Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps in Person-Centered Care and Outcomes

FINAL REPORT

AUGUST 15, 2014

NATIONAL
QUALITY FORUM

This report is funded by the Department of Health and Human Services under contract HHSM-500-2012-00009I, Task 5.

CONTENTS

EXECUTIVE SUMMARY

The current state of U.S. healthcare illuminates the need for a higher quality care that is organized around the needs of the individuals and their families. All too frequently, healthcare is received in a manner that is too impersonal and removed from the actual priorities and goals of the individuals and their families. Over the past decade, efforts have been underway to shift the healthcare paradigm from one that identifies persons as passive recipients of care to one that empowers persons to participate actively in their own care. The National Quality Strategy (NQS) priority of "*Ensuring that each person and family is engaged as partners in their care"* emphasizes this new approach and highlights key aspects of person-centered care. Emerging evidence points to the positive impact of collaborative partnerships between persons, families, and their healthcare providers on outcomes and cost.

A multistakeholder committee convened by the National Quality Forum (NQF) was tasked with developing specific recommendations for person- and family-centered care performance measurement for the Department of Health and Human Services (HHS). This report outlines a conceptual framework to define ideal person-and family-centered care (not constrained by current care delivery models) and to provide short-and intermediate-term recommendations to measure performance and progress on ideal person- and family-centered care. Building from the extensive work undertaken to-date to define person-and family-centered care, the Committee agreed to the following definition and core concepts as an organizing structure to identify specific measure concepts.

Person- and family-centered care is:
An approach to the planning and delivery of care across settings and time that is centered around collaborative partnerships among individuals, their defined family, and providers of care. It supports health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values.

The following core concepts were identified as important components of ideal person- and family-centered care to guide performance measurement.

- Individualized care—I work with other members of my care team so that my needs, priorities, and goals for my physical, mental, spiritual, and social health guide my care.
- Family—My family is supported and involved in my care as I choose.
- Respect, dignity, and compassion are always present.
- Information sharing/communication—There is an open sharing of information with me, my family, and all other members of my care team(s).
- Shared decisionmaking—I am helped to understand my choices and I make decisions with my care team, to the extent I want or am able.
- Self-management—I am prepared and supported to care for myself, to the extent I am able.

- Access to care/convenience—I can obtain care and information, and reach my care team when I need and how I prefer.

The committee highlighted three key principles that should inform the identification of measure concepts for person- and family-centered care. They should be:

- Selected and/or developed in partnership with individuals to ensure measures are meaningful to those receiving care;
- Focused on the person's entire care experience, rather than a single setting, program, or point in time; and
- Measured from the person's perspective and experience (i.e., generally person-reported unless the person receiving care is not the best source of the information).

The Committee identified specific measure concepts for potential measure development (Appendix D) and made the following recommendations related to priorities for measuring performance on person- and family-centered care.

Overarching Recommendations

- Integrate individual and family input into the ongoing dialogue and decisions as performance measures are developed.
- Focus measurement on person-reported experiences and other outcomes over structures and processes.
- Highlight and build on work underway whenever possible.
- Consider the evolving healthcare system. With a rapidly changing delivery system, eyes should be on where we are going as opposed to where we currently stand.
- Go beyond silos of accountability and measurement.
- Consider actionability by those being measured.

Short-Term Recommendations

- Consider starting with one simple question from the individual's perspective such as "how is your care working out for you?" or "do you feel like you were well taken care of?" This type of question could be asked in any setting in any situation.
- Alternatively, consider initially focusing on patients with higher levels of need such as individuals with multiple comorbidities, advanced dementia, and serious illnesses, or those in underserved or disadvantaged populations.
- Consider available Consumer Assessment of Healthcare Providers and Systems (CAHPS) performance measures.
- Convene a group comprised of experts on CAHPS and Patient Reported Outcomes Measurement Information System (PROMIS) for mutual learning and measure development. This combines the CAHPS expertise in identifying experience with care measures related to many of the core concepts and the PROMIS expertise in applying new methods of measurement.
- Explore the person-centered care label concept. Such a label would provide a standardized way of communicating information related to some aspects of an organization's person- and family-centeredness, particularly systems features.

Intermediate-Term Recommendations

- With the joint CAHPS/PROMIS group mentioned above, explore developing a "Person-centered Care 10"patient-level scale—similar to the PROMIS global health scale, which is a global assessment of health-related quality of life in 10 questions.
- Incorporate the full healthcare experience beyond a single setting.
- Advance family experience individual-level scales.
- Fund research to advance measurement of person- and family-centered care.

PROJECT FOUNDATION

Over the past ten years, the use of healthcare performance measurement has sharply increased in the United States, 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 further advances 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.

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, and person-centered care and outcomes. The recommendations generated through these projects will help align broader measure development efforts by ensuring that financial and human resources are strategically targeted to create measures that matter to patients and families, and drive improvement in health and healthcare. This report presents findings in the topic area of person-centered care and outcomes.

FIGURE 1. NATIONAL QUALITY STRATEGY AIMS AND PRIORITIES

BACKGROUND

Over the past decade, spurred by the Institute of Medicine (IOM) 2001 Crossing the Quality Chasm report,[1] efforts have been underway to shift the healthcare paradigm from one that identifies persons as passive recipients of care to one that empowers persons to participate actively in their own care. The National Quality Strategy (NQS) priority of "*Ensuring that each person and family is engaged as partners in their care"* emphasizes this new approach and highlights key aspects of person-centered care. These include patients and their families taking an active role in their own healthcare, which is tailored to their unique circumstances (e.g., cultures, disabilities, and social backgrounds), and creating care practices that support patient and family engagement in making decisions that align with their values and preferences.[2]

Emerging evidence points to the positive impact of collaborative partnerships between persons, families, and their healthcare providers. People who actively engage in their healthcare are more likely to stay healthy and manage their conditions, while patients who lack the skills to manage their care incur higher costs than patients who are highly engaged.[3] Family support has been linked to better patient self-management and outcomes in patients with one or more chronic conditions,[4] and their involvement in pediatric care has shown promising results, such as improved health outcomes and decreased healthcare costs.[5]

In its 2013 report Best Care at Lower Cost, the IOM reinforced patient and family engagement by putting forward key characteristics of a continuously learning healthcare system, including the need to anchor systems in patient needs and perspectives, and promoting the inclusion of patients, families, and caregivers as vital members of the continuously learning care team. A primary strategy suggested by the IOM is for public and private payers—including CMS—to promote patient-centered care through measurement and reporting programs and payment models.[6]

Despite the commitment to center healthcare on persons and families, performance measurement as a tool to support system redesign has lagged behind, partly due to the complexity of what person- and family-centered care entails. Many pioneering organizations—such as the Picker Institute, the Commonwealth Fund, the Institute for Patient- and Family-Centered Care, and Planetree—have aimed to describe person- and family-centered care. These efforts have been grounded in extensive research, and informed by expert panels, focus groups, and numerous dialogues between persons, families, and health professionals from many disciplines. The following frameworks and common attributes of person-centered care emerging from these efforts have formed the foundation for current and future measure development, including this project. They are closely intertwined, yet each offers a unique perspective of the multidimensional concept of person-centered care.

- The Picker Institute's principles of patient-centered care are respect for patients' values, preferences and expressed needs; coordination and integration of care; information, communication, and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; continuity and transition; and access to care.[7]
- Key attributes of patient-centered care based on a systematic review of nine models and frameworks (including the ones listed here) supported by the Commonwealth Fund are education and shared knowledge; involvement of family and friends; collaboration and team management; sensitivity to nonmedical and spiritual dimensions of care; respect for patient

needs and preferences; and free flow and accessibility of information.[7]

- The Institute for Patient- and Family-Centered Care identifies core concepts of respect and dignity, information sharing, participation, and collaboration.[8]
- Planetree's 11 core dimensions of patient-centered care, including structures and functions necessary for culture change; human interactions; patient education and access to information; family involvement; nutrition program; healing environment; arts program; spirituality and diversity, integrative therapies, healthy communities; and measurement.[9]

Two movements embraced person-and family-centered care from their inception: independent living for persons with disabilities and hospice and palliative care for patients with terminal and serious illness. Both of these movements focused on individuals being actively engaged in decisions about their care.

Person-centered care is rooted in the Independent Living Movement and the Americans with Disabilities Act (ADA), both stemming from the civil rights movement. The Independent Living movement is anchored in the fundamental principle that people with disabilities are entitled to the same civil rights, options, and control over choices in their own lives as people without disabilities. More holistic approaches to healthcare were ushered in as demedicalization and deinstitutialization movement began, which in turn promoted individual empowerment and responsibility for owning, defining and meeting one's own needs.[10]

Hospice and palliative care programs were developed to improve quality of life during terminal illness or the trajectory of serious illness. Although there are some differences in philosophy, both are based on central tenets of addressing the whole person, including physical, emotional, and spiritual needs and the right to be informed and choose desired treatments.[11]

A recent report by the Health Foundation, which summarized themes from more than 23,000 studies regarding person-centered care measurement, highlighted key messages including lack of agreement about which tools to use to measure person-centered care; no "silver bullet" or best measure to cover all aspects of person-centered care; difficult to know the most appropriate way to measure person-centered care until it is clearly defined; combining a range of methods and tools such as patient surveys, interviews, and observations of clinical encounter to provide the most robust measure of person-centered care; and local testing of measures to assess their usefulness in the United Kingdom.[12]

PROJECT PURPOSE AND GOALS

This project to prioritize measure gaps aims to set forth the ideal state—or the "North Star"—of person-centered care. The current healthcare system is fragmented and not conducive to person-and family-centered care, so it is important to first envision person- and family-centered care in an ideal system and then consider recommendations in the context of moving from the present to the ideal. This work was guided by a multistakeholder group to develop specific recommendations for person- and family-centered care performance measurement. The approach to developing the Committee recommendations has been included in **Appendix A** and the Committee roster in **Appendix B**.

The specific goals of this project were to:

- Envision ideal person- and family-centered care (not constrained by current care delivery models) and use that vision as a framework for performance measurement.
- Make short- and intermediate-term recommendations to measure performance and progress on ideal person- and family- centered care.

RELATED PROJECTS

This project is part of a suite of multistakeholder efforts at NQF that aim to promote person- and family-centered care. Concurrent with the prioritizing measure gaps work, the NQF-convened Measure Applications Partnership (MAP) identified **families of measures** — sets of aligned measures that includes available measures and measure gaps spanning programs, care settings, and levels of analysis — to address the NQS priorities related to person- and family-centered care, affordable care, and population health. Families of measures signal the highest priorities for measurement and best available measures within a particular topic, as well as critical measure gaps that must be filled to enable a more complete assessment of quality. Families of measures are intended to promote alignment of performance measurement across federal programs and private-sector initiatives. Accordingly, MAP uses families of measures to guide its annual pre-rulemaking recommendations on the selection of measures for specific federal programs.

Building on prior and current NQF work, including the patient-reported outcomes (PROs) domains developed through the **Patient-Reported Outcomes in Performance Measurement project**, and the person- and family-centered care definition and core concepts established in this project, MAP identified a family of person- and family-centered care measures. To aid in the selection of measures, MAP identified priority areas for measuring person- and family-centered care, which include: interpersonal relationships, patient and family engagement, care planning and delivery, access to support, and quality of life, including measures of physical and cognitive functioning, symptom and symptom burden (e.g., pain, fatigue), and treatment burden (on patients, families, caregivers, siblings)

The key themes that emerged when identifying this family of measures include the following:

- Measurement should capture patients' experience of care as well as include patient-reported outcomes that are meaningful to patients.
- Collaborative partnerships between persons, families, and their care providers are critical to enabling person- and family-centered care across the healthcare continuum.
- Future measure development should focus on patient-reported outcomes that offer a more holistic view of care, considering individuals' goals, needs, and preferences as well as their overall well-being.

The second project focusing on this topic is The **Person- and Family-Centered Care endorsement project**. During this project, NQF will evaluate and endorse performance measures focused on person- and family-centered care and the outcomes of particular interest to patients, including health-related quality of life, functional status, and experience with care.

Another related activity during this project was a review of patient-reported outcomes being developed or used in the US and England focused on depression, functional status after hip replacement, and functional status after knee replacement. The purpose of this activity was to identify similarities and differences that can be explored by HHS and NHS to identify best practices and opportunities for collaboration and co-development of standards. (See **Appendix F**.)

Finally, a subtask under the umbrella measurement gaps project was focused on **care coordination**. Care coordination is related to some of the core concepts identified for person- and family-centered care, particularly information sharing/communication.

DEFINITION AND CORE CONCEPTS FOR PERSON- AND FAMILY-CENTERED CARE

In order to make suggestions about how to measure performance related to person- and family-centered care, it is necessary to have a clear picture of what it is and know how to recognize it. Building from the prior work cited above, the Committee agreed to the following definition and core concepts as an organizing structure to identify specific measure concepts. A crosswalk of these core concepts to the IOM's person- and family-centered care concepts and new rules, the Institute for Patient- and Family-Centered Care core concepts, the Picker Institute principles, The Commonwealth Fund key attributes of patient-centered care, and Planetree's core dimensions is provided in **Appendix C**.

The Committee noted that there were a variety of ways to state the definition and core concepts and acknowledged the overlap among some of the core concepts. They decided that for the purpose of guiding development of performance measures, it was preferable to have more discrete core concepts than broader and more encompassing concepts.

Definition of Person- and Family-Centered Care

For this project the Committee used the term *person- and family-centered care to* be the most inclusive of recipients of healthcare services and their families and caregivers. However, other terms such as person-centered, patient-centered, consumer-centered, personalized or individualized care generally embody the same concepts. In this report, individuals, persons, and patients are used interchangeably.

There are a variety of definitions, attributes, and frameworks relevant to person- and family-centered care. Various descriptions may use different terms, language, or grouping of concepts, but they are fundamentally aligned. Following is a definition that was developed through this work.

> **Person- and family-centered care is:**
>
> *An approach to the planning and delivery of care across settings and time that is centered around collaborative partnerships among individuals, their defined family, and providers of care. It supports health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values.*

The definition is consistent with definitions used by the Institute for Patient- and Family-Centered Care and the Institute of Medicine (IOM).

The Institute for Patient- and Family-Centered Care provides this definition 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.[8]

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 is:

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.[1]

Individuals and families may engage in the planning, delivery, and evaluation of care at four levels:

- Clinical encounter: in direct care, care planning, and healthcare decisionmaking.
- Practice or organizational system level: in quality improvement and system redesign.

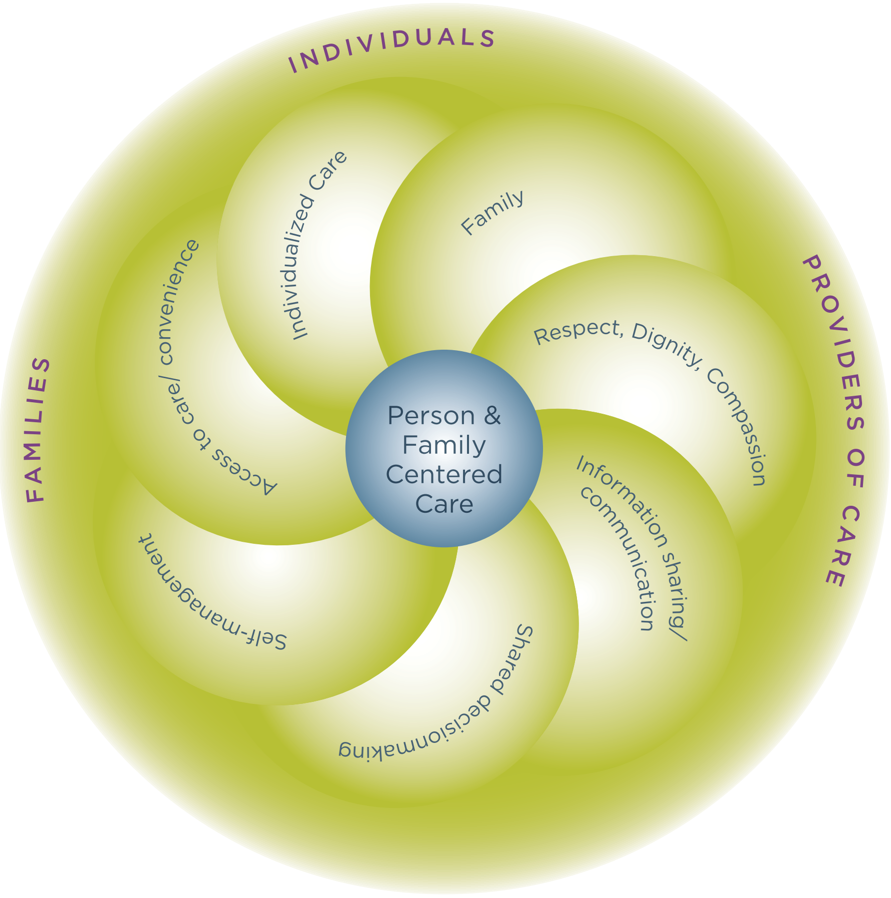
- Community level: in bringing together community resources with healthcare organizations, individuals, and families.
- Policy levels: in setting public policy locally, regionally, and nationally.

The essence of person- and family-centered care, as described in the following core concepts, is demonstrated at the clinical encounter. However, one key system level feature that facilitates the delivery of person- and family-centered care is engaging individuals and families in quality, safety, and system redesign activities. At the policy level, it is important to engage individuals and families in efforts to focus performance measurement on aspects of care that are most important to those receiving care.

Person- and Family-Centered Care Core Concepts to Guide Performance Measurement

The Committee identified the following core concepts as important components of ideal person- and family-centered care to guide performance measurement (Figure 2). The Committee noted that all of the core concepts must be evident in order to experience person- and family-centered care and that none of the core concepts alone signifies person- and family-centered care. The Committee also noted the interrelationship among the core concepts. For example, the "family" concept specifically addresses involvement in care and need for support, but all the other concepts also extend to the family, especially, when the patients are

FIGURE 2. PERSON-AND FAMILY-CENTERED CARE CORE CONCEPTS TO GUIDE PERFORMANCE MEASUREMENT



1. Individualized care – I work with other members of my care team[a] so that my needs, priorities, and goals for my physical, mental, spiritual, and social health guide my care.
2. Family – My family[b] is supported and involved in my care as I choose.
3. Respect, dignity, and compassion are always present.
4. Information sharing/communication – There is an open sharing of information with me, my family, and all other members of my care team(s).
5. Shared decisionmaking – I am helped to understand my choices and I make decisions with my care team, to the extent I want or am able.
6. Self-management – I am prepared and supported to care for myself, to the extent I am able.
7. Access to care/convenience – I can obtain care and information and reach my care team when I need and how I prefer.

---

[a] **Care Team** includes individuals and families and all healthcare and supportive services workers who interact with them.

[b] **Family** is defined by each individual.

children or others for whom decisions must be made in full or in part by surrogates. Each core concept is further described and exemplified with a vignette in the following section.

Other Dimensions of Quality

Individuals and their families also have great interest in receiving care that is safe, effective, and affordable. These dimensions of quality are related to person- and family-centered care and are enhanced and improved in a person-centered system. Nonetheless, safety, effectiveness, and affordability are the focus of other quality performance measures and are not specifically addressed in this set of recommendations.

Individualized Care

I work with other members of my care team[a] *so that my needs, priorities, and goals for my physical, mental, spiritual, and social health guide my care.*

Each person is unique with respect to their priorities and goals for health. Care not aligned with a person's priorities and goals in relation to their healthcare needs could be less effective and more burdensome. Since each person is part of a larger network of social and cultural norms, spiritual beliefs, interpersonal relationships, and economic needs, the care team should consider all aspects of health that influence an individual's care. Individuals should work in partnership with their care team to ensure that their priorities and goals are reflected in their plan of care. When persons' priorities, needs, and goals for physical, mental, spiritual, and social health determine the care and how it is rendered, the plan of care will better reflect issues most important to patients.

[a] Care Team includes individuals and families and all healthcare and supportive services workers who interact with them.

vignette

"Molly" is 50 years old, has chronic, disabling pain in her back and knees, and is the primary caregiver for her ailing mother. Having moved recently, Molly felt isolated and struggled with depression and alcohol misuse. When she sought healthcare services, she immediately found a comforting environment, and a tightly integrated care team. At her first visit, she met with her new doctor, her nurse, a personal health coach, and an onsite behavioral health specialist. This team has partnered with Molly to address her health issues and personal goals that she herself prioritized. During this tough time, Molly lost her driver's license, due to an episode of DWI. She was unable to drive to her orthopedic appointment, but her health coach took a morning to drive her there. This specialist visit proved essential for later scheduling of pain-reducing surgery. On the drive back, they chose a scenic route, stopping at a mountain view, which gave Molly quiet time to re-center herself. Molly still recounts that day as transformative. When she briefly became homeless, the care team helped her find housing and also coached her on job interviewing skills. Molly continues to work on mental health issues, but now does so with regular support from her care team, and she has much less physical pain. She has found a job, is highly engaged in her healthcare, and feels empowered.

Family

My family[b] is supported and involved in my care as I choose.

Many individuals have a support system that often reaches beyond traditional family members. Therefore, “family” is defined by each individual. A person’s wishes about family involvement and care providers should be respected and supported by the care team. Family members often play a critical role in decisionmaking, following the plan of care, and safety. Patients who are unable to direct their own care (including children) rely heavily on a family member to make decisions and navigate the healthcare system. Because patients’ and family members’ preferences, needs, and goals may diverge, care teams need to be sensitive to family issues and dynamics and ensure proper communication and support for family caregivers to equip them to be part of a team whose ultimate goal is to provide optimal care for the patient.

