TO: Person-Centered Cared and Outcomes Advisors
FR: Karen Pace and Mitra Ghazinour
DA: 10/15/13
SU: Person-Centered Care and Outcomes Planning Call on 10/22 (or alternate date as scheduled)

The purpose of our upcoming call is to:

- Provide an overview of the project;
- Obtain suggestions for focusing the scope of this project to accomplish the objective of recommending specific performance measures that address person-centered care and outcomes for implementation or development; and
- Discuss implications for conceptual framework and environmental scan.

Action Needed:

- Review this briefing memo
- Be prepared to discuss the key questions and make suggestions
- Participate on the conference call

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Background

Person-centered care has been identified as a key element to achieving a safer, more effective and efficient healthcare system, as well as being essential to the core principles of respect and autonomy. Numerous reports have identified the lack of performance measures to monitor the provision of patient-centered care and progress on improvement, and recent reports on gaps in performance

measures have identified the need for more specific recommendations on what to measure and how to measure performance on patient-centered care.

Definitions

Generally for this project, we will use the term ***person-centered*** to encompass persons receiving healthcare or supportive services; their families and support systems may be included. The term ***patient-centered*** may be used interchangeably.

NQF endorses ***performance measures*** defined as a numeric quantification of heatlhcare quality for a designated accountable healthcare entity, such as hospital, health plan, nursing home, clinician, etc.

Project Purpose and Timeline

The objective of this project is to develop targeted recommendations to advance the area of measurement of person- and family-centered care, shared decisionmaking, and person-centered communication, and to address gaps in performance measures of person- and family-centered care, shared decisionmaking and person-centered communication. The scope of this project will be based in part on the discussion questions laid out on page 5 below.

Specific tasks include:

- identify and use a conceptual framework
- conduct environmental scan of relevant measures and measure concepts
- analyze measure gaps
- obtain key stakeholder (committee) recommendations for measurement
- utilize NQF process for multistakeholder input and of public comment

This HHS-funded project will build on and/or inform two other HHS initiatives to the extent possible:

- A memorandum of understanding between HHS and the National Health Service (NHS) in England to align around common patient centered outcome measures
- Office of the National Coordinator 's certification of EHRs

The project is to be completed over 11 months.

Activities	Dates
Finalize Person-Centered Care and Outcomes Committee	12/15/2013
Committee web meeting: Feedback on draft framework	1/30/2014
In-person Committee (2-day) meeting: Develop multistakeholder recommendations to address priorities for measure development, endorsement, and research	4/7-8/2014
Public comment period (3 weeks)	July 2014
Public webinar: Feedback on report recommendations	July 2014
Deliverable: Final Committee Report	**8/15/2014**

Conceptual Basis

Definition and Core Concepts

There is much consensus and overlap among the various conceptualizations of person-centered care. The Institute for Patient and Family Centered Care provides a definition and identifies core concepts that are consistent with the various conceptualizations.

> *Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.*
>
> *The core concepts include:*
> ***Respect and dignity.*** *Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.*
>
> ***Information Sharing.*** *Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.*
>
> ***Participation.*** *Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.*
>
> ***Collaboration.*** *Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.*

Across Time and Conditions

An aspect of person-centered care not mentioned above is that care is not constrained to particular settings or providers of care or restricted to one condition. These are key tenets of the episode of care and multiple chronic conditions frameworks. Patients' experiences of care span settings and clinicians, and patients often have multiple conditions simultaneously. These frameworks are provided in the appendix.

Focused on Outcomes of Interest to Persons Receiving Services

Implied in the concept of person-centered care is attention to outcomes that are valued by and meaningful to persons receiving services. Often these outcomes are directly reported by the persons who receive the services rather than by clinicians and are referred to as patient-reported outcomes (PROs), which are discussed in the next section.

Performance Measurement of Person-Centered Care

In terms of performance measurement, the patient and family generally will be the best source of information on patient-centered care. NQF's 2012 project on Patient-Reported Outcomes (PROs) in Performance Measurement, identified the domains of PROs as: health-related quality of life/functional

status, symptom/symptom burden, experience with care (including shared decisionmaking and engagement), and health-related behaviors. PROs were viewed not only as a way to measure quality of care, but also an important avenue to engage patients and health professionals in creating a person-centered health system. Therefore, patient-reported outcomes (PROs) will be the primary basis for performance measurement related to patient- and family-centered care (see Appendix). However, other outcomes are of great interest to patients but do not required patient report (e.g., mortality, readmission). Measures of structures and processes also could be useful if there are well-defined, evidence-based structures and processes that are essential to patient- and family-centered care.

