

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.



July 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.



CROSS-PROVINCIAL CHEER STUDIES

IWK Health REB, in Halifax, has reviewed and approved it's first CHEER study as Board of Record, for a study with sites in Nova Scotia and Ontario! Much hard work went into making this happen with onboarding of REB members and staff, training on the platform and swift execution of agreements between the IWK and other sites in Ontario.

Congratulations to the REB staff and the REB members and the research team for this achievement. Particular thanks go to Joanne Street in the REB Office who has worked so diligently to learn a new ethics management system as well as facilitating review for REB members.

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. Guidance for new users of the system can also be found on the [CHEER website](#).



IWK Health



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MaRS Centre, West Tower
Toronto, Ontario
M5G 1M1 Canada
www.ctontario.ca
www.childhealth.ca

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

If you would like to use the CHEER system for your study and need any help, please feel free to reach out to Megan Allore and Miranda Miller, cheer@queensu.ca.



CAREB CONFERENCE

In April the CHEER team presented at the CAREB conference. Our talk “Single ethics review of child health research across Canada – Key learnings from the CHEER project” focused on some of the key facilitators and barriers the CHEER project has experienced when implementing single ethics review in Canada. This included:

- ▶ The importance of researcher and senior institutional leadership support
- ▶ Stakeholders may not have the agency/power to implement change
- ▶ Common consent templates should be created with input from across the country
- ▶ The big picture of increasing access to child health research can sometimes be lost in administrative minutia

Key learnings from the CHEER project were highlighted and the talk focused on the future impact of the learnings from CHEER when implementing single ethics review. The presentation resulted in rich discussion, and we are grateful to CAREB for the opportunity to speak at this conference.



**CAREB- ACCER 2025
VIRTUAL CONFERENCE**



Past Advances and Future Considerations for Ethical Research

Visit: conference.careb-accer.org

April 29, 2025 - May 1, 2025



PAN-CANADIAN WORKING GROUP

On April 9th, the CHEER Pan-Canadian Working group met in person to discuss the CHEER consent template implementation updates, the MICYRN-CHEER consultation Service and Legacy building for the project. The group, made up of institutional research ethics managers and systems experts, representing BC, AB, MB, SK, QC, ON, NS and NL, discussed how to further publicize the CHEER Interventional Consent Template in their jurisdictions as well as harmonizing privacy language required in consent forms. We have since collected privacy language requirements from these jurisdictions and the informed consent working group are reviewing some proposed language that will be added to the CHEER Interventional Consent template. The update schedule for the consent template was decided as well as what other materials need to be developed. The group decided the development of assent materials would be beneficial for the research community.

We would like to thank members of this group for their valued support and continued engagement with the CHEER project. This group will be meeting again in the fall.

MICYRN-CHEER-RAREKIDSCAN - ANNUAL MEETING

Taking advantage of MICYRN and RareKidsCAN organizing their annual conference in Ottawa on April 9-11th, the CHEER leadership team and the MICYRN Research Institute Directors and Board of Directors met on April 9th. The CHEER Operational Management Team also attended this meeting. This meeting provided updates to the research community on the CHEER project goals and Dr. Quynh Doan presented work done at UBC and BC Children's on consent form translation and lessons learned.



Diversity & Inclusion in Pediatric Research, From Idea to Implementation

Dr. Quynh Doan – Senior Executive Director
Jennifer Claydon – Director, Clinical Research Operations
BC Children's Hospital Research Institute

April 2025

Qualitative Interviews with Researchers



- A narrative inquiry approach was adopted to examine the experiences of researchers and hospital leaders
- Semi-structured one-on-one interviews with 26 investigators, research staff, & hospital leaders
- Recordings transcribed and line-by-line coding done through Nvivo
- Manuscript submitted

Legacy Planning for the project was discussed as well as how generative AI and machine learning could be leveraged to create site specific consent templates. There are plans for a meeting with the CHEER team, Dr. Doan's team and others to discuss further how AI can be used. It was highlighted that even with resources that document what local requirements are required for consent forms and other participant facing documents, it is still very labour intensive to generate multiple consent forms for a multisite study. Consent builder tools that utilize AI and machine learning may be a way to alleviate this and increase efficiency when conducting multi-site research.



In discussing the future of the CHEER Project, it was noted that the learnings from CHEER and many of the resources developed (e.g., CHEER consent form template and Board of Record Agreement) will help to advance [CanReview](#), the [Accelerating Clinical Trials \(ACT\)](#) funded pan-Canadian single ethics review initiative. Pediatric clinical trials will be able to achieve single REB reviews through the CanReview platform. CHEER studies will continue to be supported and the CHEER platform available for use. Until CanReview is fully implemented and operational at all MICYRN member institutions, CHEER and MICYRN will continue to provide the Pediatric Research Ethics Review Consultation Service.



RareKids
CAN

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

MICYRN 

better health for mothers and children



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.



