


## Exploring the perspectives of caregivers of urban Inuit children on child health knowledge mobilisation

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### ABSTRACT

Our study sought to explore the experiences of caregivers of urban Inuit children with respect to child health knowledge acquisition to develop community-specific best practices for health promotion initiatives. A needs assessment was conducted to understand how caregivers access child health knowledge and services; what child health issues require improved knowledge mobilisation; and how caregivers would like to access this knowledge. Four focus groups were held with twenty-four parents and caregivers of Inuit children. Child health knowledge acquisition was influenced by dynamics of trust and discrimination, making caregivers' social networks and Indigenous health services highly valued sources. Health topics identified as requiring improved knowledge mobilisation were those in which caregivers faced tensions between Indigenous and non-Indigenous ways of knowing. Such topics included parenting and development, adolescent mental and sexual health, common childhood illnesses, infant care, and nutrition. Caregivers preferred a multi-modal approach to health promotion, highlighting importance of in-person gatherings while also valuing accessible multi-media components. The presence of Elders as facilitators was especially important for child development, parenting, and nutrition. For health promotion to be effective, it must consider community-specific health knowledge sharing processes; tensions between Indigenous and non-Indigenous ways of knowing; and community ownership in health promotion endeavors.

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## Introduction

It is well documented from a decade of research that Canadian Inuit children experience significant health disparities compared to non-Inuit children. These include a higher prevalence of respiratory infections [1,2], otitis media [3,4], iron deficiency anaemia [5], early childhood caries [6] and food insecurity [7]. 54% of Nunavut Inuit live in overcrowded households [8], and Indigenous children across Canada are grossly overrepresented in the child welfare system [9]. While fewer studies have examined the health status of Inuit children in urban settings, one notable study demonstrated that living in an urban setting with closer proximity to healthcare resources was *not* associated with improved birth and infant outcomes among Inuit and First Nations peoples [10]. Together, these disparities highlight an urgent need for the development of community-based health promotion and intervention efforts targeting the health needs of Inuit children living in urban areas.

Inuit health research and health promotion should necessarily involve participatory and co-creative approaches in their development, centred on community ownership and inviting of traditional and Inuit specific knowledge [11,12]. For health knowledge mobilisation strategies to be designed in culturally-safe and culturally-specific manners, it is crucial that they be informed by community-specific ways of knowing and processes of health knowledge acquisition. In this spirit, [13], partnered with the Tungasuvvingat Inuit Family Resource Centre in Ottawa to study perspectives on health knowledge acquisition and dissemination strategies among urban Inuit. To our knowledge, no such study has explored these important themes in the context of urban Inuit children, specifically. We aimed to explore the perspectives of parents and caregivers of Inuit children residing in Ottawa on the processes that impact child health knowledge mobilisation for the purpose of informing future community-based child health knowledge mobilisation initiatives.

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## Materials and methods

### *Ethics approval and consent*

Our study protocol was reviewed by the Children's Hospital of Eastern Ontario Research Institute's Research and Ethics Board and deemed an activity outside the scope of research subject to REB (as per Article 2.5 of the Tri-Council Policy Statement 2 (see supplemental attachment). We nonetheless conducted the study according to the Tri-Council Policy Statement's core principles and guidelines for ethical conduct for research involving human participants. Informed written consent was collected at the start of each focus group, including consent to audio record the discussion for the purpose of later transcribing the recorded data. No identifying information was collected. Participants were notified of the intention for publication as part of the informed consent process at the start of the focus groups and were informed that they may withdraw consent at any time. To facilitate participation, each participant was provided free transportation to the centre, a community meal, free childcare during the session, and a \$25 gift card.

### *Setting*

According to the 2016 Canadian Census, Ottawa is home to the largest Inuit population living outside Inuit Nunangat, the traditional Inuit homeland. The Inuuqatigiit Centre for Inuit Children, Youth and Families (henceforth referred to as Inuuqatigiit, previously the Ottawa Inuit Children's Centre) was established in 2005 as a community agency serving Inuit children, youth, and families living in Ottawa with a mandate to promote healthy childhood development, foster positive parenting, and support the retention of Inuit culture and language. Inuuqatigiit is the only licenced full day, year-round Inuit specific childcare centre in Ottawa making it an ideal site for this study.

