NATIONAL QUALITY FORUM

Meeting Materials

Priority Setting for Health Care Performance Measurement: Addressing Performance Measure Gaps in Priority Areas

Person-Centered Care and Outcomes

Agenda

Priority Setting for Health Care Performance Measurement: Addressing Performance Measure Gaps in Priority Areas

Person-Centered Care and Outcomes Committee Meeting

April 7-8, 2014

NQF Conference Center at 1030 15th Street NW, 9th Floor, Washington, DC

Remote Participation Instructions:

Streaming Slides and Audio Online

- Direct your web browser to: http://nqf.commpartners.com
- Under “Enter a Meeting” type the meeting number for Day 1: **672434** or for Day 2: **672434**
- In the “Display Name” field, type your first and last name and click “Enter Meeting”

Teleconference

- Committee members: Dial **877-457-4684** and use conference ID code for Day 1: **97499908** and for Day 2: **97551287**
- Non-Committee Members: Dial **855-840-2973** and use conference ID code for Day 1: **97499908** and for Day 2: **97551287**

Meeting Objectives:

- Finalize definition/core concepts of ideal person- and family-centered care
- Identify how to measure person- and family-centered care (i.e., the core concepts)
- Prioritize opportunities for person-centered care performance measurement , i.e., short-term vs. longer-term

Day 1: Monday, April 7, 2014

8:30 am **Breakfast**

9:00 am **Welcome and Introductions**
(**Introductions:** name, title, organization; *Please share with us your views on receiving, delivering, and/or measuring person- and family-centered care*.)
Sally Okun, *Co-Chair*
Uma Kotagal, *Co-Chair*
Karen Pace, *Senior Director, Performance Measurement*
Wendy Prins, *Senior Director, Strategic Partnerships*

9:40 am **Setting the Stage**
Sally Okun (5-7 min)
Uma Kotagal (5-7 min)

- Goals for the meeting, review agenda
- Expectations for Committee discussions
- Clarifications of scope, objectives (relationship to PRO-PMs and other aspects of quality – safe, effective, affordable; developing measure concepts; priorities; short and longer-term recommendations)

Kevin Larsen*, **MD,** Office of National Coordinator of Health IT, HHS* (5-7 min)

- Opening Remarks - Context for Project

10:00 am **Project Overview and Related NQF Projects**
Mitra Ghazinour, Project Manager

- Project Overview and Timeline
- PROs and Performance Measurement
- Person- and Family-Centered Care Endorsement project
- MAP Person- and Family-Centered Care Family of Measures
- Patient and Family Engagement Action Team

10:15 am **Break**

10:30 am **Definition and Core Concepts for Person- and Family-Centered Care**
Facilitator: ***Uma Kotagal***

- Review current draft (5 min)

- **Panel - Exemplars of the Core Concepts**
Describe one real-life vignette that exemplifies the core concept (can include patient-provider interaction, best practice, systems to support the core concept)
(5 min each)
    1. Whole Person, goal, priorities – ***Gene Nelson, MPH, DSc,*** Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH
    2. Care I need, when, where, how I prefer – ***Uma Kotagal, MBBS, MSc,*** *Cincinnati Children's Hospital Medical Center, Cincinnati, OH*
    3. Respect, dignity, compassion – ***Anne Walling, MD, PhD,*** *University of California-Los Angeles, Los Angeles, CA*
    4. Collaborate in decisions – ***Michael Lepore, PhD,*** *Planetree, Atlanta, GA*

5. Family – ***Jennifer Wolff, PhD,*** *Johns Hopkins Bloomberg School of Public Health, Baltimore, MD*
6. Information – ***Bruce Leff, MD,*** *Johns Hopkins University School of Medicine, Baltimore, MD*
7. Time valued – ***Dave deBronkart, Jr.,*** *Society for Participatory Medicine, Nashua, NH*
8. Communication – ***Troy Fiesinger, MD,*** *Memorial Family Medicine Residency, Sugar Land, TX*

- Discussion (30 min)

11:45 am **Definition and Core Concepts for Person- and Family-Centered Care**
Facilitator: ***Uma Kotagal*** *(5 min)*

- **Panel of Patient and Patient/Consumer Representatives**
Key Question: Do the definition and core concepts capture your view of ideal person-and family centered care?
(5 min each)

  - ***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*
  - ***Mary MacDonald, MS, BA,*** *American Federation of Teachers, Washington, D.C.*
  - ***Maureen Connor, RN, MPH,*** *Institute for Patient-and Family-Centered Care, Eugene, OR*
  - ***Sally Okun, RN,*** *PatientsLikeMe, Cambridge, MA*

  - Discussion (25 min)

12:45 pm **Lunch**

1:15 pm **Opportunity for Public Comment**

1:30 pm **Definition and Core Concepts for Person- and Family-Centered Care**
Facilitator: ***Uma Kotagal***

Committee discussion
Each committee member identifies level of support; any objections that would prevent moving forward? Can we resolve now, or come back to later?

2:00 pm **Measurement Framework**
Karen Pace

- Overview of NQF endorsement criteria
- Performance measure vs. practice vs. instrument/tool
- Clarify PRO-PM in relation to person-and-family- centered care
- Review measurement framework
- Review measure concept
- “Nutrition label” concept
- Instructions for work groups

2:20 **Innovative Approaches**

- Systems approach to Convenience (related to core concepts #2, #7)
  James L. Holly, MD, *Southeast Texas Medical Associates (SETMA)* (8-10 min)

- Overview of PROMIS
  Susan Yount, PhD, Feinberg School of Medicine, Northwestern University (8-10 min)

- Using PROMIS items specific to an individual's priorities and goals (related to core concept #1)
  Amy Eisentstein, PhD, Feinberg School of Medicine, Northwestern University (8-10 min)

- Question and Answer (15 min)

3:05 **Break**

3:15 **Small Group Work: Identify Measure Concepts**
Generate performance measure concepts (using measurement framework worksheets)

- **Group 1: (Concepts 1 & 2)**
  Leader: Staff recorder:
- **Group 2: (Concepts 3 & 4)**
  Leader: Staff recorder:
- **Group 3: (Concepts 5 & 6)**
  Leader: Staff recorder:
- **Group 4: (Concepts 7 & 8)**
  Leader: Staff recorder:

4:45 pm **Report Out from Small Groups**
Facilitator: ***Sally Okun***
All Committee Members

- Share progress in creating potential measure concepts
- Q&A with other committee members

5:15 pm **Adjourn**

Day 2: Tuesday, April 8, 2014

8:00 am **Breakfast**

8:30 am **Welcome, Goals, Review Agenda, Recap of Day 1, Clarifications**
Sally Okun*, Co-Chair*
Karen Pace*, Senior Director, NQF*

8:45 am **Opportunity for Public Comment**

9:00 am **Measurement Framework and Measure Concepts from Day 1**
Facilitator: **Sally Okun**

- Review
- Clarifications, suggestions for additions or deletions

10:00 am **Priorities for filling performance measure gaps**
Karen Pace

- Considerations for identifying priorities (NQF criteria – hierarchical preference for outcome, evidence, performance gap, short vs. longer-term)
- Other

10:15 am **Break**

10:30 am **Small Group Work: Prioritize the measure concepts for performance measurement**
Identify the highest priority measure concepts

11:45 am **Report out from small groups**
Facilitator: ***Sally Okun***
All Committee Members

12:30 pm **Lunch**

1:15 pm **Identify Short-Term and Long-Term Recommendations**
(Priority vs. Resource Investment)
Facilitator: ***Sally Okun***
All Committee Members

- Round-robin discussion from each committee member regarding short and longer-term recommendations
- Full Committee discussion

2:30 pm **Opportunity for Public Comment**

2: 45 pm **Wrap Up/Next Steps**

3:00 pm **Adjourn**

03/31/14

Draft Person- and-Family-Centered Care: Definition and Core Concepts

The following definition and core concepts were revised after review of the Committee poll results (reported in this document) with the co-chairs. The definition and core concepts are intended to represent what individuals and their families experience when care is person- and-family-centered. There are many processes and structures that could be implemented to achieve the experience embodied in the core concepts, which will be explored in the accompanying measurement framework.

Individuals and their families desire and expect care that is also safe, effective, affordable, and provided in a healing environment. These are important areas of quality and often related to person- and family-centered care; however, they will not be the focus of identifying performance measures for person-and-family-centered care.

Definition of Person- and Family-Centered Care

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.

Core Concepts

The following core concepts build on the overarching definition and do not repeat concepts such as defined family or responsive to an individual’s priorities. The term “care partners” is used to refer to all providers of care, as well as family care partners, and to emphasize the collaborative partnership.

1. My care partners strive to know me as a whole person and take into account my priorities and goals for physical, mental, spiritual, and social health.
2. I receive the care I need — no more, no less—when, where, and how I prefer.
3. My care partners treat me and my family with respect, dignity, and compassion.
4. I collaborate in decisions about my care to the extent I desire or am able, or I choose the care partner I prefer to collaborate in those decisions for me.
5. My family care partners include those I choose and their role is supported by other care partners.
6. My care partners provide information, in a format I prefer, to:
    - answer my questions and help me understand my choices — about my health, health problem, treatment, care, costs, or providers; and
    - increase my confidence and capacity to care for myself to the extent I am able.
7. My care partners value my time and use it efficiently and effectively.
8. Communication with and among my care partners is honest, transparent, and coordinated across settings and time.

Committee Poll on Definition and Core Concepts

The results of the poll of the Committee's level of support and suggestions for the draft definition and core concepts are provided on the following pages.

Definition

Person- and family-centered care is an approach to the planning, delivery, and evaluation of care across settings and time that is anchored by, respectful of, and responsive to the individual's preferences, needs, and values (including involvement of family/caregiver) to ensure that individual preferences, needs, and values guide all aspects of care in partnership with providers of care.

Overall support	16	89%
Support	**7**	39%
Can Live With	9	50%
Do Not Support	**2**	11%

COMMITTEE COMMENTS

- I can live with it, however, there are too many attributes being included in one statement which makes is very complicated. In addition, at a minimum I would suggest that we break the statement into two sentences (put a period after......family/caregiver). Start a new sentence and say....."This is to ensure that individuals......."
- The definition is redundant by listing individual preferences, needs and values…as anchored by then saying it ensures the same words used to guide all aspects of care. My suggestion is to make changes from anchored by to the end: PFCC is…..that is anchored by mutually beneficial and collaborative partnerships between patients, their families and health care providers that ensures healthcare is responsive to an individual's priorities, preferences and values (including involvement of family/caregiver) in order to promote health and well-being while maintaining their dignity and control.
- I recommend deleting "to ensure that...providers of care." While the addition of "partnership with providers" is a step toward recognizing the role care providers must play, the phrase "guide all aspects of care" suggests a unidirectionality, from the patient, that undermines the importance of the interactive relationships between patient/family/informal caregivers and providers.
- Individual's experiences of care should be considered. For example, if this is my 3rd kidney transplant and one of my brothers who donated a kidney suffered irreversible post-op consequences, I'd like you to think about that in regard to my pre-transplant care. I believe that experiences are distinct from preferences, needs, and values, although others may consider experiences a subset of this. In fact, the draft core concept, "Know me and consider all of me in my care- health conditions, physical, mental, emotional, spiritual, social" includes health conditions. It's not so much the health conditions but the experiences of this condition that we individual care to.
- I'm not sure we need to restate 'individual preferences, needs and values" Could it say "...to ensure that these guide..."
- I'd prefer "govern" to "guide" in the last sentence.
- Assessment of preferences and goals etc is implied, rather than explicit. how does this def work for patients who don't value this type of care, who don't want partners in care?

- wording is a little awkward added word (improvement) to phrase that follows: approach to the planning, delivery, evaluation and improvement of care
- I agree with the concepts in this definition. However, the definition seems to be provider-centric. It suggests that providers should be mindful of patient/family concerns. I would prefer to see a definition that provides a more engaged view of the person in their health management. Integrating concerns is the first step, and the definition covers this. But, suggesting that individuals are "co-producers" of knowledge about their own condition and "collaborators" in the ways in which that knowledge is used is a stronger and more active way of describing person-centered care. I will share a reference from our group on this topic.
- I am not sure that "evaluation of care" is essentially part of the provision of care. Separation of the evaluation of care from its implementation seems like it may be necessary to avoid a slippery slope into expanding this topic to 'person- and family-centered care and evaluation'. I also find the omission of empowerment/information/education from the definition to be a shortcoming.
- I see family-centered care as a component of person-centered care. That is, if the person wants their family involved, the care providers are set up to provide a family-centered approach. I would simplify this by calling it person-centered care. The parentheses capture this concept so that it is not lost.

Core Concepts

1. Know me and consider all of me in my care- health conditions, physical, mental, emotional, spiritual, social

Overall support	14	78%
Support	**10**	56%
Can Live With	4	22%
Do Not Support	**4**	22%

COMMITTEE COMMENTS

- A few things bother me about this - 1) it doesnt take into account the concept of prioritizing what is important to me. As a provider, I don't know how I would possibly consider ALL those elements in considering care. This is fine in theory but how to you operationalize it? Whereas if i know you and know what your priorities are in care, that would be something different. 2) this to me implies a passivity on the part of the patient - the provider is deciding my care and i am a recipient of it. I would like to see a more active component to this statement.
- Rephrase. Consider all of me in my care of health conditions in terms of physical, social, emotional (conceptually, emotional includes mental hence my recommendation is to use one or the other) and social
- I am concerned about word "consider"…this word suggests that it is factored in but may not be the primary driver of health care choices. The phrase seems to be too narrowly focused on what providers should do…I think of concepts more broadly and not prescriptive. I am ambivalent about supporting this. How would we measure this?

