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

Person-Centered Care and Outcomes Committee
In- Person Meeting

April 7-8, 2014

NATIONAL QUALITY FORUM

Welcome

COMMITTEE MEMBERS	
Sally Okun, RN (Co-Chair)	PatientsLikeMe
Uma Kotagal, MBBS, MSc (Co-Chair)	Cincinnati Children's Hospital Medical Center
Ethan Basch, MD, MSc	University of North Carolina at Chapel Hill
Dave deBronkart, Jr.	Society for Participatory Medicine
Joyce Dubow, MUP	AARP
Jennifer Eames-Huff, MPH	Consumer-Purchaser Disclosure Project
Troy Fiesinger, MD	Memorial Family Medicine Residency
Christopher Forrest, MD, PhD	The Children's Hospital of Philadelphia, University of Pennsylvania
Lori Frank, PhD	Patient-Centered Outcomes Research Institute
Priti Jhingran, BPharm, PhD	GlaxoSmithKline
Lisa Latts, MD, MSPH, MBA, FACP	LML Health Solutions, LLC
Bruce Leff, MD	Johns Hopkins University School of Medicine
Michael Lepore, PhD	Planetree
Mary MacDonald, MS, BA	American Federation of Teachers
Mary Minniti (*Maureen Connor*)	Institute for Patient-and Family-Centered Care
Eugene Nelson, MPH, DSc	Dartmouth Institute for Health Policy and Clinical Practice
Mark Nyman, MD, FACP	Mayo Clinic
Laurel Radwin, RN, PhD	Veterans Administration
Anne Walling, MD, PhD	University of California-Los Angeles

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Setting the Stage

Uma Kotagal, Co-Chair

Sally Okun, Co-Chair

Prioritizing Measure Gaps: Person-Centered Care and Outcomes 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 (Morning Session)

9:00: Welcome and Introductions

9:40: Setting the Stage

10:00: Project Overview and Related NQF Projects

10:15: Break

10:30: Definition and Core Concepts for Person- and Family-Centered Care (Panel- Exemplars of the Core Concepts)

11:45: Definition and Core Concepts for Person- and Family-Centered Care (Panel of Patient and Patient/Consumer Representatives)

12:45: Lunch

Day 1: Monday, April 7, 2014 (Afternoon Session)

1:15: Opportunity for Public Comment

1:30: Definition and Core Concepts for Person- and Family-Centered Care (Committee Discussion)

2:00: Measurement Framework

2:20: Innovative Approaches

3:05: Break

3:15: Small Group Work: Identify Measure Concepts

4:45: Report Out from Small Groups

5:15: Adjourn

Day 2: Tuesday, April 8, 2014 (Morning Session)

8:30: Welcome, Goals, Review Agenda, Recap of Day 1, Clarifications

8:45: Opportunity for Public Comment

9:00: Measurement Framework and Measure Concepts from Day 1

10:00: Priorities for filling performance measure gaps

10:15: Break

10:30: Small Group Work: Prioritize the measure concepts for performance measurement

11:45: Report out from small groups

12:30: Lunch

Day 2: Tuesday, April 8, 2014 (Afternoon Session)

1:15: Identify Short-Term and Long-Term Recommendations

2:30: Opportunity for Public Comment

2:45: Wrap Up/Next Steps

3:00: Adjourn

Expectations for Committee

- Everyone participate
- Open sharing of, and respect for, views, perspectives, agreements, and differences
  - Audience will also have opportunity to provide comments for the committee's consideration
- Help to work toward consensus
- Help to meet objectives
- Help to stay on time

Scope for this Project: Person- and Family-Centered Care Other Domains of Quality

IOM Domains of Quality

- Safe
- Effective
- **Patient-centered**
- Timely
- Efficient
- Equitable

National Quality Strategy Priorities

- Making care safer
- Each **person and family are engaged as partners**
- Effective **communication and coordination** of care
- Most effective prevention and treatment practices
- Best practices for healthy living
- Making quality care more affordable

Clarifying the Term Measure

- Patient-level measure – patient-level data such as BP, lab value, or score on a PROM (e.g., depression score on PHQ-9, responses for a CAHPS composite)

- Provider or organization-level measure – "performance measure"
  aggregate of patient-level data for a specified entity (e.g., percentage of patients with depression remission at 6 mo.)