### *Study design and data collection*

This study was informed by settler-colonial theory, recognising the manner in which health science research has historically perpetuated colonial processes and systemic marginalisation among Indigenous groups [14]. In this spirit, we employed a community-based participatory research approach emphasising shared power and decision-making between the research team and community partners, and thereby centring the narrative on the voices of communities. The design also incorporated the centre's own ethical framework for conducting research

which was developed in the context of previous internally conducted focus groups [15]. The study was conceived and implemented in partnership with three Inuuqatigiit staff members and all planning meetings were held onsite at Inuuqatigiit.

The needs assessment was conducted according to descriptive qualitative study methods using focus groups to generate data [16]. Epistemological considerations behind the use of focus groups included *Unikkaaqatiginniq*, an Inuit concept of story-telling [17]. As noted by Healey and Tagak, the use of story-telling in Inuit community research allows for the incorporation of Inuit oral culture and recognises this millennia-old method of knowledge transmission. Story-telling also allows research participants to draw on personal experiences and anecdotes to illustrate points, deepening insight into the data [17]. Since, within this context, "interviews are conversations conducted in a natural, comfortable setting", focus groups were held at Inuuqatigiit, a familiar community setting, and included a meal of country food shared by study participants and research team members to support relationship-building and engagement.

Participants of our study were expectant parents and caregivers of Inuit children currently accessing programmes at Inuuqatigiit. Caregivers were defined as parents (including adoptive or foster parents), grandparents, or any other family member caring for Inuit children. Recruitment took place over a period of 3 weeks. Flyers describing the study were posted at Inuuqatigiit inviting eligible individuals to participate in a focus group. Parents attending certain programming (such as early year drop-ins, healing circles, parenting programmes, and event nights) were also approached by Inuuqatigiit staff to inform them of the study and invite them to participate.

The focus group guide was co-developed by the study team and Inuuqatigiit staff members and centred on three principal study questions:

- (1) How do urban Inuit parents and caregivers currently acquire child health knowledge?
- (2) Regarding what specific child health topics do they feel a need for improved knowledge mobilisation?
- (3) What are their preferred formats for child health knowledge mobilisation?

Focus groups were facilitated jointly by three Inuuqatigiit staff members and three study authors (DB, BH, RJ), who have had experience providing medical care to Inuit children and families in both Ottawa and Nunavut. Informed consent was collected at the start of each focus group, including consent to audio

record the discussion for the purpose of later transcribing the recorded data. No identifying information was collected. Demographic surveys were offered in both English and Inuktitut, and an Inuktitut-speaking facilitator was present in the event that a participant wished to express themselves using Inuktitut.

### Data analysis

Participant demographic data were analysed using descriptive statistics. Focus group transcripts were uploaded to NVivo 12 (QSR International Pty Ltd.), a qualitative data analysis software, to facilitate the coding that supported our thematic analysis. The coding scheme (Appendix A) was inductively developed over multiple rounds by three members of the research team (DN, BH and DB). The final round of coding was then performed independently by one team member, a qualitative research specialist (DN). The coded data were reviewed by two team members (BH and DB) to ensure accuracy. Any disagreements in the coding were settled by team consensus. The data were then categorised into groups and overarching themes in light of the guiding research questions and study objectives.

## Results

### A: Demographics

Twenty-four parents/caregivers participated in four focus groups, of which twenty-one (88%) identified as Inuit. Participants ranged in age from 19 to 40 years old. The majority of participants (88%) identified as female. Participants had lived a median of 15 years in an urban setting (interquartile range 10–23). Seventeen participants (71%) cared for children aged 5 or younger.

### B: Current sources of child health knowledge

Participants identified many knowledge sources that they turned to when attempting to obtain information related to children's health. These fell into four broad categories: online resources, social networks, Indigenous-specific health services, and non-Indigenous-specific health services. Participants described advantages and disadvantages associated with each category.

#### Online resources

Online resources were described as accessible and convenient. They were often identified as a first point of contact, albeit difficult to trust and navigate. Participants either turned to specific medical websites

(e.g. WebMD) and trusted hospital resources or used a general search engine. Major barriers associated with online resources included difficulty sorting through the high volume of information available and in evaluating credibility. One participant stated, *"you're searching for an authority on something, but maybe don't quite know where to go"*. Another participant described difficulty obtaining specific guidance when health issues present themselves: *"You read enough things and it could be either the common cold or cancer right? And that's not helpful"*.

#### Social networks

Social networks included family, friends, and peers. They were considered a highly accessible and trustworthy source of health knowledge. Several participants expressed the benefits of turning to family or friends with lived experience. As one participant stated: *"My best friend – she has three kids and she's kind of been through everything with them. So, she's my go to"*. Another participant likewise articulated with respect to breastfeeding: *"I asked my friends that have kids that breastfed and that's how I learned"*.

