

# CHILD EDII\*, Health Equity, & 16Y Protocol Strategic Planning Workshop

\* Equity, Diversity, Inclusion, and Indigeneity (EDII) strategy

Kingbridge Conference Centre

July 22 & 23, 2024



## Executive Summary



## Objectives

To advance CHILD's:

- Equity, Diversity, Inclusion, and Indigeneity (EDII) strategy
- Participant engagement
- 16-year data collection protocol

## Attendance

|   |  |  |
|---|--|--|
| <b>41</b><br>Attendees<br>32 in person<br>9 virtual | <b>14</b> CHILD Staff  | <b>9</b> National Coordinating Centre (NCC) Staff<br><b>5</b> Site Staff |
|   | <b>13</b> CHILD Researchers  | <b>6</b> Study & Site Leaders<br><b>7</b> Researchers                    |
|   | <b>10</b> Invited Guests   | <b>5</b> Facilitators & Speakers<br><b>5</b> Invited Researchers         |
|   | <b>6</b> CHILD Family Members*   |  |
| <b>10</b><br>Institutions                           | BC Children's Hospital Research Institute, McGill University, Queens University, The Hospital for Sick Children, Simon Fraser University, University of Alberta, University of Manitoba, University of Montreal, University of Saskatchewan, University of Toronto |  |

\* Members of the National Parent Engagement Committee (NPEC)

## Program

|                       |                                 |   |
|-----------------------|---------------------------------|---|
| <b>13</b><br>Sessions | <b>8</b> Panels & Presentations | <b>Topics:</b> Equity, Diversity & Inclusion (EDI), Unconscious Biases, Indigenous Strategy, Health Equity, Data Usage, Participant Experience  |
|                       | <b>2</b> Group Activities       | <b>Topics:</b> Health Equity, 16Y Protocol  |
|                       | <b>3</b> Closed Door Sessions   | <ul style="list-style-type: none"> <li>• Youth breakout</li> <li>• National Coordinating Centre-CHILD sites</li> <li>• National Parent Engagement Committee &amp; Knowledge Mobilization</li> </ul> |

For details, see Appendix I: Meeting Guide

A brief event write-up with photos is available [here](#).

## Key Takeaways

### Priorities identified in workshop discussions:

#### 1. Overcoming data collection barriers in 16-year process:

- [Learn from other cohorts](#), literature reviews and people with lived experience – including low-participation/dropout families in CHILD
- [Build community with youth](#), including through actionable knowledge mobilization that they co-design; facilitate peer support and team-building activities among youth
- [Prioritize simplified questionnaires/online data collection](#) using gamification and reward incentives; allow pausing of questionnaires
- [Reimburse transit costs](#) for visits, hold visits on weekends and evenings

#### 2. Expanding and deepening participant and community partner relationships:

- [Mentor CHILD youth in the sciences](#) through project-based learning; organize summer/winter lectures for parents and youth and more regular in-person events
- [Contact youth](#) more frequently, not just for data collection; hold more regular in-person activities
- [Expand the Youth Council](#) and give youth leadership opportunities; support youth-organized events including youth-led talks; provide youth more opportunities for interaction and peer support
- [Hold site-specific townhall meetings](#) with researchers, staff and families (discuss what's working and what's not; solicit participant input on research priorities; discuss research process and results)
- [Accelerate knowledge translation](#)/data sharing, including through kid-friendly communications and by sharing individualized data with participants
- [Establish site-specific parent advisory committees](#), facilitate parent learning and interaction through communications/newsletters and potentially online platforms
- [Expand reach](#), knowledge mobilization and consultation with partners/stakeholders (physicians, government, provincial health, schools, etc.); empower youth as ambassadors/advocates, including with policymakers

