

# NATIONAL QUALITY FORUM

## National Voluntary Consensus Standards for Patient Outcomes: Child Health

### Summary of the Child Health Steering Committee meeting

May 5-6, 2010

*Committee Members Present:* Charles Homer, MD (co-chair); Marina Weiss, PhD (co-chair); Allan Lieberthal, MD; 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; Phillip Kibort, MD, MBA; Nancy Fisher, MD, MPH; Faye Gary, EdD, RN

*Committee Members Participating via Conference Call:* Marlene Miller, MD, MSc

*NQF Staff Present:* Helen Burstin, MD, MPH; Reva Winkler, MD, MPH (clinical consultant); Nicole McElveen, MPH (senior project manager); Heidi Bossley, MSN, MBA (senior director); Ashley Morsell, MPH (research analyst); Nalini Pande, JD (senior director, Strategic Partnerships)

*Others present:* Jay Berry, Children's Hospital Boston; Lisa Burgerson, Children's Hospital Boston; Amos Deinard, The School of Public Health at the University of Minnesota; Rita Munley-Gallagher, the American Nursing Association; Michael Murphy, Massachusetts General Hospital; Nina Rauscher, Children's Hospital Boston.

*Others Participating via Conference Call:* Mark Antman from the Physician Consortium for Performance Improvement; Christina Bethel, Child and Adolescent Health Measurement Initiative (CAHMI); Debra Bingham, California Maternal Quality Care Collaborative; John Bott, Agency for Healthcare Research and Quality; Nicolia Eldred, CAHMI; Kerri Fei from the Physician Consortium for Performance Improvement; Barbara Fivush, the Physician Consortium for Performance Improvement; Elliott Main, California Pacific Medical Center; Scott Stumbo from CAHMI.

## WELCOME AND INTRODUCTIONS

The meeting began with an introduction of committee members and NQF staff. The co-chairs welcomed the Committee and reviewed the project objectives: 1) evaluation of submitted candidate standards and 2) identification of gap areas where more performance measures are necessary. The co-chairs suggested a plan to deal with candidate measures identified as "process measures," should they arise. The Committee was asked to disclose any conflict of interest pertaining to the measures being discussed. The Committee also was informed of an opportunity to extend their work with NQF by serving as the Steering Committee to review

# NATIONAL QUALITY FORUM

candidate standards submitted in NQF's upcoming CHIPRA project, scheduled to begin in July. The new project would be an opportunity to evaluate both outcome and process measures, and perhaps re-evaluate some of the measures submitted to the Patient Outcomes project in a more effective forum. The Committee was very enthusiastic about participating in the new project. Ms. McElveen gave a slide presentation to review the overall Patient Outcomes project as well as specific details regarding currently NQF-endorsed® child health measures, including outcome measures. She reminded the Committee how it defined outcome measures in the Call for Measures, to maintain consistency in the scope of the project and evaluation of the measures.

## POPULATION-BASED CANDIDATE STANDARDS

On April 12, 2010, the Steering Committee convened via conference call to discuss four population-level candidate standards submitted by the Agency for Healthcare Quality Research (AHRQ). A conference call [summary](#) is available online for review. Following the call, the Committee was asked to make final voting decisions on each NQF evaluation criterion and an overall recommendation for endorsement. During the in-person meeting, the Committee's voting results were discussed and reviewed further. For each candidate standard, the Committee members reviewed the measure details and information provided by the measure developer to ensure a well-informed vote. The measure developer was present via conference call to answer questions. After discussion, the Committee voted again on the recommendations of the candidate standards:

**OT3-054-10:** *Urinary tract infection admission rate (pediatric)*

**Vote: 0 – yes; 14 – no; 1 – yes with conditions**

The majority of the Committee agreed not to recommend this measure for endorsement. Many Committee members questioned the preventability of urinary tract infections (UTIs) especially for very young children. In general, the Committee believed the measure does not provide actionable information that would improve quality. The Committee also noted concerns with potential misuse of the measure at facility or provider levels of analysis as well as the potential unintended consequence of avoiding appropriate admissions. The Committee suggested the measure might be stratified by age and gender to address the various causes of UTIs at different ages.