Measuring Person- and Family-Centered Care Relationship to PRO-based Performance Measures

- Patient-reported outcome (PRO): any report of the status of a patient's (or person's) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.
- PRO Domains
  - Health-related quality of life (including functional status);
  - Symptoms and symptom burden (e.g. pain, fatigue);
  - **Experience with care** (e.g. communication, decisionmaking, engagement)
  - Health behaviors (e.g., smoking, diet, exercise)

Measuring Person- and Family-Centered Care Relationship to PRO-based Performance Measures

- The experience of person- and family-centered care as reflected in the core concepts will often be measured as an experience with care PRO (e.g., survey)
- Using PRO tools/instruments might be used when delivering person-centered care (if used actively to identify goals/priorities, manage care, assess progress, etc.)
- Not all PROs are indicators of person- and family-centered care
  - For example, change or improvement in function after hip surgery is an indicator of treatment effectiveness, rather than person- and family-centered care

Task - Identify Potential Performance Measure Concepts

- The definition and core concepts will serve as our starting point – they describe what it is we want to attempt to measure
- Classic areas of quality assessment:
  Structure → Process → Outcome
  - The core concepts can be thought of as the experience of receiving person- and family-centered care – in other words, the outcomes (e.g., I collaborate in decisions . . .)
  - There are various structures (e.g., use of standardized decisionmaking tools) and processes of care (e.g., co-produce a plan of care) that can be used to achieve those experiences

Task - Priority Setting

- What information would be meaningful to consumers?
- What is relevant across setting, time, programs?
- What should be measured only from the person's experience?
- There could be multiple ways and variations to achieve the core concepts – when considering various structures and processes, are there any that standout as something that all should do in the same way and be codified in a national standard for measuring performance?
- Are there some things (particularly structures/systems) that would be more suitable for a standardized label of information pertaining to person- and family-centered care?

HHS Context for Project

Kevin Larsen,
Office of National Coordinator(ONC)

Project Overview and Related NQF Projects

Specific Tasks for Person-Centered Care and Outcomes Priority Setting Project

1. Convene a multistakeholder committee of experts including patients and patient advocates
2. Identify existing models and core concepts as a basis for envisioning the ideal state or "north star" of person-centered care
   - Draft definition and draft core concepts
3. Seek input from patients (and families) on what information (i.e., performance measures) would be useful for assessing person-centered care (i.e., "nutrition label" or dashboard of person-centered care).
   - Explore what already has been done by groups such as the Institute for Patient and Family Centered Care and Patients Like Me to find out what matters most to patients and families
   - Explore whether there are any existing measures/tools used by patient advocacy groups for assessing person centered care

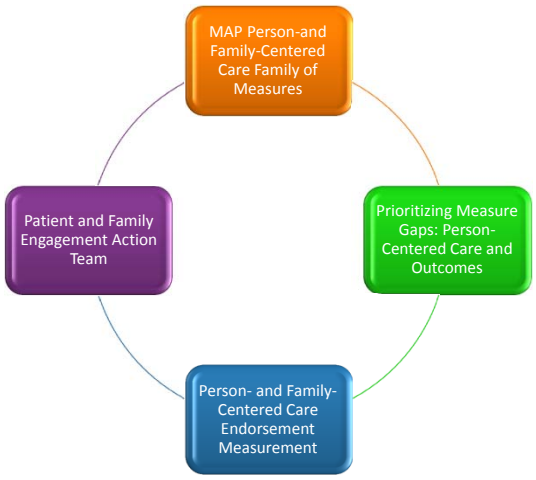
Specific Tasks for Person-Centered Care and Outcomes Priority Setting Project

