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Estimation of Post-Acute Conditions Associated with COVID-19 Vaccine Impact and Effectiveness Among Children and Adolescents in Canada

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Findings Report

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Brad Griffin, President
Ipsos Public Affairs
Signed on March 25th, 2025

This public opinion research report presents the results of a research design that included in-depth interviews (n=88) and an online quantitative survey (n=209) conducted by Ipsos Public Affairs on behalf of the Public Health Agency of Canada. The research study was conducted from June 27, 2024, to February 20, 2025.

Cette publication est aussi disponible en français sous le titre : **Estimation des syndromes post-COVID-19 associés à l'impact et à l'efficacité du vaccin contre la COVID-19 chez les enfants et les adolescents au Canada.**

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Abbreviations

AB	Alberta
ATL	Atlantic
BC	British Columbia
BIPOC	Black, Indigenous, and other people of colour
CDC	The Centers for Disease Control and Prevention
COVID-19	Coronavirus Disease 2019
ER	Emergency room
GI	Gastrointestinal
HCD	Human-centered design
MB	Manitoba
MIS-C	Multi-system inflammatory syndrome in children
mRNA	Messenger ribonucleic acid
NACI	National Advisory Committee on Immunization
NASEM	National Academies of Sciences, Engineering, and Medicine
NU	Nunavut
NWT	Northwest Territories
ON	Ontario
PASC	Post-acute sequelae of SARS-CoV-2
PCC	Post-COVID condition
PEM	Post exertional malaise
POR	Public opinion research
POTS	Postural orthostatic tachycardia syndrome
PHAC	Public Health Agency of Canada
QC	Quebec
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
SK	Saskatchewan
SSRDs	Somatic symptoms and related disorders
UNWGT	Unweighted
VE	Vaccine effectiveness
VH	Vaccine hesitancy
WGT	Weighted
WHO	World Health Organization
YK	Yukon

Executive summary

Background and Research Objectives

Children and adolescents infected with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) can develop long-term symptoms that are commonly known as post COVID-19 condition (PCC), Long COVID, or post-acute sequelae of SARS-CoV-2 infection (PASC). Numerous knowledge gaps remain about the frequency, characteristics, and risk factors that lead to PCC, along with PCC's impact on the everyday functioning and development of children and adolescents. There is an urgent need to improve the management of persons affected.

The overall objectives of this public opinion research (POR) were to do the following:

- Identify the spectrum of clinical symptoms, natural history, and distinct phenotypes recognized as sequelae of SARS-CoV-2 infection among children and adolescents (defined as persons ≤ 19 years of age);
- Measure COVID-19 vaccine uptake and impact against COVID-19 severe outcomes, PCC, Long COVID, and MIS-C among vaccine-eligible participants;
- Identify gaps related to health care needs, service delivery, recovery trajectories, and health disparities by vaccination status among children and adolescents living with Long COVID and/or MIS-C;
- Understand the impact of Long COVID and MIS-C on the health-related quality of life and behavioural health of children and adolescents, as well as their effects on the well-being of caregivers and family, especially among disadvantaged groups;
- Understand the burden of PCC and MIS-C on caregivers, families, healthcare workers, and experts, and explore their opinions and experiences with COVID-19 vaccination in preventing Long COVID and/or MIS-C.

Research Methodology

Qualitative Methodology

The research objectives were primarily addressed through a comprehensive qualitative design that used a human-centered design approach. The qualitative research was complemented by an open-link quantitative survey. This combined approach has proven to be cost-effective and time efficient.

The research included the following audiences:

- Parents or legal guardians of children or adolescents who were 19 years or younger with a history of suspected, probable, or confirmed SARS-CoV-2 infection, and had a diagnosis of Long COVID and/or MIS-C from a physician or healthcare professional between 2021 and 2024;
- Adolescents 16–19 years of age with a history of suspected, probable, or confirmed SARS-CoV-2 infection that had received a diagnosis of Long COVID and/or MIS-C from a physician or healthcare professional between 2021 and 2024;
- Healthcare providers who had either diagnosed or treated patients under the age of 19 with Long COVID and/or MIS-C and had administered COVID-19 vaccines to pediatric patients;
- Researchers and academics whose area of study or expertise was related to Long COVID or MIS-C, particularly in children and adolescents;
- Advocates or representatives from Long COVID-19 support groups, such as COVID long haulers support groups, patient support and advocacy groups, and parent groups.

The qualitative research design was national in scope. The in-depth interviews were offered in both official languages (i.e., English and French) and were conducted online from June 27, 2024 to February 20, 2025. Interviews were hosted on MS Teams and lasted between 45 and 60 minutes.

The human-centered design was used to explore the impact of PCC among children and adolescents and their caregivers, health care researchers and professionals, and Long COVID support groups in Canada. The qualitative discussion guides focused on understanding the experiences and needs of people impacted by PCC, the work that needs to be done to improve their quality of life and care based on what they consider to be the highest priority, and the health services solutions that would have the most impact from their perspective.

Recruitment took place through various channels, given the diverse intended audience for this POR. Parents or legal guardians of children or adolescents were recruited through established qualitative research panels of the general public. This strategy was supplemented with outreach and snowballing to reach parents who were not registered on research panels. Outreach was conducted through Long COVID support groups on social media by contacting their network administrators.

A total of 88 in-depth interviews were conducted across all intended audiences. The table below shows how the interviews were broken down.

Intended audience	Total number of participants
Parents of children and adolescents with Long COVID or MIS-C	**65** qualitative in-depth interviews: • **54** parents of children and adolescents with Long COVID • **11** parents of children and adolescents with MIS-C
Healthcare providers	**12** qualitative in-depth interviews
Researchers and/or academics	**7** qualitative in-depth interviews
Advocates or support group representatives	**4** qualitative in-depth interviews

All aspects of the project, including recruitment of participants, were guided according to the Standards for the Conduct of Government of Canada Public Opinion Research – Qualitative Research.

Quantitative Methodology

To complement the qualitative exploration of the experiences of families affected by Long COVID and MIS-C, an open-link quantitative online survey was developed. The survey was intended for parents of children and adolescents, as well as adolescents aged 16–19 years who were eligible to participate themselves without parental supervision.

The quantitative component of the research was offered in both official languages (i.e., English and French) and was hosted online on an accessible and device-agnostic survey platform. The survey was pre-tested on November 25, 2024 to assess the clarity of the survey questions and to confirm the survey's length. No issues were flagged during the pre-test. The survey was launched on November 25, 2024, promoted for 12 weeks, and closed on February 20, 2025. The average length of the survey was 25 minutes and a total of **209 surveys were completed**. The quantitative methodological report, survey questionnaire, and topline results (n=209) have been provided under separate cover.

Incentives

Participants were offered an incentive for participating in the qualitative research: healthcare providers were offered $500, and members of other intended audiences were offered $200.

Interpretation of Report Findings

The qualitative findings presented in this report are intended to reveal a range of opinions and experiences and should not be extrapolated to the broader population as they are not statistically generalizable.

Contract Value

The total contract value for the project was $299,835.10, including applicable taxes.

Key Findings and Conclusions

The Patient Journey for Long COVID

Profile of Study Participants with Long COVID

The qualitative research captured the experiences of **54 children and adolescents** who developed Long COVID during the study period. There were 6 infants and toddlers under the age of 2 years; 12 preschool-aged children who were 3 to 5 years old; 23 school-aged children who were 6 to 11 years old; and 13 adolescents who were 12 to 19 years old. A total of 23 children and adolescents were female and 31 were male. Notably, most children and adolescents included in this study (45 among 54) did not have any ongoing or chronic health conditions prior to developing Long COVID.

Moreover, the sample was diverse in terms of the following:

- During the study period, 32 among 54 children and adolescents had one confirmed or suspected SARS-CoV-2 infection. Many children and adolescents had been infected with SARS-CoV-2 multiple times: 13 among 54 had two SARS-CoV-2 infections and 9 among 54 had three SARS-CoV-2 infections.
- Most children and adolescents with Long COVID contracted the wild type VOC (14 among 54 children and adolescents) prior to March 2021 or the Omicron VOC and its sublineages (28 among 54 children and adolescents) after January 2022.
- There was some variation regarding the total number of suspected or confirmed SARS-CoV-2 infections and the timing of those infections that led to Long COVID in children and adolescents. For those who experienced multiple SARS-CoV-2 infections, it was often the most recent infection or the one in which symptoms felt “more severe” that seemed to trigger Long COVID symptoms.
- The COVID-19 vaccination status differed among children and adolescents: 13 were unvaccinated, 8 were partially vaccinated, and 33 had received at least a primary series (i.e., two doses) of the COVID-19 vaccine. The timing of their vaccination relative to their Long COVID diagnosis also varied.

Living with Long COVID

Among the 54 children and adolescents who developed Long COVID symptoms during our study period, 48 had a diagnosis of Long COVID from a physician or healthcare professional between 2021 and 2024. Long COVID is defined in this report as the continuation or development of new symptoms 3 months after the initial confirmed or probable SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation. In this research, Long COVID symptoms experienced by children and adolescents were often complex and unique to the individual; they displayed a range of symptoms of different severities that fluctuated and evolved over time.

The most common symptoms experienced by the children and adolescents captured in this study were fatigue, headaches, cough, muscle aches and pain, and shortness of breath upon exertion. These symptoms aligned with those identified by healthcare workers as being the most common among the adolescent patients they diagnosed or treated.

Parents were asked to report the severity of their children's Long COVID symptoms. Based on their responses, three classifications of cases emerged: mild cases (12 among 54 children and adolescents), moderate cases (28 among 54 children and adolescents), and severe cases (14 among 54 children and adolescents). Parents' self-reported assessment tended to be based on the range of their children's symptoms, their severity, and their duration.

The impact of Long COVID symptoms on the children represented in this research was widespread, and occurred across four dimensions:

1. Physical impact – For those who had mild and moderate cases of Long COVID, the physical impact was tied to the discomfort and/or pain associated with the symptoms they experienced. The physical impact was all-encompassing for children with severe symptoms. These children were in near constant pain or severe discomfort that impacted their mobility and their cognitive functioning.

