
Karon Cook, PhD, Northwestern University
Chicago, IL
Thursday, September 28, 2017
Relevant Disclosure

Research Advisory Board, Consultant
Focus on Therapeutic Outcomes (FOTO)
“PROMs are a tool for patient-provider communication and have the potential to be as valuable to the clinical encounter as a stethoscope is to the physical examination.”
Let’s Measure Stuff That’s Important to Patients.

Great Idea!

We’ll take it from here.
Maybe we should ask patients what they think is important.

Concern about Content Coverage
PRO Scores Informed Research
e.g., FDA
How Do We Complete the Circle?

Personalized Recommendations

Patient-facing Reports
What’s Been Done for a Long Time

• Tailored intervention, based on needs assessment

• Screening for “disorders” (pain, depression, anxiety, alcohol misuse/abuse)

• But what about all the other measures we assess? (fatigue, insomnia, social function)
### PROMIS® Physical Function, Version 1.2

<table>
<thead>
<tr>
<th>T-Scores:</th>
<th>25</th>
<th>30</th>
<th>35</th>
<th>40</th>
<th>45</th>
<th>50</th>
<th>55</th>
<th>60</th>
</tr>
</thead>
</table>

**Are you able to do chores such as vacuuming or yard work?**

- w/o any difficulty
- a little difficulty
- w/some difficulty

**Are you able to go up and down stairs at a normal pace?**

- w/o any difficulty
- w/a little difficulty
- w/some difficulty
- w/much difficulty
- unable to do

**Are you able to go for a walk of at least 15 minutes?**

- w/o any difficulty
- a little diff.
- w/some difficulty
- w/much difficulty
- unable to do

**Are you able to run errands and shop?**

- w/a little difficulty
- w/some difficulty
- w/much difficulty
- unable to do

**Does your health now limit you in doing two hours of physical labor?**

- not at all
- very little
- somewhat
- quite a lot
- cannot do

**Does your health now limit you in doing moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?**

- not at all
- very little
- somewhat
- quite a lot
- cannot do
Participants take and score the PCS.

Meaning of scores based on literature.

Emphasize that Pain Catastrophizing can be reduced.

Scores tracked over time.
Perspective

Patient-Reported Outcomes — Are They Living Up to Their Potential?

Judith F. Baumhauer, M.D., M.P.H.

Comments open through July 12, 2017
Collects scores from patients on 3 PROMIS domains

148,000 unique patients

1.1 million PROMIS assessments.
Preoperative PROMIS scores predict likelihood of clinically meaningful benefit from foot and ankle surgery.

Example: PF score of 42, 94% chance of not experiencing a minimal clinically important difference in function after surgery.
“In effect, the patient, in direct consultation with his or her physician, gets to answer that crucial question: ‘How will this treatment decision affect someone like me?’”
NQF qualified measures
Risk-adjusted rankings of rehabilitation services

Intake scores
Age
Acuity
Sex

Comorbidities
Payer
Surgical History
Exercise History
Thank you for your responses! Here is your functional score TODAY and the RESULT that people similar to you TYPICALLY experience by the end of therapy.

<table>
<thead>
<tr>
<th>TODAY: 47</th>
</tr>
</thead>
<tbody>
<tr>
<td>TYPICAL RESULT: 69</td>
</tr>
</tbody>
</table>

Scores range 0-100; higher scores represent higher function.

Patients who improve this much typically are able to do the following with little or no difficulty.

