NATIONAL
QUALITY FORUM

Interim Report from the National Quality Forum: Priority Setting for Person-Centered Care and Outcomes—A Draft Conceptual Framework and Draft Environmental Scan

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Contents

Project Purpose and Scope

Over the past ten years, the use of U.S. healthcare performance measurement has exploded, yet it is widely recognized that many gaps in important measurement areas still exist. Section 1890(b)(5) of the Social Security Act requires the National Quality Forum (NQF), as the consensus-based entity, to describe gaps in endorsed quality and efficiency measures in the Annual Report to Congress and the Secretary of the Department of Health and Human Services (HHS). Building on work done by NQF in 2011 and 2012 on the status of measure gaps more broadly, this project is intended to further advance the aims and priorities of the National Quality Strategy (Figure 1) by identifying priorities for performance measurement; scanning for potential measures and measure concepts to address these priorities; and developing multistakeholder recommendations for future measure development and endorsement.

Figure 1: National Quality Strategy Aims and Priorities

In 2013, HHS contracted with NQF to focus on five specific measurement areas, including:

- Adult Immunizations
- Alzheimer’s Disease and Related Dementias
- Care Coordination
- Health Workforce
- Person-Centered Care and Outcomes

The recommendations generated through these projects will be instrumental in aligning broader measure development efforts by ensuring that financial and human resources are strategically targeted to lead us to the measures that matter to patients and families, and measurement strategies that will drive improvement in health and healthcare.

Setting Priorities for Person-Centered Care and Outcomes Performance Measurement

This project will be guided by a multistakeholder group that will develop specific recommendations for performance measurement to address person- and family-centered care, including measures based on patient-reported outcomes. Patient-reported outcomes offer important insights into the efficacy of healthcare delivery, but additional aspects of patient-centered care also are important, including patient-centered communication, shared decisionmaking, and the concordance of care plans with patient preferences, values, and goals.

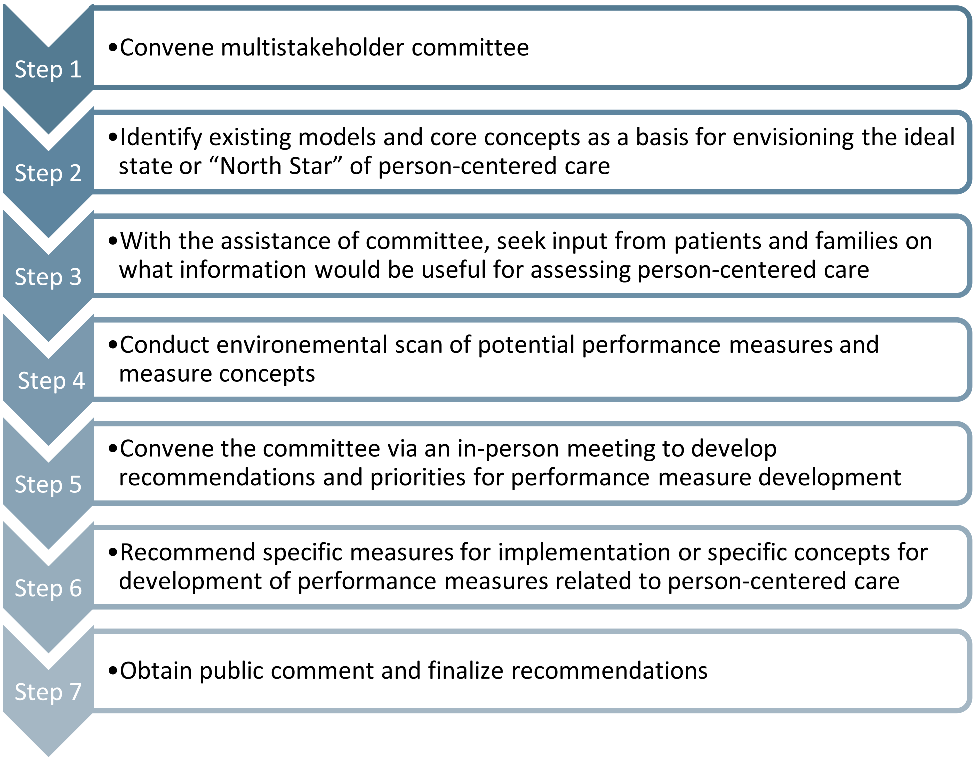
The specific goals of this project are to:

- Envision ideal person- and family-centered care (not constrained by current care delivery models) and use as a framework for performance measurement.
- Make short- and intermediate- term recommendations to measure performance and progress on ideal person- and family- centered care. The working definition of measures of person- and family-centered care and outcomes includes these characteristics: meaningful to consumers; built with consumers; measures persons through their entire care experience, rather than a single setting or program; and include patient-reported outcomes.
- Offer multistakeholder feedback on how measures identified in the joint HHS/NHS program on patient-centered outcomes align with ideal person-centered care and short and intermediate-term recommendations for performance measurement.

