

NQF

NATIONAL QUALITY FORUM

**Child Healthcare
Quality Measurement
and Reporting**

WORKSHOP
PROCEEDINGS

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Quality Measurement
and Reporting**

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Editors

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Foreword

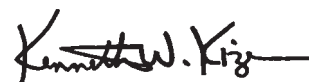
Although advances in public health and healthcare have dramatically improved the health of America's children, far too many children still do not receive healthcare services that would benefit them, and too many others receive inappropriate or harmful care. Moreover, healthcare for children is often difficult to access or of uneven quality. Systematic efforts are needed to improve the quality, availability, and equity of healthcare for children if continued health improvement is to be achieved.

It is important to recognize that children cannot be considered merely "little adults." They have their own unique physical and behavioral characteristics, and consequently, their healthcare needs differ from those of adults. This has important implications for quality measurement. Unfortunately, performance measures applicable to children are markedly underrepresented in the universe of national healthcare voluntary consensus standards.

On January 8, 2004, the National Quality Forum (NQF) convened a workshop to address the needs for performance measures and quality indicators in children's healthcare. The NQF workshop, "Child Healthcare Quality Measurement and Reporting," sought to identify appropriate child- and adolescent-focused healthcare performance measures and to recommend to NQF areas for further development. The workshop's 33 invited participants identified 7 immediate priorities and 2 potential priority areas for the standardization of children's healthcare measures and identified 3 potential priority areas where development of measures are needed. In addition, participants made recommendations about how the scope of future NQF projects should account for children.

We thank the National Association of Children's Hospitals and Related Institutions and the March of Dimes for their support of this workshop. We also thank the workshop's participants for their generous commitment of time and intellectual input.

NQF and its 215 Member organizations are committed to improving the quality of healthcare delivered to children through the advancement of national voluntary consensus standards for performance measurement and through public reporting.



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Child Healthcare Quality Measurement and Reporting

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Child Healthcare Quality Measurement and Reporting: Executive Summary

Performance measurement and quality improvement are rapidly becoming integral parts of the day-to-day activities of healthcare organizations, and they are of great interest to purchasers and consumers of care. Performance measures specific to care for children, however, are not widely used outside of specialty settings, and they rarely appear in national measure sets. Given the unique healthcare needs and characteristics of children, the paucity of child-relevant measures in widespread use is problematic.

The National Quality Forum (NQF) has endorsed few standards pertaining to children in its activities to date. To address this problem, NQF convened a *Workshop on Child Healthcare Quality Measurement and Reporting* on January 8, 2004.¹ The workshop sought to identify areas where measures specific to and important to children and adolescents exist and to recommend priority areas for further NQF activities related to children.

Conclusions

Workshop participants came to the following conclusions:

- Measures of the quality of healthcare that are meaningful for adults cannot be assumed to have the same applicability to healthcare for children. Children differ fundamentally from adults in their development, dependency, patterns of illness and disability, and demographic characteristics.
- Sufficient work on quality measurement exists in a number of children's healthcare priority areas to support national agreement on and implementation of quality measures relevant to children.

¹The meeting discussion was supported by a background paper, "Measures of Children's Health Care Quality: Building towards Consensus," prepared by L. Simpson, D. Dougherty, D. Krause, C. Manyan-Ku, and J. Perrin, September 19, 2003, manuscript in preparation.

Priorities

The group identified the following priorities for NQF regarding the standardization of quality measures and/or other related activities for children's healthcare:

Top Priorities

- Asthma.
- Patient safety, particularly in inpatient settings.
- Children with special healthcare needs (CSHCN), including both condition-specific (e.g., cystic fibrosis) and non-disease-specific (e.g., coordination of care) measures.
- Preventive care, including (but not limited to) immunization, injury prevention, and avoidable hospitalizations.
- Coordination of care (both as a priority itself and as a measurable component of other priority areas).
- Perinatal care, particularly neonatal intensive care.
- Mental healthcare, including attention deficit disorder and other conditions with high prevalence and morbidity.