Some of the reasons it has been difficult to make specific recommendations for performance measures include the following.

- There are 1000s of instruments to measure patient-reported outcomes with very little use in clinical practice. Often there are multiple instruments on the same topic with lack of consensus on which ones to use.
- As identified in the PRO project, very few PRO-based performance measures have been developed to date and require substantial methodological expertise to develop.
- Person-centered care encompasses abstract concepts (e.g., respect, shared decision-making, patient preferences identified and incorporated) and applies to all aspects of healthcare and clinical conditions (hospital care, home care, CHF, joint replacement).
- In some cases, multiple strategies have been identified to accomplish the same goals (e.g., for family involvement – open visiting hours, facility design, include in case conferences, etc.) and performance measures could unnecessarily limit or direct provider efforts and innovation.

There are a few examples in the US in which PROs have been implemented for performance measurement (Consumer Assessment of Healthcare Providers and Systems (CAHPS); functional status from health outcome survey (HOS) for Medicare managed care; MN Community Measurement-depression remission). England's NHS uses PROs for performance measurement in four surgical procedures - hip or knee replacements, varicose vein surgery, or groin hernia surgery (see NHS Choices web site).

Potential Approaches to Focus this Project

Person-centered care and outcomes is a broad topic and to get to the desired level of specificity for recommendations to facilitate performance measurement, the project must be adequately and appropriately focused. Although it is important to not prematurely narrow the scope, we ask the advisory group to help us identify what can be accomplished to advance this area of performance measurement within the parameters of this project.

Following are some potential approaches to stimulate thinking and begin the discussion. These are not considered to be the only options – there may be other approaches or some combination that should be considered.

Key Questions

- What are the pros and cons to consider for each approach listed below?
- What other approaches or combinations should NQF consider when focusing this project?

1. Conduct an in-depth analysis of the NHS PRO-based performance measurement system and make recommendations for implementation in the US (the PRO pathway framework can be used to guide an analysis as illustrated in the Appendix – click here)

PROs

- Allows an in-depth analysis that can identify how their success with specific instruments, performance measures, and reporting results could be implemented or modified for the US.
- Other?

CONs

- Currently focused on four surgical procedures (hip and knee replacement, inguinal hernia repair, and varicose veins), which may not be seen as a priority in the US.
- Other?

2. Conduct an in-depth analysis of US examples of using PROs (CAHPS, HOS, MN Community measurement) and make recommendations of how their use could be expanded (e.g., use HOS for other groups and specific types of conditions such as hip replacement, CHF; add components to CAHPS for additional aspects of patient-centered care such as engagement).

PROs

- Uses successful examples that have already implemented specific instruments, performance measures, and reporting components
- Other?

CONs

- These specific topics may not be seen as a priority for expansion.
- Other?

3. Identify most important areas for performance measure development beginning with input from the persons receiving services and then identifying outcomes responsive to healthcare interventions as laid out in the pathway for developing PRO-based performance measures provided in the Appendix.

PROs

- Seeks input directly from patients as the authoritative source about what is meaningful to and valued by them.
- Other?

CONs

- This does not resolve the issue of the great number of potential topics (e.g., types of conditions) and the scope would still need to be narrowed in order to target the right patients to provide input. One modification might be reaching consensus on a particular domain of PROs (HRQoL/functional status, symptom/symptom burden, experience with care including engagement, shared decisionmaking; health-related behaviors) and then proceeding to identify what should be measured. However, some domains such as HRQoL/functional status also could still be quite broad, especially if focused on specific conditions.
- Other?

4. Identify if there are PRO instruments/scales [PROM] with substantial use in clinical practice, indicating readiness to develop performance measures and/or conduct an in-depth analysis of PROMIS and how to move to implementation and performance measurement.

PROs

- If an instrument to measure a PRO {PROM} is already in use, then the data are available to begin developing and testing a performance measure.
- Other?

CONs

- May be difficult to obtain this information – the literature typically includes studies about the development and testing of PROMs, but not necessarily about ongoing use in practice.
- Other?