- I can live with it but I'm not thrilled with the "consider all of me" - some people might find that intrusive and not understand the intent it to consider the whole person versus consider every nuance of their life. How about "Know me and consider me as a whole person"
- How does one "know me"? assessment of these domains is critical
- Emotional health is a component of mental health so is redundant; spirituality is part of well-being not health, so would strike. My concept of spirituality is that it refers to finding meaning in life   If we strike the words "emotional" and "spiritual" I can live with it

2. Give me care when and how I need it

Overall support	15	83%
Support	**8**	44%
Can Live With	7	39%
Do Not Support	**3**	17%

COMMITTEE COMMENTS

- Same concerns as above. Feels passive.
- Provide me care when and how I need it
- This misses the opportunity for explicit expectations about individuals participating in the decision-making process around care choices. The word " give" suggests a passive role for patient and not a participatory one….partnerships are about actions "with" people not the traditional "doing to and for patients"
- Can we really commit to giving care whenever the patient determines? Should this be qualified to say, "Whenever possible, give me care when and how I need it"?
- Seems to be missing "where"
- Give me the care I need - no more, no less -- when I need it. (May be clunky but I'd like to see something that acknowledges some folks get care they may be unaware that they don't need.)
- Is this realistic in our delivery system designed for convenience of providers, not patients?

3. Treat me with respect and dignity

Overall support	17	94%
Support	**17**	94%
Can Live With	0	0%
Do Not Support	**1**	6%

COMMITTEE COMMENTS

- Perhaps defining what respect and dignity looks like …for instance Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- I would like to see "compassion" added

4. Treat me as a partner in my care

Overall support	15	88%
Support	**10**	59%
Can Live With	5	29%
Do Not Support	**2**	12%

COMMITTEE COMMENTS

- This is where we can add the concept of joint decision making.
- Could add to #6
- Again, I would suggest the word "involve" instead of "treat". for this concept
- I'd qualify this a bit to tailor the partnership to the individual's preferences. Something like, "Involve me at the level I desire to be a partner in my care."
- I don't like the word 'treat' in this context. Maybe "Engage me as a partner in my care"
- I would like to see something that includes "give me the information I need to be an informed partner in decision-making about my care."
- Collaborate with me as a partner in my care
- Clarity on what 'as a partner' means and potentially rewording this may be valuable

5. Include my family/caregiver when I choose and provide support to them

Overall support	15	88%
Support	**10**	59%
Can Live With	5	29%
Do Not Support	**2**	12%

COMMITTEE COMMENTS

- Caregiver to me says this is a person who is old and infirm. Wouldn't feel like this applies to me. And what if I want a friend or "family of choice" to be included?
- I do not understand this one......May be this needs to be rephrased.
- I support the concept, but need to take into account the wide scope of surrogate decision-making (see recent JAMA Internal Medicine Paper published this month entitled "Scope and Outcomes of Surrogate Decision Making Among Hospitalized Older Adults." Also much of surrogate decision making occurs when the patient is unable to participate in decisions and so identifying surrogates in advance is a very important component of patient and family centered care. Perhaps a more inclusive wording would be, "Know and Understand who is important to me as a source of support (e.g. family/caregiver) and involve them in my care as appropriate and provide support when needed." Wording probably needs more work.
- I support the concept but wonder if this wording has more clarity - Honor my definition of who I consider family and my choices about how they will participate in care and decision-making.

- I like the concept of 'when I choose' but I wonder if including it adds a barrier for times when I'm not able to choose
- Include my family/caregiver" in education and decision-making" when I choose and provide support to them.
- Implies that patient needs to make a clear decision to push decisions on to family. in some cultures, e.g. some Asian cultures, that decision may be operative, but not actively declared, and asking the patient may not be in line with cultural norms

6. Give me the information I need and want about my care or provider and to help me take care of myself

Overall Committee Support: %72

Overall support	13	81%
Support	**8**	50%
Can Live With	5	31%
Do Not Support	**3**	19%

COMMITTEE COMMENTS

- I am not completely understanding this one too since I was not able to participate in all the discussions while I was out, What I do not understand is the last part of it. That is help me take care of myself.
- The wording is confusing. Is this getting at effective communication? or quality measurement reporting? or e learning tools?
- I would suggest that the quality of the information is paramount. How the information is shared is important…engaging patients and families is critical. Give me…assumes a passive role with patients and doesn't create expectations about the quality and usability of the information... unbiased and affirming information that builds on my strengths and is useful to me in making health care choices or taking care of myself. What about: Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- This is actually more than one concept. Sometimes an individual will want information and yet prefer to have someone else do the caretaking. How about, "Give me the information I need and want about my health, health problem, care or provider." and "Help me to learn to care for myself at the level that I prefer."
- I don't think we should confound the terms "care or provider". Maybe "Give me the information I want and need about my care and the help I need to care for myself."
- Give me and my family/caregiver the information I need to fully understand my illness/condition and to take care of myself.
- Consider making last phrase a separate element: help me take care of myself
- Revised: Give me the information I need and want about my care or provider and help me take care of myself. Also, this seems heavily multi-loaded. I recommend considering that we pull out the support for self-care aspect and make it a separate domain.

- I think important to add the concept of give me information "in a way that I can understand". Oftentimes patients are given information but it doesn't meet them where they are at...needs to be provided in way that is understandable.

7. Do not waste my time or add to my burden unnecessarily

Overall support	14	78%
Support	**10**	56%
Can Live With	4	22%
Do Not Support	**4**	22%

COMMITTEE COMMENTS

- What does "add to my burden?" mean? that seems to imply don't tell me the truth if it will burden me. Where is the value of transparency and honesty in here?
- Seems like some of these concepts are descriptive of standards for patient centered medical homes.
- I recommend adding "and support me in making the best use of provider and caregiver time."
- I would avoid the negative here and also consider as two separate concepts. Try "Respect my time" for one. Is there another term for burden? Some people consider the amount of time and work to care for themselves and others in a spiritual sense and not as a burden at all. How about "Adjust requests for my time and energy based upon my personal preferences"?
- Unclear what "my burden" is
- Inappropriate or unnecessary care needs to be called out more directly. It is partially captured by don't waste my time but not fully and it's an important concept unto itself.

8. *Communicate and cooperate with all of my providers of care*

Overall support	16	89%
Support	**11**	61%
Can Live With	5	28%
Do Not Support	**2**	11%

COMMITTEE COMMENTS

- This is limited by the fragmented U.S health care system and is essential to have but not a solution at the individual physician level, it is a system problem.
- This is a really important one. The way I think about it is continuity of care.
- Consider inclusion of the point that health care institutions should ensure continuity of care across venues
- I think there are current practices where health care professionals communicate and cooperate with each other but may not include the patient and/or family in these conversations. That is not patient- and family-centered care. If this was to be included I would suggest it explicitly set the bar high for communication that occurs with patient and is inclusive of other care providers.

- In my world, a "provider" is an MD, PA or APN (advanced practice nurse).Aren't we talking about all clinician and non-clinician members of the team? Also, collaborate is more apt than cooperate. Would rephrase as "Communicate and collaborate with all of my health care team members."
- I would add "collaborate"
- I wonder how this works in a model that has a primary care provider. Is it make sense for all the providers to be communicating with one another, or does the primary care serve that role. Perhaps communicate and cooperate with my other providers. It's the "all" doesn't make sense.

****Give me care that matches my preferences, values, goals, decisions** (Incorporated into #4-decsionmaking and #1-priorities and goals)*

Overall support	16	89%
Support	**11**	61%
Can Live With	5	28%
Do Not Support	**2**	11%

COMMITTEE COMMENTS

- Better - maybe would prefer priorities more than preferences.
- Again I would replace "give" with "provide"
- I agree with intent, but it's not just "giving care", it should be ensuring timely involvement of the patient in care planning or eliciting preferences for care in a way that is timely and acceptable to the patient. For example, "Maximize my readiness and ability to participate in shared decision making to ensure that my medical care is guided by my preferences, values, and goals.
- Again, would prefer something where the active engagement (to the degree they choose) is included
- I recommend this be modified to address information sharing between providers and patients/families/informal caregivers, and the potential for preferences, etc. to be informed by that sharing.
- If they aren't giving me care that matches "decisions" I've made, that's a very serious problem. Would like to see something a little stronger like "respect my preferences, values, goals and decisions"

Additional core concepts that you think should be considered

COMMITTEE COMMENTS

- Had trouble with the online survey. I just had a few suggested word changes, but generally support the definition and concepts put forth.
- Please see my prior email following our last committee call. From our discussion, it seems that from a measurement perspective, patient-centered care encompasses the domains of communication, decision-making, and care delivery processes. Some of the measurable components of these domains may include:

    a. adequate patient-provider communication;
    b. clear plan made for health issues the individual patient cares about;
    c. patient/family understanding of treatment options (including comparative benefits + harms of these options), goals of care, and plan for follow-up;
    d. personalized decision-making processes;
    e. discussion and transparency of cost and coverage;
    f. plan for and effective coordination with other providers;
    g. actual follow-up for health issues; provision and explanation of test results;
    h. monitoring of symptoms and functional status;
    i. provision of patient portal;
    j. access to support/discussion groups;
    k. access to navigator services
    l. respect, compassion in interactions
- As above, the concept of honesty and transparency. Also something about treat me as an EQUAL partner in my care - the concept that this is an equal partnership rather than an unequal one.
- There was no specific ones on shared decision making between the provider and patient to take into perspective the wishes, preferences and the desires of the patient
- Providers communicate effectively with me--importance of high quality communication skills, expressing empathy, good bedside manner, etc.
- Collaboration is a key concept that is not here…I think some of the "concepts" above have attempted to put the concepts in patient language. If that is the case, they have not spoken at a broad enough level to be effective. For instance, if I wanted to put the concept of information sharing into patient language I might say something like…Information provided to me was in a format that answered my questions, helped me understand my choices and honored my preferences for receiving information in formats that increased my confidence in what I could do to improve my health and meet my goals for care.
- Given the difficulties the health IT industry is now encountering as they try to deliver our health data to us (patients), should we consider explicitly saying something about "Give me full access to all my medical records, in a way I can understand"?
- Ask me what's on my mind before telling me what's on yours.
- * Would like to see something about being a full partner in decision making. * Would also like to see something that includes informing me of the cost of treatment options.
- Not quite sure how to state it, but in care of people with multiple conditions and providers who seek to maximize performance on quality indicators, tests may be done that aren't truly needed for patient, but help provider meet so-called standards. person centered care would put interest of patient before provider or health system in this situation
- Provide my care in a healing environment (e.g., quiet, clean)
- I don't see anything on providing high quality care on things that matter most to the patient.

NATIONAL
QUALITY FORUM

Person- and Family-Centered Care

Performance Measurement

A quality performance measure is a numeric quantification of quality for an entity providing healthcare services. A performance measure score is based on an aggregation of data for the patients served.

NQF Criteria for Endorsing Performance Measures

NQF endorses performance measures based on an evaluation of the measure against a standard set of criteria to ensure it is suitable for use in accountability applications (e.g., public reporting, pay-for-performance), in addition to performance improvement. Because endorsement initiates processes and infrastructure to collect data, compute performance results, report performance results, and improve and sustain performance, NQF endorsement is intended to identify those performance measures that are most likely to facilitate achievement of high quality and efficient healthcare for patients. NQF's criteria are organized around five major concepts with subcriteria that further describe how the main criteria are demonstrated. The criteria are arranged in a hierarchy for review and evaluation as follows.

Main criteria

- **Importance to Measure and Report** (this is not the same as "Important to do") - Extent to which the specific measure focus is evidence-based, important to making significant gains in healthcare quality, and improving health outcomes for a specific high-priority (high-impact) aspect of healthcare where there is variation in or overall less-than-optimal performance. This is a must-pass criterion. If a measure does not meet the importance criterion, then the other criteria are less meaningful.

- **Reliability and Validity: Scientific Acceptability of the Measure Properties** - Extent to which the measure, as specified, produces consistent (reliable) and credible (valid) results about the quality of care when implemented. This is a must-pass criterion. The goal of measuring performance is to make valid conclusions about quality; if a performance measure is not reliable and valid, there is a risk of misclassification and improper interpretation.

- **Feasibility** - Extent to which the specifications, including measure logic, require data that are readily available or could be captured without undue burden and can be implemented for performance measurement. Ideally, performance measurement should create as little burden as possible; however, if an important and scientifically acceptable measure is not feasible, alternative approaches and strategies to minimize burden should be considered.

- **Usability and Use** - Extent to which potential audiences (e.g., consumers, purchasers, providers, policymakers) are using or could use performance results for both accountability and performance improvement to achieve the goal of high-quality, efficient healthcare for individuals or populations. NQF-endorsed measures are intended to be used for decisions related to accountability and improvement. New measures should have a credible plan for implementation in accountability applications and rationale for use in improvement. Measures undergoing endorsement maintenance are expected to be in use.