General Approach

The project approach will follow the outline depicted below in Figure 2 to complete this project.

Figure 2: Seven-Step Process for Person-Centered Care and Outcomes Priority Setting Project



Step 1 •Convene multistakeholder committee

Step 2 •Identify existing models and core concepts as a basis for envisioning the ideal state or “North Star” of person-centered care

Step 3 •With the assistance of committee, seek input from patients and families on what information would be useful for assessing person-centered care

Step 4 •Conduct environemental scan of potential performance measures and measure concepts

Step 5 •Convene the committee via an in-person meeting to develop recommendations and priorities for performance measure development

Step 6 •Recommend specific measures for implementation or specific concepts for development of performance measures related to person-centered care

Step 7 •Obtain public comment and finalize recommendations

Convene multistakeholder committee

NQF will convene a 20-member multistakeholder committee to provide guidance to meet the project objectives. Committee members are appointed based on their expertise and experience related to person- and family-centered care and patient-centered outcomes measurement. Additionally, the multistakeholder committee is representative of a variety of healthcare settings, community-based services, and patients and patient advocates across the lifespan. A small group of advisors provided preliminary input on the project while the full committee was being seated. NQF will convene the full committee (see roster in Appendix A) for two web meetings and one in-person meeting in 2014.

Identify existing models and core concepts as a basis for envisioning the ideal state or "North Star" of person-centered care

This project will identify the ideal state—or the "North Star"—of person-centered care. The current healthcare system remains fragmented and not conducive to person-and family-centered care. Therefore, it is important to first envision person- and family-centered care without the constraints imposed by the current system and then make recommendations in the context of moving from the present to the ideal. The following sources provided a starting point for drafting the conceptual framework, which appears in the following section.

- The National Quality Strategy (NQS) priority of *Ensuring that each person and family is engaged as partners in their care* highlights key aspects of a person-centered measurement, including assigning patients and their families an active role in their own healthcare, which is tailored to their cultures, languages, disabilities, health literacy levels, and social backgrounds.
- The Institute of Medicine (IOM) aim of patient-centeredness which entails that a patient-centered care considers patient's cultural traditions, their personal preferences and values, their family situations, and their lifestyles.
- The Institute for Patient- and Family-Centered Care definition and core concepts of respect and dignity, information sharing, participation, and collaboration.
- Patient- reported outcome (PRO) domains developed through the *NQF Patient-Reported Outcomes and Performance Measurement project* (health-related quality of life (HRQoL)/functional status, symptom/symptom burden, experience with care including engagement and shared decisionmaking, and health-related behaviors).

Seek input from patients and families on what information would be useful for assessing person-centered care

NQF will work closely with patients and patient advocates to identify areas for measurement that matters most to the patients and their families. NQF will explore the efforts that are currently underway by consumer groups such as the Institute for Patient and Family Centered Care and PatientsLikeMe and identify whether there are any existing measures/tools used by patient advocacy groups for assessing person-centered care.

Conduct an environmental scan of measures and measure concepts

NQF will conduct an environmental scan of relevant performance measures and measure concepts that map to the PRO measure domains stated above. The initial scan will draw measures and measure concepts from the sources listed in Appendix C. Additionally, staff will conduct outreach with committee members and the previously convened NQF PRO Expert Panel to identify promising examples of person-centered care performance measurement, as well as measures identified in joint HHS/NHS on patient-centered care. Further environmental scanning will be conducted once the conceptual framework has been vetted by the committee. Using the PRO domains will likely result in too broad a scope and will need to be focused and refined as the committee envisions ideal person- and family-centered care and agrees on the conceptual framework.