[b] Family is defined by each individual.

vignette

“Mr. Samuel” is a 30-year-old Romanian bricklayer with hypertension. He lives with his parents, with whom he emigrated. When his doctor prescribed medication and a low salt diet, his parents doubted the efficacy of medical treatment and felt that the diet would mean their lifestyle would have to change too. Mr. Samuel was caught between his physician and his parents. He resolved the dilemma by complying with the treatment plan in part which meant taking his medication irregularly and following his diet for only a few days. Partial compliance ironically convinced both the doctor and the family that each was right. The doctor saw it as a confirmation that the patient must try harder, and the family was convinced that the treatment was not working. Mr. Samuel’s blood pressure remained high. The doctor soon recognized the situation and invited the patient’s parents to come in with him. He explained their son’s hypertension and the rationale for the treatment plan. He enlisted their help, clearly indicating that they could bring about some change for their son. The patient’s mother was engaged as an expert on diet. The parents gave their permission for the son to take the medication. By being proactive, the physician worked through a less than fully supportive network.

Adapted from the book “Family Oriented Primary Care” by Susan McDaniel.[13]

Respect, Dignity, and Compassion

Respect, dignity, and compassion are always present.

Interpersonal relationships between individuals, families, and care team members should be based on mutual respect, dignity, and compassion to foster collaborative partnerships. High quality communication, such as active listening; common courtesies, such as knocking and privacy; responding to emotions with empathy; and being respectful of patients' time should be expected. An organizational culture in which healthcare workers are treated with respect, dignity, and compassion promotes those attributes in interactions with patients. A respectful environmental design supports privacy and collaboration and also a welcoming space for family involvement.

vignette

"Leonard" has advanced non-small cell lung cancer, and he is on an inpatient ward for pneumonia. He has been followed by an outpatient oncology clinic and has been receiving chemotherapy. Leonard understands his disease and prognosis, and he feels supported by his oncologist and outpatient palliative care team. A social worker, who is part of his outpatient team, has provided resources to help deal with financial strain. A chaplain has assisted him with spiritual concerns and referred his son to a support group, which has really helped the family. His interdisciplinary medical team has supported him in talking openly with his family. Still, his current hospitalization has made him anxious, and he has many questions for his oncologist. Next morning, his doctor visits him after 8:00 o'clock to make sure he is awake, and before entering, knocks on his door. Leonard welcomes him into the room. "How are you feeling?" his doctor asks. "Better," says Leonard, "but I'm pretty anxious." His doctor nods and says, "I know it can be hard being in the hospital. Is there anything I can do for you?" They briefly discuss his concerns and decide to set a meeting with Leonard's oncologist and palliative care team later that day. Leonard feels listened to and less nervous. He is focused on fighting his disease and knows that his care team will work with him to make a plan before he leaves the hospital. Leonard is looking forward to his son's high school graduation this spring.

Information Sharing/Communication

There is an open sharing of information with me, my family, and all other members of my care team(s).

Accurate and timely information is critical to effective and efficient healthcare services and also an important element of some other core concepts, particularly individualized care, shared decisionnmaking, and self-management. Information exchange is bidirectional from patients and families to the care team, from the care team to patients and families, and between care team members and other care teams. Open dialogue and a free flow of information between individuals and their care team support collaborative partnerships and patients in engaging in their care. Effective information sharing requires adequate time, person-centered communication, and attention to health literacy. Providers who spend adequate time with their patients, encourage questions, and respond in a manner that is easy to understand encourage patients to be better informed about their health conditions and treatment options. Systems help support effective exchange of information with patients and care team members. To expand exchange of information beyond the confines of clinical settings, other modes of communication (e.g., email, patient portals, telephone) allow for seamless flow of information. Communication and exchange of information is important between and among care teams to ensure an effective coordination during transitions and hand-offs.

vignette

In New York State, patients can log in to the Health Information Exchange and see all of their information across all healthcare providers who are exchanging information in the State. Other places, like the Geisinger Health System, have a patient portal where all of the clinicians' notes are freely available. No regulation requires this, but it's something you can imagine anyone finding value in: "I want an organization that releases my lab results instantly and gives me open access to my notes." Having relevant information puts patients in a much better place to choose a provider who will meet their goals and expectations.

Shared Decisionmaking

I am helped to understand my choices and I make decisions with my care team, to the extent I want or am able.

Individuals are ultimately responsible for their health and live with the consequences of decisions about their care. Some individuals (including children) require surrogate decisionmakers. Ideally, decisions about specific treatments and the overall plan of care are made in collaboration between individuals and their care teams. However, the range of desired input from patient versus care team varies from person to person based on an individual's wishes and ability and also could vary for an individual based on the type of decision and over time. Assessment and periodic reassessment of patients' preferences, values, and goals should drive healthcare decisions. Systems can provide the tools to support the care team and patients to engage in shared decisionmaking. As an individual's health status changes and an illness progresses, preferences and goals may change; these changes should always be in an up-to-date and shared care plan. Finally, advance care planning is a critical component of designing care that agrees with a person's preferences, values, and goals.

vignette

When I was pregnant with my second child, I tried to find a midwife with my insurance. There were only four midwives at one area hospital my insurance would cover. This hospital is known as the baby mill. So four midwives treat a very large metropolitan area. Two were busy, and one was going on vacation, so I didn't get a midwife. I stuck with my OB/GYN, and I felt like she would really respect my wishes. I wanted to have the connection with the doctor, because I was going to be doing a vaginal birth after cesarean (VBAC). I went asking around to get insider information on VBAC rates, and the hospital I ended up choosing actually shares that information in their classes. They're well-known for having really high VBAC rates. I felt like my doctor was very collaborative in the decisions, because there were other physicians in the practice who did not agree with my choices, but my doctor wrote it everywhere, made it known. So it didn't matter what physician I got; my choices were going to be respected.

Self-Management

I am prepared and supported to care for myself, to the extent I am able.

Most healthcare occurs outside healthcare facilities and clinical encounters as individuals and their families follow an agreed upon plan of care. In 2003, the Institute of Medicine defined self-management support as "the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support."[14] Managing chronic conditions and multiple comorbidities can be a daunting task that requires a great amount of time and effort for individuals and the families who support them. To increase an individual's confidence and ability to be an agent in their own care, ample support and education are needed to help them manage their health needs as effectively as possible. Families also need to be included in education and supported to assist patients in self-management.

vignette

Darryl is a nine-year-old with severe persistent asthma who has four to eight visits a year to the Emergency Department. He lives with his mother and sister and sometimes spends weekends with his father or his aunt and grandmother. Darryl sometimes forgets to take his medications or forgets to bring the meds with him when staying with relatives. He also has difficulty getting his medications refilled due to insurance denial. The providers at Darryl's primary care clinic asked the right questions and really tried to understand Darryl's circumstances. First, they repackaged the medications that he used as an inpatient for use in the outpatient setting because when Darryl returned to the hospital it was often because he hadn't filled his medications. Second, they sent staff to do a home visit to assess what needed to be done and to teach Darryl and his mother how to manage his condition. Third, they found a local pharmacy that would deliver refills to Darryl. The pharmacy was linked to the Medicaid database which allowed the care team to know that Darryl received his medications. All of the support and care that Darryl and his mother received outside of the clinical setting helped them to manage his condition more effectively.

Access/Convenience

I can obtain care and information, and reach my care team when I need and how I prefer.

Timely and easy access to care and information has positive effects on satisfaction, self-management, and outcomes. Systems that value patients' time also convey respect. For example, the scheduling of multiple appointments on the same day, minimal wait times, and weekend and after-hours appointments recognize that patients and their families have full and busy lives beyond their healthcare issues. The ability for patients to access the information they need and want, such as test results, clinical notes, self-management resources, and up-to-date plan of care also fosters efficiency in that it could replace the need for direct contact with the care team or help focus the encounter on the most pressing issues. Access and convenience influence satisfaction, contribute to building trust between individuals and their care team, and facilitate achieving the best health outcomes for patients and their families.

vignette

Five years ago I was diagnosed with cancer. I live in a small town with a number of different medical centers that aren't interconnected. They're different private groups. On a Friday afternoon I went in for a biopsy. They thought it was going to be benign. But by Friday evening, the pathologist had read it and called me and said it was cancer. I had an appointment with my primary care doctor on Monday morning. I was in the waiting room for about two minutes. The doctor was in the room about three minutes later, and I had a great conversation with him. My doctor said, "you know, I think you should see an oncologist. Where would you like to go?" And I said, "I'd like to go here in town." Then he told me, "I'll see what I can do." He left the room. Ten minutes later he came back and told me I had an appointment at 1:00pm that same day. "In the meantime," my doctor said, "you've got an appointment for a CAT scan down the street. And we scheduled some time for you to have lunch in between." He gave me my after-visit summary with all of my information and the pathology report. I drove down the street to the CAT scan place. They were waiting for me. I got my CAT scan right away. I waited another two minutes, and they handed me the CAT scan image on a CD. I went to lunch. At 1:00pm I went to the oncologist and I waited, like a minute or two in the waiting room. The oncologist said, "Hi, I've talked to your doctor. I've read your CAT scan. I've read your pathology report. Let's talk about your cancer."

FRAMEWORK FOR PERFORMANCE MEASUREMENT OF PERSON- AND FAMILY-CENTERED CARE

The framework for measuring person- and family-centered care combines the core concepts discussed above and the structure-process-outcome framework for quality assessment as illustrated in Table 1. Specific considerations for measuring person- and family-centered care are discussed in this section. The Committee identified potential structure, process, and outcome measure concepts, which are provided in **Appendix D**.

TABLE 1. MEASUREMENT FRAMEWORK FOR PERSON- AND FAMILY-CENTERED CARE

Core Concept	Structure Concepts	Process Concepts	Outcome Concepts
	Organizational structure or systems that support person- and family-centered care	*Interaction between person/family and the care team that is intended to facilitate achieving the experience reflected in the core concepts*	*Desired outcomes of person- and family-centered care (particularly the experience with care)*
1. Individualized care – I work with other members of my care team[a] so that my needs, priorities, and goals for my physical, mental, spiritual, and social health guide my care.			
2. Family – My family[b] is supported and involved in my care as I choose.			
3. Respect, dignity, and compassion are always present.			
4. Information sharing/ communication – there is an open sharing of information with me, my family, and all other members of my care team(s).			
5. Shared decisionmaking – I am helped to understand my choices and I make decisions with my care team, to the extent I want or am able.			
6. Self-management – I am prepared and supported to care for myself, to the extent I am able.			
7. Access/convenience – I can obtain care and information, and reach my care team when I need and how I prefer.			

[a] **Care Team** includes individuals and families and all healthcare and supportive services workers who interact with them.

[b] **Family** is defined by each individual.

Structure Process Outcome

The classic structure-process-outcome approach to quality assessment can be applied to person- and family-centered care. Structure refers to the capacity of a healthcare organization to provide high-quality healthcare (e.g., staff experience and training, information systems, electronic health records). Process refers to a healthcare-related activity performed for, on behalf of, or by a patient (e.g., lab test, x-ray, surgery, medication, physical assessment). Outcome refers to the health status of an individual (or change in health status) resulting from healthcare — desirable or adverse (e.g., improved function, survival). Resource use (e.g., cost) and experience with care are also considered outcomes for performance measures. Patient-reported outcomes (PRO) are 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 include:

- 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)

The PRO domain of experience with care is most relevant to measurement of person- and family-centered care.

Considerations of Structure, Process, and Outcome Measures for Person- and Family-Centered Care

Structure and Process

When a body of empirical evidence shows that a specific healthcare structure or process influences a desired outcome, it establishes an appropriate standard of care. National standard performance measures focused on those evidence-based structures and processes can be useful indicators of quality of care and also provide direction to those providing care. NQF-endorsed performance measures are used in accountability applications such as public reporting and pay-for-performance programs and should be based on strong enough evidence to hold all relevant healthcare units accountable. However, developing national standard performance measures based on structures and processes that support person- and family-centered care poses some challenges.

First, some structures and processes may not be as meaningful to individuals as information on the experience of person- and family-centered care as exemplified in the core concepts. This is especially true if the performance measure is essentially focused on whether or not documentation of a specific process occurred. For example, a performance measure that captures whether there is a plan of care (yes/no) is less meaningful than an outcome measure that captures whether individuals think their care plans reflect their individual priorities, goals, and needs.

Second, there may be multiple ways, through various structures and processes of care to achieve the core concepts. For example, there are many ways the care team works with individuals and families in shared decisionmaking, developing an individualized plan of care, or preparing them for self-care management, which could vary depending on the individual and the context of care. Additionally, the existing empirical evidence might not be strong enough to identify the most effective approach for achieving the desired outcomes and the focus of a national standard performance measure used in accountability programs. Involving individuals and families in the meaningful development of empirical evidence can help develop a robust body of knowledge in this area.

An advantage of structure and process measures is that they do signal what should be done. This can be useful for improvement activities or to inform patients about what they should expect.

However, as noted above, a strong evidence base is necessary for creating a national standard performance measure. Process measures of promising interventions or practices can be used locally for performance improvement even though not ready to be endorsed and used in accountability programs.

Outcome, PRO

Outcome performance measures of person- and family-centered care are likely to be person-reported outcomes (PRO) of the experience with care; however, there could be other outcomes that do not require patient report. NQF's prior work on **PRO-based performance measures** noted that desired outcomes should be identified and then the best source of information for each outcome. In the PRO report, PRO domains were identified as health-related quality of life/functional status, symptom/symptom burden, experience with care (including engagement and shared decisionmaking), and health-related behaviors (e.g., smoking). In that project it was clarified that PRO refers to the outcome concept, PROM refers to the person-level measure (i.e., instrument, tool, survey), and PRO-PM refers to the performance measure based on the aggregated person-level PROM data.

In addition to being organizing concepts, the core concepts of person- and family-centered care can be considered outcomes because they represent the desired experience with care. PRO-PMs in the other domains are not necessarily indicators of person- and family-centered care as described by the core concepts. For example, a PRO-PM on improvement in function or decrease in pain for persons receiving a hip or knee replacement is more an indicator of treatment effectiveness than person-centeredness. (See **Appendix F** for a related task reviewing PRO-PMs for depression, hip and knee replacement measures.) However, the process of using PROMs such as symptom and function scales could be viewed as a possible indicator of delivering person-centered care if they are incorporated into the assessment and management of care. That is, the results are reviewed, discussed with persons, used to co-develop a plan of care, and to monitor progress on reaching goals. If the PROM is simply administered to fulfill a requirement for measurement, it will not facilitate person-centered care and may increase burden and frustration.

Outcome performance measures, including PROs, are often preferred because they most directly address the reasons for seeking and providing healthcare and valued experiences. They also encompass more aspects of care than narrow process measures. However, outcome performance measures used in accountability applications may be more methodologically challenging due to the potential need for case-mix adjustment.

PRIORITIES AND RECOMMENDATIONS FOR PERFORMANCE MEASUREMENT

Performance measurement for person- and family-centered care primarily should be directed at measuring the person-reported experience represented by the core concepts. The Committee identified some key structures, processes, and outcomes related to person- and family centered care (**Appendix D**). Although some structures and processes that facilitate the delivery of person- and family-centered care were identified, the Committee agreed that the priority is measuring the person and family experience with care as represented by the core concepts. However, some of the structures that support person- and family-centered care could be incorporated into a standard label as discussed in the next section.

Principles for Measure Development

Three key principles should inform the identification of measure concepts for person- and family-centered care. Performance measures should be:

- selected and/or developed in partnership with individuals to ensure measures are meaningful to those receiving care;
- focused on the person's entire care experience, rather than a single setting, program, or point in time; and
- measured from the person's perspective and experience (i.e., generally person-reported unless the person receiving care is not the best source of the information).

The Committee made recommendations for the staging and prioritization of measure development to advance person-centered care. Following are overarching, short- and intermediate-term recommendations:

Overarching Recommendations

- Integrate individual and family input into the ongoing dialogue and decisions as performance measures are developed. Utilize forums and methods that will engage individuals and families from diverse backgrounds to ensure that the measures are meaningful for broad and diverse populations.
- Focus measurement on person-reported experiences and other outcomes when possible over measures of structures and processes of care. Experience with care and other outcomes are generally of most interest to individuals and families. Measuring performance on outcomes allows flexibility in the approaches used to deliver and transform care. Measuring outcomes can have the advantage of parsimony and less burden than measuring multiple structures and processes.
- Highlight and build on work underway whenever possible. There is a substantial history of work and rich examples of transformative person- and family-centered care that can inform performance measurement.
- Consider the evolving healthcare system. With a rapidly changing delivery system, eyes should be on where we are going as opposed to where we currently stand. Retail clinics such as Walgreens and CVS are becoming a new primary care delivery system and offer another avenue for person- and family-centered care.

- Go beyond silos of accountability and measurement. Delivering and improving person- and family-centered care should involve systems and will require a consideration of all relevant units of analysis and settings.

- Consider actionability by those being measured. Experience with care measures should focus on experiences that are influenced by those delivering care. Historically, experience with care performance measures are based on data from a sample of anonymous individuals. That feedback may not lend itself to typical performance improvement activities where one can review records to identify specific practices that contributed to the outcome. However, if people are hesitant to give forthright assessments without anonymity, that needs to be balanced against greater specificity for process of care investigations.

Short-Term Recommendations

- Consider starting with one simple question from the individual's perspective such as "how is your care working out for you?" or "do you feel like you were well taken care of?" This type of question could be asked in any setting in any situation.

- Alternatively, consider initially focusing on patients with higher levels of need such as individuals with multiple comorbidities, advanced dementia, and serious illnesses, or those in underserved or disadvantaged populations. These individuals are most in need of high quality person-centered care that emphasizes collaborative partnerships between the individual and family and the care team to achieve care represented in the core concepts. If it can work with these patient groups, then it could be adapted and scaled for the broader population.

- Consider available Consumer Assessment of Healthcare Providers and Systems (CAHPS) performance measures. Many important performance measures based on current CAHPS surveys address the identified core concepts. Some examples are provided in the table of potential measure concepts in **Appendix D**. A listing of the CAHPS performance measures and their component questions was included in the environmental scan and tagged according to the person- and family-centered care core concepts. See **Appendix E** and the accompanying **Excel file** submitted as a deliverable to HHS. The most salient measures could serve as a foundation for a composite measure of person- and family-centered care. Given the breadth and scale of CAHPS, systems-level measurement might also be possible. As has been mentioned in many conversations, the issue of proxy responses for individuals unable to complete the CAHPS will need to be addressed.

- Convene a group comprised of experts on **CAHPS** and Patient Reported Outcomes Measurement Information System (**PROMIS**) for mutual learning and measure development. This combines the CAHPS expertise in identifying experience with care measures related to many of the core concepts and the PROMIS expertise in applying new methods of measurement. In the short term, they could identify existing measures that are good enough and in the longer term work toward developing a patient-level measure of person-centered care that is similar to the PROMIS-10 and ultimately could be used in performance measurement.

- Explore the person-centered care label concept presented in a following section. Such a label would provide a standardized way of communicating information related to some aspects of an organization's person- and family-centeredness, particularly systems features. Guidance from individuals receiving care should inform what is included as well as how to best illustrate this information for optimal use.

Intermediate-Term Recommendations

- With the joint CAHPS/PROMIS group mentioned above, explore developing a “Person-centered Care 10”patient-level scale—similar to the PROMIS global health scale, which is a global assessment of health-related quality of life in 10 questions. Consideration could be given to measure cascades where scales for all the core concepts could be developed to allow users to focus on the core concepts of most interest. The data from patient-level scales then need to be aggregated for an organizational-level performance measure.

- Incorporate the full healthcare experience beyond a single setting. Currently, experience of care measures are focused on a person’s experience in a single healthcare setting. A fully realized person- and family-centered care occurs over time and across settings and expands beyond the walls of hospitals and physician offices. Efforts should focus on assessing a person’s full experience of their healthcare. This will be particularly important as we move full steam toward integrated care delivery models which will be accountable for a person’s full spectrum and entire experience of care. However, if not measured at a broad system level, methods for attributing performance to a specific accountable entity need to be developed.

- Advance family experience individual-level scales. Currently, the availability of family experience measures is severely limited, which presents a significant gap, particularly for family members of patients with serious illnesses and complex care needs. Consideration should be given to creating a strong system for eliciting and addressing the needs of families and caregivers, particularly when the care plan relies heavily on their involvement. The data from individual-level scales then need to be aggregated for an organizational-level performance measure.

- Fund research to advance measurement of person- and family-centered care. Some potential research topics include: vetting the core concepts with individuals and families; developing patient-level measures of experience with care measures on person- and family-centered care such as the PROMIS-10; develop methods for aggregating patient-level data into performance measures; determining when anonymity is needed for experience with care measures on person- and family-centered care; and identifying which clinical outcomes are influenced by person- and family-centered care.

STANDARD LABEL FOR PERSON- AND FAMILY-CENTERED CARE

Although systems such as a patient portal for access to the clinical record support the delivery of person- and family-centered care, structural measures that generally are yes/no indicators are often not useful to discriminate differences in performance in comparative quality assessments. However, standardized information about the structures and systems employed by various organizations to support person- and family-centered care could be useful to individuals to identify providers who will best meet their needs and preferences, especially related to the core concept of access/convenience and information sharing/communication. These could be explored as potential elements of a standardized label for person-centered care ("nutrition label" concept). For example, information about extended hours, time to get an appointment, communication via email, open visiting policy and inclusion in staff reports could be helpful in finding healthcare services that best meet a person's needs or preferences. This type of information does not necessarily require reporting quantitative data or interpretation in comparison to average performance for the feature. However, information provided in a standard format would allow individuals to weigh various aspects in terms of what is most important to them.

Such a label would not be intended to encompass all performance measurement of person- and family-centered care. However, the label could also identify participation in external performance measurement programs and provide links to other performance measures of the core concepts of person-and family-centered care as well as measures of safety, quality, and affordability that are important to patients.

Key aspects of the label concept include a standardized list of features, definitions, and layout as seen with a nutrition label. The sample label below includes organizational features that could be included in a label about person- and family-centered care. Full development of the label would need to explicitly involve individuals and families in the prioritization of the standard features that would be most useful. This process would be an important collaborative effort to a person- and family-centered approach to developing measures. This could be incorporated into follow-up work by NQF.