Potential Priority Areas

- Other acute care areas, particularly trauma, pain, respiratory, and cardiovascular care. (The level of agreement among participants and the availability of evidence/measures for these areas were not as strong as those for the top-priority areas.)
- Usual source of care as a population-level measure of quality.

Priority Areas Where Relevant Measures Are Needed

- Diabetes.
- Dental Care.
- Obesity.

Recommendations

Workshop participants made the following recommendations:

NQF should:

- engage immediately in national consensus projects in child healthcare quality measurement and pursue funding to standardize measures in collaboration with other organizations that are interested in the priority areas identified; and
- establish a policy to:
 - include children as a target population in all future NQF projects, or provide an explicit rationale if children are excluded; and
 - include experts knowledgeable in healthcare across the lifespan in all future NQF projects, as appropriate.

NQF projects should:

- examine each candidate measure in general measure sets to evaluate its specific implications for children, including reporting and sample size implications;
- for measure sets aimed at children's healthcare, give specific consideration to the implications of public versus private healthcare coverage (e.g., implications of health plan enrollment lapses);
- as part of meeting the goal of addressing all six aims of healthcare quality, seek out and include measures of efficiency for children's healthcare in all relevant measure sets, and do not limit efficiency measures to inpatient care;
- ensure that state Medicaid agencies are involved in vetting child-focused measure sets; and
- seek a balance between standardization (for comparable results) and flexibility (to allow states to incorporate current approaches to assessment) of data sources.

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Child Healthcare Quality Measurement and Reporting

Introduction

Measuring and publicly reporting how well healthcare providers and systems perform in delivering high-quality care is becoming a familiar activity across much of the healthcare system. Performance measurement in the realm of children's healthcare, however, is still relatively rare. Considering the importance of children's health to population health, remarkably little information about the quality of care is available to parents, policymakers, and health professionals.

The National Quality Forum (NQF) endorses voluntary consensus standards, focusing on quality measurement, and fosters their adoption and use through national, multistakeholder consensus. To date, there are relatively few NQF-endorsed consensus standards that address the health conditions, healthcare needs, and services that are of particular importance to children, despite considerable interest in such measures. (A list of NQF-endorsed standards with explicit reference to children can be found in appendix D.) During the NQF consensus development process on standardizing hospital performance measures for public reporting, for example, consumers, purchasers, and children's healthcare providers alike repeatedly voiced major concern regarding the absence of suitable quality measures of hospital care for children.

The dearth of child-specific measures in NQF's early measure standardization projects is due in part to the difficulty involved in identifying existing performance measures pertaining to children's conditions that are suitable for patient-level decisionmaking and public reporting in the topic areas addressed by these projects (e.g., hospital care, nursing home care). The relative paucity of

children's measures compared with those for adults also reflects the lower visibility of children's healthcare for most payers (as expenditures for children's healthcare are relatively low compared with spending for other groups) and the fact that health insurance and access to care have tended to be higher priorities for advocacy groups than has been quality of care. Notwithstanding these limitations, NQF convened a group of children's healthcare and quality experts to begin assessing how it could more vigorously and effectively pursue children's healthcare quality initiatives.

Workshop Overview

On January 8, 2004, NQF convened a group of 33 invited participants, including consumers, provider and health plan representatives, purchasers, researchers, and experts in children's healthcare quality, for a workshop in Washington, D.C., to seek advice on how it could begin to address the need for standardization and adoption of healthcare performance measures of particular relevance to children or to undertake other children's healthcare-related quality activities.

The purpose of the workshop was to identify the areas of children's healthcare (e.g., care settings, health conditions, age groups, or defined areas of care) for which NQF efforts would have the greatest effect in stimulating improvements in children's health, and that therefore should be the highest priority topic areas for future NQF consensus projects and related activities. Specifically, workshop participants addressed the following questions:

- What aspects of children's healthcare are especially important targets for quality reporting and improvement?
- For which of these areas is research and development in quality measurement relatively mature—i.e., there is a reasonable potential for identifying fully developed, useful measures? To what extent have such measures been identified?

