

Department of Research Abstracts

U.S. & CANADIAN PEDIATRIC CLINICAL RESEARCH NETWORKS: ENUMERATION, CHARACTERIZATION, & POTENTIAL FOR ALLIANCE Eric J. Slora, Donna L. Harris, Alison B. Bocian, Richard C. Wasserman. PROS, Department of Research, American Academy of Pediatrics, Elk Grove Village, IL; Department of Pediatrics, University of Vermont, Burlington, VT. **Presented at the May 2009 Pediatric Academic Societies Annual Meeting.**

BACKGROUND: Pediatric clinical research networks (PCRNs) have a 50-year record of advancing pediatric care, but have been poorly described and inadequately characterized. While PCRNs face many common challenges in multi-institutional collaborative research, no attempts have been made at cross-network alliance.

OBJECTIVE: To enumerate and characterize U.S. and Canadian PCRNs, and assess their interest in allying with one another.

DESIGN/METHODS: Internet searches and consultations with research professionals were used to identify PCRNs. Identified PCRN leaders were approached via email to complete a survey describing their network and selected characteristics (e.g., network longevity, funding sources, productivity, study topic areas & designs), and perceived benefits of an alliance of PCRNs.

RESULTS: Seventy-five PCRNs exclusively devoted to pediatric research were identified (88% US-based). Of these 75 networks, 51 (68%) responded to the survey. Among respondents, 53% were specialist (e.g., neonatology, critical care), 26% general or primary care, and 22% disease-specific PCRNs (e.g., cancer, diabetes). Geographically, 41% of networks were international, while 33% were national and 22% regional. Overall, 88% indicated one or more sources of network infrastructure funding including federal government (63%), charitable foundation (26%), university (16%), and professional society (12%), with 31% of networks having multiple sources. PCRNs conduct a wide variety of study types, most commonly observational (82%) and interventional (63%). With respect to longevity, only 17% of PCRNs are >20 years old, and over one third were founded after 2000. Although 84% of networks currently are collecting data, 49% have conducted 5 or fewer studies. Seventy-six percent of PCRNs favor participation in a PCRN coalition. Respondents cited collaborating on potential studies (59%), advocating for PCRNs (57%), addressing IRB issues (49%), sharing strategies for recruitment (47%), and generating ideas for policy making (45%) as potential benefits.

CONCLUSIONS: Although some PCRNs have had decades of activity, many are relatively young, and nearly half lack extensive project experience. The overwhelming majority of PCRNs perceive multiple benefits in a continuing, multidisciplinary alliance to advance the PCRN field.