**OT3-055-10:** *Gastroenteritis admission rate (pediatric)*

**Vote: 14 – yes; 1 – no**

The majority of the Committee agreed this measure should be recommended for endorsement but raised concerns that the measure might reflect variations in social situations and resources, such as outpatient hydration, parental education on home care, and need for hospitalization

# NATIONAL QUALITY FORUM

when the social situation is complex. Some members noted that this measure should reflect the use of rotavirus vaccination in the population. They were in agreement that the measure was useful but suggested some sort of accompanying tool be developed to enable facilities to ensure accurate implementation.

**OT3-056-10:** *Diabetes, short-term complication rate (pediatric)*

**Vote: 4 – yes; 11 – no**

The majority of the Committee agreed this measure should not be recommended for endorsement, particularly as the measure does not differentiate primary hospitalizations when the diagnosis of diabetes is first made. Committee members noted differences between patients who have Type I and Type II diabetes; Type I diabetes is often initially diagnosed when a child is hospitalized for the first time for a short-term complication of the condition. The measure specifications do not exclude undiagnosed diabetes cases, nor is there coding available for first-time admissions for diabetes. It was noted that at the population-based level, the diabetes complication rate might be relatively stable. The Committee recommended exploring possibilities for excluding undiagnosed diabetes admissions from the measure specifications.

**OT3-057-10:** *Asthma admission rate (pediatric)*

**Vote: 10 – yes; 4 – no; 1 – yes with conditions**

The majority of the Committee agreed this measure should be recommended for endorsement but raised concerns about harmonization of age diagnosis for asthma. Previous NQF-endorsed measures for childhood asthma do not include ages younger than 5 years because of misclassification and coding errors. A Committee member noted that age 5 is the earliest that pulmonary function tests can be administered to confirm the diagnosis of asthma. The developers informed the Committee that they have included ages 2 to 5 years because hospitalizations are higher in that age group. The Committee mentioned that conventional wisdom on asthma diagnosis suggests that you cannot diagnose asthma before age 2, but others would say there is “wobble room” between ages 2 and 5. Also, it may be easier to clinically diagnose a child with asthma over the age of five.

In addition to their specific votes on the candidate standards, the Committee members emphasized the importance of using these measures only at the population-level and agreed that NQF should consider establishing guidelines for endorsement of population-based measures and their use.

## CANDIDATE STANDARD EVALUATION

Dr. Winkler discussed the importance of capturing the evaluation of the main criteria by the Committee members. The Committee had been divided into work groups to conduct a

# NATIONAL QUALITY FORUM

preliminary evaluation of the sub criteria prior to the meeting. A summary of the preliminary evaluation was used to introduce each candidate standard for discussion. Committee members noted that some of the submitted candidate standards were process measures. For each standard, the Committee determined whether or not it was within the scope of the Outcomes project. Standards that were within scope were evaluated further and discussed based on each of the four evaluation criteria: importance to measure, scientific acceptability, usability, and feasibility. The workgroup members assigned to provide a preliminary review of the measures facilitated the discussion of their initial sub criteria evaluations and opened the floor for discussion with other committee members. After discussion on each evaluation criterion, the Committee members voted on the criteria.

## STANDARDS NOT IN THE SCOPE OF THE OUTCOMES PROJECT

Five of the candidate standards were determined to be process measures and out of scope of the Outcomes project, and therefore did not move forward for further evaluation:

- **OT3-035-10:** Children who take medication for ADHD, emotional, or behavioral issues
- **OT3-040-10:** Children who live in neighborhoods with certain essential amenities
- **OT3-042-10:** Children who receive the mental health care they need
- **OT3-049-10:** Primary caries prevention intervention as part of well/ill child care as offered by primary care medical providers
- **OT3-050-10:** Children who receive standardized developmental and behavioral screening

## ADDITIONAL INFORMATION NEEDED FOR EVALUATION

Six candidate standards were not discussed fully at this meeting and will be reviewed at a later time because additional information was required for the Committee to conduct a complete evaluation. The Committee believed that to make an informed decision some clarifications, updates, and edits would be required to the submitted standards. The Committee will review these candidate standards at a later date to make an endorsement recommendation:

- **OT3-029-10:** Standardized adverse event ratio for children and adults undergoing cardiac catheterization for congenital heart disease
- **OT3-033-10:** National Survey of Children's Health 2007--Quality Measures
- **OT3-034-10:** National Survey of Children with Special Health Care Needs 2005/2006--Quality Measures
- **OT3-038-10:** Children who receive effective care coordination of healthcare services when needed
- **OT3-043-10:** Pediatric Symptom Checklist (PSC)