#### 3. Making research more relevant/impactful:

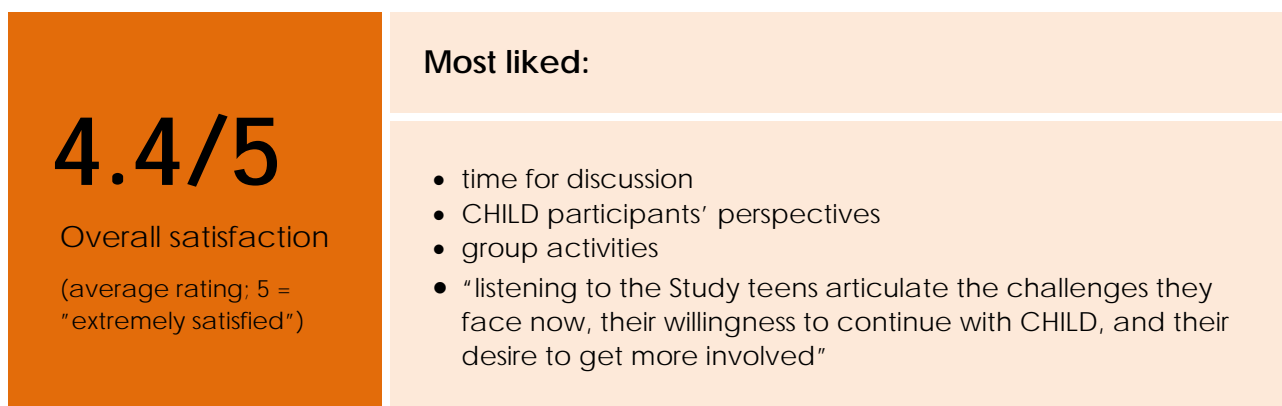
- [Develop mixed methods](#)/qualitative components
- [Include research topics of interest to youth](#), especially mental health (bullying, anxiety, academic pressure, screen/social media addiction) and risky behaviours (vaping, substance use, suicide), using very direct questions
- [Involve CHILD participants](#) in interpreting results and translating them to the broader public

## Next Steps

- Implement CHILD's [Knowledge Mobilization and Patient Engagement Plan](#) to actively engage youth, their families, and our partners throughout the research process.
- Expand recruitment efforts for the [Youth Advisory Council](#), which will begin in early 2025.
- Enhance representation in and re-engage CHILD's [Knowledge Mobilization Stakeholder Advisory Committee](#), set to relaunch in early 2025.
- Organize more in-person events, including [Youth Conferences](#), to provide youth with enhanced learning, leadership, and networking opportunities.
- Develop a [Town Hall Series](#) to keep families informed about our study's progress, answer their questions, and gather valuable feedback.

## Evaluation / Participant Feedback

Based on responses to the post-event survey:

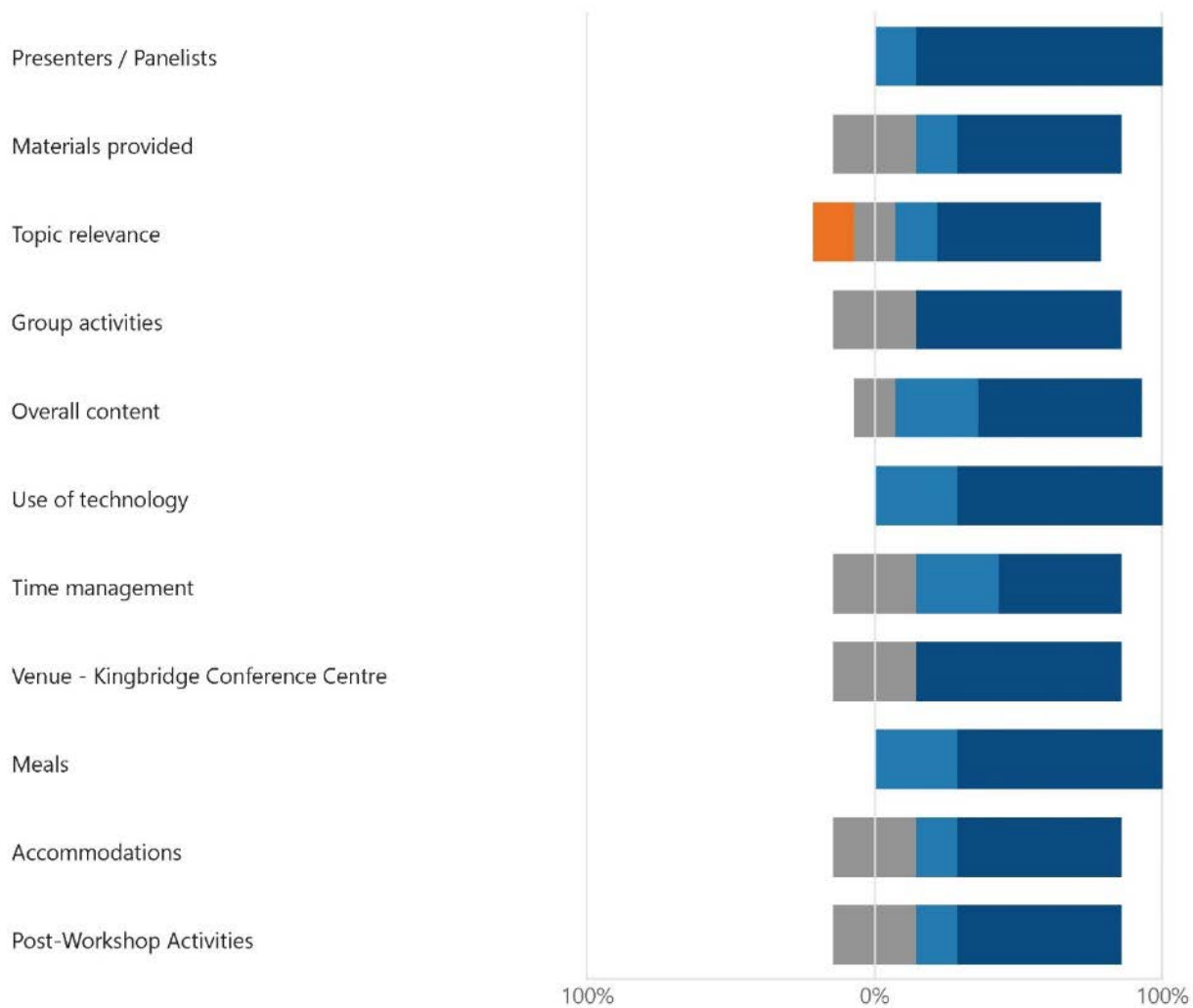


Were your expectations of the event met?



## How satisfied are you with the following aspects of the event?

■ Very dissatisfied  
 ■ Somewhat dissatisfied  
 ■ Neither satisfied nor dissatisfied  
 ■ Somewhat satisfied  
 ■ Very satisfied



## Appendix I: Meeting Guide

# **CHILD EDII, Health Equity, & 16Y Protocol Strategic Planning Workshop**

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Kingbridge Conference Centre  
July 22 & 23, 2024

**Meeting Guide** (abridged)





## Welcome

Dear Attendees,

I am delighted to extend a warm welcome to you all on behalf of the CHILD Cohort Study to our EDII, Health Equity, & 16Y Strategic Planning Workshop held against the inspiring backdrop of Kingbridge Conference Centre. This workshop marks a crucial step in ensuring that the CHILD Cohort Study not only continues to gather relevant, comprehensive data but does so in a manner that is sensitive to the diverse backgrounds and experiences within our cohort and research community. Thank you so much for being a part of this important process!

As we embark on planning for the CHILD's 16-year milestone, it is imperative that we design protocols that maximize meaningful research opportunities without overburdening study participants, and that promote inclusivity, respect participant and community needs and sensitivities, while upholding the highest ethical standards.

