



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.



# November 2024

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 PAEDIATRIC RESEARCH ETHICS CONSULTING SERVICE

Through consultations with various stakeholders, several areas where CHEER can provide support for making efficiencies in a multi-jurisdictional landscape were identified. The CHEER working group of institutional research ethics managers and systems experts, has identified areas where CHEER can provide support for making efficiencies in a multi-jurisdictional landscape. To do this, MICYRN and CHEER are launching the Paediatric Research Ethics Consulting Service. To pilot this, a Central Ethics Review Manager position is being created, seated within MICYRN and CHEER to act as facilitator for multi-site, cross-provincial paediatric studies. The aim of this role will be to provide hands-on support for researchers when submitting their ethics applications for multi-site research. The Central Ethics Review Manager will not only provide a valuable service for child health researchers and their teams but also to REBs across the country.

Megan Allore will be stepping into the role as Central Ethics Review Manager. Megan brings a wealth of experience from her work with the Queen's University Queen's Vice Principal Research Portfolio. Megan worked first as an ethics coordinator and then as Ethics Compliance Advisor. In January 2024, Megan joined the CHEER team as interim Project Manager and has since been working closely with the CHEER and MICYRN teams to transition into this role.



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The logo for MICYRN features the word "MICYRN" in a bold, dark blue, sans-serif font. To the right of the text is a graphic consisting of several overlapping squares in shades of purple, green, and yellow, arranged in a larger square shape.

# MICYRN

*better health for mothers and children*



This centralized support will collaborate with local experts from each collaborating-site to facilitate ethics submissions and support the work of REB offices. To do this a network of collaborating-site ethics navigators is being established. The collaborating-site ethics navigators will support the Central Ethics Review Manager with expertise of the submission process and the ethics management system in their jurisdiction. One key aim of the Paediatric Research Ethics Consulting Service is the creation of a library of local requirements and nuances to facilitate fast and efficient submission of ethics applications.



By creating a network of ethics experts seated in REB offices across the country and building up a library of local requirements and nuances, the Pediatric Research Ethics Consultation Service will be positioned to ease the administrative burden currently experienced by child health researchers when applying for ethics approval for multi-site, cross provincial studies. Additional goals of the network are collection of metrics and building a community of collaboration and open communication.



Research project 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).

We will be launching this service in the coming weeks. If you have a study you think will be eligible and would like to use this service please contact us at [megan.allore@micryrn.ca](mailto:megan.allore@micryrn.ca)

## CHEER CONSENT TEMPLATES

**We are incredibly excited to announce that the CHEER interventional consent form template is finished!**

It received community review with our Patient and Family Advisory Committee and is now ready to be shared with the CHEER community.



**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



The CHEER pediatric assent/consent committee met bi-weekly since February 2024 to finalize the CHEER Interventional Consent Template. This template has been created to meet needs across provinces. Additionally, we have also created a short form version. This simplified version aims to make it easier for researchers and participants to understand. Where possible we have aligned language with other regions and jurisdictions. These templates will live on the [CHEER](#) website and be freely accessible to researchers wishing to use them. They will be updated periodically as changes are required, for example legislative changes requiring amendments to privacy language.

We are so appreciative of the PFAC for spending their time reviewing and meeting with us, we had very rich discussions around template language and received lots of great feedback to incorporate. We would also like to thank the CHEER pediatric assent/consent committee for all their hard work on the templates.



We hope these templates will enhance communication and understanding for families taking part in research and researchers find it easier to use a single template across multiple institutions, creating efficiency in research initiation. We thank the committee for their commitment to enhancing the pediatric research experience.



## CHEER WORKING GROUP OF INSTITUTIONAL REB MANAGERS AND SYSTEM EXPERTS

The CHEER working group met again in Halifax in September. Discussions centred on the Paediatric Research Ethics Consulting Service as well as collection of metrics. A significant goal of this CHEER working group is to collect metrics from across the country for ethics application submission to approval timelines. By collecting data from jurisdictions, the working group can identify areas which need more support to improve efficiency and channel resources. Metrics collected can be further applied more broadly to determine Canadian competitiveness for study initiation and inform policy as part of the fourth CHEER project deliverable, the final report and recommendations.