4. Conduct an environmental scan of potential performance measures, status of development, and alignment with concepts of person-centered care
   - Draft environmental scan
   - Input of this committee and prior PRO Expert Panel to identify examples where measurement of performance on person-centered care is occurring
5. At the in-person meeting, review the above inputs and create the vision of the ideal state or "north star" of person-centered care and identify how best to measure performance and progress in the delivery of person-centered care.
6. Based on the ideal person-centered care, recommend specific measures for implementation or specific concepts for development of performance measures
   - Short-term and longer-term recommendations
7. Obtain public comment, and then finalize recommendations.

Timeline

- June 16, 2014 – Final Conceptual Framework, Final Environmental Scan, and Draft Report due to HHS
- June 23-July 14, 2014 – Draft report will be available for public comment
- June 30, 2014 – Public webinar to receive feedback on draft report recommendations
- August 15, 2014 – Final Committee report due to HHS

NQF's Current Work on Person- and Family-Centered Care



Definition and Core Concepts for Person- and Family-Centered Care

Draft Definition for 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.

Draft Core Concepts

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.

Draft Core Concepts- Cont'd

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 if efficiently and effectively.
8. Communication with and among my care partners is honest, transparent, and coordinated across settings and time.

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)

Whole Person, goal, priorities

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.

Presenter:

Gene Nelson, MPH, DSc, Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH

Care I need, when, where, how I prefer

I receive the care I need — no more, no less—when, where, and how I prefer.

Presenter:

Uma Kotagal, MBBS, MSc, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Respect, Dignity, Compassion

My care partners treat me and my family with respect, dignity, and compassion.

Presenter:

Anne Walling, MD, PhD, University of California-Los Angeles, Los Angeles, CA

Collaborate in Decisions

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.

Presenter:

Michael Lepore, PhD, Planetree, Atlanta, GA

Family

My family care partners include those I choose and their role is supported by other care partners.

Presenter:

Jennifer Wolff, PhD, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Information

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.

Presenter:

Bruce Leff, MD, Johns Hopkins University School of Medicine, Baltimore, MD

Time Valued

My care partners value my time and use it efficiently and effectively.

Presenter:

Dave deBronkart, Jr., Society for Participatory Medicine, Nashua, NH

Communication

Communication with and among my care partners is honest, transparent, and coordinated across settings and time.

Presenter:

Troy Fiesinger, MD, Memorial Family Medicine Residency, Sugar Land, TX

Panel of Patient and Patient/Consumer Representatives

(*Do the definition and core concepts capture your view of ideal person-and family-centered care?*)

Panel presenters

- ***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*

Opportunity for Public Comment

Definition and Core Concepts for Person- and Family-Centered Care

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?*)

Measurement Framework

Overview of NQF Endorsement Criteria

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.

NQF Criteria and Hierarchy

- Evidence, Performance Gap, Priority: Importance to Measure and Report (*must-pass*)
  - If does not meet this criterion, the other criteria less meaningful
- Reliability and Validity: Scientific Acceptability of the Measure Properties (*must-pass*)
  - If not a reliable and valid, risk of misclassification and improper interpretation
- Feasibility
  - Create as little burden as possible, or try to minimize burden
- Usability and Use
  - If no plan for use in accountability applications, NQF endorsement not necessary
- Comparison to Related and Competing Measures

Measure Concepts - Importance to Measure and Report

- Evidence to Support the Measure Focus or Rationale for Outcomes, including PROs (*must-pass*)
  - Empirical evidence for structure, process, intermediate clinical outcomes
  - Outcomes – rationale influenced by at least one healthcare structure, process, intervention, service
- Performance Gap, including disparities (*must-pass*)
- High Priority (*must-pass*)
  - For PROs – information demonstrating it is valued and meaningful to patients/consumers
- For composite performance measures: quality construct and rationale (must-pass)

