# Exploring the Experiences and Information Needs of Parents Caring for a Child With a Urinary Tract Infection: A Qualitative Study

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### **Abstract**

Urinary tract infections (UTIs) are common in children, however, clinical practice variations can leave parents unsure how to care for their child. We aim to develop knowledge tools that provide evidence-based information about pediatric UTIs. To inform tool development, we asked parents to share their experiences and information needs in caring for a child with a UTI. Using qualitative description methods, I6 semistructured interviews were conducted with I8 parents. Parents were recruited through the emergency department (ED) of a major Canadian urban pediatric hospital. Five major themes emerged: (I) parent descriptions of their child's symptoms and behaviors; (2) UTIs have an effect on the entire family; (3) reasons for going to the ED; (4) parent experiences with UTI treatment, management, and follow-up strategies for their child; and (5) parent information needs and preferred information sources for UTIs. Our findings highlight the diversity of UTI symptoms children experience, which causes uncertainty and confusion for parents. This diversity suggests the development of knowledge tools for parents about UTIs is needed.

#### **Keywords**

urinary tract infection, pediatrics, child health, parent experience, qualitative methods, information needs, parents, children

### Introduction

Urinary tract infections (UTIs) are among the most common bacterial infections in infants and children. Urinary tract infections are defined as a colonization of bacteria anywhere along the urinary tract. The cumulative incidence of childhood UTIs is estimated to be between 5% and 12% (1). Children with uncomplicated UTIs generally recover without consequences following administration of adequate antimicrobial therapy (2). A small proportion of children will experience long-term consequences including renal scarring, hypertension, and chronic renal insufficiency (3). The risk of long-term complications associated with UTIs can be minimized with early recognition and timely treatment.

Guidelines and recommendations on the management of UTIs have evolved since the early 2000s (4–6). Despite this evolution, treatment variability prevails. Factors influencing variability include age, presenting symptoms, difficulty in urine collection, contamination of samples, and medical history (4,6). Current imaging, prophylaxis, and prolonged follow-up strategies place a heavy burden on patients, families, and health care resources that may carry risks without evidence of benefit (7).

Diagnosing UTIs in children can be difficult as symptoms are often nonspecific including fever, abdominal tenderness, vomiting, screaming, and general fatigue; even these common symptoms may be absent in many children (8–10). The nonspecificity and widespread misconceptions about UTI symptoms present challenges not only for doctors to detect UTIs, but also challenges parents faced with the decision to seek medical care for their child (10). As a result, parents may delay seeking medical care if overt signs (eg, changes in urine odor), despite being clinically unfounded, are not present (8,11). Diagnosis of UTIs can only be confirmed following urine culture results, which can take 24 to 48 hours (8).

Anxiety and uncertainty are common for parents when a child becomes ill and parents' perceptions of the illness can

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affect their confidence and ability to provide care for their child (12). These feelings about acute childhood illness lead parents to seek information on whether to seek help from a health-care professional (12). As parents play a vital role in preventing, detecting, and managing UTIs in children, it is imperative that health information is shared with parents and families in ways that are easy to understand and address their unique information needs (6,13). Parental resources tend to focus on medical information and often neglect the day-today impacts such as missed work, challenges with childcare, and schedule adjustments. Furthermore, there is little research into parents' experiences and perspectives on the detection and treatment of pediatric UTIs, despite parents often being the ones deciding to seek medical advice (10,14,15). A recent review identified only 2 qualitative studies exploring these phenomenon, both of which were dated from the early 2000s (15). Since then, clinical practice guidelines have been updated and new information about pediatric UTIs have been released (4,5). Furthermore, it has been suggested that understanding parents' perspectives about common childhood conditions may highlight misconceptions, knowledge gaps, or systemic issues contributing to the high burden of these illnesses, such as UTIs (16,17).

We aim to develop knowledge tools that provide evidence-based information about pediatric UTIs to increase knowledge, awareness, relevance, and meaning for parents. To inform the development of these tools, we wanted to explore parents' experiences caring for a child with a UTI, where they look for health information, and what their information needs are regarding pediatric UTIs. Understanding these aspects will be useful in developing an educational intervention for parents to enhance UTI awareness. The objectives of this qualitative study were to describe parents' experiences taking care of a child with a UTI and to identify their information needs in managing their child with a UTI.