## CROSS-PROVINCIAL CHEER STUDIES

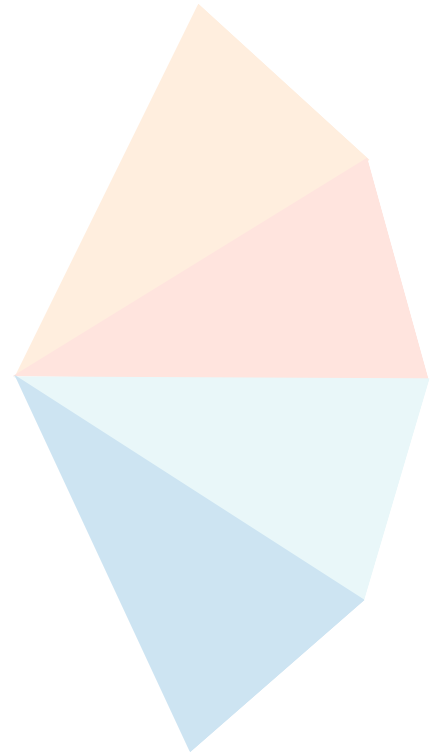


CHEER has received its first paediatrics studies with sites in both Ontario and Nova Scotia. These are the first studies for CHEER that will have sites in more than one province. We are delighted that CHEO and SickKids REB are acting as Board of Record and look forward to receiving more CHEER studies with sites in multiple provinces.



***CHEER is a valuable program that allows us to significantly reduce the administrative burden for researchers and REBs, while maintaining rigorous ethical standards. It allows us to expedite the review process by fostering greater transparency and collaboration between researchers across Canada and between researchers and REBs, ultimately promoting more efficient research. The CHEER team works hard to continue to build a strong foundation by leveraging existing frameworks and tools. We are so pleased to be part of [or to support and contribute to] this growing initiative!***

***Dr. Cécile Bensimon and Sarah Tagliapietra, CHEO REB***



We are starting the process of onboarding the HREA in Newfoundland and will soon be accepting studies with a lead site in Newfoundland. If you would like to use CHEER for your study, please feel free to reach out to Miranda Miller, [cheer@queensu.ca](mailto:cheer@queensu.ca).

## CHEER EDUCATION PROGRAM

We are thrilled to announce that the Participant Assent and Consent module is LIVE on our [website](#)! This module covers a breadth of consent and assent considerations for child health research. Much effort has gone into creating this module and we would like to thank all of our subject matter experts and reviewers for their time, commitment and expertise.



Two modules, Participant Recruitment and Patient and Public Engagement are also live and can be accessed [here](#)

Work is underway to translate the modules into French. The final two modules, Data and Study Design are expected to be launched early 2025.

## CHEER Research Program: Participant Consent and Assent

START MODULE



### Departure from the General Principles of Consent and Assent



### Assent



In child health research, one must consider the consent process and the developing capacity of the participant. Given that the potential participant may not be able to consent on their own behalf, it is important to involve the child in the consent process. This is where assent comes in.<sup>3</sup>

Assent is the involvement of a child in the decision-making process. Assenting is providing potential participants with information that they can understand so that they can express their wishes about participation. Assent is based on the ability of the potential participant, and may range from a conversation with basic information with a young child who nods "yes" to an assent form that resembles the consent form.<sup>3</sup>

### The Principles of Consent and Assent

As a researcher, it is important to understand the principles of consent and assent. These principles include that consent and assent must be:

In this section, you will explore the ethical complexities surrounding alterations to general principles of consent. You will examine departures from standard consent practices, such as the secondary use of information and human



We are also excited to announce the start of the 2024-2025 webinar series. With an exciting array of speakers lined up, please join us for what promises to be thought provoking and intriguing virtual event series. Recordings of the events will be available on our website for those unable to attend.

We held our first webinar on October 29, on Empowering REBs: Infusing Research Oversight with Equity, Diversity, Inclusion, and Accessibility. 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](#).

## CHEER



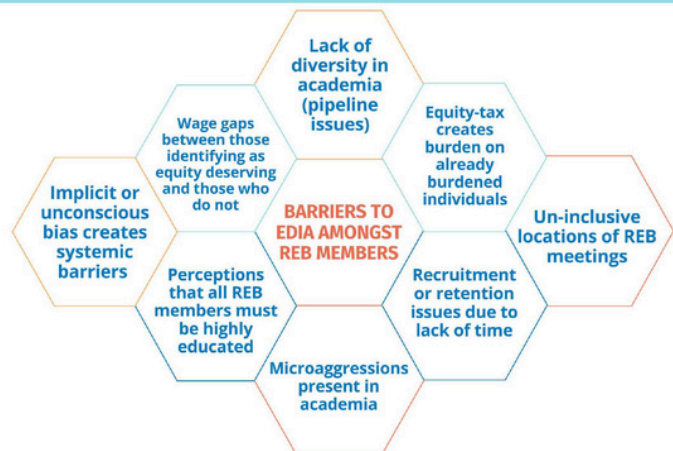
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### CHEER Webinar Series 2024-2025