PRO, PROM, PRO-PM

Concept	Patients with Clinical Depression	Persons with Intellectual or Developmental Disabilities
PRO (patient-reported outcome)	Symptom: depression	Functional Status-Role: employment
PROM (instrument, tool, single-item measure)	PHQ-9©, a standardized *tool* to assess depression	Single-item measure on National Core Indicators Consumer Survey: *Do you have a job in the community?*
PRO-PM (PRO-based performance measure)	Percentage of patients with diagnosis of major depression or dysthymia and initial PHQ-9 score >9 with a follow-up PHQ-9 score <5 at 6 months (NQF #0711)	The proportion of people with intellectual or developmental disabilities who have a job in the community

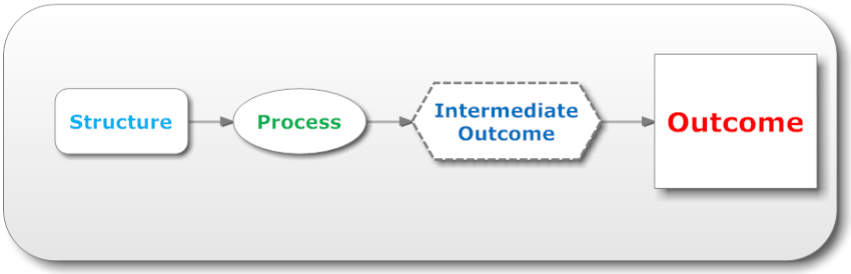
Clarify PRO-PM in Relation to Person- and Family-Centered Care

- Identified core concepts for person- and family-centered care would be in the PRO domain of experience with care
- PRO-PMs for other domains (health-related quality of life/functional status, symptom/symptom burden and health-related behaviors) – primarily indicators of treatment effectiveness
- Systems and processes related to using PROMs (symptom and function scales) could be viewed as an important structures or processes for delivering person-centered care IF incorporated into the assessment and management of patient care

Additional Considerations for Measurement of 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
- 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)

Quality Assessment Framework Structure-Process-Outcome



NQF – Hierarchical Preference for Measures of:

- Outcomes linked to evidence-based process/structures
- Outcomes of substantial importance with plausible process/structure relationships
- Intermediate outcomes
- Process/structures most closely linked to desired outcomes

Proximal to Desired Outcome

- Preference for outcomes or processes/structures closely linked – generally proximal to the desired outcome
- More distal may be necessary but not sufficient

Structure →	Process →	Outcome
Organization policy/ procedures to use patient-reported data ↓ Identified set of PROMs most relevant to their patient population	Staff identify appropriate PROM to use ↓ Ask patient to complete the PROM ↓ Review the PROM results with the patient ↓ Use as a basis for co-producing a plan of care based on patient's priorities and goals	I collaborate in decisions about my care

Person- and Family-Centered Care

- Outcome – Desired outcomes including experience reflected in the core concept
- Process - Interaction between person/family and providers of care that are intended to facilitate achieving the experience reflected in the core concepts – includes interventions, treatments, services
- Structure - Organizational structure or systems that support providing person- and family-centered care – indicate capacity to deliver care

Draft Framework –think about what might be measured related to the core concepts

Core Concept	Structure	Process	Outcome (Intermediate clinical, health outcome, including PRO)
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 with my grandkids, I will be able to tend my garden without being in constant pain, etc.)	• 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