FIGURE 3. SAMPLE STANDARD LABEL FOR PERSON- AND FAMILY-CENTERED CARE

Person- and Family-Centered Care

Organizational Statement of
Person- and Family-Centered Care: 2-3 sentences

Individual/Family Advisory Group:	Yes/No
URL link:	
Individual Portal to Electronic Health Record:	Yes/No
Entire Record:	Yes/No
Partial Access – Test Results:	Yes/No
– Clinical Notes:	Yes/No
Link to Personal Health Record:	Yes/No

Nonemergency Communication

Phone: Yes/No email: Yes/No text: Yes/No

Languages spoken/interpreters available:

Hours of Operation: (including extended hours evenings, weekends)

Ease of Scheduling Appointments

Same-day appointments:	Yes/No
Avg. # days to available appointment:	xx days

For Facilities

Open visiting policy:	Yes/No

ENVIRONMENTAL SCAN OF PERFORMANCE MEASURES FOR PERSON- AND FAMILY-CENTERED CARE

The final environmental scan of potential performance measures related to person- and family-centered care can be found in an accompanying **Excel document** submitted as a deliverable to HHS. Because of the potential to address many of the aforementioned core concepts, CAHPS surveys and their associated performance measures were mapped to the core concepts. CAHPS surveys reviewed in the scan are used in a variety of care settings including inpatient, outpatient, post-acute care and long-term care (PAC/LTC), and specific populations such as End-Stage Renal Disease (ESRD) and people with mobility impairment. A number of non-CAHPS performance measures were also identified to address the core concepts. Table 2 provides a snapshot of the number of CAHPS measures and non-CAHPS measures mapped to the core concepts. As the core concepts are not mutually exclusive, a number of measures were thought to be relevant to more than one core concept. **Appendix E** includes a crosswalk of each survey tool, at the measure level, to the core concepts.

TABLE 2. ENVIRONMENTAL SCAN OF MEASURES BY CORE CONCEPTS

Core Concepts	CAHPS Measures N=108	Non-CAHPS Measures N=66
Individualized Care	25	22
Family	8	6
Respect, dignity, and compassion	23	5
Information sharing/ communication	58	13
Shared decisionmaking	8	10
Self-management	6	26
Access to care/convenience	32	7

Most notably, a large number of the performance measures in the array of CAHPS surveys addressed many aspects of communication and interpersonal relationships and fewer measures captured shared decisionmaking, family involvement and support, and self-management. Evaluation of non-CAHPS measures also revealed a large gap in the measurement areas related to the core concepts of family and shared decisionmaking. Although a larger number of non-CAHPS measures were mapped to self-management, the majority of them only evaluated whether education was provided and did not address the individual's understanding or level of confidence in ability to manage care or adhere to treatment. Even though the CAHPS survey instruments address many of the core concepts, significant gaps remain as they do not comprehensively address each of the measurement areas. Additionally, the importance of capturing the experiences of people with very serious illness who are unable to participate in the survey must be addressed.

ENDNOTES

1 Institute of Medicine Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century,* Washington, DC: National Academy Press;2001.

2 U.S.Department of Health and Human Services. *National Strategy for Quality Improvement in Health Care 2013 Annual Progress Report to Congress.* 2013. Available at http://www.ahrq.gov/workingforquality/nqs/nqs2013annlrpt.htm.

3 Robert Wood Johnson Foundation. What we're learning: engaging patients improves health and health care. *Quality Field Notes.* 2014;(3):1-4.

4 Rosland AM. *Sharing the Care: The Role of Family in Chronic Illness.* Sacramento, CA: California HealthCare Foundation (CHCF); 2009. Available at http://www.chcf.org/publications/2009/08/sharing-the-care-the-role-of-family-in-chronic-illness.

5 Committee on Hospital Care.American Academy of Pediatrics. Family-centered care and the pediatrician's role. *Pediatrics.* 2003;112(3 Pt 1):691-697.

6 Institute of Medicine. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America.* Washington, DC: National Academies Press; 2012. Available at http://www.iom.edu/Reports/2012/Best-Care-at-Lower-Cost-The-Path-to-Continuously-Learning-Health-Care-in-America.aspx.

7 Shaller D. *Patient-Centered Care: What Does It Take?* New York, NY: Commonwealth Fund; 2007.

8 Institute for Patient- and Family-Centered Care. Frequently asked questions. *Institute for Patient- and Family-Centered Care.* Available at: http://www.ipfcc.org/faq.html. Updated December2010.

9 Frampton SB, Guastello S. Patient-centered care: more than the sum of its parts-Planetree's patient-centered hospital designation programme. *World Hosp Health Serv.* 2010;46(4):13-16.

10 McDonald G, Oxford M. Independent living history: a brief history of the Independent Living Movement. *Access Living.* Available at: http://www.accessliving.org/index.php?tray=topic&tid=top626&cid=134. Updated 2008.

11 Connor SR. *Hospice and Palliative Care: The Essential Guide,* 2nd ed. New York: Routledge, Taylor and Francis Group, LLC;2009.

12 de Silva D. *Helping Measure Person-Centred Care: a Review of Evidence About Commonly Used Approaches and Tools Used to Help Measure Person-Centered Care.* London, UK: The Health Foundation; 2014.

13 McDaniel SH, Campbell TL, Hepworth J, Lorenz A. *Family-Oriented Primary Care,* 2nd ed. New York, NY: Springer;2005.

14 Institute of Medicine. *Priority Areas for National Action: Transforming Health Care Quality. Executive Summary.* Washington, DC: National Academies Press; 2003. Available at http://www.nap.edu/openbook.php?record_id=10593&page=R1.

APPENDIX A:
Project Approach and Methods

The project approach followed the outline depicted below in Figure A1 to complete this project.

FIGURE A1. SEVEN-STEP PROCESS FOR PERSON-CENTERED CARE AND OUTCOMES PRIORITY SETTING PROJECT

Step **1** Convene multistakeholder committee

Step **2** Identify 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 the committee, seek input from patients and families on what information would be useful for assessing person-centered care

Step **4** Conduct environmental scan of potential performance measures and measure concept

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 convened a 19-member multistakeholder committee to provide guidance to meet the project objectives. Committee members were 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. NQF convened the full committee (see roster in Appendix B) 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. Building on prior work, this project identified 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 to move from the present to the ideal.

Seek input from patients and families on what information would be useful for assessing person-centered care. NQF worked closely with patients and patient advocates to identify areas for measurement that matter most to the patients and their families. NQF explored the efforts that are currently underway by consumer groups to 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 conducted an environmental scan of CAHPS surveys and relevant performance measures and measure concepts mapped to the person- and family-centered care core concepts. Additionally, NQF conducted outreach to a number of stakeholders including the previously convened NQF PRO Expert Panel to identify examples of person-centered performance measures that address the identified core concepts as well as to identify any additional areas that should be considered for measuring person- and family-centered care.

Convene the multistakeholder committee via an in-person meeting to develop recommendations and priorities for performance measure development. The multistakeholder committee met in person on April 7-8, 2014 to create the vision of the ideal state or "North Star" of person-centered care and make recommendations for measuring the progress and performance of systems that support person- and family-centered care.

Recommend specific measures for implementation or specific concepts for development of performance measures related to person-centered care. The Committee weighed the pros and cons of different types of performance measures including structure, process, and outcome measures to make short- and long-term recommendations on the specific measures or measure concepts most impactful to advance person-centered care.

Obtain public comment, and finalize recommendations. NQF held a public webinar to solicit feedback on the draft report. Comments from the public and HHS were incorporated into the final report submitted to HHS on August 15, 2014.

APPENDIX B:
Person-Centered Care and Outcomes Committee Roster

COMMITTEE MEMBERS	
Uma Kotagal, MBBS, MSc (Co-Chair)	Cincinnati Children's Hospital Medical Center, Cincinnati, OH
Sally Okun, RN (Co-Chair)	PatientsLikeMe, Cambridge, MA
Ethan Basch, MD, MSc	University of North Carolina at Chapel Hill, Chapel Hill, NC
Dave deBronkart, Jr.	Society for Participatory Medicine, Nashua, NH
Joyce Dubow, MUP	AARP, Washington, D.C
Jennifer Eames-Huff, MPH	Consumer-Purchaser Disclosure Project, San Francisco, CA
Troy Fiesinger, MD	Memorial Family Medicine Residency, Sugar Land, TX
Christopher Forrest, MD, PhD	The Children's Hospital of Philadelphia, University of Pennsylvania, Philadelphia, PA
Lori Frank, PhD	Patient-Centered Outcomes Research Institute, Washington, DC
Priti Jhingran, BPharm, PhD	GlaxoSmithKline, Research Triangle Park, NC
Lisa Latts, MD, MSPH, MBA, FACP	LML Health Solutions, LLC, Denver, CO
Bruce Leff, MD	Johns Hopkins University School of Medicine, Baltimore, MD
Michael Lepore, PhD	Planetree, Atlanta, GA
Mary MacDonald, MS, BA	American Federation of Teachers, Washington, DC
Mary Minniti, BS, CPHQ and Maureen Connor, RN, MPH (substitute for Mary Minniti in the April in-person meeting)	Institute for Patient-and Family-Centered Care, Eugene, OR Claremont Consulting Partners
Eugene Nelson, MPH, DSc	Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH
Mark Nyman, MD, FACP	Mayo Clinic, Rochester, MN
Laurel Radwin, RN, PhD	Veterans Administration, Manchester, NH
Anne Walling, MD, PhD	University of California-Los Angeles, Los Angeles, CA

DEPARTMENT OF HEALTH AND HUMAN SERVICES REPRESENTATIVES	
Cille Kennedy	Office of the Assistant Secretary for Planning and Evaluation
Kevin Larsen, MD, FACP	Office of the National Coordinator for HIT (ONC)
Ellen Makar, MSN, RN-BC, CCM, CPHIMS, CENP	Office of the National Coordinator for HIT (ONC)
Jennifer Wolff, PhD	Johns Hopkins Bloomberg School of Public Health, Atlantic Philanthropies Health and Aging Policy & APSA Congressional Fellow

NATIONAL QUALITY FORUM STAFF	
Karen Pace, PhD, MSN	Senior Director
Mitra Ghazinour, MPP	Project Manager
Kaitlynn Robinson-Ector, MPH	Project Analyst
Wendy Prins, MPH, MPT	Vice President

APPENDIX C:

Crosswalk of Core Concepts for Person- and Family-Centered Care

Person-Centered Care and Outcome Core Concepts	Institute of Medicine New Rule/What Patients Should Expect from Their Healthcare	Picker Institute Principles of Patient-Centered Care	Institute of Patient- and Family-Centered Care Core Concepts	The Commonwealth Fund Key Attributes of Patient-Centered Care	Planetree Core Dimensions
1. Individualized care – I work with other members of my care team[a] so that my needs, priorities, and goals for my physical, mental, spiritual, and social health guide my care.	**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 for patients' values, preferences, and expressed needs,** including an awareness of quality-of-life issues, involvement in decision-making, dignity, and attention to patient needs and autonomy.	**Respect and dignity.** Healthcare 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.	**Respect for patient needs and preferences** **Sensitivity to nonmedical and spiritual dimensions of care**	Human interactions– A model that embraces continuity, consistency, and accountability in care and permits staff to **personalize care for each patient**. **Spirituality** and Diversity– Documenting and addressing the needs of diverse cultural groups.
2. Family – My family[b] is supported and involved in my care as I choose.		**Involvement of family and friends** in decisionmaking and awareness and accommodation of their needs as caregivers.		**Involvement of family and friends**	**Family involvement–** Flexible, 24-hour, patient-directed visitation.
3. Respect, dignity, and compassion are always present.		**Respect for patients' values, preferences, and expressed needs**, including an awareness of quality-of-life issues, involvement in decision-making, dignity, and attention to patient needs and autonomy.	**Respect and dignity.** Healthcare 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.	**Respect for patient needs and preferences**	

Person-Centered Care and Outcome Core Concepts	Institute of Medicine New Rule/What Patients Should Expect from Their Healthcare	Picker Institute Principles of Patient-Centered Care	Institute of Patient- and Family-Centered Care Core Concepts	The Commonwealth Fund Key Attributes of Patient-Centered Care	Planetree Core Dimensions
4. Information sharing/ communication – there is an open sharing of information with me, my family, and all other members of my care team(s).	**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." **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.	**Information, communication, and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care, and health promotion.	**Information Sharing.** Healthcare 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.	**Education and shared knowledge** **Free flow and accessibility of information**	**Patient education and access to information-** Educational materials are available for patients and families and accessible to staff.
5. Shared decisionmaking – I am helped to understand my choices and I make decisions with my care team, to the extent I want or am able.	**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.		
6. Self-management – I am prepared and supported to care for myself, to the extent I am able.	**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.	Continuity and transition as regards information that will help **patients care for themselves** away from a clinical setting, and coordination, planning, and support to ease transitions.	Participation. Patients and families are encouraged and supported in **participating in care** and decision-making at the level they choose.		

Person-Centered Care and Outcome Core Concepts	Institute of Medicine New Rule/What Patients Should Expect from Their Healthcare	Picker Institute Principles of Patient-Centered Care	Institute of Patient- and Family-Centered Care Core Concepts	The Commonwealth Fund Key Attributes of Patient-Centered Care	Planetree Core Dimensions
7. Access/ convenience – I can obtain care and information, and reach my care team when I need and how I prefer.	**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.	**Access to care,** with attention to time spent waiting for admission or time between admission and placement in a room in the inpatient setting, and waiting time for an appointment or visit in the outpatient setting.			

[a] **Care Team** includes individuals and families and all healthcare and supportive services workers who interact with them.

[b] **Family** is defined by each individual.

APPENDIX D:
Measure Concepts for Person- and family-Centered Care

Definitions

Person- and family-centered care is**:** *An approach to the planning and delivery of care across settings and time that is centered around collaborative partnerships among individuals, their defined family, and providers of care. It supports health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values.*

*Care team includes individuals and families and all healthcare and supportive services workers who interact with them.

**Family is defined by each individual.

Notes

- The Committee recommended that the priority for performance measurement is the outcome concepts, primarily person-reported experience with care.
- Sample CAHPS performance measures are indicated for each core concept. A listing of the CAHPS performance measures and their component questions was included in the environmental scan and tagged according to the person- and family-centered care core concepts. See summary in **Appendix E** and details in the accompanying **Excel document** submitted as a deliverable to HHS.
- Some structure concepts might be suitable for a standardized label and are indicated with [label] in the following table.

Core Concept	Structure Concepts	Process Concepts	Outcome Concepts
	Organizational structures or systems that support person- and family-centered care Organization and system features include:	Interactions between person/ family and the care team that facilitate achieving the experience reflected in the core concepts Care team interactions include:	Desired outcomes of person- and family-centered care (particularly the experience with care) Person/family experience or other outcomes include:
Overarching	• Person/family advisory groups [potential for standard label of person- and family-centered care]	• At the end of each encounter ask: – What went well? – What could we do better to work with you and your family? – Do you feel like you were well taken care of?	• My care was exactly what I needed when and how I preferred

Core Concept	Structure Concepts	Process Concepts	Outcome Concepts
1. Individualized care – I work with other members of my care team* so that my needs, priorities, and goals for my physical, mental, spiritual, and social health guide my care.	• System supports use of person-reported tools: – Standard person-reported outcome measures (PROMs) that match the person's view of what matters or what bothers or interferes with their life – Person-centered outcome measures (PCOMs) that may be highly individualized (e.g., my treatment will be successful if I can walk up the bleachers at Fenway Park on the 4th of July with my grandkids; I will be able to tend my garden without being in constant pain, etc.) – Tools to assess preferences for care and decisionmaking style/ approach	• Find out what the individual's healthcare priorities and goals are—what matters most and/or what is most bothersome to the person using standard PROMs and PCOMs • Provide systematic assessment of PROs and well-being • Arrange home team visit by a care team member (chronic illness) • Use the PROM and/or PCOM with persons to co-develop the plan, mange care, and monitor progress • Create a comprehensive individualized plan that incorporates the individual's needs, priorities, and goals for physical, mental, spiritual, and social health	• My care team members know me • My preferences for care/ treatment are supported • What's important to me is at the center of my care • The care I received matches my goals and preferences • My care team asks me about my top health goals and most important health problems **Sample CAHPS Performance Measures** • Providers Pay Attention to Your Mental or Emotional Health (Adult only) – Patient-Centered Medical Home Item Set • Providers Support You in Taking Care of Your Own Health – Patient-Centered Medical Home Item Set
2. Family – My family** is supported and involved in my care as I choose.	• Practice infrastructure, e.g. Relationship with appropriate services to support – practice and non-practice based. • Environment design: welcomes and supports family involvement • Family support/discussion groups [label] • Recertification requirements for providers ties to family engagement as part of the evaluation process.	• Ask about family support and involvement in care • Assess family caregivers' strengths and limitations and identify ways to support their participation	• Assessment of PF/ CF experience WRT Support of family care partners by other care partners **Sample CAHPS Performance Measures** • Nursing Home Provides Information/ Encourages Respondent Involvement - CAHPS Nursing Home Family Survey • Including family and friends - Experience of Care and Health Outcomes (ECHO) Survey
3. Respect, dignity, and compassion are always present.	• Culture of respect: everyone is treated with respect and dignity • Respectful environmental design: Support for privacy for persons and families • Systems are respectful of persons and clinicians time	• Utilize person-centered communication – Positive support: empathy, legitimizing – Active listening	• I and my family are treated with respect, dignity, and compassion • My time was respected **Sample CAHPS Performance Measures** • Providers are Polite and Considerate – CAHPS Clinician (NQF#005) • Nurses/Aides' Kindness/ Respect Towards Resident – CAHPS Nursing Home Family Survey

Core Concept	Structure Concepts	Process Concepts	Outcome Concepts
4. Information sharing/ communication – there is an open sharing of information with me, my family, and all other members of my care team(s).	• Time is allocated for care team to answer all questions • Information sharing architecture (Information Commons) • Systems approach to health literacy • Systems support access to personal information – Individual portal to health record, clinical notes, care plan, test results [label] – Connect to personal health record – Procedure for corrections • Systems allow individuals to obtain standard information on: – Health problems – Treatments – Providers (profile, quality) [label] – Costs • System are able to receive information in a flexible manner by: – Time – Mode-paper, electronic, in person – Literacy level – Language – Readiness to learn – Sensory impairment • Integrated, interoperable electronic health record (EHR)	• Utilize person-centered communication – High levels of elicitation, checking for understanding, open-ended questions • Bidirectional information sharing • Use systematic approach to collect information • Help individuals/care team prepare for visit/encounter – Identify what the person wants to accomplish before the visit through email, phone – Encourage individuals to prepare a list of questions – Encourage individuals to bring someone along if desired • Keep individuals/family informed through processes such as bedside change of shift report, rounds, and discharge planning	• My care team listened to me • I had time to share what was important to me with my care team • My questions were answered in a way I could understand • I know what to do before my next visit • I know who to contact if I have additional questions • I have an assigned contact person for my care team • I can obtain any information I need when I need it, in a format I prefer • My care team has the right information at the right time (also could ask care team) • My care team keeps me, my family, and other care teams informed of my status and care plan • All my care team members provide consistent information once we have agreed on a plan of care • Information is reviewed, verified, and corrected if an error is identified **Sample CAHPS Performance Measures** • How Well Providers (or Doctors) Communicate with Patients - CAHPS Clinician (NQF #0005) • Individual Item: Follow up on Test Results - CAHPS Clinician (NQF #0005)

Core Concept	Structure Concepts	Process Concepts	Outcome Concepts
5. Shared decisionmaking – I am helped to understand my choices and I make decisions with my care team, to the extent I want or am able.	• Organization has clear requirements for engagement • Staff training in engagement • System tools to support engagement and shared decisionmaking	• Elicit preferences for shared decisionmaking • Collaborate with individuals to make decisions and to co-produce and implement a care plan that has the best chance of attaining the person's goals • Discuss and obtain advance directives • Ask about surrogate decisionmakers	• I was told about treatment options and their pros and cons and had time to review before making a decision • I was given choices that honored what was important to me and my family • Individual/family understanding of treatment options and their pros and cons • My care team and I agree on my plan of care • Care received matches individual's choices about treatment – Utilization measures (e.g., emergency visits, treatments, procedures, tests) in relation to the individual's decisions about treatment **Sample CAHPS Performance Measures** • Providers Discuss Medication Decisions (Adult) – CAHPS PCMH • Parents' Experiences with Shared Decisionmaking – CAHPS Item Set for Children with Chronic Conditions
6. Self-management – I am prepared and supported to care for myself, to the extent I am able.	Systems support self-management • Options for support – individual and family support/discussion groups online, group meetings, etc. [label] • Person/family instruction/ education – written, video, languages • Coaches, educators, mentors (peer, professional) • Network of community resources	• Provide instructions and training in format preferred by individual/family • Assess activation (PAM) and provide appropriate coaching/ support based on activation level • Check understanding/ comprehension of key points • Refer to appropriate resources	• I am confident that I can manage my own care • I received the information I needed to take care of myself • I know what to do to manage my condition to maintain or improve my health • I know what problems to watch for and what to do if they occur • I understand the potential impact on my health if I choose to change my care from the agreed plan • Adherence to treatment measures (e.g., prescription filled and taken) **Sample CAHPS Performance Measures** • Providers Support You in Taking Care of Your Own Health - CAHPS PCMH • Disease self-management – CAHPS Item Set for Addressing Health Literacy

Core Concept	Structure Concepts	Process Concepts	Outcome Concepts
7. Access/ convenience – I can obtain care and information, and reach my care team when I need and how I prefer.	• At a system level, time is viewed as important (i.e., respectful not to waste) • Availability of a help line for questions • Options for communications with follow-ups (multiple channels for communication telephone/e-mail/text [label] • Individual portal to health record, clinical notes, care plan, test results [label] • One stop shopping for care with integrated EHR • Weekend and after-hours appointments; virtual appointments • Same-day appointments • Systems for managing flow and waiting times • Systems for coordinating visits with multiple providers on the same day • Navigator/coach/ coordinator services [label] • Interdisciplinary care team, including navigator, social worker/case manager/coach; all have clearly defined roles • Average length of time in days between the day a person makes a request for an appointment with a physician and the third available appointment for a new patient physical, routine exam, or return visit exam. (IHI) [label] • Average waiting time (for scheduled appointment, ED visit, hospital admission, etc.) [label]		• I can access my care team when needed • **I** get everything I need when and how I prefer • I know who to contact for what reasons • My schedule or availability determines when my care is provided • My time was used efficiently • My care team cared about my time • When I have to wait, I am given an explanation and choices about how to deal with the delay **Sample CAHPS Performance Measures** • Getting Timely Appointments, Care, and Information – CAHPS Clinician (NQF #0005) • Getting Timely Answers to Medical Questions by E-mail – CAHPS Clinician (NQF #0005)

APPENDIX E:
Crosswalk of CAHPS Surveys and the Person- and Family-Centered Care Core Concepts

The following table provides a crosswalk of CAHPS surveys at the measure level to the person- and family-care core concepts. The accompanying Excel document includes the comprehensive list of CAHPS surveys, their corresponding measures, and the individual items/questions related to each measure.