2. Psychosocial impact – For most children, their experience of Long COVID was accompanied by some form of emotional, social, or behavioural impact. The impact was heightened among older children, adolescents, and in cases where Long COVID symptoms lasted for a prolonged time. Parents reported that their children became frustrated with not being able to keep up with friends or partake in sports and social activities, which in turn resulted in feelings of anxiety and depression.

3. Day-to-day impact – All children had to adjust their daily lives to manage their Long COVID symptoms. Adaptations were most drastic in severe cases of Long COVID. These children and adolescents had to engage in constant calculations about the physical "cost" of their recovery following any form of exertion. They missed a substantial amount of their schooling, and they often required twelve hours or more of sleep per day.

4. Impact on parents – All parents mentioned feelings of emotional distress from seeing their child ill, and to a lesser degree, feelings of helplessness given the general newness of Long COVID. Among families affected by the most severe cases of Long COVID, parents reported incurring significant financial costs associated with accessing a range of care and treatment options for their children. Additionally, parents who opted to become full-time caregivers to their children lost income.

The current health status of children and adolescents with Long COVID represented in this study was decidedly mixed: many no longer experience any symptoms (33 among 54) and have returned to a state of "normal", while others continue to experience Long COVID symptoms to this day (21 among 54), be it lingering and residual symptoms or full-blown symptoms that continue to heavily impact their quality of life.

No clear trends or patterns in Long COVID health outcomes were found when comparing the experiences of children who were unvaccinated with those who were vaccinated. The qualitative nature of the study means that it is not possible to draw any definitive conclusions about the impact of COVID-19 vaccination on health outcomes for children affected by Long COVID. This will be addressed more fully by examining the complementary quantitative results from the open-link survey under a separate cover.

Seeking Solutions

Parents of children and adolescents with less severe Long COVID symptoms tended to have fewer touchpoints in their care journey and generally reported positive experiences with the quality of care they received. These participants typically received a diagnosis from a family doctor or an emergency room physician and often required minimal follow-up care. Comparatively, parents whose children had more severe Long COVID symptoms paradoxically often struggled to receive a diagnosis, accessed multiple channels of care leading up to a diagnosis, and continued to seek out various forms of care and treatment. They often expressed disappointment and dissatisfaction with the care they received.

By synthesizing the positive and negative experiences of the Long COVID care journey as described by parents, healthcare providers and support groups, this research offers a number of considerations for delivering a human-centered approach to Long COVID care.

Empathy and validation. The demeanour of healthcare providers was a key source of satisfaction and dissatisfaction with the quality of care received. All parents wished for their concerns about their children's health to be taken seriously and for their children's symptoms to be validated. Indeed, one of the biggest frustrations some parents expressed was feeling dismissed by their healthcare provider.

Clear diagnostic guidelines. While some parents reported positive experiences related to receiving a diagnosis, the research suggests that there is an opportunity to improve diagnostic guidelines for healthcare providers. Parents whose children experienced the most debilitating Long COVID symptoms faced numerous challenges in attempting to obtain a formal diagnosis. The challenges included skepticism from healthcare providers about their child's symptoms, a lack of acknowledgement of Long COVID as a condition among Canadian doctors and a reluctance or unwillingness to provide a diagnosis, and a sense that healthcare providers were pushing psychiatric explanations or treatment for their child's symptoms. For their part, healthcare providers also noted the challenges posed by the lack of clear diagnostic biomarkers for Long COVID and its symptomatic overlap with other physical and psychiatric conditions. They saw an opportunity to enhance their diagnostic skills through various resources and training.

Knowledge level and openness to learn more. Parents were generally cognizant that the SARS-CoV-2 virus and Long COVID were novel, and the medical community was still learning about them. Despite its newness, several parents praised the healthcare professionals who worked with their children for their knowledge about Long COVID, their willingness to provide a formal diagnosis, and their efforts to stay up to date with the latest guidance and research. A number of parents also felt comforted by their healthcare provider's openness to consider research they found themselves through their personal research into the condition. Healthcare providers also felt that there was a lack of knowledge and awareness about Long COVID in the medical community, which impacted the ability of healthcare providers to identify, diagnose, and treat Long COVID.

Access to specialist care. Higher levels of confidence and satisfaction with care were evident among several participants who had accessed specialist care. Some parents who accessed care from a doctor or specialist affiliated with a children's hospital tended to display higher levels of comfort in the care they received because of the doctor's expertise in children's health. A couple of parents whose children were severely impacted by Long COVID sought out care from doctors based in the United States who were at the "cutting edge" of research. These parents felt that access to specialist Long COVID care and treatment protocols was lacking in Canada. They had disappointing experiences when accessing care from Long COVID clinics because the providers in the clinics appeared to have lower levels of knowledge about Long COVID and potential treatment options than they did.

Proactivity and reassurance around treatment protocols. The newness of Long COVID created a high level of uncertainty and anxiety among parents regarding their child's recovery trajectory. These negative feelings appeared to be somewhat alleviated in cases where parents felt that healthcare providers were proactive and offered a clear path for alleviating symptoms. Trust in the treatment guidance offered by healthcare providers appeared to be tied to the general demeanour of healthcare providers and their levels of knowledge about Long COVID. Participants reported more negative experiences if they felt that their healthcare provider was dismissive, and/or had limited knowledge about the available treatment options and the long-term trajectory or outcomes for Long COVID.

Timely access to care. Long wait times were another main driver of dissatisfaction with the care journey. Some parents reported having to wait for weeks in order to access their family doctor, which resulted in some turning to walk-in clinics or emergency departments. The "lockdowns" introduced to manage the COVID-19 pandemic also presented barriers to accessing care from primary care physicians. Others reported having to wait for weeks or even months after being referred to a specialist. In discussing wait times, participants generally acknowledged that timely access to care is a long-standing systemwide issue.

In terms of the treatment protocols received by children, these varied widely and were primarily dependent on the severity of their symptoms. Parents and healthcare professionals were unable to single out a specific treatment option that appeared to be particularly effective; they tended to attribute recovery to a combination of remedies and the general passage of time. From the perspective of researchers, subject matter experts, and those working in a support group or advocacy capacity, treatment approaches that solely worked to alleviate specific symptoms were insufficient. They frequently mentioned the knowledge and research gap related to Long COVID, specifically regarding the treatment for and long-term outcomes of Long COVID. There were calls for further government investment in medical research about Long COVID (especially Long COVID in children, as the general lack of knowledge and expertise about Long COVID is compounded in the case of children), as well as the development of care models for those experiencing Long COVID.

Information Needs

Parents generally felt that they were more informed about Long COVID nowadays compared to the start of their child's Long COVID journey. The information needs of parents tended to be fairly consistent and centred around identifying the underlying causes of symptoms, how to manage and treat symptoms and underlying causes, and the longer-term impact on their child's physical health and development. Parents also generally relied on a mix of information that their healthcare providers gave them and information they found themselves through their own online research. Many parents noted that they were in the habit of supplementing the health information offered by their healthcare provider with their own research and information, even if it was a simple Google search to validate the information provided by healthcare providers.

Parents of children with more severe cases and/or those who felt their children's care needs were not met by healthcare providers were more likely to conduct extensive research online. These parents were also most active in online social media groups for parents in general or for parents of children with Long COVID. They appreciated hearing about the experiences of other parents navigating this newer condition, especially about various management and treatment protocols that appeared to work.

The Patient Journey for Multisystem Inflammatory Syndrome

Profile of Study Participants with MIS-C

The incidence of MIS-C is lower in the general population than that of Long COVID. Despite this, the study captured a small number of parents (n=11) whose children had been affected by MIS-C. Children with MIS-C tended to be younger, with none over the age of 11 years at the time of diagnosis, and male. Nonetheless, the sample was somewhat diverse in terms of the following:

- Parents reported that their children had at least one (7 among 11 children), two (2 among 11 children), or ≥ 4 (2 among 11 children) confirmed or suspected SARS-CoV-2 infections.
- This research captured the experiences of children who were infected with different COVID-19 variants of concern (VOCs), with 7 among 11 acquiring an infection during the pre-Omicron predominance period.

- Most children had received at least two doses of a COVID-19 primary series vaccine. Several also received booster doses. There were three cases of children who were unvaccinated.

All parents described their children as being "normal," "healthy," and "active" prior to their SARS-CoV-2 infection that led to MIS-C. One parent reported that their child had ongoing kidney issues, but the other parents reported that their children had no ongoing or pre-existing health conditions.

Living with MIS-C

At the time of their initial SARS-CoV-2 infection, children's symptoms tended to be described as "mild" and largely consisted of those associated with the common cold or flu such as nasal congestion, headaches, fatigue, and fever. The MIS-C symptoms that emerged over time tended to be considerably more severe in nature and included acute gastrointestinal symptoms (e.g., diarrhea, abdominal pain, vomiting); shortness of breath or difficulty breathing; and body numbness, swelling, and aches. In the self-reported severe cases of MIS-C, parents said that their children experienced skin rashes, mucocutaneous inflammation signs, and low blood pressure.

The impact of MIS-C symptoms on children, as reported by parents, were primarily physical. The physical impacts took several forms, including discomfort related to gastrointestinal symptoms, and occasionally with associated weight loss; difficulty breathing due to respiratory symptoms, which often led to difficulties sleeping; and for some, the physical pain or discomfort related to other symptoms. The severity of MIS-C symptoms had implications for the mental health of children. For children who were younger and/or had not been in the hospital before, their experience was described by parents as "traumatizing" and caused significant stress or anxiety for the child due to the unfamiliar environment. The impact on children's day-to-day lives was significant during the peak of their symptoms when they were hospitalized.

Nearly all parents reported that their children had fully recovered from MIS-C and were no longer experiencing any symptoms. Parents were "cautiously optimistic" about their child's future and expressed minimal concern about the potential long-term impact of MIS-C on their child's health.

