

# National Consensus Standards for Palliative and End-of-Life Care

*Standing Committee Orientation*

*Karen Johnson  
Rachel Roiland  
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# Welcome and Introductions

# Project Team



**Karen Johnson**  
Senior Director



**Rachel Roiland**  
Senior Project Manager



**Jean-Luc Tilly**  
Project Analyst

# Standing Committee

**R. Sean Morrison, MD (co-chair)**

**Deborah Waldrop, Ph.D, LMSW, ACSW (co-chair)**

**Bob Archuleta, MD**

**Margie Atkinson, D. Min, BCC**

**Amy J. Berman, BSN**

**Eduardo Bruera, MD**

**Cleanne Cass, DO, FAAHPM, FAAFP**

**Michelle Caughey, MD, FACP**

**George Handzo, BCC, CSSBB**

**Arif H. Kamal, MD, MHS, FACP, FAAHPM**

**Alice Lind, MPH, BSN**

**Ruth MacIntosh, RN**

**Alvin Moss, MD, FACP, FAAHPM**

**Douglas Nee, Pharm D., MS**

**Laura Porter, MD**

**Cindi Pursley, RN, CHPN**

**Amy Sanders, MD, MS, FAAN**

**Tracy Schroepfer, Ph.D, MSW**

**Linda Schwimmer, JD**

**Christine Seel Ritchie, M.D. MSPH**

**Robert Sidlow, MD, MBA, FACP**

**Karl Steinberg, MD, CMD**

**Paul E. Tatum, MD, MSPH, CMD, FAAHPM, AGSF**

**Gregg VandeKieft, MD, MA**

**Debra Wiegand, PhD, MBE, RN, CHPN, CCRN, FAHA, FPCN, FAAN**

# Agenda for the Call

- Overview of NQF
- Overview of the Consensus Development Process
- Overview of NQF's portfolio of Palliative and End-of-Life Care measures
- Review of project activities and timelines
- Roles of the Standing Committee, co-chairs, NQF staff
- Overview of NQF's measure evaluation criteria
- Overview of SDS Trial Period
- SharePoint Tutorial
- Next steps

# The National Quality Forum: A Unique Role

Established in 1999, NQF is a non-profit, non-partisan, membership-based organization that brings together public and private sector stakeholders to reach consensus on healthcare performance measurement. The goal is to make healthcare in the U.S. better, safer, and more affordable.

**Mission:** To lead national collaboration to improve health and healthcare quality through measurement

- An Essential Forum
- Gold Standard for Quality Measurement
- Leadership in Quality

# NQF Activities in Multiple Measurement Areas

- **Performance Measure Endorsement**
  - 600+ NQF-endorsed measures across multiple clinical areas
  - 16 empaneled standing expert committees
- **Measure Applications Partnership (MAP)**
  - Advises HHS on selecting measures for 20+ federal programs, Medicaid, and health exchanges
- **National Quality Partners**
  - Convenes stakeholders around critical health and healthcare topics
  - Spurs action on patient safety, early elective deliveries, and other issues
- **Measurement Science**
  - Convenes private and public sector leaders to reach consensus on complex issues in healthcare performance measurement such as attribution, alignment, sociodemographic status (SDS) adjustment

# NQF Consensus Development Process (CDP)

## 8 Steps for Measure Endorsement

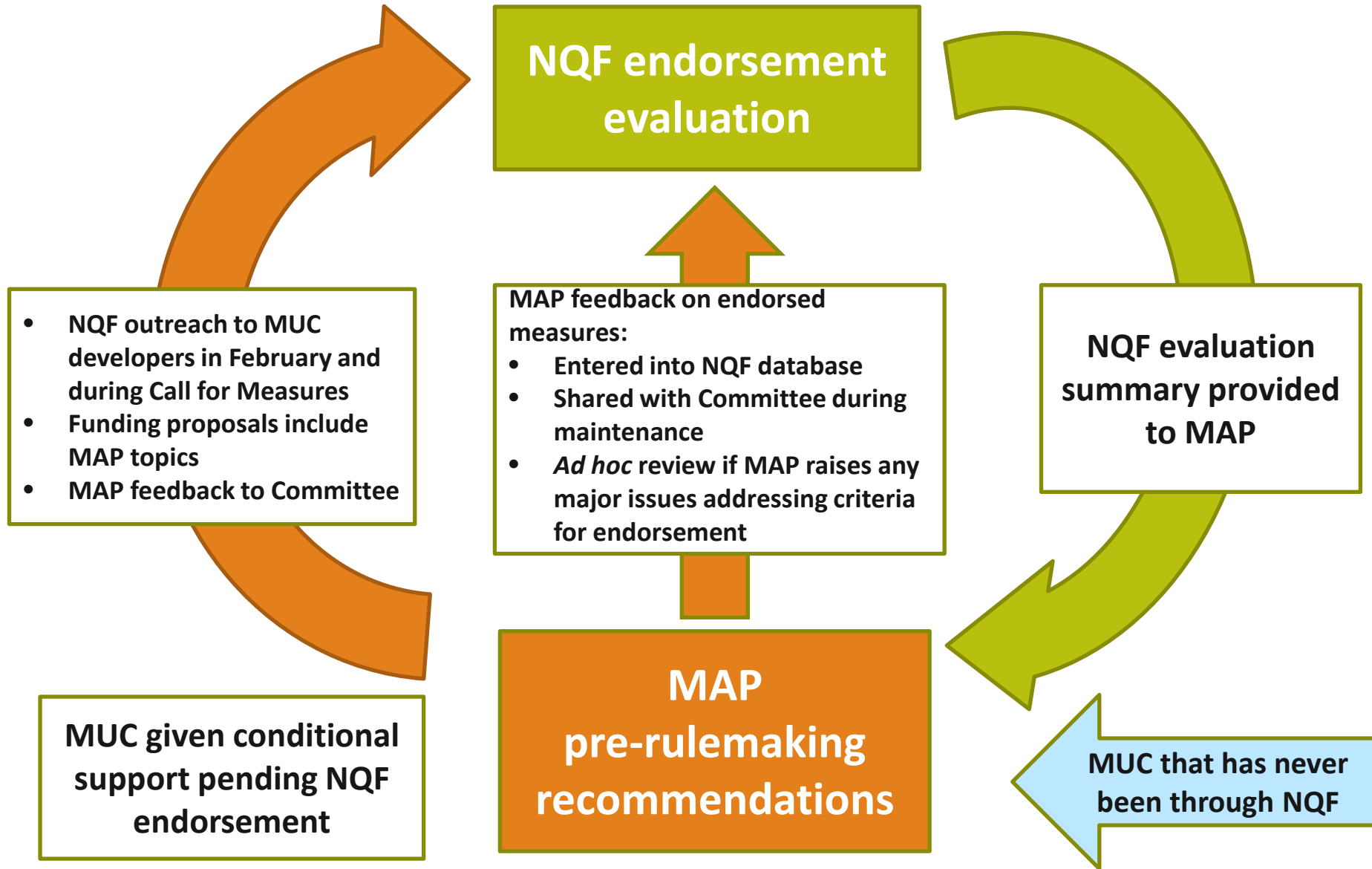
- Call for nominations for Standing Committee
- Call for candidate standards (measures)
- Candidate consensus standards review
- Public and member comment
- NQF member voting
- Consensus Standards Approval Committee (CSAC) decision
- Board Ratification
- Appeals



