Presenting Author Name
Mateja Carevic

Presenting Author Category
Non-Trainee

Research Category
Community Health / Policy

Abstract Title
RareKids-CAN: Building a Knowledge Mobilization and Synthesis Platform for Pediatric Rare Disease Clinical Trials

Background
Rare diseases (RDs) affect 6–8% of the population, with most presenting in childhood. In Canada, children with RDs face diagnostic delays, limited treatments, and high healthcare costs. To address these challenges, RareKids-CAN: Pediatric Rare Disease Clinical Trials and Treatment Network was established. A central component is the Knowledge Synthesis and Mobilization sub-platform, designed to accelerate access to evidence and improve pediatric RD clinical trial participation and experiences.

Objective
The sub-platform pursues six objectives: (1) foster collaboration across parents, clinicians, researchers, and knowledge translation experts; (2) synthesize existing evidence on families' knowledge needs regarding pediatric RD clinical trials; (3) identify information needs and barriers experienced by healthcare providers and researchers; (4) understand parents' experiences and decision-making challenges; (5) co-create tailored resources such as website content, decision aids, and educational tools; and (6) evaluate these resources for usability, accessibility, and engagement.

Methods
The sub-platform includes 12 members, representing parent partners, pediatric clinicians, researchers (neurologist, clinical scientist, nursing faculty, PhD student), and communication specialists. Members meet quarterly to review activities, provide strategic guidance, and support resource development. A scoping review is underway to map parental knowledge needs. Semi-structured interviews are being conducted with healthcare providers, researchers, and allied professionals to identify gaps and barriers. A qualitative study with parents is planned to explore lived experiences and decision-making. All findings will inform the co-creation of knowledge mobilization resources, refined iteratively through feedback and formally evaluated.

Results
Preliminary findings reveal significant gaps in the literature and emphasize the need for tailored, high-quality resources in the Canadian context. Dissemination will occur through peer-reviewed publications, conferences, and network collaborations.

Conclusion
By connecting research, clinical, and family communities, RareKids-CAN enables identification of knowledge gaps and co-creation of solutions. This initiative aims to improve access to trustworthy information, enhance informed decision-making, and ultimately improve outcomes for children with rare diseases.

Authors

Name	Role	Profession
Mateja Carevic	Presenting Author	Knowledge Broker
Terry Klassen	Co Author	Head of Pediatrics Department
Annie Mabbot	Co Author	PhD Student
Amanda-Doherty-Kirby	Co Author	Parent Partner
Homira Osman	Co Author	Pediatric Neurologist
Lisa Knisley	Co Author	Assistant Professor