- Vigorous activities, like running, lifting heavy objects, participating in strenuous sports
- Walking more than a mile
- Lifting or carrying groceries
- Walking several blocks
- Getting down to and up from the floor
- Participating in recreation
- Moderate activities, like moving a table, pushing a vacuum cleaner, bowling, or playing golf
- Climbing several flights of stairs
- Performing heavy activities around your home
- Changing positions quickly like sitting to standing

Here are the questions we asked and how you responded today:

Talk to your therapist about these results!
<table>
<thead>
<tr>
<th>Activity (Question)</th>
<th>Your responses today</th>
<th>Response after typical gain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reach a shelf that is at shoulder height</td>
<td>Much difficulty</td>
<td>No difficulty</td>
</tr>
<tr>
<td>Turn a faucet in the same direction as your affected arm</td>
<td>I can't do this</td>
<td>No difficulty</td>
</tr>
<tr>
<td>Taking off glasses or sunglasses</td>
<td>Some difficulty</td>
<td>No difficulty</td>
</tr>
<tr>
<td>Turn a faucet in the opposite direction as your affected arm (e.g., turn left if it is your right shoulder that is affected)?</td>
<td>Much difficulty</td>
<td>No difficulty</td>
</tr>
<tr>
<td>Flushing the toilet</td>
<td>Much difficulty</td>
<td>No difficulty</td>
</tr>
<tr>
<td>Using your hand on the affected arm to wash the side of your face on the same side as your affected shoulder</td>
<td>I can't do this</td>
<td>No difficulty</td>
</tr>
</tbody>
</table>
Talk to your therapist about these results!

What can you do to get the best results?

- Do your home exercises as prescribed by your therapist
- Attend all scheduled appointments
Bringing the Clinical Potential of PROMS to Patients Receiving Orthopedic Care

Julie Fritz, PhD, PT

University of Utah
Relevant Disclosure

Research Advisory Board, Focus on Therapeutic Outcomes (FOTO)
Among 155 conditions, diabetes had the highest healthcare spending in 2013 ($101.4 billion), Ischemic heart disease was the second-highest, ($88.1 billion), and low back and neck pain accounted for the third-highest amount, with estimated healthcare spending of $87.6 billion.

Spending on low back and neck pain and on diabetes increased the most over the 18 years, by an estimated $57.2 billion and $64.4 billion, respectively.

Percentage of visits for acute or acute-on-chronic low back pain (NAMCS and NHAMCS surveys)

Rajee et al, Bone Joint J, June, 2014

Knezevic et al, Anesthesiology, January, 2016
Potential of PROMs and Orthopedic Care

• High utilization of low-value care
• Mismatch between patients expectations and care provided
• Suboptimal outcomes
Potential of PROMs and Orthopedic Care

• Aggregate PROM data
  – Evaluate system performance and quality initiatives

• Individual patient PROM data
  – Enhance communication between patients and clinicians
    • Incorporating PROMs into shared decision making to ensure outcomes that matter to patients are accounted for in clinical decisions.
  – Facilitate patient engagement, empower patients to be more involved in their care.
  – Detect patient problems
$3.5 BILLION Expense Budget

50% GROWTH IN 4 YEARS

1.7 MILLION Patient Visits

ACCESS

4 Hospitals
11 Community Clinics
15 Regional Partners
10% of the Continental U.S.
1,380 Physicians
Vision for PROMs at University of Utah

• Lead the country in systemic collection of PROMs across patients (inpatient & outpatient)
• Lead the country in using the PROM data to improve healthcare
  – Integrate PROM data into value-based care analyses
  – Use PROM data to inform medical decision-making
  – Use PROM data to predict outcomes
  – Use PROM data in population health analyses
Tactics for PROM Collection at University of Utah

• Providers, office staff understand this is operations, not research
• Instruments: CATs, VAS, Simple questionnaires
• Collect only what is needed. System logic to administer instruments based on self reported change in symptoms, date of last instruments completed
• Home based remote collection enabled
• PRO results discussed with patient at time of visit
Volume Trends

Completed Assessments and Registered mEVAL Patients

- Red line: Total Completed Assessments
- Gray line: Total New mEVAL Patients

Count of Completions

- Y-axis: 0 to 130,000
- X-axis: 2016-09 to 2017-05
Person with low back pain

With or without sciatica

Exclude specific causes of low back pain, for example:
- Cancer
- Infection
- Trauma
- Inflammatory disease
- Cauda equina