# Measure Application Partnership (MAP)

- Provides input to HHS during pre-rulemaking on the selection of performance measures for use in public reporting, performance-based payment, and other federal programs
- Identifies gaps for measure development, testing, and endorsement
- Encourages measurement alignment across public and private programs, settings, levels of analysis, and populations to promote coordination of care delivery and reduce data collection burden

# CDP-MAP INTEGRATION – INFORMATION FLOW



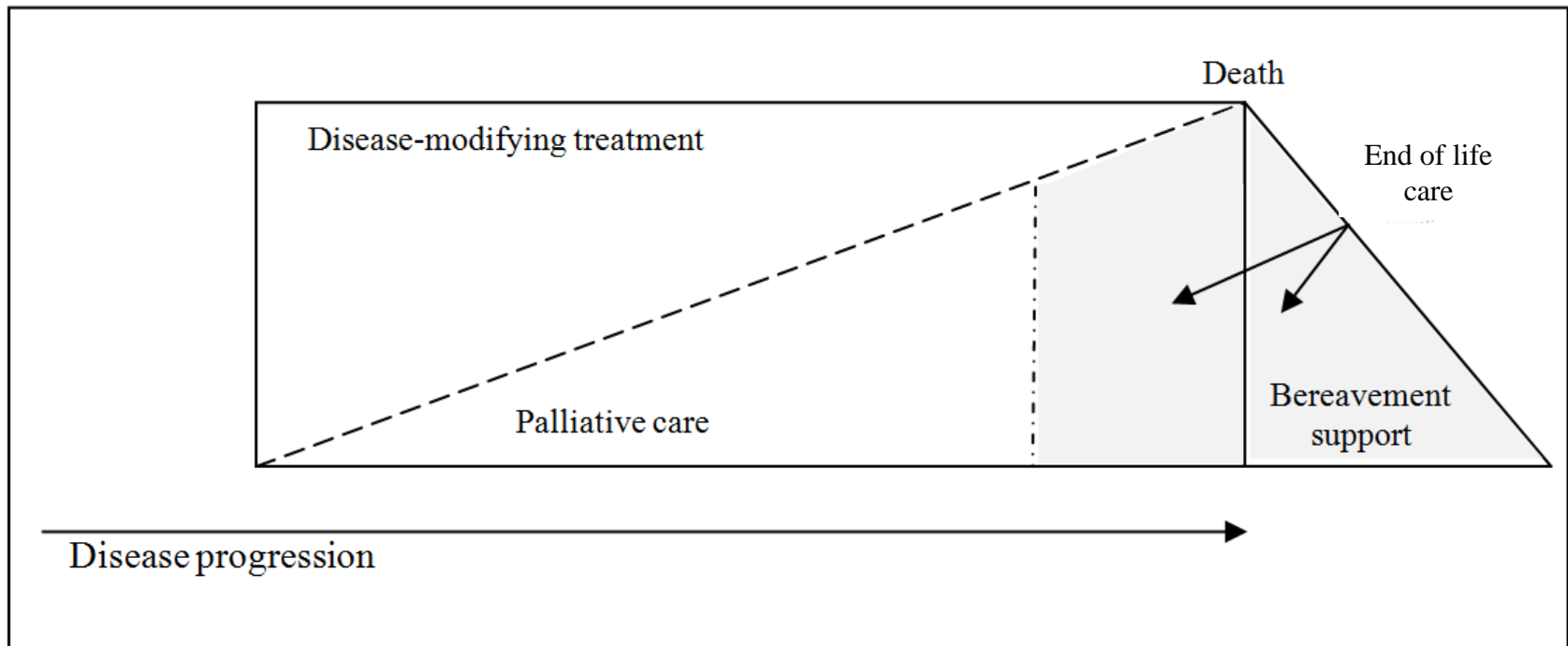
# Palliative and End-of-Life Care Project

- This project will evaluate measures related to Palliative and End-of-Life Care that can be used for accountability and public reporting for all populations and in all settings of care. This project will address topic areas including:
  - Assessment and management of physical, psychological, and spiritual aspects of care
  - Care planning
  - Appropriateness of care
- NQF solicits new measures for possible endorsement
- NQF currently has 35 endorsed measures within the area of Palliative and End-of-Life Care. Endorsed measures undergo periodic evaluation to maintain endorsement – “maintenance”.