The impact of COVID-19 vaccination on the health outcomes of children affected by MIS-C after a SARS-CoV-2 infection will be addressed in future publications by combining the small number of cases captured in this study with those from the open-link survey results.

Seeking Solutions

For most parents, their first and primary point of care was the hospital. Parents went to the hospital after their child's initial SARS-CoV-2 infection when their symptoms became unmanageable at home or a cause of concern. These children were then admitted to the hospital and received treatment for varying amounts of time ranging from 48 hours to 10 days.

Parents generally expressed high levels of satisfaction with the quality of care they received. They mentioned that healthcare workers were supportive, proactive, and knowledgeable, and that they received prompt diagnosis and treatment. The only challenges parents mentioned were related to the larger structural issues within the entire healthcare system at that time, namely the strain being placed on healthcare facilities due to the COVID-19 pandemic and the shortage of healthcare workers.

Once discharged from the hospital with significantly reduced symptoms, children were taken home to be monitored. Children often attended follow-up appointments, which typically involved check-ups and routine bloodwork, while any residual symptoms cleared over the subsequent month or two. Parents were appreciative of the fact that their children were being monitored. They also reported having few issues with accessing care.

Information Needs

Though participants felt more informed about the condition because their children were affected by it, several still did not feel very knowledgeable about the condition itself and its effects on children. These information gaps, however, did not appear to be because of healthcare providers' unresponsiveness to parents' questions, or because of the relative newness of MIS-C presenting as a post-COVID condition.

There were a couple of parents who turned to online sources for information about MIS-C. The severity of their children's condition prompted them to seek out as much information as they could. The main challenges they faced were being able to digest all the information they found and filtering out untrustworthy sources.

Attitudes Towards COVID-19 Vaccination

Most parents who took part in the study had their children vaccinated with at least a primary series of the COVID-19 vaccines. Parents' comfort levels with the primary series and booster doses varied and fluctuated over time. That said, the underlying factors that drove uptake and hesitancy were fairly consistent and are summarized in the table below.

Drivers	Explanation of driver
Drivers of vaccine uptake	
Vaccine confidence	• Belief in the protection offered by the COVID-19 vaccines
Motivation	• Desire to follow public health messaging on COVID-19 vaccination • A pro-vaccination and pro-science stance
Trust	• Trust in public health and healthcare professionals
Drivers of vaccine hesitancy	
Safety concerns	• Immediate adverse side effects • Longer-term side effects • Perceived lack of evidence on safety due to the newness of COVID-19 vaccines • Hearing stories of others being affected by adverse side effects • Unsure how a child weakened by PCC would react to vaccination
Efficacy concerns	• Experience of becoming infected with COVID-19 and developing PCC despite being vaccinated diminished confidence in the vaccine's efficacy
Practical issues	• Child ineligible for COVID-19 vaccination at the height of public health messaging about vaccination
Declining perceived disease risk	• Perceived reduced risk of a SARS-CoV-2 infection as time went on • Belief in child having acquired "natural immunity" from previous SARS-CoV-2 infections
Social processes	• Lack of health professional recommendations on COVID-19 vaccine boosters

The research findings from the healthcare provider interviews were in line with the findings reported above on parents' experiences and attitudes. Uptake of COVID-19 vaccines was generally weaker among children compared to uptake among their adult patients. Vaccine safety was the main concern healthcare providers encountered when speaking to parents that were hesitant about vaccinating their children with the COVID-19 vaccines. Parents were concerned about potential side effects arising as a result of fast COVID-19 vaccine development.

Healthcare providers generally had a pro-vaccine stance. That said, there was one participant who had experienced some initial hesitation around the safety of the vaccines and another who felt that healthcare workers had no choice but to get vaccinated. Healthcare providers in primary care settings who encountered vaccine-hesitant parents provided them with information and reassured them about the benefits of vaccination. However, because of the context of the COVID-19 pandemic and heightened concerns about vaccine safety, they left the choice of vaccination up to parents.

Perceived Efficacy of the COVID-19 Vaccines Against Post COVID-19 Condition

This research found that parents and healthcare providers felt that it was unclear whether or not COVID-19 vaccines protected children against PCC. At best, some parents of children affected by Long COVID “chose to believe” that the vaccine helped mitigate the severity of their child’s SARS-CoV-2 infection; however, it was impossible for them to prove this point. In contrast, several parents were disappointed and shocked that their children developed PCC even though they were vaccinated before their diagnosis. These first-hand experiences thus resulted in the strongly held belief that the COVID-19 vaccine “does not work” and validated, where applicable, pre-existing hesitations towards the vaccine. No one suggested that the COVID-19 vaccines contributed to their children’s SARS-CoV-2 infection or PCC diagnosis.

Only a small number of parents vaccinated their children following a PCC diagnosis. An even smaller number vaccinated their children as a way to treat Long COVID. This small group reported that they had not seen a marked improvement in their child’s symptoms following vaccination.

Healthcare providers also had little to offer in terms of explaining how the COVID-19 vaccines improved health outcomes for children and young people who experienced PCC. Some felt unable to comment because they did not have a large enough PCC caseload to arrive at any conclusions or because they had not consulted any scientific literature on the matter.

Conclusion

Canadian data regarding the prevalence and incidence of PCC in children and adolescents remain scarce, although PCC seems to be less frequent in children and adolescents compared to adults. Vaccination appears to be an important preventative measure against COVID-19 severe outcomes. With most of the population by now both vaccinated and infected, repeated booster doses may add little incremental value against long COVID. More research is needed to better understand the impact of vaccination and newer variants on PCC prevalence and symptoms in children and adolescents.

The findings of this POR suggest that PCC appears to pose major burdens at the individual and health systems levels, affecting key domains, including health, function, health services utilization, and the economy. Therefore, it is critical that governments understand the magnitude of this burden and plan accordingly. A multifaceted approach, including one that applies to a human centered design, will be needed to maximize access to diagnostic care for PCC, and to improve education and training for health care professionals.

1. Research Background, Objectives, and Methodology

1.1 Background

Children and adolescents infected with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) can develop long-term symptoms that are commonly known as post COVID-19 condition (PCC), Long COVID, or post-acute sequelae of SARS-CoV-2 infection (PASC).[1]

In 2022, the World Health Organization (WHO) established a clinical case definition of PCC using the work they did to define PCC in adults.[1] This definition states that PCC in children and adolescents is the continuation or development of new symptoms 3 months after an initial confirmed or probable SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.[1] While common symptoms of Long COVID can include fatigue, shortness of breath, and cognitive dysfunction, over 200 different symptoms have been reported that can have an impact on everyday functioning. Children and adolescents who have Long COVID can have any mix of them.[2]

Very few studies have focused on PCC in children and adolescents. However, two recent cohort studies have documented the main symptoms of Long COVID in early childhood (birth through 5 years)[3] and school-aged children and adolescents[4] in the United States. Compared to previous research,[5-8] these studies found that Long COVID symptomology is similar but distinct between these age ranges, as well as from adults. Infants, toddlers, and preschool-aged children are more likely to have symptoms that parents can observe, such as poor appetite, sleepiness, and respiratory symptoms such as a cough. [2,3] School-aged children are more likely to have neurological symptoms, such as trouble focusing, trouble sleeping, or feeling lightheaded. [2,4] They may also have back or neck pain, headache, stomach pain, or vomiting. Sometimes they have behavioral changes. Adolescents are more likely to have a change or loss in smell or taste, pain, fatigue-related symptoms, trouble with memory, and light-headedness. Post exertional malaise (PEM) has been reported in children and adults with Long COVID. [2,4] PEM is a flare of symptoms and/or the appearance of new symptoms even after minimal exertion, including physical activity, mental exertion, and sensory overload. Often presenting 24 hours after the triggering event, PEM is different from just being more tired than normal after an activity or feeling muscle soreness.[2] These symptoms may have serious and long-term consequences during childhood and adolescence, an essential period for social and educational development.[9]

Numerous knowledge gaps remain regarding risk factors, symptoms, natural history, and sequelae of COVID-19 in children and adolescents, particularly in different childhood age groups. More research is needed to further characterize this condition and improve the management of persons affected.[10]

People of all ages, including children, can get very sick with COVID-19. A recent meta-analysis estimated that the incidence of PCC is 10–30% in non-hospitalized individuals and 50–70% in hospitalized individuals.[11] While the reasons why PCC develops remain to be fully elucidated, viral persistence has been proposed as a potential driver of PCC symptoms in both adults and children.[12,13]

Children with underlying medical conditions are at increased risk of getting very sick from a SARS-CoV-2 infection compared to children without underlying medical conditions. Current evidence suggests that children with special healthcare needs, including genetic, neurological, or metabolic conditions, or with congenital heart disease, can be at increased risk for severe illness from COVID-19. Similar to adults, children with obesity, diabetes, asthma, chronic lung disease, sickle cell disease, or immunosuppression may also be at increased risk for severe COVID-19.[14]

As of June 2023, 3.5 million Canadian adults reported experiencing long-term symptoms following a COVID-19 infection.[15,16] However, there is currently no official estimate for the number of Canadian children and adolescents affected by PCC. Estimates from early in the pandemic indicated that more than 40% of people diagnosed with COVID-19 experienced symptoms beyond the acute illness (four or more weeks after infection).[15] However, more recent evidence suggests that about 10% to 20% of unvaccinated people and 2% to 10% of vaccinated people experience symptoms 12 weeks beyond the acute illness.[15] It is postulated that the low prevalence of persistent symptoms is a result of high vaccination rates and less virulent variants. An estimated 57,000 to 78,000 people in Ontario have had or are currently experiencing post-COVID-19 condition.[17,18]

The estimated prevalence of PCC in children ranges from 2% to 66%. This variability reflects the marked heterogeneity in case ascertainment and methodology of existing studies, as well as the lack of an appropriate comparison group. It remains unclear to what extent children experience SARS-CoV-2 sequelae and how PCC features in children may differ from those in adults.[19-21] In the United States, Long COVID is common and affects 10% to 20% of children with a history of COVID-19.[2] With almost 6 million American children potentially affected, this is higher than the number of children with asthma, the most common chronic health problem in children.[2]

