Patient Reported Outcomes for Care and Research: Move into the 21st Century Practice of Neurology

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Rational for PRO Collection
Value-based Care

Value = \frac{\text{Outcome}}{\text{Cost}}

- “Measuring, reporting, and comparing outcomes are perhaps the most important steps toward rapidly improving outcomes and making good choices about reducing costs”

Michael Porter, NEJM, 2010
Rationale for PRO Collection
Patient-centered care

Patient-centered care has become central to vision of future health care delivery system

The question patients ultimately care about is:
“Do I feel better?

• Institute of Medicine - “Crossing the Quality Chasm” (2001) listed patient-centered care as one of its six aims
• Patient-centered medical societies have started - such as Society for Participatory Medicine, and the Institute for Patient and Family-Centered Care.

Rationale for PRO Collection
Patient-centered care

• Affordable Care Act:
  – Patient medical homes
  – Patient-Centered Outcomes Research Institute (PCORI)
  – National Quality Strategy – patient engagement is a priority to help achieve better care, better health, and lower costs
Rationale for PRO Collection

Patient demand

- Patients clamoring for data on how they are doing

Patientslikeme.com

PRO Collection

Increasing Regulatory Requirements for Assessment of Health Status reported by the Patient

1. Cancer Program Accreditation
   - American College of Surgeons
   - Psychosocial assessment

2. Reimbursement for PT/OT/ST
   - CMS
   - Functional status at initial, 10th, and discharge visits

3. Cardiac Rehabilitation Program Certification
   - Amer. Association of Cardiovascular and Pulmonary Rehab.
   - Health-related quality of life assessment

4. Comprehensive Stroke Center Certification
   - American Stroke Association
   - Depression assessment
# Clinical Quality Measures for 2014 CMS EHR Incentive Programs for Eligible Professionals that involve PRO Measures

<table>
<thead>
<tr>
<th>CMS eMeasure ID</th>
<th>NQF #</th>
<th>Measure Title/Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMS161v1</td>
<td>0104</td>
<td>Major Depressive Disorder: Suicide Risk Assessment (each visit)</td>
</tr>
<tr>
<td>CMS169v1</td>
<td>0110</td>
<td>Bipolar Disorder and Major Depression: Appraisal for alcohol or chemical substance use (new diagnosis)</td>
</tr>
<tr>
<td>CMS157v1</td>
<td>0384</td>
<td>Oncology: Medical and Radiation – Pain Intensity Quantified (% of visits)</td>
</tr>
<tr>
<td>CMS2v2</td>
<td>0418</td>
<td>Preventive Care and Screening: Screening for Clinical Depression and Follow-Up Plan</td>
</tr>
<tr>
<td>CMS159v1</td>
<td>0710</td>
<td>Depression Remission at 12 Months (% with PHQ9&gt;9 with follow-up PHQ9 &lt; 5)</td>
</tr>
<tr>
<td>CMS160v1</td>
<td>0712</td>
<td>Depression Utilization of the PHQ9 tool (pts with diagnosis of depression/dysthymia)</td>
</tr>
<tr>
<td>CMS177v1</td>
<td>1365</td>
<td>Child &amp; Adolescent Major Depressive Disorder: Suicide Risk Assessment (qvisit)</td>
</tr>
<tr>
<td>CMS82v1</td>
<td>1401</td>
<td>Maternal depression screening (% children 6 mo whose mother had depression screening)</td>
</tr>
<tr>
<td>CMS66v1</td>
<td>TBD</td>
<td>Functional status assessment for knee replacement (baseline and 60-180d post)</td>
</tr>
<tr>
<td>CMS56v1</td>
<td>TBD</td>
<td>Functional status assessment for hip replacement (baseline and 60-180d post)</td>
</tr>
<tr>
<td>CMS90v2</td>
<td>TBD</td>
<td>Functional status assessment for complex chronic conditions</td>
</tr>
</tbody>
</table>

**Is PRO collection feasible.. and possibly helpful in clinical practice?**
An Example of Systematic PRO Collection
Cleveland Clinic Knowledge Program

• Began in 2007 as a collaboration between the Neurological Institute, Imaging Institute, & Information Technology Division

• Strategic Goals

  – Incorporate the collection and tracking of patient reported outcomes into existing clinical work flows

  – To use PROs and health information technology to help optimize healthcare management and delivery
Knowledge Program Questionnaires
Question Dependencies

Standard Question Types
Questionnaires
Custom

Questionnaire given to multiple sclerosis patient

Knowledge Program Integration within the EHR

Knowledge Program
Provider Review

European Quality of Life (EQ-5D), interviewer reported: Index = 0.696 (range: 0-1.0, a higher score indicates a better quality of life)

- Mobility: (1) I have no problems in walking about.
- Self-Care: (1) I have no problems with self-care.
- Usual Activities: (2) I am unable to perform my usual activities.
- Pain / Discomfort: (1) I have some pain or discomfort.
- Anxiety / Depression: (2) I am extremely anxious or depressed.