## **Methods**

# Ethical Approval

This exploratory study employed qualitative descriptive approaches (18,19). The University of Alberta Health Research Ethics Board and Alberta Health Services (AHS) granted institutional ethics approval prior to participant recruitment (REB Pro00062904). All participants provided written informed consent prior to participation. Reporting of this study followed the Consolidated Criteria for Reporting Qualitative Research checklist (See supplementary file) (20).

# Sample

Participant recruitment occurred by convenience sampling from the Stollery Children's Hospital emergency department (ED), in Edmonton, Alberta. In the ED, clinical team members identified eligible participants via the ED information system and notified the Stollery Children's research recruitment team so potential participants could be approached

face-to-face after triage. Participants were eligible if they met the following inclusion criteria: (1) parent of a child 16 years old or younger; (2) parent presenting to the Stollery Children's Hospital ED seeking care for a child with UTI symptoms; and (3) parent is fluent in English. Potential participants were provided with a study information letter outlining the purpose of the study.

### **Data Collection**

Research assistants trained in qualitative data collection (AC and SLP) followed up with interested parents via telephone to schedule an interview at a mutually agreed upon date, time, and location or by telephone. After obtaining written informed consent, parents completed demographic forms. An interview guide was originally developed by the senior author (SDS), with adjustments made by a research assistant (AC), based on results from the team's knowledge synthesis on UTIs, to explore caregiver experiences with child UTIs (15). Interview questions moved from general to more specific and interviews later in the data collection period became more focused (see Interview Guide, Supplementary File). All interviews were digitally recorded and transcribed verbatim by a professional transcriptionist and interviewers recorded detailed field notes during each interview. Data collection and analysis occurred concurrently until no new information emerged from the interviews, suggesting data saturation (21).

# Data Analysis

Sandelowski's approach of data reduction for qualitative analysis was used (22). Data analysis was managed in NVivo 11 (23). Demographic data were analyzed descriptively. The steps in data analysis included the following: first, transcripts were reviewed in detail several times by a research assistant (AC). Second, reflective memos extracting facts, storylines, topics, and content about each transcript were developed. Third, memos were grouped into broader categories according to recurring emergent themes by AC and reviewed by all authors (22).

Rigor was guided through application of validity and reliability strategies proposed by Morse (24). We addressed validity and reliability through development of a coding system to ensure meaning of the analysis was consistent among all authors. Our coding system was constructed through development of "preliminary codes" based on major categories that emerged from the text. Validity and reliability were further addressed through thick descriptions and maintaining a comprehensive audit trail documenting all decisions made throughout the research process. Discussions among authors regarding the coding system, analytic procedures, findings, and interpretations also enhanced analytic rigor (24). Demographic data were analyzed using measures of central tendency.

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**Table 1.** Demographic Characteristics of Sample of Parents of Children With UTI.

Variable	N	%
Gender <sup>a</sup>		
Male	3	16.7
Female	15	83.3
Parents age		
20-30 years	5	27.8
31-40 years	10	55.6
41-50 years	2	11.1
51 years and older	1	5.5
Marital status		
Married/partnered	17	94.5
Single .	1	5.5
Household income		
Less than CAD\$25 000	2	11.1
CAD\$25 000-CAD\$49 999	1	5.5
CAD\$50 000-CAD\$74 999	1	5.5
CAD\$75 000-CAD\$99 999	2	11.1
CAD\$100 000-CAD\$149 999	6	33.3
CAD\$150 000 and over	4	22.2
Prefer not to answer	2	11.1
Highest level of education		
Some postsecondary	2	11.1
Postsecondary certificate/diploma	6	33.3
Postsecondary degree	5	27.8
Graduate degree	3	16.7
Other	2	11.1
Number of children at home		
I	6	33.3
2	7	38.9
3	3	16.7
4	2	11.1
Age of child brought to ED		
Less than I year old	6	33.3
I-2 years old	5	27.8
3-4 years old	I	5.5
5-6 years old	3	16.7
7 years and older	3	16.7
Frequency of UTI		
First episode	7	43.8
Recurring episodes	9	56.2

Abbreviations: ED, emergency department; UTI, urinary tract infection. <sup>a</sup>There are 18 parents versus 16 children as in 2 interviews, both parents consented to participate.