- Of the identified areas, which are likely to be the most rapidly productive targets for NQF consensus efforts, and why? What are the next steps in pursuing NQF consensus in these areas?
- What other actions can and should be taken to enable future consensus and implementation of performance measures in other important areas of children's healthcare? What is needed to enhance the discussion of issues specific to children in the course of other NQF projects that address performance measures for the general population?

The workshop discussion was supported by background research conducted by Dr. Lisa Simpson and colleagues.²

Priorities and Measures in Children's Healthcare

Dr. Simpson and her colleagues reviewed the web sites of key organizations involved in healthcare and healthcare quality to determine what these organizations viewed as the most important priority areas for quality improvement in healthcare for children. They then identified the following 10 topic areas or domains: asthma; patient safety; children with special healthcare needs (CSHCN); preventive care; perinatal care; acute care; mental health; diabetes; dental care; and obesity. Finally, they gauged the availability of existing quality measures that were judged

to address needs and characteristics specific to children for each of these 10 topic areas. (See box A for a description of these characteristics.)

Box A – Unique Characteristics of Children

Development: Children have a rapid, dynamic developmental trajectory with constantly changing capabilities. This has implications for how care is measured and improved.

Dependency: Children depend on their families and communities for quality of care.

Differential Epidemiology: The diseases most commonly and severely affecting children, and the course and appropriate treatment of these diseases, are different than those for adults. As a result, targets for quality measurement are different.

Demographics: Children are the most diverse subgroup of the population ethnically, racially, and economically. The high prevalence of poverty among children leads to systems of care that are different for children than for adults, with children's care relying heavily on public funding programs.

The fact that adult health problems often have childhood antecedents (e.g., obesity) also means that improving care for these childhood conditions may merit high priority because such improvements are important in preventing adult morbidity and loss of productivity and function.

²L. Simpson, D. Dougherty, D. Krause, C. Manyan-Ku, and J. Perrin, "Measures of Children's Health Care Quality: Building towards Consensus," September 19, 2003, manuscript in preparation.

Overall, 442 quality measures that addressed 1 or more of the 10 priority domains for children’s healthcare quality were identified. Because the survey that was used focused on measures identified through quality improvement and general healthcare quality measure sources, the number of measures captured by this approach is likely to be an underestimate of the total number of child-relevant measures.³ Table 1 summarizes the general characteristics of the 442 measures: Process measures predominate, although the relative prevalence of process and outcome measures varies by healthcare topic. Of note, 21 percent of the mental health

measures were outcome measures versus 84 percent of the general primary care measures.

Although an underestimate, the identification of 442 measures in only 10 topic areas demonstrates that there is no obvious lack of quality of care measures for areas important to children’s healthcare. The perceived deficiency of child healthcare quality measures may result from disagreement among experts about the state of the science in quality measurement in this area, because information on the reliability and validity of many measures is not readily available. It also may result from a lack of coordination in quality measure development and testing. Many of the identified measures were “boutique measures” – developed in isolation for very specific purposes (often research).

Based on their classification of measures in the 10 identified priority domains, Simpson et al. arranged the domains in four tiers based on the level of activity in these areas by healthcare organizations and the prevalence of quality measures in each area. (See box B.) It was emphasized that these tiers do not necessarily indicate an area’s importance. Rather, they are a starting point for discussing which of the many important areas of children’s healthcare appear to be the subject of significant interest among healthcare organizations, as indicated by level of activity, and have a reasonable pool of existing quality measures.