# Previous NQF Work in Palliative and End-of-Life Care

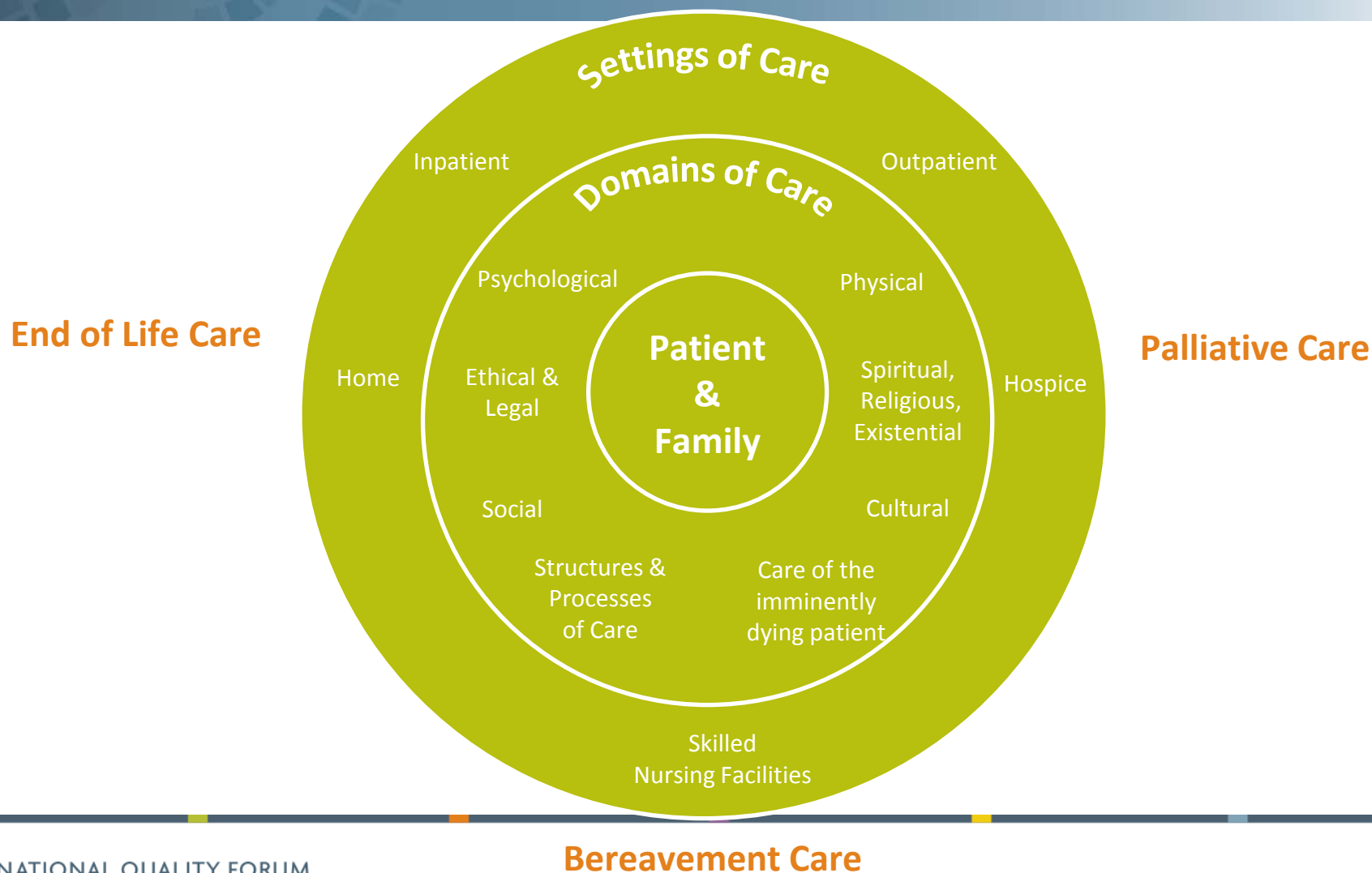
- Measurement Framework and Preferred Practices (2006)
  - Scope; structural elements; domains of care; levels of measurement; outcomes
  - 38 preferred practices, organized by domain and IOM dimensions of care
- Endorsement: Palliative care and End-of-Life Care (2012)
  - 14 measures endorsed
- MAP PAC/LTC workgroup: Performance Measurement Coordination Strategy (2012)

# Continuum of Care – Palliative and End-of-Life Care



*Adapted from NQF, 2006*

# Draft Measurement Framework



# Palliative and End-of-Life Care Portfolio of NQF-Endorsed Measures

- Physical aspects of care (n=14)
  - Pain (n=11)
  - Dyspnea (n=2)
  - Constipation (n=1)
- Experience of care (n=7)
  - CAHPS survey measures
  - Bereaved Family Survey

# Palliative and End-of-Life Care Portfolio of NQF-Endorsed Measures

- Care of the imminently dying patient (n=6)
  - Appropriateness of care
- Ethical and legal aspects of care (n=3)
  - Care planning
- Psychological and psychiatric aspects of care (n=2)
  - Health-related quality of life
- Cultural aspects of care (n=2)
- Spiritual, religious, and existential aspects of care (n=1)



# Measures Under Evaluation in this Project

## Physical aspects of care

- 1617: Patients Treated with an Opioid who are Given a Bowel Regimen
- 1634: Hospice and Palliative Care -- Pain Screening
- 1637: Hospice and Palliative Care -- Pain Assessment
- 1628: Patients with Advanced Cancer Screened for Pain at Outpatient Visits
- 0209: Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment
- 1638: Hospice and Palliative Care -- Dyspnea Treatment
- 1639: Hospice and Palliative Care -- Dyspnea Screening

# Measures Under Evaluation in this Project

## Care of the imminently dying patient

- 0210 : Proportion of patients who died from cancer receiving chemotherapy in the last 14 days of life
- 0211 : Proportion of patients who died from cancer with more than one emergency department visit in the last 30 days of life
- 0213 : Proportion of patients who died from cancer admitted to the ICU in the last 30 days of life
- 0216 : Proportion of patients who died from cancer admitted to hospice for less than 3 days
- 0215 : Proportion of patients who died from cancer not admitted to hospice
- 1625 : Hospitalized Patients Who Die an Expected Death with an ICD that Has Been Deactivated