## **Results**

## Demographics

Thirty-eight parents were eligible for participation, with 22 being unreachable or refusing participation. The main reasons for refusal were time constraints or not interested at the time. Thus, AC and SLP conducted 16 semistructured interviews with 18 parents. Participant demographics of both parents and children are presented in Table 1. The mean age of children was 3.3 years.

# **Themes**

Five major themes emerged: (1) parents' descriptions of their child's symptoms and behaviors; (2) UTIs have an effect on the entire family; (3) parents' reasons for taking their child to the ED; (4) parent experiences with UTI treatment, management, and follow-up strategies for their child; and (5) parent information needs and preferred information sources for UTIs. Quotes supporting each theme are presented in Table 2.

# Theme 1: Parent Descriptions of Their Child's Symptoms and Behaviors

Symptoms of UTIs varied among children. Age and severity of infection influenced symptom presentation. For instance, parents with older children (>3 years) reported that pain with urination was easy to detect as older children could verbalize this experience. Yet for parents with younger children (<3 years), symptoms did not always clearly suggest a UTI. The presence and grade of fever varied among all children. Some parents (n = 5) reported foul smelling or cloudy urine. The presence of blood in the urine, reflected one atypical case in our study. Parents commonly reported their child becoming irritable when experiencing a UTI, regardless of age.

Seven children (44%) were experiencing a UTI for the first time. Of these, 5 were less than 2 years old. The remaining children (n=9,56%) had recurring UTIs. Of these, 3 had underlying kidney conditions making them susceptible to UTIs. Parents of children with recurring UTIs reported easier symptom recognition and management as parents became familiar with UTI presentations. Interestingly, some parents who experienced UTIs before, but with a different child, indicated they were still unable to recognize UTI symptoms because they are nonspecific and children can present differently.

# Theme 2: UTIs Have an Effect on the Entire Family

Overall, parents reported caring for a child with a UTI impacts daily life. Witnessing their child experience a UTI evoked emotional distress. Parents described feeling "concerned," "helpless," and "stressed." Emotions heightened when children could not fully explain what was happening to them. One parent reported feeling unprepared, not only in regard to their child's symptoms, but also in relation to managing other demands like childcare. For some, the emotional stress subsided with experience. Some parents of children experiencing recurring UTIs expressed greater confidence in handling the situation and knowing what to expect. In contrast, experience with previous UTIs did not make a difference for some parents, especially if their previous experience was with a different child. Daily routines were often disrupted as parents typically took time away from work to care for their child. Parents often lost sleep from being awake all night with their child. Children often missed school or childcare due to pain from the UTI.

 Table 2. Participant Quotes to Support Thematic Analysis.

Thematic analysis	Participant quotes
Theme I: Parent descriptions of their child's symptoms and behaviors	"Most of the time, they were pretty similar. Because once we figured out what the symptoms were, we could catch them earlier. The earlier ones [first experiences] they were further along, 'cause we didn't know any better. We didn't realize that was the case. We had no idea." (Interview 3, child age 7 years)  "He he couldn't pee, he would pee like dribbles and then, but it would like burn, sting, hurt, he would bounce up and down on the toilet, he would squeeze my hand." (Interview 8, child age 7 years)  "She said it hurt to pee, and she wanted to pee but it wasn't coming out." (Interview 3, child age 7 years)  "I just knew something was a little off. There was no fever. I had no like abnormal diapers or anything like that. It was really like she was acting totally fine and then she started shaking." (Interview 12, child age 17 months)  "She never had a fever, actually, in any of them." (Interview 3, child age 7 years)  "And I noticed when he had peed, that it was really cloudy in his little tub." (Interview 13, child age 7.5 months)
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Tielle 2. O is lave all effect of the efful of all life	those opt "Yeah, I was likege for 12 ho all." (Inte "Well, as tir symptom
	know the drill. First couple of times, you don't really know." (Interview 3, child age 7 years)  "Yeah, one of my other children—one of my daughters had [a UTI] when she was about three. And she only had it once. It was more— it was more obvious. Like, 'cause she wouldn't go to the toilet. And she was screaming and she—she had a temperature as well."  (Interview 10, child age 2 months)  "We've never had a baby with a UTI so we didn't know what was going on. I just felt bad. I didn't know what was happening. Like this is my second child. So like, I should know what's happening." (Interview 2, child age 4 months)  "Also it affected not just me, but him, he missed out on school, the teachers were texting and calling me my sister had to help me out so that I could go to work." (Interview 8, child age 7 years)
Theme 3: Reasons for going to the ED	"I just knewsomething was a little off." (Interview 12, child age 17 months)  "And so, knowing that having given her some Tylenols to stop with the pain, trying to give her baths ah, with some Epsom salts, which was things that we've done in the past ah, were not helping. And so, that's when we ended up um why we ended up taking her to the Emerg." (Interview 16, child age 2 years)  "He couldn't tolerate it [the pain] so said, "I wanna go to the doctor." (Interview 5, child age 5 years)