- Health state: 69 (8 - 100, a higher score indicates a better perceived health state)

Update Comments

Here Have You Seen a Specialist in the Past? (Not Necessary)

Update Comments

Patient Health Questionnaire (PHQ-9), interviewer reported, Score: 11
- Individual responses: 1,1,1,2,1,1,2,1,1

Score interpretation:

<table>
<thead>
<tr>
<th>Score</th>
<th>Depression severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>Minimal</td>
</tr>
<tr>
<td>5-8</td>
<td>Mild</td>
</tr>
<tr>
<td>9-14</td>
<td>Moderate</td>
</tr>
<tr>
<td>15-19</td>
<td>Moderate-Severe</td>
</tr>
<tr>
<td>20-27</td>
<td>Severe</td>
</tr>
</tbody>
</table>

Update Comments

Knowledge Program
Provider Review

****** ALERT ******

PHQ-9 screening suggests moderate-to-severe depression

Recommended actions: (Final decision depends on your clinical judgment)

1. Provide depression literature to patient (family)
2. Encourage patient (family) to seek further assessment from PCP or behavioral healthcare specialist
3. Consider initiating antidepressant medication and following patient

PHQ-9 Score: 27 of 27, individual responses: 3,3,3,3,3,3,3,3,3,3

Patient: Zs Test Mouse, Minnie
MRN: 56872876
Knowledge Program

Flowsheets track status over time

- Depression Screen (PHQ9) of patient:

Example of Neurology Measures

<table>
<thead>
<tr>
<th>Outcome/Analysis</th>
<th>Clinical Care/Analysis</th>
<th>Clinical Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>• European Quality of Life</td>
<td>• Patient Health Questionnaires 9 (depression screen)</td>
<td>• # seizures in last 4 weeks</td>
</tr>
<tr>
<td>• Epilepsy Quality of Life</td>
<td>• Epilepsy Neurotoxicity Scale</td>
<td>• CAGE Alcohol Screen</td>
</tr>
<tr>
<td>• PROMIS tools</td>
<td>• Generalized Anxiety Disorder 7</td>
<td>• # falls in the past month</td>
</tr>
<tr>
<td>• Stroke Impact Scale 16</td>
<td>• STOP (OSA screen)</td>
<td>• Flu vaccine</td>
</tr>
<tr>
<td>• Pain Disability Index</td>
<td>• Epworth Sleepiness Scale</td>
<td>• Epilepsy-related ER visits within the past 3 months</td>
</tr>
<tr>
<td>• Headache Impact Test 6</td>
<td>• Early Autism Screening Tool</td>
<td>• Days missed from usual activity within past month</td>
</tr>
<tr>
<td>• Modified Rankin scale</td>
<td>• Columbia Suicide Severity Rating Scale</td>
<td>• Driving</td>
</tr>
<tr>
<td>• Friedrich Ataxia Scale (Ataxia)</td>
<td>• Impulse-Compulsive Disorder in Parkinson's</td>
<td></td>
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<tr>
<td>• Fisher grade (ICH)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Toronto Western Spasmodic Torticollis Rating Scale</td>
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<td></td>
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</tbody>
</table>

Best Practice Alerts
Relevant Education information print with After Visit Summary
Preselected orders
Knowledge Program Data Collection*

Number of Patient Encounters with HSM data, by month

Thousands

*HSM includes PRO and provider-completed measures

Knowledge Program Health Status Data

KP Database Statistics

• >1,000 providers actively contributing to data collection
• 173 patient or provider validated questionnaires
  (additional 354 individual questions)
• Over 1.34 million patient visits contain PRO data
• Over 18 M responses
• >330,000 individual patients with PRO data
• Over 500,000 completions of the Patient Health Questionnaire 9 (depression screen)

Data as of 5/7/2014
Can PROs be useful for research?
### Comparative Effectiveness Research – then and now

<table>
<thead>
<tr>
<th></th>
<th>Traditional</th>
<th>Near Future</th>
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</thead>
<tbody>
<tr>
<td>Research</td>
<td>“Comparative Effectiveness Research”</td>
<td>“Patient-centered” outcomes Research</td>
</tr>
<tr>
<td>Clinical documentation</td>
<td>Paper medical records</td>
<td>Electronic health records</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Non-standardized mention of health status in documentation: “patient doing well”</td>
<td>Systematic collection of patient-reported outcomes</td>
</tr>
</tbody>
</table>

*Ability to leverage patient-reported outcome measures with clinically-derived electronic data will offer tremendous research opportunities*

### Examples of research questions that can be explored using PRO Data combined with EHR Data

- Evaluation of factors associated with patient-centered outcomes
- Evaluation of Relationships between Different Outcomes
- Prediction Modeling
- Comparative effectiveness of interventions
- Cost-effectiveness of interventions
The Research Value of Data on Large Cohorts of Patients

‘The most successful researchers of the 21st century will be those who have the largest and best-defined cohorts of patients’. 

Elias Zerhouni, MD, Director
National Institutes of Health
Cleveland, Ohio
July, 2004

Ability to generate new knowledge will grow exponentially with improved health information connectivity

Adapted from STM 2010;2(57):1-3
The Future of PROs for Care and Research

• PROs will likely become an integral part of healthcare in the near future
• PRO data can be used real-time to help understand patient’s health status and identify most appropriate interventions
• They will enable clinicians to identify strengths and weaknesses in the care provided, and to benchmark their outcomes against those of peers
• PRO data will help usher in a new era of clinical research and discovery.