Participants also preferred turning to family and friends as they were felt to provide information that was more personal and holistic. Mothers, in particular, were identified by many participants as a first point of contact. One participant described the benefits of receiving health knowledge from her mother: *"My mom ... she's a better doctor than the other doctors because she's all about the side effects of medication, the body of the child, ... she considers all those steps and what is the best decision"*.

#### Indigenous-specific health services

When participants sought professional health advice, they preferred to access Indigenous-specific health services, particularly a local Inuit-specific family health centre. This centre was described as accessible, safe, welcoming, and able to cater to the unique needs of the urban Inuit community. Commenting on the issue that many health specialists in the South do not accept Nunavut health card numbers, one participant related: *"They [the local Inuit health team] know which health care providers take [Nunavut Health] cards"*. Another participant expressed appreciation for the ability to receive services in Inuktitut: *"It's good they have Inuit case managers there who speak your own language"*.

#### Non-indigenous-specific health services

These services encompassed Telehealth [A government service offering 24 hour on-call registered nurse

support for health information and triaging), primary care, emergency room, specialist, and mental health services both at the local tertiary care children's hospital and in the community. Many participants felt that calling Telehealth yielded knowledge that was too general to address their specific concerns or resulted in the recommendation to seek an in-person assessment. One participant summarised her experience of Telehealth as *"Every time I call they always say go to emergency"*.

While many participants were satisfied with the health advice received from primary care providers, specialists and mental health teams, some identified significant barriers related to cultural differences and discrimination. One common experience that emerged was implicit racist assumptions based on clients' appearance. As one participant noted: *"Both my brother and sister visibly look Inuk, whereas I don't. They've gotten a lot of questions around addiction and stuff like that ... that [the physician] wouldn't dare say to me ... I do think there is still definitely some of that preconceived notion about Indigenous people, like everybody has diabetes, everybody has some kind of substance abuse issues"*. Another participant noted a lack of cultural competence on the part of healthcare workers, such as a lack of knowledge of traditional food practices and refusing to accept an *amauti* as an acceptable way to transport a newborn baby: *"I mean, [a car seat] is very important when you're driving, but we are just [walking] out of the hospital using our own packing parka to take the baby out, we're fine. We don't need a car seat"*.

Barriers to receiving adequate health advice from non-Indigenous sources stemmed from a tendency to avoid confrontation in the face of authority. One participant noted: *"Like in Inuit culture, it [can be] considered rude to ask questions. So let's say you go to a doctor, if the doctor doesn't give you information and you don't want to be rude by asking questions, it's like, how come the doctor didn't tell me this or the doctor didn't tell me that?"*

### **C: Child health topics of interest**

There were five broad categories of child health topics for which caregivers expressed a need for better information: parenting and development; adolescent mental and sexual health; common childhood illnesses; infant care; and nutrition.

#### **Parenting and development**

Participants identified a need for improved guidance on a variety of issues relating to healthy childhood

development. This included recognising and managing developmental and behavioural concerns, recognising signs of trauma, navigating differing parenting styles, enhancing communication with one's children, limit-setting with screen time, and healthy sleep. A pervasive issue expressed by participants with respect to these topics was a sense of cultural dissonance between Indigenous and Western approaches. One participant objected to the very concept of healthy sleep for infants: *"What bothers me about that question is that in reality, babies don't have a healthy sleep. A healthy baby will keep you up every two hours"*.

Another participant noted significant differences in attitude towards children who appear to have developmental challenges: *"The traditional kind of approach that Inuit have is children grow at their own pace. And you work with their strengths"*. In the words of another participant: *"I kind of live in both worlds ... I kind of follow two streams ... On one side I'm like I need the doctors to make sure she's okay. And then other things I'm like, she's fine"*.

#### **Adolescent mental and sexual health**

Participants expressed a need for improved guidance on communicating with their adolescent children about topics such as safe sex, mental health, and suicide. One participant stated: *"I have a 16-year-old ... I don't know how to talk to her about safe sex ... She doesn't want to talk about it with me. But I want to talk to her about it. And I don't know the right words. You know, we stopped talking about it, because I don't know how"*. Another participant described an ongoing stigma around suicide and the need for better support to hold open conversations about it with youth: *"How can we talk to our children about [suicide]? My friend died by suicide a couple of weeks ago and I told my kids. They couldn't come to understand it. But they're growing older now and I'm pretty sure they're going to start realizing what I want them to understand and why ... to help to talk to them about mental health"*.