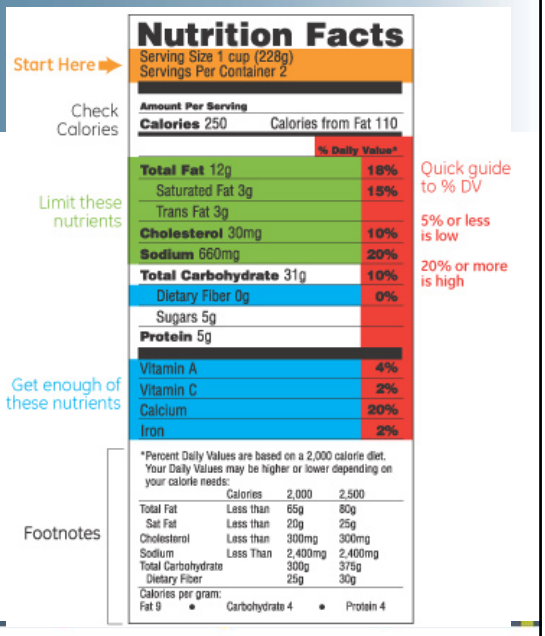
Key Questions

- Is there evidence for structures or processes 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 or processes to support person- and family-centered care be useful in a standard label?
- Are there other outcomes that can be measured besides the experiences represented by the core concepts?
- 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 better able to do what I want and need to do) is it an indicator of treatment effectiveness or person-centered care?

Label for Person- and Family Centered Care

"Nutrition Label" Idea

- Standard set of items
- Standard definitions
- Standard ways to present information
- Standard format/layout



Label for Person- and Family Centered Care

Key Questions

- Are there certain types of information related to person- and family-centered care that could be provided in a standardized label?
- Would it 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
Access to price list: URL link

Work Groups to Identify Performance Measure Concepts

- Four groups - two core concepts for each group
- Goal is to identify three to five promising performance measure concepts for each core concept
- Identify any items that might be useful for a standardized label
- Performance Measure Concept
  - What structure, process or outcome should be measured? (*e.g., experience of being treated with respect, care received matches decisions*)
  - What patients should be included? (*e.g., all, hospitalized*)
  - What is the data source? (*e.g., patient-reported, EHRs*)
  - Whose performance should be measured? (*e.g., hospital, ACO, health plan*)

Innovative Approaches

National Quality Forum
Person- and Family-Centered Care

James L. Holly, MD
CEO, Southeast Texas Medical Associates, LLP
ww.setma.com

April 7, 2014

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The Key Is Coordination

- The statement on its face seems an oversimplification. How can doing things, the way patients want, when they want, where they want and how they want, contribute to the achievement of quality outcomes?

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The Key Is Coordination

- **"Coordination of Care"** is the process an organization goes through to assure that patients receive the care they need and **Coordinated Care** is the outcome, i.e., the experience and perception the patient has when the care has been organized for continuity, for convenience and for compliance."

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Convenience & Quality

- Initially, the idea of **convenience** in the scheduling of multiple appointments at the same time was the extent of SETMA's understanding of this element of coordination.
- Eventually, "convenience" was translated into the understanding that **coordinated care** means more than just making patients comfortable; it meant and it resulted in:

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Convenience & Quality

1. Convenience for the patient, which
2. Results in increased patient satisfaction, which contributes to
3. The patient having confidence that the healthcare provider cares for the patient personally, which
4. Increases the trust that the patient has in the provider, all of which

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Convenience & Quality

5. Increases compliance (adherence) in the patient obtaining healthcare services recommended, which
6. Promotes cost saving in travel, time and expense of care, which
7. Results in increased safety, quality of care and cost saving for the patient.

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Convenience & Quality

This requires intentional efforts to identify opportunities to:

1. Schedule visits with multiple providers on the same day, based on auditing the schedule for the next 30-60 days to see when a patient is scheduled with multiple providers and then to determine if it is medically feasible to coordinate those visits on the same day.

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Convenience & Quality

2. Schedule multiple procedures, based on auditing of referrals and/or based on auditing the schedule for the next 30-60 days to see when a patient is scheduled for multiple providers or tests, and then to determine if it is medically feasible to coordinate those visits on the same day.

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Convenience & Quality

3. Scheduling procedures or other tests spontaneously on that same day when a patient is seen and a need is discovered.
4. Recognizing when patients will benefit from case management, or disease management, or other ancillary services and working to provide the resources for those needs.

