

Summary and Status/Outcome of Activities Quick Strike 1- Research Project

Children with Complex Health Conditions: Let's Learn Who They Are and How to Serve Them!

Summary

In August 2015, a research team, led by Shelley Doucet, PhD, UNB-Saint John, Rima Azar, PhD, Mount Allison University, and William Montelpare, UPEI, secured an operating grant from CIHR (\$100,175) under the SPOR PIHCI Quick Strike Program. Matching funds were also obtained from the New Brunswick Children's Foundation. The Quick Strike Project was entitled "Children with Complex Health Conditions: Let's Learn Who They Are and How to Serve Them! The overall purpose of the research was to improve health care for children with complex health conditions and their families. This was a qualitative descriptive study guided by four research questions:

Q1: How are children with complex health conditions (CCHC) defined?

Status/Outcome: Led by Dr. Rima Azar. A concept analysis and literature review was conducted. Publication is a work in progress and will be submitted to the Journal Acta Paediatrica.

Q2: What are the needs of CCHC and their families?

Status/Outcome: Qualitative interviews and focus groups were conducted with families and stakeholders in New Brunswick and Prince Edward Island to identify needs, services available and barriers to accessing services. The stakeholders included social, education, and health stakeholders. In NB, this included 19 families and 67 stakeholders, and for PEI, there were 13 families and 21 stakeholders interviewed. Barriers to accessing services included service gaps in mental health services, rehabilitation and other service areas, policy barriers, as well as challenges with care coordination, navigation, and resources. The findings will inform new and existing integrated and innovative service delivery models for CCHC and their families. The results were published in the Journal of New Brunswick Studies (i.e. "Falling Through the Cracks: Barriers to Accessing Services for Children with Complex Health Conditions and their Families in New Brunswick". A Protocol paper for the overall study was also published.

Q3: What services & programs are available to address the needs of CHCC and their families?

Status/Outcome: An environmental scan was conducted in NB and PEI to develop an inventory of existing government and community-based programs and services available to children with CCHC and their families. A standardized data collection tool was used, with the following data fields: description of services, eligibility criteria, languages in which services are provided, referral requirements, potential costs for the service, areas served, and website/ contact information. The environmental scan was completed using website searches and personal telephone contact, and as per their request, was provided to stakeholders in the PEI Health System for their use.

Q4: What information is gained by applying a comprehensive algorithm about CCHC to administrative data sets?

Status/Outcome: Led by Dr. William Montelpare. The availability of epidemiological data to identify and classify CCHC and to inform program development has been limited. A standardized algorithm, the Pediatric Medical Complexity Algorithm (PMCA) is being applied to physician billing data for pediatric patients ages 0-19 years who had a physician visit between April 2012 and March 2015. The PMCA classifies children into 3 levels of medical complexity: children with complex chronic disease (C-CD), non-complex chronic disease (NC-CD), and no chronic disease (N-CD) (Simon et al., 2014). This work is in progress.

Over 700 chart audits were completed in the Spring and Summer of 2016. The chart audits reviewed charts of pediatric patients ages 0-19 who were referred to pediatricians during the period April 1, 2012 to March 31, 2015 in PEI (2 sites) and NB (2 sites). Chart audits provide epidemiological assessments of disease conditions and document healthcare utilization and referral patterns. The chart audit data are currently being analyzed. It is anticipated that a paper reporting on the results of the algorithm and chart audit will be submitted for publication at a future date.

Scoping Review

During the course of the study, the research team also began a scoping review of the use of environmental scans in health services. A protocol paper was prepared and submitted but not accepted. It will be revised and re-submitted.

Papers Published to Date from Quick Strike 1

- Doucet, S., Nagel, D.A., Azar, R., Montelpare, W., Charlton, P., Hyndman, N., Luke, A., & Stoddard, R. (2017). A mixed-methods Quick Strike research protocol to learn About children with complex health conditions and their families. *International Journal of Qualitative Methods* 16, 1-12.
- Charlton, P., Azar, R., Luke, A., Doucet, S., Montelpare, W., Nagel, D.A., Hyndman, N., & Thompson, K. (2017). Falling through the cracks: Barriers to accessing services for children and families with complex health conditions in New Brunswick. *Journal of New Brunswick Studies* (in press)