Simpson et al. concluded that sufficient measures exist to warrant exploration of consensus measure sets in one or more

Table 1 – Characteristics of Children’s Healthcare Quality Measures (N=442) in 10 Priority Areas

Sector of care

- 32.6 % specific to ambulatory care
- 27.1 % specific to inpatient care
- Remaining measures applied to both and/or other settings

Type of measure (*not mutually exclusive*)

- 61.8 % process measures
- 35.1 % outcome measures
- 1.4 % structure measures

Age groups (*not mutually exclusive*)

- 25.1 % applicable to age 0 - 5
- 12.2 % applicable to age 6 - 12
- 20.8 % applicable to adolescents
- 46.4 % applicable to all age groups

Source: L. Simpson, D. Dougherty, D. Krause, C. Manyan-Ku, and J. Perrin, “Measures of Children’s Health Care Quality: Building towards Consensus,” September 19, 2003, manuscript in preparation.

³Beal AC, Co JPT, Dougherty D, et al. Quality measures for children’s health care. *Pediatrics*. 2004;113(1):199-209.

Box B – Classification Scheme for Children’s Healthcare Quality Measures

Tier 1: *High level of activities and numerous measures ready for use*

- Asthma

Tier 2: *High level of activities, but fewer measures*

- Patient safety
- Children with special healthcare needs (CSHCN)
- Preventive care
- Perinatal care

Tier 3: *Moderate level of activities and measures that are not quite “there”*

- Acute care
- Mental health

Tier 4: *Moderate level of activity and relevance, but few or no fully tested measures exist*

- Diabetes
- Dental care
- Obesity

priority areas. NQF could consider the identified measures as falling into one of the following categories: ready for NQF consideration; requires future testing and development (i.e., used and tested in research setting, but not yet widely implemented); or not suitable for NQF consideration. Greater adoption and use of quality measures for children’s healthcare would be valuable for several purposes, including:

- ensuring rapid translation of clinical research into practice;
- setting standards of participation in federally sponsored programs;
- helping parents and purchasers make choices;
- holding providers accountable for ensuring quality care;
- establishing benchmarks to stimulate quality improvement; and
- conducting ongoing national surveillance on trends in quality.

Workshop Discussion

In keeping with the objectives, discussion focused on considerations and criteria for establishing priority areas, potential priority areas, and recommendations to NQF. In addition, discussion focused on ways in which children and adolescents could be included in general healthcare improvement projects and ways in which implementation of future NQF projects relating to children could be enhanced.

Considerations in Establishing Priority Areas for NQF Activity

The 10 topic areas identified by the researchers who prepared the background paper each met 2 criteria that were fundamental for future NQF consensus activity around quality measures. First, they are areas for which there is considerable prior assessment of importance. Additionally, there is evidence of strong interest among multiple stakeholder groups. In identifying these 10 areas, the authors also considered general criteria that had been used in previous NQF discussions regarding priorities (box C). Workshop participants considered these topic areas and the criteria that underlay their identification and then focused the initial discussion on specific additional values and characteristics that should be represented by the priority areas to be recommended to NQF.

Box C – Criteria Used in Previous NQF Discussions of Priorities

- Consistent with broad-based national goals.
- Important as defined by:
 - impact on outcomes (survival, quality of life, patient preferences, costs); and
 - burden of disease, including costs.
- Represents a dimension of the patient-centered care experience.
- Improvement is possible (variability, malleability).
- Disparities/serious quality problems exist.

Condition-specific versus cross-cutting topics. Participants debated the benefits of focusing on particular conditions, which would provide the advantage of greater depth and richness of measurement, versus focusing on topics that cut across many conditions and affect a greater number of children. One concern about the former approach was that participants lacked confidence that a broad base of scientifically sound measures exists for very many of the disease conditions. Cross-cutting measures, such as infection rates, mortality, and care coordination measures, were attractive to some participants because such measures are relevant to many providers and populations beyond children. On the other hand, cross-cutting measures would not address other core issues, such as adequacy of treatment or under-diagnosis. Also, many current measures of cross-cutting topics may lose experiences specific to children if children are not sampled and analyzed separately.

Participants concluded that the set of child-specific priority areas appropriate for NQF focus should include both condition-specific and cross-cutting topics. One participant noted that it is possible to get both condition-specific and cross-cutting data at one time through some survey measures, especially if they are combined with administrative data.