Though it is very rare, some children who had COVID-19 may later develop multisystem inflammatory syndrome in children (MIS-C), a serious complication of SARS-CoV-2 infection characterized by a hyperinflammatory response, with illness onset typically 2−6 weeks after infection.[22-26] Signs of MIS-C include fever, multi-organ system involvement, and laboratory evidence of inflammation. It can be challenging for healthcare professionals to make a definitive MIS-C diagnosis because there is no specific diagnostic biomarker and because it can resemble other illnesses, including acute COVID-19, toxic shock syndrome, and Kawasaki disease (KD). As of July 1, 2025, over 9,780 cases and 80 deaths that meet the CDC's case definition have been reported in the United States, with half of cases among children aged 5–13 years.[27] COVID-19 vaccination has been shown to protect against MIS-C in the United States. children aged 5−11 years and adolescents aged 12−18 years.[28] Other countries have also demonstrated COVID-19 vaccine effectiveness against MIS-C.[29,30]

Additionally, children and adolescents aged 18 years and younger who have had COVID-19 are up to 2.5 times more likely to be newly diagnosed with diabetes 30 days or more after having a SARS-CoV-2 infection. There is limited data on the safety of COVID-19 vaccines in people who have had MIS-C. Additionally, it is currently unknown how likely a person is to re-experience a dysregulated immune response following SARS-CoV-2 reinfection or an MIS-like illness following COVID-19 vaccination.[27,31]

New evidence from studies supported by the U.S. National Institutes of Health (NIH) shows that PCC symptoms and diagnostic experiences vary among different racial and ethnic groups. Two studies show that Black and Hispanic Americans experience more symptoms and health problems related to PCC than White Americans, but that they are less likely to receive a PCC diagnosis.[32]

Preventing COVID-19 in children and adolescents is important to slow the spread of SARS-CoV-2 and protect them from severe illness. Everyone ages six months and older is eligible to receive a COVID-19 vaccine in Canada, yet vaccination coverage among children and adolescents is lower than in older age groups.[33] There is an urgent need to understand the prevalence of PCC, the characteristics and risk factors that lead to PCC, as well as PCC's impact on the everyday functioning and development of children and adolescents. The long-term outcomes of the condition are currently unknown and need to be studied with standardized definitions and data collection methods.[10,21]

1.2 Research Objectives

This public opinion research (POR) consisted of two components, a series of qualitative in-depth interviews and a quantitative survey. It was conducted to understand the impact of COVID-19 vaccination on children and adolescents with post-COVID condition (PCC) or Long COVID, and multisystem inflammatory syndrome in children (MIS-C) in Canada.

Specifically, the research was driven by the following objectives:

- Identify the spectrum of clinical symptoms, natural history, and distinct phenotypes recognized as sequelae of SARS-CoV-2 infection among children and adolescents (defined as persons ≤ 19 years of age);

- Measure COVID-19 vaccine uptake and impact against COVID-19 severe outcomes, PCC, Long COVID, and MIS-C among vaccine-eligible participants;
- Identify gaps related to health care needs, service delivery, recovery trajectories, and health disparities by vaccination status among children and adolescents living with Long COVID and/or MIS-C;
- Understand the impact of Long COVID and MIS-C on the health-related quality of life and behavioural health of children and adolescents, as well as their effects on the well-being of caregivers and family, especially among disadvantaged groups;
- Understand the burden of PCC and MIS-C on caregivers, families, healthcare workers, and experts, and explore their opinions and experiences with COVID-19 vaccination in preventing Long COVID and/or MIS-C.

This report is divided into four main sections. Section 1 presents the research background, objectives, and methodology. Section 2 presents the findings related to the patient journey for Long COVID, and covers the experience of living with Long COVID, the journey of seeking treatment, and informational needs. Section 3 presents comparable findings with respect to the patient journey for MIS-C. The findings on attitudes and the perceived impact of COVID-19 vaccination are presented in Section 4.

1.3 Research Methodology

The research objectives were primarily addressed through a comprehensive qualitative design that used a human-centered design approach. The qualitative research was complemented by an open-link quantitative survey. This multi-modal research design was undertaken to achieve the research objectives. This combined approach has proven to be cost-effective and time efficient.

1.3.1 Study Participants

The research included the following audiences:

- Parents or legal guardians of children or adolescents who were 19 years or younger with a history of suspected, probable, or confirmed SARS-CoV-2 infection; and had a diagnosis of Long COVID and/or MIS-C from a physician or healthcare professional between 2021 and 2024;
- Adolescents 16–19 years of age with a history of suspected, probable, or confirmed SARS-CoV-2 infection that had received a diagnosis of Long COVID and/or MIS-C from a physician or healthcare professional between 2021 and 2024;
- Healthcare providers who had either diagnosed or treated patients under the age of 19 with Long COVID and/or MIS-C and had administered COVID-19 vaccines to pediatric patients;
- Researchers and academics whose area of study or expertise was related to Long COVID or MIS-C, particularly in children and adolescents;
- Advocates or representatives from Long COVID support groups, such as COVID long haulers support groups, patient support and advocacy groups, and parent groups.

1.3.2 Qualitative Methodology

The qualitative research design was national in scope. The in-depth interviews were offered in both official languages (i.e., English and French) and were conducted online from June 27, 2024 to February 20, 2025.

Qualitative research is very well suited to uncovering what matters to patients. The human-centered design was used to explore the impact of PCC among children and adolescents and their caregivers, health care researchers and professionals, and Long COVID support groups in Canada. The qualitative discussion guides focused on understanding the experiences and needs of people impacted by PCC, the work that needs to be done to improve their quality of life and care based on what they consider to be the highest priority, and the health services solutions that would have the most impact from their perspective.

Recruitment of Participants and Sample Profile

Recruitment took place through various channels, given the diverse intended audience for this POR. Parents or legal guardians of children or adolescents were recruited through established qualitative research panels of the general public. This strategy was supplemented with outreach and snowballing to reach parents who were not registered on research panels.

Outreach was conducted through Long COVID support groups on social media by contacting their network administrators. A short online screening questionnaire was shared and those who were eligible were followed up by telephone for additional screening. Participants who completed the study were encouraged to provide referrals of other families that they knew who had been affected by PCC.

More than 15,000 parents and caregivers panelists were screened via a short online questionnaire to determine their eligibility. Approximately 800 responses were received, of which 32 were pre-qualified. Those who pre-qualified were then recontacted by telephone and were administered the full screening questionnaire.

PHAC data indicates that MIS-C is rare, with only 269 cases reported nationally between March 2020 and October 2021.[34] Given the low incidence rate of MIS-C in Canada, recruitment took place through various channels to ensure a large enough sample size was attained so that reliable conclusions could be drawn from the data.

Parents who completed the qualitative research were asked for their consent to engage their children or adolescents in the research. Many opted not to as they were concerned that the detailed line of questioning may be upsetting or re-traumatizing for their children.

Healthcare providers were recruited through established qualitative research panels for healthcare workers and by cold-calling Long COVID clinics. Extensive desk research was conducted to identify researchers, academics, advocates, and representatives of support groups in the fields of Long COVID and MIS-C. Email and telephone outreach were used to recruit contacts identified.

Despite the low incidence rate of PCC and MIS-C in Canada, extensive effort was made to engage participants from across the country as well as those who belonged to equity-seeking groups, specifically, racialized and Indigenous individuals.

This research study was registered with the Canadian Research and Insights Council, which allowed prospective participants to check the legitimacy of the research.

A total of **88 in-depth interviews were conducted** across all the intended audiences (Table 1).

Table 1. Number of qualitative in-depth interviews completed by each intended audience group

Intended audience	Total number of participants
Parents of children and adolescents with Long COVID or MIS-C	**65** qualitative in-depth interviews: • **54** parents of children and adolescents with Long COVID • **11** parents of children and adolescents with MIS-C
Healthcare providers	**12** qualitative in-depth interviews
Researchers and/or academics	**7** qualitative in-depth interviews
Advocates or Long COVID support group representatives	**4** qualitative in-depth interviews

Table 2. Region and language of each intended audience group

Intended audience	Region (language) of intended audience			
	Ontario (EN)	Quebec (FR)	Atlantic region (EN)	Western and Northern regions (EN)
Parents of children and adolescents with Long COVID	12	8	6	28
Parents of children and adolescents with MIS-C	4	4	0	3
Healthcare providers	5		6	1
Researchers and/or academics	3	1		3
Advocates or Long COVID support group representatives	2			2

Participants were recruited according to the Standards for the Conduct of Government of Canada Public Opinion Research – Qualitative Research.

Qualitative Research Instruments

A qualitative recruitment screener was developed to screen for eligible parents and healthcare workers. PHAC designed the qualitative discussion guide with review and input from Ipsos researchers. The questions were designed to provide a deeper understanding of the following: the spectrum of symptoms for Long COVID and MIS-C; COVID-19 vaccine uptake, perceptions, and impact; healthcare usage and experiences; recovery trajectory; the impact of Long COVID and MIS-C on both the child and family; and information sources used and experiences accessing information about Long COVID and MIS-C. All research instruments used for each population group can be found in the Appendix.

Qualitative Fieldwork

Online fieldwork was necessary given the national scope of this project and the importance of obtaining perspectives from diverse and geographically dispersed participants. The qualitative in-depth interviews were hosted on MS Teams and lasted between 45 and 60 minutes. Given the hard-to-reach nature of the intended audience for the study, fieldwork took place between June 27, 2024 and February 20, 2025. Table 3 below shows the incentive amounts offered to each intended audience group.

Table 3. Breakdown of incentives by intended audience group

Intended audience	Incentive amount
Parents of children and adolescents with Long COVID or MIS-C	$200
Healthcare providers	$500
Researchers and/or academics	$200
Advocates or Long COVID support group representatives	$200

Qualitative Analysis and Interpretation of Findings

Interviews were recorded for analysis and reporting purposes. A thematic approach was used for analyzing the qualitative findings. A framework of themes and subthemes was created based on fieldnotes taken by the moderators. This framework was then expanded upon by listening back to recordings and referring to transcripts. The qualitative findings presented in the subsequent sections are intended to reveal a range of opinions and experiences, and should not be extrapolated to the broader population as they are not statistically generalizable.

