NATIONAL
QUALITY FORUM

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

Learning Collaborative 2017 Webinar

Wednesday, August 30, 2017

WELCOME

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President & CEO

National Quality Forum

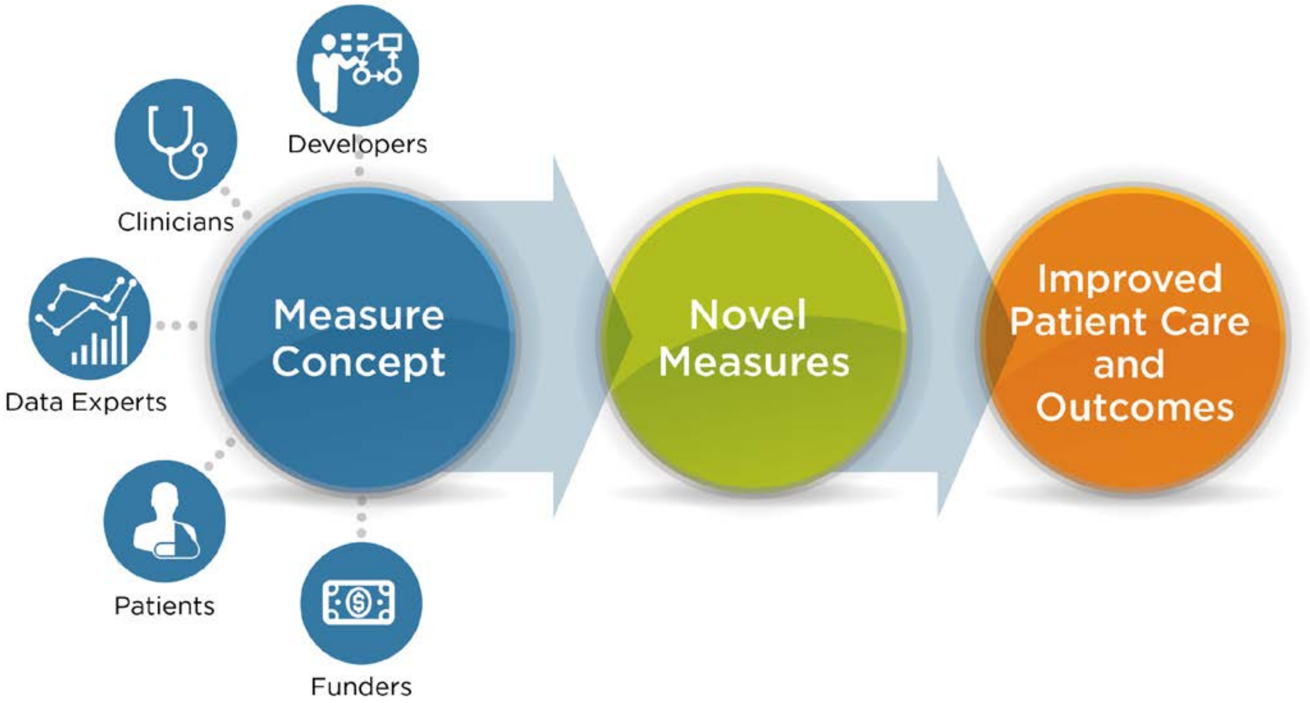
NQF Strategic Direction

- 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



Developers

Clinicians

Data Experts

Patients

Funders

Measure Concept

Novel Measures

Improved Patient Care and Outcomes

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

Patients → **Data** → **Insights**

Patients

- 500,000+ patients
- 2,700+ conditions

Data

- 40+ million structured data points
- 4+ million free-text posts
- 15+ PROMs

Insights

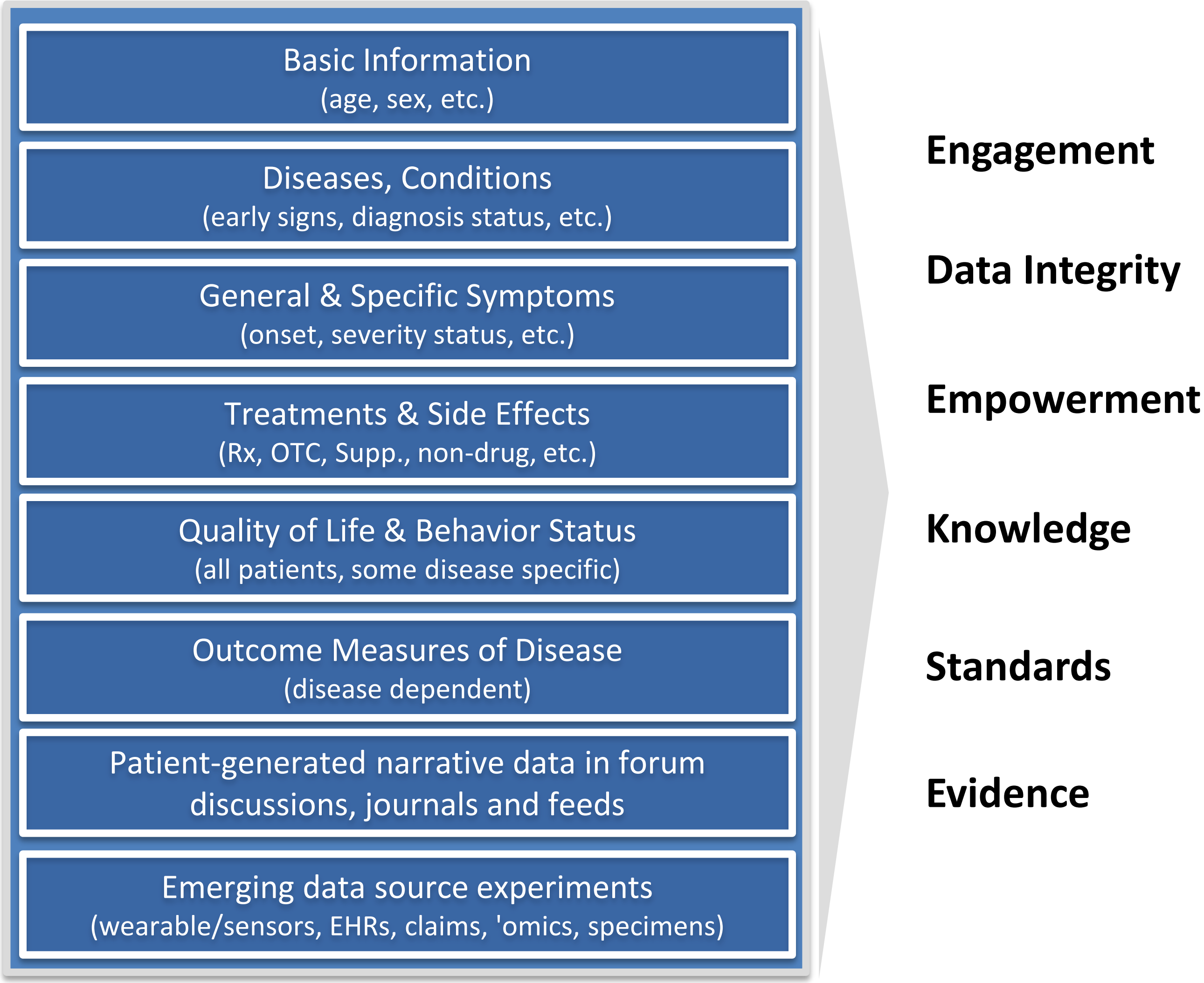
- 100+ peer-reviewed publications
- Patient-generated taxonomy
- FDA Research Collaboration
- iCarbonX Alliance/DigitalMe

Slide courtesy of PatientsLikeMe.

Patient Data Informatics

Patient voice translated into computable clinically relevant data elements

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



Basic Information
(age, sex, etc.)

Diseases, Conditions
(early signs, diagnosis status, etc.)

General & Specific Symptoms
(onset, severity status, etc.)

Treatments & Side Effects
(Rx, OTC, Supp., non-drug, etc.)

Quality of Life & Behavior Status
(all patients, some disease specific)

Outcome Measures of Disease
(disease dependent)

Patient-generated narrative data in forum discussions, journals and feeds

Emerging data source experiments
(wearable/sensors, EHRs, claims, 'omics, specimens)

Engagement

Data Integrity

Empowerment

Knowledge

Standards

Evidence

Slide courtesy of PatientsLikeMe.