Convene the multistakeholder committee via an in-person meeting to develop recommendations and priorities for performance measure development

The multistakeholder committee will meet in person to use the input generated from patients and patient advocates, and findings from the discussions about the conceptual framework and the environmental scan to create the vision of the ideal state or "North Star" of person-centered care. Further work on the conceptual framework will be a substantial component of the in-person meeting.

Recommend specific measures for implementation or specific concepts for development of performance measures related to person-centered care

The committee will weigh the pros and cons of different types of performance measures including structure, process, and outcome measures to make short- and intermediate-term recommendations on the specific measures or measure concepts most impactful to advance person-centered models of care.

Obtain public comment, and finalize recommendations

NQF will develop and post its draft report for public comment and submit to HHS by June 16, 2014. NQF also will hold a public webinar to solicit feedback on the draft report. Comments from the public and HHS will be incorporated into the final report, which will be submitted to HHS by August 15, 2014.

Draft Conceptual Framework

In this project we will use the term *person- and family-centered* to be the most inclusive of recipients of healthcare services and their families and informal caregivers. However, other terms such as person-centered, patient-centered, consumer-centered, personalized or individualized care also generally embody the same concepts. Although this project will envision ideal person- and family-centered care as the basis for making recommendations related to performance measurement, the following provides considerations for the committee's discussions.

Definition and Core Concepts

There are a variety of definitions, attributes, and frameworks (see Appendix B) relevant to measuring health system performance on person- and family-centered care. Various descriptions may use different terms, language, or grouping of concepts, but they are fundamentally aligned. Following is a proposed definition and conceptual representation of the core concepts, followed by the rationale.

> *Person- and family-centered care is an approach to the planning, delivery, and evaluation of healthcare that is anchored by, respectful of, and responsive to the individual's preferences, needs, and values (including involvement of family) to ensure that individual values guide all clinical decisions.*

Key aspects of a person- and family-centered perspective of care, which overlay basic expectations for receiving safe and effective care across time and settings, are presented in Figure 3—importantly in lay language.

Figure 3. Core Concepts of Person- and Family-Centered Care

The definition and core concepts will be reviewed and refined by the committee as it envisions ideal person- and family-centered care.

Rationale for Definition and Core Concepts

This section identifies the specific resources that inform and support the above definition and core concepts. The definition combines elements from definitions provided by the Institute for Patient- and Family-Centered Care and the Institute of Medicine (IOM).

The Institute for Patient- and Family-Centered Care provides a definition and identifies core concepts for patient- and-family centered care:

> *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, information sharing, participation, and collaboration.*

This definition is consistent with an oft-cited definition from the IOM's 2001 Report *Crossing the Quality Chasm* in which patient-centeredness was identified as one of the six aims for improvement of the healthcare system.

> *Patient-centered—providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.*

More recently, in its 2013 report *Best Care at Lower Cost,* the IOM offered key characteristics of a continuously learning healthcare system, including the need to *anchor systems on patient needs and perspectives*, and *promote the inclusion of patients, families, and other caregivers as vital members of the continuously learning care team*.

The IOM's *Crossing the Quality Chasm* report also identified "new rules" for an improved healthcare system and what patients should expect in contrast to the general approach prevalent at the time of the report. Many of the new rules and expectations are especially relevant to patient-centeredness, and although they were written over 10 years ago, the rules for redesign remain enduring concepts today. Although progress has been made, there is much room for improvement throughout the healthcare system, particularly in regards to person-centered care.

Below, Table 1 crosswalks the IOM's person- and family-centered care concepts and new rules with the Institute for Patient- and Family-Centered Care core concepts, and relevant National Quality Strategy priorities and long-term goals, particularly the priorities related to engaging persons and families in their care and communication and coordination of care. Some of the new rules, particularly, evidence-based care (science) and safety (rows 5 and 6) are considered foundational to, but not specific attributes of, person-centered care. There are many performance measures related to safety and effectiveness and that will not be the focus for measuring person-centered care.