1.3.3 Quantitative Methodology

To complement the qualitative exploration of experiences of families affected by Long COVID and/or MIS-C, an open-link quantitative online survey was developed.

The survey was intended for the following audiences:

- Parents or legal guardians of children or adolescents who were 19 years or younger with a history of suspected, probable, or confirmed SARS-CoV-2 infection, and had a diagnosis of Long COVID and/or MIS-C from a physician or healthcare professional between 2021 and 2024;
- Adolescents 16–19 years of age with a history of suspected, probable, or confirmed SARS-CoV-2 infection that had received a diagnosis of Long COVID and/or MIS-C from a physician or healthcare professional between 2021 and 2024.

The quantitative component of the research was offered in both official languages (i.e., English and French) and was hosted online on an accessible and device-agnostic survey platform.

The survey was pre-tested on November 25, 2024 to assess the clarity of the survey questions and to confirm the survey's length. No issues were flagged during the pre-test. The survey was launched on November 25, 2024, promoted for 12 weeks, and closed on February 20, 2025. The average length of the survey was 25 minutes and a total of **209 surveys were completed**.

Additionally, the quantitative survey included a recontact question, allowing anyone who was willing to also be recruited for participation in the qualitative component of the research. The final survey instrument met federal government standards for public opinion research.

Quantitative Survey Instrument

PHAC took the lead in designing the quantitative survey instrument. A copy of the survey is included in the Appendix of the quantitative methodological report. The project was registered with the Canadian Research Insights Council to allow respondents to verify the legitimacy of the survey as a research initiative sponsored by the Government of Canada. Survey respondents were informed of their rights under the Privacy Act, the Personal Information Protection and Electronic Documents Act, and the Access to Information Act. Additionally, respondents were reassured that their rights were protected throughout the research process.

Quantitative Survey Fieldwork

The open-link quantitative survey was disseminated using different approaches to reach the intended audience and to collect the perspectives of as many respondents as possible. This dissemination approach included the following actions:

- Requesting social media Long COVID support group administrators to share the survey link among their members;
- Sharing the survey link with individuals who participated in the qualitative part of the study to allow them to participate in the quantitative portion of the study;
- Promoting the survey link via paid social media advertising on Instagram and Facebook (more details are provided below).

The paid social media campaign intended to reach Canadian parents of of children or adolescents who were 19 years or younger on Facebook and Instagram. The campaign was optimized to drive traffic to the survey link and ran in both post and story formats. Two waves of paid advertising were launched: wave one ran from November 25 to December 4, 2024 and wave two ran from January 24 to 28, 2025. Advertisement campaigns do not typically run for longer than 10 days because they simply stop performing; people will not click repeatedly on the same content.

The quantitative methodological report, survey questionnaire, and topline results (n=209) have been provided under separate cover.

2. The Patient Journey for Long COVID

In qualitative terms, this research involved a very strong representation of children and adolescents with Long COVID, with 52 parents speaking to the experiences of their children and two older adolescents aged 18–19 years sharing their experiences.

2.1 Profile of Study Participants with Long COVID

This section provides relevant information and socio-demographic characteristics of the children or adolescents with Long COVID (n=54) that were included in this study. Specifically, it outlines their age, gender, and self-reported health status prior to and after contracting a SARS-CoV-2 infection and receiving a Long COVID diagnosis. This section describes any socio-demographic characteristics, risk factors, and trends associated with Long COVID as identified by the healthcare providers who participated in this study. It also discusses the timing of children's and adolescents' SARS-CoV-2 infection that led to the development of Long COVID and their current COVID-19 vaccination status, as well as prior to their SARS-CoV-2 infection and Long COVID diagnosis.

Age and Pre-Long COVID Health Status of Study Participants

Participant demographic characteristics are presented in Table 4. There were 6 infants and toddlers under the age of 2 years; 12 preschool-aged children who were 3 to 5 years old; 23 school-age children who were 6 to 11 years old; and 13 adolescents who were 12 to 19 years old. A total of 23 participants were female and 31 were male.

Table 4. Demographic characteristics of children and adolescents who were affected by Long COVID

Demographic characteristics	Participants (n=54)
Age at time of diagnosis (years)	
Infants and toddlers (2 or younger)	6
Preschool-aged children (3 to 5)	12
School-age children (6 to 11)	23
Adolescents (12 to 19)	13
Gender	
Female	23
Male	31
Region	
Atlantic region	6
Ontario	12
Quebec	8
Western and Northern regions	28

Among the **healthcare providers** represented in this research, there were very few who identified any significant patterns related to the age or overall profile of children with Long COVID. However, this may be a result of the sample of healthcare providers in this research, many of whom had only diagnosed or treated a handful of children with Long COVID. For those who did have more experience working with children with Long COVID, they noted that adolescents aged 12–17 years were more often affected.

Most of the children and adolescents represented in this research were described as healthy (45 among 54 children and adolescents) prior to contracting their initial SARS-CoV-2 infection, that is, they had no ongoing or chronic health conditions. There were only a few who had pre-existing conditions such as seasonal allergies and mild asthma (7 among 54 children and adolescents), all of which were relatively minor and did not require medical attention. Few children and adolescents previously experienced health conditions, which parents believed to be completely unrelated to their child's experience of Long COVID, such as genetic or kidney diseases (2 among 54 children and adolescents).

This pattern was confirmed by **healthcare workers**, who reported that most of their child and adolescent patients with Long COVID did not have any pre-existing or chronic health conditions. Similarly, they reported that it was uncommon for patients to have pre-existing conditions, and that those who did tended to be affected by conditions such as asthma, diabetes, or pre-existing mental health conditions (e.g., anxiety, depression).

The **researchers and subject matter experts** who took part in the study were generally unable to comment definitively on patterns about pre-existing health conditions in children and adolescents with Long COVID due to the limited amount of published research on this topic. One participant noted that there was some indication of increased risk and a greater likelihood of hospitalization for those with comorbidities, such as respiratory conditions, allergic rhinitis, and heart disease.

SARS-CoV-2 Infection and VOC Predominance Period

During the study period, 32 among 54 children and adolescents had one confirmed or suspected SARS-CoV-2 infection. Many children and adolescents had been infected with SARS-CoV-2 multiple times: 13 among 54 had two SARS-CoV-2 infections and 9 among 54 had three SARS-CoV-2 infections.

Most children and adolescents with Long COVID contracted the wild type VOC (14 among 54 children and adolescents) prior to March 2021 or the Omicron VOC and its sublineages (28 among 54 children and adolescents) after January 2022. There were a few who contracted COVID-19 when Alpha, Beta, and Gamma VOCs (7 among 54 children and adolescents) were spreading. Few contracted the Delta VOC (5 among 54 children and adolescents) (Table 5).

There was some variation regarding the total number of suspected or confirmed SARS-CoV-2 infections and the timing of those infections that led to Long COVID in children and adolescents. For those who experienced multiple SARS-CoV-2 infections, it was often the most recent infection or the one in which symptoms felt “more severe” that seemed to trigger Long COVID symptoms.

Table 5. Number of children and adolescents with Long COVID based on when they had a SARS-CoV-2 infection that led to symptoms

Timing of SARS-CoV-2 infection and circulating VOC	Number of children with Long COVID
Wild type VOC – Pre-March 2021	14
Alpha/Beta/Gamma VOC – April to June 2021	7
Delta VOC – July to December 2021	5
Omicron VOC and sublineages – January 2022 to present	28

2.2 Living with Long COVID

Among the 54 children and adolescents who developed Long COVID symptoms during our study period, 48 had a diagnosis of Long COVID from a physician or healthcare professional between 2021 and 2024.

This section explores the variety, evolution, and severity of symptoms experienced by children and adolescents, as reported by their parents. It begins by detailing the symptoms associated with the initial SARS-CoV-2 infection and then describes the more complex Long COVID symptoms that emerged. Long COVID symptoms are then categorized based on their level of severity, namely, mild, moderate, and severe. This section then outlines the three-dimensional impact of Long COVID symptoms on the lives of children, encompassing physical, psychosocial, and day-to-day activities, as well as their impact on parents and caregivers. Finally, this section explores any differences that emerged across children with varying vaccination statuses, discusses children’s current state of well-being, and reveals parents’ outlook with regard to their children’s future health status.

2.2.1 SARS-CoV-2 Infection and Long COVID Symptoms Experienced

The symptoms experienced by children and adolescents with Long COVID varied widely from common symptoms (e.g., fatigue, headaches) to fluctuating and unique symptoms (e.g., cognitive issues, gastrointestinal symptoms) that varied in intensity and duration.

Symptoms of the Initial SARS-CoV-2 Infection

There were some similarities in the symptoms among children and adolescents whose initial SARS-CoV-2 infection progressed to Long COVID. However, their symptoms had varying degrees of severity. These symptoms tended to be described by parents as “flu-like” or “a more extreme version of a common cold,” often including fatigue, congestion, fever, chills, cough or sore throat, and headaches.

Only one COVID-19 case was asymptomatic. For most children and adolescents, these symptoms were mild (23 among 54) or moderate (18 among 54), and parents were generally able to manage them at home without seeking medical attention. Some parents reached out to their family doctor for support or guidance in managing their child’s symptoms, and were often instructed to monitor the symptoms and take their child to the hospital if their symptoms worsened significantly. There were a handful of children and adolescents (12 among 54) whose initial symptoms were so severe that they warranted medical attention. Medical care typically involved a visit to the emergency room, where doctors occasionally provided fluids. However, they often sent parents home to monitor their children as there was little they could do.