Another participant described the challenges caused by generational and geographic differences when communicating with her teenaged child: *"With my fourteen-year-old, there are times where I'll have a conversation with him. He'll always tell me, 'Well, that happened to you, or that happened to grandma but we are today ... It's harder for my kids to relate to because they're raised here. They were born here'"*.

#### **Common childhood illnesses**

Participants expressed the need for better guidance on the recognition, management, and prevention of common childhood illnesses such as fever, ear



infections, and strep throat. One participant stated: *“My son always gets strep throat ... I’d like to know how come he keeps getting sick? What can we do to prevent it? Am I doing things wrong that he keeps getting sick?”* In particular, one participant commented on the need for education on child health issues that would be unfamiliar to families from the North: *“Our environment here is different. We don’t have trees and grass [back home]. You guys have a lot of things. So I think it’s great that you guys educate our parents on ... poison ivy and things like that. And ... heat rashes because we don’t experience that up north”*. Some participants also expressed the need for better information surrounding immunisations and in particular, the flu vaccine.

### **Infant care**

Although less prominent than other topics, participants expressed a need for better information on aspects of routine newborn care including breastfeeding, infant sleep, and risks/benefits of circumcision. As one participant stated, this was especially important for new parents who did not have family members locally to turn to: *“Because being an expectant parent for the first time, you don’t know where to reach out, especially if you don’t have someone to rely on like an aunty or a mother. And it’s hard to find these resources readily available”*.

### **Nutrition**

Another less prominent topic that emerged was better guidance on optimising healthy nutrition, understanding how nutrition affects a child’s health, and managing picky eating. Participants mentioned the need for nutrition guidance that incorporates traditional country food but that is also specific to living in an urban centre. One participant expressed having felt discouraged when her physician discouraged consumption of traditional foods: *“She [my physician] was opposed to me eating [caribou or fish] raw, but that’s my ethnic food of choice, right? Now, my daughter, she eats it, and she loves it”*.

### **D: Preferred formats for child health mobilisation**

Participants discussed preferences with respect to three general formats for health knowledge mobilisation, including in-person sessions, technological resources, and printed materials. Preferences with regards to facilitator were also discussed.

#### **In-person sessions**

In-person sessions were valued since they foster a sense of community through dialogue and the sharing of lived-experiences. Commenting on the focus group,

one participant stated: *“Even groups like this to have relatable experiences, it helps you feel less isolated I guess. It goes a long way to know that you’re not alone”*. One participant commented: *“I like the more face-to-face stuff where I can really like get into a question”*. Another stated: *“The most effective and frankly, the most interesting way to share information and learn is by the in-person meetings”*. In-person sessions held in familiar community settings were described as safe places where participants would feel comfortable asking questions. As one participant stated: *“You get to ask questions with other parents that you know ... it’s easier to ask questions around people you know”*. The main challenges presented with in-person groups related to location choice, scheduling, transportation, and childcare needs.

#### **Technological resources**

Technological resources encompassed audio and video materials that would not require in-person attendance. These were preferred for their ease of access and flexibility. Podcasts were frequently mentioned as examples: *“Podcasts, or just recorded audio files, are very accessible because you can administer them almost anytime”*. Participants also mentioned apps, social media groups, online videos, discussion forums, and websites as potentially helpful modes of delivery. Disadvantages associated with these types of resources revolved around a lack of interactivity and the belief that technological platforms do not foster a sense of community.

#### **Printed materials**

Participants expressed conflicting opinions about the usefulness of printed materials. Some participants appreciated printed handouts as long as the material was short and concise, while others were adamant that these could never replace the interactivity of face-to-face sessions. One participant stated: *“Having that conversation face to face is what works, and the pamphlets don’t work”*. In general, printed materials were preferred as a supplemental resource rather than a stand-alone resource for child health information.

#### **Facilitator preferences**

With regards to who should be designing and implementing any of the potential child health initiatives discussed, there was an overarching sentiment among participants that it was important for an Inuit community member Elder to be involved for topics that have significant cultural dimensions such as child development, child-rearing, and nutrition. As articulated by one participant: *“There’s a lot of value in language and culture. So it means a lot more when it’s run by our own*

people". The involvement of an Elder would also be more inviting, as articulated by this participant: "If there's an elder there speaking to something like country food, to me that that actually makes it more inviting and accessible".

On the other hand, some participants felt that the presence of an Elder was less necessary for certain health topics where the presence of a healthcare professional was deemed more important. One participant state: "I think when it comes to medicine, or health care, it's not necessary for an Elder to be there". Participants did express the sentiment that non-Inuit facilitators should at the very least have robust training in cultural safety. Inuktitut translation was also endorsed as necessary for any of the potential initiatives, albeit recognising the challenge of providing interpretation that would encompass the diversity of Inuktitut dialects spoken by local families.