Self management is important for all patients, even those with acute symptoms and/or sciatica

Provide self management information
- Information on nature of pain
- Encouragement to continue activities

Has Any Treatment Been Attempted?
- YES
  - Is Patient Improving?
    - YES
      - Continue Treatment; emphasize self-management
    - NO
      - Consider Medication Options (See box G)

- NO
  - Has patient had NSAIDs, PT or exercise for at least 6 wks?
    - YES
      - Consider Spine Specialist referral
    - NO
      - Consider Physical Therapy referral (See box H)

Follow-Up in 4-6 weeks
Limiting Low-Value Care for Back Pain

$$V = \frac{Q + S}{\text{(QUALITY)} + \text{(SERVICE)} + \text{(COST)}}$$

- 3,854 Unique patients with new consult for LBP in UU Health
- 951 Had PT and/or PMR visit within 180 days
- 485 (51.0%) PT was first
- 466 (49.0%) PMR was first
- 13.6% proceeded to have PMR visit
- 51.9% proceeded to have PT visit
- 22.3% Ad. Imaging
- 9.3% Injections
- 1.7% Surgery
- 40.3% Ad. Imaging
- 32.0% Injections
- 7.5% Surgery
Patient with LBP scheduling a new specialist consultation

Will patient’s insurance reimburse PT prior to MD visit?

YES

Does patient want to schedule with PT?

YES

Schedule PT Visit

NO

Schedule Specialist Visit

YES

Schedule Specialist Visit

NO

Schedule Specialist Visit

Diagram showing the calculation of value (V) as the ratio of quality (Q) plus service (S) over cost (C): 

\[ V = \frac{Q + S}{C} \]
Percentage Compliant

Project Month

- **REACH** (percentage of eligible patients enrolled in RapidAccess)
- **ADOPTION** (percentage of eligible patients offered RapidAccess)
Radiographs: 23.5%
MRI/CT: 26.1%
Injection: 8.7%
Surgeon: 3.5%
Surgery: 2.2%
PT First: 65.9%
Specialist First: 25.9%
PROMIS PF-CAT scores
Most patients don’t embark on a healthcare experience with a thorough understanding of available treatment options and their anticipated health outcomes. They need tools to help them make value-based, fully informed decisions about their care.
Personalized Decision-Making with PROMs
Personalized Decision-Making with PROMs
Activity Measure for Post-Acute Care™ (AM-PAC) “6-Clicks” Basic Mobility Short Form (6-Clicks-Mobility)

Please check the box that reflects your (the patient’s) best answer to each question.

<table>
<thead>
<tr>
<th>How much help from another person do you currently need... (If the patient hasn’t done an activity recently, how much help from another person do you think he/she would need if he/she tried?)</th>
<th>Total</th>
<th>A Lot</th>
<th>A Little</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Turning from your back to your side while in a flat bed without using bedrails?</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>2. Moving from lying on your back to sitting on the side of a flat bed without using bedrails?</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>3. Moving to and from a bed to a chair (including a wheelchair)?</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>4. Standing up from a chair using your arms (e.g., wheelchair, or bedside chair)?</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>5. To walk in hospital room?</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>6. Climbing 3-5 steps with a railing?</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
</tbody>
</table>
1,797
Patients undergoing spine surgery at University of Utah Health and discharged home

Mean age: 56.9 (±14.6) years
Gender: 43.8% female
Procedure: 77.3% lumbar (40% fusion)
Length of Stay: 2.9 (±2.3) days

D/C AM-PAC:* 42.0 ±8.5
63 (3.5%)
30-day unplanned readmission

D/C AM-PAC:* 45.9 ±9.3
1,734 (96.5%)
Not readmitted
PROMIS PF-CAT scores
Bringing the Clinical Potential of PROMS to Patients Receiving Orthopedic Care

- Shared Decision-Making around patient-centered outcomes
- Predictive Analytics to Tailor Treatment Plan
- Outreach and monitoring beyond the clinic

“By making PROMs an integral part of clinical care, providers can use them to improve an individual patient’s care as well as in aggregate to improve care of a population”

Neil Wagle, Partners HealthCare; Brigham and Women’s Hospital,
Priorities and Interventions in SCI Rehabilitation: Incorporating the Patient’s Voice Using PROMs

Vanessa Noonan, PhD PT
Needs and priorities of patients change throughout the SCI continuum.
During the acute care phase . . . . .