Beneficial to consumers. All participants agreed that all priority areas recommended to NQF should meet the criterion of providing benefit to children and their families, and measures eventually undergoing consensus should meet that criterion as well.

Holding consumer focus groups was noted as a way to obtain more detailed information on what is important to families.

Reflect a range of age groups. Participants also noted that different programs, organizations, and measure sets define children differently. The U.S. Census defines children as age 1 through 18 years. In contrast, the American Academy of Pediatrics defines children as 0 through 21 years of age; private health insurance may cover children up to age 23.5 years if they are in college; and State Children's Health Insurance Program (SCHIP) and Medicaid programs may define eligible children variably as extending through age 18, 19, or 20 years. Participants agreed to recommend that for NQF purposes, all age groups to which a priority topic or measure applies should be considered important.

Health versus healthcare. Measures of health and health improvement do not necessarily measure healthcare performance. For example, it was noted that SCHIP has shown that the health status of 10,000 children who were followed has improved, but the measures used cannot tell us why this change occurred because none was used to pinpoint what type of care was responsible for the health improvement, what type of care effectively improves health, and which areas of care need improvement. Also, some measures apply to population-level health status, but these cannot easily be used for patient-level decisionmaking.

Participants agreed that both health status and the quality of delivered healthcare are important to measure, and it was noted

that survey measures (in which a parent or a teen is the respondent) sometimes measure both. Similarly, both preventive and therapeutic care are important to include in the scope of priority areas for NQF. Inpatient and outpatient care also should be represented.

Alignment with current initiatives.

Participants discussed several ongoing performance reporting and quality improvement initiatives and their relationship to children's healthcare. The Leapfrog Group initiative, for example, currently focuses on stimulating improvements in patient safety in hospitals through public reporting; it recently has adopted a new "leap" that incorporates the remainder of the NQF-endorsed safe practices that it had not previously included. Future NQF-endorsed patient safety consensus standards relevant to children would be more likely to be implemented as part of this initiative if they were consistent with its priorities. Two voluntary reporting initiatives in Wisconsin that involve many large multi-specialty group practices in a quality collaborative also were described.

A recent survey of the measurement and quality improvement priorities of children's hospitals found that patient safety and medication management were high priorities for comparative measures, as were newborn care and the needs of disabled and chronically ill children (CSHCN). Other areas listed as high-priority topics by hospital respondents were pediatric intensive care, pain management, hematology/oncology, respiratory systems (including asthma, which had

previously been identified as a priority), cardiovascular surgery, general surgery, neurology, neurosurgery, trauma injury, and endocrine-metabolic and digestive disorders.

Ability to address all six aims of quality, including efficiency.

Although five of the six aims of healthcare quality articulated by the Institute of Medicine are well-accepted components of healthcare quality, it was noted that one aim — efficiency — is not currently represented by measures in most quality performance measure sets, including those endorsed by NQF. Measures of economic efficiency are important to purchasers, especially in the inpatient care setting, because such a high proportion of the cost of children's healthcare occurs in this setting. Several participants pointed out, however, that the hospital setting also is the area where children are least likely to receive care. Thus, even a small improvement in efficiency in an ambulatory setting, where children receive most of their care, can have a large impact on resources and the ability to improve quality.

Adequacy of evidence underlying measures.

Participants noted that although measures exist for many children's healthcare conditions, the rigor of the scientific evidence supporting them varies considerably. Particular challenges are involved in establishing good evidence to support performance measures for care provided for developmental and behavioral issues. Participants did not attempt to agree on the particular kinds and strength of evidence that should support performance measures

for children's healthcare, but they did agree that limiting consideration to measures with evidence from randomized trials would be unduly restrictive. They also agreed, however, that attention to establishing standardized performance measure sets generally should be focused on areas where the evidence base is strong.