During our time together, we will delve into topics such as countering implicit bias, defining health equity within CHILD, and approaches to building out an Indigenous strategy as part of a larger equality, diversity, inclusion (EDII) strategy for CHILD. We will discuss ways to build meaningful and active participant family engagement in governance, priority setting, research goals and knowledge translation. And we will initiate planning for the Study's 16-year protocol, especially in terms of identifying questions of value to participants, specifically the youth, and researchers.

You all who have responded to our invitation represent a wealth of knowledge, experience and disciplinary breadth. Among us are CHILD staff, leaders and researchers, and various invited experts with insight into the challenges and opportunities ahead as the Study advances into its next stage. Most importantly, we also have representatives from some of the families participating in the cohort whose partnership is indispensable and whose 'in-the-trenches' perspectives will help to ground the entire discussion.

Everyone's insights will be invaluable to this process, and we encourage active participation and open dialogue throughout our sessions, as well as a chance to unwind and (re)connect with some familiar and not so familiar faces.

Thank you once again for your commitment to advancing our study's mission through thoughtful planning and meaningful partnerships. We look forward to productive discussions and collective efforts in ensuring the ongoing success of CHILD.

Sincerely,



Elissa Brookes, Program Manager  
*CHILD National Coordinating Centre*

## Acknowledgements

We would like to thank you the site leads, our coordinators and all CHILD research staff at each of our four study sites across Canada, as well as our participant families for your continued dedication to the CHILD study that has carried us to this critical point in our CHILD journey, as we prepare for our 16Y visit. Without you, this would not be possible.





## Meet Your Speakers

### DR. FRANCINE BUCHANAN



research partner, and a former strategy consultant.

Dr. Francine Buchanan is the Senior Manager, Patient, Family & Community Engagement at The Hospital for Sick Children (Ontario, Canada) and the Ontario Child Health Support Unit (OCHSU). In this role, Francine supports a Patient-Centred Health Care philosophy by ensuring patients and families can partner with the healthcare system to co-create a future for children's health care that reflects their lived experiences. Francine's goal is to ensure patient, family and community voices are key drivers for change in healthcare. Francine brings a diverse background of skills and experience to her work, as parent to a child with complex healthcare needs, a health researcher, a parent

### DR. STUART TURVEY



Dr. Stuart Turvey is a Professor of Pediatrics at The University of British Columbia where he holds both the Canada Research Chair in Pediatric Precision Health and the Aubrey J. Tingle Professorship in Pediatric Immunology. He is a clinician-scientist and Pediatric Immunologist based at BC Children's Hospital. Dr. Turvey's research program focuses on determining the early-life origins of asthma and allergic disease, and harnessing the power of genomics to diagnose, treat and prevent pediatric immune disorders. His ability to transition from the clinic to the lab allows Dr. Turvey to take a precision health approach sensitive to the child's developmental course. His work determines and responds to the underlying cellular, molecular and genetic abnormalities responsible for disease.

### DR. KOZETA MILIKU



through a life course perspective. Dr. Miliku also serves as the Clinical Science Officer of the CHILD Cohort Study and co-chairs the EDII committee of the Developmental Origins of Health and Disease (DOHaD) Canada Society."

Dr. Kozeta Miliku is an Assistant Professor in the Department of Nutritional Sciences at the University of Toronto. She earned her Medical Doctorate from the Medical University of Tirana in Albania and completed her doctoral degree in Clinical Epidemiology at the Erasmus University Medical Centre in the Netherlands. Dr. Miliku conducted postdoctoral research at the University of Manitoba and McMaster University, focusing on the intersection of nutrition and genetics in the developmental origins of chronic diseases, including cardiometabolic health, asthma, and allergies in Canadian children. At the University of Toronto, Dr. Miliku's research lab studies the impact of nutrition