- Priority: loss of motor function (walking, hand/arm function, respiratory function)
- Patients have a limited ability to retain any information during acute care
- Perspectives of patients and families differ
- Development of clinical prediction rules can assist clinicians in counseling their patients regarding ‘priority areas’
During the community phase . . . . .

- Priority: management of body functions (bowel, bladder, sexual function), arm/hand function (tetraplegia) and mobility (paraplegia)
- Adaptation – response shift
- Development of self-management programs to ensure people with SCI can manage their health and participate in the community
Value of PROMs in SCI Rehabilitation

Aggregate Level Data

- Population
- SCI Centers

Patient Level Data

- Clinicians
- Patients

Comparison to Other Health Conditions

Ensure Optimal Care Across Centers

Screen and Inform Treatment

Personalize Treatment
Personalizing Treatment for Patients Using PROMs

Opportunities

• Provide scores back to patients in a meaningful format
• Assess and monitor health
• Inform shared decision making and self-management

Considerations

• Must ensure patients know how to act on the information
• Must ensure services are available if needs are identified
• Changes in health often require behavior change
• Need to evaluate
spinal cord injury + your body

- Affects every physiological system
- 7 to 30 secondary complications
  - Average is 15
- Chronic and complex condition

- psycho-social issues
- respiratory problems
- cardiovascular complications
- autonomic dysreflexia
- trunk mobility issues/paralysis
- pressure ulcers
- bladder/bowel dysfunctions
- upper limb mobility issues/paralysis
- sexual dysfunction & infertility
- lower limb mobility issues/paralysis
- osteoporosis
- neuropathic pain
Importance of Self-Management

Self-management refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established [4].
“Theory-based self-management to improve bladder health in persons with SCI”

Dalton Wolfe, PhD
Demographics

SCI QoL
• Bladder Management Difficulties (Short Form)
• Bladder Complications

University of Washington Self Efficacy Scale

Bladder Behavior Assessment

**Classify Patients**

• Pre-intender
• Intender
• Actor

**Tailor Information**

• Pre-intender – Information Resources
• Intender – Action Plan
• Actor – Maintenance Plan
Bladder question

About Me

Please select statements all that apply

- I am aware of the need to empty my bladder.
- I am usually continent.

Please select the method that best reflect the bladder management technique you currently use

- Indwelling Catheterization (Urethral

In the past, have any of the following conditions affected your urinary system?

- Urinary Tract Infections
- Urinary Incontinence or Leakage
- Bladder or Kidney Stones
- Bladder Cancer
- Kidney Disease
- Bladder Injury
- Reconstructed Bladder
- Other

When was the last time you had the following screening or assessments done by a healthcare provider?

- Bladder Ultrasound:
  - Within the last 12 months
  - More than 12 months
  - Never
  - I don’t know

- Urodynamic Study:
  - Within the last 12 months
  - More than 12 months
  - Never
  - I don’t know

If you’ve had any other screenings recently, let us know:

X-ray

- Within the last 12 months
- More than 12 months
- Never
- I don’t know
### My Bladder Health Risk Assessment

The next set of questions will help you reflect on what you do to keep your bladder healthy.