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
0005 CAHPS Clinician & Group (Updated June 2012)	Core Items in Adult 12-Month and Visit Surveys 2.0 and the Child 12-Month Survey 2.0	Access to care *Getting Needed Care *Getting Care Quickly							yes
0005 CAHPS Clinician & Group (Updated June 2012)	Core Items in Adult 12-Month and Visit Surveys 2.0 and the Child 12-Month Survey 2.0	Most recent visit							yes
0005 CAHPS Clinician & Group (Updated June 2012)	Core Items in Adult 12-Month and Visit Surveys 2.0 and the Child 12-Month Survey 2.0	Provider communication with child			yes	yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Core Items in Adult 12-Month and Visit Surveys 2.0 and the Child 12-Month Survey 2.0	Provider communication			yes	yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Core Items in Adult 12-Month and Visit Surveys 2.0 and the Child 12-Month Survey 2.0	Development	yes			yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Core Items in Adult 12-Month and Visit Surveys 2.0 and the Child 12-Month Survey 2.0	Prevention	yes			yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Core Items in Adult 12-Month and Visit Surveys 2.0 and the Child 12-Month Survey 2.0	Clerks and receptionists at provider's office			yes				
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	After hours care							yes
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Being informed about appointment start			yes	yes			

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Chronic conditions							yes
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Communication with providers			yes	yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Cost of care (prescriptions)				yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Cultural competence			yes	yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Health improvement	yes			yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Health information technology				yes			yes
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Health literacy			yes	yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Health promotion and education	yes			yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Patient-centered medical home (PCMH)	yes			yes			yes
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Shared decisionmaking				yes	yes		
0005 CAHPS Clinician & Group (Updated June 2012)	Adult Supplemental Items	Your care from specialists in the last 12 months				yes			yes
0005 CAHPS Clinician & Group (Updated June 2012)	Child Supplemental Items	Screening items for children with chronic conditions	yes						yes
0005 CAHPS Clinician & Group (Updated June 2012)	Child Supplemental Items	Provider communication with child				yes			

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
0005 CAHPS Clinician & Group (Updated June 2012)	Child Supplemental Items	Provider communication				yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Child Supplemental Items	Provider thoroughness	yes						
0005 CAHPS Clinician & Group (Updated June 2012)	Child Supplemental Items	Patient-Centered Medical Home Item Set	yes			yes			yes
0005 CAHPS Clinician & Group (Updated June 2012)	Child Supplemental Items	Prescription medicines				yes			
0005 CAHPS Clinician & Group (Updated June 2012)	Child Supplemental Items	Shared decisionmaking				yes	yes		
0258 CAHPS In-Center Hemodialysis Survey Core Composites (Updated December 2007)	In-Center Hemodialysis	Nephrologists' Communication and Caring			yes	yes			
0258 CAHPS In-Center Hemodialysis Survey Core Composites (Updated December 2007)	In-Center Hemodialysis	Quality of Dialysis Center Care and Operations			yes	yes			yes
0258 CAHPS In-Center Hemodialysis Survey Core Composites (Updated December 2007)	In-Center Hemodialysis	Providing Information to Patients				yes	yes		
0166 CAHPS Hospital Survey (Updated January 2008)	Hospital/Acute Care Facility	Communication with Nurses			yes	yes			
0166 CAHPS Hospital Survey (Updated January 2008)	Hospital/Acute Care Facility	Communication with Doctors			yes	yes			
0166 CAHPS Hospital Survey (Updated January 2008)	Hospital/Acute Care Facility	Responsiveness of Hospital Staff							yes

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
0166 CAHPS Hospital Survey (Updated January 2008)	Hospital/Acute Care Facility	Cleanliness of the Hospital Environment	yes						
0166 CAHPS Hospital Survey (Updated January 2008)	Hospital/Acute Care Facility	Quietness of the Hospital Environment	yes						
0166 CAHPS Hospital Survey (Updated January 2008)	Hospital/Acute Care Facility	Pain Management	yes						
0166 CAHPS Hospital Survey (Updated January 2008)	Hospital/Acute Care Facility	Communication about Medicines				yes			
0166 CAHPS Hospital Survey (Updated January 2008)	Hospital/Acute Care Facility	Discharge Information				yes			
0166 CAHPS Hospital Survey (Updated January 2008)	Hospital/Acute Care Facility	An updated HCHAPS would include the 3-Item Care Transition Measure (CTM-3) (which is now required by CMS as part of the HCAPS reporting)	yes	yes		yes		yes	
0517 CAHPS Home Health Care Survey (Updated May 2009)	Home Health	Patient Care			yes	yes			
0517 CAHPS Home Health Care Survey (Updated May 2009)	Home Health	Communication with Health Care Providers and Agency Staff				yes			
0517 CAHPS Home Health Care Survey (Updated May 2009)	Home Health	Specific Care Issues Related to Pain and Medication				yes			
0006 CAHPS 4.0 Health Plan Survey (Updated December 2007)	Core Items (Medicaid and commercial)	Access: Getting Needed Care							yes

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
0006 CAHPS 4.0 Health Plan Survey (Updated December 2007)	Core Items (Medicaid and commercial)	Access: Getting Care Quickly							yes
0006 CAHPS 4.0 Health Plan Survey (Updated December 2007)	Core Items (Medicaid and commercial)	How Well Doctors Communicate				yes			
0006 CAHPS 4.0 Health Plan Survey (Updated December 2007)	Core Items (Medicaid and commercial)	Health Plan Customer Service			yes	yes			
0009 (NQF endorsement applies to 3.0 version of this survey) CAHPS Item Set for Children with Chronic Conditions 4.0 Version (Updated July 2008)	Ambulatory Care	Parents' Experiences with Prescription Medicines		yes					yes
0009 (NQF endorsement applies to 3.0 version of this survey) CAHPS Item Set for Children with Chronic Conditions 4.0 Version (Updated July 2008)	Ambulatory Care	Parents' Experiences Getting Specialized Services for Their Child		yes					yes
0009 (NQF endorsement applies to 3.0 version of this survey) CAHPS Item Set for Children with Chronic Conditions 4.0 Version (Updated July 2008)	Ambulatory Care	Parents' Experiences with the Child's Personal Doctor or Nurse	yes						

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
0009 (NQF endorsement applies to 3.0 version of this survey) CAHPS Item Set for Children with Chronic Conditions 4.0 Version (Updated July 2008)	Ambulatory Care	Parents' Experiences with Shared Decision-making		yes			yes		
0009 (NQF endorsement applies to 3.0 version of this survey) CAHPS Item Set for Children with Chronic Conditions 4.0 Version (Updated July 2008)	Ambulatory Care	Parents' Experiences with Getting Needed Information about Their Child's Care		yes		yes			
0009 (NQF endorsement applies to 3.0 version of this survey) CAHPS Item Set for Children with Chronic Conditions 4.0 Version (Updated July 2008)	Ambulatory Care	Parents' Experiences with Coordination of Their Child's Care		yes					
1741 CAHPS Surgical Care Survey (Updated December 2011)	Ambulatory Care; Hospital/ Acute Care Facility	Information To Help You Prepare For Surgery				yes			
1741 CAHPS Surgical Care Survey (Updated December 2011)	Ambulatory Care; Hospital/ Acute Care Facility	How Well Surgeon Communicates With Patients Before Surgery				yes			
1741 CAHPS Surgical Care Survey (Updated December 2011)	Ambulatory Care; Hospital/ Acute Care Facility	Surgeon's Attentiveness on Day of Surgery				yes			
1741 CAHPS Surgical Care Survey (Updated December 2011)	Ambulatory Care; Hospital/ Acute Care Facility	Information To Help You Recover From Surgery	yes			yes			
1741 CAHPS Surgical Care Survey (Updated December 2011)	Ambulatory Care; Hospital/ Acute Care Facility	How Well Surgeon Communicates With Patients After Surgery			yes	yes			

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
1741 CAHPS Surgical Care Survey (Updated December 2011)	Ambulatory Care; Hospital/ Acute Care Facility	Helpful, Courteous, and Respectful Staff at Surgeon's Office			yes				
1904 CAHPS Cultural Competence Item Set (Updated May 2012)	Clinician/Group's Cultural Competence Based on the CAHPS® Cultural Competence Item Set	Patient-provider communication			yes	yes			
1904 CAHPS Cultural Competence Item Set (Updated May 2012)	Clinician/Group's Cultural Competence Based on the CAHPS® Cultural Competence Item Set	Complementary and alternative medicine	yes						
1904 CAHPS Cultural Competence Item Set (Updated May 2012)	Clinician/Group's Cultural Competence Based on the CAHPS® Cultural Competence Item Set	Experiences of discrimination due to race/ethnicity, insurance, or language			yes				
1904 CAHPS Cultural Competence Item Set (Updated May 2012)	Clinician/Group's Cultural Competence Based on the CAHPS® Cultural Competence Item Set	Experiences leading to trust or distrust, including level of trust, caring, and truth-telling				yes			
1904 CAHPS Cultural Competence Item Set (Updated May 2012)	Clinician/Group's Cultural Competence Based on the CAHPS® Cultural Competence Item Set	Interpreter services			yes				yes
1902 CAHPS Item Set for Addressing Health Literacy (Updated May 2012)	Clinicians/Groups' Health Literacy Practices Based on the CAHPS Item Set for Addressing Health Literacy	Communication with provider			yes	yes			
1902 CAHPS Item Set for Addressing Health Literacy (Updated May 2012)	Clinicians/Groups' Health Literacy Practices Based on the CAHPS Item Set for Addressing Health Literacy	Disease self-management				yes		yes	
1902 CAHPS Item Set for Addressing Health Literacy (Updated May 2012)	Clinicians/Groups' Health Literacy Practices Based on the CAHPS Item Set for Addressing Health Literacy	Communication about medicines				yes		yes	

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
1902 CAHPS Item Set for Addressing Health Literacy (Updated May 2012)	Clinicians/Groups' Health Literacy Practices Based on the CAHPS Item Set for Addressing Health Literacy	Communication about test results				yes			
1902 CAHPS Item Set for Addressing Health Literacy (Updated May 2012)	Clinicians/Groups' Health Literacy Practices Based on the CAHPS Item Set for Addressing Health Literacy	Communication about forms				yes			
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Visit to doctor							yes
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Being examined on the examination table							yes
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Getting weighed at the doctor's office							yes
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Difficulty moving around the restroom							yes
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Difficulty moving around the restroom							yes
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Pain	yes						
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Fatigue	yes						

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Getting physical and occupational therapy							yes
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Getting speech therapy							yes
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Getting mobility equipment repaired							yes
CAHPS Item Set for People with Mobility Impairments (Updated June 2008)	Supplemental Item Set to the Health Plan Survey	Getting or replacing mobility equipment							yes
CAHPS Patient-Centered Medical Home (PCMH) Item Set (2011)	Clinician & Group (C&G) PCMH Survey (Version 5 of the C&G Survey)	Providers Pay Attention to Your Mental or Emotional Health (Adult only)	yes			yes			
CAHPS Patient-Centered Medical Home (PCMH) Item Set (2011)	Clinician & Group (C&G) PCMH Survey (Version 5 of the C&G Survey)	Providers Support you in Taking Care of your Own Health	yes					yes	
CAHPS Patient-Centered Medical Home (PCMH) Item Set (2011)	Clinician & Group (C&G) PCMH Survey (Version 5 of the C&G Survey)	Providers Discuss Medication Decisions (Adult only)				yes	yes		
CAHPS Patient-Centered Medical Home (PCMH) Item Set (2011)	Clinician & Group (C&G) PCMH Survey (Version 5 of the C&G Survey)	Access to Care							yes

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
CAHPS Patient-Centered Medical Home (PCMH) Item Set (2011)	Clinician & Group (C&G) PCMH Survey (Version 5 of the C&G Survey)	Attention to Care from Other Providers				yes			
CAHPS Patient-Centered Medical Home (PCMH) Item Set (2011)	Clinician & Group (C&G) PCMH Survey (Version 5 of the C&G Survey)	Information about Care and Appointments				yes			
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Getting treatment quickly							yes
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	How well clinicians communicate			yes	yes	yes		
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Getting treatment and information from the plan or MBHO				yes			yes
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Perceived improvement	yes						
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Information about treatment options						yes	
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Office wait							yes
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Told about medication side effects				yes			

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Including family and friends		yes					
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Information to manage condition						yes	
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Patient rights information				yes			
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Patient feels he or she could refuse treatment					yes		
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Privacy				yes			
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Cultural competency	yes						
0008 Experience of Care and Health Outcomes (ECHO) Survey 3.0 (2004)	CAHPS Behavioral Health for MCO or MBHO	Treatment after benefits are used up				yes			
0693 CAHPS Nursing Home Family Survey (2011)	Nursing Home/Skilled Nursing Facility	Meeting Basic Needs: Help with Eating, Drinking, and Toileting							yes
0693 CAHPS Nursing Home Family Survey (2011)	Nursing Home/Skilled Nursing Facility	Nurses/Aides' Kindness/Respect Towards Resident			yes				
0693 CAHPS Nursing Home Family Survey (2011)	Nursing Home/Skilled Nursing Facility	Nursing Home Provides Information/ Encourages Respondent Involvement		yes		yes	yes		

NQF #/ Survey Name and version # or date	Type and/or Setting	Measure (Name of composite or global rating)	Person- and Family-Centered Care Core Concepts						
			Individualized care	Family	Respect, dignity, and compassion	Information sharing/ communication	Shared decisionmaking	Self-management	Access/ convenience
0693 CAHPS Nursing Home Family Survey (2011)	Nursing Home/Skilled Nursing Facility	Nursing Home Staffing, Care of Belongings, and Cleanliness							yes
0691 & 0692 CAHPS Nursing Home Resident Surveys: Discharged Resident and Long-Stay Resident Instruments (slight wording changes between instruments)	Nursing Home/Skilled Nursing Facility	Environment	yes						
0691 & 0692 CAHPS Nursing Home Resident Surveys: Discharged Resident and Long-Stay Resident Instruments (slight wording changes between instruments)	Nursing Home/Skilled Nursing Facility	Care	yes		yes				yes
0691 & 0692 CAHPS Nursing Home Resident Surveys: Discharged Resident and Long-Stay Resident Instruments (slight wording changes between instruments)	Nursing Home/Skilled Nursing Facility	Communication/ Respect			yes	yes			
0691 & 0692 CAHPS Nursing Home Resident Surveys: Discharged Resident and Long-Stay Resident Instruments (slight wording changes between instruments)	Nursing Home/Skilled Nursing Facility	Autonomy	yes						
0691 & 0692 CAHPS Nursing Home Resident Surveys: Discharged Resident and Long-Stay Resident Instruments (slight wording changes between instruments)	Nursing Home/Skilled Nursing Facility	Activities	yes						

APPENDIX F:
Person-Centered Care and Outcomes: HHS/NHS Project Summary

Purpose and Scope

HHS requested NQF—with direct assistance from the United States Health and Human Services (HHS) and United Kingdom National Health Service (NHS) staff—to collect and compile basic information on conceptual specifications, data collection, and use for identified performance measures. The purpose of this activity is to identify similarities and differences that can be explored by HHS and NHS to identify best practices and opportunities for collaboration and co-development of standards.

Measures

HHS and NHS agreed on measures in three areas – depression, hip replacement, and knee replacement. NQF requested standard information on the measures from the identified contact persons. The information provided was used for the comparative analysis (see Tables 1, 2, 3). The developer for the US hospital measures for hip and knee replacements did not provide specific information and noted that there was no difference from the clinician version other than setting.

The identified measures include:

- Depression Remission at Twelve Months (NQF#0710) (HHS)
- Depression Remission at Six Months (NQF#0711) (HHS)
- Recovery rate from depression - KPI under the Improving Access to Pschycological Treatment (IAPT) programme (NHS)
- Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement (HHS)
- Hip replacement - Percentage improved on Oxford Hip Score (NHS)
- Hip replacement - Percentage improved on EQ-5D (NHS)
- Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement (HHS)
- Knee replacement - Percentage improved on Oxford knee score (NHS)
- Knee replacement - Percentage improved on EQ-5D (NHS)

Similarities and Differences

The comparison of the information provided identified several similarities and differences. The major similarities include:

- Using patient-reported assessments
- Identifying changes from before and after interventions for purposes of potentially identifying differences in quality of care across the entities whose performance is being measured
- Using or planning to use performance scores for identifiable entities in public reporting and pay-for-performance programs.

The major differences include:

- Scope and breadth of performance measurement based on PROMs
- Use of different patient-level instruments for hip and knee replacement
- Program requirements for use of specific patient-level instruments

- Construction of the performance measure – e.g., average change vs. improvement; different benchmarks for the depression measures
- Specifications for the patients to be included or excluded

Potential Opportunities for Learning and Collaboration

Provider and Patient Participation

NHS has the most experience and impressive patient participation.

- What have been the greatest facilitators to participation?
- What barriers were encountered and resolved?
- How do the differences in health systems potentially impact participation by providers and patients?

Electronic Solutions

HHS is beginning its work on hip and knee measures with the intent of using current electronic capabilities to their fullest – electronic health records, electronic capture of patient-reported assessments; whereas the NHS began using patient-reported data some time ago and is using paper surveys that are scanned electronically.

- What are potential benefits of electronic solutions? (e.g., using patient-reported assessments in real-time with patients for decisionmaking, goal setting, monitoring progress, etc.)
- What are the potential challenges of electronic solutions? (e.g., performance measure computation –different instruments, risk adjustment)
- Are the challenges and barriers different for starting with electronic vs. moving to electronic solutions?

Patient-Reported Instruments

NHS and HHS are using the same instrument for depression – the PHQ-9. For hip and knee replacement, NHS has specified a generic and a condition-specific instrument that are required for use; whereas HHS is allowing providers the choice among three instruments – generic or condition-specific.

- Have the measurement challenges with different instruments been solved sufficiently (e.g., PROMIS work on calibration) to use multiple instrument when trying to measure performance for accountability, which generally includes comparison?
- What are the pros and cons of generic vs. condition-specific – are both needed?
- Do generic and condition-specific instruments have the same discrimination and sensitivity when used with a homogenous patient population?

Performance Measure Construction

A performance measure could aggregate patient data in a variety of ways such as average change, percent improved, percent meeting a specific benchmark. Outcome performance measures are generally risk-adjusted, but the factors and methods could vary. For the depression measures, the same instrument is used across countries, but the measures are constructed around a different benchmark.

- Who is involved in making decisions about performance measure construction?
- What is the process for performance measure development?
- To what extent are empirical analyses required and used for making decisions about performance measure construction?
- How are the final computed performance measures tested for reliability and validity and

are those properties monitored periodically?

Comparison across Countries

The differences in instruments and measure specifications would make comparisons across countries difficult to interpret. However, if that is a future goal, some things to consider and explore include:

- Population-level measurement without risk adjustment unless there is any reason to think the characteristics used in risk adjustment vary substantially across countries.
- Population-level measurement without exclusions unless there is any reason to think the characteristics used for exclusions represent a substantial portion of the target population and vary substantially across countries.
- Align inclusion criteria – would need to use the most restrictive definitions to end up with comparable patient populations unless additional data are available.

Use in Accountability Applications (public reporting and pay-for-performance)

NHS has been using the performance measures for public reporting, but is moving them into use in pay-for-performance; HHS is interested in using performance measures in pay-for-performance.

- What features make a performance measure suitable for accountability applications? (e.g., reliability of the computed performance score so that differences are not primarily a function of random noise; empirical validity testing)
- What are HHS and NHS views on differences for use in public reporting vs. pay-for-performance programs?

Relationship to Person- Centered Care

Use of patient-reported assessments alone is not necessarily indicative of person-centered care – their use can range from being an authoritative data source and data collection process for performance measurement to real-time use of the patient-reported assessments for shared decisionmaking, goal setting, co-producing care plans and monitoring progress as well as performance measurement. HHS has made person-centered care a priority in the national quality strategy.

- What are HHS and NHS views and goals related to person-centered care?
- Is the use of patient-reported assessments viewed primarily as an important source of data for performance measurement, or is performance measurement considered a byproduct of using patient-reported assessments as a tool in delivering person-centered care?

Measure Comparison Tables

Measure information in these tables is exactly as provided by the developers – any NQF notes regarding the submitted measure information appear in [*brackets and italicized*]. Some bolding was added to highlight key differences or similarities. NQF prepared the comparison notes.