The initial symptoms either persisted, often with other symptoms emerging over time, or resolved temporarily before re-emerging later. For those who experienced symptom re-emergence, the amount of time that elapsed between when symptoms ended and when they restarted varied: some children and adolescents had their symptoms return after two weeks, while others had theirs return up to four months later.

Long COVID Symptoms Experienced

Long COVID is defined in this report as the continuation or development of new symptoms 3 months after the initial confirmed or probable SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation. In this research, Long COVID symptoms experienced by children and adolescents were often complex and unique to the individual, with children or adolescents displaying a range of symptoms of different severities that fluctuated and evolved over time.

The most common symptoms reported included the following: fatigue, headaches, cough, muscle aches and pain, and shortness of breath upon exertion. There were numerous other symptoms that emerged and the range of Long COVID symptoms as captured in this study are shown in Table 6, along with an indication of how common the symptoms were.

Table 6. Long COVID symptoms experienced by children and adolescents

Body system affected	Most common symptoms	Less common symptoms
Entire body	Unusual fatigue	Fever Sleep problems Appetite loss Post-exertional malaise (PEM) Weight loss Altered taste or smell Inflammation signs
Heart and lungs	Unusual shortness of breath upon exertion Cough	Chest pain Low blood pressure
Nerves and brain	Unusual headaches	Difficulty thinking or concentrating Cognitive symptoms Unusual light-headedness or dizziness
Muscle and bones	Muscle aches and pains	Numbness in hands and feet

Body system affected	Most common symptoms	Less common symptoms
Eye, ear, nose, and throat		Sore throat Congestion
Stomach		Nausea Vomiting Diarrhea Unusual abdominal pain Constipation
Skin, hair, and nails		Skin rash Hair loss

The most common symptoms reported among children with Long COVID were the same as those identified by healthcare workers as being the most common among the adolescent patients they diagnosed or treated.

For many, their symptoms did not remain constant throughout their experience of Long COVID. Instead, their symptoms often fluctuated, with new symptoms coming and going over time. However, it should be noted that both parents and healthcare providers had challenges identifying the symptoms of younger children since infants and toddlers were not always able to effectively communicate what they were feeling or experiencing.

> *He's a toddler, so it's tricky because he can only describe his symptoms to a certain extent. A lot of it was based on my relationship with him and trying to understand what he was going through, aside from the obvious symptoms.* – Parent from Alberta, 2-year-old child

Parents were asked to self-report the severity of their child's Long COVID symptoms. Based on their responses, three classifications of cases emerged: mild cases (12 among 54 children and adolescents), moderate cases (28 among 54 children and adolescents), and severe cases (14 among 54 children and adolescents). Parents' self-reported assessment tended to be based on the range of their children's symptoms, their severity, and their duration. The severity of Long COVID symptoms by age group are shown in Table 7.

Table 7. Number of severe Long COVID symptoms experienced by different age groups

Age at time of Long COVID diagnosis (years)	Severity of Long COVID symptoms		
	Mild	Moderate	Severe
Infants and toddlers (2 or younger)	3	1	2
Preschool-aged children (3 to 5)	3	6	3
School-age children (6 to 11)	4	15	4
Adolescents (12 to 19)	2	6	5
Total	12	28	14

Mild Cases of Long COVID

Children and adolescents who experienced more common symptoms (i.e., fatigue, headaches, muscle aches, shortness of breath, cough) tended to have a milder case of Long COVID (12 among 54 children and adolescents). They often had sleep problems (because of their other symptoms) and cognitive symptoms (i.e., difficulty concentrating or "brain fog"). They occasionally lost their taste and/or smell, which led to a loss of appetite.

> *She had a runny nose, and a really sore throat. She was kind of lethargic and wasn't herself with her energy. Normally, she would be up and bouncing, but she was much more tired than usual. She was achy and it just progressed from there and she got a cough. So, it was a cough and constant sore throat, and it just kept lingering past a normal cold.* – Parent from Alberta, 3-year-old child

These symptoms did have some impact on the child's quality of life (which will be discussed further in the next subsection); however, they were often described by parents as "manageable" and more like an extreme version of the flu. These symptoms were rarely severe enough to necessitate medical attention, but some parents sought out guidance or information from their family doctor for peace of mind.

The duration of these symptoms varied quite widely across children and adolescents. Generally, some mild symptoms resolved over the course of a few months or fluctuated and gradually lessened over a longer period (i.e., six to eight months).

Moderate Cases of Long COVID

A moderate experience of Long COVID symptoms (28 among 54 children and adolescents) tended to include a wider variety of symptoms that differed slightly across individuals. However, most still experienced the common symptoms at a slightly increased severity (i.e., in comparison to those with milder experiences). Moderate Long COVID cases often experienced cognitive symptoms as well as gastrointestinal symptoms (e.g., nausea, diarrhea, vomiting, constipation), which resulted in weight loss. A handful of children also experienced rashes and chest pain.

These symptoms were typically of moderate severity, impacting quality of life and causing enough concern among parents to warrant a visit to the emergency room. For example, there were some cases where parents became concerned when the symptoms experienced by their child were becoming more severe over the course of a few weeks, or new symptoms emerged, and thus they felt that medical attention was needed. However, in most cases, the symptoms only necessitated emergency room visits or, at most, an overnight stay for monitoring, and typically did not involve any extended stays at the hospital.

The symptoms experienced in moderate cases often took slightly longer to resolve, typically upwards of three or four months. For some children, their symptoms have only gradually lessened over time and have become more manageable but have yet to fully resolve. In fact, several (9 among 28 children and adolescents) are still experiencing symptoms.

> *The symptoms came at different points and changed over time. It was persistent headaches, lots of sleep issues and he never had an issue sleeping before. His taste definitely changed to the point where he didn't even enjoy eating. He also had constant diarrhea, which got progressively worse. He was very exhausted after strenuous workouts; you know running and doing things kids normally do. He would just run out of gas very quickly and it started to happen with schoolwork and things that required a lot of attention or focus, he would start tapping out a bit. There was constant fatigue, coughing and some chest pain, and some joint issues. It went on for a good six to eight months.* – Parent from Ontario, 10-year-old child

Severe Cases of Long COVID

There were fewer severe cases of Long COVID (14 among 54 children and adolescents) in this study (Table 7). Severe cases often had the common Long COVID symptoms; however, they experienced them to a much higher degree of severity. As a result, they had a substantial impact on the child's ability to function in daily life. In several instances, symptoms expanded to include new and more severe symptoms over time. These symptoms included light sensitivity, dizziness, fainting, low blood pressure, and postural orthostatic tachycardia syndrome (POTS), a condition characterized by an abnormal increase in heart rate upon sitting up or standing. For these children, the severity of their symptoms often necessitated parents seeking out healthcare through many different channels. This experience will be further explored in Section 3.

> *She didn't make it to school for an entire year because of her symptoms, she was bedridden. I think we tried a couple hours of school two or three times that year, but she never made it back to school. The following year, she made it to school about 30% of the time. Then, she started fainting and would lose consciousness*

> *20-30 times a day. So, she was completely ridden and in a wheelchair for an entire year.* – Parent from Alberta, 13-year-old child

Half (7 among 14 children and adolescents) of all severe Long COVID cases in this study are still experiencing symptoms ≥12 months later, and they have had to adapt their daily lives and routines to manage their symptoms they best they can.

2.2.2 The Impact of Long COVID Symptoms

The impact of Long COVID symptoms on the children and adolescents represented in this research was widespread, and occurred across three dimensions:

- **Physical impact** – the impact of symptoms on their physical well-being
- **Psychosocial impact** – the impact of symptoms on their emotional, psychological, and behavioural well-being
- **Day-to-day impact** – the impact of their symptoms on various activities such as school, sports, hobbies, etc.

Physical Impact of Symptoms

The physical impact of Long COVID on children and adolescents was largely based on the severity of their symptoms: children and adolescents with milder symptoms were less impacted physically than those who experienced severe symptoms.

For children with mild symptoms, the physical impact of Long COVID was heavily tied to the discomfort and/or pain associated with the symptoms they experienced. For example, their experience of headaches, cough and sore throat, and muscle or joint pain caused discomfort that often impacted their ability to sleep (both in terms of falling asleep and staying asleep for the entire night), which created increased fatigue. These symptoms, specifically the fatigue and shortness of breath, also impacted the ability of the child to engage in physical exercise. For these children, the physical impact of Long COVID increased when their symptoms were at their worst and gradually decreased as their symptoms resolved over time.

For children and adolescents with moderate symptoms, the physical impact of Long COVID was similarly tied to the discomfort and/or pain associated with common symptoms (i.e., headaches, muscle pain, or joint pain), fatigue and difficulty sleeping, and the inability to engage in physical activity or exercise. However, for those who experienced gastrointestinal symptoms (i.e., vomiting, diarrhea, nausea) or a loss of taste and smell, there was often an associated loss of appetite and subsequent weight loss. Several parents, especially those with younger children, were concerned about their child's weight loss and expressed that it was challenging to get them to eat properly. A handful of children experienced chest pains and/or heart palpitations, which also caused significant concern among parents. These symptoms often led to an emergency room visit and the subsequent testing of their heart and lung functioning; however, these tests typically came back with normal results.

> *The taste was a huge challenge, because he loved eating. He had a sophisticated taste and enjoyed trying new things and suddenly food became a chore for him where he didn't want to eat at certain points. So, he lost weight because he was exasperated with that. The fatigue was also really challenging, because he would just run out of gas and struggle with physical activities.* – Parent from Ontario, 10-year-old child

The physical impact of Long COVID was all-encompassing for children with severe symptoms as they were often in pain or severe discomfort and regularly experienced poor mobility and cognitive functioning. The most notable impact, for a handful of children with incredibly severe cases of Long COVID, was related to their mobility. These children experienced severe fatigue (with one having received a diagnosis of extreme fatigue syndrome because of Long COVID), localized muscle and joint pain (often in their legs), and POTS. As a result of these symptoms, children struggled to move around freely and engage in any form of physical exertion, often struggling to walk more than 200 yards. Parents were often emotional, expressing frustration when discussing the need for their child to monitor their physical and cognitive exertion so as not to "overdo it." During periods when their symptoms were flaring up, or following overexertion, children were often bedridden, or they had to use a wheelchair to get around. Further, some children often experienced neurological symptoms following overexertion, which included difficulties with balance and mobility.