# Measures Under Evaluation in this Project

## **Ethical and legal aspects of care**

- 1626: Patients Admitted to ICU who Have Care Preferences Documented
- 1641: Hospice and Palliative Care – Treatment Preferences

## Spiritual, religious, and existential aspects of care

- 1647: Beliefs and Values - Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss

# Measures Under Evaluation in this Project

## **Experience of Care: 8 measures from the Hospice CAHPS survey**

- Hospice Team Communication
- Getting Timely Care
- Treating Family Member with Respect
- Getting Emotional and Religious Support
- Getting Help for Symptoms
- Getting Hospice Training
- Rating of the hospice care
- Willingness to recommend the hospice

# Activities and Timeline

\*All times ET

Meeting	Date/Time
Orientation Call	April 5, 2016, 3:00-5:00 PM
Measure Evaluation Q & A Calls	April 13, 2015 12:00-2:00 PM
Workgroup Calls <i>(you will be assigned to one of these calls)</i>	Workgroup 1: April 21, 2016 3:00-5:00 PM Workgroup 2: April 27, 2016 12:00-2:00 PM Workgroup 3: April 28, 2016 3:00-5:00 PM Workgroup 4: April 29, 2016 3:00-5:00 PM
In-Person Meeting (2 days in Washington, D.C.)	May 10-11, 2016
Post-Meeting Conference Call	May 20, 2016 3:00-5:00 PM
Post Draft Report Comment Call	August 3, 2016 3:00-5:00 PM

# Role of the Standing Committee

## *General Duties*

- Act as a proxy for the NQF multi-stakeholder membership
- Serve 2-year or 3-year terms
- Work with NQF staff to achieve the goals of the project
- Evaluate candidate measures against the measure evaluation criteria
- Respond to comments submitted during the review period
- Respond to any directions from the CSAC

# Role of the Standing Committee

## *Measure Evaluation Duties*

- All members review ALL measures
- Evaluate measures against each criterion
  - Indicate the extent to which each criterion is met and rationale for the rating
- Make recommendations to the NQF membership for endorsement
- Oversee Palliative and End-of-Life Care portfolio of measures
  - Promote alignment and harmonization
  - Identify gaps

# Role of the Standing Committee Co-Chairs

- Co-facilitate Standing Committee (SC) meetings
- Work with NQF staff to achieve the goals of the project
- Assist NQF in anticipating questions and identifying additional information that may be useful to the SC
- Keep SC on track to meet goals of the project without hindering critical discussion/input
- Represent the SC at CSAC meetings
- Participate as a SC member



# Role of NQF Staff

- **NQF project staff works with SC to achieve the goals of the project and ensure adherence to the consensus development process:**
  - Organize and staff SC meetings and conference calls
  - Guide the SC through the steps of the CDP and advise on NQF policy and procedures
  - Review measure submissions and prepare materials for Committee review
  - Draft and edit reports for SC review
  - Ensure communication among all project participants (including SC and measure developers)
  - Facilitate necessary communication and collaboration between different NQF projects

# Role of NQF Staff

## *Communication*

- Respond to NQF member or public queries about the project
- Maintain documentation of project activities
- Post project information to NQF website
- Work with measure developers to provide necessary information and communication for the SC to fairly and adequately evaluate measures for endorsement
- Publish final project report



# Measure Evaluation Criteria Overview

# NQF Measure Evaluation Criteria for Endorsement

**NQF endorses measures for accountability applications (public reporting, payment programs, accreditation, etc.) as well as quality improvement.**

- Standardized evaluation criteria
- Criteria have evolved over time in response to stakeholder feedback
- The quality measurement enterprise is constantly growing and evolving – greater experience, lessons learned, expanding demands for measures – the criteria evolve to reflect the ongoing needs of stakeholders

# Major Endorsement Criteria

## *Hierarchy and Rationale (page 29)*

- **Importance to measure and report:** Goal is to measure those aspects with greatest potential of driving improvements; if not important, the other criteria are less meaningful (***must-pass***)
- **Reliability and Validity-scientific acceptability of measure properties :** Goal is to make valid conclusions about quality; if not reliable and valid, there is risk of improper interpretation (***must-pass***)
- **Feasibility:** Goal is to, ideally, cause as little burden as possible; if not feasible, consider alternative approaches
- **Usability and Use:** Goal is to use for decisions related to accountability and improvement; if not useful, probably do not care if feasible
- Comparison to related or competing measures

# Criterion #1: Importance to Measure and Report (page 32-39)

1. **Importance to measure and report** - Extent to which the specific measure focus is evidence-based, important to making significant gains in healthcare quality, and improving health outcomes for a specific high-priority (high-impact) aspect of healthcare where there is variation in or overall less-than-optimal performance.

**1a. Evidence:** the measure focus is evidence-based

**1b. Opportunity for Improvement:** demonstration of quality problems and opportunity for improvement, i.e., data demonstrating considerable variation, or overall less-than-optimal performance, in the quality of care across providers; and/or disparities in care across population groups (pages 41-42)

