



Canadian Collaboration for Child Health: Efficiency and Excellence in the Ethics Review of Research

Collaboration pancanadienne pour la santé des enfants: Efficacité et excellence dans la révision éthique de la recherche

NEWSLETTER

The Canadian Collaboration for Child Health: Efficiency and Excellence in the Ethics Review of Research (CHEER) is a Canada-wide initiative on a mission to improve child health by streamlining research ethics review for child health research.



October 2025

Led by Clinical Trials Ontario (CTO) and the Maternal Infant Child and Youth Research Network (MICYRN), the goal of the CHEER project is to streamline the research ethics review process for multi-site child health studies across Canada with the aim of a single research ethics review.





CHEER ASSENT PROJECT

The CHEER Pan-Canadian Working group decided to prioritize assent materials. This will be one of the legacy items of CHEER that we hope will serve the paediatric research community. The working group decided that assent materials created should be engaging and informative. These materials are intended to facilitate the assent conversation and compliment the consent form.

To develop the materials, a literature review was completed to identify themes that are important to assent, for example who the study team is and why the study is being done. Next, an environmental scan of assent materials across Canada was conducted to further refine identified themes. This included review of assent templates on REB websites as well as identifying other types of assent materials such as infographics made for specific studies.



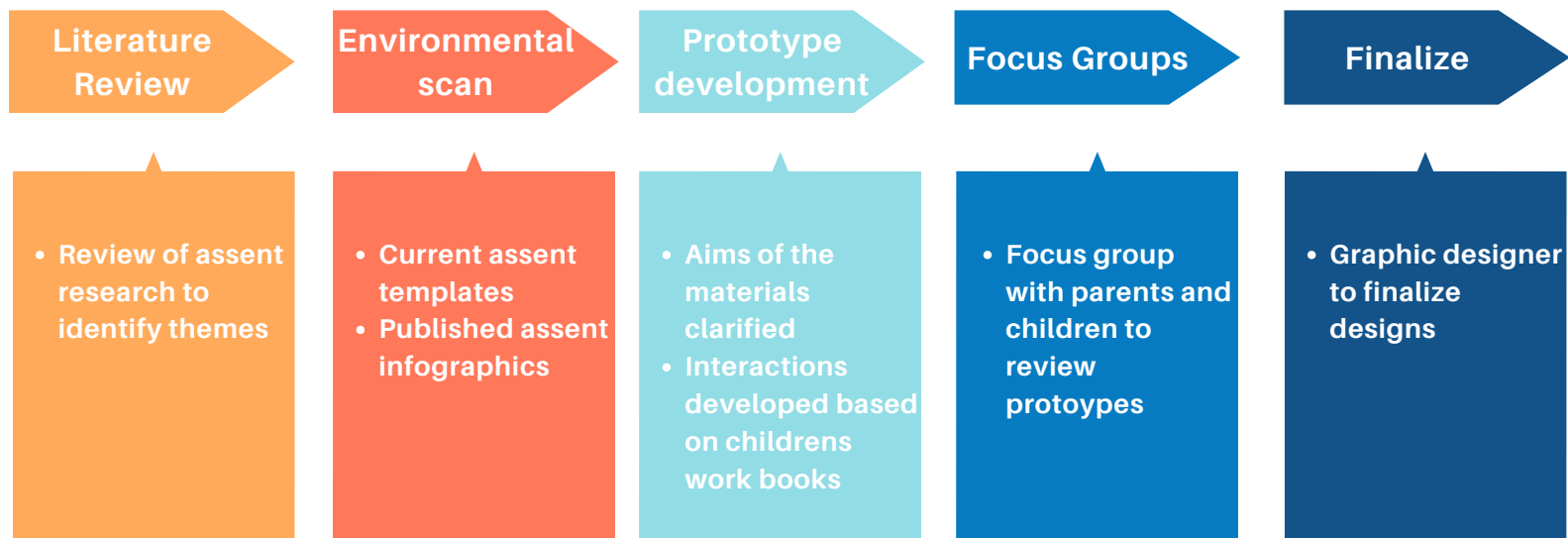


Based on what was found, prototypes were developed and the aims of the materials and target audience defined. Materials developed are:

- ▶ An adventure trail for younger children to complete with an adult that provides information about the study along the way
- ▶ A story booklet for older children to complete that includes activities for children to do whilst telling the story of the research.