### MYRTHA REYNA-VARGAS



Myrtha received her M.Sc. in Biostatistics from UofT and her B.Sc. in Bioengineering from the Autonomous University of Baja California, Mexico. She joined the Subbarao Lab in October 2018, conducting analysis of clinical and questionnaire derived data, primarily association and clustering studies. Her current projects focus on identifying growth trajectories and analysis of asthma using a precision medicine approach. Myrtha is pursuing her PhD in Epidemiology at the University of Toronto

### DR. CHARISSE PETERSON



Dr. Charisse Peterson earned a PhD in Microbiology and Immunology from The University of Utah in 2017 interrogating immune-microbiota interactions within the mammalian gut. She continued this work as a postdoctoral fellow in Dr. Brett Finlay's lab at UBC with a specific focus on early-life microbiota maturation and immune development. Dr. Peterson joined Dr. Stuart Turvey's lab in 2020 and would say that the best part of her job is working with studies like CHILD study to shine a light on all the





wonderful things that our microbiota does to support infant development. Charisse believes the more we know, the better we can protect these important bacteria to keep infants and children healthy.

#### DR. BASSEL DAWOD



Dr. Bassel Dawod is a Research Associate with CHILD at McMaster University, specializing in immunology and computational analysis. He completed a Mitacs Postdoctoral Fellowship in cancer research at IMV Inc., a clinical-stage biopharmaceutical company. He holds a PhD in Pathology, an MSc in Microbiology and Immunology from Dalhousie University, and a Medical Diploma from Aleppo University in Syria. His expertise encompasses advanced laboratory techniques such as multiplex proteomics and computational spatial analysis in allergy, infectious diseases, and cancer biology.



#### DR. ERIN KRAFT

Dr. Erin Kraft (she/her) is the Manager, Inclusion, Diversity, Equity & Accessibility (IDEA) at CGEn, a national platform for genomics sequencing and analysis. She has been working in the IDEA field for over 10 years with experience in the education, sport, and health sectors. Recently, Dr. Kraft completed the Certified Diversity Executive® credential to build on her skills to plan, implement, and evaluate IDEA strategies and initiatives across complex organizations, and to support her passion for lifelong learning.

#### TAMARA GREAVES



Tamara Greaves is the Program Manager in the Equity, Diversity, and Inclusion (EDI) Central Office at the Hospital for Sick Children (SickKids). She is responsible for the day-to-day operation and implementation of EDI strategic initiatives, policy review and development, and equity objectives for the organization. Tamara has been at SickKids since 2019, supporting both Faculty Development and EDI in the Research Institute (RI). During her time in the RI, she co-developed the SickKids Research Institute Dialogues in Diversity and DIY-Diversity and Inclusion in Your research design seminar series, as well as reviewed Faculty Office policies, inclusive recruitment practices, and programmatic strategic planning.

#### DR. MALCOLM KING



Dr. Malcolm King, a member of the Mississaugas of the New Credit First Nation, is a health researcher at the University of Saskatchewan where he serves as the Scientific Director of SCPOR, the Saskatchewan Centre for Patient Oriented Research. He also teaches and researches in Indigenous health, with a focus on wellness and engagement. From 2009 to 2016, Dr. King led the CIHR Institute of Aboriginal Peoples' Health as its Scientific Director, spearheading the development of a national health research agenda aimed at improving wellness and achieving health equity for First Nations

People, Métis and Inuit in Canada. Dr. King's international Indigenous health interests include improving Indigenous health through workforce development and provision of culturally appropriate care and developing Indigenous health indicators to monitor progress in programs aimed at achieving wellness and health equity. Dr. King received a National Aboriginal Achievement Award in 1999 and in 2016 was named a Fellow of the Canadian Academy of Health Sciences.