#### Empowering REBs: Infusing Research Oversight with Equity, Diversity, Inclusion, and Accessibility

October 29, 2024 12:00 pm EST

### Barriers to EDIA amongst REB members





## The Case



- ▶ U of Maryland & Michigan State U depts of Psychology
- ▶ Research goals: to create a comprehensive database of fatal officer-involved shootings (FOIS) that includes officer information as well as victim information
- ▶ Can then determine whether there is a correlation between the race of the officer and the race of the victim
- ▶ Deemed exempt by the University of Maryland Institutional Review Board (IRB)
- ▶ Based on publicly available data (2016)- Washington Post + Guardian databases, newspaper information police department, court documents, internet
- ▶ Exempt research under OHRP regulations receives an administrative review, but not IRB review

### RETRACTED

#### Officer characteristics and racial disparities in fatal officer-involved shootings

David J. Johnson<sup>1,2\*</sup>, Trevor Steer<sup>3</sup>, Nicole Burkoff<sup>4</sup>, Carter Taylor<sup>5</sup>, and Joseph Casarr<sup>6\*</sup>

<sup>1</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>2</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

<sup>3</sup>College of Business, University of California, Berkeley, CA, and <sup>4</sup>Department of Law, 2019 University of Texas, Austin, TX, 78712

<sup>5</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>6</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

<sup>7</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>8</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

<sup>9</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>10</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

<sup>11</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>12</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

<sup>13</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>14</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

<sup>15</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>16</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

<sup>17</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>18</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

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<sup>21</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>22</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

<sup>23</sup>Department of Psychology, University of Maryland at College Park, College Park, MD 20742, and <sup>24</sup>Department of Psychology, Michigan State University, East Lansing, MI 48824

what police departments were involved, and demographic information about civilians. However, even these databases fail to provide information about involved officers, which prevents asking whether certain types of officers are more likely to show racial bias.

If these officers fire their weapons on civilians, there are three possible outcomes: (1) They miss the civilian, (2) they result in a nonfatal hit, or (3) they result in a fatal hit. Not only do officers miss civilians the majority of times they fire (continues of hit rate range from 26 to 60% (2, 6)), many shootings do not result in fatalities. Thus, it is important to be clear at the outset that our analyses track racial disparities in the subset of shootings that result in fatalities, and not officers' decisions to use lethal force more generally.

Why should we expect officer characteristics to relate to the race of a person fatally shot? Consider of research from criminal justice that investigated whether officer characteristics relate to the degree of force used by police. Whether officer race, age, or experience predict law enforcement on officer race (1, 11), race and inexperienced officers use more force (7, 8, 10), perhaps due to their use of more aggressive tactics (e.g., shooting more steps, not 11). One issue with this research is that it focuses on whether officer characteristics increase the degree of force used, not whether force is used disproportionately by civilian race. Some researchers have proposed that racial disparities in FOIS might be driven by discrimination by White officers (12), but research on this issue is inconclusive due to a lack of officer

**Significance**  
There is widespread concern about racial disparities in fatal officer-involved shootings, and that these disparities reflect discrimination by White officers. Existing databases of fatal shootings lack information about officers, and past analyses approaches have made it difficult to assess the contributions of factors like this. We create a comprehensive database of officers involved in fatal shootings during 2016 and present evidence that White officers are more likely to be involved in fatal officer-involved shootings, and White officers are not more likely to use lethal force on Black civilians.

## Upcoming Webinars

NOV

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12

12:00 - 1:00 PM EST

Right-Sizing Health Systems for Kids through Health Research and Research Excellence with Christine Chambers and Emily Gruenwoltd

[REGISTER HERE](#)

FEB

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5

12:00 - 1:30 PM EST

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

[REGISTER HERE](#)

APR

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15

12:00 - 1:30 PM EST

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

[REGISTER HERE](#)

# CHEER Webinar Series 2024-2025

## Right-Sizing Health Systems for Kids Research Excellence with Dr. Christine Chambers and Emily Gruenwoldt

**November 12, 2024**  
**12:00 pm EST**

Children's Healthcare Canada envisions a healthcare system that is accessible, equitable, and connected, specifically designed to meet the needs of children, youth, and families. Achieving this vision requires integrating health research as a critical foundation for shaping the future of pediatric healthcare.

In this webinar, we will explore the role of research excellence and how health research drives advancements in children's health by identifying emerging trends, developing new treatments and therapies, measuring care outcomes, and reimagining innovative models of care. While investment in healthcare systems is essential, these efforts will not achieve sustained improvements without a parallel investment in health research.

