

Title: Complex Care for Kids Ontario (CCKO): A Province-Wide Integrated Care Intervention for Children with Medical Complexity (CMC) using a Patient-Engaged Evaluation Framework

PI: Nora Fayed

Lay Summary

Complex Care for Kids Ontario (CCKO) is a strategy implemented by the Provincial Council of Child and Maternal Health (PCMCH) to help improve care for children with medical complexity (CMC) and their families. CMC are defined by complex health needs and the high burden of care for their families and the health care system. CCKO brings together government agencies, researchers, health workers, and patient-families to develop a health care strategy with the objective to make care more effective and efficient. In addition, the strategy aims to improve service delivery, health, and quality of life for the patient-families involved.

The CCKO Strategy will be implemented across the province beginning July 2016. Care coordination is at the centre of the strategy. This means having one clinician, (like a nurse practitioner) working side-by-side with the child and family to connect them to the right care, in the right place, at the right time. This responsible person is called a ‘key worker’. The key worker will create a plan for each patient-family’s care, as well as make sure all the health care workers involved with the child are aware of the plan and able to follow-up their care accordingly.

In order to know if the work of the key worker is effective, we need to get parents of the children involved at all the steps and stages. Patient-families have already provided feedback about how they want the key workers to coordinate their care. The patient-families also determined the criteria by which to assess whether the key worker and the care plan are working for them through an “evaluation framework”. This framework was created in the fall of 2015; over 100 families and health and service providers determined what the top priorities for the impact of the key worker should be.

The project will test whether key workers from the CCKO Strategy and their care plans are having an impact according to the framework. We will also get feedback from patients, the key workers, and the health care providers about the strengths and challenges of the strategy for future steps.