NATIONAL QUALITY FORUM

National Voluntary Consensus Standards for Patient Outcomes

Summary of the Child Health Steering Committee meeting
November 12-13, 2009

A two-day meeting of the Patient Outcomes-Child Health Steering Committee (SC) took place on November 12-13, 2009, at the Hilton Embassy Row Hotel in Washington, DC.

Steering Committee (SC) members present: Charles Homer MD, (co-chair); Marina Weiss, PhD (co-chair); Allan Lieberthal, MD, FAAP; Sharron Docherty, PhD, CPNP (AC/PC); Bonnie Zima, MD, MPH; Lee Partridge; Donna Persaud, MD; David Clarke, MD; Ellen Schwalenstocker, PhD, MBA; Kathy Jenkins, MD, MPH; Goutham Rao, MD; Thomas McInerny, MD

Steering Committee members participating via conference call: Jane Perkins, JD, MPH

NQF Staff members present: Helen Burstin, MD, MPH; Reva Winkler, MD, MPH (Clinical Consultant); Melissa Marinelarena, RN, BSN (Project Manager); Ian Corbridge, MPH, RN (Project Manager); Bonnie Zell, MD, MS (Senior Director); Ashley Morsell, MPH (Research Analyst)

Dr. Weiss and Dr. Homer, Committee Co-chairs, opened the meeting and asked the Steering Committee (SC) members to introduce themselves, provide a brief background of their interests and experience, and disclose any specific interests pertaining to the measures being evaluated. The only disclosure was from Dr. Jenkins regarding her submission of a measure to NQF's Pediatric Cardiac Surgery project. After the Committee members' introduction, National Quality Forum (NQF) staff also introduced themselves. No audience members were in attendance.

Orientation to NQF

Dr. Burstin, Senior Vice President for Performance Measures facilitated introductory comments, including an explanation of the degree to which all members of the Committee have varied levels of experience in working with NQF.

Dr. Winkler, NQF Clinical Consultant and the outcomes project advisor, oriented the group to NQF's mission, strategic goals, and drivers and processes for endorsing performance measures. The group learned that this particular project includes two additional Steering Committees (a main committee and a mental health committee), as well as eight disease-specific technical advisory panels. The Steering Committee was asked to draw on their knowledge of existing measures in the field to identify measures for consideration now as well as set the scope of outcomes for children to identify measurement gaps.

Quality measurement was discussed with regard to the forces that drive measure development, such as the need to address gaps in performance in measurement and provide a foundation for pay-for-performance programs. Measurement at the individual physician level, disparities-sensitive measurement, cross-cutting areas, and care across multiple settings were identified as key gap areas in performance measurement. Future efforts by NQF to improve quality measurement were discussed.

Orientation to the Outcomes Project
The group was oriented to NQF's main goals for this two-day meeting, which included:

- orienting the SC to NQF current and future activities,
- informing the SC of the project goals,
- defining child outcome measures and scope of this project, and
- discussing the measure evaluation process.

To orient SC members to NQF's current work, a brief summary of issues for the NQF portfolio was provided, with an emphasis on:

- the degree to which NQF endorsed measures address children's healthcare,
- the availability of data sources to support these measures, and
- the advent of Electronic Medical Records (EHRs) as it relates to performance measurement.

The following project-specific goals, arising out of NQF's contract with the DHHS, were described to the Committee:

- identify, evaluate, and endorse additional outcome measures for child health, and
- identify gaps in existing child health outcome measures and make recommendations to fill those gaps.

Further context for the project was provided through an explanation of the NQF Consensus Development Process (CDP) with regard to the role of the SC and the role of NQF staff.

Additional information provided in the orientation to the project included a brief explanation of the online submission form, and NQF's standard measure evaluation criteria, which were revised in August 2008.

Presentation: What is Child Health?
Dr. Zell, NQF, Senior Director, Population Health gave an overview of child health through the lens of population health. She asked the Committee: How can we connect performance measures in healthcare with activities in other sectors of the community that influence health? From this, the Committee agreed that child health does not happen exclusively within the healthcare sector. Behavioral patterns are the greatest determinant of health (40 percent), followed by genetic predisposition (30 percent). Given this data, it is necessary to bridge the gap between the healthcare system and the community because of the opportunity for education and improvement in multiple settings. In addition, there should be an assessment of overlap between the healthcare system and the community in efforts to help improve health outcomes for children. Dr. Zell also discussed the concept of "joint accountability;" that is both the healthcare system and the community assuming responsibility for their roles and influence on child health at the population level.

Steering Committee discussion
Members of the Committee raised a number of topic areas to consider in further defining the nature of their role in response to their orientation to NQF's current work focus. The areas included: defining a child health outcome, determining where current outcome measures fit in the larger healthcare arena, and identifying gap areas where measures are necessary. In addition to NQF's description of the Steering Committee's role, the Committee suggested they assume some responsibility for determining how to increase the number of measures received in the formal call for measures.

Definitions
In an effort to define the scope of this project, the Committee discussed the definition of an outcome measure at length. NQF staff provided a basis for this discussion by identifying Donobedian's definition of outcomes, which "refers to changes (desirable and undesirable) in individuals and populations that are attributed to healthcare." Furthermore, NQF staff gave the Committee a list of types of outcome measures

- patient function, symptoms, healthcare-related quality of life,
- intermediate clinical outcomes,
- patient experience with care,
- service utilization as proxy or potential efficiency indicated,
- non-mortality clinical morbidity,
- healthcare acquired events/complications, and
- mortality.