- **Comparison to Related and Competing Measures** - If a measure meets the above criteria and there are endorsed or new related measures (either the same measure focus or the same target population) or competing measures (both the same measure focus and the same target population), the measures are compared to address harmonization and/or selection of the best measure. Duplication and lack of harmonization among performance measures create burdens related to inefficient use of resources measure development, increased data reporting requirements, and confusion when they produce conflicting results.

Importance to Measure and Report

When identifying measure concepts for potential performance measures, the first consideration is whether it will meet the first major criterion of *Importance to Measure and Report*. There are many things that are important to do in clinical practice, yet not all of these things necessarily rise to the level of importance required for endorsement by NQF as a national consensus standard for measuring performance. NQF has a hierarchical preference for performance measures of health outcomes (including patient-reported outcomes) as follows:

- Outcomes linked to evidence-based processes/structures
- Outcomes of substantial importance with plausible process/structure relationships
- Intermediate outcomes that are most closely linked to outcomes
- Processes/structures that are most closely linked to outcomes

Box 1. Importance to measure and report (must-pass)

1a. Evidence to Support the Measure Focus or Rationale for Outcomes, including PROs (must-pass)
1b. Performance Gap, including disparities (must-pass)
1c. High Priority (must-pass)
1d. For composite performance measures: quality construct and rationale (must-pass)

There are four subcriteria to demonstrate whether the Importance criterion is met (Box 1).

Subcriterion 1a: Evidence

This subcriterion is meant to address the question of whether there is an adequate level of empirical evidence to support a measure for use as a national consensus standard. The assumption underlying this subcriterion is that use of limited resources for measuring and reporting a measure is justified only if there is unambiguous evidence that it can facilitate gains in quality and health. For most healthcare quality measures, the evidence will be that of clinical effectiveness and a link to desired health outcomes (e.g., improved clinical outcomes, functional status, or quality of life; decreased mortality; etc.). Evidence refers to empirical studies, but is not limited to randomized controlled trials. Because not all healthcare is evidence-based, NQF will allow—under certain circumstances—an exception to the evidence subcriterion; however, granting of such exceptions should not be considered routine.

For health outcome measures and patient-reported outcome performance measures (including experience with care), NQF does not require a summary of a systematic review of the empirical evidence that links the outcomes to certain processes and/or structures of care because there are myriad processes and structures that may influence health outcomes. However, NQF does require that developers of these types of measures articulate a rationale (which often includes evidence) for how the outcome is influenced by healthcare processes or structures.

Subcriterion 1b: Performance Gap

This subcriterion is meant to address the question of whether there is actually a quality problem that is addressed by a particular measure. Again, because the measurement enterprise is resource intensive, NQF's position is to endorse measures that address areas of known gaps in performance (i.e., those for which there is actually opportunity for improvement). Opportunity for improvement can be demonstrated via data that indicate overall poor performance (in the activity or outcome targeted by the measure), substantial variation in performance across providers, or variation in performance for certain subpopulations (i.e., disparities in care).

Subcriterion 1c: High priority

This subcriterion is meant to address the question of whether the focus of a particular measure addresses a specific national health goal or priority and/or a high-impact aspect of healthcare. For example, the property of "high priority" is demonstrated when a measure is aligned with one of the National Quality Strategy priorities or with a specific national health goal (e.g., reducing hospital readmissions). Alternatively, a measure can be considered as addressing a high-priority aspect of healthcare if epidemiologic or resource use data demonstrates that the measure can affect large numbers of patients and/or has a substantial impact for a smaller population, if the associated condition is a leading cause of morbidity/mortality, and/or if the associated condition results in high resource use (current and/or future), high illness severity, or if the consequences of poor quality would severely impact patient or societal health.

Subcriterion 1d: Quality construct and rationale (relevant to composite performance measures only)

A composite performance measure is a combination of two or more component measures, each of which individually reflects quality of care, into a single performance measure with a single score. CAHPS "composites" that include multiple questions are not considered composite performance measures for purposes of NQF evaluation and endorsement because the individual questions would not be stand-alone performance measures. The first step in developing a composite performance measure should be to articulate a coherent quality construct and rationale to guide construction of the composite. Once this is determined, the developer should select which component measures will be included in the composite measure and determine how those components will be combined.

Considerations for Performance Measures of Person- and Family-Centered Care

Performance measurement for person- and family-centered care could be directed at measuring the core concepts directly through patient-reported experience with care instruments or surveys, or potentially, the related structures or processes of care when there is sufficient evidence. In addition to considering the subcriteria under Importance to Measure and Report, three key principles should also be considered when identifying measure concepts for person- and family-centered care:

- meaningful to consumers and built with consumers;
- focused on their entire care experience, rather than a single setting or program; and
- measured from the person's perspective and experience (i.e., generally patient-reported unless the patient/consumer is not the best source of the information).

Developing performance measures based on structures and processes that support person and family-centered care could pose some challenges. First, some structures and processes might not be as meaningful to consumers vs. outcome performance measures of the core concepts (i.e., experience with care). This might be the case if the performance measure is essentially focused on documentation (e.g., is there a plan of care?), or something that is quite distal to the outcome and requires additional steps, or is focused on one of multiple things that must occur in order to achieve the core concept. Some structure and process measures might be more useful to providers for performance improvement activities. Another thing to consider is whether standardized information about the structures and processes employed by various providers might be useful to patients and consumers. For example, it might be useful to know about availability of extended hours, time to get an appointment, or communication via email, to find a provider that best meets a person’s needs or preferences. These could be explored as potential elements for a standardized label for person-centered care (“nutrition label” concept).

Second, there are usually multiple ways, through various structures and processes of care to achieve the core concepts. For example, there could be a variety of approaches to facilitate shared decisionmaking or preparing patients and families for self-care management, which could vary depending on the individual and the context of care. The existing empirical evidence base might not be sufficient to identify the best approach that all should be expected to follow and be held accountable through a national performance measure.

Outcome performance measures of person- and family-centered care are likely to be patient-reported outcomes (PRO) of the experience with care. NQF’s prior work on PRO-based performance measures identified PRO domains of 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 patient-level measure (i.e., instrument, tool, survey), and PRO-PM refers to the performance measure based on the aggregated patient-level PROM data. The identified core concepts for person- and family-centered care would be in the PRO domain of experience with care. However, PRO-PMs in the other domains are not necessarily an indicator of person- and family-centered care. For example, a PRO-PM on improvement in function or decrease in pain for patients receiving a hip or knee replacement is more an indicator of treatment effectiveness than person-centeredness. 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 patient care. That is, the results are reviewed, discussed with patients, 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 actually increase patient burden and frustration.

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Framework for Performance Measurement of Person- and Family-Centered Care

The following table is organized into the classical quality assessment categories of structure, process, and outcome. The core concepts for person- and family-centered care can be considered outcomes because they are the desired patient and family experience with care. The structures and processes that are listed as illustrations in the table have been suggested by committee members or in the various references. Some existing CAHPS performance measures also have been identified for illustration. We also are compiling a separate folder and Excel file with information on the various CAHPS measures that relate to the core concepts of person- and family-centered care. It is on the Committee SharePoint site.

The purpose of the table is to frame committee discussions about performance measurement to assist with identifying what concepts to measure as indicators of performance on delivering person- and family-centered care. Once the measure concepts are identified, priorities can be identified and a search for existing measures can be more focused.

Table 1. Measurement Framework for Person- and Family-Centered Care

Core Concept	Structure	Process	Outcome (Intermediate clinical, health outcome, including PRO)
	Organizational structure or systems that support providing person- and family-centered care	*Interaction between person/family and providers of care that are intended to facilitate achieving the experience reflected in the core concepts*	*Desired outcomes of person- and family-centered care (including the experience with care reflected in the core concepts)*
	Key Questions: • *Is there evidence for structures that indicates all specified entities should implement in their systems of care and be the focus of an endorsed performance measure?* • *Could information on structures to support person- and family-centered care be useful in a standard label?*	***Key Questions:*** • *Is there evidence for processes that indicate all specified entities should implement in their systems of care and be the focus of an endorsed performance measure?* • *Could information on processes to support person- and family-centered care be useful in a standard label?*	***Key Questions:*** • *The core concepts are essentially the outcomes of person- and family-centered care. Are there other outcomes that can be measured besides the experiences represented by the core concepts?* • *The extent to which a PRO in the domains of function, symptom, and health-related behavior is improved or met will generally be an indicator of treatment effectiveness. If a PRO is a more general assessment of benefit, (e.g., perceived health benefit from care and treatment , how much I have been helped or*

Core Concept	Structure	Process	Outcome (Intermediate clinical, health outcome, including PRO)
			better able to do what I want and need to do) is it an indicator of treatment effectiveness or person-centered care?
Definition: 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.	• Patient/family advisory group	•	•
1. My care partners strive to know me as a whole person and take into account my priorities and goals for physical, mental, spiritual, and social health.	• Use patient-reported tools 1) Use standard patient reported outcome measures (PROMs) that match the person's view of what matters or what bothers or interferes with their life 2) Use 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	• Find out what the individual's health care priorities and goals are --what matters most and/or what is most bothersome to the person using approaches described under structure 1) or 2) • The PROM or PCOM is used by the patient and care partners to co-develop the plan, mange care, and monitor progress • Plan for care reflects the person's priorities and goals	• **Extent to which my care partners know me as a whole person and take into account my priorities and goals for physical, mental, spiritual, and social health.** • Care received is consistent with priorities and goals • CAHPS PCMH - Providers Support You in Taking Care of Your Own Health

Core Concept	Structure	Process	Outcome (Intermediate clinical, health outcome, including PRO)
	with my grandkids, I will be able to tend my garden without being in constant pain, etc.)		
2. I receive the care I need — no more, no less—when, where, and how I prefer.	• Extended office hours (evenings, weekends) • Same-day appointments • Options for communication – email, text, phone • Options for support – patient and family support/discussion groups online, group meetings, etc.	•	• **Extent to which I receive the care I need — no more, no less—when, where, and how I prefer.** • They gave me all the care I needed and wanted exactly when and how I needed and wanted it. • Care received is consistent with priorities and goals • Average length of time in days between the day a patient 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) • Average time it takes to get a response to a question • CAHPS Clinician (NQF#005) Getting Timely Appointments, Care, and Information • CAHPS Clinician (NQF#005) Getting Timely Answers to Medical Questions by E-mail
3. My care partners treat me and my family with respect, dignity, and compassion.	•	•	• **Extent to which my care partners treat me and my family with respect, dignity, and compassion.**
4. I collaborate in decisions about my care to the extent I desire or am able, or I choose the care partner I prefer to collaborate in those decisions for me.	•	• Care partners work with the person to make care decisions and to co-produce and implement a care plan that has the best chance of attaining patient goals	• **Extent to which I collaborate in decisions about my care to the extent I desire or am able, or I choose the care partner I prefer to collaborate in those decisions for me.** • Care received is consistent with priorities and

Core Concept	Structure	Process	Outcome (Intermediate clinical, health outcome, including PRO)
		- Discuss and obtain advance directives - Ask about surrogate decisionmakers	goals - CAHPS PCMH Providers Discuss Medication Decisions (Adult only)
5. My family care partners include those I choose and their role is supported by other care partners.	- Family support/discussion groups	- Ask about family care partners	- **Extent to which my family care partners include those I choose** - CAHPS Clinician (NQF#005) Providers are Polite and Considerate - **Extent to which my family care partners are supported by other care partners.**
6. My care partners provide information, in a format I prefer, to: a. answer my questions and help me understand my choices — about my health, health problem, treatment, care, costs, or providers; and b. increase my confidence and capacity to care for myself to the extent I am able.	- Access to quality performance ratings - Price list for services - Information on providers of care (e.g., education, training, certification)	- Discuss cost and coverage in relation to treatment options	- **Extent to which my care partners provide information, in a format I prefer, and answer my questions and help me understand my choices — about my health, health problem, treatment, care, costs, or providers** - Patient/family understanding of treatment options (including comparative benefits + harms of these options), goals of care, and plan for follow-up - CAHPS Clinician (NQF#005) How Well Providers Communicate About Medicines - **Extent to which I have confidence and capacity to care for myself to the extent I am able.** - Patient activation - Confidence in ability to manage care - Adherence to treatment
7. My care partners value my time and use it efficiently and effectively.	- Systems for managing flow	- Visits for multiple care partners coordinated for same day	- **Extent to which my care partners value my time and use it efficiently and effectively.** - Average wait time (for scheduled appointment, ED visit, hospital admission, etc.)
8. Communication with and	- Patient portal to health	-	- **Extent to which communication with and**

Core Concept	Structure	Process	Outcome (Intermediate clinical, health outcome, including PRO)
among my care partners is honest, transparent, and coordinated across settings and time.	record and test results - Connect to personal health record - Navigator services	- Description/background leading to referral /consultation request AND result of consultation is in both referring and consulting records	**among my care partners is honest and transparent** - CAHPS Clinician (NQF#005) How Well Providers (or Doctors) Communicate with Patients - **Extent to which communication is coordinated across settings and time.** - Percentage of test results provided to patient within XX time frame of receipt of final report/Average time from receipt of final report to delivery to patient - CAHPS Clinician (NQF#005) Individual Item: Follow up on Test Results
Safe, effective, affordable care- additional domains of quality desired but not dependent on being person-centered	Systems to ensure consistently delivering safe, effective, and affordable care.	Evidence-based processes and interventions	**Examples** - Intermediate clinical outcomes (e.g., HbA1c) - Health outcomes (e.g., mortality, complications) - Patient-reported outcomes (e.g., functional status, symptom relief)

Standard Label for Person- and Family-Centered Care

Information about some structures or processes that support the delivery of person- and family-centered care might be useful to consumers to identify providers who will best meet their needs and preferences. This might include things such as whether they have evening and weekend hours, access to health records, communication via email, etc. Information provided in a standardized format would allow individuals to weight various aspects in terms of what is most important to them.

