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Presenting Author Category

Non-Trainee

Research Category

Clinical

Abstract Title

First Nations youth and family engagement in youth-onset type 2 diabetes research: The iCARE cohort

Background

Meaningful collaboration between First Nations youth and families, health researchers, and clinical practitioners is essential to address ongoing health inequities resulting from policies and practices that systemically and systematically disadvantage First Nations. In Manitoba, rates of youth-onset type 2 diabetes (T2D) are the highest in the world, with First Nations youth being disproportionately affected, and at risk of early complications.

Objective

Established in 2012, improving renal Complications in Adolescents with T2D through REsearch (iCARE) focuses on holistic understandings of kidney disease as a complication of youth-onset T2D. Since 2015 the iCARE research team has included a group of young people (80% First Nations) living with T2D, family, and community members known as the iCARE Participant and Family Advisory Group (PAG). While partnerships like this are increasingly recognized as best practice, many areas of research on chronic health issues where First Nations are overrepresented lack expertise from people with lived experience.

Methods

This group meets quarterly, with additional project-specific working groups and one-on-one collaborations. The PAG bringing unique expertise, ensuring that iCARE research priorities, hypotheses, methods, analyses, interpretation, and knowledge mobilization are relevant to First Nations youth and families. This collective is characterized by meaningful relationships, power sharing, and reciprocal collaboration, including co-creation of priorities, questions, materials, with co-authorship, and co-presentation of findings.

Results

Presented collaboratively by PAG members and research staff, this poster will showcase key project priorities guided by the PAG, changes in project direction, and knowledge mobilization materials co-created by the iCARE PAG. A key patient priority of the PAG has been the importance of stress and mental health as a crucial comorbidity impacting outcomes of youth-onset T2D. This priority led to the implementation of a pilot mental health skills program (Dialectical Behavioral Therapy) to support youth living with T2D, and a collaborative community-based adapted group, co-facilitated by an Anisninew community knowledge holder and a professional with training in clinical psychology.

Conclusion

The ongoing success of the iCARE cohort study and the associated projects and findings is in large part due to the meaningful and reciprocal research partnership with the PAG. While each area of pediatric health research is unique, the iCARE PAG model serves as replicable model for application across other health and basic science research programs.

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