CHEER

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.

January 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.

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

MICYRN
better health for mothers and children

10th Anniversary
Clinical Trials Ontario

CHEER PAEDIATRIC RESEARCH ETHICS CONSULTING SERVICE

Launched in October, the consultation service has received interest from observational and clinical researchers from coast to coast 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. We have a very positive response from the research community for the consent templates, driving the goal of having one template accepted across many sites.

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).

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MICYRN

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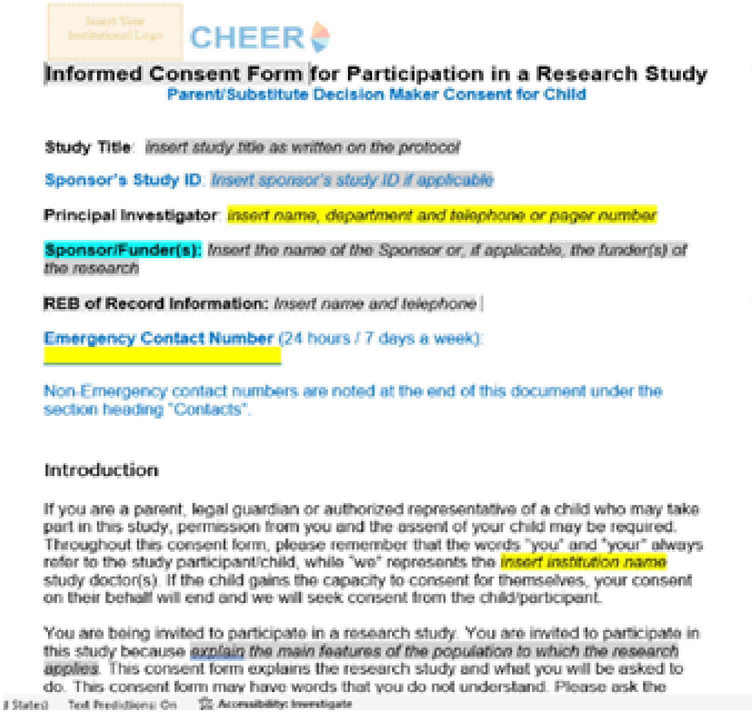
If you have a study that is eligible and would like to use this service please contact the Central Ethics Review Manager at megan.allore@micyrn.ca

CHEER CONSENT TEMPLATES

We are excited to launch the **short form** version of the CHEER Interventional Consent Form Template! For researchers looking for a framework for an interventional informed consent form, without suggested language, this template will provide an easily adaptable structure for a consent form. This short form is now available on the CHEER website.



Informed Consent Form for Participation in a Research Study
Parent/Substitute Decision Maker Consent for Child

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

Work has begun on the CHEER Observational Consent template; we hope to release this in the coming months.

If you have any feedback on the CHEER Interventional Informed Consent Form or Short Form version, please submit it to cheer@queensu.ca by **March 1st**.

CHEER NATIONAL POOL OF REVIEWERS PROGRAM

A national pool is being established by CHEER for REBs from across the country to access when seeking specific paediatric expertise. Research involving children requires unique expertise to account for unique vulnerabilities and developmental considerations in this population.

Not all REBs have a wide range of paediatric expertise amongst their membership. Establishing a pool will create a resource for REBs to utilize, allowing them to continue conducting effective reviews, particularly for very niche paediatric research.

Additionally, we hope that this will be an opportunity to build connections in our community, creating a collegial experience for colleagues to learn from one another.

For those interested in becoming part of the pool:

What You'll Do:

- Acting as Ad Hoc Advisors or temporary REB members, review paediatric research ethics submissions for REBs to ensure they meet ethical standards.
- Provide feedback to the REB on the submission to inform the REB decision.
- Reviewing an ethics submission and providing feedback to the REB will require approximately 3-4 hours. Time commitment can be flexible, members of the pool can review as much as they like.

Who We're Looking For:

- People with prior experience of serving on an REB with expertise in paediatric health research.
- Those committed to paediatric research excellence.

If you would like to join the pool please contact the CHEER Project manager at miranda.miller@queensu.ca

CROSS-PROVINCIAL CHEER STUDIES

The CHEER system has received paediatric studies with sites in both Ontario and Nova Scotia. These are the first studies for CHEER that will have sites in more than one province we and look forward to receiving more CHEER studies with sites in multiple provinces. Additionally, we are piloting a blanket Board of Record Agreement between institutions in different provinces. This Board of Record Agreement is not specific to one study, previous versions have been study specific and to reduce administrative burden we created a blanket Agreement with a term of 3 years.