## Discussion

### Accessing child health knowledge: the role of trust

Understanding the factors that influence how urban Inuit families acquire child health knowledge is essential for informing the development of future child health knowledge mobilisation initiatives. Major factors that influenced the accessibility of child health knowledge were those of trust and discrimination. While online health resources were widely used due to ease of access, their use was limited due to concerns of reliability and applicability. Conversely, obtaining health knowledge from family or friends with first-hand Northern living experience was highly valued as this knowledge were considered both trustworthy and personal. These themes are similar to those identified in the study by 13, where family, community networks, and people with similar lived experiences were among highly valued sources of health knowledge.

Participants in our study also expressed a preference for Indigenous-specific and Inuktitut-speaking health providers rather than non-Indigenous providers due to undercurrents of mistrust and racism. These undercurrents are directly related to historical trauma and ongoing systems of oppression and colonialism, including within the medical system, that have been shown to significantly impact Indigenous people's access to healthcare across many contexts (18). Particularly salient to the health of women and children is how the threat of child apprehension, in the context of the overrepresentation of Indigenous children in foster care, affects the decisions of Indigenous women to access healthcare for their children or for themselves [19].\*\*\*

[20] It is therefore absolutely critical that any health knowledge mobilisation initiative be trauma-informed and developed through an anti-oppressive and anti-colonialist lens.

### Child health topics of interest: tensions between ways of knowing

Study participants identified five broad categories of child health issues in which there was a need for improved knowledge mobilisation: parenting and development; adolescent mental and sexual health; common childhood illnesses; infant care; and nutrition. A pervasive theme that emerged across these topics was tension felt between Indigenous and non-Indigenous ways of knowing. For instance, with regard to childhood development, participants expressed tension between a traditional perspective that each child develops at his or her unique pace versus the Western paradigm of assessing developmental delay based on established normative milestones. Similar concerns were expressed with respect to tensions between the Inuit practice of feeding infants raw country food and carrying them in amautis versus the Western approach of avoiding raw meat and using car seats for infants. Finally, for Inuit parents who grew up in the North and raised children in Ottawa, cultural dissonance between parents and their adolescent children challenged their ability to discuss such topics as mental health, sexual health, and suicide. These are issues that can carry significant stigma and disproportionately affect Inuit youth [21].

The potential to integrate Indigenous and non-Indigenous perspectives is outlined in the Mi'kmaw concept of Two-Eyed Seeing [22]. In the words of Marshall et al., "Two-Eyed Seeing refers to learning to see from one eye with the strengths of ... Indigenous knowledges and ways of knowing, and learning to see from the other eye with the strengths of ... Western knowledges and ways of knowing ... and, most importantly, using both of these eyes together for the benefit of all" [22]. The Two-Eyed Seeing approach has been applied to a number of contexts including the health sciences, medical education, research paradigms, and the classroom [23,24]. Likewise, in the context of an urban Inuit community, future child health knowledge mobilisation initiatives should be designed to integrate Inuit and Western knowledges and traditions. In particular, a decolonising approach to community health promotion [25] should aim to champion Inuit knowledge systems and empower families to uphold Inuit child-rearing practices within a Western urban context.

### ***Modes of delivery: the importance of multi-modal and collaborative initiatives***

Three modes were explored with respect to health knowledge mobilisation strategies: face-to-face sessions, technological resources, and print materials. Face-to-face sessions were valued for allowing intimate and supportive conversations at the cost of accessibility due to various logistical barriers [mainly scheduling, transportation, and childcare factors]. Conversely, technological resources were valued for their accessibility, but at the cost of physical community connectedness. Paper resources were felt to be the least useful on their own, although beneficial as a supplement to other modes of delivery. It was repeatedly expressed that no single mode was necessarily best, but that multi-modal initiatives would allow for the advantages of each model to complement each other. The involvement of Elders in the inception and delivery of health knowledge mobilisation initiatives was deemed critical for topics of development, child-rearing, and nutrition in particular. However, the involvement of health care professionals was also deemed important for most topics.