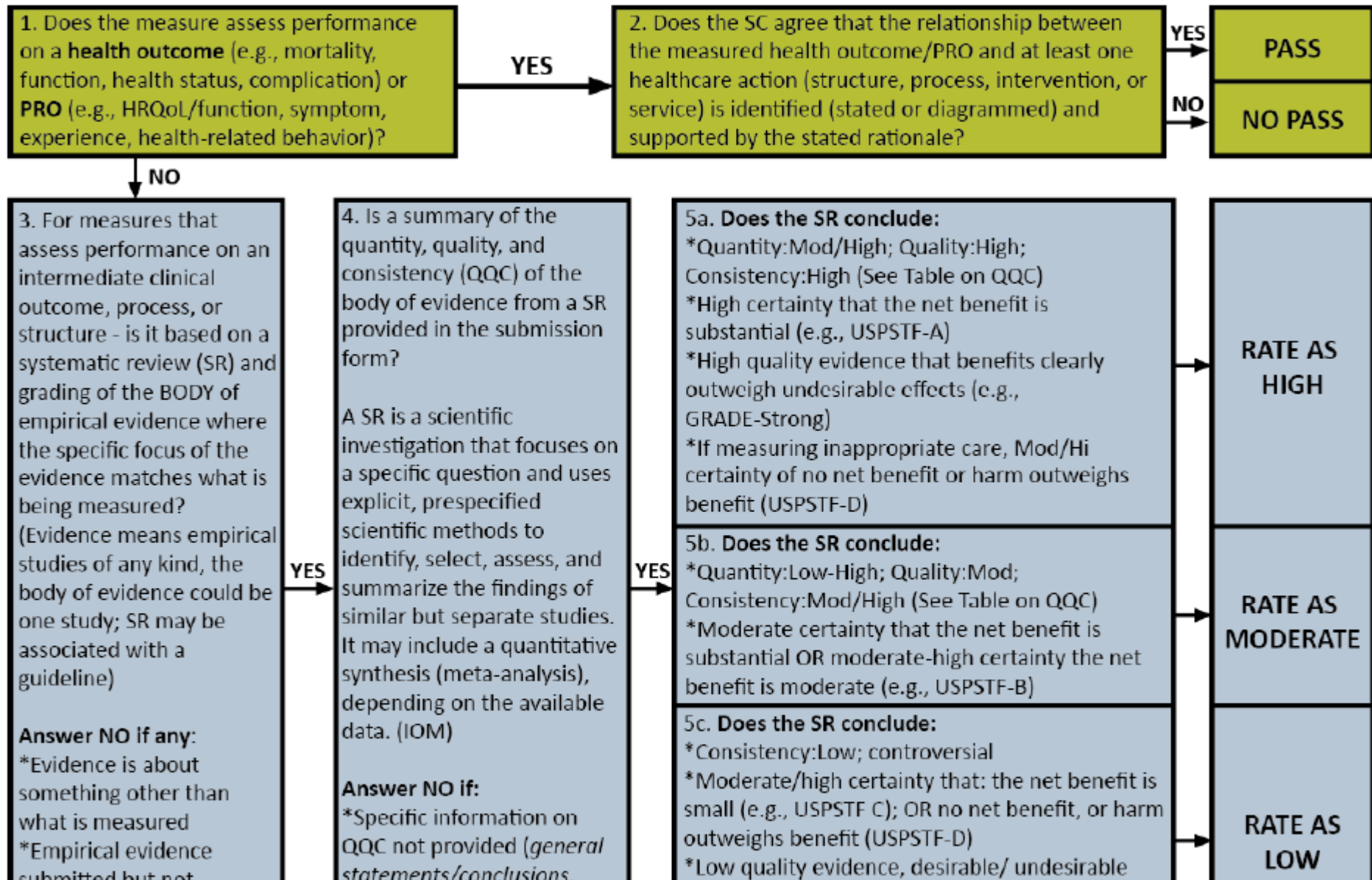
**1c. Quality construct and rationale** (composite measures only)

# Subcriterion 1a: Evidence (page 33-37)

- Outcome measures
  - A rationale (which often includes evidence) for how the outcome is influenced by healthcare processes or structures.
- Process, intermediate outcome measures
  - the quantity, quality, and consistency of the body of evidence underlying the measure should demonstrate that the measure focuses on those aspects of care known to influence desired patient outcomes
    - » Empiric studies (expert opinion is not evidence)
    - » Systematic review and grading of evidence
      - *Clinical Practice Guidelines – variable in approach to evidence review*

# Rating Evidence: Algorithm #1 – page 35

## Algorithm #1. Guidance for Evaluating the Clinical Evidence





# Criterion #1: Importance to measure and report

Criteria emphasis is different for new vs maintenance measures

New measures	Maintenance measures
<ul style="list-style-type: none"><li>• Evidence – Quantity, quality, consistency (QQC)</li><li>• Established link for process measures with outcomes</li></ul>	<p><b>DECREASED EMPHASIS:</b> Require measure developer to attest evidence is unchanged evidence from last evaluation; Standing Committee to affirm no change in evidence</p> <p>IF changes in evidence, the Committee will evaluate as for new measures</p>
<ul style="list-style-type: none"><li>• Gap – opportunity for improvement, variation, quality of care across providers</li></ul>	<p><b>INCREASED EMPHASIS:</b> data on current performance, gap in care and variation</p>

# Criterion #2: Reliability and Validity– Scientific Acceptability of Measure Properties (page 40-50)

Extent to which the measure, as specified, produces consistent (reliable) and credible (valid) results about the quality of health care delivery

## 2a. Reliability (must-pass)

2a1. Precise specifications including exclusions

2a2. Reliability testing—data elements or measure score

## 2b. Validity (must-pass)

2b1. Specifications consistent with evidence

2b2. Validity testing—data elements or measure score

2b3. Justification of exclusions—relates to evidence

2b4. Risk adjustment—typically for outcome/cost/resource use

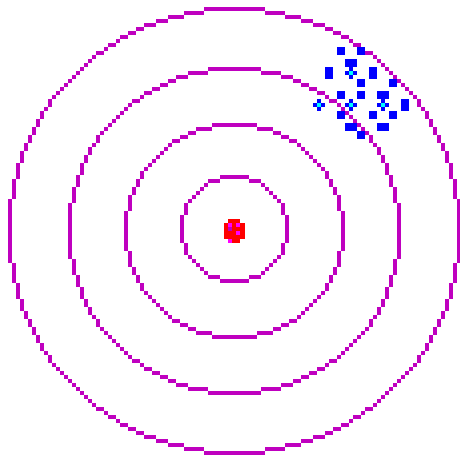
2b5. Identification of differences in performance

2b6. Comparability of data sources/methods

2b7. Missing data

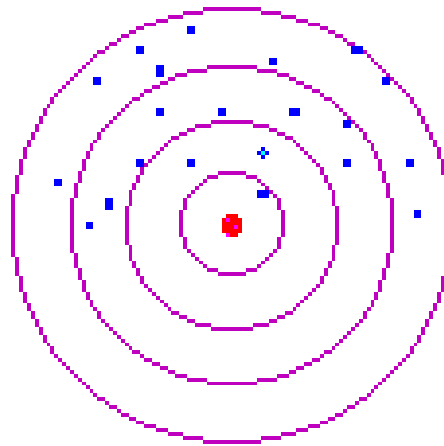
# Reliability and Validity (page 41)

Assume the center of the target is the true score...