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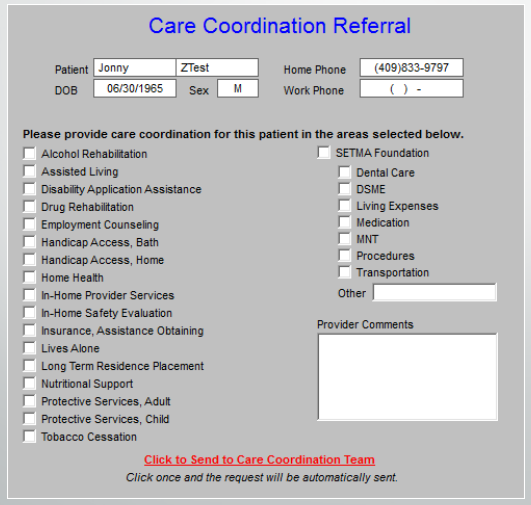
The Key Is Coordination



Care Coordination Referral

Patient: Jonny ZTest | Home Phone: (409)833-9797
DOB: 06/30/1965 | Sex: M | Work Phone: ( ) -

Please provide care coordination for this patient in the areas selected below.

- Alcohol Rehabilitation
- Assisted Living
- Disability Application Assistance
- Drug Rehabilitation
- Employment Counseling
- Handicap Access, Bath
- Handicap Access, Home
- Home Health
- In-Home Provider Services
- In-Home Safety Evaluation
- Insurance, Assistance Obtaining
- Lives Alone
- Long Term Residence Placement
- Nutritional Support
- Protective Services, Adult
- Protective Services, Child
- Tobacco Cessation
- SETMA Foundation
  - Dental Care
  - DSME
  - Living Expenses
  - Medication
  - MNT
  - Procedures
  - Transportation
- Other

Provider Comments

Click to Send to Care Coordination Team

Click once and the request will be automatically sent.

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Convenience & Quality

- It was only through this analysis that we accepted "convenience" as a worthy goal of quality care as opposed to it only being a means of "humoring" patients. This fulfilled SETMA's goal of ceasing to be the constable, attempting to impose healthcare on our patients; and, to our functionally becoming the consultant, the collaborator, the colleague to our patients, empowering them to achieve the health they have determined to have.

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IHI's High Impact Leadership

As we learn, the complexity of quality metrics, their focus and their content will change.

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IHI's High Impact Leadership

Volume	Value
Patient satisfaction	Persons as partners in their care
Increase top-line revenue	Continuously decrease per unit cost and waste
Complex all-purpose hospitals and facilities	Lower cost, focused care delivery sites
Quality departments and experts	Quality improvement in daily work for all staff

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National Quality Forum

Person- and Family-Centered Care

Susan Yount, PhD
Amy Eisenstein, PhD
Northwestern University
April 7, 2014

Patient-Reported Outcomes Measurement Information System (PROMIS)

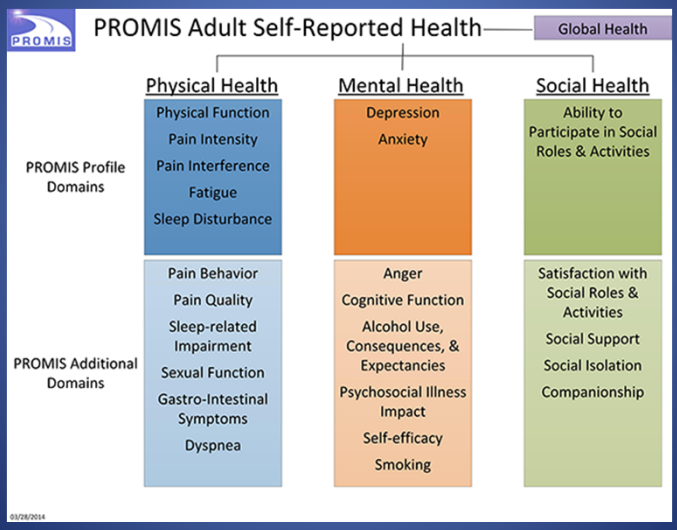
Overview of the Patient-Reported Outcomes Measurement Information System (PROMIS)