TABLE F1. DEPRESSION MEASURES

Performance Measure Title	Depression Remission at Twelve Months (NQF#0710)	Depression Remission at Six Months (NQF#0711)	Recovery rate from depression - KPI under the Improving Access to Pschycological Treatment (IAPT) programme	Comparison Notes
1. Performance Measure Developer and/or Steward	MN Community Measurement	MN Community Measurement	Health and Social Care Information Centre (HSCIC)	
2. Performance Measure Status (concept, in development, fully specified/tested, in use)	Fully specified, tested and in use. Historical data available from 2009 through current.	Fully specified, tested and in use. Historical data available from 2009 through current.	In use.	
3. Performance Measure Brief Description	Adult patients age 18 and older with major depression or dysthymia and an initial PHQ-9 score > 9 who demonstrate remission at twelve months defined as a PHQ-9 score less than 5. This measure applies to both patients with newly diagnosed and existing depression whose current PHQ-9 score indicates a need for treatment. The Patient Health Questionnaire (PHQ-9) tool is a widely accepted, standardized, publicly available, patient reported outcome tool developed by Robert Spitzer, Kurt Kroenke et.al. It is completed by the patient, ideally at each visit, and utilized by the provider to monitor treatment progress. This measure additionally promotes ongoing contact between the patient and provider as patients who do not have a follow-up PHQ-9 score at twelve months (+/- 30 days) are also included in the denominator.	Adult patients age 18 and older with major depression or dysthymia and an initial PHQ-9 score > 9 who demonstrate remission at six months defined as a PHQ-9 score less than 5. This measure applies to both patients with newly diagnosed and existing depression whose current PHQ-9 score indicates a need for treatment. The Patient Health Questionnaire (PHQ-9) tool is a widely accepted, standardized, publicly available, patient reported outcome tool developed by Robert Spitzer, Kurt Kroenke et.al. It is completed by the patient, ideally at each visit, and utilized by the provider to monitor treatment progress. This measure additionally promotes ongoing contact between the patient and provider as patients who do not have a follow-up PHQ-9 score at six months (+/- 30 days) are also included in the denominator.	The Improving Access to Psychological Therapies (IAPT) programme supports the frontline NHS in implementing National Institute for Health and Clinical Excellence (NICE) guidelines for people suffering from depression and anxiety disorders. Patients receiving services under IAPT fill out two questionnaires (PHQ-9 for depression and GAD-7 for anxiety or an alternative scale for other conditions). Patients are assessed as having clinically significant depression, if they have a sufficiently bad score on the patient-level instrument (10 or higher). The performance measure records how many of these patients recover from depression over the course of treatment.	Several differences - addressed in specific areas below

Performance Measure Title	Depression Remission at Twelve Months (NQF#0710)	Depression Remission at Six Months (NQF#0711)	Recovery rate from depression - KPI under the Improving Access to Pschycological Treatment (IAPT) programme	Comparison Notes
4. Patient-level instrument, scale, survey used to obtain patient-reported data (e.g., PHQ-9)	**PHQ-9**. Patient Health Questionnaire-Nine Questions. Tool was developed by Robert Spitzer, Kurt Kroenke et.al., is in the public domain and available at www.phqscreeners.com	**PHQ-9**. Patient Health Questionnaire-Nine Questions. Tool was developed by Robert Spitzer, Kurt Kroenke et.al., is in the public domain and available at www.phqscreeners.com	**PHQ-9** questionnaire - containing a number of depression specific questions. Questions include: "Did you have, over the last two weeks, any of the following problems (from 0 "not at all" to 4 "almost every day") little pleasure in doing things, feeling down, depressed, hopeless, trouble falling asleep, or sleeping too much, feeling tired, little energy, poor appetite, overeating, feeling bad about yourself , that you're a failure etc., trouble concentrating, moving or talking so slowly that others have noticed (or the opposite having thoughts that you'd be better off dead).	Same instrument – potential opportunity to compare performance
5. Data source - patient, clinician, other?	Data source is the ambulatory clinic's EMR. The tool is completed by the **patient**, but the data is captured by the clinic. Of note: in order for patients to be "Indexed" they need both the diagnosis of major depression or dysthymia and an elevated PHQ-9. Inclusion in the denominator cannot be based on PHQ-9 score alone.	Data source is the ambulatory clinic's EMR. The tool is completed by the **patient**, but the data is captured by the clinic. Of note: in order for patients to be "Indexed" they need both the diagnosis of major depression or dysthymia and an elevated PHQ-9. Inclusion in the denominator cannot be based on PHQ-9 score alone.	**Patient** questionnaire at each appointment	Both use patient-reported data
6. Description of how patient-level data are aggregated for the performance measure (e.g., average score, % improved, % reaching some benchmark, etc.)	**Percent of patients who reach a target of a PHQ-9 score of < 5 twelve months (+/- 30 days) following "Index".** Index is the first time in the measurement period that the patient with a diagnosis of depression or dysthymia has a PHQ-9 score > 9. Is a longitudinal, prospective measure that then looks forward to see if the patient is in remission (PHQ-9 < 5) at twelve months (+/- 30 days) following index. Rate is then calculated with the numerator of all patients with a PHQ-9 < 5 at twelve months (+/- 30 days) over a denominator of all patients with major depression or dysthymia who were indexed in the measurement period.	**Percent of patients who reach a target of a PHQ-9 score of < 5 six months (+/- 30 days) following "Index".** Index is the first time in the measurement period that the patient with a diagnosis of depression or dysthymia has a PHQ-9 score > 9. Is a longitudinal, prospective measure that then looks forward to see if the patient is in remission (PHQ-9 < 5) at six months (+/- 30 days) following index. Rate is then calculated with the numerator of all patients with a PHQ-9 < 5 at six months (+/- 30 days) over a denominator of all patients with major depression or dysthymia who were indexed in the measurement period.	**%age of patients reaching a benchmark score of 10 on the PHQ-9, below which they are considered recovered** (Note, however, that, in the future, the definition of 'recovery rate' may change: e.g. might give partial score to those who did not cross the threshold for recovery, but made some substantial progress)	Both calculate a percentage achieving a specified benchmark. Different benchmarks hinder comparability (discussed in #7). NHS considering partial credit for substantial progress.

Performance Measure Title	Depression Remission at Twelve Months (NQF#0710)	Depression Remission at Six Months (NQF#0711)	Recovery rate from depression - KPI under the Improving Access to Pschycological Treatment (IAPT) programme	Comparison Notes
7. Performance measure numerator (i.e., the outcome) - brief statement	Adults age 18 and older with a diagnosis of major depression or dysthymia and an initial (index) PHQ-9 score greater than nine who achieve remission at twelve months as demonstrated by a twelve month (+/- 30 days) **PHQ-9 score of less than five**.	Adults age 18 and older with a diagnosis of major depression or dysthymia and an initial (index) PHQ-9 score greater than nine who achieve remission at six months as demonstrated by a six month (+/- 30 days) **PHQ-9 score of less than fiv**e.	Patients whose **PHQ-9 score has fallen below 10**	Different benchmarks HHS – remission = PHQ-9 < 5 NHS – recovery = PHQ-9 <10 **Questions:** • How are the scores of <9 and <5 interpreted based on the research on the PHQ-9? • What is considered a clinically meaningful change?
8. Performance measure denominator (i.e., target population) - brief statement	**Adults age 18 and older with a diagnosis of major depression or dysthymia and an initial (index) PHQ-9 score greater than nine**.	**Adults age 18 and older with a diagnosis of major depression or dysthymia and an initial (index) PHQ-9 score greater than nine**.	**Patients who started a IAPT treatment during the period or were already in treatment at the beginning of the period, but had not recovered below a score of 10**. [*age?*]	Seem comparable HHS – specific diagnoses + PHQ-9 >9; adult 18+ NHS – in IAPT treatment (*presumably for depression, but not stated*) + PHQ-9 > 9; although adult not stated, in #13 indicate potential expansion to adolescents so presumably currently limited to adults
9. Exclusions/ exceptions from the performance measure	Patients who **die, are a permanent resident of a nursing home or are enrolled in hospice** are excluded from this measure. Additionally, patients who have a diagnosis (in any position) of **bipolar or personality disorder** are excluded.	Patients who **die, are a permanent resident of a nursing home or are enrolled in hospice** are excluded from this measure. Additionally, patients who have a diagnosis (in any position) of **bipolar or personality disorder** are excluded.	All patients are asked to fill in the questionnaire, but for the ‘recovery rate’ statistics, those who rated below 10 at initial assessment are excluded, because they were not deemed to have a clinically significant condition at that point.	HHS – exclude those who die, reside in nursing home, enrolled in hospice, or have bipolar or personality disorder diagnosis NHS – no such exclusions
10. Risk or case mix adjustment of the performance measure-method and factors (or rationale if not adjusted)	Stratification by risk category/ subgroup This measure is **risk adjusted based on severity band** of the PHQ-9 which is based on the initial PHQ-9 score. Severity bands are defined as 10 to 14- moderate depression, 15 to 19- moderately severe depression and 20 to 27- severe depression. The following variables are also included in the risk adjustment model: insurance product type and age bands (18-25, 26-50, 51-65, and 66+).	Stratification by risk category/ subgroup This measure is **risk adjusted based on severity band** of the PHQ-9 which is based on the initial PHQ-9 score. Severity bands are defined as 10 to 14- moderate depression, 15 to 19- moderately severe depression and 20 to 27- severe depression. The following variables are also included in the risk adjustment model: insurance product type and age bands (18-25, 26-50, 51-65, and 66+).	**None** - even though IAPT dataset includes the necessary information.	HHS – risk-adjusted based on severity of depression NHS – not risk-adjusted
11. Level of analysis (hospital, physician, etc.)	**Facility, Clinician : Group/Practice**	**Facility, Clinician : Group/Practice**	**Provider**, **Clinical Commissioning Group**	Both measure performance for individual clinicians and larger groups

Performance Measure Title	Depression Remission at Twelve Months (NQF#0710)	Depression Remission at Six Months (NQF#0711)	Recovery rate from depression - KPI under the Improving Access to Pschycological Treatment (IAPT) programme	Comparison Notes
12. Setting	**Ambulatory Care** : Clinician Office, Behavioral Health/Psychiatric : Outpatient	**Ambulatory Care** : Clinician Office, Behavioral Health/Psychiatric : Outpatient	The questionnaires are filled in by all patients every time they have an **IAPT assessment or IAPT treatment session**.	Comparable
13. What are potential considerations for expansion of the performance measure - to additional settings, levels of analysis, patient populations?	Would like to consider and recommend the inclusion of **adolescents in this patient population; ages 12 and older**. At the time the measure was developed, the PHQ-9 was not validated for younger than 18, but is now validated for adolescents as well. Although not currently reported at this level; reporting by provider could be an option with a sufficient volume.	Would like to consider and recommend the inclusion of **adolescents in this patient population; ages 12 and older**. At the time the measure was developed, the PHQ-9 was not validated for younger than 18, but is now validated for adolescents as well. Although not currently reported at this level; reporting by provider could be an option with a sufficient volume.	There is development of IAPT indicators for **Child and Adolescent's** Mental Health services as well as plans to develop IAPT measures for severe mental health conditions.	Both are considering expansion to include children and adolescents
14. Timeframe for aggregating data for performance score (e.g., 12 mo., 6 mo., etc.)	Follow-up PHQ-9 scores are assessed 13 months after index date to allow for twelve months +/- 30 days. Need to build in the assessment period to allow for all patients in the measurement period to be assessed within the correct window of time.	Follow-up PHQ-9 scores are assessed 7 months after index date to allow for six months +/- 30 days. Need to build in the assessment period to allow for all patients in the measurement period to be assessed within the correct window of time.	Data is produced quarterly, but aggregated at a monthly level.	Unclear about the aggregation period for the performance score: HHS – Are data aggregated for 12 months or some other timeframe? NHS – Is it only 1 month of data or rolling 12 months of data refreshed monthly? Quarterly is mentioned in #25.
15. Timeframe for collecting patient-level data (e.g., before and 6 mo. after surgery)	PHQ-9 scores are collected for each patient from the **time they meet the inclusion criteria** of diagnosis ICD-9 codes and PHQ-9 score greater than nine (this is the index or anchor date) **until thirteen months have elapsed**. This allows for calculation of a remission rate +/- 30 days from the index date.	PHQ-9 scores are collected for each patient from the **time they meet the inclusion criteria** of diagnosis ICD-9 codes and PHQ-9 score greater than nine (this is the index or anchor date) **until seven months have elapsed**. This allows for calculation of a remission rate +/- 30 days from the index date.	At **every assessment or session**. *[is there a set period of time in which the patient outcome is determined?]*	HHS – specified timeframe for determining patient outcome - eliminates variability due to time. NHS – not stated - does the episode end when PHQ-9 <9? **Question:** What are the pros/cons of each approach?
16. Please provide a URL or citation where information on the performance measure (e.g., development, testing, detailed specifications) is available.	http://mncm.org/wp-content/uploads/2014/01/Depression_Care_Measures_DDS_2014-Final-12.19.2013.pdf	http://mncm.org/wp-content/uploads/2014/01/Depression_Care_Measures_DDS_2014-Final-12.19.2013.pdf	http://www.iapt.nhs.uk/data/	

Performance Measure Title	Depression Remission at Twelve Months (NQF#0710)	Depression Remission at Six Months (NQF#0711)	Recovery rate from depression - KPI under the Improving Access to Pschycological Treatment (IAPT) programme	Comparison Notes
17. Please provide a URL or citation where information on the patient-level instrument (e.g., development, testing) is available.	www.phqscreeners.com User Guide at www.phqscreeners.com/instructions/instructions.pdf The PHQ-9 Validity of a Brief Depression Severity Measure www.ncbi.nlm.nih.gov/pmc/articles/PMC1495268/	www.phqscreeners.com User Guide at www.phqscreeners.com/instructions/instructions.pdf The PHQ-9 Validity of a Brief Depression Severity Measure www.ncbi.nlm.nih.gov/pmc/articles/PMC1495268/	The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues. For research information, contact Dr. Spitzer at rls8@columbia.edu. http://onlinelibrary.wiley.com/doi/10.1046/j.1525-1497.2001.016009606.x/full	
DATA COLLECTION AND USE OF PATIENT-LEVEL DATA				
18. Is use of the patient-level instrument required or voluntary? If required, please describe.	Use of the tool is required for the measure; both for inclusion in the denominator and for calculation of the numerator.	Use of the tool is required for the measure; both for inclusion in the denominator and for calculation of the numerator.	Voluntary - but we have a 95% completion rate	Comparable The specified tool is required, but patient completion is voluntary
19. How are the patient-level data collected (e.g., paper, computer, web, in-office, mail, interview, etc.)?	Can be collected using a variety of administrative modes including **paper, dry-erase laminated in clinic, computer (EMR, iPad, kiosk), electronically via patient portal, mail with return to clinic or by telephone**.	Can be collected using a variety of administrative modes including **paper, dry-erase laminated in clinic, computer (EMR, iPad, kiosk), electronically via patient portal, mail with return to clinic or by telephone**.	**Paper**, in the office as part of the consultation/treatment session	HHS – multiple modes NHS - paper
20. What additional data are required (e.g., mode/method, date of patient-level data, provider ID, patient ID, diagnosis, procedures, dates)?	We collect medical group ID, clinic ID, Provider ID, diagnosis code, PHQ-9 contact date (does not need to be at a visit), PHQ-9 score. Also some standard demographic information (DOB, gender, zip, race, language) that is not needed for measure calculation but some are used for risk adjustment.	We collect medical group ID, clinic ID, Provider ID, diagnosis code, PHQ-9 contact date (does not need to be at a visit), PHQ-9 score. Also some standard demographic information (DOB, gender, zip, race, language) that is not needed for measure calculation but some are used for risk adjustment.	The following are collected (though not required to calculate the measure): NHS number GP practice code Gender Date of birth Ethnicity IAPT intervention received Psychotropic medication Employment details Work and Social Adjustment questionnaire IAPT diagnosis Detailed patient experience questionnaire	HHS – additional data for risk adjustment NHS – additional data including interventions, medications, diagnosis, employment, which would provide opportunity for other analyses or research, perhaps risk adjustment

Performance Measure Title	Depression Remission at Twelve Months (NQF#0710)	Depression Remission at Six Months (NQF#0711)	Recovery rate from depression - KPI under the Improving Access to Pschycological Treatment (IAPT) programme	Comparison Notes
21. Can providers use the information in real-time for patient care? If so, please describe.	**Yes**, definitely. Tool is easy to score (simple addition) and score equates to severity of depression symptoms. Many providers use results to track progress over time.	**Yes**, definitely. Tool is easy to score (simple addition) and score equates to severity of depression symptoms. Many providers use results to track progress over time.	**Yes**.	Both indicate could be used in real-time.
22. Can patients access their data in real-time? If so, please describe.	Yes. The tool is very easy to score and frequently patients score the tool themselves. Though the severity breakdowns are not typically a part of the tool, patients can be educated about what their scores mean.	Yes. The tool is very easy to score and frequently patients score the tool themselves. Though the severity breakdowns are not typically a part of the tool, patients can be educated about what their scores mean.	No.	Seems comparable HHS – seems to indicate the patient could use the tool at any time, but not necessarily able to access their scores that were completed at the visit
23. Please provide a URL or citation where information on data collection is available.	www.phqscreeners.com User Guide at www.phqscreeners.com/instructions/instructions.pdf The PHQ-9 Validity of a Brief Depression Severity Measure www.ncbi.nlm.nih.gov/pmc/articles/PMC1495268/	www.phqscreeners.com User Guide at www.phqscreeners.com/instructions/instructions.pdf The PHQ-9 Validity of a Brief Depression Severity Measure www.ncbi.nlm.nih.gov/pmc/articles/PMC1495268/	The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues. For research information, contact Dr. Spitzer at rls8@columbia.edu. http://onlinelibrary.wiley.com/doi/10.1046/j.1525-1497.2001.016009606.x/full	
USE OF PERFORMANCE MEASURE				
24. What government (or other) programs use the performance measure and was date (year) of initial use?	CMS Meaningful Use Stage 2 2012 - current. Selected for PQRS EHR in 2014. Several other federal programs are considering for use in 2015 (Physician Compare, VPBM) as recommended by NQF's Measure Application Partnership	MN Department of Health Statewide Quality Reporting and Measurement System (SQRMS) 2009 - current MN Bridges to Excellence P4P 2009 - current	[*See #3 - Improving Access to Psychological Therapies (IAPT) programme supports the frontline NHS in implementing National Institute for Health and Clinical Excellence (NICE) guidelines for people suffering from depression and anxiety disorders.*]	

Performance Measure Title	Depression Remission at Twelve Months (NQF#0710)	Depression Remission at Six Months (NQF#0711)	Recovery rate from depression - KPI under the Improving Access to Pschycological Treatment (IAPT) programme	Comparison Notes
25. How is the performance measure used (e.g., public reporting, payment incentives)?	Measure is **publicly reported** on our consumer facing website, MN HealthScores located at www.mnhealthscores.org. Please see our MNCM slate of measures for more detailed information about use: http://mncm.org/wp-content/uploads/2013/04/Slate-of-MNCM-Measures-for-2014-Reporting_FINAL_Approved-by-Board_10-16-2013.pdf	Measure is **publicly reported** on our consumer facing website, MN HealthScores located at www.mnhealthscores.org. Measures are used by health plans in their pay-for-performance contracts with providers (i.e. Blue Cross, Health Partners, Medica) in addition to a pay-for-performance program administered by MN Bridges to Excellence. Please see our MNCM slate of measures for more detailed information about use: http://mncm.org/wp-content/uploads/2013/04/Slate-of-MNCM-Measures-for-2014-Reporting_FINAL_Approved-by-Board_10-16-2013.pdf	The performance measure is (has been?) published on a quarterly basis for purposes of **public reporting**. **A derived measure will be used in the NHS Outcome Framework**.	HHS – public reporting and pay-for-performance in MN; being considered by CMS for national use NHS – public reporting for the IAPT; unclear about “derived measure for NHS Outcome Framework”
26. What is the scope and breadth of adoption?	**Statewide (MN)** adoption and reporting. 191 medical groups representing 799 clinic site locations. In 2012 dates of service 80,076 patients were included in the denominator.	**Statewide (MN)** adoption and mandatory reporting under health reform law (SQRMS). 191 medical groups representing 799 clinic site locations. In 2012 dates of service 86,167 patients were included in the denominator.	**IAPT** has almost 100,000 scores each quarter (i.e. 100,000 patients closing their treatment in each quarter).	HHS – state of MN NHS – IAPT programme – is the programme national?
27. Optional if available: What has been the impact from use of the performance measure?	Small incremental improvements in outcome rates, which are dependent on follow-up with the patient. Also demonstrating improvement in follow-up rate (ability to connect and assess patient) at twelve months. Still opportunity in both the outcome and the process of following up with patients.	Small incremental improvements in outcome rates, which are dependent on follow-up with the patient. Also demonstrating improvement in follow-up rate (ability to connect and assess patient) at six months. Still opportunity in both the outcome and the process of following up with patients. Analysis of over 18,000 patients with a follow-up PHQ-9 obtained at six months demonstrated 24% in remission, 27% with mild depression, but almost half the patients with significant depressive symptoms (24% moderate, 15% moderately severe and 10% with severe depression.		