Documented Institutional Requirements for the IWK 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.

If you would like to use CHEER for your study, please feel free to reach out to Miranda Miller, cheer@queensu.ca.

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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

CHEER EDUCATION PROGRAM

The first draft for the Data module is now complete and in the first round of review! We hope to be launching this module in the coming months. We expect the first draft of the Study Design module to also be completed in the coming weeks.

NEWSLETTER JANUARY 2025

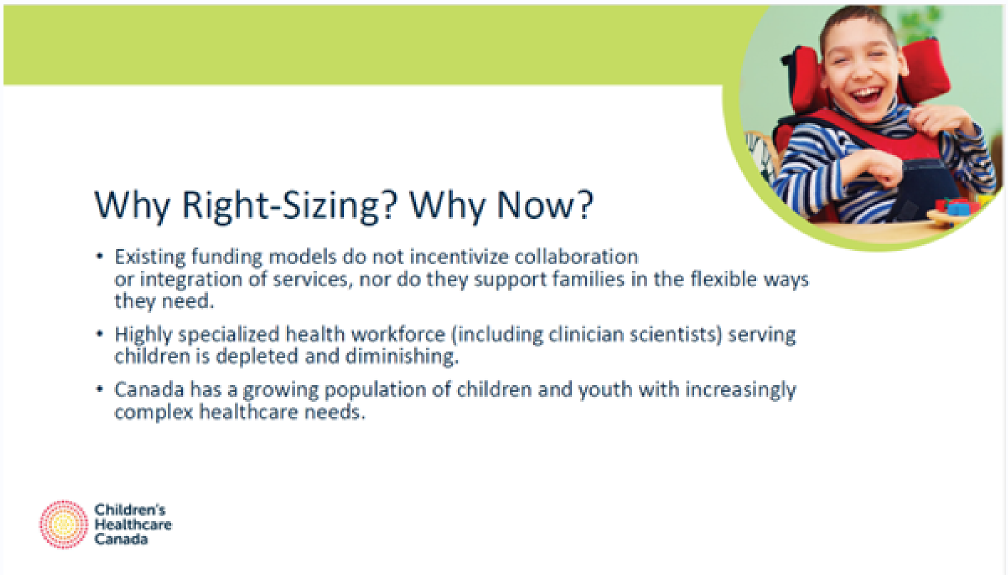
Modules in Participant Recruitment, Patient and Public Engagement and Consent and Assent are live on our website and can be accessed here

CHEER Research Program: Participant Consent and Assent

Work is underway to translate the modules into French.

Our next webinar in the 2024-2025 webinar series is soon approaching, Reimagining Indigenous Research Ethics in Canada: Charting a New Course with Dr. Sean Hillier. Register for this event here. Recordings of the events will be available on our website for those unable to attend.

We held the second event of the 2024-2025 webinar series on November 12, 2024, Right-Sizing Health Systems for Kids through Research Excellence with Christine Chambers and Emily Gruenwoldt. We would like to thank all those who attended and the rich discussions on this very timely topic. The video and captions are now available on the CHEER website and can be found here.