#### DR. ALEXANDRA KING



Dr. Alexandra King is a member of Nipissing First Nation (Ontario). She is an Internal Medicine Specialist with a focus on HIV/AIDS, hepatitis C (HCV) and HIV/HCV co-infections. Dr. King is the inaugural Cameco Chair in Indigenous Health and Wellness at the University of Saskatchewan, endowed by the Royal University Hospital Foundation through its Royal Care Campaign. She works with Indigenous communities and relevant stakeholders to understand the health and wellness needs of First Nations and Métis



peoples in Saskatchewan and the structural changes needed for improved Indigenous health outcomes. She leads work that enhances Indigenous health education; advocates for improvements and funding; ensures the sustainability of effective services and supports; and facilitates knowledge and resource mobilization to support improved Indigenous health and wellness. Dr. King brings leadership skills in culturally safe and responsive research and care, reconciliation, Two-eyed Seeing (bringing together Indigenous and Western worldviews or forms of knowledge) and Ethical Space—which needs to be created when peoples with disparate worldviews are poised to engage each other.

#### LILY HOFFMAN



Lily Hoffman (15) is a student athlete. She is thrilled to be back in Ontario with her fellow cohort to discuss the future of CHILD.

**Parent: Harmoni Hoffman**

#### BRYNN EDDIE



Brynn Eddie lives in a small town in Ontario with her parents and younger sister. She recently graduated Grade 8 in June and will be attending high school in September. Brynn enjoys reading fiction novels and is an avid visual artist.

**Parent: Aaron Eddie**

#### MAX DOUCAS



Max Doucas is 15 years old and is heading into Grade 10 in September. Loves playing video games with his friends and enjoys weight training. Earlier this year, Max participated in the first CHILD Youth Camp and last August he was interviewed in one of the segments with Dr Stuart Turvey on the latest research studies of CHILD.

**Parent: Natasha Doucas**

### Our Time Together

#### PURPOSE

The theme for this year's CHILD Retreat is 'Moving Forward'. As we design our 16-year CHILD visits, we are at a pivotal stage where we can involve key members of the CHILD community to drive where the study is going in terms of design, strategy, engagement and knowledge mobilization.

#### Goals:

1. Share our CHILD vision objectives
2. Discuss strategic future direction of CHILD
  - a. Set groundwork for an Equity, Diversity, Inclusion & Indigenous (EDII) strategy
3. Develop site Participant Engagement (PE) strategy, including:
  - a. Ideal PE state across sites
  - b. Resources needed to sustain an engaged participant community at each site





## EVENT FORMAT

The workshop sessions will in the form of in-person and virtual presentations and breakout sessions geared towards our research staff, participant partners, and field experts in EDII and health equity. Each session can be joined via the shared registration link shared further down in the meeting guide.

All attendees wishing to virtually participate in the sessions must register online and join at any time using the same link for each session that fits their schedule.

### Meeting Venue:

Kingbridge Conference Centre, 12750 Jane St, King City, ON L7B 1A3  
North Wing - Main Auditorium and Meeting Rooms 20, 22, 23

The Meeting Rooms are on the North Wing 2<sup>nd</sup> floor and can be accessed from the main floor using the staircase 1) the elevators located behind the business service desk or 2) the lobby staircase located in across from the registration table. Each room is marked with the event title, for easy reference.

