Measuring What Matters to Patients: Integrating the Patient Experience into Quality Measures

Learning Collaborative 2017 Webinar

Wednesday, August 30, 2017
Shantanu Agrawal, MD, MPhil
President & CEO
National Quality Forum
NQF Strategic Direction

- Prioritize measures
- Reduce, select, and endorse measures
- Collect and act on feedback from the field
- Accelerate innovation

Improve healthcare quality, safety, and affordability
NQF Measure Incubator

Getting to Quality Measures that Matter
NQF Learning Collaborative

- **Purpose:** identify and share best practices around tough issues of measure development and to creatively collaborate on identifying solutions

- **Includes** stakeholders interested in measurement, such as measure developers, researchers, data entities, purchasers, patient organizations, and clinician groups
Today’s Panelists

- Ben Heywood, MBA, co-founder and president, PatientsLikeMe
- Marc Boutin, JD, CEO, National Health Council
- Helen Burstin, MD, MPH, FACP, chief scientific officer, NQF
- Tracy Spinks, senior director, NQF
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>
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<tbody>
<tr>
<td>500,000+ patients</td>
<td>40+ million structured data points</td>
<td>100+ peer-reviewed publications</td>
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<tr>
<td>2,700+ conditions</td>
<td>4+ million free-text posts</td>
<td>Patient-generated taxonomy</td>
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<tr>
<td></td>
<td>15+ PROMs</td>
<td>FDA Research Collaboration</td>
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<td>iCarbonX Alliance/DigitalMe</td>
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Patient Data Informatics

<table>
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<tr>
<th>Basic Information</th>
<th>Diseases, Conditions</th>
<th>Treatments &amp; Side Effects</th>
<th>General &amp; Specific Symptoms</th>
<th>Quality of Life &amp; Behavior Status</th>
<th>Outcome Measures of Disease</th>
<th>Patient-generated narrative data in forum discussions, journals and feeds</th>
<th>Emerging data source experiments</th>
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<tr>
<td>(age, sex, etc.)</td>
<td>(early signs, diagnosis status, etc.)</td>
<td>(Rx, OTC, Supp., non-drug, etc.)</td>
<td>(onset, severity status, etc.)</td>
<td>(all patients, some disease specific)</td>
<td>(disease dependent)</td>
<td></td>
<td>(wearable/sensors, EHRs, claims, 'omics, specimens)</td>
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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.
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
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
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.*
NQF FRAMEWORK
PRO TO NQF-ENDORSED PRO-PM

PRO → PROM → PRO-PM

patient-reported outcomes
information on the patient, told by the patient, without interpretation

instrument, tool, single-item measure
way to collect information told by the patient without interpretation

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)
Audience Question & Answer
Wrap Up & Announcements
Authors and Acknowledgements

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Learning Collaborative 2017
Focus on Patient-Centered Healthcare Measurement

▪ Up next. . .
  ▫ September 25 webinar highlighting Principles for Making Health Care Measurement Patient-Centered (register here)
  ▫ NQF will open its 2017 Innovation Challenge in Fall 2017

▪ To learn more, please contact NQF at incubator@qualityforum.org
THANK YOU
Appendix
Patient Representativeness Roadmap and Rubric

*Six Guiding Principles*

1. Define - Objective(s) for each engagement effort
2. Understand – Full population and subpopulations
3. Specify – Minimum targets for representativeness
4. Plan – To achieve the minimum target defined
5. Evaluate – Progress on achieving target
6. Document – How the plan was defined, targeted, achieved, and assessed

*Slide courtesy of National Health Council.*
**Patient Representativeness Roadmap and Rubric**

*Examples of Good and Poor Practice*

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<th>Define</th>
<th>Good</th>
<th>Poor</th>
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<tr>
<td>• Identify patient population and minimum target(s).</td>
<td>• Ignored sources of information on the full patient population and no targets were established.</td>
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<tr>
<td>• Articulate appropriate and feasible efforts and document limitations, missing data, and other challenges.</td>
<td>• Lacks a plan to meet targets, evaluation strategies, and/or learnings are not shared.</td>
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*Slide courtesy of National Health Council.*