Join us as we discuss the evolving concept of research excellence and the critical role of health research in "right-sizing" health systems for kids and how renewed investments in research can secure a brighter, healthier future for Canada's youngest generations.



**Dr. Christine Chambers, PhD RPsych  
FRSC FCAHS (she/her/hers)**  
Scientific Director, Institute of Human  
Development, Child and Youth  
Health, CIHR



**Emily Gruenwoldt, President &  
CEO, Children's Healthcare  
Canada; Executive Director,  
Pediatric Chairs of Canada**

**[REGISTER HERE](#)**



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éthique de la recherche

[cheerchildhealth.ca](http://cheerchildhealth.ca)



# CHEER Webinar Series 2024-2025

## Right-Sizing Health Systems for Kids through Research Excellence

November 12, 2024 12:00 pm EST



**Dr. Christine Chambers, PhD RPsych FRSC FCAHS (she/her/hers) Scientific Director, Institute of Human Development, Child and Youth Health, CIHR**

Dr. Christine Chambers is an international leader in the study of children's pain and an innovator in patient engagement, partnerships and knowledge mobilization. As a clinical psychologist and national voice for children's health, Christine creates purposeful connections with diverse groups to move research from ideas to impact, improving the daily lives of children, youth and families. Twice named one of Canada's Top 100 Most Powerful Women by the Women's Executive Network, Christine has published over 200 articles in peer-reviewed scientific journals and is recognized in the top 2% of the most cited scientists in the world.

As Scientific Director of the Institute of Human Development, Child and Youth Health (IHDCYH) at the Canadian Institutes of Health Research (CIHR), Christine is steering a bold vision to foster research that promotes better beginnings, vibrant childhoods and empowered youth. She is a Professor and Tier 1 Canada Research Chair in Children's Pain at Dalhousie University and faculty member in the Centre for Pediatric Pain Research at IWK Health Centre. Her acclaimed research program has helped establish Canada as a leader in children's pain research. She is also the Scientific Director of Solutions for Kids in Pain (SKIP).

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**Emily Gruenwoldt, President & CEO, Children's Healthcare Canada;  
Executive Director, Pediatric Chairs of Canada**



Emily is a trusted voice and passionate champion for Canada's 8 million kids. As the President & CEO of Children's Healthcare Canada, a national, non-profit association representing over 40 healthcare delivery organizations serving children, youth and families, she advances a vision for healthy, vibrant children and youth. Emily is also Executive Director of the Pediatric Chairs of Canada.

Previously, Emily brought her strategic leadership to Solutions for Kids in Pain (a federally funded Networks Centre of Excellence), the Canadian Medical Association, and to the Board tables of The Ottawa Hospital, Arnprior Regional Health, and Carefor Home and Healthcare Services. She is the co-founder of Emerging Health Leaders and EmpowerHER, two national networks created to advance the development of health systems leaders.

[cheerchildhealth.ca](https://cheerchildhealth.ca)



## CHEER STRATEGIC PLANNING MEETING, VANCOUVER

In June, CHEER held a Strategic Planning Meeting at the [Perinatal & Child Health Research Annual Meeting](#). Many groups focused on child health research were involved in this weeklong series of events. The CHEER Operational Management Committee attended this meeting along with members of the CHEER community from across the country. We would like to thank everyone who attended, the CHEER project provided progress updates for the project with opening remarks by Dr. Christine Chambers, the Scientific Director, CIHR Institute of Human Development, Child and Youth Health.

Strategic discussion for the Paediatric Ethics Consultation Service took place, with support for the Pediatric Research Ethics Consultation Service gained. Discussions centered on the barriers to streamlining such as legislation and advocacy for achieving single review in Canada.

Perinatal & Child Health Research Annual Meetings

*Bringing the Canadian Community Together*

June 2 – 7, 2024

Sheraton Wall Centre - Vancouver, BC





## 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](mailto: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

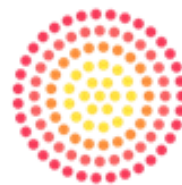
- ▶ 16 paediatric hospitals/research institutes
- ▶ 23 research intensive networks
- ▶ Health Canada
- ▶ Children's Healthcare Canada

#### Knowledge Users



Health  
Canada

Santé  
Canada



Children's  
Healthcare  
Canada



Santé  
et Services sociaux

Québec



#### This project is supported by

CIHR Institute of Human Development, Child and Youth Health, CIHR Institute of Genetics