Summary of considerations. Participants concluded that priority areas for NQF projects on children's healthcare quality should:

- encompass both condition- and non-condition-specific healthcare domains;
- be aligned with purchaser and other initiatives when possible (e.g., the Leapfrog Group and accreditors' initiatives) to maximize implementation;
- address all sites and settings of care (e.g., inpatient, outpatient);
- span the continuum of care; and
- address all pediatric age and racial/ethnic groups.

Areas that are considered in future NQF consensus projects and other activities relevant to children's healthcare should:

- be important to families, relevant to providers, and have measures that are feasible to collect;
- include actionable measures that have the ability to identify improvements in care (i.e., not limited to health status measures);
- include patient-centered measures;
- have an existing evidence base that can be assessed; and
- consider existing measures, if already widely used, as current measures are not standardized.

These areas also may include measures from any of the three quality measurement domains (structure, process, or outcome).

Discussion of Candidate Priorities

Workshop participants discussed the 10 topic areas presented by Dr. Simpson and other topics considered important to varying degrees. Participants agreed that all were important, but focused on their assessment of the maturity of quality measurement in each area.

Asthma. Many measures of the quality of healthcare for children with asthma exist, but their use is uncoordinated. Even the definition of asthma is not standardized. The considerable amount of current asthma measure development activity in this area includes the PEDI-Q measures work by the National Association of Children's Hospitals and Related Institutions (NACHRI) and work conducted by the Child Health Corporation of America, Medical Management Planning, and the Nemours Foundation in collaboration with the Joint Commission on Accreditation of Healthcare Organizations to identify hospital-related asthma measures. NQF activity to standardize asthma measurement can help focus quality measurement and improvement for this condition.

Patient safety. Participants observed that patient safety measures are very important. Measures in hospital settings, such as those included in the Leapfrog Group initiative, inpatient medication safety, and safety issues related to perinatal care (e.g., hyperbilirubinemia) are probably the more mature measurement areas in patient safety and the most ripe for standardization. However, participants agreed that patient safety measures in other settings, if not adequately available, should be a focus of research and development.

CSHCN. There was general agreement that children with disabilities and chronic illnesses (those described as the CSHCN population under Medicaid) are an important focus of healthcare quality measurement and reporting—and measures, including well-known survey measures, exist. Coordination of care measures would be important cross-cutting measures for this population.

Preventive care. Participants viewed prevention as a very high priority for children; it was noted that most hospitalizations for young children result from conditions that are

preventable with good primary care. However, the state of measurement was assessed as highly variable, with some areas (e.g., immunization) having many evidence-based measures, but great inconsistency in measurement definitions and methods; standardization in this case would be of great benefit. In other areas of prevention (e.g., tobacco use prevention, obesity treatment to prevent disease), measures are less well developed or lack a strong evidence base and would be a good focus for more measurement research and development.

Two topics related to primary care and prevention were proposed by one or more participants as candidates for NQF activity:

- Standardize screening practices, growth charts, and injury prevention practices. Standardizing the way children's growth is recorded would be of especially great benefit.
- Establish a standardized way to measure the usual source of care. Participants agreed that having a usual source of care is a prerequisite for quality healthcare for children, although children with a usual source of care still do not necessarily receive care that is consistently of high quality.

Perinatal care. This topic was judged by participants to be consistent with purchaser initiatives and hospital priorities. Participants also agreed with the researchers that measures are available for perinatal care, perinatal patient safety, and neonatal care.

Acute care. Aside from measures related to patient safety (including infections), asthma, and perinatal care, the current state of quality performance measures in most areas of acute care for children was judged to be uncertain by workshop participants. One participant noted that patient survey-based measures for acute care provided to children could address a number of elements of interest.

Measures of the quality of trauma care provided to children were noted as acute care measures of particular interest, as many emergency visits and hospitalizations of children are related to trauma; trauma prevention is relevant to preventive care measures. Although the state of development of broadly applicable performance measures for trauma care was discussed, this area was noted as a very active one for quality improvement and the development of guidelines and measures. It appears to be an area that is promising for performance measurement and one that is of interest for further discussion.