5. Other Suggestions?

PROs

-

CONs

Key Questions

Given the advisory group's discussion and suggestions:

- Are the conceptual frameworks presented in the Appendix appropriate for this project?
- What other approaches may be more effective for an environmental scan than literature search?

Appendix

Person-centered Care and Outcomes – Relevant Frameworks

Patient-Reported Outcomes and Performance Measurement

	Definition	Example: Patients With Clinical Depression	Persons with Intellectual or Developmental Disabilities
PRO (patient-reported outcome)*	The concept of any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.	Symptom: depression	Functional Status-Role: employment
PROM (instrument, tool, single-item measure)	Instrument, scale, or single-item measure used to assess the PRO concept as perceived by the patient, obtained by directly asking the patient to self-report (e.g., PHQ-9).	PHQ-9©, a standardized tool to assess depression	Single-item measure on National Core Indicators Consumer Survey: *Do you have a job in the community?*
PRO-PM (PRO-based performance measure)	A performance measure that is based on PROM data aggregated for an accountable healthcare entity (e.g., percentage of patients in an accountable care organization whose depression score as measured by the PHQ-9 improved).	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)	The proportion of people with intellectual or developmental disabilities who have a job in the community

***PRO Domains**

- Health-related Quality of Life (HRQOL) including functional status
- Symptom/Symptom burden
- Experience with Care (including patient engagement, shared decisionmaking, communication)
- Health-related Behaviors (e.g., smoking, diet)

Pathway from PRO to NQF-Endorsed PRO-PM

The pathway displayed in Figure 2, and described in detail below lays out the critical steps in developing a PRO-based performance measure suitable for endorsement by NQF and generating the evidence that it meets NQF criteria for endorsement. It begins with the conceptual basis for identifying a PRO for performance measurement; the pathway then proceeds through selecting a PROM and developing and testing a performance measure to achieving NQF endorsement of a PRO-PM and using the performance

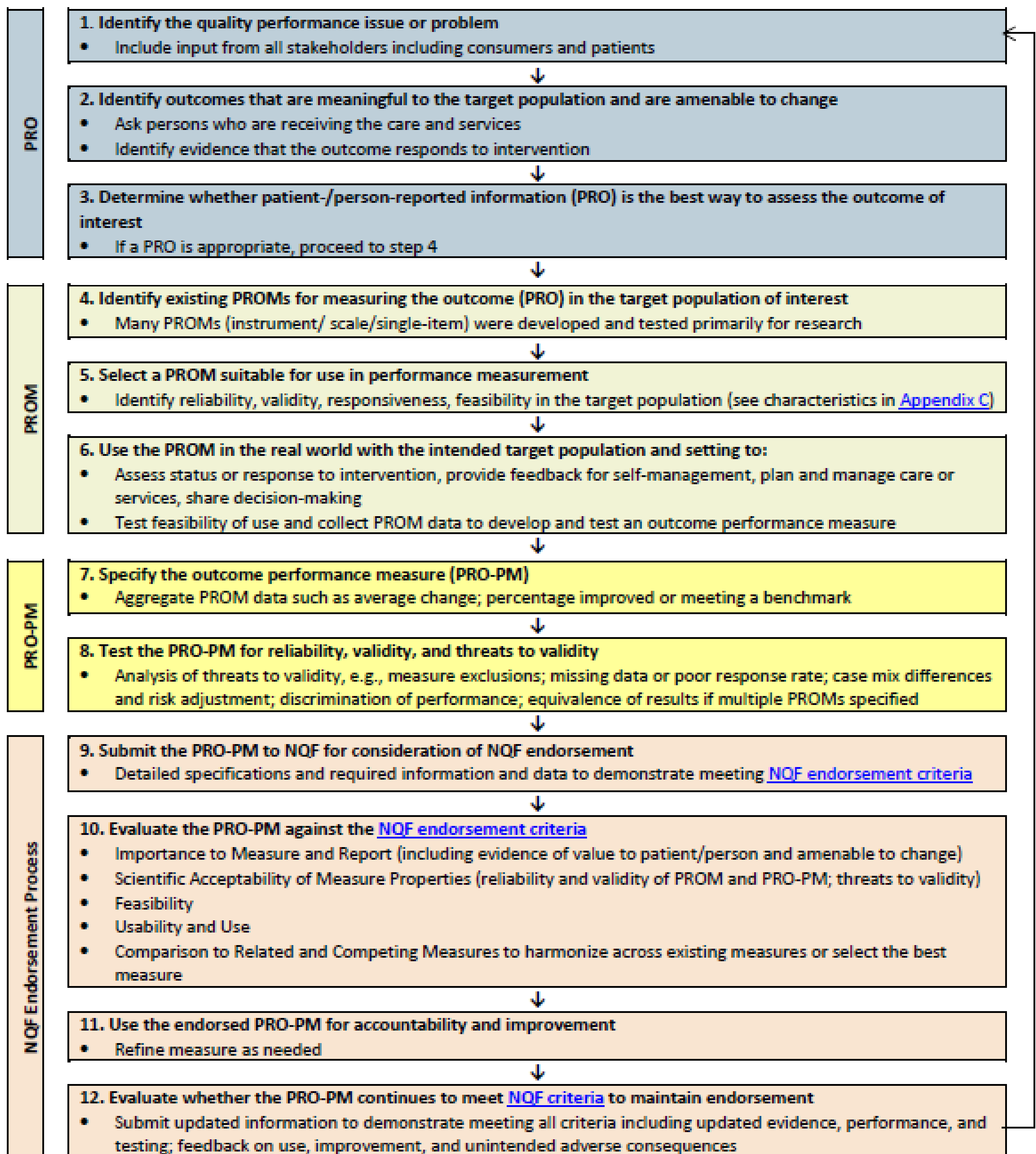
measure for accountability and performance improvement. This pathway describes how a PROM may form the basis of a PRO-PM that NQF could eventually endorse based on the NQF criteria.

