HealthMeasures and the Future of PRO-based Performance Measures

Helen Burstin, MD, MPH
Chief Scientific Officer, NQF

HealthMeasures Users Conference
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National Quality Strategy

**Priorities**

- Make care safer by reducing harm caused in the delivery of care.
- Strengthen person and family engagement as partners in care.
- Promote effective communication and coordination of care.
- Promote effective prevention and treatment of chronic disease.
- Work with communities to promote best practices of healthy living.
- Make care affordable.
U.S. Policy Environment: From Volume to Value

All Medicare Fee-For-Service (FFS) payments

- 68% FFS linked to quality in 2011
- >80% Alternative payment models in 2014
- 85% FFS linked to quality in 2016
- 90% Alternative payment models in 2018
NQF Prioritization Framework

- National Priorities
- Driver Measures
- Priority Measures
- Improvement Strategies
### NQF Prioritization Criteria

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Outcome-focused</strong></td>
<td>Preference for outcome measures and measures with strong link to improved outcomes and costs</td>
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<tr>
<td><strong>Improvable and actionable</strong></td>
<td>Preference for actionable measures with demonstrated need for improvement and evidence-based strategies for doing so</td>
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<tr>
<td><strong>Meaningful to patients and caregivers</strong></td>
<td>Preference for person-centered measures with meaningful and understandable results for patients and caregivers</td>
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<tr>
<td><strong>Support systemic and integrated view of care</strong></td>
<td>Preference for measures that reflect care that spans settings, providers, and time to ensure that care is improving within and across systems of care</td>
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# National Priorities

<table>
<thead>
<tr>
<th>National Priorities</th>
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<tbody>
<tr>
<td>Optimal health (including function, survival)</td>
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<tr>
<td>Patient experience (including care coordination, shared decisionmaking)</td>
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<tr>
<td>Preventable harm/complications</td>
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<tr>
<td>Prevention/healthy behaviors</td>
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<tr>
<td>Total cost/high value care</td>
</tr>
<tr>
<td>Access to needed care</td>
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<tr>
<td>Equity of care</td>
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# High-Impact Outcomes

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<td>Well-being and function</td>
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Moving to value-based health care demands a better way of measuring outcomes.

Outcomes, especially patient-reported outcomes are significantly under-represented in available measures\(^1\)

ICHOM

Guiding Principles: Selection of Patient Reported Outcomes

- Psychometric Soundness
- Person-centered
- Meaningful
- Actionable
- Implementable
The Pathway from PROs to PRO-PMs

**PRO**
- Identify the quality performance issue (include broad input)
- Identify outcomes meaningful to target population and amenable to change
- Determine whether (PRO) is the best way to assess the outcome of interest

**PROM**
- Identify existing PROMs for measuring the outcome in the target population
- Select PROM suitable for use in performance measurement (e.g., reliable, valid, feasible)
- Use the PROM in real world with the intended target population and setting

**PRO-PM**
- Specify the outcome performance measure (e.g., average change, percentage improved or meeting a benchmark)
- Test PRO-PM for reliability, validity, and threats to validity (e.g., measure exclusions; missing data; poor response rate; risk adjustment; discrimination of performance; equivalence of results across PROMs)
PRO-PM Example: Depression Remission

**PRO** → **PROM** → **PRO-PM**

**PRO**

*patient-reported outcomes*

Information on the patient, told by the patient, without interpretation

**PROM**

*instrument, tool, single-item measure*

Way to collect information told by the patient without interpretation

**PRO-PM**

*PRO-based performance measure*

Way to aggregate the information that has been shared and collected into a reliable, valid measure of performance

**Symptom: depression**

**Patient Health Questionnaire (PHQ-9©), a standardized tool to assess depression**

**Percentage of patients with diagnosis of major depression or dysthymia and initial PHQ-9 score >9 with a follow-up PHQ-9 score <5 at 6 months (NQF #0711)**
Explore how to best integrate the patient experience into the development of performance measures driven by outcomes that are meaningful and relevant to patients.
Objectives

Amplifying the Patient’s Voice

- Explore novel approach to inform measurement
- Identify, prioritize, contextualize quality-of-life outcomes
- Establish foundational model for developing measures using aggregated data from online communities
PatientsLikeMe/NQF PRO Stakeholder Listening Sessions

- More meaningful data.
- Uncover problems only patients can evaluate.
- Assess value and costs in more complete way.
- Increase ability to connect what we pay for to health improvement.
- Empower patients to engage in decisions and choose according to preferences.
# About PatientsLikeMe