Table 1. Crosswalk of Core Person- and Family-Centered Care Concepts

	Institute of Medicine			Institute of Patient- and Family-Centered Care	National Quality Strategy
	Prior Approach	New Rule	What Patients Should Expect from Their Health Care	Core Concepts	Priority and *Goal*
1	Care is based primarily on visits.	Care is based on continuous healing relationships.	**Beyond patient visits:** You will have the care you need when you need it . . . whenever you need it. You will find help in many forms, not just in face-to-face visits. You will find help on the Internet, on the telephone, from many sources, by many routes, in the form you want it.		**Patient and Family Engagement.** *Improve patient, family, and caregiver experience of care related to quality, safety, and* ***access*** *across settings.*
2	Professional autonomy drives variability.	Care is customized according to patient needs and values.	**Individualization:** You will be known and respected as an individual. Your choices and preferences will be sought and honored. The usual system of care will meet most of your needs. When your needs are special, the care will adapt to meet you on your own terms.	**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.	**Patient and Family Engagement.** *In partnership with patients, families, and caregivers—and using a shared decisionmaking process—develop culturally sensitive and understandable care plans.*
3	Professionals control care.	The patient is the source of control.	**Control:** The care system will take control only if and when you freely give permission.	**Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.	**Patient and Family Engagement.** *Enable patients and their families and caregivers to navigate, coordinate, and manage their care appropriately and effectively.*

	Institute of Medicine			Institute of Patient- and Family-Centered Care	National Quality Strategy
	Prior Approach	New Rule	What Patients Should Expect from Their Health Care	Core Concepts	Priority and *Goal*
4	Information is a record.	Knowledge is shared and information flows freely.	**Information:** You can know what you wish to know, when you wish to know it. Your medical record is yours to keep, to read, and to understand. The rule is: "Nothing about you without you."	**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.	
5	Decision making is based on training and experience.	Decision making is evidence-based.	**Science:** You will have care based on the best available scientific knowledge. The system promises you excellence as its standard. Your care will not vary illogically from doctor to doctor or from place to place. The system will promise you all the care that can help you, and will help you avoid care that cannot help you.		**Patient and Family Engagement.** *Improve patient, family, and caregiver experience of care related to* ***quality****, safety, and access across settings.*
6	Do no harm is an individual responsibility.	Safety is a system property.	**Safety:** Errors in care will not harm you. You will be safe in the care system.		**Patient and Family Engagement.** *Improve patient, family, and caregiver experience of care related to quality,* ***safety****, and access across settings.*

	Institute of Medicine			Institute of Patient- and Family-Centered Care	National Quality Strategy
	Prior Approach	**New Rule**	**What Patients Should Expect from Their Health Care**	**Core Concepts**	**Priority and *Goal***
7	Secrecy is necessary.	Transparency is necessary.	**Transparency:** Your care will be confidential, but the care system will not keep secrets from you. You can know whatever you wish to know about the care that affects you and your loved ones.	**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.	
8	The system reacts to needs.	Needs are anticipated.	**Anticipation:** Your care will anticipate your needs and will help you find the help you need. You will experience proactive help, not just reactions, to help you restore and maintain your health.		**Effective communication and coordination.** *Improve the quality of life for patients with chronic illness and disability by following a current care plan that anticipates and addresses pain and symptom management, psychosocial needs, and functional status.*
9	Cost reduction is sought.	Waste is continuously decreased.	**Value:** Your care will not waste your time or money. You will benefit from constant innovations, which will increase the value of care to you.		

	Institute of Medicine			Institute of Patient- and Family-Centered Care	National Quality Strategy
	Prior Approach	**New Rule**	**What Patients Should Expect from Their Health Care**	**Core Concepts**	**Priority and *Goal***
10	Preference is given to professional roles over the system.	Cooperation among clinicians is a priority.	**Cooperation:** Those who provide care will cooperate and coordinate their work fully with each other and with you. The walls between professions and institutions will crumble, so that your experiences will become seamless. You will never feel lost.		**Effective communication and coordination of care.** *Improve the quality of care transitions and communications across settings.*

Performance Measurement

The goal of this project is to make specific recommendations for measuring health system performance on person- and family-centered care. The need for performance measures for person-centeredness has been often identified, but has lacked specific recommendations about exactly what and how to measure it beyond the array of Consumer Assessment of Healthcare Providers and System (CAHPS) experience of care measures.

Performance measurement in this area is challenging for several reasons. First, most of the attributes or characteristics are abstract concepts and not easily defined by one data point. Second, each person may define or interpret them differently. Third, there may be multiple strategies or approaches for achieving the desired experience and they may not have a strong evidence base; therefore process performance measures may be too prescriptive and not allow sufficient flexibility. Fourth, although there is evidence that person-centered care is associated with better health or clinical outcomes, such measurement alone does not provide a sufficient indicator of person- and family-centeredness. Finally, some of the attributes are supported by structures and systems such as extended office hours, email communication, access to EHRs and may not need a formal performance measure; rather a standard set of information (label) about such organizational structures may be more useful.