In their efforts to develop the scope of the project, starting with this list, the Committee delved further into defining "child health outcome." Members discussed adding *child development* which entails physical, social, emotional, and cognitive growth. The consensus was that this is a critical part of a child's life, and we need to be specific when identifying what part of the developmental process is being addressed when considering it an outcome. Another topic added was *patient and family functioning.* The Committee agreed that it is imperative to consider the ability or inability to attain optimal functionality on the trajectory of childhood. With that, the Steering Committee also thought ability to maintain functionality should be evaluated. Another consideration was *parental experience with care.* For younger children,"patient experience of care," is actually experience of care as assessed by the parent, which entails both communication with the child and communication with the parent. A parent's perception of the degree of improvement, or lack thereof, for a given condition should be considered the level of effectiveness or outcome of a particular intervention.

The Steering Committee also discussed including indicators reflecting child well-being from other traditional child care sectors, such as incarceration rates, school attendance/absenteeism and performance, physical fitness, and behavioral changes such as seat belt use.

After adding to the topic list the Committee then briefly spoke on what data sources could be utilized to gather the information for childhood outcomes. After discussing various sources and what implications they would have on different conditions, the Committee concluded that they did not want to be restrictive about the data sources used to capture information about particular outcomes.

Current Child Health Outcome Measures

In response to a Committee request; NQF staff provided the following information on the most costly conditions for children.

Top 5 Most Costly Conditions for Children (Based on 2006 cost data from AHRQ website)

Cost	Condition
$ 8.9 billion	Depression
$ 8.0 billion	Asthma
$ 6.1 billion	Trauma
$ 3.1 billion	Acute bronchitis
$ 2.9 billion	Acute infectious disease

This table generated a more in-depth conversation around other conditions, and areas of consideration and how the associated outcomes may be relevant to the project. One issue was the evaluation of outpatient care for children. The Committee agreed that outpatient care for children is critical in improving health outcomes because of the small volume of children who receive inpatient hospital care. They also noted that much of the cost of pediatric healthcare is generated in inpatient settings in addition to these settings often seeing the most vulnerable children, so these outcomes would be vital. Alignment between pertinent adult health issues to which children are also susceptible should also be considered. There are many conditions, i.e. *heart disease,* that are primarily assessed in adults, but warrant consideration in a project such as this because children are also afflicted. Coupled with that, there was talk of the importance of examining health issues that are unique to children. The Committee acknowledged that most pediatric care is ambulatory, so measures of the outcomes of common ambulatory care issues and conditions (mental health, asthma, ADHD, acute care, etc.) are necessary. Lastly, the Committee considered the role process measures play relative to this project: can they be used as a proxy for measuring outcomes? This approach is helpful in scenarios where outcome measures are not feasible and the process is directly and closely linked to the actual outcome. An example was *child immunization;* the rationale being that receiving the vaccine is a process that affects an outcome that cannot easily be measured.

Gap Areas

One of the major responsibilities of the Steering Committee is to help identify areas beyond those already listed in the general categories where childhood outcome measures are necessary. They came up with the following list of areas that should be considered:

- medication adherence,
- reduction of high risk behaviors, and
- disease reduction.

Drafting the "Call for Measures"

The Committee was charged with creating the content of the Call for Measures that NQF will announce in January 2010. They created a framework that stratified children based on multiple dimensions (age groupings, FACCT framework[1], care setting, National Priorities Partnership (NPP) priorities) to help highlight what specific details should be addressed in the call. The Committee agreed that measure developers should consider outcomes based on a standardized approach to evaluating in-hospital and out-hospital morbidity. In addition, it was decided that the term "*caregiver*" encompasses parents as well as other potential caregivers, and is therefore suitable for use here. The final discussion point was whether to include measures on "young adults" and what age range to use. Any cutoff is arbitrary, but the Committee chose the AAP age range of 0-21, as it is most widely used, though it is recognized that this range may not mirror the ages covered by public and private insurance. The collaborative effort of the NQF staff and the Committee to finalize a list of types of child health outcomes will be included in the call for measures.

Identifying and Evaluating Candidate Outcome Measures

Dr. Winkler oriented the Committee to NQF's Measure Evaluation process. In addition, the Committee was asked to consider whether they are aware of additional resources for seeking out existing outcome measures, not including those identified by NQF in their environmental scan report. The following resources were named as potential avenues for seeking additional measures:

- National Institutes of Health (NIH),
- AAP and its sub-specialties,
- Family Voices,
- Society for Research in Childhood Development,
- Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD),
- insurance agencies,
- Academy Health,
- Cystic Fibrosis Foundation,
- State Mental Health Director's Association,
- National Alliance on Mental Illness (NAMI),
- Autism Speaks,
- Bi-polar Foundation,
- Teen Depression and Suicide,
- NQF Consumer Council,
- American Board of Pediatrics, and
- National Association of Rare Disease.

Members of the Committee were asked to help solicit submission of measures appropriate to this project. NQF staff suggested that measure developers have incentive to submit their measures to NQF given that NQF endorsement initiates a certain amount of authority, increases the likelihood that a measure will be more widely used, and allows a measure to be recognized at the national level.

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[1] Foundation for Accountability http://www.markle.org/archives/facct/

Next steps

Dr. Winkler outlined the next activities for the Steering Committee:

1. disseminate the draft version of the Call for Measures to the Committee for final revisions, and
2. determine specific dates for the April in-person Steering Committee in Washington, DC.

There was discussion of mental health issues becoming robust within the child population so the Child Health Steering Committee will need to collaborate with the Mental Health Steering Committee to discuss cross-cutting issues. In addition, the Steering Committee was encouraged to continue to think about gaps in the NQF portfolio as it relates to outcome measures.

No public comment was offered.