*Our mission is to improve the lives of patients through new knowledge derived from shared real-world experiences and outcomes*

- Founded in 2004 as a direct response to family’s experience with chronic disease
- Online, open, patient-facing community for patients with life changing conditions
- Started in ALS and expanded to all conditions
- Deep patient data and experience in ~40 life-changing conditions
- Free to join and free of advertising

<table>
<thead>
<tr>
<th>Patients</th>
<th>Data</th>
<th>Insights</th>
</tr>
</thead>
<tbody>
<tr>
<td>500,000+ patients</td>
<td>40+ million structured data points</td>
<td>100+ peer-reviewed publications</td>
</tr>
<tr>
<td>2,700+ conditions</td>
<td>4+ million free-text posts</td>
<td>Patient-generated taxonomy</td>
</tr>
<tr>
<td></td>
<td>15+ PROMs</td>
<td>FDA Research Collaboration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>iCarbonX Alliance/DigitalMe</td>
</tr>
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*Slide courtesy of PatientsLikeMe.*
Patient Voice
translated into computable
clinically relevant
data elements

Data codified using:
- ICD10
- SNOMED
- MedDRA
- ICF

Engagement
Data Integrity
Empowerment
Knowledge
Standards
Evidence

Slide courtesy of PatientsLikeMe.
Approach

Amplifying the Patient’s Voice

- Qualitative and quantitative patient experience data
  - Patient Profiles
  - Survey Data
  - Forum & Free Text Data
- Prioritize outcomes of greatest importance

PLM Communities

- COPD 2,500 Patients
- MS 51,000 Patients
- RA 10,000 Patients
Key Findings
Amplifying the Patient’s Voice

- Measures that focus on common symptoms may be more valuable than ones that focus on specific diagnoses
- Online patient community offered real-world solutions
  - Improved data quality
  - Representative patient experience
  - Illuminated patient concerns
  - Prioritized symptoms

Click here to access the study report Measuring What Matters to Patients: Innovations in Integrating the Patient Experience into Development of Meaningful Performance Measures.
### Complexity of Care: PatientsLikeMe COPD Analysis

<table>
<thead>
<tr>
<th>Condition</th>
<th>Affected (%)</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>74.5%</td>
<td>1,361</td>
</tr>
<tr>
<td>Pain</td>
<td>69.4%</td>
<td>1,354</td>
</tr>
<tr>
<td>Shortness of breath (dyspnea)</td>
<td>59%</td>
<td>966</td>
</tr>
<tr>
<td>Insomnia</td>
<td>52.4%</td>
<td>1,327</td>
</tr>
<tr>
<td>Anxious mood</td>
<td>46.1%</td>
<td>1,322</td>
</tr>
<tr>
<td>Depressed mood</td>
<td>45.4%</td>
<td>1,342</td>
</tr>
<tr>
<td>Cough</td>
<td>41.8%</td>
<td>942</td>
</tr>
<tr>
<td>Phlegm</td>
<td>36.3%</td>
<td>809</td>
</tr>
<tr>
<td>Wheezing</td>
<td>35.9%</td>
<td>924</td>
</tr>
</tbody>
</table>
Your joints today
Swollen joints?
Mark the joints that are swollen today. If none is swollen please continue to the next question.

Your joints today
Painful joints?
Mark the joints that are painful today. If none is painful please continue to the next question.

Earlier
Later
<<Previous part
Print the whole summary

Patient’s overview

Your disease activity

Din sjukdomsaktivitet  Din hälsodata  Din behandling

Earlier

Later

Danska 2015 2016
Mar 31  Apr 27  Jun 15  Jul 02  Nov 19  Feb 16  Mar 10  Mar 15  Mar 30
DAS28
High 10 9 8
Hög 7
Medium 5
Low 4
Inaktiv 3
Låg 2

<<Previous part
Print the whole summary
= Föregående del
Skriv ut hela översikten

Swedish Rheumatology Quality Register: Patient Module

NATIONAL QUALITY FORUM

SRQ
Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment (Basch et al)

JAMA. Published online June 04, 2017. doi:10.1001/jama.2017.7156

Overall Survival Among Patients With Metastatic Cancer Assigned to Electronic Patient-Reported Symptom Monitoring During Routine Chemotherapy vs Usual
Why we measure? 

*Improve healthcare quality*
Quality Imperative

Not everything that counts can be counted, and not everything that can be counted counts.

~William Bruce Cameron

But.....

You can’t improve what you don’t measure.

~ W. Edwards Deming
Helen Burstin, MD, MPH, FACP
hburstin@qualityforum.org
@HelenBurstin