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

MICYRN

better health for mothers and children





CHEER ASSENT PROJECT

One of the requests of the CHEER working group of ethics managers and systems experts is to create engaging assent materials with images and colours that would be appealing to children. Work has started on the creation of these materials and once they have undergone community review and pilot testing, they will be open access materials available on the CHEER website. In addition to assent materials designed specifically for children, we are also creating materials for families. These materials are intended to introduce research and provide information in a comprehensible format that may be helpful to families. We understand that having a child in a clinical trial can be extremely taxing on the entire family, so our aim is to create useful materials that are helpful at a glance.





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.



Study Title: *insert study title as written on the protocol*
Sponsor's Study ID: *insert sponsor's study ID if applicable*
Principal Investigator: *insert name, department and telephone or pager number*
Sponsor/Funder(s): *insert the name of the Sponsor or, if applicable, the funder(s) of the research*
REB of Record Information: *insert name and telephone*
Emergency Contact Number (24 hours / 7 days a week):
Non-Emergency contact numbers are noted at the end of this document under the section heading "Contacts".

Introduction

If you are a parent, legal guardian or authorized representative of a child who may take part in this study, permission from you and the assent of your child may be required. Throughout this consent form, please remember that the words "you" and "your" always refer to the study participant/child, while "we" represents the *insert institution name* study doctor(s). If the child gains the capacity to consent for themselves, your consent on their behalf will end and we will seek consent from the child/participant.

You are being invited to participate in a research study. You are invited to participate in this study because *explain the main features of the population to which the research applies*. This consent form explains the research study and what you will be asked to do. This consent form may have words that you do not understand. Please ask the

1 | Status: Text: Provisions: On Accessibility: Investigate

CHEER EDUCATION PROGRAM

We are thrilled to announce the launch of our 4th education module on Data!

Access the module [here](#). This module walks learners through some of the ethical considerations around data associated with child health research. Topics covered in this module include data collection methods, data storage, the use of artificial intelligence and Indigenous data sovereignty. We would like to express our thanks to Dr. Nancy Butcher for writing the content and to the Subject Matter Experts for their review, 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.

These modules are intended to be interactive as well as educational and are open access. Our final module on Study Design is currently being reviewed by SMEs and we look forward to launching this module in the coming months.

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](#)



CHEER Research Program | Research Data

START MODULE

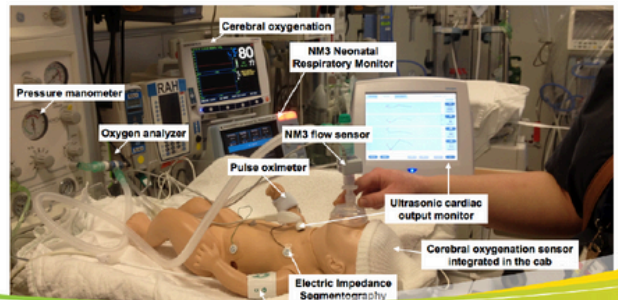


Work is underway to translate the modules into French.

Our most recent webinar on parents and neonatal consent included presentations from a neonatologist and two parents: Dr. Georg Schmolzer, Betsy Pilon and Rebecca Pearce. It was fantastic to hear their perspectives on this very important topic. All of our past webinars can be viewed again and are available [here](#) on the CHEER website.

Parents and Neonatal Research

Georg M Schmolzer
Centre for the Studies of Asphyxia and Resuscitation, Royal Alexandra Hospital, Edmonton, Canada; Dept. of Pediatrics, University of Alberta, Edmonton, Canada



WHEN EVERY MINUTE COUNTS

Consenting families in time-sensitive neonatal trials

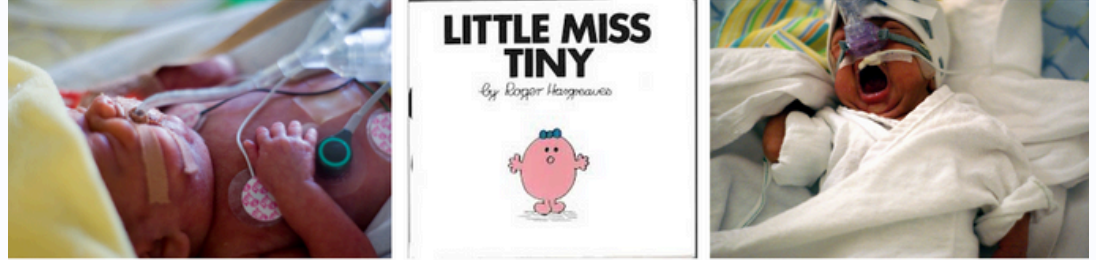


HALO OF SUPPORT

Model for Patient-Centered Clinical Trials



Where am I and what just happened?



Pearce, R., & Baardsnes, J. (2012). Term MRI for small preterm babies: Do parents really want to know and why has nobody asked them? *Acta Paediatrica*, 101(10), 1013-1015.

We will soon be announcing the dates for our next webinar series, watch this space!

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.

"Participating in the CHEER qualification process provides us with the opportunity to receive feedback from our colleagues and learn from one another, sharing best practices across Canada. Even having gone through the process before, the re-qualification visit provides a fresh set of eyes and allows us to continuously improve how we do things (and share our best practices with others as well!)."

**Kathleen Austin,
Manager/Research Ethicist
Sinai Health**

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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