>
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<tbody>
<tr>
<td>Quality of Life</td>
<td></td>
<td></td>
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<tr>
<td>Components</td>
<td></td>
<td>Global</td>
</tr>
<tr>
<td>Shortfalls</td>
<td></td>
<td>Symptoms Activity</td>
</tr>
<tr>
<td>Importance</td>
<td></td>
<td>Participation</td>
</tr>
<tr>
<td>Priorities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personalized measures</td>
<td></td>
<td>Society</td>
</tr>
<tr>
<td>Single Index</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standardized Index</td>
<td></td>
<td>QALY</td>
</tr>
</tbody>
</table>

**Global**

- **Symptoms**
- **Activity**
- **Participation**

**Society**

- **QALY**

**Patient**

- **Global**

**Clinician**

- **Standardized Index**
Summary

- Measurement needs considerable thought
- If we do not get the measurement correct, the rest will be flawed
  - Understanding and fixing
- One size may not fit all
  - Personalized measures
- One measure may not capture all that is relevant
  - Need statistical methods for multiple outcomes
- Not all things can be added up
- Different constructs have different conceptual models
  - Formative (symptoms, participation, health status)
  - Reflective (true latents)
One size may not fit all