Performance Measure Title	Depression Remission at Twelve Months (NQF#0710)	Depression Remission at Six Months (NQF#0711)	Recovery rate from depression - KPI under the Improving Access to Pschycological Treatment (IAPT) programme	Comparison Notes
28. Please provide a URL or citation where information on the use of performance measure is available.	Consumer facing website at www.mnhealthscores.org http://www.mnhealthscores.org/?p=our_reports&sf=clinic&category_section=category_condition&category=4&sub_category=7&name_id=&compare=&search_phrase=&zipcode=&within=5 Annual Health Care Quality Report http://mncm.org/wp-content/uploads/2013/04/2013-HCQR-Final-1-13-2014.pdf	Consumer facing website at www.mnhealthscores.org http://www.mnhealthscores.org/?p=our_reports&sf=clinic&category_section=category_condition&category=4&sub_category=7&name_id=&compare=&search_phrase=&zipcode=&within=5 Annual Health Care Quality Report http://mncm.org/wp-content/uploads/2013/04/2013-HCQR-Final-1-13-2014.pdf	http://www.iapt.nhs.uk/data/	HHS – reported by group NHS – reported by Primary Care Trust (PCT); reporting at this site seems to be different than the measure described above – number of cases 'moving to recovery'
OTHER				
29. Additional information		Both the six month and twelve month remission measures were re-tooled for e-Measure specification in the initial project NQF/HHS but the six month remission measure was not selected for meaningful use implementation. In MN, we tend to focus more on the six month remission measure; some recent feedback (2013) from Jurgen Unutzer, indicated that the six month measure has the greatest size effect. Data from the ICSI DIAMOND project indicates that remission does occur most frequently between the five and seven month (six month) window.		

TABLE F2. HIP REPLACEMENT MEASURES

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
1. Performance Measure Developer and/or Steward	Measure Developer: – Measure Development Contractor: Booz Allen Hamilton – Measure Developer: National Committee for Quality Assurance – PROM Subject Matter Experts: The Dartmouth Institute	Health and Social Care Information Centre (HSCIC)	Health and Social Care Information Centre (HSCIC)	
2. Performance Measure Status (concept, in development, fully specified/tested, in use)	In development - being specified and tested as an electronic clinical quality measure (eCQM)	In use since April 2009	In use since April 2009	
3. Performance Measure Brief Description	Percentage of patients aged 18 years and older with primary total hip arthroplasty (THA) who achieved functional status improvement as assessed by a pre-and post-surgery patient-reported functional status assessment	Patient reported improvement in health status following an elective procedure. Using a pre- and a post-operative survey. PROMs are currently collected separately for hip replacement, knee replacement, groin hernia and varicose veins. Patients' self-reported health status (sometimes referred to as health related quality of life (HRQoL)) is assessed through a mixture of generic and disease or condition-specific questions.	Patient reported improvement in health status following an elective procedure. Using a pre- and a post-operative survey. PROMs are currently collected separately for hip replacement, knee replacement, groin hernia and varicose veins. Patients' self-reported health status (sometimes referred to as health related quality of life (HRQoL)) is assessed through a mixture of generic and disease or condition-specific questions.	Several differences - addressed in specific areas below

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
4. Patient-level instrument, scale, survey used to obtain patient-reported data (e.g., PHQ-9)	Generic Instruments: – **PROMIS Global 10** – **VR 12** Condition-Specific Instruments – **HOOS**	The **Oxford Hip Score** has more focus on hips related health questions. These scores comprise of twelve multiple choice questions relating to the patient's experience of pain, ease of joint movement and ease of undertaking normal domestic activities such as walking or climbing stairs. Questions include: How would you describe the pain you usually have in your hip? Have you been troubled by pain from your hip in bed at night? Have you had any sudden, severe pain (shooting, stabbing, or spasms) from your affected hip? Have you been limping when walking because of your hip? For how long have you been able to walk before the pain in your hip becomes severe (with or without a walking aid)? Have you been able to climb a flight of stairs? Have you been able to put on a pair of socks, stockings or tights? After a meal (sat at a table), how painful has it been for you to stand up from a chair because of your hip? Have you had any trouble getting in and out of a car or using public transportation because of your hip? Have you had any trouble with washing and drying yourself (all over) because of your hip? Could you do the household shopping on your own? How much has pain from your hip interfered with your usual work, including housework?	The **EQ-5D** index captures in a single value a range of generic health issues based on five dimensions: (i)Mobility; (ii)Self-care e.g. washing and dressing; (iii) Usual activities e.g. work, study, housework, family or leisure activities; (iv) Pain / discomfort; (v) Anxiety / depression. Currently the three level EQ-5D index is used, i.e. there are three possible answers in each category: no problem (1), some problem (2) and severe problems (3). The EuroQol group provides a mapping of all possible EQ-5D scores to a HrQoL, with 11111 (no problem) being equal to a QoL of 1, while 33333 (severe problems in all dimensions) has a QoL score of approximately -0.5, i.e. is considered worse than death. **The mapping has been derived in valuation studies, in which UK residents were asked to imagine conditions described by different EQ-5D and value improvements against these conditions (e.g. time-trade off). As such, the EQ-5D QoL scale does not represent the patient's, but the public's view.** EQ-5D Visual Analogue Scale is also used (a measure in which patients indicate their QoL on a visual scale)	Use of different instruments within the US and across countries could hinder comparability unless all instruments calibrated to a standard scale as has been done with some of the PROMIS work The EQ-5D is scaled based on UK residents value for improvements, which might pose unique challenges to calibration HHS – 2 generic – PROMIS 10, VR 12; 1 condition-specific- HOOS NHS – 1 generic – EQ-5D; 1 condition-specific – Oxford Hip

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
5. Data source - patient, clinician, other?	**Patient**	**Patient** (through pre-operative and post-operative questionnaires (at least six months after surgery)) Patients are matched to Hospital Episode Statistics data which provides other information about each patient	**Patient** (through pre-operative and post-operative questionnaires (at least six months after surgery)) Patients are matched to Hospital Episode Statistics data which provides other information about each patient	Both use patient-reported data
6. Description of how patient-level data are aggregated for the performance measure (e.g., average score, % improved, % reaching some benchmark, etc.)	**% improved** (based on pre-op vs post-op FSA patient level outcomes rolled-up to eligible-professional (EP) level)	Unadjusted and Adjusted **average health gain** based on the pre-op and post-op scores; **%improved**	Unadjusted and Adjusted **average health gain** based on the pre-op and post-op scores; **%improved**	HHS – percent improved NHS – average health gain and percent improved
7. Performance measure numerator (i.e., the outcome) - brief statement	Patients who completed pre- and post-surgery functional status assessments using a qualifying general or condition-specific tool, and whose **functional status improved** [*how is improvement defined?*]	**Difference in Score between post-op and pre-op** questionnaires. *[#6 also mentions improvement - how is improvement defined?*]	**Difference in Score between post-op and pre-op** questionnaires. *[#6 also mentions improvement - how is improvement defined?*]	HHS – improvement, but not defined NHS – difference between post-op and pre-op scores; mentioned percent improved in #6, but not defined **Question:** How is improvement defined? (e.g., any positive change; clinically meaningful change- if so, how determined)
8. Performance measure denominator (i.e., target population) - brief statement	**Adults aged 18 and older** with a **primary total hip arthroplasty (THA)** and **at least one outpatient encounter** during the measurement year	Not provided [*based on #3* - elective *procedure for hip replacement*] [*any age?]*	Not provided [*based on #3* - elective *procedure for hip replacement*] [*any age?]* [*not just primary? See #13 – separate for replacement (primary?) and renewal (subsequent replacements?)*]	Differences could hinder comparability HHS – 18+, primary hip replacement [is it only *elective procedures because exclude trauma - see #9*]; at least one outpatient encounter [*why is this necessary?*] NHS – elective hip replacement including replacement and renewal procedures (see #13) [*does it include only adults?*] **Question:** Do the differences in specifications results in substantive differences in patients included?

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
9. Exclusions/ exceptions from the performance measure	Patients with **multiple trauma** at the time of the total hip arthroplasty or patients with **severe cognitive impairment**	If patient **consent is not given** Codes excluded are identified in Annexe 1 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf particularly **bi-lateral knee/hip replacements**	If patient **consent is not given** Codes excluded are identified in Annexe 1 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf particularly **bi-lateral knee/hip replacements**	Differences could hinder comparability HHS – multiple trauma; severe cognitive impairment NHS – lack of consent; bilateral replacement **Question:** Do the differences in specifications results in substantive differences in patients included?
10. Risk or case mix adjustment of the performance measure- method and factors (or rationale if not adjusted)	**TBD** - Cross-contractor collaboration with CMS/Yale-CORE team and ONC HITECH/Booz Allen team	**Unadjusted and casemix adjusted** data produced: https://www.gov.uk/government/publications/patient-reported-outcome-measures-proms-in-england-the-case-mix-adjustment-methodology Case-mix adjustment controls for a number of factors that affect the health gain between pre- and post-operative survey (e.g. some comorbidities, ethnicity, age, gender , QoL score in the pre-operative survey)	**Unadjusted and casemix adjusted** data produced: https://www.gov.uk/government/publications/patient-reported-outcome-measures-proms-in-england-the-case-mix-adjustment-methodology Case-mix adjustment controls for a number of factors that affect the health gain between pre- and post-operative survey (e.g. some comorbidities, ethnicity, age, gender , QoL score in the pre-operative survey)	HHS – not decided NHS – unadjusted and casemix adjusted
11. Level of analysis (hospital, physician, etc.)	**Eligible professiona**l (EP) [*does this mean individual surgeon?*]	Monthly data: high level data aggregated to **provider** and **PCT** or **CCG** commissioner level. Annual breakdowns by protected characteristics Quarterly data pack with record-level but disclosure controlled data extracts	Monthly data: high level data aggregated to **provider** and **PCT** or **CCG** commissioner level. Annual breakdowns by protected characteristics Quarterly data pack with record-level but disclosure controlled data extracts	HHS – eligible professional [*individual surgeon?*] NHS – provider [*individual surgeon?*], primary care trust (PCT) (being replaced w/new structure), and clinical commissioning group (CCG)
12. Setting	**Ambulatory/Outpatient** [*Yale working on* hospital *measure using same approach*]	Pre-operative questionnaire may be filled in at **pre-operation eligibility appointment**. Post-operative questionnaire is typically sent to patients some six months after the operation.	Pre-operative questionnaire may be filled in at **pre-operation eligibility appointment**. Post-operative questionnaire is typically sent to patients some six months after the operation.	Comparable
13. What are potential considerations for expansion of the performance measure - to additional settings, levels of analysis, patient populations?	The individual EP measure could be rolled-up to **other levels of analysis** and aggregation	The most recent Hip and Knee PROMS data has been **split into replacement and renewal measures**.	The most recent Hip and Knee PROMS data has been **split into replacement and renewal measures.**	HHS- considering additional levels of analysis NHS – split replacement and renewal procedures

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
14. Timeframe for aggregating data for performance score (e.g., 12 mo., 6 mo., etc.)	N/A - Current contract is specific to individual EP measures [*what is proposed time for aggregating data to produce performance score? (e.g., 12 mo)]*	High level summary figures are reported monthly. A score comparison tool along with interactive maps are produced quarterly. The finalised annual dataset is reported annually, 18months after collection.	High level summary figures are reported monthly. A score comparison tool along with interactive maps are produced quarterly. The finalised annual dataset is reported annually, 18months after collection.	Unclear about the aggregation period for the performance score: HHS –? NHS – Is it 3 months of data or rolling 12 months of data refreshed quarterly? What is the difference between quarterly and annual?
15. Timeframe for collecting patient-level data (e.g., before and 6 mo. after surgery)	ONC HITECH project team recommendation after consideration of Joint CMS/Yale-Core and ONC HITECH/Booz Allen TEP input: – **Pre-op: Within 3 months prior to THA** – **Post-op: 6-9 months after TKA/ THA**	The **pre-op** questionnaire should happen in the **interval between the patient being assessed as fit for surgery and the treatment taking place**. However, there is local discretion as to when precisely it is administered before the procedure. [*post-op* at least 6 mo after surgery – *see #5; any endpoint?*]	The **pre-op** questionnaire should happen in the **interval between the patient being assessed as fit for surgery and the treatment taking place**. However, there is local discretion as to when precisely it is administered before the procedure. [*post-op* at least 6 mo after surgery – *see #5; any endpoint?*]	Some differences – not sure of effect HHS – within 3 months prior to surgery; 6-9 months after surgery NHS – interval between assessment fit for surgery and the surgery; at least 6 months after surgery **Question:** How much does the time between assessment as fit for surgery and the actual surgery vary and how does it compare to 3 months?
16. Please provide a URL or citation where information on the performance measure (e.g., development, testing, detailed specifications) is available.	Recently, HHS directed measure development contractors to load proposed measures into the new JIRA Measures Under Consideration - Development (MUC-D) project. This JIRA project houses the basic information translated from the MUC list plus additional information such as the HQMF measure specifications once drafted: http://jira.oncprojecttracking.org/browse/MUCD	http://www.hscic.gov.uk/proms	http://www.hscic.gov.uk/proms	

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
17. Please provide a URL or citation where information on the patient-level instrument (e.g., development, testing) is available.	PROMIS Global 10: http://www.nihpromis.org/Science/PubsDomain/Global_health.aspx n PROMIS VR 12: <Cannot find any reference to VR12 - is it now “SF12a”?> Overall Citations: http://www.nihpromis.org/Science/PublicationsYears.aspx Condition-Specific Instruments HOOS: http://www.koos.nu/hoospres.html [*VR 12 http://www.herc.research.va.gov/resources/faq_a07.asp*]	The Oxford Hip Score is developed by the Isis group: http://www.isis-innovation.com/outcomes/orthopaedic/ohs.html See Also Appendix 3 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf	EQ-5D is developed by the EuroQol Group http://www.euroqol.org See Also Appendix 3 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf	
DATA COLLECTION AND USE OF PATIENT-LEVEL Data				
18. Is use of the patient-level instrument required or voluntary? If required, please describe.	The **use of at least one of the listed PROMs is required** as this measure is intended to help fill gap areas identified by NQS.	**Providers are required to collect and report PROMs**, under the terms of the Standard NHS Contract for Acute Services. However filling in the questionnaires by patients is voluntary.	**Providers are required to collect and report PROMs**, under the terms of the Standard NHS Contract for Acute Services. However filling in the questionnaires by patients is voluntary.	HHS – requires use of 1 of 3 instruments NHS – requires use of 2 instruments
19. How are the patient-level data collected (e.g., paper, computer, web, in-office, mail, interview, etc.)?	PROM data is **expected to be received electronically from the patient** (e.g. patient web portal, tablet, mobile, kiosk)	**Paper based**, then electronically scanned http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf%20particularly%20bi-lateral%20knee/hip%20replacements	**Paper based**, then electronically scanned http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf%20particularly%20bi-lateral%20knee/hip%20replacements	Different modes could affect comparability but mode effect can be identified and controlled

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
20. What additional data are required (e.g., mode/method, date of patient-level data, provider ID, patient ID, diagnosis, procedures, dates)?	This outcome measure is based on the initial MU-2 building block process measure (CMS56v2) located within the zip file referenced: http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/2014_eCQM_EP_June2013.zip This is an EP measure expected to be reported by individual clinicians per the eligibility requirements of the Meaningful Use Program. **The data elements within the MU-2 measure are as follows:** • **"Diagnosis, Active: Fracture - Lower Body"** • **"Diagnosis, Active: Severe Dementia"** • **"Encounter, Performed: Face-to-Face Interaction"** • **"Encounter, Performed: Office Visit"** • **"Encounter, Performed: Outpatient Consultation"** • **"Functional Status, Result: Functional Status Assessment for Hip Replacement"** • **"Patient Characteristic Birthdate: birth date"** • **"Procedure, Performed: Primary THA Procedure"** Supplemental data elements: • **"Patient Characteristic Ethnicity: Ethnicity"** • **"Patient Characteristic Payer: Payer"** • **"Patient Characteristic Race: Race"** • **"Patient Characteristic Sex: ONC Administrative Sex"**	Data include: **Patient-identifiable information (used for linkage purposes eg to Hospital Episode Statistics** (HES) or National Joint Registry (NJR) but not made available for wider analysis); Additional questions about the **patient's own health, including whether they have pre-existing conditions such as arthritis or diabetes**. [*items for case mix adjustment – see #10*]	Data include: **Patient-identifiable information (used for linkage purposes eg to Hospital Episode Statistics** (HES) or National Joint Registry (NJR) but not made available for wider analysis); Additional questions about the **patient's own health, including whether they have pre-existing conditions such as arthritis or diabetes**. [*items for case mix adjustment – see #10*]	

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
21. Can providers use the information in real-time for patient care? If so, please describe.	It is **expected** that the implementation of this eCQM will **allow surgeons to have access to pre and post-surgical FSA Hip assessment score data at the point of care, while they are treating the patient**. We were able to demonstrate this during field-testing of our MU-2 building block process measure.	**Funnel plots of adjusted scores** allow providers to identify areas which are significantly below average. http://www.hscic.gov.uk/catalogue/PUB12662 Not 'real-time' per se since subject to the delays of data collection and processing. [*this is about the provider's performance score – what about the individual patient's score at the time of care?*]	**Funnel plots of adjusted scores** allow providers to identify areas which are significantly below average. http://www.hscic.gov.uk/catalogue/PUB12662 Not 'real-time' per se since subject to the delays of data collection and processing. [*this is about the provider's performance score – what about the individual patient's score at the time of care?*]	HHS – planning real-time collection at the point of care NHS – pre-op data is collected at time of visit (see #12) so presumably available in real time; post-op questionnaire is sent to the patient
22. Can patients access their data in real-time? If so, please describe.	Similar to above response as the **intent of the measure is to have both the patient and surgeon reviewing the pre and post-surgical FSA Hip assessment score data at the point of care**. It a given site utilizes a patient portal or similar, the patient could have access to their pre and post-assessment score data online	Similarly, **not 'real-time'** since subject to the delays of data collection and processing. However **the score comparison tools** provided would allow patients to identify poor performing hospitals and the visualisation tool helps display all the information. [*this is about the provider's performance score – what about the individual patient's score at the time of care?*]	Similarly, **not 'real-time**' since subject to the delays of data collection and processing. However the **score comparison tools** provided would allow patients to identify poor performing hospitals and the visualisation tool helps display all the information. [*this is about the provider's performance score – what about the individual patient's score at the time of care?*]	HHS – planning real-time collection at the point of care; patient access later would depend on patient portal NHS – pre-op data is collected at time of visit (see #12) so presumably available in real time; post-op questionnaire is sent to the patient
23. Please provide a URL or citation where information on data collection is available.	PROMIS Global 10: http://www.nihpromis.org/Science/PubsDomain/Global_health.aspx n PROMIS VR 12: <Cannot find any reference to VR12 - is it now "SF12a"?> Overall Citations: http://www.nihpromis.org/Science/PublicationsYears.aspx Condition-Specific Instruments HOOS: http://www.koos.nu/hoospres.html	The Oxford Hip Score is developed by the Isis group:http://www.isis-innovation.com/outcomes/orthopaedic/ohs.html See Also Appendix 3 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf	EQ-5D is developed by the EuroQol Group http://www.euroqol.org See Also Appendix 3 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf	

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
USE OF PERFORMANCE MEASURE				
24. What government (or other) programs use the performance measure and was date (year) of initial use?	This measure is proposed for inclusion in Stage 3 of the CMS Meaningful Use Program expected January 1 2017. This measure is also expected to be included in the ONC certification process for Stage 3 as well.	NHS England, Department of Health (2009/10) Original 2009/10 guidance: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_092625.pdf	NHS England, Department of Health (2009/10) Original 2009/10 guidance: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_092625.pdf	
25. How is the performance measure used (e.g., public reporting, payment incentives)?	**Proposed for payment incentive** (MU Program)	The data and reporting is **publicly available**. The intention is to link PROMs into payment for performance whereby persistent poor performers may have funding adjusted. The PROMS data will be used as **part of the Best Practice Tariff (BPT) coming into use from April 2014** (see section 3.2.3) http://www.monitor.gov.uk/sites/default/files/publications/Impact%20assessment%20of%20proposals%20for%20the%20201415%20National%20Tariff%20Payment%20System.pdf	The data and reporting is **publicly available. The intention is to link PROMs into payment for performance whereby persistent** poor performers may have funding adjusted. The PROMS data will be used as **part of the Best Practice Tariff (BPT) coming into use from April 2014** (see section 3.2.3) http://www.monitor.gov.uk/sites/default/files/publications/Impact%20assessment%20of%20proposals%20for%20the%20201415%20National%20Tariff%20Payment%20System.pdf Also used in the NHS Outcomes Framework:	HHS- proposed for payment incentive NHS – public reporting; pay for performance in 2014

Performance Measure Title	Functional Status Assessment and Improvement for Patients who received a Total Hip Replacement	Hip replacement - Percentage improved on Oxford Hip Score	Hip replacement - Percentage improved on EQ-5D	Comparison Notes
26. What is the scope and breadth of adoption?	To be determined based on the continued adoption of HIT and EHR use and the extent of participation in the MU-3 Program	The coverage is England (not UK). In 2012/13, there were **241,435 PROMs-eligible procedures** carried out in hospitals and **180,697 pre-operative questionnaires returned so far**, a headline participation rate of **74.8 %** (74.7 % for 2011-12) - this **includes procedures for hips, knees, groin hernia and varicose vein procedures**. For the 180,697 pre-operative questionnaires returned, **166,363 post-operative questionnaires were sent out2, of which 103,853 have been returned so far - a return rate of 62.4 %** (79.6% 2011-12).	The coverage is England (not UK). In 2012/13, there were **241,435 PROMs-eligible procedures** carried out in hospitals and **180,697 pre-operative questionnaires returned so far, a headline participation rate of 74.8 %** (74.7 % for 2011-12) - this includes procedures for hips, knees, groin hernia and varicose vein procedures. For the 180,697 pre-operative questionnaires returned, **166,363 post-operative questionnaires were sent out2, of which 103,853 have been returned so far - a return rate of 62.4 %** (79.6% 2011-12).	HHS – unknown NHS – data includes 4 procedures; [*assume that questionnaires include both instruments*]; if rates similar across procedures then very high patient participation 74.8% for pre-op, 62.4% return rate for post-op
27. Optional if available: What has been the impact from use of the performance measure?	To be determined based on the extent of participation in the MU-3 Program. The use of the initial MU-2 building block process measure may be an indication of future use of the expanded outcome measure			
28. Please provide a URL or citation where information on the use of performance measure is available.	This measure is currently being specified and tested for proposed inclusion in MU-3. The specifications for the initial MU-2 building block process measure (CMS56v2) can be found within the zip file referenced: http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/2014_eCQM_EP_June2013.zip			
OTHER				
29. Additional information	At this point in time, we are projecting July 31, 2014 as the date we complete HQMF measure specification and testing at up to four proposed clinical practice test site locations, and September 29, 2014 as the date we submit for NQF endorsement consideration.			