- I always drink 6-8 cups of fluids a day.
  - [ ] Strongly Agree
  - [ ] Agree
  - [ ] Neither Agree nor Disagree
  - [ ] Disagree
  - [ ] Strongly Disagree

- I know how to recognize the signs and symptoms of bladder problems (e.g., urinary tract infections, bladder stones, "high pressure / overactive bladder").
  - [ ] Strongly Agree
  - [ ] Agree
  - [ ] Neither Agree nor Disagree
  - [ ] Disagree
  - [ ] Strongly Disagree

- I know when to seek appropriate medical attention pertaining to my bladder health.
  - [ ] Strongly Agree
  - [ ] Agree
  - [ ] Neither Agree nor Disagree
  - [ ] Disagree
  - [ ] Strongly Disagree

- I visit my doctor for annual checkups that include a bladder ultrasound and/or other bladder assessments (e.g., urodynamics, scope).
  - [ ] Strongly Agree
  - [ ] Agree
  - [ ] Neither Agree nor Disagree
  - [ ] Disagree
  - [ ] Strongly Disagree

- My caregiver always wash their hands before and after my caregiver empty the drainage bag or switch to/from the leg bag.
  - [ ] Strongly Agree
  - [ ] Agree
  - [ ] Neither Agree nor Disagree
  - [ ] Disagree
  - [ ] Strongly Disagree

- My caregiver always make sure to keep the insertion area clean, i.e., wash with soap and water regularly.
### My Bladder Health Risk Assessment

Below is a summary which reflects your previous answers.

<table>
<thead>
<tr>
<th>Category</th>
<th>Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>At risk</td>
</tr>
<tr>
<td>Fluid Intake</td>
<td>At risk</td>
</tr>
<tr>
<td>Hygiene</td>
<td>At risk</td>
</tr>
<tr>
<td>Checkups</td>
<td>At risk</td>
</tr>
<tr>
<td>Medical Attention</td>
<td>At risk</td>
</tr>
<tr>
<td>Empty Frequency</td>
<td>At risk</td>
</tr>
<tr>
<td>Empty Routine</td>
<td>At risk</td>
</tr>
</tbody>
</table>

The great news is that you will learn how to make changes, set goals and get support to improve your bladder health.
Lessons Learned

• PROMs provide valuable information

• Implementation can be challenging:
  o Individuals must be ready to receive the information
    (In-patient setting was too early)
  o Individuals in the community are busy
  o Value of a peer mentor in providing the education
    (health coach)

• Self-management resources must be centralized
  (one stop shop)

• Technology must be accessible
FUTURE DIRECTIONS
Canadian SCI Network
Clinicians, Patients and Families Select Relevant Domains Across SCI Continuum

SCI QoL and Neuro-QoL
- Physical
- Mental
- Social

Implement into Care Across the SCI Continuum
- Inform shared decision-making and self-management (behavior change)

Infrastructure
- Peer mentors/health coaches
- Data capture (in-hospital and remote)
- Reporting (patients, clinicians, administrators-program, national)
- Evaluation
Informed Self-Management

DL Wolfe, PhD; S Mills, MEd; J Shepherd, MBA; C Craven, MD; and the E-Scan Investigative Team

Self-management comprises the interventions, training and skills provided to individuals with spinal cord injury (SCI) that support them in effectively managing all aspects of their lives (see Figure 1.0).

Program indicators:

- **Process** (administer PROMs at time-points)
- **Structure** (staff resources, e.g. peer support)
- **Outcome** (meaningful change in PROM scores)
Future Directions

Need to:

- Continue to engage people with SCI
- Understand ‘response shift’ following injury
- Study implementation of PROMs (e.g. behavior change)
- Consider effects of patient factors on ‘norms’ (e.g. age, # comorbidities)
- Continually evaluate (e.g. program indicators)

Goal:

*Personalized care (consider person, impact of injury, treatment goals) at each stage of the SCI continuum to ensure people with SCI can actively participate in their community.*
Acknowledgements

Vanessa Noonan, PhD PT
Director, Research and Best Practice

Rick Hansen Institute
Tel: 604-824-2727
Email: vnoonan@rickhanseninstitute.org