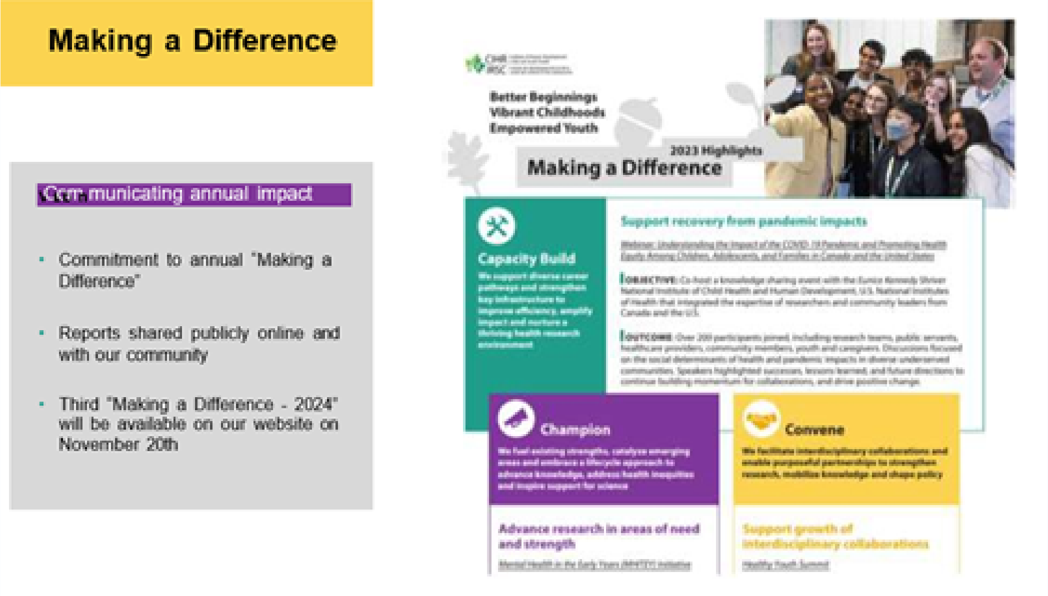


Why Right-Sizing? Why Now?

- Existing funding models do not incentivize collaboration or integration of services, nor do they support families in the flexible ways they need.
- Highly specialized health workforce (including clinician scientists) serving children is depleted and diminishing.
- Canada has a growing population of children and youth with increasingly complex healthcare needs.

Children's Healthcare Canada

NEWSLETTER JANUARY 2025



Making a Difference

Communicating annual impact

- Commitment to annual "Making a Difference"
- Reports shared publicly online and with our community
- Third "Making a Difference - 2024" will be available on our website on November 20th

Better Beginnings
Vibrant Childhoods
Empowered Youth

2023 Highlights

Making a Difference

Capacity Build

We support diverse career pathways and strengthen key infrastructure to improve efficiency, amplify impact and nurture a thriving health research environment

Support recovery from pandemic impacts

Webinar: Understanding the Impact of the COVID-19 Pandemic and Promoting Health Equity Among Children, Adolescents, and Families in Canada and the United States

OBJECTIVE: Co-host a knowledge sharing event with the Eunice Kennedy Shriver National Institute of Child Health and Human Development, U.S. National Institutes of Health that integrated the expertise of researchers and community leaders from Canada and the U.S.

OUTCOME: Over 200 participants joined, including research teams, public servants, healthcare providers, community members, youth and caregivers. Discussions focused on the social determinants of health and pandemic impacts in diverse underserved communities. Speakers highlighted successes, lessons learned, and future directions to continue building momentum for collaborations, and drive positive change.

Champion

We fuel existing strengths, catalyze emerging areas and embrace a lifecycle approach to advance knowledge, address health inequities and inspire support for science

Advance research in areas of need and strength

Mental Health in the Early Years (MHEY) initiative

Convene

We facilitate interdisciplinary collaborations and enable purposeful partnerships to strengthen research, mobilize knowledge and shape policy

Support growth of interdisciplinary collaborations

Healthy Youth Summit

Upcoming Webinars

FEB 5

REGISTER HERE

12:00 - 1:30 PM EST

Reimagining Indigenous Research Ethics in Canada: Charting a New Course with Sean Hillier

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APR 15

REGISTER HERE

12:00 - 1:30 PM EST

Optimizing Ethical Research: Implementing Ongoing Consent Models in Neonatal Studies with Georg Schmolzer, Betsy Pilon and Rebecca Pearce

CHEER REB QUALIFICATION PROGRAM

The Health Research Ethics Authority in Newfoundland is beginning their on-boarding as a CHEER qualified REB. Additionally, we have a number of REBs undergoing their first CHEER re-qualification visit in the coming months. Qualification lasts for 3 years with REBs completing annual reporting as a means of communicating changes such as new REB members.

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, Holland Bloorview Kids Rehabilitation Hospital Research Ethics Board, the IWK, Nova Scotia and the Health Research Ethics Authority, NL.

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

- Operational Management Team
- REB Advisory Committee
- Patient & Family Advisory Committee
- Strategic Implementation Advisory

Supporters

- 16 paediatric hospitals/research institutes
- 23 research intensive networks
- Health Canada
- Children's Healthcare Canada

Knowledge Users

Health Canada Santé Canada

Children's Healthcare Canada

NEWFOUNDLAND AND LABRADOR HREA HEALTH RESEARCH ETHICS AUTHORITY

Santé et Services sociaux Québec

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CIHR IRSC
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Instituts de recherche en santé du Canada