- 2004 – 2014 NIH Roadmap/Common Fund ($85M)
- Network of 15 academic institutions
- Self-reported physical, mental and social health for adults, children and parent-proxies
- Assessment of domains of physical, mental, and social health
- Application of mixed methods and modern measurement theory

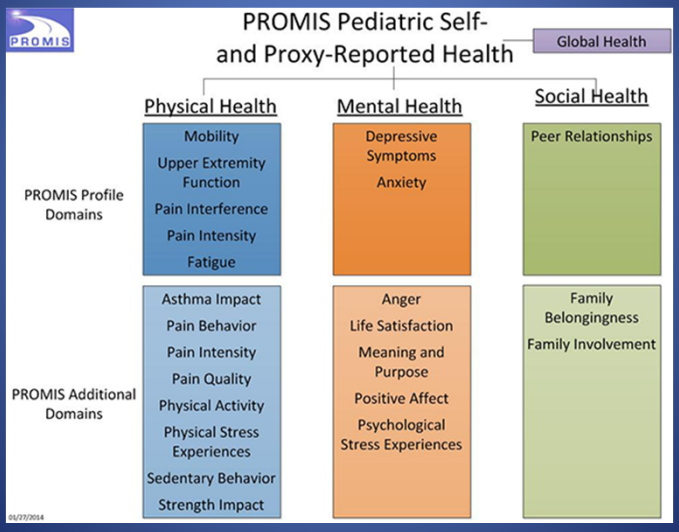
Unique Features of PROMIS

- Comparability
  - Measures standardized: common domains and metrics across conditions, allowing for comparisons across domains and diseases
- Reliability and Validity
  - All metrics for each domain rigorously reviewed and tested
- Flexibility
  - Can be administered in a variety of ways, in a different forms (static short forms, CAT, customizable)
- Inclusiveness
  - PROMIS encompasses all people, regardless of literacy, language, physical function or life course

Adult Framework



Pediatric Framework



PROMIS Measures

- Short forms
  - Static, administered on paper or via AC, 4-20 items
  - Profiles
    - 4-, 6- or 8-items from 6 (peds) or 7 (adult) domains (depression, anxiety, physical function, pain interference, fatigue, sleep disturbance, and satisfaction with participation in social roles, *peer relationships*), single pain intensity item
  - PROMIS Global Health (10 items)

PROMIS Measures

- Computerized adaptive testing (CAT)
  - Banks of item adaptively administered
  - Average 4-6 items per CAT
  - Maximum precision
  - Requires computer

PROMIS Metric

- Measures
  - Adult: >40 domains; expanding to >50
  - Pediatric: 9 domains; expanding to >20 (also parent-proxy measures for many domains)
- Metric
  - T-score metric: mean = 50, s.d. = 10
  - Referenced to the 2000 U.S. general population
    - Currently being re-centered to 2010
  - High scores reflect more of domain construct

Advantages to PROMIS

- Improved measurement
  - Increased power → reduced sample size
- Adaptability
- Low patient burden
- Comparability
- Royalty-free

Assessment Center
(www.assessmentcenter.net)

- Sponsored by the NIH:
  - Hardware, software maintenance and new feature development, help desk
- Enables creation of study-specific URLs
  - Participant interface for data collection
  - Administration of PROMIS, Neuro-QoL, NIH Toolbox short forms and CATs
  - Download PDFs
- Instrument Library
- Real-time data export

More Information

- www.nihpromis.org
- www.assessmentcenter.net

Standardizing and Personalizing Patient-Centered Rheumatoid Arthritis Treatment Targets

Goals of the Study

- To evaluate the added value of PROMIS to an existing *Treat to Target (T2T)* RA treatment program.
- To use PROMIS to standardize the patient-centered targets of pain, fatigue, depression, physical function, and social function.
- To individualize (personalize) these treatment targets in patient-centered language that retains valid and responsive measurement.