TABLE F3. KNEE REPLACEMENT MEASURES

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
1. Performance Measure Developer and/or Steward	Measure Developer: – Measure Development Contractor: Booz Allen Hamilton – Measure Developer: National Committee for Quality Assurance – PROM Subject Matter Experts: The Dartmouth Institute	Health and Social Care Information Centre (HSCIC)	Health and Social Care Information Centre (HSCIC)	
2. Performance Measure Status (concept, in development, fully specified/tested, in use)	In development - being specified and tested as an electronic clinical quality measure (eCQM)	In use since April 2009	In use since April 2009	
3. Performance Measure Brief Description	Percentage of patients aged 18 years and older with primary total knee arthroplasty (TKA) who achieved functional status improvement as assessed by a pre-and post-surgery patient-reported functional status assessment	Patient reported improvement in health status following an elective procedure. Using a pre- and a post-operative survey. PROMs are currently collected separately for hip replacement, knee replacement, groin hernia and varicose veins. Patients' self-reported health status (sometimes referred to as health related quality of life (HRQoL)) is assessed through a mixture of generic and disease or condition-specific questions.	Patient reported improvement in health status following an elective procedure. Using a pre- and a post-operative survey. PROMs are currently collected separately for hip replacement, knee replacement, groin hernia and varicose veins. Patients' self-reported health status (sometimes referred to as health related quality of life (HRQoL)) is assessed through a mixture of generic and disease or condition-specific questions.	Several differences - addressed in specific areas below

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
4. Patient-level instrument, scale, survey used to obtain patient-reported data (e.g., PHQ-9)	Generic Instruments: – **PROMIS Global 10** – **VR 12** Condition-Specific Instruments – **KOOS**	The **Oxford Knee Score** has more focus on Knee related health questions. These scores comprise of twelve multiple choice questions relating to the patient's experience of pain, ease of joint movement and ease of undertaking normal domestic activities such as walking or climbing stairs. Questions in line with those on the Oxford Hip Score.	The **EQ-5D** index captures in a single value a range of generic health issues based on five dimensions: (i)Mobility; (ii)Self-care e.g. washing and dressing; (iii) Usual activities e.g. work, study, housework, family or leisure activities; (iv) Pain / discomfort; (v) Anxiety / depression. Currently the three level EQ-5D index is used, i.e. there are three possible answers in each category: no problem (1), some problem (2) and severe problems (3). The EuroQol group provides a mapping of all possible EQ-5D scores to a HrQoL, with 11111 (no problem) being equal to a QoL of 1, while 33333 (severe problems in all dimensions) has a QoL score of approximately -0.5, i.e. is considered worse than death. **The mapping has been derived in valuation studies, in which UK residents were asked to imagine conditions described by different EQ-5D and value improvements against these conditions (e.g. time-trade off). As such, the EQ-5D QoL scale does not represent the patient's, but the public's view.** EQ-5D Visual Analogue Scale is also used (a measure in which patients indicate their QoL on a visual scale)	Use of different instruments within the US and across countries could hinder comparability unless all instruments calibrated to a standard scale as has been done with some of the PROMIS work The EQ-5D is scaled based on UK residents value for improvements, which might pose unique challenges to calibration HHS – 2 generic – PROMIS 10, VR 12; 1 condition-specific- KOOS NHS – 1 generic – EQ-5D; 1 condition-specific – Oxford Knee
5. Data source - patient, clinician, other?	**Patient**	**Patient** (through pre-operative and post-operative questionnaires (at least six months after surgery)) Patients are matched to Hospital Episode Statistics data which provides other information about each patient	**Patient** (through pre-operative and post-operative questionnaires (at least six months after surgery)) Patients are matched to Hospital Episode Statistics data which provides other information about each patient	Both use patient-reported data

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
6. Description of how patient-level data are aggregated for the performance measure (e.g., average score, % improved, % reaching some benchmark, etc.)	**% improved** (based on pre-op vs post-op FSA patient level outcomes rolled-up to eligible-professional (EP) level)	Unadjusted and Adjusted **average health gain** based on the pre-op and post-op scores; **%improved**	Unadjusted and Adjusted **average health gain** based on the pre-op and post-op scores; **%improved**	HHS – percent improved NHS – average health gain and percent improved
7. Performance measure numerator (i.e., the outcome) - brief statement	Not provided [*Based on #3 – achieved* functional status improvement *as assessed by a pre-and post-surgery patient-reported functional status assessment*]	**Difference in Score between post-op and pre-op questionnaires**.	**Difference in Score between post-op and pre-op questionnaires**.	HHS – improvement, but not defined NHS – difference between post-op and pre-op scores; mentioned percent improved in #6, but not defined **Question:** How is improvement defined? (e.g., any positive change; clinically meaningful change- if so, how determined)
8. Performance measure denominator (i.e., target population) - brief statement	Not provided [*Based on #3* – 18 years and older with primary total knee arthroplasty (TKA)] [*require one outpatient encounter as with hip?*]	Not provided [*Based on #3* – elective knee replacement]	Not provided [*Based on #3* – elective knee replacement]	Differences could hinder comparability HHS – 18+, primary knee replacement [is it only *elective procedures?*] NHS – elective knee replacement including replacement and renewal procedures (see #13) [*does it include only adults?*] **Question:** Do the differences in specifications results in substantive differences in patients included?
9. Exclusions/ exceptions from the performance measure	Not provided [*same as for hip – multiple trauma, severe cognitive impairment?*]	If patient **consent is not given** Codes excluded are identified in Annexe 1 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf particularly **bi-lateral knee**/hip replacements	If patient **consent is not given** Codes excluded are identified in Annexe 1 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf particularly **bi-lateral knee**/hip replacements	HHS –? NHS – lack of consent; bilateral replacement

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
10. Risk or case mix adjustment of the performance measure-method and factors (or rationale if not adjusted)	**TBD** - Cross-contractor collaboration with CMS/Yale-CORE team and ONC HIECH/Booz Allen team	**Unadjusted and casemix adjusted** data produced: https://www.gov.uk/government/publications/patient-reported-outcome-measures-proms-in-england-the-case-mix-adjustment-methodology Case-mix adjustment controls for a number of factors that affect the health gain between pre- and post-operative survey (e.g. some comorbidities, ethnicity, age, gender , QoL score in the pre-operative survey)	**Unadjusted and casemix adjusted** data produced: https://www.gov.uk/government/publications/patient-reported-outcome-measures-proms-in-england-the-case-mix-adjustment-methodology Case-mix adjustment controls for a number of factors that affect the health gain between pre- and post-operative survey (e.g. some comorbidities, ethnicity, age, gender , QoL score in the pre-operative survey)	HHS – not decided NHS – unadjusted and casemix adjusted
11. Level of analysis (hospital, physician, etc.)	**Eligible professional** (EP)	Monthly data: high level data aggregated to provider and **PCT or CCG commissioner** level. Annual breakdowns by protected characteristics Quarterly data pack with record-level but disclosure controlled data extracts	Monthly data: high level data aggregated to provider and **PCT or CCG commissioner level**. Annual breakdowns by protected characteristics Quarterly data pack with record-level but disclosure controlled data extracts	HHS – eligible professional [*individual surgeon?*] NHS – provider [*individual surgeon?*], primary care trust (PCT) (being replaced w/new structure), and clinical commissioning group (CCG)
12. Setting	**Ambulatory/Outpatient** [*Yale working on* hospital *measure using same approach*]	Pre-operative questionnaire may be filled in at **pre-operation eligibility appointment**. Post-operative questionnaire is typically sent to patients some six months after the operation.	Pre-operative questionnaire may be filled in at **pre-operation eligibility appointment**. Post-operative questionnaire is typically sent to patients some six months after the operation.	Comparable
13. What are potential considerations for expansion of the performance measure - to additional settings, levels of analysis, patient populations?	The individual EP measure could be rolled-up to **other levels of analysis and aggregation**	The most recent Hip and Knee PROMS data has been **split into replacement and renewal measures**.	The most recent Hip and Knee PROMS data has been **split into replacement and renewal measures**.	HHS- considering additional levels of analysis NHS – split replacement and renewal procedures
14. Timeframe for aggregating data for performance score (e.g., 12 mo., 6 mo., etc.)	N/A - Current contract is specific to individual EP measures	High level summary figures are **reported monthly**. A score comparison tool along with interactive maps are produced **quarterly**. **The finalised annual dataset** is reported annually, 18months after collection.	High level summary figures are **reported monthly**. A score comparison tool along with interactive maps are produced **quarterly**. The **finalised annual dataset** is reported annually, 18months after collection.	Unclear about the aggregation period for the performance score: HHS –? NHS – Is it 3 months of data or rolling 12 months of data refreshed quarterly? What is the difference between quarterly and annual?

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
15. Timeframe for collecting patient-level data (e.g., before and 6 mo. after surgery)	ONC HITECH project team recommendation after consideration of Joint CMS/Yale-Core and ONC HITECH/Booz Allen TEP input: – **Pre-op: Within 3 months prior to THA** – **Post-op: 6-9 months after TKA/THA**	The **pre-op questionnaire should happen in the interval between the patient being assessed as fit for surgery and the treatment** taking place. However, there is local discretion as to when precisely it is administered before the procedure. [*post-op* at least 6 mo after surgery – *see #5; any endpoint?*]	The **pre-op questionnaire should happen in the interval between the patient being assessed as fit for surgery and the treatment taking place**. However, there is local discretion as to when precisely it is administered before the procedure. [*post-op* at least 6 mo after surgery – *see #5; any endpoint?*]	Some differences – not sure of effect HHS – within 3 months prior to surgery; 6-9 months after surgery NHS – interval between assessment fit for surgery and the surgery; at least 6 months after surgery **Question:** How much does the time between assessment as fit for surgery and the actual surgery vary and how does it compare to 3 months?
16. Please provide a URL or citation where information on the performance measure (e.g., development, testing, detailed specifications) is available.	Recently, HHS directed measure development contractors to load proposed measures into the new JIRA Measures Under Consideration - Development (MUC-D) project. This JIRA project houses the basic information translated from the MUC list plus additional information such as the HQMF measure specifications once drafted: http://jira.oncprojecttracking.org/browse/MUCD	http://www.hscic.gov.uk/proms	http://www.hscic.gov.uk/proms	
17. Please provide a URL or citation where information on the patient-level instrument (e.g., development, testing) is available.	PROMIS Global 10: http://www.nihpromis.org/Science/PubsDomain/Global_health.aspx PROMIS VR 12: <Cannot find any reference to VR12 - is it now "SF12a"?> Overall Citations: http://www.nihpromis.org/Science/PublicationsYears.aspx Condition-Specific Instruments KOOS: http://www.koos.nu/koospresentation.html [*VR 12 http://www.herc.research.va.gov/resources/faq_a07.asp*]	The Oxford Knee Score is developed by the Isis group: http://www.isis-innovation.com/outcomes/orthopaedic/oks.html See Also Appendix 3 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf	EQ-5D is developed by the EuroQol Group http://www.euroqol.org See Also Appendix 3 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf	

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
DATA COLLECTION AND USE OF PATIENT-LEVEL DATA				
18. Is use of the patient-level instrument required or voluntary? If required, please describe.	The use of **at least one of the listed PROMs is required** as this measure is intended to help fill gap areas identified by NQS.	**Providers are required to collect and report PROMs**, under the terms of the Standard NHS Contract for Acute Services. However filling in the questionnaires by patients is voluntary.	**Providers are required to collect and report PROMs**, under the terms of the Standard NHS Contract for Acute Services. However filling in the questionnaires by patients is voluntary.	HHS – requires use of 1 of 3 instruments NHS – requires use of 2 instruments
19. How are the patient-level data collected (e.g., paper, computer, web, in-office, mail, interview, etc.)?	PROM data is **expected to be received electronically from the patient (e.g. patient web portal, tablet, mobile, kiosk**)	**Paper based**, then electronically scanned http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf%20particularly%20bi-lateral%20knee/hip%20replacements	**Paper based**, then electronically scanned http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf%20particularly%20bi-lateral%20knee/hip%20replacements	Different modes could affect comparability but mode effect can be identified and controlled

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
20. What additional data are required (e.g., mode/method, date of patient-level data, provider ID, patient ID, diagnosis, procedures, dates)?	This outcome measure is based on the initial MU-2 building block process measure (CMS66v2) located within the zip file referenced: http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/2014_eCQM_EP_June2013.zip This is an EP measure expected to be reported by individual clinicians per the eligibility requirements of the Meaningful Use Program. The data elements within the MU-2 measure are as follows: • ”Diagnosis, Active: Fracture - Lower Body” • ”Diagnosis, Active: Severe Dementia” • ”Encounter, Performed: Face-to-Face Interaction” • ”Encounter, Performed: Office Visit” • ”Encounter, Performed: Outpatient Consultation” • ”Functional Status, Result: Functional Status Assessment for Knee Replacement” • ”Patient Characteristic Birthdate: birth date” • ”Procedure, Performed: Primary TKA Procedure” Supplemental data elements: • ”Patient Characteristic Ethnicity: Ethnicity” • ”Patient Characteristic Payer: Payer” • ”Patient Characteristic Race: Race” • ”Patient Characteristic Sex: ONC Administrative Sex”	Data include: Patient-identifiable information (used for linkage purposes eg to Hospital Episode Statistics (HES) or National Joint Registry (NJR) but not made available for wider analysis); Additional questions about the patient’s own health, including whether they have pre-existing conditions such as arthritis or diabetes.	Data include: Patient-identifiable information (used for linkage purposes eg to Hospital Episode Statistics (HES) or National Joint Registry (NJR) but not made available for wider analysis); Additional questions about the patient’s own health, including whether they have pre-existing conditions such as arthritis or diabetes.	

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
21. Can providers use the information in real-time for patient care? If so, please describe.	It is expected that the implementation of this eCQM will **allow surgeons to have access to pre and post-surgical FSA Knee assessment score data at the point of care, while they are treating the patient**. We were able to demonstrate this during field-testing of our MU-2 building block process measure.	**Funnel plots of adjusted scores** allow providers to identify areas which are significantly below average. http://www.hscic.gov.uk/catalogue/PUB12662 Not 'real-time' per se since subject to the delays of data collection and processing. [*this is about the provider's performance score – what about the individual patient's score at the time of care?*]	**Funnel plots of adjusted scores** allow providers to identify areas which are significantly below average. http://www.hscic.gov.uk/catalogue/PUB12662 Not 'real-time' per se since subject to the delays of data collection and processing. [*this is about the provider's performance score – what about the individual patient's score at the time of care?*]	HHS – planning real-time collection at the point of care NHS – pre-op data is collected at time of visit (see #12) so presumably available in real time; post-op questionnaire is sent to the patient
22. Can patients access their data in real-time? If so, please describe.	Similar to above response as the **intent of the measure is to have both the patient and surgeon reviewing the pre and post-surgical FSA Knee assessment score data at the point of care**. It a given site utilizes a patient portal or similar, the patient could have access to their pre and post-assessment score data online	Similarly, not 'real-time' since subject to the delays of data collection and processing. However the **score comparison tools** provided would allow patients to identify poor performing hospitals and the visualisation tool helps display all the information. [*this is about the provider's performance score – what about the individual patient's score at the time of care?*]	Similarly, not 'real-time' since subject to the delays of data collection and processing. However the **score comparison tools** provided would allow patients to identify poor performing hospitals and the visualisation tool helps display all the information. [*this is about the provider's performance score – what about the individual patient's score at the time of care?*]	HHS – planning real-time collection at the point of care; patient access later would depend on patient portal NHS – pre-op data is collected at time of visit (see #12) so presumably available in real time; post-op questionnaire is sent to the patient
23. Please provide a URL or citation where information on data collection is available.	PROMIS Global 10: http://www.nihpromis.org/Science/PubsDomain/Global_health.aspx PROMIS VR 12: <Cannot find any reference to VR12 - is it now "SF12a"?> Overall Citations: http://www.nihpromis.org/Science/PublicationsYears.aspx Condition-Specific Instruments KOOS: http://www.koos.nu/koospresentation.html	The Oxford Knee score is developed by the Isis group: http://www.isis-innovation.com/outcomes/orthopaedic/oks.html See Also Appendix 3 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf	EQ-5D is developed by the EuroQol Group http://www.euroqol.org See Also Appendix 3 of http://www.hscic.gov.uk/media/1537/A-Guide-to-PROMs-Methodology/pdf/PROMS_Guide_v5.pdf	

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
USE OF PERFORMANCE MEASURE				
24. What government (or other) programs use the performance measure and was date (year) of initial use?	This measure is proposed for inclusion in Stage 3 of the CMS Meaningful Use Program expected January 1 2017. This measure is also expected to be included in the ONC certification process for Stage 3 as well.	NHS England, Department of Health (2009/10) Original 2009/10 guidance: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_092625.pdf	NHS England, Department of Health (2009/10) Original 2009/10 guidance: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_092625.pdf	
25. How is the performance measure used (e.g., public reporting, payment incentives)?	**Proposed for payment incentive** (MU Program)	The data and reporting is **publicly available**. The intention is to link PROMs into payment for performance whereby persistent poor performers may have funding adjusted. The PROMS data will be used as part of the Best Practice Tariff (BPT) **coming into use from April 2014** (see section 3.2.3) http://www.monitor.gov.uk/sites/default/files/publications/Impact%20assessment%20of%20proposals%20for%20the%20201415%20National%20Tariff%20Payment%20System.pdf	The data and reporting is **publicly available**. The intention is to link PROMs into payment for performance whereby persistent poor performers may have funding adjusted. The PROMS data will be used as **part of the Best Practice Tariff (BPT)** coming into use from April 2014 (see section 3.2.3) http://www.monitor.gov.uk/sites/default/files/publications/Impact%20assessment%20of%20proposals%20for%20the%20201415%20National%20Tariff%20Payment%20System.pdf	HHS- proposed for payment incentive NHS – public reporting; pay for performance in 2014
26. What is the scope and breadth of adoption?	**To be determined** based on the continued adoption of HIT and EHR use and the extent of participation in the MU-3 Program	The coverage is England (not UK). In 2012/13, there were **241,435 PROMs-eligible procedures** carried out in hospitals and **180,697 pre-operative questionnaires returned so far**, a headline **participation rate of 74.8 %** (74.7 % for 2011-12) - this includes procedures for hips, knees, groin hernia and varicose vein procedures. For the 180,697 pre-operative questionnaires returned, 166,363 **post-operative** questionnaires were sent out2, of which 103,853 have been returned so far - a **return rate of 62.4 %** (79.6% 2011-12).	The coverage is England (not UK). In 2012/13, there were **241,435 PROMs-eligible procedures** carried out in hospitals and **180,697 pre-operative questionnaires returned so far**, a headline **participation rate of 74.8 %** (74.7 % for 2011-12) - this includes procedures for hips, knees, groin hernia and varicose vein procedures. For the 180,697 pre-operative questionnaires returned, 166,363 **post-operative** questionnaires were sent out2, of which 103,853 have been returned so far - a **return rate of 62.4 %** (79.6% 2011-12).	HHS – unknown NHS – data includes 4 procedures; [*assume that questionnaires include both instruments*]; if rates similar across procedures then very high patient participation 74.8% for pre-op, 62.4% return rate for post-op

Performance Measure Title	Functional Status Assessment and Improvement for Patients who Received a Total Knee Replacement	Knee replacement - Percentage improved on Oxford knee score	Knee replacement - Percentage improved on EQ-5D	Comparison Notes
27. Optional if available: What has been the impact from use of the performance measure?	To be determined based on the extent of participation in the MU-3 Program. The use of the initial MU-2 building block process measure may be an indication of future use of the expanded outcome measure			
28. Please provide a URL or citation where information on the use of performance measure is available.	This measure is currently being specified and tested for proposed inclusion in MU-3. The specifications for the initial MU-2 building block process measure (CMS66v2) can be found within the zip file referenced: http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/2014_eCQM_EP_June2013.zip			
OTHER				
29. Additional information	At this point in time, we are projecting July 31, 2014 as the date we complete HQMF measure specification and testing at up to four proposed clinical practice test site locations, and September 29, 2014 as the date we submit for NQF endorsement consideration.			

APPENDIX G:
Public Comments

General Comments

Administration for Community Living

Shawn Terrell

The document in general is well written and does a great job of discussing many of the complexities that define modern person-centered planning. Overall, our comments are about shifting the perspective a bit toward the value base underlying person centered planning (civil rights, empowerment, etc.), more focus on the skills necessary to effectively perform the person centered planning function, and a discussion of the specific methodologies that have been developed over the past 30 years.

The overarching "true north" approach, while commendable, is incomplete. We believe the document would benefit from an additional focus on home and community based services and the broader social services array. Home and community based service programs have fostered the development of person centered planning since 1981. In fact, person centered planning goes back to the roots of the Americans with Disabilities Act found in the Independent Living Movement in the 1970s which itself grew directly out of the civil rights movement. Independent living philosophy is the result of people with disabilities to demand equal rights in health care, and the broader society by demedicalizing and deinstitutionalizing their lives. It is a philosophy based on empowerment, inclusion, and self-determination. One of the primary aspects of the independent living movement is the idea of consumer direction over the planning process and the delivery of services and supports. With this backdrop, person centered planning and outcomes become foundational to way quality measures should be developed to support the broadest possible quality of life goals a person may have.