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Thematic analysis	Participant quotes
Theme 4: Parent experiences with UTI treatment, management, and follow-up strategies for their child	"Ah, and to be very honest, I think it was a little bit of a traumatic experience for her [child], because um, the nurse was having difficulty as, inserting the catheter. And so ah, my—my daughter was quite quite upset, because ah, they had to try three separate times." (Interview 16, child age 2 years) "It's so hard to get a urine sample from a kid who had never had done it before, who is in pain. Who doesn't know um She—she didn't wanna wipe herself with that um, alcohol rub thing. Because it was very, very — ah, it stinks, right? So it was so hard. So I had to put my hand ah, right there and give her the — the — ah, like the cup under her. She — she didn't wanna sit on the toilet in the hospital.
Theme 5: Parent information needs and preferred information sources for UTIs	Ah, she didn't wanna pee in the cup." (Interview 9, child age 4 years)  "I usually prefer to go to the doctor. Because there's a lot of misinformation on the Internet." (Interview 3, child age 4 months)  "but I also think that they do need to inform you a bit better, because like I really didn't know what the outcome would be. Like if you know — and I didn't understand why they didn't give him the antibiotic the first time. And they didn't really answer that question either." (Interview I0, child age 2 months)  "So um, I've used Health Link in the past. Um, and depending on the severity [of the UTI] and whether or not we're able to get in to our pediatrician—ah, it helps us to make our decision whether or not ad, we utilize the ER." (Interview I6, child age 2 years)  "Ah, I would really not look anything serious up online, just 'cause there's so much misinformation out there. I wean, if there was like I mean—and there very well could be and I just don't know. Like if there—but if there was something. I like if Alberta Health Services had like a—you know, a parenting thing, like website. Yeah, of course I would like at that." (Interview I2, child age I2 months)  "Um, I think a lot of parents are—well, probably most are probably online, and probably Googling symptoms just as I do. If there was like a specific Alberta Health Services—or like a—Canadian system or something—whether it was a website or an app—with information that like—as you could trust, for sure." (Interview I3, child age 7.5 months)  "They IUTIs! would happen and we didn't really know what was going on or why, what the cause of it was." (Interview I2, child age 7.5 months)
	"Ah, and I just kinda made sure - change the diapers a little bit more frequently. I feel like we were doing that enough already, but obviously like just based on what I've been hearing um, from people I've worked with – and so yeah – I mean, I know UTIs can be common, especially with baby girls. Ah, and it's just something that that can happen." (Interview I2, child age I7 months)

Abbreviations: ED, emergency department; UTI, urinary tract infection.

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# Theme 3: Parents' Reasons for Taking Their Child to the ED

Parents reported different reasons for deciding to go to the ED. The main reasons reported were symptoms not improving, the presence of fever, and parent intuition that something was wrong with their child but unsure what. Other reasons reported were the ED being the only option at the time and older children asking to go to the doctor because they were "having a hard time peeing" or experiencing unbearable pain.