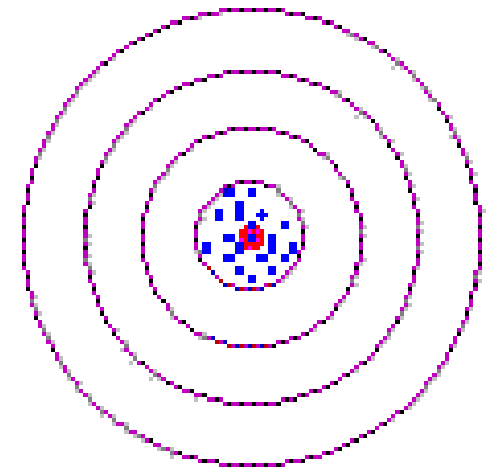
**Reliable  
Not Valid**

Consistent,  
but wrong



**Neither Reliable  
Nor Valid**

Inconsistent &  
wrong



**Both Reliable  
And Valid**

Consistent &  
correct

# Measure Testing – Key Points (page 41)

**Empirical analysis** to demonstrate the reliability and validity of the *measure as specified*, including analysis of issues that pose threats to the validity of conclusions about quality of care such as exclusions, risk adjustment/stratification for outcome and resource use measures, methods to identify differences in performance, and comparability of data sources/methods.

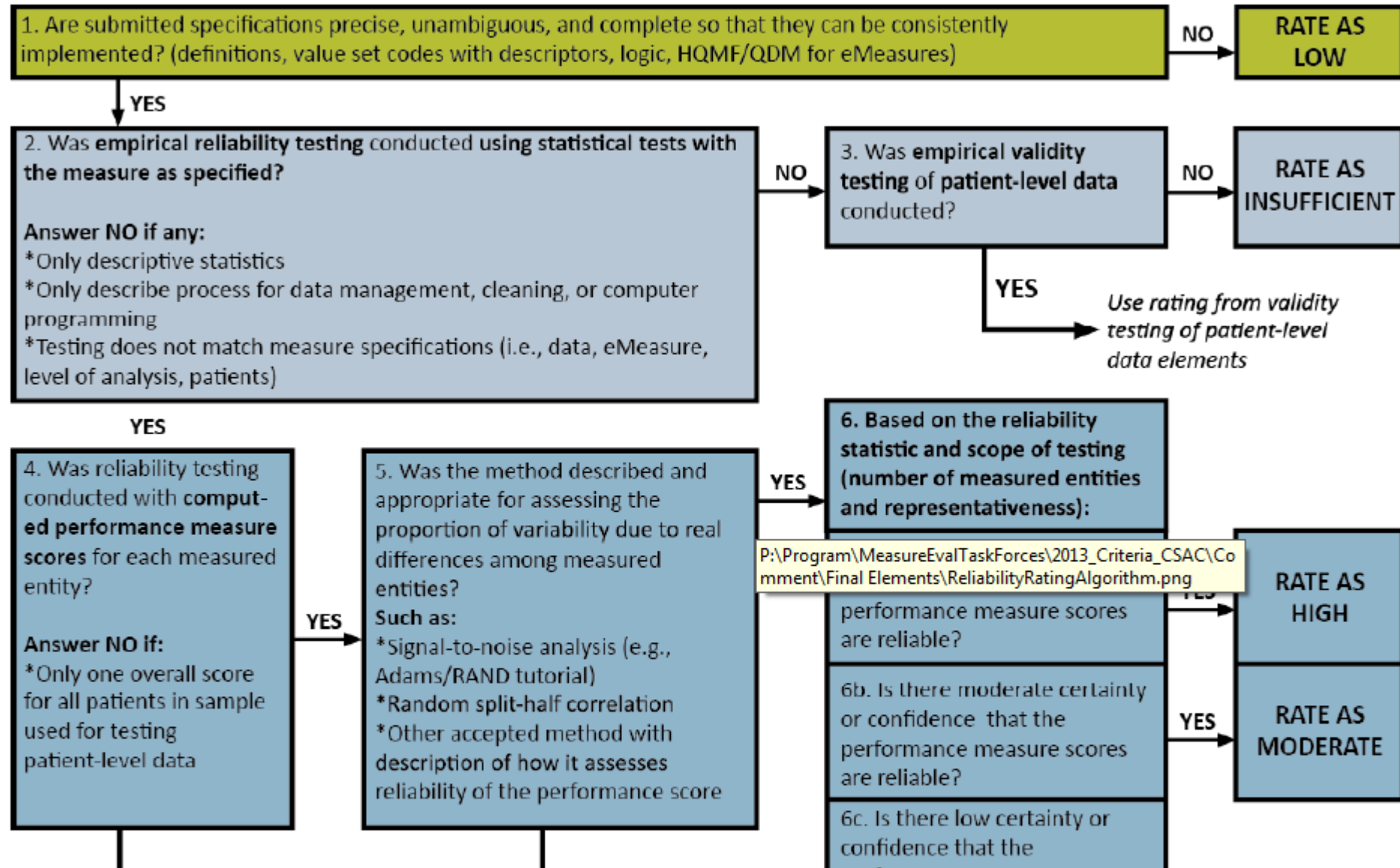
# Reliability Testing (page 42)

## Key points - page 43

- Reliability of the **measure score** refers to the proportion of variation in the performance scores due to systematic differences across the measured entities in relation to random variation or noise (i.e., the precision of the measure).
  - Example - Statistical analysis of sources of variation in performance measure scores (signal-to-noise analysis)
- Reliability of the **data elements** refers to the repeatability/reproducibility of the data and uses patient-level data
  - Example –inter-rater reliability
- Consider whether testing used an appropriate method and included adequate representation of providers and patients and whether results are within acceptable norms
- Algorithm #2 – page 44