The quality performance measurement enterprise includes multiple stakeholders who collaborate to develop performance measures, including methodologists and statisticians, as well as those receiving care and services, those whose performance will be measured, and those who will use performance results. In this discussion, the reference to developers includes all the participants in developing performance measures, not just formal measure developer organizations.

Although NQF is involved in the last section of the pathway, the earlier steps have implications for whether a performance measure will be suitable for NQF endorsement. Thus, they are intended to serve as a guide and best practices to help ensure that PRO-PMs will meet NQF criteria. For example, steps 1 and 2 in the pathway indicate that patients (as broadly defined as above) should be involved in identifying quality issues and outcomes that are meaningful to those receiving the healthcare and support services. If patients are involved at those steps, then developers will have amassed the information needed to demonstrate that the outcome is of value to patients. In the context of using this pathway leading to an NQF-endorsed performance measure, step 2 also suggests that developers identify outcomes with evidence that the outcome is responsive to intervention.

The steps shown in Figure 2 and described below are intended to help ensure that a proposed performance measure will meet NQF criteria for endorsement.

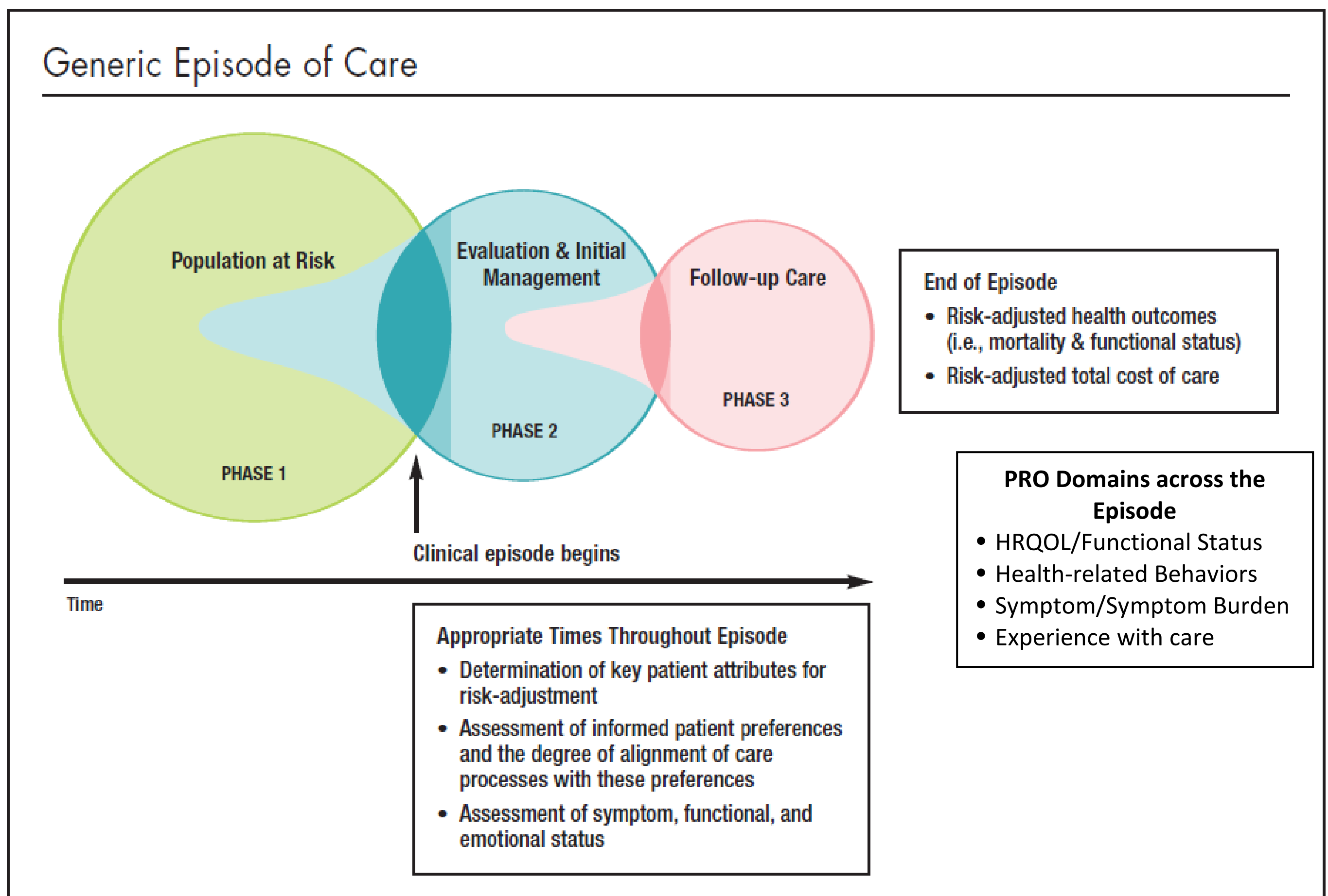
Figure 2. Pathway from PRO to NQF-endorsed PRO-PM



[Episodes of Care Measurement Framework]

Episode of Care

An episode of care is defined as "a series of temporally contiguous healthcare services related to the treatment of a given spell of illness or provided in response to a specific request by the patient or other relevant entity." The Committee developed a generic episode of care model, which can be used to track the core components—population at risk, evaluation and initial management, and follow-up care—that must be measured and evaluated over the course of an episode of care. These components are foundational to any assessment of efficiency. This model is adaptable to multiple types of episodes, and the construct is designed to be applied to a broad set of health conditions; this report has applied it to two different types of conditions—acute myocardial infarction and low back pain—to allow for examination of an acute condition and transition between providers and settings, as well as a chronic, preference-sensitive condition in which shared decision making plays a significant role. Subsequent work has been completed on breast and colorectal cancers, diabetes, and substance use illness.