# Theme 4: Parent Experiences With UTI Treatment, Management, and Follow-Up Strategies for Their Child

Most children, regardless of age, were treated similarly. All parents reported being prescribed oral antibiotics for 7 to 10 days. Two children with severe infections were prescribed additional doses of intravenous antibiotics to be administered at the hospital daily. Parents reported giving their child Tylenol or Advil to manage symptoms of pain and fever. All children with recurring UTIs were taking prophylactic antibiotics daily. Diagnosis was typically made by symptoms reported by parents, urine samples, and blood tests. For younger children, obtaining a urine sample required catheterization, whereas older children were able to urinate in a cup midstream. Obtaining urine samples was not always easy and was often described as traumatic for both the child and parent.

Parents were typically advised that symptoms should clear within 7 to 10 days once starting the antibiotic and to make a follow-up appointment with their family doctor or pediatrician. For some children with recurring UTIs, a referral was made to a nephrology specialist (n = 4) or children were sent for an ultrasound of the kidneys to rule out damage or abnormalities (n = 2).

# Theme 5: Parent Information Needs and Preferred Information Sources for UTIs

Parents commonly reported turning to their health care provider (HCP), typically their family doctor or pediatrician, when their child became ill. Talking to an HCP was preferred to seeking information about their child's illness on the Internet.

Despite preferring to receive information from their HCP about UTIs, only 2 parents reported receiving any information from their HCP and the information they did receive was to inform them when they should take their child back to the doctor if symptoms persisted. In the province of Alberta, AHS Health Link provides a 24/7 telephone nurse advice and general health information service. Parents reported phoning AHS Health Link (n = 6), where they could speak to an HCP over the phone before going to the ED or clinic.

Parents reported using the Internet to search signs and symptoms to try figuring out what their child was experiencing. Parents would return to the Internet to find more information once their child received a diagnosis. Parents would typically use search engines such as Google. However, parents also admitted not knowing where to find credible information. Most parents reported avoiding social media to seek health information of any kind. One parent reported "browsing" through a mom group on Facebook. Seeking advice from family and friends was not common among our participants. Parents appeared to have a knowledge deficit in relation to the causes and prevention of UTIs. Most parents understood that UTIs were caused by bacteria but were unsure where the bacteria came from.

### **Discussion**

This qualitative study provides a comprehensive up-to-date perspective on parents' experiences caring for their child with a UTI, the symptoms and behaviors exhibited by children with UTIs, factors influencing parents to seek medical care for their child's UTI, the effects UTIs have on quality of life for children and families, and insight into what kind of information parents want and need about UTIs. Our findings revealed that UTIs are common in children and cause substantial parental concern, disruption to daily activities, extensive health services use, and indirect health care costs.

Our study findings suggest that parents' abilities to recognize signs and symptoms of pediatric UTIs varied and was often compromised due to the nonspecific symptoms their child exhibited. Harmsen et al reported similar findings and concluded that since UTI symptoms in children are often atypical, parents may not think of a UTI as a possible problem, which may be a barrier to seeking medical care and receiving a prompt diagnosis (10). In our study, parents whose child had a UTI for the first time reported greater difficulty in recognizing signs and symptoms and seeking timely medical care compared to parents of children experiencing recurring UTIs. This suggests that once parents have the knowledge and awareness of UTI symptoms, children may receive more prompt care and treatment (10,14).

In a survey of 52 parents of children with UTIs, 71% stated if they suspected their child had a subsequent UTI, they would collect a urine sample and see their doctor immediately (14). Parents in our study also reported taking proactive measures when they suspected their child was experiencing another UTI, such as collecting urine samples or requesting an antibiotic. However, some parents who experienced UTIs before, with a different child, were still unable to recognize UTI symptoms because they are nonspecific, and children can present differently. This finding suggests that while UTI symptoms may present similarly each time one child experiences a UTI, they may not present similarly among all children. This presents challenges in educating parents about how to recognize a UTI.

Although parents in our study preferred to speak to an HCP for information on UTIs, many still turned to the Internet. Although parents did not indicate why they chose to look up more information after receiving a diagnosis, it may be due to receiving inadequate or not enough

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information from HCPs. Our findings suggest that parents typically reported receiving information on treatment regimes, such as antibiotics, or when to come back to the ED rather than causes of the infection or prevention strategies. It is critical for parents to understand potential risks of pediatric UTIs and what can be done to prevent them from occurring to improve health outcomes for their child. Despite emphasis on patient collaboration in health care, HCPs may not adequately be addressing the information needs of parents of children with UTIs.