# Rating Reliability: Algorithm #2 – page 44

## Algorithm #2. Guidance for Evaluating Reliability



# Validity testing (pages 45-49)

## Key points – page 48

### ■ Empirical testing

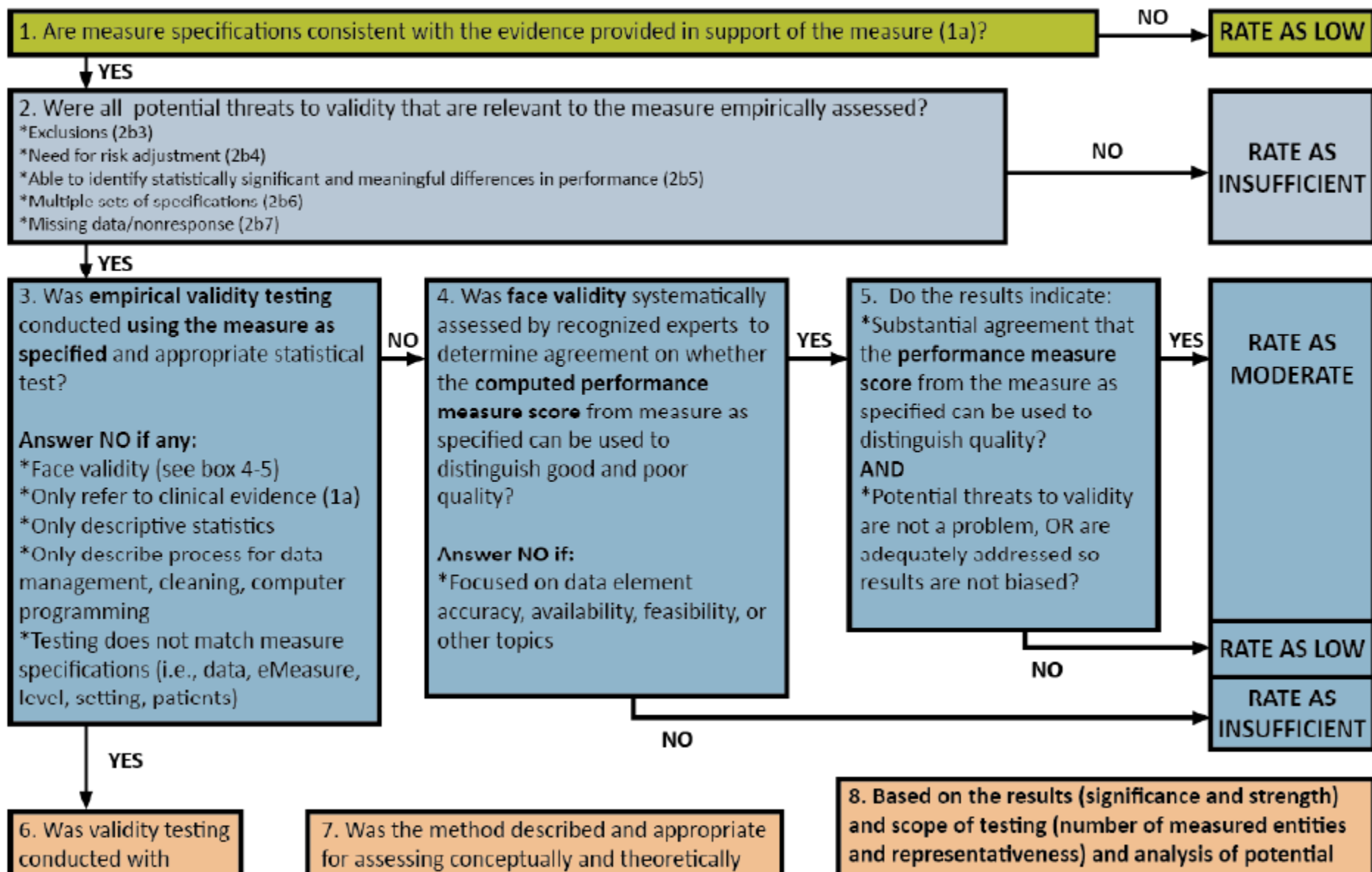
- *Measure score* – assesses a hypothesized relationship of the measure results to some other concept; assesses the correctness of conclusions about quality
- *Data element* – assesses the correctness of the data elements compared to a “gold standard”

### ■ Face validity

- Subjective determination by experts that the measure appears to reflect quality of care

# Rating Validity: Algorithm #3 – page 49

## Algorithm #3. Guidance for Evaluating Validity





# Threats to Validity

- Conceptual
  - Measure focus is not a relevant outcome of healthcare or not strongly linked to a relevant outcome
- Unreliability
  - Generally, an unreliable measure cannot be valid
- Patients inappropriately excluded from measurement
- Differences in patient mix for outcome and resource use measures
- Measure scores that are generated with multiple data sources/methods
- Systematic missing or “incorrect” data (unintentional or intentional)

# Criterion #2: Scientific Acceptability

New measures	Maintenance measures
<ul style="list-style-type: none"><li>• Measure specifications are precise with all information needed to implement the measure</li></ul>	NO DIFFERENCE: Require updated specifications
<ul style="list-style-type: none"><li>• Reliability</li><li>• Validity (including risk-adjustment)</li></ul>	<p><b>DECREASED EMPHASIS:</b> If prior testing adequate, no need for additional testing at maintenance with certain exceptions (e.g., change in data source, level of analysis, or setting)</p> <p>Must address the questions for SDS Trial Period</p>

# **Criterion #3: Feasibility (page 50)**

## **Key Points – page 51**

Extent to which the required data are readily available, retrievable without undue burden, and can be implemented for performance measurement.

**3a: Clinical data generated during care process**

**3b: Electronic sources**

**3c: Data collection strategy can be implemented**

# Criterion #4: Usability and Use (page 51)

## Key Points – page 52

Extent to which potential audiences (e.g., consumers, purchasers, providers, policymakers) are using or could use performance results for both accountability and performance improvement to achieve the goal of high-quality, efficient healthcare for individuals or populations.