Psychosocial Impact of Symptoms

For most children, Long COVID was accompanied by some form of emotional, social, or behavioural impact; however, the type of impact they experienced varied widely depending on the age of the child, and the severity and time frame of their symptoms.

The psychosocial symptoms of infants and toddlers (2 years of age or younger) and preschool-aged children (3 to 5 years of age) who were under 5 years old at the time of their diagnosis were largely behavioural, at least as far as parents understood, given the inability of children to communicate their feelings at a young age. This often took the form of children becoming increasingly frustrated and acting out or becoming sad and withdrawn because they felt isolated during their peak symptoms. They had difficulty "keeping up" with their friends or felt that they were "different" from their friends because of their symptoms.

> *He was young at the time, and we told him we had to take precautions and take it easy. But he was unhappy with the situation. He was confined and he couldn't interact with other kids, and he had all these symptoms. He didn't take it well. He was very shocked and frustrated by it, and we couldn't do much to help him at the time.* – Parent from British Columbia, 7-year-old child

Among school-aged children and adolescents, the psychosocial impact was heightened. Parents often noted that their child developed mental health issues such as anxiety and depression over time. This was especially true for those who experienced their symptoms over a longer period. For some, their mental health issues were related to the social challenges that emerged because of Long COVID. For example, they were unable to engage in sports or extracurricular social activities and thus felt separated from their social network. Or, they felt ostracized and even bullied by their peers due to the taboo nature of Long COVID symptoms and their efforts to avoid reinfection (i.e., wearing a mask). At the same time, in an interview with an adolescent affected by a very severe case of Long COVID, his resiliency and positivity were evident. This was further highlighted in interviews with parents of other school-aged children and adolescents.

Impact of Symptoms on Daily Activities

Like the physical impact of symptoms, the impact of symptoms on the day-to-day life and activities of children and adolescents was entirely dependent on the severity of their symptoms.

For mild and moderate cases of Long COVID whose symptoms resolved, the impact of their symptoms was largely constrained to the period in which they were the most severe. For example, several children had to miss some school or sit out from their regular sports and extracurricular activities for a few weeks or months. For others, there were periods where they were unable to engage in their hobbies (e.g., playing video games) due to their symptoms and a general lack of energy. These impacts were often frustrating for children, but they were temporary as children were typically able to gradually return to their regular day-to-day life and activities as symptoms began to lessen.
For those with moderate symptoms of Long COVID that had yet to resolve but had lessened over time, there was often a lingering impact on day-to-day activities. These children occasionally had a flare-up of symptoms that required them to miss school or their sports and extracurricular activities. However, missing activities was noted as being infrequent. There were only a handful of children who had played competitive sports (i.e., soccer or hockey) prior to their initial SARS-CoV-2 infection who, due to their persistent symptoms of fatigue and shortness of breath upon exertion, were no longer able to participate in these sports.

> *He's still not 100% back to what he used to be. He can't do basketball or soccer anymore. He can't really do swimming anymore because he gets shortness of breath. He gets bummed out too because he'll see all his friends doing these sports, but he can't do them anymore.* – Parent from British Columbia, 10-year-old child

Similar to the physical impact, for those with severe symptoms of Long COVID, the impact of their symptoms was all-encompassing, affecting their mobility (as previously mentioned), their ability to attend school, their ability to engage in hobbies and spend time with friends, as well as all other aspects of their lives. A couple of parents mentioned the burden placed on their child because of their Long COVID symptoms: their children had to constantly calculate the physical "cost" of their recovery following any form of exertion, such as walking a few blocks, doing schoolwork, or spending thirty minutes with their friends. For these children, and a few others, engaging in any form of exertion (e.g., physical, intellectual, social, etc.) often led to them requiring days in bed to recover. Those with severe Long COVID symptoms often experienced flare-ups that could last months at a time, causing them to miss a substantial amount of their schooling and to sleep for twelve hours or more per day. In these cases, both parents and children had to adapt their lifestyles to accommodate significantly decreased energy levels and limited capacity for exertion. In one case, an adolescent decided to take a "gap year" from "normal" life in order to get better. He felt that his efforts to integrate "productive" tasks in this life, such as attending school or seeking a job, were hindering his recovery.

> *She does two classes in-person per week and some online classes. But she can't go to most of them, because of her symptoms. She misses twenty-five to forty percent of her classes still.* – Parent from Alberta, 12-year-old child

Impact on Parent(s)/Caregiver

In discussions about the impact of Long COVID, parents and caregivers were also asked about how this condition impacted them, their partner, and their families. They often reported that their child's symptoms had either psychosocial or financial impacts on them.

The psychosocial impact was more widespread, with nearly all parents reflecting on the emotional turmoil and distress associated with having a child who is ill and suffering. Parents mentioned feelings of helplessness, particularly given that Long COVID was a new medical condition and that there was a lack of information and clear treatment options available. This sense of helplessness was further perpetuated because there was no scientifically proven remedy that parents or caregivers could give their child to alleviate their symptoms of pain and discomfort. For parents with younger children, these feelings of helplessness were often exacerbated by the challenges of communicating with children who had not fully developed the ability to speak or describe what symptoms they were experiencing. Among parents with children who had been experiencing Long COVID symptoms for extended periods of time (i.e., over a year), there were high levels of frustration and exasperation, with one parent stating that they were "devasted" and "don't understand why we can't get a child out of pain." Several parents of children and adolescents who had severe cases of Long COVID became emotional during the interviews when describing the debilitating impact that Long COVID had on their once healthy, active, and social children.

> *It was hard feeling like there wasn't enough available information, especially when it came to her chest pains and shortness of breath. She plays volleyball and basketball, and she was scared to do that, because of her chest pain. And the thing is, without the knowledge or information, a parent can't try and calm them down. There was nothing I could do to help or make it better or even provide information.* – Parent from Ontario, 15-year-old child

The financial impact of Long COVID on parents was slightly less common and often concentrated among parents of children with more severe cases that required higher levels of care. For example, children that experienced severe Long COVID symptoms for extended periods of time and were unable to attend school regularly often required a parent to provide care as needed. Additionally, for several parents, there were significant responsibilities and time commitments associated with advocating for their child in a healthcare setting and educating healthcare providers about the needs of their child. In these cases, one or both parents often had to drastically adjust their lifestyle to accommodate the needs of their child, which involved taking a leave of absence, moving to remote work, or quitting their job. For dual-parent families, this often led to financial strain. For single-parent families, their child's Long COVID was an even higher burden and often created significant financial concerns.

> *We have financial issues. We have to pay for the treatments, and I know we don't pay for the normal doctor visits, but I have to take off work or my partner has to take off work. It would really help to have some financial support.* – Parent from Ontario, 16-year-old child

To compound the financial burden placed on parents to provide full-time care for children with severe cases of Long COVID, there was often a great cost associated with seeking out care and treatment from specialists. For example, some parents chose to have their children treated by psychiatrists, physiotherapists, and naturopaths to alleviate their symptoms and the psychosocial impact of Long COVID. A small number of parents reported spending upwards of tens of thousands of dollars to seek out care and treatment for their children outside of Canada (which will be discussed in further detail in Section 3). The costs associated with accessing care and treatments were noted by many parents as being quite high. Additionally, they were rarely covered by insurance because Long COVID was a novel medical condition and there were a lack of official treatment protocols. Another parent reported that they had spent a significant amount of money on private tutoring to ensure that their child would not fall too far behind on their education. A couple of parents of adolescents with ongoing severe cases of Long COVID had also started the process of planning for the longer-term financial security of their child in the event that they did not make a full recovery from Long COVID. This included applying to access benefits for disability and setting up a trust to cover future living costs.

For parents living in more rural and remote locations, the impact of managing their child's Long COVID on a daily basis was heightened. They described the lack of care options within their community and the need to travel a long distance, or even out of province, in order to access specialist care for their children. This involved significant time and financial commitment on their part.

To manage the impact that Long COVID had on their lives, many parents leaned on their social networks, particularly close friends and family, for support with caregiving responsibilities. This social support allowed some parents to partially return to work and manage other responsibilities. There were a handful of parents who reported using parents' groups, community groups, or bulletin board threads on social media as a source of emotional support, specifically through sharing their experiences and hearing about the experiences of other parents in similar circumstances. This was highly valued by parents due to the newness of Long COVID and the limited amount of information they were able to obtain through "official" health sources.

2.2.3 Current Well-being and Future Outlook for Long COVID

The current health status of children and adolescents with Long COVID represented in this study was decidedly mixed: many no longer experience any symptoms (33 among 54 children and adolescents) and have returned to a state of "normal", while others continue to experience Long COVID symptoms to this day (21 among 54 children and adolescents), be it lingering and residual symptoms or full-blown symptoms that continue to heavily impact their quality of life (Table 8).

For those no longer experiencing symptoms, the amount of time it took for them to recover ranged widely, from a few months to over a year, with no identifiable patterns contributing to their recovery timeline. That said, the mildest cases tended to have symptoms that resolved over a shorter period of time, while the most severe cases generally still experience symptoms to this day.

Table 8. Duration of Long COVID symptoms and recovery status

Long COVID characteristics	Number of children with Long COVID
Duration of symptoms post PCC diagnosis	
≤ 2 months	6
3–6 months	19
7–11 months	12
≥ 12 months	17
Admitted to hospital or ICU	
No	31
Yes	23
Recovery status	
Recovered	33
Still experiencing symptoms	21

Broadly, parents of children whose symptoms had completely resolved tended to have a positive or at least a "cautiously optimistic" outlook on the future and had minimal concerns about the potential long-term impact of Long COVID on their child. Some parents attributed their positivity to the ways in which their child had returned to their pre-COVID state. Others had a more pragmatic attitude, noting that as a parent it is their responsibility to remain optimistic about the future for the sake of their child. There were only a few parents who expressed concern about the potential long-term impact of Long COVID, despite their child having made a full recovery. These concerns often came from parents who had very young children; they were worried about the toll that Long COVID took on their child's body (i.e., on their lungs due to the coughing and shortness of breath) and the potential impact it may have had on their development.