Mental health. Mental health has a high morbidity level and high prevalence in children. Workshop participants suggested that, in addition to the outcomes-based mental healthcare quality measures identified in the background paper, a number of process measures related to children's mental health and substance abuse also exist.⁴ Participants generally agreed that children's mental healthcare appeared to have a sufficient pool of measures to benefit from NQF activity.

⁴ An inventory of mental health and substance abuse quality measures can be found at the web site of the Center for Quality Assessment and Improvement in Mental Health (www.cqaimh.org). In addition, measures of interpersonal aspects of mental healthcare for children have been developed by the Mental Health Statistics Improvement Project and the Children and Adolescent Mental Health Initiative.

Diabetes, dental care, and obesity.

Participants agreed that although measures for adult diabetes care are well established, comparable measures for children are few, and the topic needs additional measure development before an adequate set of child diabetes care measures can be established. Dental care for children faces a similarly inadequate number of existing performance measures, despite its importance for children. Measures of quality of care for addressing obesity do not yet exist.

Coordination of care. Participants repeatedly noted that coordination of care was an important focus for quality measurement and NQF activity. Although care coordination is a critical component of quality for most of the other topic areas discussed, participants believed that it was an important focus for quality measurement and, to the extent that measures exist, an NQF consensus activity in its own right.

Recommended Priority Areas

Workshop participants recommended the following areas as priorities for NQF activities related to children's healthcare quality measurement and improvement:

Top Priorities:

- Asthma.
- Patient safety, particularly in inpatient settings.
- CSHCN, including both condition-specific (e.g., cystic fibrosis) and non-disease-specific (e.g., coordination of care) measures.
- Preventive care, including (but not limited to) immunization, injury prevention, and avoidable hospitalization.
- Coordination of care (both as a priority itself and as a measurable component of other priority areas).
- Perinatal care, particularly neonatal intensive care.
- Mental healthcare, including attention deficit disorder and other conditions with high prevalence and morbidity.

Potential Priority Areas: The following additional areas were discussed by participants as possible priority areas, but formal agreement on them was not reached during the workshop:

- Other acute care areas, particularly trauma, pain, respiratory care, and cardiovascular care (the level of agreement among participants and the availability of evidence/measures for these areas were not as strong as those for the top-priority areas).
- Usual source of care as a population-level measure of quality.

Priority Areas Where Relevant Measures Are Needed:

Workshop participants found that although the following areas are of high priority for improving children's healthcare, further development and testing is needed of the relevant quality measures.

- Diabetes.
- Dental care.
- Obesity.

Conclusions and Recommendations

Over the course of the workshop, participants repeatedly noted the importance of determining how to ensure that children do not remain a neglected population in national quality measurement debates. In discussing the strength of a recommendation to NQF in this regard, participants agreed that the results of the workshop should include language specific to the importance of giving particular attention to children as a distinct population with unique characteristics and healthcare needs, although ideas regarding the preferred wording differed.

Workshop participants concluded the following:⁵

- Measures of the quality of healthcare that are meaningful for adults cannot be assumed to have the same applicability to healthcare for children. Children differ fundamentally from adults in their development, dependency, epidemiology, and demographics.
- Sufficient work on quality measurement exists in a number of child healthcare priority areas to support national agreement on and implementation of quality measures relevant to children.