One general area where we believe there could be some additional useful information is in regards to the skill set necessary to perform the consumer engagement functions of person centered planning. It is generally agreed across many engagement approaches that without a strong and trusting relationship between the consumer and the person centered planning professional, there is little reliability in the goals that find their way into the plan of care. This lack of reliability may also significantly confound outcomes related to goal attainment. Without significant attention paid to the process of goal development to ensure that the goals are indeed owed by the consumer, there is little one can say about consumer driven goal attainment levels on measurement side.

Our recommendations are that the core concepts section of the document include the work developed over the last 30 years on person centered planning methodologies. We appreciate the focus on shared decision making as an important recent development. However, SDM is but one of many planning methods that should be reviewed in the document. Other approaches include the following:

- Person Centered Planning
- Essential Lifestyle Planning
- MAPS
- PATH
- Wellness Recovery Action Planning
- Family Support Planning
- Motivational Interviewing
- Decision Support

It should be noted that several of person centered planning methods mentioned above have an evidence base and tools to measure fidelity to the model. The environmental scan would be enhanced with a review of these measurement tools as well.

Additionally, a person centered planning method is best thought of as a skill set that, in its fullest application, often exerts pressures on traditional health and health related systems. For instance, the practice of person centered planning does not easily lend itself to highly structured approaches such that might be necessary for a functional assessment. Instead, person centered planning is a highly variable processes, tailored to the specific needs and interests of each individual. This point needs to be clearly discussed with emphasis on the implied measurement challenges. Also, because of its consumer driven nature, person centered planning methods often result in needs that extend well beyond the boundaries of any one or even a few programs. While this latter point was covered to a large degree in the document, it would need to be emphasized again in the context of the planning processes itself.

Finally, the document should discuss the differences between functional assessments and person centered planning, particularly the role of functional assessments in the development of the person centered plan of care. It is our experience that there needs to be a clear delineation between the two. A person centered planning process is focused on determining the quality of life goals, dreams, and desires of the person and then reaching a balance between this person driven perspective and any health and safety issues that may arise during a functional assessment process. There then must be a consumer driven context within which to negotiate conflicts that may arise between these two distinct processes. Service and support needs flow from the results of the negotiation process. This negotiated outcome is the core of an effective person centered planning process. The document would benefit from a clear articulation of these differences.

> NQF Response

We added a recognition of work in the disabilities field. The core concepts were intended to capture the experience of person-centered care, not all the potential methods of achieving it. However, the potential measure concepts in Appendix D do address some of the structures and processes that facilitate person- and family-centered care.

American Academy of Orthopaedic Surgeons

Tony Wheeler

The American Academy of Orthopaedic Surgeons (AAOS), representing more than 18,000 Board-certified orthopaedic surgeons, appreciates the opportunity to provide comments on the National Quality Forum (NQF) reports on Prioritizing Measures, specifically in the areas of Person-Centered Care and Outcomes and Care Coordination.

The AAOS commends the NQF on its efforts to improve the quality of care for patients and shares the recognized importance of quality measurement in health care. Beginning in July, 2014, the AAOS is launching its Performance Measures Committee. This committee consists of nine orthopaedic surgeons charged with developing and implementing evidence-based performance measures to be used in public reporting and value-based payment strategies. We are excited for this committee to get underway and work with the NQF to address the need for quality measurement that improves care and is useful to patients, particularly with musculoskeletal conditions.

NQF Reports on Person-Centered Care and Outcomes and Care Coordination

The AAOS is pleased to see a strong focus on patient-centered care and developing measures that recognize the importance of coordinating care for patients receiving treatment across a variety of settings and modalities. Care coordination is a particularly significant topic for patients with musculoskeletal conditions, who often require care from multiple providers throughout different stages of their condition. In 2013, the AAOS published a primer for its members on Musculoskeletal Care Coordination, and we found many common principles between that document and the present NQF report on performance measurement in care coordination.

Conclusion

The AAOS is committed to ensuring that patients receive the highest quality of care, and believes evidence-based quality measurement is an important part of that commitment. We are pleased to see the present suite of reports and find much common ground with the principles therein, particularly in the area of care coordination. We look forward to continuing to building our relationship with the NQF as we become ever-active contributors to the quality measurement domain. If you have any questions regarding our comments, please do not hesitate to contact William Shaffer, MD, AAOS Medical Director at 202-548-4430 or at shaffer@aaos.org.

> NQF Response

Support, no response needed

GlaxoSmithKline

Deborah Fritz

GlaxoSmithKline supports the holistic approach this report advocates and agree that Patient Reported Outcomes (PROs) are an important aspect of improving quality of care and outcomes. We look forward to further development in the area of Person-Centered Care and Outcomes and appreciate the opportunity to review this report.

> NQF Response

Support, no response needed

Highmark

Christine Pozar

This is the softer side of care delivery but one of the most important in realizing outcome success. We are very supportive of person-centered care and what it stands for.

> NQF Response

Support, no response needed

National Partnership for Women & Families

Courtney Roman

The National Partnership for Women & Families has spent nearly two decades advocating for the inclusion of patients, families, advocates, and consumers as equal partners in health care transformation efforts. We believe strongly that shifts in thinking and practice are required to move our health care system to one that is truly patient- and family-centered.

We appreciate the work of the Expert Panel and NQF staff to identify performance measure gaps in person-centered care and outcomes. We believe this effort is a step forward in the aim to ensure that the unique insights, perspectives, and experiences of patients, families, consumers, and advocates drive quality improvement and overall transformation.

The National Partnership for Women & Families has a long history of advocating for the use of performance measures to drive accountability and we believe that performance measures also have an important role in facilitating culture change. Overall, we are very supportive of the deliverable proposed by the Committee. Below we provide some comments on specific components of strength as well as suggested improvements:

Report strengths:

- Identifies a multi-layered approach to changing care and describes how patients can be involved at every level. This approach is aligned with the National Partnership's own change model, which we use with health care providers and patients and families around the country.
- Recognizes and builds upon the extensive prior work on patient- and family-centered care undertaken by various organizations.
- Focuses on prioritizing measures gaps for the ideal care state, which we believe will help facilitate movement in that direction.
- Offers a robust definition of person-and family-centered care and core concepts associated with the definition.
- Acknowledges the important role outcomes play in driving better performance and the priority patients, families, and consumers put on outcomes measures.

Submission 1 of 2.

> NQF Response

Support, no response needed

National Partnership for Women & Families

Courtney Roman

National Partnership for Women & Families (Submission Part 2 of 2)

Areas for improvement:

- The initial background discussion is focused on patient engagement, conflating the term with person-centered care. In our experience, patient engagement and partnering with patients and families are strategies for achieving person-and family-centered care.
- Missing from core concept #1 is an explicit recognition of partnership. We strongly encourage the Expert Panel to review the report and ensure that truly collaborative and meaningful partnership

with patients and families is at the heart of this work. At times, the tone shifts from doing "with" patients and families to, instead, doing "to" or "for"—the latter of which we advise against. (For example, the mention of asking patients "How is your care working out for you?" as opposed to "Members of my care team and I work in partnership to ensure my needs and goals are met.") We suggest continuously emphasizing throughout this report that person- and family-centered care can only be achieved by partnering with patients and families at all levels of care.

- Regarding plan of care, the report should emphasize the need for patients and their providers to develop the plan collaboratively.
- We caution on the use of "to the extent I am able" in the core concepts, making sure the individual is determining their level of ability and it is not assumed or superimposed.
- While available CAHPS measures address aspects of the core concepts, there are still significant gaps. We feel a stronger statement should be made around improving CAHPS measures to address identified gaps.
- In regard to the standard label for person- and family-centered care suggestion, we appreciate that the Expert Panel clearly stated that patients and families would be involved in its design. However, we would strongly suggest gathering input and recommendations from patients and families prior to any significant plans being made to move this idea forward. By involving patients and families as early on in the process as possible, there is more of an opportunity to ensure the standard label concept would resonate with the individuals who would actually be utilizing it.

Thank you again for your efforts on this crucial body of work and for your consideration of our comments.

– -National Partnership for Women & Families

> NQF Response

Core concept #11 explicitly states that "I work with other members of my care team . . . And the explanation uses the language of partnership.

The suggestion of asking "How is your care working out for you? came directly from a patient and the committee agreed it might be a useful question. All of these suggestions will require further review and development.

Pacific Business Group on Health

David Hopkins

Consumer-Purchaser Alliance Comments on Priority Setting for Health Performance Measurement: Addressing Performance Measure Gaps in Person-Centered Care and Outcomes

It is widely agreed upon that time has come for shifting the current culture of health care to person-centered care. Making this a reality, however, will require concerted focus and change and challenge even the most dedicated to ensuring this happens. Thus, instilling accountability through performance measures will be an important tool in facilitating the culture shift.

We very much appreciate the endeavors of the Expert Panel and NQF staff in helping to move this agenda forward, of articulating definitional core concepts and proposing measure concepts. Overall, we are very supportive of the work product. Below we provide some comments on what we particularly liked and where improvements can be made.

Strengths of the report

Builds on other frameworks and acknowledges significant contributions already made to advancing person-centered care.

Focuses on prioritizing measures gaps for the "north star", the ideal care state, which will help push in that direction.

Identifies a multi-layered approach to changing care and how patients can be involved at every level.

Robust definition of person-centered care and core concepts.

Recognizes the important role outcomes play in driving better performance.

Areas for improvement

The initial background discussion is focused primary on patient engagement, almost treating that interchangeable with person-centered care. Patient engagement is a strategy for achieving person-centered care.

Missing from core concept #1 is an explicit recognition of partnership. Rather, it could be re-stated to "Members of my care team and I work together so that my needs…" or "I partner with other members of my care team so that my needs…".

Regarding plan of care, the report should emphasize the need for patients and their providers to develop the plan collaboratively and for them to view it as some sort of "contract".

Caution on the use of "to the extent I am able" in the core concepts, making sure the individual is determining their level of ability and it is not assumed or superimposed.

While available CAHPS measures address aspects of the core concepts, there are still significant gaps. A stronger statement should be made around improving CAHPS measures to address identified gaps.

Thank you again for attending to this important work and considering our feedback.

> NQF Response

Core concept #11 explicitly states that "I work with other members of my care team . . . And the explanation uses the language of partnership."

Conceptual Framework

America's Health Insurance Plans

Carmella Bocchino

We support NQF's efforts to prioritize measure gaps that promote person-and family-centered care. We recommend NQF consider modifying this framework to incorporate the patient as a part of the care team, rather than placing the patient at the center with services occurring around the individual (as depicted in Figure 2). Patients need to know that they are an integral part of the health care team and work with providers to determine the best choices and decisions for their health.

> NQF Response

The committee agreed that patients and families are part of the care team and chose to convey it through the language of "partnership." Ultimately, the person's needs should be central.

Center to Advance Palliative Care

Emily Warner

Thank you for your work addressing this important aspect of healthcare quality. The Center to Advance Palliative Care makes the below comments regarding the conceptual framework.

P. 2 and 3: We support inclusion of previous work in this area, but encourage NQF to look outside of single papers and reports in its exploration of consonant work. The field of palliative care has been developed precisely to improve patient-centered care for all people with serious illness (regardless of diagnosis or stage of disease), and there is a tremendous body of literature in this field, including the National Consensus Project's (NCP) Clinical Practice Guidelines for Quality Palliative Care (http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf) which utilizes an 8-domain framework for the provision of high-quality patient-centered care to people with serious illness. By way of reference and consideration, these domains are: Structure and Processes of Care; Physical Aspects of Care; Psychological and Psychiatric Aspects of Care; Social Aspects of Care; Spiritual, Religious and Existential Aspects of Care; Cultural Aspects of Care; Care of the Patient at the End of Life; and Ethical and Legal Aspects of Care. We suggest citing the NCP guidelines in the text or in Appendix C. There is substantial overlap in concepts between "patient-centered care" and palliative care, and it would be wasteful to neglect such a large body of work because of variation in monikers.

P. 13, 14. We are concerned about the prioritization of outcome measures over structure and process measures, and the failure of this report to identify the benefits of structure and process measures. When a structure or process is linked to quality improvements, it is appropriate to prioritize those measures for implementation, and indeed process measures can be more constructive for quality improvement than outcome measures because they are actionable. There is already extensive literature that palliative care processes improve patient and family satisfaction, pain and symptoms, and quality of life, but sadly not everyone who needs palliative care receives it. Structure and process measures are particularly important to improve quality of care for people with very serious illness, who are too ill to participate in patient surveys. The draft report on workforce measures stated it well, that "while structure measures can often be a blunt instrument for assessing quality, good structure, a sufficiency of resources and proper system design, can be the most important means of protecting and promoting quality of care." (Addressing Performance Measure Gaps in the Health Workforce, p. 7)

> NQF Response

Added recognition and reference to hospice and palliative care to background.

Included discussion of advantages of process measures and challenges of outcome measures.

Children's Hospital Association

Ellen Schwalenstocker

I am pleased to offer these comments on behalf of the Children's Hospital Association. Although we agree with the core concepts to guide performance measurement, we are concerned that the "I" statements and explanations provided for each concept do not adequately recognize the essential role of family members, including parents, for patients for whom decisions must be made in full or in part by others. This point is made under the family concept, but it is important to recognize that it applies to all of the concepts. The Association suggests including a paragraph in the document to strengthen this point. We appreciate the vignette under self-management, which is illustrative. Additionally, it is important to think about person-reported outcomes from the patient, parent/caregiver and family perspectives. In children's health care, outcomes such as work productivity for the parent or family stress are important - as is the child's functional health status and quality of life. Under the access/convenience concept, the word "convenience" may not adequately convey the needs of patients and families that are faced with serious illness. The burden on patients and families is substantial, especially for those with multiple chronic conditions. Providing the right care, at the right time and in the right place does more than influence satisfaction - it is critical to achieving the best health outcomes for patients and their families.

> NQF Response

We added some language to specifically identify children in the description of core concept family and shared decisionmaking.

Maine Health Management Coalition

Susan Schow

We support efforts to focus on this challenging area of health performance measurement and applaud the Expert Panel and NQF staff for advancing the understanding of this topic. This is an area with very limited use of metrics and we encourage the development, testing and adoption of more valid measures of person-centered care outcomes. Thank you for the opportunity to provide input.

> NQF Response

Support, no response needed

Priorities and Recommendations for Performance Measurement

Altarum Institute

Anne Montgomery

Anne Montgomery and Joanne Lynn

NQF has done well in putting forth a framework to organize a system to measure the performance and progress of person-centered care and outcomes (PFCC). As drafted, the working definition of measures for PFCC should be "meaningful to consumers; built with consumers; …[reflect the] entire care experience, rather than a single setting or program; and…[encompass] patient-reported outcomes."

The draft document further notes that PFCC measure development is embedded in the Measure Applications Partnership, which is meant to build a family of measures that support PFCC, including measures for "patient and family involvement in decisions about healthcare…joint development of treatment goals and longitudinal plans of care [emphasis added]…evaluating patient and family experience of care, and ability to self-manage."

These are excellent goals. To achieve them, we urge that the short-term recommendations be strengthened to:

1) Include a clear call to the Office of the National Coordinator for Health Information Technology to rapidly create a flexible and partly narrative template for health and social services providers to use in creating longitudinal care plans for individuals with higher level of care needs, all of whom are treated across multiple programs and providers. If made an immediate priority, such a template would make the principle of shared decision-making a reality, which NQF correctly notes is predicated on the ability of a care system to both record and adjust an individual's services as preferences and goals change. Furthermore, NQF states that performance measures that only record "whether there is a plan of care (yes/no) is less meaningful than an outcome measure that captures whether individuals think their care plans reflect their individual priorities, goals and needs." Care plan performance measurement requires much more.

2) Take a proactive stance on assessment of family caregivers that is at least as strong as the requirement for states to assess family caregivers where they are essential to the services of Medicaid beneficiaries living in the community. Specially, in the final regulation for the 1915(i) home and community-based services (HCBS) regulation published in January 2014, CMS states: "When there is a caregiver involved, an assessment of the caregiver's needs is essential to facilitate the individual's linkage to needed supports." This language is significantly stronger than NQF's: "Consideration should be given to creating a strong system for eliciting and addressing the needs of families and caregivers, particularly when the care plan is heavily reliant on their involvement." NQF recommendations should not be weaker than CMS has already implemented in a relevant program.

> NQF Response

The comment refers to tools to help achieve person- and family-centered care rather than an organizational level performance measure. These are useful suggestions for ONC and will be included in full in the public comments.

America's Health Insurance Plans

Carmella Bocchino

We support using patient reported outcome (PRO)-based measures and recommend focusing on assessing outpatient care and specifically the physician managing the episode of care and rehabilitative services. We also recommend the development of PRO-based measures for pain and functional status with an initial focus on musculoskeletal pain, spine surgery, and functional status for joint replacement.

Additionally, while we agree that family may play a critical role in decision-making, we caution that not every patient may wish to have family involvement. A patient's care team needs to be sensitive to the patient's wishes, as well as family issues and dynamics, to ensure optimal care for the patient.

> NQF Response

The committee agreed that family is defined by the patient and is involved as the patient chooses.

Although PROs on pain and function are tools for delivering person-centered care, the performance of a provider on performance measures such as percentage of patients with improved function or percentage of patients with pain controlled are indicators of treatment effectiveness.

CAPC

Emily Warner

Thank you for the opportunity to comment on this important work. The Center to Advance Palliative Care makes the below comments regarding priorities and recommendations.

p. 15. Overarching Recommendations bullet 2 contradicts Overarching Recommendations bullet 6. We agree with bullet 6—that we should focus on actionable measures—i.e. measures that will help in quality improvement initiatives. We recommend removing or rewording bullet 2 to prevent conflicting messages.

P. 15, 16. We are in very strong agreement with NQF in its recommendation to focus on patients with higher levels of need. These are the individuals most vulnerable to receiving poor care, who have the most contact with the healthcare system, and who may have the most difficulty in advocating for themselves.

We suggest that this point be the first of the short-term recommendations. We also commend NQF for identifying the issue that CAHPS surveys miss those with serious illness, and that this issue must be addressed, and that focus should be placed on advancing family experience measures.

P. 30. We also applaud NQF for including utilization measures as outcome concepts in the shared decision-making field. Emergency interaction with the acute care system can be traumatic for patients and often is specifically unwanted by patients and families, and ED visits are often a sign that the patient and family are not receiving the care they need to remain safely and comfortably at home.

Finally, we suggest that the committee consider expeditiousness as a principle for establishing priorities in measurement and research. There are many measures currently available that need additional testing and specification, but that would improve care quality, if implemented, relatively quickly. This is in contrast to starting with a new measure or measure concept that has not been developed at all. It is important that we improve patient-centered care as quickly as possible, particularly for the tens of millions of people who will be diagnosed with a serious illness in the next five years. For these individuals, a key aspect of quality improvement is that quality improvement begins now, not 10 years from now. We believe including expeditiousness as a guiding principle will encourage CMS and others to invest resources more effectively.

> NQF Response

Bullet 2 is intended to focus on experience with care and outcomes. Bullet 6 does not refer to measures of discrete structure or processes - just that structure and processes of care affect experience and outcomes. This was clarified.

Measure gaps can be filled by measures that are currently in development and use if they are submitted for endorsement to be used more broadly in accountability.

Center for Outcome Analysis

James Conroy

Many people with disabilities who receive supports are not connected with any family members, so it might be wise to take that into account in the

Change “partnerships among individuals, their defined family, and providers of care”

to: partnerships with explicitly shared power among individuals, their defined family and/or freely chosen allies, and providers of care.”

(Th primary impetus for person-centered planning in the disability world from 1981 onward was to decrease provider dominance of people’s everyday lives. Medicaid is by its very nature a “provider-payment-system,” and that can dangerously diminish people’s ability to set the goals and aspirations that mean something to them.)

> NQF Response

Although “power” or “control” may be areas of concern, the committee thinks that “partnership” conveys the desired relationship.

Children’s Hospital Association

Ellen Schwalenstocker

As HHS works to address the Committee’s recommendations, the Children’s Hospital Association would like to emphasize the importance of ensuring that work on measurement development and use addresses patients and families across the lifespan, including infants, children and adolescents. The Association agrees strongly with the overarching recommendation that these efforts should go beyond “silos of accountability and measurement.” In terms of intermediate recommendations, it may be worthwhile to consider the use of qualitative experience of care information to drive improvement. Recognizing the need to minimize reporting burden, qualitative information may provide important insight that is not possible with only quantitative scores.

> NQF Response

For national standard performance measurement, quantitative assessments are necessary. However, qualitative data as suggested are useful in constructing person- and family-centered measurement tools as well as in organizational quality improvement efforts.

Quality Outcomes, LLC

Dan Williamson

As the concepts of the PCMH and the PCMN evolve and become more clear, it seems to me that a measure or set of measures that can help identify patient needs would be valuable to the process of care coordination. Having a common measure that is validated across multiple patient populations, even more so.

A simple to administer and understand measure that accomplishes these goals is the PROMIS-29. It is also validated for patient self-administration. It measures functional quality of life indicators across multiple domains. For instance, the PROMIS-29 provides scores on Physical Function, Anxiety, Depression, Fatigue, Sleep Disturbance, Social Participation and Pain Interference. Additionally, the patient can indicate their current pain level. It can be administered over time to document improvement as well.

I would like to see this measure endorsed as I firmly believe it neatly packages several good indicators of effective person-centered care and can be used across multiple health care settings.

> NQF Response

The comment refers to a patient-level instrument rather than an organizational level performance measure. The committee agreed that standardized assessment instruments facilitate assessing individual needs. See Appendix D for suggested measure concepts.

ISBN 978-1-933875-69-9

NATIONAL QUALITY FORUM
1030 15TH STREET NW, SUITE 800
WASHINGTON, DC 20005

www.qualityforum.org