The committee will consider these issues in order to make detailed recommendations for performance measures. Three key principles for person-centered performance measures are to be:

- meaningful to consumers and built with consumers;
- focused on their entire care experience, rather than a single setting or program; and
- measured from the person's perspective and experience (i.e., patient-reported unless not necessary such as information on extended office hours).

Patient-reported outcome measurement is a related topic that has relevance for person- and family-centered care. In a 2012 NQF project on Patient-Reported Outcomes and Performance Measurement, a PRO was defined *as 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*. PRO domains included:

- Health-related quality of life (HRQoL), including functional status
- Symptom and symptom burden
- Experience with care (including patient engagement, shared decisionmaking, communication)
- Health-related behaviors (e.g., smoking, diet)

It is clear that the experience with care domain is directly aligned with person- and family-centered care. All PRO domains represent concepts that are of interest to patients, and although obtaining the patient's report of the outcome itself signifies aspects of person-centered care, the specific PRO may not be an explicit indicator of person-centered care. For example, a performance measure on percentage of patients with improved functional status after total hip surgery (measured with a patient-reported instrument) is primarily an indicator of treatment effectiveness, which may not have been achieved through patient-centered approaches. Similarly, aspects of health-related behavior, such as adherence to activities prescribed by healthcare practitioners may be considered important for patient engagement, but may not embody person-centered care.

Table 2 provides a sample framework for the committee to consider when reviewing existing performance measures and making recommendations for new performance measures. Some examples are provided for illustrative purposes. The table addresses structure, process, and outcome as key elements of quality measurement. Core concepts from Figure 3 are represented in the table in bold; potential information that patients and families may want is represented as questions in italics; and potential metrics are represented in bold blue. This is provided for illustrative purposes and will be modified based on the committee's discussions about the definition and core concepts for person- and family-centered care.

Table 2. Sample Measurement Framework

Structure	Process	Outcome
Organizational aspects that support providing person- and family-centered care	**Interaction between person/family and healthcare providers**	**Desired outcomes of person- and family-centered care**
	Consider all of me (holistic)	
Care when/ how I need it (accessible/available) • *How long does it take to get an appointment?* o **Average time to schedule an appointment** • *Are there extended office hours?* • *How long does it take to get a response to a call or email?*		
	My preferences, values, goals, decisions • *Is care provided in line with my preferences and goals?* o **Match between stated preferences/goals and care plan**	
	Respect and dignity	
	Participate/partner in care • *How do you help me learn to manage my care?*	• **Confidence in ability to manage care** • **Adherence to activities prescribed by a provider**
Information I need or want about my care or provider • *Do I have access to my record?* • *How many patients like me do you see?* • *Where can I get information on your quality ratings?*		

Structure	Process	Outcome
Organizational aspects that support providing person- and family-centered care	**Interaction between person/family and healthcare providers**	**Desired outcomes of person- and family-centered care**
Do not waste my time • *What is the wait time for an office visit?*		
All my care providers know me and cooperate • *Are patients assigned to a primary care practitioner?*	**All my care providers know me and cooperate** • *Do you share information with my other care providers?* • *Do you get reports from my other care providers?* o **Reports on referral request and result of consultation in referring and consulting records**	

Draft Environmental Scan of Measures and Measure Concepts

This section of the report provides a broad-brush overview of the preliminary scan of measures and measure concepts related to person-centered care and outcomes, drawn from the sources listed in Appendix C. Because the conceptual framework may be considerably modified through the work of the project, at this initial stage the scan was more inclusive to encompass the most relevant PRO domains of experience with care, including engagement, shared decisionmaking, and communication; health-related quality of life and functional status; and symptom and symptom burden. This full scan included 5,962 measures, with a total of 803 identified as broadly relevant to the PRO domains. Inclusion was not limited to patient-reported outcomes. Table 3 provides a snapshot of the number of identified measures and their initial categorization by domain. As the domains are not mutually exclusive, a small number of measures were thought to be relevant to more than one domain. The full draft scan may be found in an accompanying excel document submitted as a deliverable to HHS.