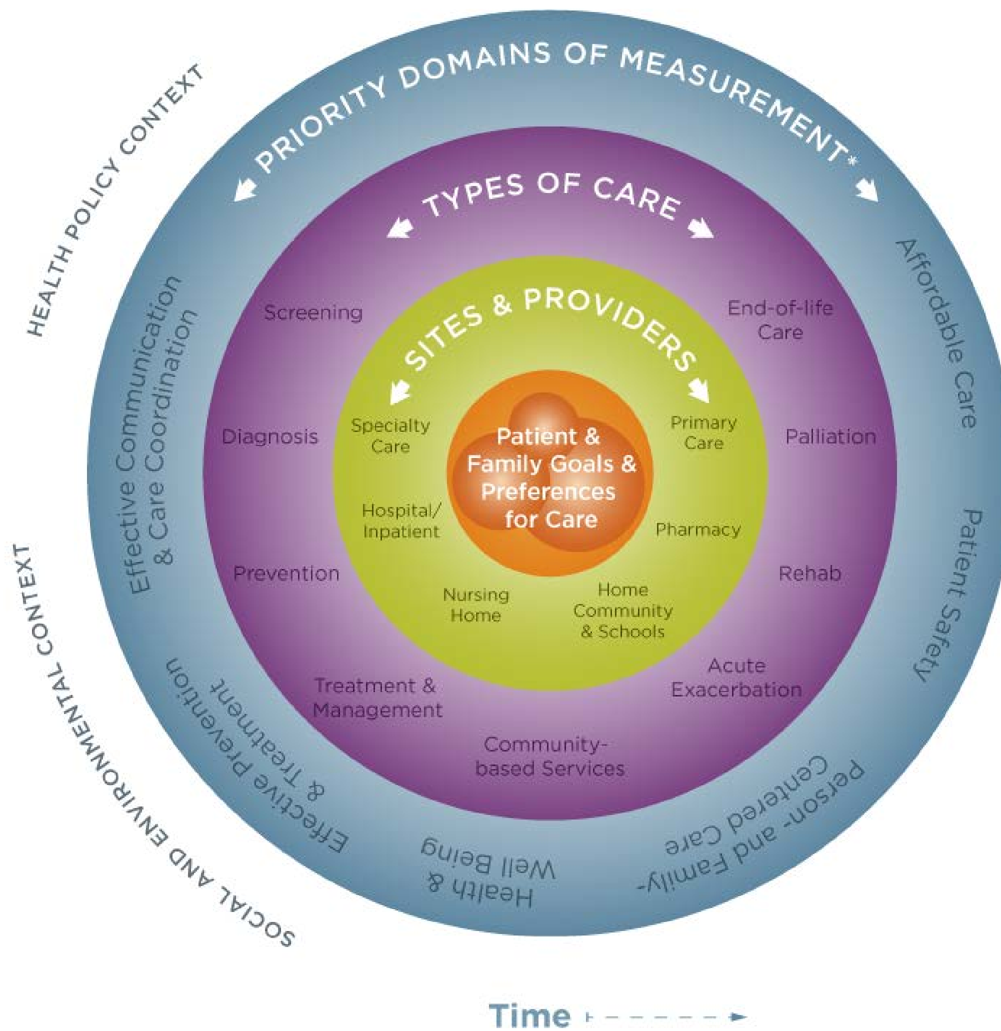
MCC Measurement Framework

The MCCs Steering Committee's measurement priorities set the stage for the development of a conceptual model to guide measurement for individuals with MCCs. This model is designed to illustrate the complexity of providing care for an individual with MCCs by showing the various ways that conditions, patient and family preferences, sites and providers of care, and types of care interact (see Figure below). Also represented in the model are the social and environmental context in which the individual lives and receives care and the public and private health policy priorities that guide the delivery of care

Within the center ring of the model is an individual with multiple different conditions that may have a greater or lesser effect on that individual. Also included in the inner ring are the family and friends who care for the individual, along with the individual's goals and preferences for care.
Depending on their conditions and preferences, individuals can receive care in various sites from various providers. Examples of sites most relevant for individuals with MCCs included in the second ring of the model are: primary care, specialty care, hospital/post-acute, nursing home, community (including school and workplace), home (including both formal and informal care), and pharmacy. The types of providers offering care to the individual (e.g., internists, hospitalists, nurse practitioners, social workers) also shift depending on the needs of the individual.

The types of care individuals receive, included in the third ring of the model (i.e., screening, primary and secondary prevention, diagnosis, treatment and management, community services, management of an acute exacerbation, rehabilitation, palliation, and end-of-life care), are not necessarily linear or mutually exclusive. For example, an individual with congestive heart failure may be seen in the hospital for an acute exacerbation but also may need continuing treatment and management of diabetes and lung cancer at the same time. Additionally, palliative care can occur at many points during the course of a disease or condition and is not exclusive to end-of-life care. End-of-life care can include hospice care, which can occur at multiple sites of care. These real-life examples reinforce the need for a flexible model that can capture the complexity of often-changing healthcare needs over time.

The outer ring of the model highlights the priority domains of measurement appropriate for use with individuals with MCCs. The domains intentionally align with the NQS to promote harmonization across public and private sector programs supporting this population. These domains support the key measure concepts for individuals with MCCs identified by the Steering Committee (see Box 1). Each priority domain of measurement may be addressed using several types of measures, including structure, process, outcome, efficiency, cost/resource use, and composite measures. The use of outcomes measures, when available, and process measures that are most closely linked to outcomes are preferable.