Our findings complement those of 13, suggesting that in the Inuit community direct oral communication strategies including audiovisual media are preferred over typical knowledge dissemination strategies such as pamphlets. Furthermore, communities need to play a significant role in the development of such initiatives, especially through the involvement of Elders as traditional sources of health information. This is consistent with previous research that has found Indigenous prenatal infant-toddler health promotion programmes to be most successful when emphasising community leadership and participation in the initiation, development, and implementation of programmes (11). Finally, the need for a collaborative approach involving traditional knowledge keepers and health care professionals further underscores the need to mobilise child health knowledge in a manner that addresses cultural tension experienced by individuals as well as those existing between Northern Indigenous parents and their children who grow up in a Southern urban environment.

### ***Limitations***

Our study is the first of its kind to explore the views of urban Inuit parents and caregivers on child health knowledge mobilisation. Acknowledging the significant heterogeneity that exists both within and between Indigenous communities, care must be taken not to generalise these perspectives to other urban or non-urban Indigenous communities. In addition, most study

participants were woman and it is unclear whether our study fully reflects the views of male caregivers. Finally, our relatively small sample size of 24 participants recruited from one community agency may not have adequately represented the diversity of experiences within the broader Ottawa Inuit community.

We acknowledge that the community perspectives shared in the study reflect the pre-CoVID-19 pandemic era. Given new challenges with social distancing, current community health knowledge mobilisation strategies need to consider the use of virtual platforms. Access to technology such as tablets, computers and high-speed internet remain significant issues facing urban and non-urban Indigenous populations [26]. It will be crucial that any virtual health knowledge mobilisation initiative be accompanied by funding that would allow for improved access to technology and connectivity among target communities.

### **Conclusion**

In conclusion, successful community child health promotion efforts must be informed by the specific factors influencing health knowledge processes in communities. Health knowledge mobilisation initiatives must be rooted in a decolonising approach; be informed by historic dynamics of mistrust related to intergenerational trauma; uphold Indigenous ways of knowing; and be developed collaboratively between health professionals and community members in a manner that empowers community ownership and participation.

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No potential conflict of interest was reported by the author(s).

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## Data availability statement

All data was collected and stored on a secure software called REDCap at the Children's Hospital of Eastern Ontario Research Institute. Coding was done using NVivo software and is securely stored. See attached codebook summary. Transcriptions are available at additional request.

## Author contributions

Brian Hummel and Daniel Bierstone are co-lead authors. All authors contributed to the conception, design, execution, and analysis of the study.

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## Focus Group Guide

### (1) Welcome and introductions

- Facilitators introduce themselves and their personal and professional experiences caring for children
- Explanation of purpose
  - We are here because we care about kids' health and well-being. We all want to help our kids grow up to be the healthiest and best they can be, and we all want to support each other in this.
  - We understand that sometimes Inuit families in Ottawa can find it difficult to get information about their children's health. We want to know if you have also had some of these challenges so that we can make things easier.
  - We also want to hear your ideas about how we can make it easier for you to find knowledge about your children's health, and in a way that feels safe. For example, one of the things we could eventually do is to set up gatherings where we can learn together, and from each other, about how to keep our children well.
  - We know that for some people a lot of these questions may have been asked before, and we don't want to keep asking the same questions. But we do hope to hear your unique stories and experiences.
  - What we talk about today will be audio recorded so that we can look at what everyone has shared and put it all together. Once we have put it all together, we will come back to present the result with you and share them with other doctors and health care workers. **NONE OF YOUR NAMES OR VOICES WILL BE IDENTIFIED. NO ONE WILL KNOW WHO SAID WHAT.** If you didn't consent to being recorded we will pause the recording for you when you speak.
  - By doing this project we hope that we can make our relationship between CHEO and Inuit

families in Ottawa even stronger, and hopefully find a way to make it easier for you to get health information about children.

- A few more things to discuss
  - You can speak and listen in whatever language you are most comfortable with. We have here ... who is available to translate if you wish. Feel free to express yourself in Inuktitut or ask for things to be translated to Inuktitut for you to listen
  - In order to keep this environment safe, we want to promise to one another that what we hear here stays here. And when we put all the information together, your names will not be used and you will never be identified in every way. We respect privacy. All of the information will be confidential.
  - All of your stories and experiences are important to us. In order for us to record everything accurately, we ask that only one person speak at a time. We also want to give everyone a chance to speak.
  - There are 9 questions and we will ask for 1hr to 1.5hrs of your time, although anyone is free to step out at any point.
  - Finally, we wish to thank you for welcoming us into your space and sharing your experiences with us. We also wish to acknowledge the wisdom of all those who came before us.
  - Does anyone have any questions for us before we begin?

Generic Prompts (to be used for any question):

- Has anyone else had that experience?
- Does anyone feel differently about that?
- Can you tell me more about ...
- Help me understand what you mean by ...
- What was that like for you?