Objectives

Amplifying the Patient's Voice

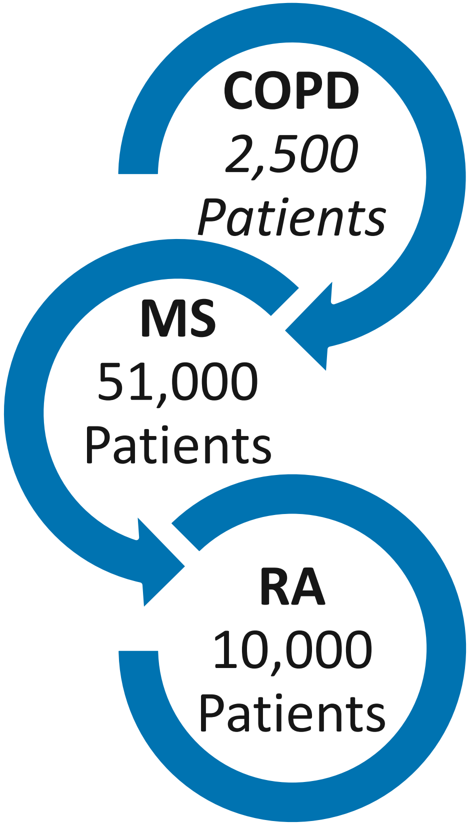
- Explore novel approach to inform measurement
- Identify, prioritize, contextualize quality-of-life outcomes
- Establish foundational model for developing measures using aggregated data from online communities

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

PLM Communities



COPD
2,500
Patients

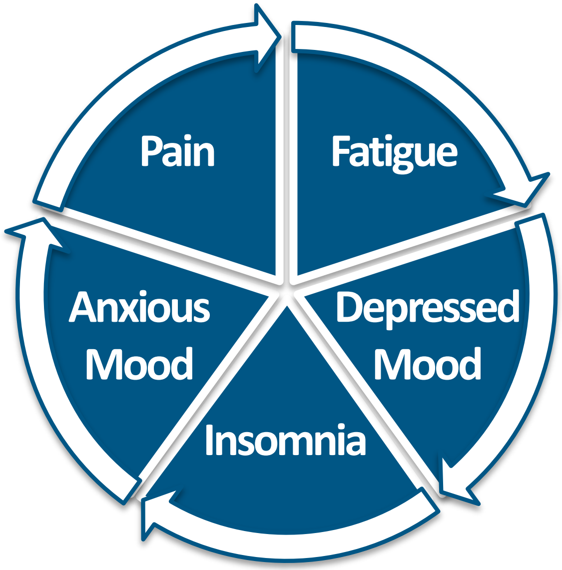
MS
51,000
Patients

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*.

NQF FRAMEWORK

PRO TO NQF-ENDORSED PRO-PM

PRO →	PROM →	PRO-PM
patient-reported outcomes	*instrument, tool, single-item measure*	*PRO-based performance measure*
information on the patient, told by the patient, without interpretation	way to collect information told by the patient without interpretation	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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- Emil Chiauzzi, PhD
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Acknowledgements

The authors thank the following for their support and helpful comments on the content of the paper.

- Alejandra Herr, MPH
  Managing Director Quality Innovation
  National Quality Forum
- Sofia Kosmetatos, MJ
  Director Media Relations and Online Communications
  National Quality Forum
- Lisa Gale Suter, MD
  Assistant Professor and Associate Director
  Yale School of Medicine and Yale/CORE
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- Timothy Vaughan, PhD
  Principle Scientist
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- Caroline W. Chan, BA
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This project was supported with funding from the Robert Wood Johnson Foundation.

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

Research | **Drug Development** | **Value** | **Quality** | **Delivery Systems**

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

Define
Understand
Specify
Plan
Evaluate
Document

Good

- Identify patient population and minimum target(s).
- Articulate appropriate and feasible efforts and document limitations, missing data, and other challenges.

Poor

- Ignored sources of information on the full patient population and no targets were established.
- Lacks a plan to meet targets, evaluation strategies, and/or learnings are not shared.

Slide courtesy of National Health Council.