⁵During the course of the workshop, participants made additional recommendations for NQF consideration as it undertakes consensus projects related to measuring children's healthcare quality or when in other projects it considers measures that may affect children: ensure that state Medicaid agencies are involved in vetting any measure sets focused on children, as Medicaid programs have a strong interest in but some concerns separate from other stakeholders, such as lack of continuity in program administrative data due to enrollment lapses; seek out and include measures of child healthcare efficiency in all relevant measure sets; do not limit measures to inpatient care; examine each candidate measure in general measure sets to evaluate its specific implications for children, including reporting and sample size implications; for measure sets aimed at children's healthcare, give specific consideration to the implications of public versus private healthcare coverage (e.g., implications of health plan enrollment lapses); seek a balance between standardization (for comparable results) and flexibility (to allow states to incorporate current approaches to assessment) of data sources; and consider undertaking a project to standardize the methods for collection of data for child growth and development. Workshop participants also reached the following general conclusions regarding performance measurement for children's healthcare, although these conclusions were not directed to NQF: there is a great need to establish a method for state program staff to share information, across both programs and states, regarding child healthcare quality measurement and quality improvement efforts; and strategies for collecting data that support measurement should improve efficiency for survey-based data collection, build on automated data capabilities, reorient current data collections to be "kid friendly," and address data issues unique to child healthcare (insurance data, given enrollment lapses).

Based on these conclusions, participants recommended that NQF:

- engage immediately in national consensus projects to standardize child health-care quality measurement and pursue funding incorporating current national initiatives in each of the priority areas identified during this workshop;
- include children (of all age groups) in all future NQF projects, or provide an explicit rationale for their exclusion; and
- include experts knowledgeable about healthcare across the life span in all future NQF projects, as appropriate.

Acknowledgments

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Appendix A

Workshop Participants and Project Staff

Workshop Participants

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Appendix B

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Appendix C

Agenda—Workshop on Child Healthcare Quality Measurement and Reporting

WASHINGTON, DC

THURSDAY, JANUARY 8, 2004

- 9:00 a.m. Overview and purpose**
 - Introductions
 - Overview of prior NQF work and relation to child healthcare
 - Purpose of the workshop
- 9:30 a.m. Priority topic areas for child healthcare quality improvement**
 - Objectives/issues
 - Summary of review findings
 - Responses and additional findings
 - Discussion of selection criteria and priority areas
- 10:30 a.m. Break**
- 10:45 a.m. The measurement landscape in high-priority areas**
 - Objectives/issues
 - Summary of review findings
 - Responses and additional findings
 - Discussion of availability of appropriate measures
- 12:00 p.m. Public comment**
- 12:30 p.m. Lunch (workshop participants and NQF staff)**
- 1:30 p.m. Discussion and recommendations**
 - Priority areas in child healthcare quality for NQF consensus
 - Other child healthcare quality measurement and reporting issues
- 3:00 p.m. Public comment**
- 3:15 p.m. Action plan/next steps**
- 3:30 p.m. Adjourn**

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Appendix D

NQF-Endorsed Voluntary Consensus Standards with Explicit Reference to Children*

Serious Reportable Events

- Infant discharged to the wrong person.
- Death or serious disability, including kernicterus, associated with failure to identify and treat hyperbilirubinemia in neonates during the first 28 days of life.

Hospital Performance Measures

- Use of relievers for inpatient asthma (*pediatric population only*).
- Use of systemic corticosteroids for inpatient asthma (*pediatric population only*).
- Neonate immunization administration.
- Neonatal mortality (risk adjusted).
- Urinary catheter-associated urinary tract infection (UTI) rate for intensive care unit (ICU) patients (*specifically includes pediatric ICUs*).
- Central line catheter-associated blood stream infection rate for ICU patients (*specifically includes pediatric ICUs*).
- Ventilator-associated pneumonia rate for ICU and high-risk nursery patients (*specifically includes pediatric ICUs and high-risk nurseries*).

N.B. A number of hospital performance measures explicitly **exclude** some or all pediatric age groups.

* Endorsed as of December 2003

Safe Practices

- For designated high-risk, elective surgical procedures or other specified care, patients should be clearly informed of the likely reduced risk of an adverse outcome at treatment facilities that have demonstrated superior outcomes and should be referred to such facilities in accordance with the patient's stated preference ("other specified care" includes diagnosis of low birth weight, expected premature delivery, or delivery with correctable major congenital anomaly).
- All patients in ICUs (both adult and pediatric) should be managed by physicians having specific training and certification in critical care medicine (critical care certified).

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