Similar to Owen et al, parents in our study reported a desire for more readily available, detailed, and reputable information about UTIs on the Internet (14). This is not surprising given the common use of the Internet in recent years, especially as a source for seeking health information (25). Despite being a large source for health information, the Internet also contains a wealth of misinformation (26), which parents in our study were aware of. What is unclear, however, is how equipped parents are to judge the credibility of online sources.

Although parents in our study were not explicit about what information they wanted to know about UTIs, our findings demonstrate a knowledge deficit in relation to causes, prevention, and symptom recognition. Previous studies found that parents indicated wanting to know more information about identifying UTIs, their seriousness, and how to prevent occurrences (10,14). These findings coupled with the knowledge deficits noted by parents in our study suggest that parents desire and require more information about pediatric UTIs. Parents' desire for credible information about their child's condition, even with the plethora of information available, is not unique to parents of children with UTIs. Other studies exploring parent information needs in relation to their child's acute illness have reported similar findings (16,17).

## Limitations

We conducted interviews at a single point in time and only with parents who were seeking care in the ED. We relied on parent self-report of their information needs and therefore recall bias is a potential limitation. Additionally, our study captures primarily mothers' perspectives and only an English-speaking sample.

## **Conclusions**

Parents play a vital role in the detection and treatment of pediatric UTIs. It is evident that UTIs can profoundly impact children and their families, and greater efforts are needed to educate parents and families about pediatric UTIs. Our findings highlight the diversity of UTI symptoms that children experience, which often causes uncertainty and confusion for parents. This diversity suggests the development of knowledge tools for parents about UTIs is even more critical. Parental experiences and information needs identified through this study will be used to create the context and

inform the development of innovative, evidence-based knowledge translation tools for parents of children with UTIs. Incorporating the care experiences of parents will ensure an engaging and relatable educational intervention for parents.

# **Practice Implications**

The findings of our study add to the limited existing literature on parent experiences and information needs in caring for a child with a UTI. Understanding the experiences of parents related to their child's acute illness and providing comprehensive education to parents about common child-hood illnesses like UTIs is essential to improving UTI management, enhancing child health outcomes, and increasing parental confidence in health care decision-making.

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### **Statement of Informed Consent**

All participants provided written informed consent prior to participation.

### Supplemental Material

Supplemental material for this article is available online.

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## **Author Biographies**

**Alyson Campbell** is a PhD candidate (Faculty of Nursing) at the University of Alberta. Alyson's research interests span both child health and knowledge translation (KT). Specifically, her doctoral work is in the areas of pediatric concussion and KT intervention development and evaluation. Her research involves a multi-phase, multi-methods study, focusing on the development and dissemination of an innovative KT tool about pediatric concussion for parents and children.

Lisa Hartling is a professor in the Department of Pediatrics at the University of Alberta. Lisa is a Canada Research Chair (Tier 1) in Knowledge Synthesis and Translation, and a Distinguished Researcher with the Stollery Children's Hospital Foundation. The focus of Lisa's work is to gather and synthesize the best available scientific evidence to help support decision-making by healthcare providers, administrators, and patients and their families.

Samantha Louie-Poon is a PhD student (nursing) at the University of Alberta. Samantha is interested in bridging concepts of health equity and social justice into knowledge translation approaches. Through her research, Samantha seeks to improve the health outcomes of migrant children resettled in Canada by examining the existing climate of health information delivery. Specifically, Samantha's research aims to develop health information that appropriately navigates cultural nuances, intersectional needs, and positional power.

Shannon D Scott is a professor in the Faculty of Nursing at the University of Alberta. She currently holds a Canada Research Chair for Knowledge Translation in Child Health and a Stollery Distinguished Researcher Award. Shannon's research program, Translating Evidence in Child Health to enhance Outcomes (or ECHO), aims to improve the health outcomes of children in Alberta and Canada through application of the best research evidence, as well as exploring factors that shape research implementation.