

THE NATIONAL QUALITY FORUM

NOTICE OF INTENT TO SUBMIT STANDARDS NATIONAL VOLUNTARY CONSENSUS STANDARDS FOR PATIENT OUTCOMES: CHILD HEALTH

NQF is initiating a consensus development project seeking endorsement of additional outcome measures for children.

NOTICE TO MEASURE STEWARDS

If, after reviewing this Notice of Intent, your organization believes it has one or more measures that address the scope and objectives of this project as described below and would like NQF to evaluate them for possible endorsement, please submit a [notice of intent to submit candidate standards](#) Wednesday, December 23, 2009. Instructions for submitting this information are given at the end of this document.

BACKGROUND

To achieve quality healthcare across the full continuum, there is a need for additional measures that specifically address various child health outcomes to which our nation's healthcare system contributes. Many outcome measures are inherently relevant because they reflect the reason consumers seek healthcare (e.g., to prevent disease, improve function, decrease pain, survive), as well as reflect the result healthcare providers are trying to achieve. To date, NQF has endorsed a few outcome measures across all ages, typically focused on mortality, readmission, and complications. However, a major gap remains for more patient-focused outcomes, such as patient or parent-reported health-related quality of life, functional status (e.g., ambulation) and productivity (e.g., days missed from school). These cross-cutting measures have the advantage of applicability across a wide range of patients across conditions and complement disease-specific outcomes. The outcomes measures should reflect - at least in part -- the care provided by the health care system in any or all settings, such as hospitals, skilled nursing facilities, home health, and ambulatory (including non-traditional sites such as school based health centers), as well as across patient-focused episodes.

SCOPE OF ACTIVITIES

To enlarge NQF's portfolio of outcome measures for children, NQF is soliciting outcome measures for child health (ages 0-21 years) applicable to any healthcare setting; applicable to any level of analysis (e.g., system, plan, practice, community); any or all settings of health care delivery; individual or composite measures; and use any data source(s). Measures that assess the entire population of a practice, plan, system or community are particularly desirable. Candidate outcome measures may be cross-cutting or condition/disease specific including, but not limited to, measures of:

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- child and family functioning, including maintenance and improvement in functioning and attaining optimal functioning (ex: school attendance and performance, physical fitness);
- symptom improvement or relief (ex: pain control; asthma control; reduced hyperactivity/impulsivity);
- growth and development (physical, cognitive, social, emotional), (ex: meeting age appropriate developmental milestones, transition to adulthood);
- patient or parent¹ reported outcomes using standardized health status or health-related quality of life assessments (physical, cognitive, emotional, social);
- intermediate clinical outcomes (ex: blood pressure; BMI percentile; HgbA1c);
- patient or parent/family experience with care (satisfaction, shared-decision making, capacity for self-management);
- behavioral change (ex: smoking cessation; medication adherence; seat belt use; reduced high-risk behavior);
- health care services utilization as a proxy for change in status (ex: unplanned admission or re-admission, ED visits);
- potentially preventable adverse social outcomes (e.g., incarceration)
- clinical morbidity from disease progression or intervention (ex: graft versus host; neurological impairment after heart surgery; chemotherapy side such as procedural pain);
- healthcare-acquired adverse event or complication (non-mortality);
- survival/mortality; and
- population health indicators, such as, suicide, STIs, rates of congenital HIV, rates of child abuse, infant mortality, etc. Consider, for example, the following populations:
 - populations with specific diseases (chronic conditions, disabilities, special needs);
 - disparities-sensitive populations (e.g., race, ethnicity, geographic); and
 - populations of children in which the health care sector shares responsibilities with others. These could include, for examples, students of a particular school or district, children and youth in the juvenile justice system, and children in custody of child welfare agencies.

¹ The term “parent” includes parent surrogates and caregivers.

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THE NQF PROCESS

The candidate measures will be considered for NQF endorsement as voluntary consensus standards. Agreement around the recommendations will be developed through NQF's formal Consensus Development Process (CDP). This project will involve the active participation of representatives from across the spectrum of healthcare stakeholders and will be guided by a Steering Committee.

Any organization or individual may submit measures for consideration. To be evaluated, candidate consensus standards must meet the following general criteria:

- Be fully developed for use (e.g., research and testing have been completed);
- Be intended for use in both public reporting and quality improvement;
- Be open source or in the public domain²; and
- Have an identified measure steward³.

Measure stewards must also have a fully executed Measure Steward Agreement with NQF. Information on submitting measures to NQF can be found on the NQF website.

FUNDING

This project is supported under a contract provided by the Department of Health and Human Services.

MEASURE STEWARDS: NOTICE OF INTENT TO SUBMIT CANDIDATE STANDARDS

Measures stewards anticipating submission of candidate measures to NQF for this project should submit a notice of intent. A Microsoft Word document containing a list of measures should be sent to outcomes@qualityforum.org no later than **Wednesday, December 23, 2009 at 6 p.m. ET**. This list should include:

- Title and description of the measure;
- Organization (indicate whether developer or steward); and
- Contact person (name, e-mail address, and telephone number)

¹ NQF requires any non-government organization submitting a measure for endorsement to execute a Measure Steward Agreement that addresses intellectual property protection and disclosure of the measure's proprietary components, including but not limited to specifications, risk adjustment methodologies, data collection instrument, data collection or analysis software, and database access. For details, please see our [Policy on Endorsement of Proprietary Measures](#).

² NQF requires any measure considered for endorsement to have an identified responsible entity and process to maintain and update the measure on a schedule commensurate with clinical innovation, but at least every 3 years. Measure stewards must execute a [Measure Steward Agreement](#) with NQF.

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CONTACT INFORMATION

For more information, contact Melissa Marinelarena at (202) 783-1300 or via e-mail at outcomes@qualityforum.org.

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