Key Questions:

- Are there certain types of information related to person- and family-centered care that could be standardized into a “nutrition label” concept?
- Would be useful to consumers?

Example of Person- and Family-Centered Care Label

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

Patient/family Advisory Group: Yes/No, URL link

Patient Portal to Health Record: Yes/No (if not entire, what components - assessments, plan of care, test results?)
Link to Personal Health Record: Yes/No

Communication options: Phone, email, text

Patient-reported tools used to co-develop plan of care and monitor progress: Yes/No

Patient/family support groups: topic areas, mode – online, in-person

Hours of Operation: (including extended hours evenings, weekends)
Ease of Appointments: same-day appointments, avg. # days to available appointment
Average wait time: xx minutes

Access to standardized quality performance measures: Person-centered care, other quality measures and URL links

Access to profiles for providers of care: URL link (education, training, certification, specialties, languages)

Insurance Plans accepted: List

Annotated Bibliography

AUDET AM, DAVIS K, SCHOENBAUM SC. ADOPTION OF PATIENT-CENTERED CARE PRACTICES BY PHYSICIANS: RESULTS FROM A NATIONAL SURVEY. *ARCH INTERN MED,* 2006;166(7):754-759.

Abstract: Little is known about the extent to which primary care physicians (PCPs) practice patient-centered care, 1 of the Institute of Medicine's 6 dimensions of quality. This article describes the adoption of patient-centered practice attributes by PCPs. METHODS: Mail survey; nationally representative physician sample of 1837 physicians in practice at least 3 years postresidency. RESULTS: Eighty-three percent of PCPs surveyed are in favor of sharing of medical records with patients. Most physicians (87%) support team-based care. But, only 16% of PCPs communicate with their patients via e-mail; only 36% get feedback from their patients. Seventy-four percent of PCPs still experience problems with availability of patients' medical records or test results; less than 50% have adopted patient reminder systems. Thirty-three percent of physicians practicing in groups of 50 or more have adopted 6 to 11 of the 11 patient-centered care practices targeted in the survey compared with 14% of solo physicians. CONCLUSION: Although some patient-centered care practices have been adopted by most PCPs, other practices have not yet been adopted as broadly, especially those targeting coordination, team-based care, and support from appropriate information systems

BERGESON SC, DEAN JD. A SYSTEMS APPROACH TO PATIENT-CENTERED CARE. *JAMA,* 2006;296(23):2848-2851.

Abstract: Providing care centered on patients' needs and expectations is a key attribute of quality care.[1] Unfortunately, despite the intent and efforts of many to improve patient centeredness, the quality of patient-clinician relationships, patient access, and continuity of care appear to be worsening in the United States[2] and lag behind other Organization for Economic Co-operation and Development (OECD) countries.[3] Clinicians do not consistently address patients' concerns,[4] do not always assess patients' beliefs and understanding of their illness, and often do not share management options with patients.[5] Patients frequently fail to recall basic elements of their care plan.[6] All this is occurring as care becomes increasingly complex and as more costs of care are borne directly by patients.

BERWICK DM. WHAT 'PATIENT-CENTERED' SHOULD MEAN: CONFESSIONS OF AN EXTREMIST. *HEALTH AFF (MILLWOOD),* 2009;28(4):W555-W565.

Abstract: "Patient-centeredness" is a dimension of health care quality in its own right, not just because of its connection with other desired aims, like safety and effectiveness. Its proper incorporation into new health care designs will involve some radical, unfamiliar, and disruptive shifts in control and power, out of the hands of those who give care and into the hands of those who receive it. Such a consumerist view of the quality of care, itself, has important differences from the more classical, professionally dominated definitions of "quality." New designs, like the so-called medical home, should incorporate that change

BETHELL C. PATIENT-CENTERED CARE MEASURES FOR THE NATIONAL HEALTHCARE QUALITY REPORT. PORTLAND, OR: FACCT—THE FOUNDATION FOR ACCOUNTABILITY; 2000.

Abstract: This paper outlines a rationale and methods for incorporating measures of patient centered care in the National Health Care Quality Report as a complement to those in other categories of importance – patient safety, effectiveness, promptness and efficiency. To the extent that patient centered care quality measures are stratified for or tailored to specific populations, they are also useful for understanding the equity of health care in America across different ethnic, racial, socioeconomic and demographic groups.

CASARETT D, SHREVE S, LUHRS C, ET AL. MEASURING FAMILIES' PERCEPTIONS OF CARE ACROSS A HEALTH CARE SYSTEM: PRELIMINARY EXPERIENCE WITH THE FAMILY ASSESSMENT OF TREATMENT AT END OF LIFE SHORT FORM (FATE-S). *J PAIN SYMPTOM MANAGE,* 2010;40(6):801-809.

Abstract: Because the Family Evaluation of Treatment at End of Life (FATE) survey was too long for routine use in the Veterans Administration (VA) health care system to measure quality of care, a shorter instrument was developed. OBJECTIVES: To evaluate the short version of the FATE survey for use as a nationwide quality measure in the VA health care system. METHODS: Fifty-one VA medical centers, including acute and long-term care, participated in this nationwide telephone survey. Family members of the patients were eligible if the patients died in a participating facility. One family member per patient was selected from medical records using predefined eligibility criteria and invited to participate. The survey consists of 14 items describing key aspects of the patient's care in his or her last month of life, one global rating, and two open-ended questions for additional comments. RESULTS: Interviews were completed with 2827 family members. Overall, the survey showed excellent psychometric characteristics, with good homogeneity (e.g., Cronbach's alpha=0.84) and strong evidence of discriminant validity. Two survey items have been targeted for quality improvement efforts in multisite collaboratives. CONCLUSION: Surveys of surrogates offer an important source of quality data that can be used to improve the quality of end-of-life care and promote accountability

CHOCHINOV HM, MCCLEMENT SE, HACK TF, ET AL. THE PATIENT DIGNITY INVENTORY: APPLICATIONS IN THE ONCOLOGY SETTING. *J PALLIAT MED,* 2012;15(9):998-1005.

Abstract: The Patient Dignity Inventory (PDI) is a novel 25-item psychometric instrument, designed to identify multiple sources of distress (physical, functional, psychosocial, existential, and spiritual) commonly seen in patients who are terminally ill. It was also designed to help guide psychosocial clinicians in their work with patients. While its validity and reliability have been studied within the context of palliative care, its utility in clinical settings has not as yet been examined. PURPOSE: The purpose of this study was to determine how psychosocial oncology professionals would use the PDI with within their practice and what utility it might have across the broad spectrum of cancer. METHODS: Between October 2008 and January 2009, psychosocial oncology clinicians from across Canada were invited to use the PDI to determine their impressions of this approach in identifying distress and informing their practice. RESULTS: Ninety participants used the PDI and submitted a total of 429 feedback questionnaires detailing their experience with individual patients. In 76% of instances, the PDI revealed one or more previously unreported concerns; in 81% of instances, clinicians reported that the PDI facilitated their work. While it was used in a wide range of circumstances, clinicians were more inclined to apply the PDI to patients engaged in active treatment or palliation, rather than those in remission, having recently relapsed, or newly diagnosed. Besides its utility in identifying distress, the PDI enabled clinicians to provide more targeted therapeutic responses to areas of patient concern.

CONCLUSIONS: While this study suggests various clinical applications of the PDI, it also provides an ideal forerunner for research that will directly engage patients living with cancer.

COMMITTEE ON THE LEARNING HEALTH CARE SYSTEM IN AMERICA, INSTITUTE OF MEDICINE. *BEST CARE AT LOWER COST: THE PATH TO CONTINUOUSLY LEARNING HEALTH CARE IN AMERICA.* WASHINGOTN, DC: THE NATIONAL ACADEMIES PRESS; 2013. AVAILABLE AT HTTP://WWW.IOM.EDU/REPORTS/2012/BEST-CARE-AT-LOWER-COST-THE-PATH-TO-CONTINUOUSLY-LEARNING-HEALTH-CARE-IN-AMERICA.ASPX.

Abstract: America's health care system has become far too complex and costly to continue business as usual. Pervasive inefficiencies, an inability to manage a rapidly deepening clinical knowledge base, and a reward system poorly focused on key patient needs, all hinder improvements in the safety and quality of care and threaten the nation's economic stability and global competitiveness. Achieving higher quality care at lower cost will require fundamental commitments to the incentives, culture, and leadership that foster continuous "learning", as the lessons from research and each care experience are systematically captured, assessed, and translated into reliable care. In the face of these realities, the IOM convened the Committee on the Learning Health Care System in America to explore these central challenges to health care today. The product of the committee's deliberations, Best Care at Lower Cost, identifies three major imperatives for change: the rising complexity of modern health care, unsustainable cost increases, and outcomes below the system's potential But it also points out that emerging tools like computing power, connectivity, team-based care, and systems engineering techniques-tools that were previously unavailable-make the envisioned transition possible, and are already being put to successful use in pioneering health care organizations. Applying these new strategies can support the transition to a continuously learning health system, one that aligns science and informatics, patient-clinician partnerships, incentives, and a culture of continuous improvement to produce the best care at lower cost. The report's recommendations speak to the many stakeholders in the health care system and outline the concerted actions necessary across all sectors to achieve the needed transformation

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COMMITTEE ON QUALITY OF HEALTH CARE IN AMERICA IOM. *CROSSING THE QUALITY CHASM: A NEW HEALTH SYSTEM FOR THE 21ST CENTURY* , WASHINGTON, DC: NATIONAL ACADEMY PRESS; 2001.

Abstract: Today's health care providers have more research findings and more technology available to them than ever before. Yet recent reports have raised serious doubts about the quality of health care in America. Crossing the Quality Chasm makes an urgent call for fundamental change to close the quality gap. This book recommends a sweeping redesign of the American health care system and provides overarching principles for specific direction for policymakers, health care leaders, clinicians, regulators, purchasers, and others. In this comprehensive volume the committee offers:

- A set of performance expectations for the 21st century health care system.
- A set of 10 new rules to guide patient-clinician relationships.
- A suggested organizing framework to better align the incentives inherent in payment and accountability with improvements in quality.
- Key steps to promote evidence-based practice and strengthen clinical information systems.

Analyzing health care organizations as complex systems, Crossing the Quality Chasm also documents the causes of the quality gap, identifies current practices that impede quality care, and explores how systems approaches can be used to implement change.

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Abstract: The Family Evaluation of Hospice Care (FEHC) survey is a 61-item questionnaire that surveys family members about care provided to the decedent by the hospice. Hospices submit their data to the National Hospice and Palliative Care Organization (NHPCO), where results are tabulated. For the first two quarters of 2004, a total of 29,292 surveys were tabulated. On average, respondents rated their overall satisfaction with care as 47.1 on a 50-point composite scale of five measures of satisfaction. Opportunities for improvement were identified for attending to family needs for support (18.2% of those surveyed reported at least one unmet need), attending to family needs for communication (10-29%), and coordination of care (22.1%). Surrogate reporting of unmet needs for pain, dyspnea, or emotional support ranged from 5.3% to 9.8%. The FEHC is a useful tool for measuring hospice performance and identifies a number of opportunities for improvement

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DAVIS K, SCHOENBAUM SC, AUDET AM. A 2020 VISION OF PATIENT-CENTERED PRIMARY CARE. *J GEN INTERN MED,* 2005;20(10):953-957.

Abstract: Patient-centered care has received new prominence with its inclusion by the Institute of Medicine as 1 of the 6 aims of quality. Seven attributes of patient-centered primary care are proposed here to improve this dimension of care: access to care, patient engagement in care, information systems, care coordination, integrated and comprehensive team care, patient-centered care surveys, and publicly available information. The Commonwealth Fund 2003 National Survey of Physicians and Quality of Care finds that one fourth of primary care physicians currently incorporate these various patient-centered attributes in their practices. To bring about marked improvement will require a new system of primary care payment that blends monthly patient panel fees with traditional fee-for-service payment, and new incentives for patient-centered care performance. A major effort to test this concept, develop a business case, provide technical assistance and training, and diffuse best practices is needed to transform American health care.

FEINBERG L. *MOVING TOWARD PERSON- AND FAMILY-CENTERED CARE.* WASHINGTON, DC: AARP PUBLIC POLICY INSTITUTE; 2012. REPORT NO.: 60.

Abstract: Person- and family-centered care (PFCC) is an orientation to the delivery of health care and supportive services that addresses an individual's needs, goals, preferences, cultural traditions, family situation, and values. PFCC can improve care and quality of life by its focus on how services are delivered from the perspective of the older adult and, when appropriate, his or her family. PFCC both recognizes and supports the role of family caregivers, who often are critical sources of support for older adults with chronic or disabling conditions.