In addition to developing prototypes, existing materials were also adapted, including a brochure explaining the concept of research initially developed by the Language Barriers Project at BC Children's Hospital. This is a gentle introduction aimed at families who may have little or no experience with research and what it means to be involved in research. The brochure is being adapted for cross Canada use and will also be translated. A [picture study schedule](#), developed for adults by [Blueprint Translational Research Group \(Ottawa Hospital Research Institute\)](#) and [Patient Partners](#) has been adapted for children and families. The picture study schedule provides the same information as would be in a traditional schedule but in pictorial format with some text.

Focus groups of children and parents were held to provide feedback on the prototype materials. Feedback included the importance of colour and clear, concise materials as well as creating two versions of story booklet, one with drawing and colouring, another with puzzles.





WHAT WILL I DO AS PART OF THE STUDY?

Phase	Week	How long will it take?	Visit Details	Study Activities	Notes
Before the study starts	Recruitment		You and your parents/caregiver will meet us, the study team, at the hospital. We will talk to you and your parents or caregivers.  	 	We will check to make sure you can be in the <u>study</u> and it is a good fit for you.
	Baseline: 4 months before randomization		You will have some tests at the hospital. 	 	We will collect some samples from your colonoscopy.
	Pre-randomization assessment		You will see your Crohn's doctor at the hospital.  	 	After this visit, if we still think this is a good fit for you, you and other kids in the study will be sorted into two groups. One group will have a special diet, and the other group will not. You can't choose your group, and you cannot change which group you are sorted into.

WHAT DO THE PICTURES MEAN?



Go to the hospital



Meet the study team



Speak with parents



Confirm you are a good fit for the study



Half day visit to the hospital



Colonoscopy



Magnetic Resonance Enterography (MRE)



See your Crohn's Doctor



Normal visit to the hospital with 10 minutes for study activities



Answer questionnaires



Bood Test

An example of the picture study schedule being piloted with a project

The materials have been made into templates by incorporating spaces for research teams to input key pieces of information, for example their names, the purpose of the research and what children will be asked to do. Another key learning from the focus groups was to create space for children to articulate their feelings about the research, for example by drawing or selecting a face that best aligns with how they feel about the research. Parents felt this was a very non-pressurized way for children to express their feelings about participating in a research study.



YOU DON'T HAVE TO BE IN THE
STUDY IF YOU DON'T WANT TO,
IT'S YOUR CHOICE.



USE THE FACES TO TELL US
HOW YOU ARE FEELING

A graphic designer has been engaged to create finalized versions of the materials that we hope to launch in the coming months.

As a reminder, the CHEER Interventional Consent Form Template is available on the CHEER [website](#) for any study teams wishing to use it and comes in a long version with templated language and a short version with just headings.

CROSS-PROVINCIAL CHEER STUDIES

CHEER continues to accept paediatric health studies with sites in Ontario, Nova Scotia and Newfoundland. Currently half of the studies in the CHEER system have sites in at least 2 provinces. Additionally, we have created a guidance document for new users of the system to help them navigate the system and a multisite ethics review style. The guidance can be found on the CHEER [website](#). If you would like to use the CHEER system for your study, please feel free to reach out to Megan Allore and Miranda Miller, cheer@queensu.ca.



As a reminder, Documented Institutional Ethics Requirements (DIERs) for IWK Health can be found on the [CHEER website](#). This document details the provincial and institutional requirements needed to be included in an ethics application for an IWK site and specific language for consent forms.



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Documented Institutional Ethics Requirements [Izaak Walton Killam (IWK) Health Centre]

Scope

The IWK Health Research Ethics Board (REB) is mandated by IWK Health to ensure all research involving human participants carried out under the auspices of IWK Health is of the highest quality, protects the interests of the human participants and of society generally, and complies with the Tri Council Policy Statement Ethical Conduct for Research Involving Human Subjects (TCPS2 - 2022).

Missions and Values

Recognizing the importance of research and the need to ensure the ethical conduct of research, the REB is built upon the guiding core ethical principles of the TCPS2 - 2022: respect for persons, concern for welfare, and justice. The independent functioning of the REB requires REB members and IWK researchers to navigate a course between the two main goals of providing the necessary protection of participants and serving the legitimate requirements of research through a transparent and accountable process for review of the ethical acceptability of research.

Privacy Considerations

IWK is subject to the provisions of the Nova Scotia Personal Health Information Act ("PHIA") and the Personal Information International Disclosure Protection Act ("PIIDPA").