() When you feel you need advice or information about you children's health, who or what sources of information do you turn to?

- Prompts:
  - Are there specific people you've turned to for help in the past?
  - Has anyone tried finding child health information online?

(3) We want to make it easier and quicker for you to get information on how to keep your kids healthy without having to always go to the doctor or emergency room. Is there anything in particular about your child's health or parenting that you'd like to learn about?

- Some potential examples as prompts if few ideas are generated:
  - What to do if you feel like your child is not walking or talking when you feel they should be
  - What to do if you feel like your child isn't learning the way you feel they should.
  - What to do when your child gets sick or has a fever.
  - Healthy living and eating for babies, children, teenagers
  - Physical activity
  - Sleep problems
  - Caring for a new baby
  - Caring for teeth
  - Vaccines/needles
  - Coping with changes in your child when they become a teenager
  - Mental health difficulties – for example sadness/depression, nervousness/anxiety, and suicide/self-harm
- Would there be any other topics of interest?
- Facilitators can also cite personal examples as parents.

Order of next questions can be dictated by conversation to this point.

(4) What would be some of the good ways to get such information?

- Prompts:
  - New community programming
  - Incorporating this into existing community programming
  - Session on child health topics
  - Inuit-specific health-related pamphlets
  - Inuit-specific health-related podcasts

(5) Who should [the above interventions] be created/ run by?

- Prompts:

- CHEO resident physicians (doctors in training)
- Inuit Elders
- Is there anyone else who you think should be involved in creating/facilitating these sessions?

- Depending on earlier comments:
  - I heard somebody say that they would be uncomfortable asking questions to a doctor – can you tell me more about that?
  - I heard somebody mention earlier that they would want an Elder to attend the session. Can you share why this is important to you?"

(6) How could they be made most inviting and accessible?

- Prompts:
  - Would it be important for people to have an Elder present, or to find a way to incorporate traditional knowledge?

(7) What else do we need to consider when planning them?

- Prompts:
  - Are there any specific logistical factors that need to be considered when planning these (such as location, time of day, childcare arrangements, language)

(8) What has worked well and what has not worked well, in the past, with regards to accessing health information?

- Prompts:
  - Are there particular barriers people have faced in the past when trying to access information about your children's health?
  - Is there anything in particular that people have found helpful in the past when trying to access information about your children's health?

(9) Conclusions

- Before we finish today, is there anything we haven't asked you about that you think is important for us to know?
- We hope that these focus groups will benefit families by enabling the creation of programming aimed at empowering families to more easily access to day-to-day information pertaining to child health and parenting
- Once again, we request that was spoken here remains here and we also reiterate our commitment to keep everything that was shared to day confidential.
- We wish to once again express gratitude to everyone for inviting us into your space, for your time, and for sharing your stories and experiences with us.



## Demographic Questionnaire

This form asks you to share some information about you and your family so that we can offer the best programmes and services for everyone. We want to get the full picture of your family and what your needs might be. Some of

the questions are personal in nature but please know that all the information you share will be kept confidential and only shared with certain staff that need to know the information. Please only answer questions you feel comfortable answering.

1. Which option describes your age?

- 18-years-old or younger
- 19–25 years-old
- 26–30 years-old
- 35–40 years-old
- 40 years-old or older
- Prefer not to answer

2. Which option best describes you?

- Male
- Female
- Non-binary
- Other
- Prefer not to answer

3. Which of these options best describes your ancestry?

- Inuit
- Metis
- First Nations
- Non-Indigenous
- Other

3. What are all the levels of education you completed?

- Elementary school until what grade \_\_\_\_\_

- High school until what grade \_\_\_\_\_
- College
- University
- Prefer not to answer

4. How many years have you lived in Ottawa? \_\_\_\_\_

5. Which of these describes your current employment status? Check all the apply.

- Student
- Not working at the present time
- Self-employed
- Employed full-time
- Employed part-time
- Prefer not to answer

6. How old are the children in your household?  
Qujannamiik!

Exploring the perspectives of caregivers of urban Inuit children on child health knowledge mobilisation

	0– 12 years	13 months – 5 years	6– 12 years	12– 18 years	19 years and older
Child 1					
Child 2					
Child 3					
Child 4					
Child 5					
Child 6					
Child 7					
Child 8					
Child 9					
Child 10					
Child 11					
Child 12					



## Guiding Research Questions

- (1) How do urban Inuit parents and caregivers currently acquire child health knowledge?
- (2) Regarding what specific child health topics do they feel a need for improved knowledge mobilisation?
- (3) What are their preferred formats for child health knowledge mobilisation?

