



We write today to urge you to include children's health care, broadly conceptualized, in your research agenda.

In order to develop our recommendations, we convened a policy advisory group consisting of both NICHQ senior staff and key external advisors from a broad set of organizations with deep expertise in children's health care and public policy. The committee quickly came to a number of major recommendations for the Committee's consideration:

- 1) At least three compelling arguments call for including children's health care as a significant focus of the comparative effectiveness research agenda:
 - a. children particularly depend on public sources of funds for their health care (Medicaid, SCHIP),
 - b. the consequences of poor health and health behaviors in childhood have long term, costly implications, and
 - c. the research base for child health has been historically under-funded.
- 2) The topics for emphasis for comparative effectiveness research in child health should reflect the unique characteristics of child health and children's health care, specifically, their
 - a. Dependency on others, leading to the importance of supporting parental capabilities,
 - b. Rapid pace of development, leading to the key role of developmental surveillance and preventive care,
 - c. Distinct epidemiology, i.e., the increasing prevalence of a few highly significant chronic conditions such as obesity and asthma and mental health, coupled with the cumulative significance of a large number of relative rare conditions, and
 - d. Relative economic disadvantage and cultural diversity
- 3) Relative economic disadvantage and cultural diversity Considering these characteristics, the scope of comparative effectiveness for children should extend beyond the medical system to include all areas where children live, learn and grow with a focus on assessing how they can best promote and maintain child health.
- 4) The comparative effectiveness agenda for children should build on the excellent work of previous Institute of Medicine Committees. We recommend the comparative effectiveness research agenda draw from the pediatric priorities articulated by the IOM

Committee that established Priority Areas for National Action. Relevant child health topics on this list included:

- Care coordination (cross-cutting)
- Self-management/health literacy (cross-cutting)
- Medication management—preventing medication errors and overuse of antibiotics
- Children with special health care needs
- Asthma—appropriate treatment for persons with mild/moderate persistent asthma
- Immunization—children and adults
- Major depression—screening and treatment
- Nosocomial infections—prevention and surveillance
- Pregnancy and childbirth—appropriate prenatal and intrapartum care
- Obesity

The key points we would emphasize in considering this list are:

- a) A focus on cross-cutting themes (care coordination, family and self management support).
- b) Consideration of children with special health care needs as a whole, as many of the issues in management (role of family, organization of services) are cross-cutting, as are many clinical issues (e.g., appropriate use of g-tubes or muscle lengthening procedures).
- c) Attention to improving birth outcomes—and, correspondingly, care in pre-conception, prenatal, intrapartum and newborn care—as these are the biggest drivers of infant and maternal mortality and responsible for substantial health care cost as well.
- d) Attention to children’s mental health, both preventive and therapeutic, especially given the apparent growth in prevalence and long-term implications of mental health conditions.
- e) A continued focus on both prevention and treatment of childhood obesity as this is increasingly a major driver (with smoking) of poor health outcomes.
- f) A particular focus on addressing conditions relevant to populations experiencing disparate health outcomes (e.g., sickle cell disease, obesity, asthma, mental health).

We also urge a broad conceptualization of comparative effectiveness research. Comparisons of clinical treatments are necessary and valuable; comparisons of models of practice, care financing, information systems, population-based strategies, and practice supports and the like are also crucially important to arrive at a more effective health care system for children and all Americans. Parents, patients and other consumers should be involved in the formulation, prioritization and communication of this research.

We, the undersigned (CEO of NICHQ and members of Policy Advisory Committee), are extremely supportive of a strong program of comparative effectiveness research and want to make sure that children can also benefit from this new and exciting endeavor. We are available to offer advice in prioritizing areas of children's health comparativeness effectiveness with you.