



SPAN
35 Halsey Street 4th Floor
Newark, NJ 07102
(973) 642-8100
(973) 642-8080 - Fax
E-Mail address: span@spannj.org
Website: www.spannj.org

Statewide Parent Advocacy Network, Inc.

Empowered Families: Educated, Engaged, Effective!

Family Voices-NJ Comments to the National Quality Forum:
Partnership for Applying Measures to Improve Quality
To Provide Input on Measure Selection for Public Reporting and Payment Programs

6/14/10

Thank you for the opportunity to comment on the proposed document “Establishment of a Partnership for Applying Measures to Improve Quality: To Provide Input on Measure Selection for Public Reporting and Payment Programs.” Family Voices is a national network that advocates to “keep families at the center of children’s health care,” with a special focus on behalf of children with special healthcare needs and their families. Our NJ Chapter is housed at the Statewide Parent Advocacy Network (SPAN), NJ’s federally funded Parent Training and Information Center which is also NJ’s Family-to-Family Health Information Center and a chapter of the Federation of Families for Children’s Mental Health. The Family Voices Coordinator also serves as the NJ Caregiver Community Action Network representative for National Family Caregivers Association in a volunteer capacity. Our comments are as follows:

In general we understand that the Patient Protection and Affordable Care Act (PPACA) has new requirements for multi-stakeholder input assigning new duties to the consensus-based entity, and that the National Quality Forum (NQF) is a consensus-based entity under Health/Human Services (HHS) and may additionally be asked to act in a consultative capacity “as a neutral convener.” We appreciate that the “consensus-based entity...is not charged with making recommendations to the Secretary, so that Partnership...substantive recommendations will not flow through the NQF Board...” We agree that “a mechanism for the NQF Board to address issues raised about the Partnership’s processes will need to be established.”

Activities of a Partnership for Applying Measures to Improve Quality

We agree that “public reporting and payment programs are construed expansively” and should cover “Medicare payment...HHS public reporting, etc.” We agree that the definition of “multi-stakeholder group” is a “collaborative of organizations representing a broad group of stakeholders” and would suggest this must include consumers and consumer groups, and particularly organizations that represent the interests of those at greatest risk of poor quality healthcare and disparate health outcomes, i.e., patients with disabilities and/or special healthcare (including mental health) needs, immigrants, speaking languages other than English, with low and moderate incomes, etc.

We strongly support that starting with 2011, HHS will “make available to the public a list of measures...being considered.” We also agree that, starting in 2012, “the entity must transmit the pre-rulemaking input of the multi-stakeholder groups to HHS,” including input to the Reporting Hospital Quality Data for the Annual Payment Update program (RHQDAPU) and the Physician Quality Reporting Initiative (PQRI).

The document states “in the longer term” it would include input on “hospital readmissions reduction” and “payment adjustment for conditions acquired in hospitals.” We would suggest however, that these should be done initially in keeping with best practices for health outcomes, including the Medicaid discontinuance of reimbursement for medical errors. The plan also relegates in the long term key issues such as the medical home (Medicare), accountable care organizations, and bundled payment approaches. We strongly urge the Partnership to begin work as soon as possible on the Medicare pilot demonstrations for the medical home, as the medical home has the potential to both reduce unnecessary expenditures and more importantly result in better health outcomes, particularly for children and youth with special healthcare needs and their families. We feel that bundled payment approaches will enhance the medical home and can be utilized under PPACA funding for Health Information Technology (HIT). Indeed, at our recent NJ Statewide Health Care Reform Implementation Conference 6/8-9, ACOs (Accountable Care Organizations) were seen as a key ingredient for both cost quality and health equity.

We were pleased to see that the new statute requires HHS “to publicly report performance information through standardized websites”. We were pleased to see that this information will meet the needs not only of hospitals, health care providers, researchers, and policymakers but most importantly patients and other consumers. As an organization that works extensively with families who speak languages other than English, it is critical that the “standardized websites” provide access to those with limited English proficiency as well as limited literacy. Further, consideration must be given to ensuring availability of performance information for those with limited or no access to the web at home, through partnerships with libraries, community-based organizations, schools and community colleges, as well as through availability of hard copies.

Key Considerations in Establishment of a Partnership for Applying Measures to Improve Quality

Involvement of stakeholder groups: We agree that there must be coordination between current activities of “quality alliances and the new activities of the Partnership...to avoid duplication of efforts.” We support the notion that the alliances will be asked for “nominations of members to serve on the Partnership and for comment on the selected members and comment on recommendations to HHS.” We would hope that the alliances would solicit prospective members on a widespread basis from a variety of external consumer advocacy groups, including in particular those representing communities who face the greatest health disparities. In addition, it would be important to include representatives who work at all levels – national, regional, state, and local – because the application of quality measures impacts each of these levels differently. These diverse perspectives would strengthen the final recommendations.

Transparency and due process: Again, we support that “public nominations must be sought for members of the multi-stakeholder groups, and public comment must be sought on member selections.” We strongly support the notion that meetings “will be publicly announced and convened in open session...Summaries of deliberations will be publicly available in a timely manner...Public comment will be sought on recommendations.” We would urge the continued availability of comments online and recommend that meetings also be broadcast as webinars or telephone conference calls to maximize accessibility to the larger public.

Analytic support for evidence-based decision making: We agree that both in-depth and quick turnaround analyses must be available. We support but are not limited to the examples of 1)an in-depth RAND project that is currently in use which includes ACOs, medical home, bundling, etc. (also support others like Mathematica, Kaiser, RWJ studies etc.); 2) the ECRI Technology and Planning Assessment due to their evidence based experience in researching medical procedures/devices/drugs and patient outcomes; as well as the 3) CHBRP (Californian Health Benefits Review Program “to provide an independent analysis of the medical, financial, and public health impacts of proposed health insurance benefits, mandates, and repeals.”

Flexible structure: We strongly support the 2 tier approach which includes the Patient-Focused Coordinating Committee as well as the “multi-stakeholder work groups addressing measures for specific care providers.” We agree that the Patient-Centered Coordinating Committee would focus on “measures needed for public reporting and payment approaches...” We would suggest collaboration with the Patient Centered Primary Care Collaborative found at www.pcpcc.net as well as the national center for medical home housed at the American Academy of Pediatrics. We strongly support the Patient-Centered Coordinating Committee addressing “shared accountability and care coordination” and highly recommend approaches like “Take Charge of Your Health” (see <http://patienteducation.stanford.edu/programs/cdsmp.html>) and Health Dialog (see www.healthdialog.com/Main/PersonalHealthCoaching/SharedDecisionMaking).

Thank you again for the opportunity to comment on the NQF proposed guidelines on Establishment of a Partnership for Applying Measure to Improve Quality.

Sincerely,

Lauren Agoratus, M.A.-parent
NJ Coordinator- Family Voices at the Statewide Parent Advocacy Network
NJ Caregiver Community Action Network-Nat'l Family Caregivers (volunteer)
35 Halsey St., 4th Fl., Newark, N.J. 07102
(800) 654-SPAN ext. 110
Email familyvoices@spannj.org
Website www.spannj.org

Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.