FINLAY E, SHREVE S, CASARETT D. NATIONWIDE VETERANS AFFAIRS QUALITY MEASURE FOR CANCER: THE FAMILY ASSESSMENT OF TREATMENT AT END OF LIFE. J CLIN ONCOL, 2008;26(23):3838-3844.

Abstract: The Veterans Affairs (VA) health care system has created a national initiative to measure quality of care at the end of life. This article describes the first phase of this national initiative, the Family Assessment of Treatment at End of Life (FATE), in evaluating the quality of end-of-life care for veterans dying with cancer. In the initial phase, next of kin of patients from five VA Medical Centers were contacted 6 weeks after patients' deaths and invited to participate in a telephone interview, and surrogates for 262 cancer patients completed FATE interviews. Decedents were 98% male with an average age of 72 years. There was substantial variation among sites. Higher FATE scores, consistent with family reports of higher satisfaction with care, were associated with palliative care consultation and hospice referral and having a Do Not Resuscitate order at the time of death, whereas an intensive care unit death was associated with lower scores. Early experience with FATE suggests that it will be a helpful tool to characterize end-of-life cancer care and to identify targets for quality improvement.

FRAMPTON SB, GUASTELLO S. PATIENT-CENTRED CARE: MORE THAN THE SUM OF ITS PARTS--PLANETREE'S PATIENT-CENTRED HOSPITAL DESIGNATION PROGRAMME. *WORLD HOSP HEALTH SERV,* 2010;46(4):13-16.

Abstract: When a nurse at the Celilo Cancer Center at the Mid-Columbia Medical Center in The Dalles, Oregon, found out that his patient was scheduled to receive chemotherapy on her wedding anniversary, he asked the woman and her husband what song they'd first danced to on their wedding day. It was "Save the Last Dance For Me," and the next day, when the couple rose from their chairs after the patient's six-hour infusion, the song began playing. Right there in the infusion area, with their arms around each other, they danced. This story illustrates the kind of care that has become the norm at the 10 hospitals in North America recognized since 2007 as patient-centred hospitals by Planetree's Patient-Centred Hospital Designation Program. At these hospitals "patient-centred care" is more than a buzzword. Rather, it's reflected in their mission statements, strategic plans, models of nursing care, and day-to-day operations. While many organizations, including the Institute of Medicine, the Institute for Healthcare Improvement, and Planetree, have endeavored to define patient-centred care, no definition conveys its essence as well as the patients at these hospitals can. "This place has a special character," one patient said in a focus group. Others have said, "You can tell the nurses here care about you as a person," "They are a special breed of people here," and "I don't think it's just a job for them; they're here for a reason." Over the past year, this series, Putting Patients First, has explored several aspects of the patient-centered approach--encouraging patients to review their medical records, lifting restrictions on family involvement in care, and lowering noise levels in hospitals, among others. We believe they show that, ultimately, patient-centered care is more than the sum of its parts

FUNG CH, HAYS RD. PROSPECTS AND CHALLENGES IN USING PATIENT-REPORTED OUTCOMES IN CLINICAL PRACTICE. *QUAL LIFE RES,* 2008;17(10):1297-1302.

Abstract: Patient-reported measures include preferences and reports about care received, health behaviors, and outcomes of care (patient satisfaction and health-related quality of life). These measures are a core aspect of health care, but there is much to be learned about how to use them to improve clinical practice. METHOD: We specify linkages among different patient-reported measures and focus upon the prospects and challenges for use of patient-reported outcomes in clinical practice. RESULTS: Patient-reported measures are important throughout the continuum of patient care. At the initial visit, patient-reported outcomes provide information about what is important to the patient, the patient's current behaviors, and the patient's baseline health-related quality of life. At subsequent visits, patient-reported outcomes help evaluate disease progression or regression as well as treatment effects. CONCLUSIONS: Patient-reported measures can help clinicians target interventions that will improve patient outcomes of care. However, there are a number of challenges in using patient-reported outcomes in clinical practice

GLASGOW RE, PEEPLES M, SKOVLUND SE. WHERE IS THE PATIENT IN DIABETES PERFORMANCE MEASURES? THE CASE FOR INCLUDING PATIENT-CENTERED AND SELF-MANAGEMENT MEASURES. *DIABETES CARE,* 2008;31(5):1046-1050.

Abstract: Health policies are important determinants of clinician and patient behavior, and an important policy issue is what items are included in healthcare quality and performance measures. There is consensus that patient-centered care and self-management support are essential evidence-based components of good diabetes care. However, most major diabetes performance measures such as the National Committee for Quality Assurance (NCQA)/American Diabetes Association (ADA) Provider Recognition Program indexes have not included self-management or psychosocial items. RESEARCH DESIGN AND METHODS AND RESULTS: We review the case for and propose a set of patient-centered, self-management indicators to be included as a standard part of diabetes quality indicators. The proposed indicators include: patient self-management goal(s), measures of health behaviors (e.g., healthy eating, medication taking, physical activity, and smoking status), quality of life, and patient-centered collaborative care. We discuss the evidence and the concerns about patient-report measures and summarize successful incorporation of such patient-centered measures in other countries and by the American Association of Diabetes Educators (AADE). CONCLUSIONS: The adage that "what gets measured, gets done" applies to diabetes management and many other areas of healthcare. Inclusion of the proposed indicators in national diabetes performance measures would be consistent with Institute of Medicine (IOM), ADA, Centers for Disease Control (CDC), Diabetes Attitudes, Wishes, and Needs (DAWN), AADE, and Society of Behavioral Medicine (SBM) recommendations. Such action would enhance both the priority and delivery of quality, patient-centered care, and diabetes self-management support.

HANSON LC, ROWE C, WESSELL K, ET AL. MEASURING PALLIATIVE CARE QUALITY FOR SERIOUSLY ILL HOSPITALIZED PATIENTS. *J PALLIAT MED,* 2012;15(7):798-804.

Abstract: Hospice and palliative care providers need ways to measure and improve care processes. We tested feasibility, usability, reliability, and validity of Prepare, Embrace, Attend, Communicate, Empower (PEACE) quality measures for palliative care. METHODS: Trained research nurses abstracted data from medical records to generate quality measures for a random sample of 460 seriously ill patients without, and 102 patients with, specialty palliative care (SPC) services. RESULTS: Patient age ranged from 16 to 99 years, 50% were women, and 24% were African American. Of 34 PEACE quality measures, 17 were feasible for hospital palliative care. Inter-rater reliability was high (kappa>0.80) for all but two quality measures. Face validity was endorsed by clinical service leaders, and construct validity was established by higher scores for patients receiving SPC. Comprehensive palliative care assessment was completed for only 10% of seriously ill hospitalized patients, compared with 56% of patients with SPC (p<0.001). Patients with moderate or severe pain were more likely to have a clinical assessment with SPC (67% versus 42%, p=0.002). Patients with SPC more often received attention for their emotional and spiritual needs (64% versus 40%, p<0.001) and documentation of preferences for life-sustaining treatments (91% versus 59%, p>0.001). Usability was endorsed by service leaders, who initiated two practice improvement projects. CONCLUSION: PEACE quality measures are feasible and reliable, and may be useful to examine and improve the quality of palliative care for seriously ill hospitalized patients as well as for patients in hospice. Research is needed to test measures for actionability and responsiveness to intervention

INSTITUTE FOR HEALTHCARE IMPROVEMENT. PERSON- AND FAMILY- CENTERED CARE RESOURCES. INSTITUTE FOR HEALTHCARE IMPROVEMENT, 2014; INSTITUTE FOR HEALTHCARE IMPROVEMENT;

Abstract: To help you with your improvement efforts, the Knowledge Center offers tools, change ideas, measures to guide improvement, IHI white papers, audio and video, improvement stories, and more. Learn about the Model for Improvement, forming the improvement team, setting aims, establishing measures, and selecting and testing changes. Measurement is a critical part of testing and implementing changes; measures tell a team whether the changes they are making actually lead to improvement. While all changes do not lead to improvement, all improvement requires change. The ability to develop, test, and implement changes is essential for any individual, group, or organization that wants to continuously improve. To accelerate our collective learning, and in the spirit of "all teach, all learn," the stories and improvement reports shared on IHI.org describe the improvement journeys and experiences of individuals, teams, and organizations. Many organizations have developed tools in the course of their improvement efforts - for example, successful protocols, order sets and forms, instructions and guidelines for implementing key changes - and are making them available on IHI.org for others to use or adapt in their own organizations. IHI white papers are designed to share with readers the problems IHI is working to address; the ideas, changes, and methods we are developing and testing to help organizations make breakthrough improvements; and early results where they exist. A variety of improvement-related video and audio content, including our rich archive of WIHI audio broadcasts and related resources.

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE. WHAT IS PATIENT- AND FAMILY-CENTERED HEALTH CARE; WHAT ARE THE CORE CONCEPTS. INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE, 2013;BETHESDA, MD: INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE;

INSTITUTE OF MEDICINE. FUTURE DIRECTIONS FOR THE NATIONAL HEALTHCARE QUALITY AND DISPARITIES REPORT, WASHINGTON, DC: NATIONAL ACADEMIES PRESS; 2010.

INSTITUTE OF MEDICINE. BEST CARE AT LOWER COST: THE PATH TO CONTINUOUSLY LEARNING HEALTH CARE IN AMERICA, WASHINGTON, DC: NATIONAL ACADEMIES PRESS; 2012.

JACKSON VA, JACOBSEN J, GREER JA, ET AL. THE CULTIVATION OF PROGNOSTIC AWARENESS THROUGH THE PROVISION OF EARLY PALLIATIVE CARE IN THE AMBULATORY SETTING: A COMMUNICATION GUIDE. *J PALLIAT MED,* 2013;16(8):894-900.

Abstract: Early, integrated palliative care delivered in the ambulatory setting has been associated with improved quality of life, lower rates of depression, and even prolonged survival. We outline an expert practice that provides a step-wise approach to cultivating prognostic awareness in patients cared for by a palliative care clinician early in the course of the patient's disease. This approach can be used by both novice and more experienced palliative care clinicians

JOHNSON BH. FAMILY-CENTERED CARE: FOUR DECADES OF PROGRESS. *FAMILIES, SYSTEMS, & HEALTH,* 2012;18(2):137-156.

Abstract: Family-centered care is a framework for the delivery of healthcare that is creating change in healthcare policies, programs, facility design, day-to-day practices of individual practitioners, and professional education. This paper traces the history of family-centered care over the past 35 yrs. It presents the conceptual basis for family centered care. It includes an overview of the origin, activities, and future directions of the Institute of Family-Centered Care, a non-profit organization founded in 1992 to advance the understanding and practice of family-centered care. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

KELLEY AS, ETTNER SL, MORRISON RS, ET AL. DISABILITY AND DECLINE IN PHYSICAL FUNCTION ASSOCIATED WITH HOSPITAL USE AT END OF LIFE. *J GEN INTERN MED,* 2012;27(7):794-800.

Abstract: Hospital use near the end of life is often undesirable to patients, represents considerable Medicare cost, and varies widely across regions. OBJECTIVE: To concurrently examine regional and patient factors, including disability and functional decline, associated with end-of-life hospital use. DESIGN/PARTICIPANTS: We sampled decedents aged 65 and older (n = 2,493) from the Health and Retirement Study (2000-2006), and linked data from individual Medicare claims and the Dartmouth Atlas of Health Care. Two-part regression models estimated the relationship between total hospital days in the last 6 months and patient characteristics including physical function, while adjusting for regional resources and hospital care intensity (HCI). KEY RESULTS: Median hospital days was 7 (range = 0-183). 53% of respondents had functional decline. Compared with decedents without functional decline, those with severe disability or decline had more regression-adjusted hospital days (range 3.47-9.05, depending on category). Dementia was associated with fewer days (-3.02); while chronic kidney disease (2.37), diabetes (2.40), stroke or transient ischemic attack (2.11), and congestive heart failure (1.74) were associated with more days. African Americans and Hispanics had more days (5.91 and 4.61, respectively). Those with family nearby had 1.62 fewer days and hospice enrollees had 1.88 fewer days. Additional hospital days were associated with urban residence (1.74) and residence in a region with more specialists (1.97) and higher HCI (2.27). CONCLUSIONS: Functional decline is significantly associated with end-of-life hospital use among older adults. To improve care and reduce costs, health care programs and policies should address specific needs of patients with functional decline and disability.

KELLY K, WOLFE N, GIBSON MJ, ET AL. LISTENING TO FAMILY CAREGIVERS: THE NEED TO INCLUDE FAMILY CAREGIVER ASSESSMENT IN MEDICAID HOME- AND COMMUNITY-BASED SERVICE WAIVER PROGRAMS. WASHINGTON, DC: AARP PUBLIC POLICY INSTITUTE; 2013.