# NATIONAL QUALITY FORUM

- **OT3-046-10:** Validated family-centered survey questionnaire for parents' and patients' experiences during inpatient pediatric hospital stay

## CANDIDATE STANDARDS REVIEW

### Candidate Standards Recommended for Time-Limited Endorsement

#### **OT3-027-10:** *Ventriculoperitoneal (VP) shunt malfunction rate in children*

This candidate standard measures the 30-day VP shunt malfunction rate for hospitals that perform cerebrospinal ventriculoperitoneal shunt operations in children age 1 month to 18 years. The Committee believed this is an important outcome to measure as shunt malfunction occurs in 10 percent of patients. The largest impact on shunt function is placement or infection control, and variation in malfunction rates ranges from 3 percent to 25 percent. This is a major problem in children's hospitals, with an estimated admission rate for shunt malfunction of 10,000 patients and \$17,000 to \$20,000 average cost. In 2003, more than 300 hospitals performed VP shunts. This measure is untested, but the Committee agreed the standard is important to measure and report as an outcome because it addresses a high-impact area for this specific population of pediatric patients. The Committee also questioned whether the time period required to gather data (three years) may be too lengthy and may affect the usability and feasibility of the measure. The developers advised that three years of data is needed to stabilize the variance of the measure. In addition, they suggested the developer explore the use of electronic healthcare data. The developer added that a period longer than 30 days is less likely to identify shunt malfunction caused by surgery; the further from the surgery, the more the risk decreases. The developer also added that the measure has been stratified among different race and ethnicity groups and found that African Americans have a higher rate of malfunction compared to whites. Overall this measure was recommended for time-limited endorsement.

**Vote: 14 – yes; 0 – no; 1 – abstention**

#### **OT3-028-10:** *Standardized mortality ratio for neonates undergoing non-cardiac surgery*

This candidate standard measures the ratio of observed to expected rates of in-hospital mortality following non-cardiac surgery among infants less than or equal to 30 days of age. The Committee agreed this candidate standard is important to measure and report as an outcome, but noted the lack of variability across sites. Surgeries in this age group typically are related to congenital anomalies. The measure was developed using the KIDS 2000 database<sup>1</sup> and validated using the KIDS 2003 database. The Committee observed the measure is based on the number of procedures rather than the number of patients who undergo any of 63 procedures because some

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<sup>1</sup>Agency for Healthcare Research and Quality, *Introduction to the HCUP KIDS' Inpatient Database (KID) 2006. Health Cost and Utilization Project (HCUP)*, Rockville, MD: AHRQ; 2008. Available at <http://www.hcup-us.ahrq.gov/reports.jsp>. Last accessed May 2010.

# NATIONAL QUALITY FORUM

patients have multiple operations. The Committee asked for more information on the survival curve for these procedures beyond 30 days. The developer noted that their initial data is limited to 1 year from 15 institutions and that variability would be more likely for a longer timeframe with more sites.

The measure combines operations of similar risk using empirically derived risk categories grouped by mortality risk. The included procedures all require anesthesia and represent 85 percent of the procedures performed. The risk model demonstrates excellent performance characteristics.<sup>2</sup> The Committee also noted that the measure is directly associating mortality to the surgery, excluding the possibility of other co-morbidities that may contribute to mortality. In addition, the Committee discussed the use of the measure among different ethnic and racial groups to show the effects across populations. Overall, the Committee supported this candidate standard and offered suggestions to the developer as to ways to refine it for the future. The developer also acknowledged that testing and analysis of the data in the future should provide more information on differences in performance. This measure was recommended for time-limited endorsement.

**Vote: 14 – yes; 0 – no**

## Standards Recommended for Endorsement

### **OT3-031-10:** *Healthy term newborn*

This candidate standard measures the percentage of term singleton live births (excluding those with diagnosis originating in the fetal period) who do not have significant complications during birth or post partum arising from the management of the birth process itself. The developer noted this measure addresses the concerns of potential impact on newborn well-being as attempts at reducing C-section rates and inductions of labor are attempted. The Committee believed this standard was very well specified using only codes from the newborn record. The developer stated that the measure has been field tested in 15 hospitals in southern California and identified a 3-4 fold variation in outcome. A Committee member noted that the standard does not account for disadvantaged populations including race, socioeconomic status, or living conditions. The developer offered that future testing based on stratification is something upcoming for the development team to look into. Overall, this measure was recommended for endorsement.