Objectives

- To add PROMIS assessments to the existing electronic health record for our RA patients in such a way that enables individualized patient goal setting.
- To evaluate the impact of a T2T approach measured clinically and through PROMIS domains.
- To individualize patient treatment targets.
- To evaluate patient satisfaction with the individualized T2T system.
- To evaluate clinician satisfaction with the individualized T2T system.

Baseline Data Summary

- T2T is an international initiative to define RA treatment targets and recommendations to measure disease severity and encourage earlier diagnosis and optimize treatment.
- However, patient concerns and patient centered outcomes have typically not been considered when implementing T2T strategies in clinical care.
- Patient and physicians consider different aspects of disease when making treatment decisions.

Research Design

- Target Population
  - 60 adult patients with a documented RA diagnosis with low disease activity and 60 with high disease activity.
- Methods
  - Baseline and 4 follow-ups over a 12 month period.
  - Assessments include clinical questionnaires, PROMIS CAT's, open-ended QOL items, and Prioritization of PROMIS domains and selection of 5 items.

Innovation

- 1 of only 2 working examples of individualized PRO assessment in RA practice.
- This PRO application is both individualized and standardized which is only possible through creative integration of IRT and qualitative clinical input from patients.

Small Group Work: Identify Performance Measure Concepts

Work Groups to Identify Performance Measure Concepts

- Four groups - two core concepts for each group
- Goal is to identify three to five promising performance measure concepts for each core concept
- Identify any items that might be useful for a standardized label
- Performance Measure Concept
  - What structure, process or outcome should be measured? (*e.g., experience of being treated with respect, care received matches decisions*)
  - What patients should be included? (*e.g., all, hospitalized*)
  - What is the data source? (*e.g., patient-reported, EHRs*)
  - Whose performance should be measured? (*e.g., hospital, ACO, health plan*)

Report Out from Small Groups

- Please summarize your discussion for the group, highlighting:
  - Promising performance measure concepts
  - Any information useful for the “label” concept
  - Any other important themes!

Welcome

Day 2: Tuesday, April 8, 2014 (Morning Session)

8:30: Welcome, Goals, Review Agenda, Recap of Day 1, Clarifications

8:45: Opportunity for Public Comment

9:00: Measurement Framework and Measure Concepts from Day 1

10:00: Priorities for filling performance measure gaps

10:15: Break

10:30: Small Group Work: Prioritize the measure concepts for performance measurement

11:45: Report out from small groups

12:30: Lunch

Day 2: Tuesday, April 8, 2014 (Afternoon Session)

1:15: Identify Short-Term and Long-Term Recommendations

2:30: Opportunity for Public Comment

2:45: Wrap Up/Next Steps

3:00: Adjourn

Recap of Day 1

Opportunity for Public Comment

Measurement Framework and Measure Concepts

from Day 1

Measurement Framework and Measure Concepts

- Review
- Clarifications, suggestions for additions or deletions

Priorities for Filling Performance Measure Gaps

Priority Considerations

- NQF criteria
  - Hierarchical preference for outcome
  - Importance to measure and report
    - » Empirical evidence or outcome with rationale
    - » Performance gap
    - » High priority (meaningful and valued by consumers)

Priority Considerations

- Meaningful to consumers and built with consumers
- Focused on their entire care experience, rather than a single setting or program
- 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)

Small Group Work: Prioritize the measure concepts for performance measurement

Report Out from Small Groups

- Identify the highest priority performance measure concepts

Identify Short-Term and Long-Term Recommendations

Short-Term vs. Long-Term Recommendations

- Readiness
  - Clinical practice
  - Infrastructure (systems)
- Resource investment needed
- Other?

Identify Short-Term and Long-Term Recommendations

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

Opportunity for Public Comment

Wrap Up/Next Steps

Upcoming Events

- **Mid-June:** Draft report available for NQF Member and public comment
- **June 30:** Webinar (open to all) to present major findings and collect stakeholder feedback
- **August:** Final report submitted to HHS and available on NQF website

Adjourn

Thank you for participating!