Abstract: This report presents findings from a 50-state survey examining how well the needs of family caregivers are assessed when states evaluate the needs of older people and adults with disabilities who qualify for home- and community-based services (HCBS) programs under Medicaid.
It is the first detailed analysis of family caregiver assessment tools and processes in use by the states in Medicaid HCBS 1915(c) and 1115 waiver programs. Forty-six states plus the District of Columbia responded to the initial survey, a 92 percent response rate. Interviews with key informants were conducted in 13 states. Family support is often essential for helping older people and adults with disabilities continue to live at home and in the community. Yet, the work of family caregivers can be demanding—physically, emotionally, and financially. If caregiver needs are not assessed and addressed, their own health and well-being may be at risk, which may, in turn, lead to burnout—jeopardizing their ability to continue providing care in the community.

LAUTRETTE A, DARMON M, MEGARBANE B, ET AL. A COMMUNICATION STRATEGY AND BROCHURE FOR RELATIVES OF PATIENTS DYING IN THE ICU. *N ENGL J MED,* 2007;356(5):469-478.

Abstract: There is a need for close communication with relatives of patients dying in the intensive care unit (ICU). We evaluated a format that included a proactive end-of-life conference and a brochure to see whether it could lessen the effects of bereavement. METHODS: Family members of 126 patients dying in 22 ICUs in France were randomly assigned to the intervention format or to the customary end-of-life conference. Participants were interviewed by telephone 90 days after the death with the use of the Impact of Event Scale (IES; scores range from 0, indicating no symptoms, to 75, indicating severe symptoms related to post-traumatic stress disorder [PTSD]) and the Hospital Anxiety and Depression Scale (HADS; subscale scores range from 0, indicating no distress, to 21, indicating maximum distress). RESULTS: Participants in the intervention group had longer conferences than those in the control group (median, 30 minutes [interquartile range, 19 to 45] vs. 20 minutes [interquartile range, 15 to 30]; P<0.001) and spent more of the time talking (median, 14 minutes [interquartile range, 8 to 20] vs. 5 minutes [interquartile range, 5 to 10]). On day 90, the 56 participants in the intervention group who responded to the telephone interview had a significantly lower median IES score than the 52 participants in the control group (27 vs. 39, P=0.02) and a lower prevalence of PTSD-related symptoms (45% vs. 69%, P=0.01). The median HADS score was also lower in the intervention group (11, vs. 17 in the control group; P=0.004), and symptoms of both anxiety and depression were less prevalent (anxiety, 45% vs. 67%; P=0.02; depression, 29% vs. 56%; P=0.003). CONCLUSIONS: Providing relatives of patients who are dying in the ICU with a brochure on bereavement and using a proactive communication strategy that includes longer conferences and more time for family members to talk may lessen the burden of bereavement. (ClinicalTrials.gov number, NCT00331877.)

LORENZ KA, ROSENFELD K, WENGER N. QUALITY INDICATORS FOR PALLIATIVE AND END-OF-LIFE CARE IN VULNERABLE ELDERS. *J AM GERIATR SOC,* 2007;55 SUPPL 2:S318-S326.

Abstract: Care for vulnerable elders, many of whom may be near the end of life, has come under increasing scrutiny in the past decade. Studies demonstrate inadequate quality of care with regard to symptom control, matching of care with patient preferences, and optimal resource use at the end of life. In this paper the authors report on 14 indicators developed to identify quality end-of-life care for vulnerable elders. The indicators, which aim to assess the provision of care to achieve a "good death," focus on patient preferences for care and on palliation. Because of the lack of clinical trial evidence relevant to end-of-life care, most of the indicators reported in this paper are based on observational data and Care for vulnerable elders, many of whom may be near the end of life, has come under increasing scrutiny in the past decade. Studies demonstrate inadequate quality of care with regard to symptom control, matching of care with patient preferences, and optimal resource use at the end of life. In this paper the authors report on 14 indicators developed to identify quality end-of-life care for vulnerable elders. The indicators, which aim to assess the provision of care to achieve a "good death," focus on patient preferences for care and on palliation. Because of the lack of clinical trial evidence relevant to end-of-life care, most of the indicators reported in this paper are based on observational data and consensus opinion.

MCCANCE T, MCCORMACK B, DEWING J. AN EXPLORATION OF PERSON-CENTREDNESS IN PRACTICE. *ONLINE J ISSUES NURS,* 2011;16(2):1.

Abstract: Person-centredness' is a term that is becoming increasingly familiar within health and social care at a global level; it is being used to describe a standard of care that ensures the patient/client is at the centre of care delivery. In this article we explore the relevance of person-centredness in the context of nursing, taking account of the ongoing critical debate and dialogue regarding developments in this field. Person-centredness is recognised as a multidimensional concept. The complexity of the concept contributes to the challenge of articulating its shared meaning and describing how it can be applied in practice. The aim of this paper is to explore some of the issues pertaining to language and conceptual clarity, with a view to making connections and increasing our shared understanding of person-centred care in a way that can impact nursing practice. We begin by describing the development of the concept of person-centredness, after which we discuss the synergies with patient-centredness and other related terms, and consider how nurses can operationalise person-centredness in their practice.

NIPP RD, KELLEY MJ, WILLIAMS CD, ET AL. EVOLUTION OF THE QUALITY ONCOLOGY PRACTICE INITIATIVE SUPPORTIVE CARE QUALITY MEASURES PORTFOLIO AND CONFORMANCE AT A VETERANS AFFAIRS MEDICAL CENTER. *J ONCOL PRACT,* 2013;9(3):E86-E89.

Abstract: A growing set of quality measures is being implemented to evaluate all components of cancer care, from diagnosis through the end of life. We investigated the Quality Oncology Practice Initiative (QOPI) quality measures portfolio. Additionally, we explored the effect of quality measure type on conformance. METHODS: We performed QOPI data collections twice per year from fall 2007 through fall 2010 and spring 2012, using chart review of the Durham Veterans Administration outpatient oncology clinic. We categorized QOPI measures as nontreatment-related supportive care (NTSC), treatment-related supportive care (TSC), diagnostic, or therapeutic. Descriptive statistics and chi(2) were used to compare longitudinal conformance. RESULTS: The majority of QOPI measures in spring 2012 assess processes of chemotherapy treatment (therapeutic, 54.3%; TSC, 8.7%) or diagnostic modalities (19.6%). Measures targeting NTSC are few (17.4%) but increased from three measures in fall 2007 to eight measures in spring 2012. During those 5 years, average conformance to NTSC, TSC, diagnostic, and therapeutic measures was 71.4%, 86.1%, 89.3%, and 75.4%, respectively ($P < .001$). Within the NTSC measures, emotional well-being and constipation assessment were least documented (41.0% and 46.3%, respectively). In spring 2012, NTSC measure conformance (75.8%) remained significantly lower than diagnostic measure conformance (91.5%; $P < .001$). CONCLUSION: Most QOPI quality measures assess diagnosis or treatment processes of care and not supportive care. Aggregate conformance to the NTSC measures was lower than that of other categories. The differential conformance demonstrates the necessity of standardized documentation methods and quality improvement efforts that remain commensurate with the increasing portfolio of supportive care measures

NQF. PATIENT REPORTED OUTCOMES (PROS) IN PERFORMANCE MEASUREMENT. WASHINGTON, DC: NQF; 2013.

Abstract: Patient and family engagement is increasingly acknowledged as a key component of a comprehensive strategy, (along with performance improvement and accountability), to achieve a high quality, affordable health system. Emerging evidence affirms that patients who are engaged in their care tend to experience better outcomes10 and choose less costly but effective interventions, such as physical therapy for low back pain, after participating in a process of shared decisionmaking.11

Promising approaches to involve patients and their families at multiple levels are being implemented across the country. Such activities include consumers serving on governance boards at hospitals and contributing to system and practice redesign to make care safer and more patient-centric.

PATIENT-CENTERED PRIMARY CARE HOME PROGRAM. *OREGON PATIENT-CENTERED PRIMARY CARE HOME STANDARDS AND MEASURES FOR RECOGNITION,TECHNICAL ASSISTANCE AND REPORTING GUIDELINES.* SALEM, OR: OREGON HEALTH AUTHORITY; 2012. AVAILABLE AT WWW.PRIMARYCAREHOME.OREGON.GOV

Abstract: The following technical assistance and reporting guidelines contain information for practices seeking recognition as Patient-Centered Primary Care Homes (PCPCH) by the state of Oregon. The guidelines provide narrative descriptions of the intent of each PCPCH measure as well as specific definitions, measurement criteria, and example strategies that PCPCH practices might employ to meet the intent of each measure. The information provided in this guide is not intended as an all-inclusive list of the strategies practices could employ to meet each PCPCH measure.
For measures requiring attestation, the guidelines describe the information a practice should be able to demonstrate during an on-site verification to support its attestation. For measures requiring additional data collection, the guidelines describe how practices should collect and submit this data. The guidelines contain specifications for calculating the measures referenced in Standards 2.A) Performance & Quality Improvement, 4.A) Personal Clinician Assigned, and 4.B) Personal Clinician Continuity. Specifications for 2.A) Performance & Clinical Quality Improvement measures can be found beginning on page 43.

PATIENT-CENTERED PRIMARY CARE HOME STANDARDS ADVISORY COMMITTEE. *STANDARDS AND MEASURES FOR PATIENT-CENTERED PRIMARY CARE HOMES.* SALEM, OR: OREGON HEALTH AUTHORITY; 2012. AVAILABLE AT WWW.PRIMARYCAREHOME.OREGON.GOV .

PELLETIER LR, STICHLER JF. ACTION BRIEF: PATIENT ENGAGEMENT AND ACTIVATION: A HEALTH REFORM IMPERATIVE AND IMPROVEMENT OPPORTUNITY FOR NURSING. *NURS OUTLOOK,* 2013;61(1):51-54.

PLANETREE. PLANETREE DESIGNATION CRITERIA FOR SITES APPLYING FOR DESIGNATION AS A PATIENT-CENTERED HOSPITAL OR A RESIDENT-CENTERED COMMUNITY. 2012;PP. 1-17.

Abstract: The designation criteria are designed to be applicable to all healthcare providers. In some cases, however, specific criteria may apply differently in various healthcare settings (acute care, continuing care, behavioral health), and not all criteria apply to all settings.
If not otherwise noted, the criteria are applied consistently across settings and the questions and documentation requests in this self-assessment should be completed by all applicants. Questions and documentation requests indicated as applying only to behavioral health settings or continuing care settings need only be satisfied by applicants serving those specified populations. If a site is inclusive of a number of settings, all the applicable criteria will be applied as appropriate, e.g. behavioral health criteria will be applied to a behavioral health unit within an acute care hospital.

REUBEN DB, TINETTI ME. GOAL-ORIENTED PATIENT CARE--AN ALTERNATIVE HEALTH OUTCOMES PARADIGM. *N ENGL J MED,* 2012;366(9):777-779.

Abstract: An alternative approach to providing better care would be to focus on a patient's individual health goals within or across a variety of dimensions (e.g., symptoms; physical functional status, including mobility; and social and role functions) and determine how well these goals are being met. For example, a person with Parkinson's disease may establish goals for symptoms, such as decreased rigidity and no falls; goals for functional status, such as the ability to get to the bathroom without assistance although requiring a walker; and goals for social function, such as the ability to use the Internet to communicate with a grandson at college and the ability to go to church. However, the patient may not be aiming to reduce tremor, walk without a walker, or continue to work for pay. Alternatively, he or she may prioritize being as mobile as possible even at the expense of medication-induced dyskinesia and mild confusion.

ROBERT WOOD JOHNSON FOUNDATION. WHAT WE'RE LEARNING: ENGAGING PATIENTS IMPROVES HEALTH AND HEALTH CARE. *QUALITY FIELD NOTES,* 2014;MARCH(3):1-4.

Abstract: People who are actively engaged in their health care are more likely to stay healthy and manage their conditions by asking their doctors questions about their care, following treatment plans, eating right, exercising, and receiving health screenings and immunizations.1 Patients without the skills to manage their health care incur costs up to 21 percent higher than patients who are highly engaged in their care.2

SEID M, MARGOLIS PA, OPIPARI-ARRIGAN L. ENGAGEMENT, PEER PRODUCTION, AND THE LEARNING HEALTHCARE SYSTEM. *JAMA PEDIATR,* 2014;168(3):201-202.

SHALLER D. *PATIENT-CENTERED CARE: WHAT DOES IT TAKE?* NEW YORK, NY: COMMONWEALTH FUND; 2007.

Abstract: Patient-centered care has become a central aim for the nation's health system, yet patient experience surveys indicate that the system is far from achieving it. Based on interviews with leaders of patient-centered organizations and initiatives, this report identifies seven key factors for achieving patient-centered care at the organization level: 1) top leadership engagement, 2) a strategic vision clearly and constantly communicated to every member of the organization, 3) involvement of patients and families at multiple levels, 4) a supportive work environment for all employees, 5) systematic measurement and feedback, 6) the quality of the built environment, and 7) supportive information technology. The report illustrates how these factors can be successfully implemented through case examples of two organizations, MCG Health System in Georgia and
Bronson Methodist Hospital in Michigan. The report concludes with a discussion of strategies at the organization and system level that can help leverage widespread implementation of patientcentered care.

STEINHAUSER KE, CHRISTAKIS NA, CLIPP EC, ET AL. FACTORS CONSIDERED IMPORTANT AT THE END OF LIFE BY PATIENTS, FAMILY, PHYSICIANS, AND OTHER CARE PROVIDERS. *JAMA,* 2000;284(19):2476-2482.