**4a: Accountability and Transparency:** Performance results are used in at least one accountability application within three years after initial endorsement and are publicly reported within six years after initial endorsement

**4b: Improvement:** Progress toward achieving the goal of high-quality, efficient healthcare for individuals or populations is demonstrated

**4c: Benefits outweigh the harms:** The benefits of the performance measure in facilitating progress toward achieving high-quality, efficient healthcare for individuals or populations outweigh evidence of unintended negative consequences to individuals or populations (if such evidence exists).

# Criteria #3-4: Feasibility and Usability and Use

New measures	Maintenance measures
Feasibility	
<ul style="list-style-type: none"><li>Measure feasible, including eMeasure feasibility assessment</li></ul>	NO DIFFERENCE: Implementation issues may be more prominent
Usability and Use	
<ul style="list-style-type: none"><li>Use: used in accountability applications and public reporting</li></ul>	<b>INCREASED EMPHASIS:</b> Much greater focus on measure use and usefulness, including both impact and unintended consequences
<ul style="list-style-type: none"><li>Usability: impact and unintended consequences</li></ul>	

# Criterion #5: Related or Competing Measures (page 52-53)

If a measure meets the four criteria and there are endorsed/new **related** measures (same measure focus or same target population) or **competing** measures (both the same measure focus and same target population), the measures are compared to address harmonization and/or selection of the best measure.

- 5a. The measure specifications are harmonized with related measures **OR** the differences in specifications are justified.
- 5b. The measure is superior to competing measures (e.g., is a more valid or efficient way to measure) **OR** multiple measures are justified.

# Evaluation process

- **Preliminary analysis:** To assist the Committee evaluation of each measure against the criteria, NQF staff will prepare a preliminary analysis of the measure submission.
  - This will be used as a starting point for the Committee discussion and evaluation
- **Individual evaluation assignments:** Each Committee member will be assigned a subset of measures for in-depth evaluation.
  - Those who are assigned measures will lead the discussion of their measures with the entire Committee

# Evaluation process (continued)

- **Workgroup calls for new Committees:** To assist Committee members with their first evaluations, Committee members and measures will be divided into groups for preliminary calls to discuss measures and share initial thoughts.
  - Ensures initial familiarity with measures
  - Allows “practice” with NQF criteria and processes
  - Gives early feedback to developers of Committee questions or concerns
- **Measure evaluation and recommendations at the in-person meeting:** The entire Committee will discuss and rate each measure against the criteria and make recommendations for endorsement.



# Questions?



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# SDS Trial Period Overview

# Background

- During a **two-year trial period**, adjustment of measures for socio-demographic (SDS) factors **will no longer be prohibited**
- Each measure must be assessed individually to determine if SDS adjustment is appropriate
- The Standing Committee will continue to evaluate the measure as a whole, including the appropriateness of the risk adjustment approach used by the measure developer
- Efforts to implement SDS adjustment may be constrained by data limitations and data collection burden

# Standing Committee Evaluation

- The Standing Committee will be asked to consider the following questions:
  - Is there a conceptual relationship between the SDS factor and the measure focus?
  - What are the patient-level sociodemographic variables that were available and analyzed during measure development?
  - Does empirical analysis (as provided by the measure developer) show that the SDS factor has a significant and unique effect on the outcome in question?
  - Does the reliability and validity testing match the final measure specifications?

# Questions?



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# SharePoint Overview

<http://share.qualityforum.org/Projects/Palliative%20and%20End%20of%20Life%20CareSitePages/Home.aspx>

- Accessing SharePoint
- Standing Committee Policy
- Standing Committee Guidebook
- Measure Document Sets
- Meeting and Call Documents
- Committee Roster and Biographies
- Calendar of Meetings

# SharePoint Overview


Please keep in mind:

- + and – signs :

## Measure Documents

 Measure Number	Name
--	------


 <b>Measure Sub-Topic : (1)</b>
--

 Add document


## Meeting and Call Documents

 Type	Name
--	------

 <b>Meeting Title : 1/30/2014 Orientation Call (1)</b>
---

 Add document

## Measure Documents


 Measure Number	Name	Description
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 <b>Measure Sub-Topic : (1)</b>
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0521
------

Heart Failure Symptoms Assessed and Addressed
---

Percentage of home health episodes heart failure were assessed for sym appropriate actions were taken whe heart failure.
--

 Add document


## Meeting and Call Documents

 Type	Name
---	------

 <b>Meeting Title : 1/30/2014 Orientation Call (1)</b>
---



NQF Cardiovascular Project Orientation Agenda 
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 Add document

# Measure Worksheet and Measure Information

- Measure Worksheet
  - Preliminary analysis, including eMeasure Technical Review if needed
  - Pre-evaluation comments
  - Public comments
  - Information submitted by the developer
    - » Measure specifications
    - » Items related to Gap, Feasibility, and Usability & Use
    - » Evidence and testing attachments



# Next Steps

- Measure Evaluation Q&A Call
  - April 13, 2016, 12:00-2:00 PM
- Work Group calls
  - Workgroup 1: April 21, 2016 3:00-5:00 PM
  - Workgroup 2: April 27, 2016 12:00-2:00 PM
  - Workgroup 3: April 28, 2016 3:00-5:00 PM
  - Workgroup 4: April 29, 2016 3:00-5:00 PM
- In-Person Meeting
  - May 10-11, 2016

# Project Contact Info

- Email: [palliative@qualityforum.org](mailto:palliative@qualityforum.org)
- NQF Phone: 202-783-1300
- Project page:  
[http://www.qualityforum.org/Palliative and End-of-Life Care Project 2015-2016.aspx](http://www.qualityforum.org/Palliative_and_End-of-Life_Care_Project_2015-2016.aspx)
- SharePoint site:  
<http://share.qualityforum.org/Projects/Palliative%20and%20End%20of%20Life%20CareSitePages/Home.aspx>

# Questions?



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