### CATEGORISED CODES

#### SOURCES OF CHILD HEALTH KNOWLEDGE

Indigenous-focused service  
Medicine  
Social networks  
Telehealth  
Online

#### BARRIERS TO ACCESSING CHILD HEALTH KNOWLEDGE

Complaints of previous care  
Discrimination and Fears  
Cultural differences  
Gaps in care  
Systems navigation

#### CHILD HEALTH TOPICS OF INTEREST

Common childhood conditions  
Pregnancy and Infant Care  
Nutrition  
Parenting, Behaviours, Development  
Adolescent Health

#### MODES OF DELIVERY & FACILITATOR PREFERENCES

In person group  
Paper  
Technologies  
Other Considerations  
Inuit or Inuit Elder  
Health Practitioner

#### ACCESS FACTORS

Cultural competence for healthcare providers  
Childcare  
Food  
Language  
Location  
Scheduling  
Transportation

### Codebook (alphabetised)

CODE	DEFINITION
Adolescent Health	Health topics of interest: comments specific to teenagers (mental health, sexual health)
Childcare	Access factors: comments related to childcare
Common childhood conditions	Health topics of interest: comments related to common conditions (heat rash, ear infections, etc.)
Complaints of previous care	Barriers: Participants expressing complaints, dissatisfaction, recalling past negative experiences while accessing care
Cultural competence	Participants expressing importance of cultural competence for physicians/facilitators working with Inuit population
Cultural differences	Barriers: Participants highlighting differences in culture, lifestyle, parenting (e.g. sleeping, diet, transport)
Discrimination and Fears	Barriers: Participants suggesting that previous treatment or practices felt discriminatory (specific to Inuit identity)
Food	Access factors: comments related to food
Gaps in care	Barriers: comments related to gaps in care
Health Practitioner	Facilitator preferences: comments related to healthcare provider-led learning (doctor, nurse)
In person group	Mode of education: comments related to in-person/group learning, workshops, etc.
Indigenous-focused service	Sources of health information; Indigenous-focused organisations (e.g. Wabano, IT, Akausivik)
Inuit or Inuit Elder	Facilitator preferences: comments related to elders/inuit facilitators for teaching/learning
Language	Access factors: comments related to language
Location	Access factors: comments related to location
Medicine	Sources of health information (includes hospital visits, family physician, nurses)
Nutrition	Health topics of interest
Online	Sources of health information; medical or other (e.g. google MD, hospital websites, forums)
Other Considerations (Mode)	Mode of education: general comments related to styles of learning
Paper	Mode of education: comments related to reading/paper/pamphlets (excluding online)
Parenting, Behaviours, Development	Health topics of interest: comments related to parenting, discipline
Pregnancy and Infant Care	Health topics of interest: comments related to pregnancy and infant health (breastfeeding, etc.)

(Continued)



(Continued).

CODE	DEFINITION
Scheduling	Access factors: comments related to scheduling
Social networks	Sources of health information; Non-medical, informal (e.g. family, peers)
Systems navigation	Barriers: comments related to difficulty navigating health care system, including issues with health cards, billing, etc
Technologies	Mode of education: comments related to online, apps, podcasts, etc.
Telehealth	Sources of health information; toll-free numbers
Transportation	Access factors: comments related to transportation

1 May 2019 Dr. Radha Jetty  
Consulting Paediatrics  
Dear Jetty,

<b>Romeo#</b>	20,190,189
<b>REB#</b>	19/35X
<b>Title:</b>	Child Health Promotion through Community Educational Sessions in an Urban Inuit Community: A Needs Assessment

The above submission was reviewed under the delegated stream, which is reserved for protocols that present no more than minimal risk to subjects.

Upon review of the application and protocol, it was noted that the project outlined a needs assessment. The purpose of the needs assessment is to explore the needs of Inuit families living in Ottawa with regards to accessing information on child health topics and to determine whether community sessions would be a suitable format to deliver this information. Importantly, a needs assessment is not considered research as defined by TCPS 2 (*e.g. an undertaking intended to extend knowledge through a disciplined inquiry and/or systematic investigation*).

**Accordingly, CHEO REB approval is not required, as the application and protocol do not fall under the jurisdiction of the CHEO REB.**

The application will be marked as withdrawn in ROMEQ.

Should you have any questions or wish to discuss this further, please contact the office of the REB at extension 2128 or 3350.

Regards,



Richard Carpentier, Ph.D.  
Chair, CHEO Research Ethics Board