Abstract: A clear understanding of what patients, families, and health care practitioners view as important at the end of life is integral to the success of improving care of dying patients. Empirical evidence defining such factors, however, is lacking. OBJECTIVE: To determine the factors considered important at the end of life by patients, their families, physicians, and other care providers. DESIGN AND SETTING: Cross-sectional, stratified random national survey conducted in March-August 1999. PARTICIPANTS: Seriously ill patients (n = 340), recently bereaved family (n = 332), physicians (n = 361), and other care providers (nurses, social workers, chaplains, and hospice volunteers; n = 429). MAIN OUTCOME MEASURES: Importance of 44 attributes of quality at the end of life (5-point scale) and rankings of 9 major attributes, compared in the 4 groups. RESULTS: Twenty-six items consistently were rated as being important (>70% responding that item is important) across all 4 groups, including pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a "whole person." Eight items received strong importance ratings from patients but less from physicians (P<.001), including being mentally aware, having funeral arrangements planned, not being a burden, helping others, and coming to peace with God. Ten items had broad variation within as well as among the 4 groups, including decisions about life-sustaining treatments, dying at home, and talking about the meaning of death. Participants ranked freedom from pain most important and dying at home least important among 9 major attributes. CONCLUSIONS: Although pain and symptom management, communication with one's physician, preparation for death, and the opportunity to achieve a sense of completion are important to most, other factors important to quality at the end of life differ by role and by individual. Efforts to evaluate and improve patients' and families' experiences at the end of life must account for diverse perceptions of quality. JAMA. 2000;284:2476-2482

STENGER RJ, SMITH J, MCMULLAN JB, JR., ET AL. DEFINING THE MEDICAL HOME: THE OREGON EXPERIENCE. *J AM BOARD FAM MED,* 2012;25(6):869-877.

Abstract: The patient-centered medical home (PCMH) is emerging as a key strategy to improve health outcomes, reduce total costs, and strengthen primary care, but a myriad of operational measures of the PCMH have emerged. In 2009, the state of Oregon convened a public, legislatively mandated committee charged with developing PCMH measures. We report on the process of, outcomes of, and lessons learned by this committee. METHODS: The Oregon PCMH advisory committee was appointed by the director of the Oregon Department of Human Services and held 7 public meetings between October 2009 and February 2010. The committee engaged a diverse group of Oregon stakeholders, including a variety of practicing primary care physicians. RESULTS: The committee developed a PCMH measurement framework, including 6 core attributes, 15 standards, and 27 individual measures. Key successes of the committee's work were to describe PCMH core attributes and functions in patient-centered language and to achieve consensus among a diverse group of stakeholders. CONCLUSIONS: Oregon's PCMH advisory committee engaged local stakeholders in a process that resulted in a shared PCMH measurement framework and addressed stakeholders' concerns. The state of Oregon now has implemented a PCMH program using the framework developed by the PCMH advisory committee. The Oregon experience demonstrates that a brief public process can be successful in producing meaningful consensus on PCMH roles and functions and advancing PCMH policy.

TEMEL JS, GREER JA, MUZIKANSKY A, ET AL. EARLY PALLIATIVE CARE FOR PATIENTS WITH METASTATIC NON-SMALL-CELL LUNG CANCER. *N ENGL J MED,* 2010;363(8):733-742.

Abstract: Patients with metastatic non-small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease. METHODS: We randomly assigned patients with newly diagnosed metastatic non-small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy-Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care were collected from electronic medical records. RESULTS: Of the 151 patients who underwent randomization, 27 died by 12 weeks and 107 (86% of the remaining patients) completed assessments. Patients assigned to early palliative care had a better quality of life than did patients assigned to standard care (mean score on the FACT-L scale [in which scores range from 0 to 136, with higher scores indicating better quality of life], 98.0 vs. 91.5; P=0.03). In addition, fewer patients in the palliative care group than in the standard care group had depressive symptoms (16% vs. 38%, P=0.01). Despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care (33% vs. 54%, P=0.05), median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, P=0.02). CONCLUSIONS: Among patients with metastatic non-small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American Society of Clinical Oncology Career Development Award and philanthropic gifts; ClinicalTrials.gov number, NCT01038271.)

TENO JM, CLARRIDGE BR, CASEY V, ET AL. FAMILY PERSPECTIVES ON END-OF-LIFE CARE AT THE LAST PLACE OF CARE. *JAMA,* 2004;291(1):88-93.

Abstract: Over the past century, nursing homes and hospitals increasingly have become the site of death, yet no national studies have examined the adequacy or quality of end-of-life care in institutional settings compared with deaths at home. OBJECTIVE: To evaluate the US dying experience at home and in institutional settings. DESIGN, SETTING, AND PARTICIPANTS: Mortality follow-back survey of family members or other knowledgeable informants representing 1578 decedents, with a 2-stage probability sample used to estimate end-of-life care outcomes for 1.97 million deaths from chronic illness in the United States in 2000. Informants were asked via telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours. MAIN OUTCOME MEASURES: Patient- and family-centered end-of-life care outcomes, including whether health care workers (1) provided the desired physical comfort and emotional support to the dying person, (2) supported shared decision making, (3) treated the dying person with respect, (4) attended to the emotional needs of the family, and (5) provided coordinated care. RESULTS: For 1059 of 1578 decedents (67.1%), the last place of care was an institution. Of 519 (32.9%) patients dying at home represented by this sample, 198 (38.2%) did not receive nursing services; 65 (12.5%) had home nursing services, and 256 (49.3%) had home hospice services. About one quarter of all patients with pain or dyspnea did not receive adequate treatment, and one quarter reported concerns with physician communication. More than one third of respondents cared for by a home health agency, nursing home, or hospital reported insufficient emotional support for the patient and/or 1 or more concerns with family emotional support, compared with about one fifth of those receiving home hospice services. Nursing home residents were less likely than those cared for in a hospital or by home hospice services to always have been treated with respect at the end of life (68.2% vs 79.6% and 96.2%, respectively). Family members of patients receiving hospice services were more satisfied with overall quality of care: 70.7% rated care as "excellent" compared with less than 50% of those dying in an institutional setting or with home health services (P<.001). CONCLUSIONS: Many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect. Family members of decedents who received care at home with hospice services were more likely to report a favorable dying experience

WALLING A, LORENZ KA, DY SM, ET AL. EVIDENCE-BASED RECOMMENDATIONS FOR INFORMATION AND CARE PLANNING IN CANCER CARE. *J CLIN ONCOL,* 2008;26(23):3896-3902.

Abstract: The practice of oncology is characterized by challenging communication tasks that make it difficult to ensure optimal physician-patient information sharing and care planning. Discussions of diagnosis, prognosis, and patient goals are essential processes that inform decisions. However, data suggest that there are deficiencies in this area. We conducted a systematic review to identify the evidence supporting high-quality clinical practices for information and care planning in the context of cancer care as part of the RAND Cancer Quality-Assessing Symptoms, Side Effects, and Indicators of Supportive Treatment Project. Domains of information and care planning that are important for high-quality cancer care include integration of palliation into cancer care, advance care planning, sentinel events as markers for the need to readdress a patient's goals of care, and continuity of care planning. The standards presented here for information and care planning in cancer care should be incorporated into care pathways and should become the expectation rather than the exception

WALLING AM, TISNADO D, ASCH SM, ET AL. THE QUALITY OF SUPPORTIVE CANCER CARE IN THE VETERANS AFFAIRS HEALTH SYSTEM AND TARGETS FOR IMPROVEMENT. *JAMA INTERN MED,* 2013;173(22):2071-2079.

Abstract: Characterizing the quality of supportive cancer care can guide quality improvement. OBJECTIVE: To evaluate nonhospice supportive cancer care comprehensively in a national sample of veterans. DESIGN, SETTING, AND PARTICIPANTS: Using a retrospective cohort study design, we measured evidence-based cancer care processes using previously validated indicators of care quality in patients with advanced cancer, addressing pain, nonpain symptoms, and information and care planning among 719 veterans with a 2008 Veterans Affairs Central Cancer Registry diagnosis of stage IV colorectal (37.0%), pancreatic (29.8%), or lung (33.2%) cancer. MAIN OUTCOMES AND MEASURES: We abstracted medical records from diagnosis for 3 years or until death among eligible veterans (lived >/= 30 days following diagnosis with >/= 1 Veterans Affairs hospitalization or >/= 2 Veterans Affairs outpatient visits). Each indicator identified a clinical scenario and an appropriate action. For each indicator for which a veteran was eligible, we determined whether appropriate care was provided. We also determined patient-level quality overall and by pain, nonpain symptoms, and information and care planning domains. RESULTS: Most veterans were older (mean age, 66.2 years), male (97.2%), and white (74.3%). Eighty-five percent received both inpatient and outpatient care, and 92.5% died. Overall, the 719 veterans triggered a mean of 11.7 quality indicators (range, 1-22) and received a mean 49.5% of appropriate care. Notable gaps in care were that inpatient pain screening was common (96.5%) but lacking for outpatients (58.1%). With opioids, bowel prophylaxis occurred for only 52.2% of outpatients and 70.5% of inpatients. Few patients had a timely dyspnea evaluation (15.8%) or treatment (10.8%). Outpatient assessment of fatigue occurred for 31.3%. Of patients at high risk for diarrhea from chemotherapy, 24.2% were offered appropriate antidiarrheals. Only 17.7% of veterans had goals of care addressed in the month after a diagnosis of advanced cancer, and 63.7% had timely discussion of goals following intensive care unit admission. Most decedents (86.4%) were referred to palliative care or hospice before death. Single- vs multiple-fraction radiotherapy should have been considered in 28 veterans with bone metastasis, but none were offered this option. CONCLUSIONS AND RELEVANCE: These care gaps reflect important targets for improving the patient and family experience of cancer care

WENNBERG JE, FISHER ES, STUKEL TA, ET AL. USE OF HOSPITALS, PHYSICIAN VISITS, AND HOSPICE CARE DURING LAST SIX MONTHS OF LIFE AMONG COHORTS LOYAL TO HIGHLY RESPECTED HOSPITALS IN THE UNITED STATES. *BMJ,* 2004;328(7440):607.

Abstract: To evaluate the use of healthcare resources during the last six months of life among patients of US hospitals with strong reputations for high quality care in managing chronic illness. DESIGN: Retrospective cohort study based on claims data from the US Medicare programme. PARTICIPANTS: Cohorts receiving most of their hospital care from 77 hospitals that appeared on the 2001 US News and World Report "best hospitals" list for heart and pulmonary disease, cancer, and geriatric services. MAIN OUTCOME MEASURES: Use of healthcare resources in the last six months of life: number of days spent in hospital and in intensive care units; number of physician visits; percentage of patients seeing 10 or more physicians; percentage enrolled in hospice. Terminal care: percentage of deaths occurring in hospital; percentage of deaths occurring in association with a stay in an intensive care unit. RESULTS: Extensive variation in each measure existed among the 77 hospital cohorts. Days in hospital per decedent ranged from 9.4 to 27.1 (interquartile range 11.6-16.1); days in intensive care units ranged from 1.6 to 9.5 (2.6-4.5); number of physician visits ranged from 17.6 to 76.2 (25.5-39.5); percentage of patients seeing 10 or more physicians ranged from 16.9% to 58.5% (29.4-43.4%); and hospice enrollment ranged from 10.8% to 43.8% (22.0-32.0%). The percentage of deaths occurring in hospital ranged from 15.9% to 55.6% (35.4-43.1%), and the percentage of deaths associated with a stay in intensive care ranged from 8.4% to 36.8% (20.2-27.1%). CONCLUSION: Striking variation exists in the utilisation of end of life care among US medical centres with strong national reputations for clinical care

ZILL JM, SCHOLL I, HARTER M, ET AL. EVALUATION OF DIMENSIONS AND MEASUREMENT SCALES IN PATIENT-CENTEREDNESS. *PATIENT PREFER ADHERENCE,* 2013;7:345-351.