## Workshop Agenda

### DAY 1 – Monday, July 22<sup>nd</sup> | 900am – 400pm (EST)

|                |   |            |
|----------------|---|------------|
| 700 – 8:45AM   | <b>BREAKFAST &amp; REGISTRATION</b><br>Connections Dining Room   Registration desk located outside Auditorium   |            |
| 900 – 910 AM   | <b>Opening Ceremony</b><br>Dr. Francine Buchanan, The Hospital for Sick Children  | Auditorium |
| 910 – 940 AM   | <b>Why is EDII Important in the CHILD Study?</b><br>Dr. Stuart Turvey, BC Children’s Hospital   |            |
| 940 – 1000 AM  | <b>Equity Diversity &amp; Inclusion</b><br>Dr. Erin Kraft, The Hospital for Sick Children   | Auditorium |
| 1000 - 1020 AM | <b>Unconscious Biases</b><br>Tamara Greaves, The Hospital for Sick Children   | Auditorium |
| 1020 – 1045 AM | <b>Indigeneity and Indigenous ways of knowing equity, diversity &amp; inclusion</b><br>Dr. Alexandra King, University of Saskatchewan<br>Dr. Malcolm King, University of Saskatchewan | Auditorium |
| 1045 – 1100 AM | <b>Break</b> (Auditorium Alcove)  |            |
| 1100 – 1200 PM | <b>Panel Discussion: EDII &amp; Unconscious Biases</b><br>Facilitated by Dr. Francine Buchanan  |            |
| 1200 – 130 PM  | <b>BUFFET LUNCH</b> (Connections Dining Room)   |            |





|               |   |
|---------------|---|
| 130 -230 PM   | <p><b>Group activity 1: Envisioning CHILD's Under a Health Equity Lens</b></p> <p>The audience has been divided into 6 groups. Each group will be assigned one of the following CHILD "core themes" to focus on: <i>Infection, Microbiome, Mental health, Asthma &amp; Allergy, Indoor and outdoor environment, and lifestyle (diet, physical activity, etc)</i>. Follow the printed instructions at your tables.</p> <p><b>Group 1</b> Meeting Room 20<br/> <b>Group 5</b> Meeting Room 22<br/> <b>Group 2, 3, 4, 6</b> Auditorium</p> |
| 230 – 245 PM  | Break (Auditorium Alcove)   |
| 245 - 345 PM  | <p><b>Summary from group activity: How do we get where we want to go?</b> Auditorium<br/> Facilitated by Dr. Francine Buchanan</p>  |
| 345 – 400 PM  | Closing remarks Auditorium  |
| 500 – 600 PM  | Cocktail Mixer (Bridges Bar)  |
| 600 – 730 PM  | Dinner (Connections Dining Room)  |
| 800 – 1100 PM | <p><b>Fireside Chat (Connections Courtyard)</b><br/> Catch up with old friends and make some new ones by the fire pyramid just outside Connections Dining Room</p>  |

#### DAY 2 – Tuesday, July 23<sup>rd</sup> | 900am – 230pm (EST)

|              |  |
|--------------|--|
| 700 – 845 AM | <p><b>BUFFET BREAKFAST</b> (Connections Dining Room)</p>   |
| 900 – 920 AM | <p><b>Recap: What did we learn from Day 1?</b> Auditorium<br/> Dr. Francine Buchanan, The Hospital for Sick Children</p>   |
| 845 – 945 AM | <p><b>Speaker Panel: CHILD Study from the researcher's perspective – Why do we get all these data?</b> Auditorium</p> <p>Asthma &amp; Lung Function, Myrtha Reyna, The Hospital for Sick Children<br/> Nutrition &amp; Diet, Dr. Kozeta Miliku, University of Toronto<br/> Inflammation &amp; Immunity, Dr. Bassel Dawod, McMaster University<br/> Human Microbiome, Dr. Charisse Petersen, BC Children's Hospital<br/> Physical Activity &amp; Environment, Dr. Jeff Brook, University of Toronto</p> |