**Vote: 14 – yes; 0 – no**

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<sup>2</sup>Son JK, Lillehei CW, Gauvreau K, Jenkins KJ, A risk adjustment method for newborns undergoing noncardiac surgery, *Ann Surg*, 2010;251(4):754-758.

# NATIONAL QUALITY FORUM

## **Candidate Standards Derived from the National Survey of Children’s Health (NSCH) 2007**

Data for the next four recommended population-level measures are derived from the National Survey of Children’s Health (NSCH) 2007, which asks the parent or guardian respondents a variety of questions about their child’s health.

### **OT3-032-10:** *Number of school days children miss due to illness*

This population-level candidate standard asks how many days were missed from school due to illness or injury among a sample of children and adolescents ages 6 to 17 years. The Committee believed this measure was an important public health measure, although it is not condition specific. The Committee also agreed this measure was very important, usable, and feasible, but raised concerns with the validity of the data collected, particularly the absence of clearer definitions of injury or illness and the lack of differentiation between “healthy kids” and “unhealthy kids.” Committee members mentioned the possibility for responder bias because the number of school days missed is based on caregiver recollection as opposed to some standard method of collection, i.e., school records. In addition, the national survey is administered only every four years, which can limit its usefulness. The Committee suggested the measure developer explore other means of capturing the data, such as including this question in other instruments that are administered more frequently. Overall, the committee recommended this measure for endorsement.

**Vote: 12 – yes; 3 – no**

### **OT3-036-10:** *Children who have no problems obtaining referrals when needed*

This candidate standard asks parents or guardians about their perceived difficulty in obtaining referrals for children when needed for optimal health. The majority of Committee members agreed this is an outcome measure but argued it also is a process measure. The developer noted that the intent of the measures is to assess access to healthcare for children. The Committee agreed this measure was important to measure and report but held varying opinions on the scientific acceptability, usability, and feasibility. Committee members raised concerns about the possibility of reporter bias because this standard is based on a parent’s report and subjective definition of “needed” versus “wanted.” The developer referenced a study conducted to evaluate the degree of need from a provider perspective and a parental perspective, and the results did demonstrate some lack of correlation. The Committee suggested this population-level measure could be supported by more specific provider-level measures to identify specific access issues. Overall, the Committee recommended this measure for endorsement, pending further clarifications on the specifications by the measure developer.

**Vote: 9 – yes; 6 – no**

# NATIONAL QUALITY FORUM

## **OT3-039-10:** *Children who live in communities perceived as safe*

This candidate standard ascertains the parents' perceived safety of the child's community or neighborhood. The Committee was impressed overall with this measure and agreed the topic area addressed an important social determinant of health and is well specified. The Committee noted that the term "safe" needs to be defined explicitly because of varying parent perspectives stemming from location, upbringing, and political views. The point was raised that safety also may need to be evaluated outside the realm of medical care, i.e., in juvenile detention centers or in relation to housing. Overall, the Committee recommended this measure for endorsement.

**Vote: 13 – yes; 1 – no**

## **OT3-044-10:** *Children who have inadequate insurance coverage for optimal health*

This candidate standard is designed to determine whether or not current insurance program coverage is adequate for the child's health needs. Committee members suggested the importance of this measure in the context of health reform to assess new plans and programs. They noted that this measure is the parents' perception of the insurance plan, which can be subjective and can vary by socioeconomic status. The measure developer responded to the concerns of the Committee, stating that the measure has strong face validity and can be stratified by vulnerability characteristics or income. Overall, this measure was recommended for endorsement.

**Vote: 11 – yes; 0 – no**

## **Candidate Standards Not Recommended for Endorsement**

### **OT3-037-10:** *Children living with illness: the effects of condition on daily life*

This candidate standard measures the extent to which the conditions of children with special healthcare needs result in limitations of their daily activities despite healthcare services they receive. The Committee agreed this measure was important to measure and report but raised several concerns about its scientific acceptability. Committee members discussed the issue of confounding relative to the individual patients captured in the numerator, recommending that risk adjustment needs to be incorporated into the testing. The Committee also suggested that the measure be developed further to include stratification data based on diagnoses to create an outcome measure that is more actionable. They advised the developer that grouping children in categories for the outcome of interest is another possible idea if stratification by diagnoses does not prove useful. The Committee acknowledged this candidate standard is derived from a national survey and therefore is feasible, especially at the population level. They did not believe



# NATIONAL QUALITY FORUM

that this candidate standard as constructed was ready to be included in the existing NQF portfolio of measures and did not recommend it for endorsement.