Abstract: Patient-centeredness has gained importance over the last two decades. However, there is an absence of theoretical clarity regarding the term patient-centeredness. This results in inconsistent measurement of patient-centeredness, which leads to difficulties in comparing research results. To overcome these difficulties, the aims of this study are (1) to identify the dimensions of patient-centeredness and include them in an integrative model, (2) to select and assess the most relevant dimensions of the model, (3) to identify and assess measurement instruments and find evidence for the selected dimensions, and (4) to assess the relevance and applicability of the conceptualization and measurement of patient-centeredness in clinical practice and health services research. METHODS: This project is divided into four phases. First, a systematic review will be conducted to identify the constructs and dimensions of patient-centeredness. Second, experts (eg, researchers, clinicians, and patient representatives) will assess and prioritize the identified relevant dimensions using a Delphi survey. Third, the selected dimensions will be assessed regarding their operationalization, and the results will be summarized in a systematic review. Evidence of the measures will be assessed in a scoping review. Fourth, an expert workshop will be held. Experts will assess the results of the previous phases regarding the relevance and applicability of the conceptualization and measurement of patient-centeredness. DISCUSSION: This study will provide an integrative model of patient-centeredness based on the current literature. This model can be used to improve upon the comparability of research results. Through a detailed insight into the existence and evidence of measurement dimensions of patient-centeredness, existing gaps in this field will be shown. Finally, the expert assessment will show the relevance and feasibility of the concept and measures in clinical practice and health services research. Therefore, this study will contribute important knowledge to enhance future research on patient-centeredness and establish a foundation for its implementation

NATIONAL QUALITY FORUM

Roster & Biographies

Multistakeholder Input on Priority Setting for Health Care Performance Measurement: Getting to Measures that Matter

Person-Centered Care and Outcomes Committee Roster

Uma Kotagal, MBBS, MSc (CO-Chair)
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PatientsLikeMe, Cambridge, MA

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Society for Participatory Medicine, Nashua, NH

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Person-Centered Care and Outcomes Committee Biographies

Uma Kotagal, MBBS, MSc, is senior vice president for quality, safety and transformation and executive director of the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center. As director of the Anderson Center, Dr. Kotagal oversees the development of disease management teams and development and institution of evidence-based clinical practice guidelines. Dr. Kotagal was director of the neonatal intensive care units at the University Hospital and at Cincinnati Children's for several years. While practicing, Dr. Kotagal recognized that care and outcomes improvement were a system property. She completed additional training, receiving her masters of science in clinical epidemiology and clinical effectiveness from the Harvard School of Public Health, and refocused her clinical efforts on quality transformation at a systems level. She was also a visiting scholar at the Center for Risk Analysis at the Harvard School of Public Health and a visiting professor at the Tufts New England Medical Center, in the Division of Clinical Decision Making, completing further training in the field of decision and cost effectiveness analyses.

Sally Okun, RN is the Vice President for Advocacy, Policy and Patient Safety at PatientsLikeMe in Cambridge, MA. She is responsible for the company's patient advocacy initiatives; she participates and contributes to health policy discussions at the national and global level; and she is the company's liaison with government and regulatory agencies. Sally joined the company in 2008 as the manager of Health Data Integrity and Patient Safety overseeing the site's medical ontology including the curation of patient-reported health data and an ever-evolving patient vocabulary. She also developed and manages the PatientsLikeMe Drug Safety and Pharmacovigilance Platform. Prior to joining PatientsLikeMe Sally, a registered nurse, practiced as a palliative and end-of-life care specialist. In addition as an independent consultant she contributed to multiple clinical, research, and educational projects focused on palliative and end-of-life care for numerous clients including Brown University, Harvard Medical School, MA Department of Mental Health, Hospice Education Network and the Robert Wood Johnson Foundation.

Ethan Basch, MD, MSc, is an oncologist and outcomes researcher at Memorial Sloan-Kettering Cancer Center who directs a program on patient-reported outcomes, clinical informatics, comparative effectiveness and product safety evaluation. He leads the National Cancer Institute's PRO-CTCAE initiative to develop a standardized patient-centered approach to adverse event reporting in clinical trials. Dr. Basch is a member of the PCORI Methodology Committee and chairs the Patient-Centeredness Workgroup. He is immediate past Chair of the American Society of Clinical Oncology Clinical Practice Guidelines Committee, member of the Comparative Effectiveness Research Task Force and liaison to the Quality of Care Committee.

Dave deBronkart, widely known as e-Patient Dave, is a cancer patient and blogger who, in 2009, became a noted activist for healthcare transformation through participatory medicine and personal health data rights. In 2007 he was diagnosed with metastatic kidney cancer. He ultimately beat the disease by accessing online resources, seeking information about his disease on the web and sharing access to his medical record. Dave is now a nationally and internationally known spokesperson for the e-Patient movement and shares his experience as an empowered, engaged patient leader.

Joyce Dubow, MUP, is a member of the NQF Board of Directors. She served two terms on the Consensus Standards Approval Committee and was its inaugural chair. She co-chaired the Patient-reported Outcomes technical committee and represents AARP on the Coordinating Committee of the Measure Application Partnership and the National Priorities Partnership. She has served on numerous NQF steering and ad hoc committees including: the Steering Committee and Workshop on National Voluntary Consensus Standards for Hospital Care, the Steering Committee for Additional Priority Areas for Hospitals; the HCAHPS Review Committee; the Steering Committee for Standardizing Ambulatory Care Performance Measures; the Steering Committee on National Consensus Standards for the Reporting of Healthcare-associated Infections Data; the Priority and Goal Setting Steering Committee on Efficiency; and the Ad Hoc Committee on Improving NQF's Consensus Development Process. She represents AARP on the Consumer Council.

Jennifer Eames Huff, MPH, is Director for the Consumer-Purchaser Disclosure Project. The Consumer-Purchaser Disclosure Project is a group of leading employer, consumer, and labor organizations improving health care quality and affordability by advancing public reporting of provider performance information so it can be used for improvement, consumer choice, and payment. Ms. Huff brings over seventeen years' experience working in the arena of health care performance measurement to the project. Prior to joining PBGH Ms. Huff was a Health Economist at Genentech, where she contributed to the development and commercialization of products by overseeing patient reported outcomes and providing economic assessments. Before that, she was a Program Officer at the California HealthCare Foundation (CHCF). While at CHCF she managed a portfolio of projects related to patient safety, health disparities and the public reporting of provider performance. When she left the Picker Institute in Boston, Ms. Huff was Director of Client Services. At the Picker Institute, she helped clients measure patients' experience with care and use the information for improvement, public reporting, and financial rewards. Her clients included hospital associations, health systems and employer coalitions located throughout the US. She also has held quality management positions at health systems in New England. Ms. Huff earned a BA with Honors from Wellesley College and an MPH in Health Policy and Management from University of California at Berkeley.

Troy Fiesinger, MD, currently serves on the faculty of the Memorial Family Medicine Residency Program in Sugar Land, Texas and holds an adjunct assistant professorship at the Texas A&M University. He graduated from Baylor College of Medicine in 1996 and completed his residency at East Carolina University in 1999. He then worked for Scott and White Healthcare in Waco, Texas. While there he helped lead quality improvement efforts as the Regional Clinic Director for Quality and Safety. He then served as the medical director for a federally-qualified health center and residency faculty in Conroe, Texas. He has participated in performance measure workgroups for the AMA's Physician Consortium for Performance Improvement, the American Board of Medical Specialties, and the National Quality Forum. He previously served on the AAFP's Commission on Quality and Practice.

Christopher Forrest, MD, PhD, is a Professor of Pediatrics and Health Care Management at the University of Pennsylvania and Children's Hospital of Philadelphia (CHOP). He leads a research center that focuses on the measurement of health across the life course and development of a national pediatric learning health system. He provides leadership for a federally funded Pediatric Quality Measures Program Center of Excellence, a national program in pediatric learning health systems (which are dedicated to advancing the health of children through research, quality improvement, and informatics), the National Children's Study health measurement network, and the NIH's Patient Reported Outcome Measurement Information System's (PROMIS) Executive Committee and serves on the Steering Committee for the National Children Study's Health Measurement Network.

Lori Frank, PhD, has worked as a PRO researcher for over 15 years. At PCORI Dr. Frank's work as Director, Engagement Research focuses on the patient perspective on comparative effectiveness research. As Executive Director of the Center for Health Outcomes Research at United BioSource she led multiple PRO development and psychometric evaluation studies, and initiated and led the Cognition Initiative, now part of the Critical Path Institute PRO Consortium. Her published work includes both qualitative and quantitative studies of PROs. Dr. Frank serves on the Memory Screening Advisory Board of the Alzheimer's Foundation of America and has also served on the Center for Trauma and the Community of Georgetown University Department of Psychiatry, engaging patients and clinicians from local clinics for the under-served in the research process.

Priti Jhingran, BPharm, PhD, is Senior Director in US Health Outcomes at GlaxoSmithKline. Dr. Jhingran is an Institutional Council member of ISPOR since 2007 and participated in various workstreams. In addition, Dr. Jhingran was the founding Co-Director of the Patient Reported Outcomes (PRO) Consortium in 2009 for 2 years. Dr. Jhingran has been a lead/contributing researcher for many PROs that have become mainstream assessment tools in various diseases areas. These include Asthma Control test, Migraine Specific Quality of Life Questionnaire, COPD Assessment Tool, and many more. Most recently, Dr. Jhingran was appointed on the PCORI Advisory Board focusing on Diagnosis, Treatment, and Prevention.

Lisa Latts, MD, MSPH, MBA, FACP, is the Principle for LML Health Solutions, a healthcare quality and delivery system transformation consulting firm. Prior to this, Dr. Latts was a Vice President with WellPoint. In her 14 years with WellPoint, Dr Latts led WellPoint's innovative quality strategy, which included initiatives to measure and improve the health of WellPoint's members and communities, measure and promote health equity, patient safety and many others. She was instrumental in developing many of WellPoint's delivery system reform initiatives such as Patient-Centered Medical Home, Centers of Excellence, and Medical Tourism. She is a nationally-known leader and has served on many national committees including with NCQA and NQF.

Bruce Leff, MD, is Professor of Medicine at the Johns Hopkins University Schools of Medicine and Public Health. He is an active clinician in the ambulatory, home, nursing home, rehabilitation, and hospital settings. His research focuses on innovative models of patient-centered care and the care of people with multiple chronic conditions. He was a co-author of the white paper for NQF on performance measurement for people with multiple chronic conditions. He is currently working on the development of quality measures for people cared for in medical house calls practices. He is a member of the MAP post-acute and long-term care committee.

Michael Lepore, PhD, is Planetree's Director of Research and an adjunct Assistant Professor in Health Services, Policy & Practice at Brown University. A sociologist by training, Dr. Lepore transitioned to health services research after working as a nursing assistant in long-term care. His research examines patient-centered care, and healthcare quality, access, and equity. With Planetree, a network of healthcare organizations committed to patient-centered care, Dr. Lepore's work focuses on implementing and evaluating patient-centered care across the spectrum of healthcare settings internationally. A recognized thought leader, Dr. Lepore was an invited speaker at numerous venues in 2013, including the NQF annual conference.

Mary Minniti, is a Certified Professional in Healthcare Quality. She has worked in quality improvement and community organizing for more than 30 years. She joined the Institute for Patient- and Family-Centered Care in 2011 as a Program and Resource Specialist and provides onsite training and technical assistance to health care organizations, develops publications and resources, and serves as faculty for the Institute's seminars and conferences. Her work with the Institute began in 2003 as guest faculty for an intensive training seminar.

Mary MacDonald, MS, BA, is Director, Healthcare division of American Federation of Teachers. Previously worked for national AFL-CIO and served as faculty on the extension division of Cornell University's School of Industrial and Labor Relations. Currently Chair of the NQF Consumer Council. Served on the Board of the Maryland Health Care Foundation. U.S. Labor representative for development of ILO standard on substance abuse in the workplace, Geneva, Switzerland. U.S. representative and panelist at United Nations Conference on Drugs in the Workplace, Seville, Spain. M.S. in Industrial and Labor Relations from Cornell University.

Eugene Nelson, MPH, DSc, is Professor of Community and Family Medicine at The Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth Medical School; Director, Population Health Measurement Program, The Dartmouth Institute; Director, Population Health and Measurement, Dartmouth-Hitchcock Medical Center. Dr. Nelson is a national leader in health care improvement and the development and application of measures of quality, system performance, health outcomes, value, and patient and customer perceptions. His work to develop the "clinical value compass" and "whole system measures" to assess health care system performance has made him a well-recognized quality and value measurement expert. He is the recipient of The Joint Commission's Ernest A. Codman award for his work on outcomes measurement in health care. Dr. Nelson, who has been a pioneer in bringing modern quality improvement thinking into the mainstream of health care, helped launch the Institute for Healthcare Improvement and served as a founding Board Member.

Mark Nyman, MD, FACP, has been involved with Quality Improvement activities over the last 18 years. Involvement has included guideline development and implementation at Mayo Clinic and with the Institute for Clinical Systems Improvement; six years of service - Board of Directors for Minnesota

Community Measurement (MNCM); and current membership - MNCM Measurement Advisory Reporting Committee. He is the chair of Mayo Clinic's Patient Profile Subcommittee, a new committee charged with standardizing the capture of data (answers to clinical questions obtained in a discrete electronic format) from patients including Patient Reported Outcomes, and includes standardization of the content across the entire practice.

Laurel Radwin, RN, PhD, after conducting qualitative research of nurses' and patients' perceptions of coordinated, individualized, responsive and proficient care, and completing performance measurement coursework, Laurel Radwin, RN, PhD, developed and tested patient-reported measures. One scale is included in the AHRQ's Atlas of Care Coordination Measures and has been translated into 15 languages. Dr. Radwin is currently studying care coordination for Veterans who transition among settings, and has comprehensively reviewed measures of coordination from clinicians' and patients' perspectives. Furthermore, Dr. Radwin's scales have been shown to be sensitive to diverse patients' perceptions of care, and her contribution to disparities research has been formally recognized by Howard University.

Anne Walling, MD, PhD, is a palliative care physician and health services researcher who has focused on measuring and improving the quality of care for patients with life-limiting illness including those with hope for cure. She has worked with RAND's ACOVE (Assessing Care of Vulnerable Elders) and ASSIST(Assessing Symptoms Side Effects and Indicators of Supportive Treatment) quality measurement projects. Her research with quality measures has lead in part to the National Quality Forum Endorsement for RAND end of life quality indicators.