** Each priority domain of measurement may be addressed using several types of measures, including structure, process, outcome, efficiency, cost/resource use, and composite measures. The use of outcomes measures, when available, and process measures that are most closely linked to outcomes is preferable.*

Framework for Analyzing NHS PRO-Based Performance Measures

	Pathway from PRO to NQF-endorsed PRO-PM	Research Questions
PRO	**1. Identify the quality performance issue or problem** • Include input from all stakeholders including consumers and patients	• What was NHS' rationale for selecting the four elective procedures (hip and knee replacement, groin hernia repair, and varicose vein surgery) in its PROMs program? • What are future plans for additional areas?
	↓	
PRO	**2. Identify outcomes that are meaningful to the target population and are amenable to change** • Ask persons who are receiving the care and services • Identify evidence that the outcome responds to intervention	• Were patients involved in the identification of the outcomes?
	↓	
PRO	**3. Determine whether patient-/person-reported information (PRO) is the best way to assess the outcome of interest** • If a PRO is appropriate, proceed to step 4	• Did NHS explore clinician assessed outcome measures?
	↓	
PROM	**4. Identify existing PROMs for measuring the outcome (PRO) in the target population of interest** • Many PROMs (instrument/ scale/single-item) were developed and tested primarily for research	• What was the basis of the NHS selection of the PROMs used in the program? • What other PROMs were considered but not used in the program?
	↓	
PROM	**5. Select a PROM suitable for use in performance measurement** • Identify reliability, validity, responsiveness, feasibility in the target population (see characteristics in Appendix C)	• How did NHS make the decision to use both disease-specific (e.g., Oxford Hip and knee Score) and generic (EQ-5D) PROMs?
	↓	
PROM	**6. Use the PROM in the real world with the intended target population and setting to:** • Assess status or response to intervention, provide feedback for self-management, plan and manage care or services, share decision-making • Test feasibility of use and collect PROM data to develop and test an outcome performance measure	• Are clinicians using PROMs in routine practice? • Are PROMs being used to aid in shared decision-making and care planning? • What data collection and transmission methods are being used? • Are electronic health records being used in storing and transmitting PROMs data? • What steps are taken to preserve the privacy of patient health information?
	↓	
PRO-PM	**7. Specify the outcome performance measure (PRO-PM)** • Aggregate PROM data such as average change; percentage improved or meeting a benchmark	• What methods for aggregation does NHS use for calculating performance measures?
	↓	

	Pathway from PRO to NQF-endorsed PRO-PM	Research Questions
	8. Test the PRO-PM for reliability, validity, and threats to validity • Analysis of threats to validity, e.g., measure exclusions; missing data or poor response rate; case mix differences and risk adjustment; discrimination of performance; equivalence of results if multiple PROMs specified	• What types of risk adjustment or stratification methods have been used to address differences in patient severity of illness? • What strategies have been used to ameliorate low response rates or increase patient participation in completing PROMs questionnaires?
	↓	
NQF Endorsement Process	**9. Submit the PRO-PM to NQF for consideration of NQF endorsement** • Detailed specifications and required information and data to demonstrate meeting NQF endorsement criteria	• What type of process does NHS have for vetting the adequacy of performance measures used in its program?
	↓	
	10. Evaluate the PRO-PM against the NQF endorsement criteria • Importance to Measure and Report (including evidence of value to patient/person and amenable to change) • Scientific Acceptability of Measure Properties (reliability and validity of PROM and PRO-PM; threats to validity) • Feasibility • Usability and Use • Comparison to Related and Competing Measures to harmonize across existing measures or select the best measure	
	↓	
	11. Use the endorsed PRO-PM for accountability and improvement • Refine measure as needed	• How are PRO- based performance measures being used in England (e.g., QI, accountability, shared decision-making, research)? • Has there been any implementation challenges associated with the nationwide use of PRO-based performance measures? If yes, what strategies has NHS used to overcome the barriers?
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	12. Evaluate whether the PRO-PM continues to meet NQF criteria to maintain endorsement • Submit updated information to demonstrate meeting all criteria including updated evidence, performance, and testing; feedback on use, improvement, and unintended adverse consequences	• Has there been an impact analysis to identify whether using PRO-based performance measures has improved health and delivery of healthcare or to discern any undesirable or unintended consequences?

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