**Vote: 0 – yes; 15 – no**

## **OT3-048-10:** *Plan of Care for Inadequate Hemodialysis*

This candidate standard measures the percentage of patients age 17 and under who have a diagnosis of end-stage renal disease (ESRD) and receive hemodialysis with a documented plan of care for inadequate hemodialysis. The committee noted this candidate standard is similar to an already existing NQF time-limited endorsed measure for adults maintained by the same developer but reported in a different KT/V value. Regarding specifications, the Committee believed the number of patients who did not have a documented plan of care will be very small, which in turn would offer very limited results. In addition, the definition of a “documented plan” should be more explicit and account for adequacy of the plan of care. The Committee suggested to the measure developer to stratify the reporting results of the measure by age and include elements of the plan of care and also mentioned that an upcoming NQF project may be more suitable for this measure. They recognized this standard addresses a gap area in measuring KT/V values; they were in agreement, however, that it needs to be developed further before being considered for endorsement.

**Vote: 6 – yes; 8 – no**

## **Candidate Standards Determined To Be Out of Scope**

### **OT3-035-10:** *Children who take medication for ADHD, emotional, or behavioral issues*

This candidate standard measures the number of children from 2 to 17 years old who take medications for attention deficient hyperactive disorder (ADHD), emotional, or behavioral issues. The Committee generally believed this to be a process measure rather than an outcome. Nevertheless, a concern with appropriate medication use for emotional disorders is prominent among multiple stakeholders, including members in the fields of pediatrics, child psychology, education, and social work. The proposed indicator lumps a specific diagnosis for which stimulant medication is recommended with the broad category of “emotional or behavioral issues”. Given the variable level of scientific evidence for medication treatment for psychiatric disorders and high rates of co-morbidity across psychiatric disorders; questions were raised regarding need to improve alignment of recommended medication treatment and clinical need.

**Vote: 1 – in scope; 13 – out of scope; 1 abstention**

### **OT3-040-10:** *Children who live in neighborhoods with certain essential amenities*

This candidate standard is designed to assess whether or not children live in neighborhoods

# NATIONAL QUALITY FORUM

that contain elements that are known to have an impact on health status and functioning. The Committee agreed that the candidate standard was more of a structural measure than an outcome measure. The focus of the measure is the utilization of specific infrastructure (sidewalk, bike paths, recreation facility, libraries, and parks). These elements are defined by the measure developer as “essential amenities” that must be available to qualify for having met the measure requirements. The Committee agreed this measure was more focused on the availability of these amenities as opposed to any observed outcome that would result from that utility. Although the elements described are those of the “built environment,” which closely relate to health issues (especially diabetes), this candidate standard does not measure a patient outcome.

**Vote: 0 – in scope; 14 – out of scope**

## **OT3-042-10:** *Children who receive the mental health care they need*

This candidate standard measures the percentage of children ages 2 to 17 years who have an ongoing condition requiring mental healthcare who actually have seen a mental healthcare professional in the past 12 months. Further discussion is merited to address the problem of heterogeneity of training and disciplines among specialty mental health professionals that provide care to Medicaid child populations. The Committee agreed this was a process measure and thus out of scope for this project, but that it may be suitable for another NQF project.

## **OT3-049-10:** *Primary caries prevention intervention as part of well/ill child care as offered by primary care medical providers*

This candidate standard measures the number of states currently reimbursing for the primary caries prevention intervention as identified by a specific code to reflect application of fluoride varnish to the teeth of high-risk children. The measure developer described the American Academy of Pediatrics oral health initiative recommending that fluoride varnish should be applied quarterly to the teeth of high-risk children (children who received Medicaid and children in the Children’s Health Insurance Program) without a dental home. The developer also noted that the American Academy of Family Physicians supports this practice. The Committee agreed this measure was important and filled a gap area among healthcare for children, but raised several concerns about the precision of the specifications, which indicate several options for the numerator and denominator. The Committee also noted a dental home is not clearly defined. It observed there were two measures described – the number of varnish applications over the number of EPSDT exams<sup>3</sup> and the number of children with varnish over the number of children with exams. The Committee also mentioned that in the past there have

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<sup>3</sup>Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Programs, as defined by the Health Resources and Services Administration, are a child health component of Medicaid required in every state and designed to improve the health of low-income children by financing appropriate and necessary pediatric services.