PIIDPA generally prohibits the access, disclosure, transfer or storage of personal information outside of Canada except with consent of the individual or institutional CEO approval in required circumstances. Any access, disclosure, transfer or storage of research participant personal information outside of Canada should be specifically authorized in the informed consent process. Should an REB of Record identify any circumstances involving a non-consensual access, disclosure, transfer, or storage of personal information outside of Canada

PAN-CANADIAN WORKING GROUP

The CHEER Pan-Canadian Working group met virtually in September for updates on the CHEER Informed Consent Template, and the CHEER-MICYRN Consultation Service and Assent materials that have been developed.

The group is made up of institutional research ethics managers and systems experts, representing BC, AB, MB, SK, QC, ON, NS and NL. The CHEER informed consent template was discussed and the group decided that CHEER would make a strong recommendation for its use for CHEER studies. The CHEER ICF template is a paediatric interventional consent template that is available on the [CHEER website](#). This template can be used across the country when applying for ethics approval for interventional child health studies. A short version with only headings and a long version with templated text is available. The group also agreed that the template will be translated to French. The French version of the template can be used for non-clinical trial interventional paediatric research in Québec. The group reviewed assent materials that are being developed, these will also be translated into French initially, with more languages being added later.

We would like to thank members of this group for their valued support and continued engagement with the CHEER project.



CHEER PAEDIATRIC RESEARCH ETHICS REVIEW CONSULTATION SERVICE

The consultation service continues to receive interest from researchers across the country and there has been significant support for the coordination of streamlined informed consent documents across sites. The Central Ethics Review Manager is working with CHEER Navigators across the country to socialize the ethics review consultation service and CHEER consent template. Researchers have found it helpful to ask their questions to one key contact prior to submitting their multi-site ethics applications.

Research projects eligible for this service must be:

- ▶ Multicentre with study sites located in at least 2 provinces. The lead site may be in any province. A multicentre study conducted in two phases with a pilot phase at a single site or in one province is eligible.
- ▶ Prospective pediatric observational or interventional health research study
Peer reviewed research, i.e., by a designated steering committee and/or granting body (i.e.: CIHR).

If you have a study that is eligible and would like to use this service please contact the Central Ethics Review Manager at megan.allore@micyrn.ca or use the intake form available on both [CHEER](#) and [MICYRN](#) websites.



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MICYRN

better health for mothers and children





CHEER EDUCATION PROGRAM

MODULES

We are thrilled to announce the launch of our 5th education module on Study Design!

Access the module [HERE](#)! This module walks learners through some of the ethical considerations around study design considerations relevant to child health research. Topics covered in this module include introduction to research methodologies, considerations for a paediatric population when designing a study, study procedures and interventions and selecting and measuring study outcomes. We would like to express our thanks to Dr. Nancy Butcher and the Subject Matter Experts for their knowledge and time, the Patient and Family Advisory Committee for their review and the team at the Office of Professional Development and Educational Scholarship (OPDES) at Queen's University for bringing this module to life.

We have also completed translation of Module 1, Participant Recruitment to French! Access the module [HERE](#). Work continues to translate the remaining modules. We would like to thank the hard work of our dedicated translation validator who reviewed the initial translation of the module. Additional thanks go to the team at the Office of Professional Development and Educational Scholarship (OPDES) at Queen's University for their expertise in translating education modules.

All the modules can be found [here](#) on the CHEER website.

CHEER Education Module Topics:

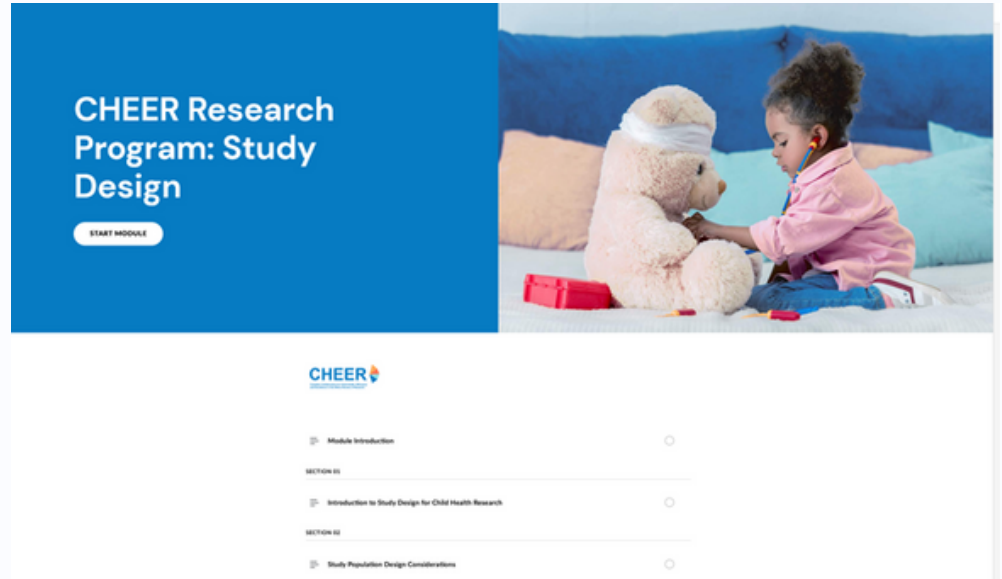
[Participant Recruitment](#)

[Patient and Public Engagement](#)

[Participant Consent and Assent](#)

[Study Design](#)

[Data](#)



WEBINARS

On September 11, we held the first webinar of the 2025-2026 series. Dr. Susan Docherty-Skippen and Nora Spinks hosted a webinar on Access to Clinical Trials for Military Connected Families. This talk provided a unique perspective on understanding the needs, health impacts, and research participation barriers for children connected to the military. A video of the event can be found [here](#), along with the slides, transcript and additional resources.

Access to Clinical Trials for Children from Military-Connected Families:

Understanding Unique Needs, Health Impacts, and Research Participation Barriers.

September 11, 2025

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Nora Spinks
CEO, Work-Life Harmony
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REGISTER NOW FOR OUR NEXT WEBINAR

NOV

13

12:00 - 1:00 PM EST

Integrating the patient perspective in pediatric clinical care through the implementation of Voxe: An electronic patient-reported outcome measure platform with Samantha Anthony and Sarah Pol

This webinar will explore the patient perspective in paediatric care. It will enhance knowledge around child and family-centred care and patient-reported outcome measures (PROMs) in clinical practice. Provide insight into the perspectives of key stakeholders including patients, caregivers and healthcare providers, around PROMs in clinical care. Increase understanding of potential barriers and facilitators to the implementation of PROMs in practice and provide an opportunity to learn about the creation and clinical implementation of Voxe – an electronic PROM platform to capture patients' voices.



Samantha Anthony
PhD MSW RSW



Sarah Pol MSc

[REGISTER HERE](#)

EDUCATION SESSION

CHEER hosted a 45 minute education session on Ethics Made Easier: Avoid Common Mistakes and Understand REB Expectations. This session, hosted by Miranda Miller and Megan Allore provided strategies for smoother applications and fewer revisions and common pitfalls when applying for ethics. We gave tips and tricks to help applying for ethics go smoothly and talk about why the REB might be asking for more information. Watch the recording [here](#).



CHEER REB QUALIFICATION PROGRAM

The Hospital for Sick Children Research Ethics Board, Western University Health Sciences Research Ethics Board, Sinai Health Research Ethics Board and Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board all underwent re-qualification for CHEER this year. The CHEER qualification visit is a collegial experience with sharing of best practices and building community. The CHEER qualification focuses on the standards that the research ethics board must adhere to with a paediatric lens. Discussions center around paediatric specific issues such as: how to manage continuous consent when a child gains capacity to consent or how incidental findings in children are handled.



CHEER qualified REBs include: The Hospital for Sick Children Research Ethics Board, Children's Hospital of Eastern Ontario (CHEO) Research Ethics Board, Western University Health Sciences Research Ethics Board, Ontario Cancer Research Ethics Board (OCREB), Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, Sinai Health Research Ethics Board, Holland Bloorview Kids Rehabilitation Hospital Research Ethics Board, the IWK Health in Nova Scotia and the Health Research Ethics Authority in Newfoundland.

If you would like to discuss CHEER qualification for your REB, please reach out to the project manager, Miranda Miller (cheer@queensu.ca).



ACKNOWLEDGMENTS

CHEER Principal Investigators, Co-Investigators and Collaborators

CHEER Committees

- ▶ CHEER Pan-Canadian Working Group
- ▶ The Operational Management Team
- ▶ Patient & Family Advisory Committee
- ▶ MICYRN Research Institute Directors

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