|                |   |  |
|----------------|---|--|
| 945 – 1015 AM  | <p><b>Speaker panel: CHILD Study from the youth and family perspective</b></p> <p>In this panel the NPEC (parents and youth) will join the speakers from the previous session in a table at the front, and they will be asked questions by the facilitator or audience about their experience participating in CHILD.</p> <p><b>Sara Celemin, Tatiana Celemin &amp; Reuben Celemin</b> - <i>Edmonton Site</i><br/> <b>Maxime Doucas-Mooy &amp; Natasha Doucas</b> - <i>Vancouver Site</i><br/> <b>Brynn Eddie &amp; Aaron Eddie</b> - <i>Toronto Site</i><br/> <b>Lily Raine Hoffman &amp; Harmoni Hoffman</b> - <i>Winnipeg Site</i></p>                                       | Auditorium   |
| 1015 – 1030 AM | <b>Break (Auditorium Alcove)</b>  |  |
| 1030 – 1100 AM | <p><b>CHILD Data: Who's Data, Who's Questions?</b></p> <p>Dr. Kozeta Miliku, University of Toronto</p>  | Auditorium   |
| 1100 – 1115 AM | <p><b>Youth Presentation: What does Health Equity mean to us?</b></p> <p><i>Facilitated by Anitha Ithayalingam and Dayla Kablawi</i></p> <p><b>Sara Celemin</b> – <i>Edmonton Site</i><br/> <b>Maxime Doucas-Mooy</b> – <i>Vancouver Site</i><br/> <b>Brynn Eddie</b> – <i>Toronto Site</i><br/> <b>Lily Raine Hoffman</b> – <i>Winnipeg Site</i></p>   | Auditorium   |
| 1115 – 1215 PM | <p><b>Group activity 2: CHILD 16Y protocol – Working Together</b></p> <p>The audience will be divided into 6 groups of 6 or 7 participants. Each group will be asked to answer the following questions:</p> <ol style="list-style-type: none"> <li>1. How can we make 16Y data collection better, easier, higher quality?</li> <li>2. How do we get youth participants excited and engaged with CHILD's future?</li> <li>3. Which research areas should we prioritize for adolescent health?</li> <li>4. How can CHILD influence meaningful shifts around adolescent health?</li> </ol> <p><b>Group 1, 3, 5</b><br/> <b>Group 2</b><br/> <b>Group 4</b><br/> <b>Group 6</b></p> | <p>Auditorium</p> <p>Meeting Room 20</p> <p>Meeting Room 22</p> <p>Meeting Room 23</p> |
| 1215 – 115 PM  | <b>BUFFET LUNCH (Connections Dining Room)</b>   |  |
| 115 – 200 PM   | <p><b>Group activity summary:</b></p> <p><b>What did we learn? What do we need to do?</b></p> <p><i>Facilitated by Dr. Francine Buchanan</i></p>  | Auditorium   |
| 200 – 230 PM   | <b>Closing Remarks</b>  | Auditorium   |





### CLOSED DOOR SESSIONS

|  |                 |
|--|-----------------|
| <b>Monday, July 22<sup>nd</sup>, 2024 @ 115 – 430 PM</b>   |                 |
| <b>Envisioning CHILD's Under a Health Equity Lens – Youth Breakout Session</b><br><i>(Facilitated by Anitha Ithayalingam and Dayla Kablawi)</i>  | Meeting Room 23 |
| <p>During the Group Activity 1: Envisioning CHILD Under a Health Equity Lens session on Day 1, youth participants will attend a workshop focused on health equity. They will be introduced to the concept of health equity and the factors contributing to health inequities. They will also learn about the difference between equity and equality while exploring the social determinants of health.</p> <p>A presentation on what was discussed will follow on DAY 2.</p> |                 |
| <b>Monday, July 22<sup>nd</sup>, 2024 @ 400 – 430 PM</b>   |                 |
| <b>NCC – CHILD Site Meeting</b> <i>(Facilitated by Elissa Brookes)</i><br>NCC to meet with CHILD site leads and coordinators to discuss local REB action plan regarding GPS data sharing.  | Auditorium      |
| <b>Tuesday, July 23<sup>rd</sup>, 2024 @ 300 – 400 PM</b>  |                 |
| <b>NPEC Meeting</b> <i>(Facilitated by Anitha Ithayalingam)</i><br>NPEC families to meet with CHILD Kmb Program Manager to discuss future direction of NPEC, both at the site and national level, Youth Council, and CHILD Kmb strategy.   | TBD             |