# NATIONAL QUALITY FORUM

been issues with the content associated with an EPSDT visit. The Committee agreed this is a process measure but also acknowledged that dental care is a very important area and strongly recommended the developer submit a measure with precise specifications in upcoming NQF projects.

**Vote: 0 – in scope; 15 – out of scope**

## **OT3-050-10:** *Children who receive standardized developmental and behavioral screening*

This candidate standard uses age-specific items to assess whether or not parents received a standardized questionnaire addressing developmental concerns at a healthcare visit. The Committee reached consensus on deferring this measure as a process measure and out of scope, but one that may be suitable for an upcoming NQF project.

## **Candidate Measures Requiring Additional Information to Complete Evaluation**

### **OT3-029-10:** *Standardized adverse event ratio for children and adults undergoing cardiac catheterization for congenital heart disease*

This candidate standard measures the ratio of observed to expected clinically important preventable and possibly preventable adverse events in patients undergoing cardiac catheterization for congenital heart disease. Approximately 100 institutions perform catheterizations averaging 300 to 1200 per year for an overall total of 50,000 procedures nationwide. Catheterization is evolving from a primary diagnostic modality to a significant interventional procedure in which the risk of adverse events is greater. The Committee agreed this measure is important but raised concerns about the specifications, usability, and feasibility of the measure. The Committee questioned why adults were included in the target population and suggested separating the children from the adults because the outcomes observed will vary based on the patient's age, though the developer reported that age was not a statistically significant predictor of adverse events. The Committee discussed inclusion of possibly preventable events within the definition of adverse events. The developer noted the International Pediatric Cardiac Coding group is standardizing codes for these adverse events. Committee members questioned the reproducibility of the definition of "preventability." The developer addressed the Committee's concerns about the age group by explaining that the standard is designed to capture the entire population for institutions conducting the procedure and that it could be adjusted to measure only children. The Committee determined that more information and clarification was needed around wording of setting and provider, age restrictions, and defining unpreventable events. It was also suggested that testing on "unpreventable adverse events" be conducted. Lastly the Committee agreed clarification of numerator and denominator is needed. Ultimately, the committee decided to review the standard at a later date.

# NATIONAL QUALITY FORUM

## **OT3-033-10:** *National Survey of Children's Health 2007 – Quality Measures*

This candidate standard is a population-based survey designed to assess how well children nationwide and in each state are measuring on key quality indicators. This measure is composed of 15 individual measures, and the results of each measure are reported separately. The developer informed the Committee that it also has a composite measure that was not submitted. The Committee expressed interest in reviewing this composite, as it is possible that some of the individual measures that were submitted may be more useful and informative if included in a composite. The Committee agreed that more information was needed on the response rates and response bias and suggested that the number of hours the caregiver spent with a child could be included as a measurement variable. It also noted that the survey is lengthy, which may discourage participation and reduce response rates. The Committee could not come to a conclusion about whether or not the survey (as is) serves more as a way of capturing information, as opposed to a way of measuring a certain outcome. An advantage, it noted, is that the survey is widely used. The Committee recommended the developer consider the Committee's comments and discussion and reconsider whether the measure should be submitted as an individual measure or a composite of 15 separate measures.

## **OT3-034-10:** *National Survey of Children with Special Health Care Needs 2005/2006 – Quality Measures*

This candidate standard is a population-based survey designed to assess how well the nation and each state is performing on measures specifically for children with special healthcare needs. This measure is also composed of 15 individual quality health measures. The committee raised similar concerns and questions as with measure OT3-033-10. Additional information from the measure developer regarding the individual components within this measure was requested. The Committee therefore decided to review the measure in its entirety at a later date.