Table 3: Environmental Scan of Measures by Domain

Person- and Family-Centered Care Domain	Number of Measures
Experience with Care (including engagement, shared decisionmaking, and communication)	464
Health-Related Quality of Life (including Functional Status	180
Symptom and Symptom Burden	163
Other	13

While many duplicate measures were fairly easily identified and removed, it was beyond the scope of this project to compare and contrast all of the measures from different sources to eliminate all potential duplicates. As the committee narrows the scope of the project, it can provide additional guidance in terms of where a more in-depth review of specific measures may have merit.

Experience with Care

Most notably, the overwhelming number of measures identified fell into the domain of experience with care, many of which were individual elements of the array of CAHPS survey tools. These measures and tools cover not only a variety of care settings and types of care, but also several disease-specific populations. Several private-sector survey tools were also identified and included in the scan. Individual performance measures associated with these tools cover many aspects of patient and family experience, including information sharing, goal setting, and communication, as well as concepts of respect, dignity, cultural competency, participation, and collaboration. In considering the ideal state, opportunities may exist to draw from these existing metrics to consider the path forward for performance measurement.

Health Related Quality of Life

This category of measures includes those related to physical, mental, emotional, and social functioning. Most of the identified measures focus on functional status and limitations in activities or personal care, with some focused on health status more generally (e.g., mentally unhealthy days; work/school absenteeism). Many of the measures in this category are clinician assessed, such as those developed for and implemented in home care and nursing home settings. With limited information on measure specifications, it is difficult to discern if others are patient-reported or clinician assessed, or whether they are performance measures or patient-level instruments or tools. Regardless, it is not yet clear whether these measures will fit the conceptual framework for person- and family-centered care. Although of interest to persons receiving services, they may be more appropriately considered indicators of treatment effectiveness.

Symptom and Symptom Burden

This category revealed many measures focused on assessment and management of pain and depression across types of care and disease populations, including many outcome measures. Again, with limited information on measure specifications, it is difficult to discern whether these are patient-reported symptoms or measures from the perspective of the healthcare providers such as whether pain was assessed. The committee may wish to consider whether these sufficiently incorporate patient reports of symptom and burden. As with HRQoL/functional status, measures of symptom and symptom burden are extremely important to persons receiving services but may be more appropriately considered indicators of treatment effectiveness.

Next Steps

Committee Input to Finalize Framework

The person-centered care and outcome multistakeholder committee will convene via a web meeting in January 2014 to provide input on the draft conceptual framework and strategies for seeking input from patients, families, and their advocate organizations on what should be measured.

During a two-day in-person meeting, the multistakeholder committee will develop the vision of the ideal state or “North Star” of person-centered care and identify how best to measure performance and progress in the delivery of person-centered care. The committee will identify promising measures or specific concepts for development of performance measures that help advance an ideal state of a person-centered model of care. The final report will include the conceptual framework and priorities for measure development, and will be delivered to HHS in August 2014.

Continuation of Scan for Measures and Measure Concepts

Under the guidance of the multistakeholder committee, further scanning will be performed by NQF staff to identify potential measures and concepts to address the conceptual framework domains as they are refined. The committee will be the best source to assist with the identification of relevant and promising performance measures and concepts related to person- and family-centered care.

Additionally, in early 2014 NQF will begin soliciting measure concepts through NQF's new Measure Inventory Pipeline. This pipeline will serve as an important source of information for HHS and other stakeholders on current measure development efforts within the broader healthcare community. NQF staff will conduct outreach to specific stakeholder groups to encourage the submission of measures that may address important gap areas, and will encourage the committee to assist with this outreach. A final environmental scan will be submitted as an accompanying deliverable to HHS in August 2014.

Committee Recommendations on Priorities for Performance Measurement

A two-day in-person meeting is scheduled for April 2014 during which the committee will continue to refine its framework to identify and prioritize gaps in quality measures related to person- and family-centered care, consulting the environmental scan as appropriate. The group also will identify areas in which quality measures are unavailable or inadequate to address these gaps. The final report, which will include the final conceptual framework, environmental scan, and recommendations for prioritized measure development, will be delivered to HHS in August 2014.

Appendix A: Person-Centered Care and Outcomes Committee Roster

COMMITTEE MEMBERS	
Ethan Basch, MD, MSc	University of North Carolina at Chapel Hill, Chapel Hill, NC
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Karen Adams	Vice President, Strategic Partnerships
Wendy Prins	Senior Director, Strategic Partnerships

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