## **OT3-038-10:** *Children who receive effective care coordination of healthcare services when needed*

This candidate standard measures the need and receipt of care coordination services for children who required care from at least two types of healthcare services. The Committee agreed this measure was important and liked the concept of capturing parental satisfaction. The Committee also agreed the candidate standard addresses two important areas: satisfaction with the coordination of care and communication. But with two different constructs (coordination and communication), issues related to validity were discussed. In addition, the measure asks parents four specific questions related to care coordination, and Committee members raised concerns about how the answers to these questions are combined when calculating the results of the measure. Another concern was the issue that communication is subjective and may result in reporter bias. The developer stated there is an algorithm that further depicts what is included in the calculation of the measure. The Committee agreed it needs to review all relevant

# NATIONAL QUALITY FORUM

information before making recommendations, suggesting the developer separate the measure into two components and provide any relevant algorithms. This candidate standard will be reviewed again at a later date when all of the additional materials are made available.

## **OT3-043-10:** *Pediatric Symptom Checklist (PSC)*

This candidate standard measures the overall psychosocial functioning in children ages 4 to 16 years. The developer offered insight on how the PSC survey relates to outcomes, stating that the survey was designed as a screening tool, but because of frequent use, it is now being used in hospitals in Massachusetts to capture and track patient outcomes. The developer also stated that there is a published study from Cambridge, where the tool was tested on more than 1,000 participants, in which the data show that positive screens are reported when this tool is used. To offer more background, the developer informed the Committee that literature exists supporting the notion that psychosocial issues are routinely not identified nor acted upon. In addition, this tool was also used in numerous studies as a “pre-post” evaluation tool of children who have victims of domestic violence (in small settings). The Committee agreed this measure was important and mentioned the scarcity of psychosocial tests for young children, particularly those as young as 4 years old. The Committee did raise concerns about the data to link the score of the PSC to an improved outcome, the lack of clarity in the measure’s specifications and possible need for further development for use with Spanish-speaking populations. The consensus was that this is a good candidate standard but that it may be a process measure. The Committee recommended that the measure developer further develop the specifications, specifically defining the numerator and the population for whom this measure is intended. This measure will be reviewed at a later date when all information is available.

## **OT3-046-10:** *Validated family-centered survey questionnaire for parents’ and patients’ experiences during inpatient pediatric hospital stay*

This candidate standard evaluates the parents’ care experiences during inpatient pediatric hospital stays and is composed of 62 individual questions. The Committee voiced great enthusiasm for this measure and agreed it was important to measure and report. However, concerns were raised about the scientific acceptability of the measure, specifically the number of questions and biases such as parental expectations and the fact that those who are generally more pleased with service and experience may be inclined to complete the survey more than others. In addition, the specific domains of the measure (i.e., experience with the nurse, care coordination, admission process, etc.) were discussed, and the Committee expressed an interest in possibly developing composite measures and appropriate scoring for those domains. The Committee also noted the similarities between this survey and the Hospital Consumer Assessment of Healthcare Provider Surveys (HCAHPS) but noted that the population for the HCAHPS surveys does not include children. The Committee suggested harmonization with the HCAHPS survey. The Committee also discussed the use of this measure, which has not been

# NATIONAL QUALITY FORUM

applied across institutions, and raised concerns about how well it would work in hospitals that serve both children and adults. The measure developer mentioned that this survey was intended to focus on the parent's satisfaction/experience, but not necessarily the process of care (instructions for discharge). The developer also mentioned they are building another survey to address the elements of the care provided. In addition, the measure developer also has considered reducing the number of questions in the present survey. The Committee requested additional information about the measure, including comparative data on reliability and validity, clearer specifications for reporting, and domain scores. This measure will be reviewed at a later date when all information is available.

## **GAPS IN IMPORTANT OUTCOME MEASURES FOR CHILDREN**

To address the second goal of the Outcomes project, the Committee identified areas for development of needed outcome measures. Identified topic areas include:

- Parent preference regarding treatment and medications administered. The Committee agreed this is a parameter associated with measuring outcomes for children that needs to be incorporated in the decisionmaking.
- More detailed measures on the plan/provider level to answer the "why" questions that arise within population-level measurement.
- Measures around referral management.

## **NEXT STEPS**

### **Project Progression**

Due to time constraints, the Committee did not complete the evaluation of two candidate standards (OT3-041-10: Children who attend schools perceived as safe and OT3-045-10: Measure of medical home for children and adolescents). These measures will be reviewed and evaluated during a future conference call. NQF staff will compose a meeting summary reflecting the voting. The Committee noted that so far it had recommended nine measures for endorsement.