Among those still experiencing symptoms, those with lingering symptoms outnumbered those still experiencing full-blown symptoms. There were quite a few children who had not yet fully "bounced back" and still experienced lingering symptoms of fatigue, headaches, and shortness of breath upon exertion. These lingering symptoms were often not as severe as those that children had experienced at the peak of their illness or at the time of their diagnosis. Further, they were typically seen by parents as more of an inconvenience rather than as having a significant impact on their child's well-being and quality of life. Comparatively, there were a small number of children, typically those with the most severe cases of Long COVID, who were still experiencing symptoms to their fullest extent (i.e., symptoms that are seriously detrimental to their well-being and quality of life).

Parents' future outlook was slightly more complex if their child was still experiencing very severe symptoms. These parents often found themselves struggling to imagine their child's symptoms completely resolving, given that in some cases the child had been experiencing symptoms for several years. They expressed substantial concerns about the long-term impact of Long COVID on their child, specifically regarding their child's cognitive development (i.e., following the extended period in which their child had experienced cognitive symptoms) and what their child's adult life would look like if their symptoms persisted (particularly for adolescents who were approaching adulthood).

For one parent, their concerns were related to the ability of their teenager to secure a full-time job and receive a post-secondary education in the future, given the severity of their symptoms. They also reflected on the likelihood that their child would have to apply for and potentially rely on disability credits from the government.

2.3 Seeking Solutions for Long COVID

This section outlines the diverse care journeys of children with Long COVID and their families, as reported by the parents and older adolescents aged 18–19 years who took part in this research. It dives into their experience seeking out care, from the initial point of contact with the healthcare system, through to receiving a diagnosis and any follow-up care or treatments. This section also describes the varying levels of healthcare engagement children and adolescents had based on the severity and complexity of their symptoms. It explores the factors that drove satisfaction and dissatisfaction throughout this care journey and identifies the different channels of care and support accessed by children and their families. Finally, this section concludes by discussing the perspectives of healthcare providers and researchers regarding Long COVID treatment methods.

2.3.1 Overview of Care Journeys for Long COVID

The care journeys experienced by parents and their children and adolescents varied quite widely in terms of care settings and the duration and frequency of contact points with the healthcare system, and were largely based on the severity and range of symptoms children and adolescents experienced. Those with less severe symptoms tended to receive a diagnosis from a family doctor or emergency room physician, and often required minimal follow-up care. Comparatively, those with severe symptoms often struggled to receive a diagnosis, accessed multiple channels of care before being diagnosed, and continued to seek out various forms of care and treatment after their diagnosis. Parents tended to express satisfaction with the overall quality of care they received if their child had a milder case of Long COVID that required less contact with the healthcare system. Parents with higher satisfaction appreciated the attitude and knowledge of healthcare providers, as well as their ability to provide a clear path forward for managing symptoms.

On the other hand, parents often expressed dissatisfaction with the care they received if their child had complex symptoms and/or if they required higher levels of contact with the healthcare system. Their dissatisfaction was often related to challenges accessing care, and a perceived lack of knowledge and/or dismissive attitude of healthcare providers.

2.3.2 The Journey Leading up to a Diagnosis for Long COVID

Initial Point of Care

For most parents, they initiated their journey of seeking care for their children and adolescents because they needed information and guidance from a healthcare provider about the health of their child. They also wanted to receive answers about the cause of their child’s symptoms, why their symptoms were not resolving, and/or how to manage or alleviate their symptoms.

The first point of care for parents and their children was often their family doctor who, in most cases, had a close relationship and familiarity with the child and their medical history. This existing relationship was typically what drove parents to seek out care or guidance from the family doctor as a starting point. Several parents were able to access their family doctor without difficulty because they lived in close proximity to their doctor’s office or because they had a close relationship with the family doctor.
However, some parents reported challenges in accessing primary care or securing an appointment with their family doctor due to lengthy wait times and occasionally shorter appointments. This was particularly common for those with children who developed Long COVID earlier in the pandemic. They frequently acknowledged that these challenges were rarely the fault of their family doctor specifically, and instead were due to a shortage of healthcare workers and the broader burden on the healthcare system at that time.

A handful of parents visited the hospital emergency room as the first point of care for their child because they did not have a family doctor, they felt that they would not be able to access their family doctor in a timely manner, or they had a child with new and/or alarming symptoms (e.g., chest pains) that were concerning enough to warrant a visit to the emergency room. These parents often noted long wait times at the hospital; however, this was seen as being related to the broader burden on the healthcare system at the time rather than a function of the hospital providing poor care.

Satisfaction with the Initial Point of Care for Long COVID

Parents were decidedly mixed in their satisfaction with the initial point of care for their child. Their level of satisfaction was often influenced by the attitude and effort that their healthcare provider displayed during visits. Specifically, higher levels of satisfaction were reported among parents who had healthcare providers that validated their experience; provided answers, guidance, and solutions; and were determined to have positive treatment outcomes. For example, satisfied parents had healthcare providers that offered tests and assessments to mitigate their concerns and rule out other diagnoses, provided clear guidance for managing and monitoring symptoms, and provided a diagnosis at the initial point of care. There were a few parents, particularly those who had a close relationship with their family doctor or had a child experiencing relatively mild symptoms, who expressed satisfaction with the initial care they received, even if the family doctor was unsure of the symptoms or unable to provide a clear path forward. In these cases, their satisfaction was primarily driven by the doctor's willingness to hear them out, the fact that they validated the symptoms experienced by their child, and the perception of parents that the doctor was acting in the best interests of their child.

Conversely, parents were dissatisfied primarily due to the inaction of healthcare providers and their inability to provide a clear path forward to manage their child's symptoms. There were several instances where parents felt that healthcare providers dismissed the symptoms their child was experiencing or were unable to provide an explanation for the symptoms. In these cases, parents were often advised to monitor their child's symptoms at home, and were instructed to take them to the emergency room should the severity of symptoms increase.

This response was often frustrating for parents who had children with mild symptoms, but they were able to monitor and manage symptoms at home using over-the-counter treatments or home remedies (which will be discussed further in Section 2.3.3). In some instances, the child's symptoms persisted, leading parents to take their child back to a family doctor or the emergency room. This visit often led to a diagnosis. However, for those with severe symptoms, this delay in diagnosis was deeply unsatisfactory, given the impact of the symptoms on their child's quality of life. For these parents, dissatisfaction with the initial point of care was often the catalyst for their subsequent efforts to seek out care and information through different channels.

2.3.3 Long COVID Diagnosis Experiences

Most parents were able to receive a diagnosis for their child with relative ease. However, this was not common across all parents, with some struggling for months and years to receive a diagnosis from healthcare providers. It seemed that the ability of parents to receive a diagnosis for their child was less related to the severity of their symptoms and more related to healthcare providers' awareness of Long COVID and their willingness to provide a formal definition for a condition that, particularly earlier in the pandemic, was not well understood.

Children who easily received a diagnosis often had mild to moderate symptoms. Additionally, their diagnosis was received within a few points of contact with the healthcare system and within six months of symptom onset. For example, there were several parents who, following their initial point of care visit (e.g., their family doctor or the emergency room), were sent home to monitor their child's symptoms and seek out further care if the symptoms did not resolve over the next couple weeks. At a later date, when their child's symptoms still hadn't resolved, they returned either to the emergency room or their family doctor. This second visit often resulted in a Long COVID diagnosis if their healthcare provider was relatively knowledgeable of and familiar with Long COVID, which was often the case. For a few participants, there were one or two additional contact points with the healthcare system before they received a diagnosis.

These parents tended to be relatively satisfied with the diagnostic process, but were only offered high-level information about what it entailed. For some, the process involved getting blood work and other tests done. For others, it primarily involved ruling out other conditions. Numerous parents seemed to believe that the healthcare provider giving the diagnosis was as knowledgeable and well-informed about Long COVID as they could have been, given that it was a relatively new condition.

However, while there were several parents who moved through the diagnosis process with ease, there were others who faced immense difficulties. There were a handful of parents, particularly those with children and adolescents experiencing severe and debilitating symptoms, who visited numerous physicians and specialists to receive a formal Long COVID diagnosis for their child. One parent and their child attended 82 medical appointments with various specialists before they were able to receive a formal diagnosis from a healthcare provider in the United States. The challenges faced by these parents and their children in seeking out a diagnosis were wide-ranging and included skepticism from healthcare providers about their child's symptoms, a lack of acknowledgement of Long COVID among Canadian doctors and a reluctance or unwillingness or provide a diagnosis, and a sense of being pushed by healthcare providers towards psychiatric explanations or treatment for their symptoms. For a minority of parents, there was extreme frustration and concern expressed about the recent statement from the Canadian Pediatric Society[37] about somatic symptoms and related disorders (SSRDs). They felt this may further encourage healthcare providers to turn to psychiatric explanations rather than validating or fully exploring the Long COVID symptoms experienced by children.

As these parents moved through the healthcare system, they were routinely met with dismissive attitudes and ignorance. They attributed these attitudes, and their challenges in receiving a diagnosis, to not only the lack of research and information about this condition in Canada, but also to the lack of clear diagnostic criteria provided by the government and the use of standard testing as a diagnostic practice that did not appropriately capture the range of Long COVID symptoms.

Given the treatment of their children in the Canadian healthcare system, a few parents felt that they had no choice but to seek a diagnosis outside of Canada. These parents travelled to the United States, and one also travelled to Germany, to seek out testing (which included microplot diagnostic testing and the Tilt table test) that would help build their case for a Long COVID diagnosis and prove that the symptoms experienced by their child did have a physiological basis. Even after these parents received formal diagnoses from physicians in the United States, they continued to receive push back from Canadian doctors. Eventually, however, they did receive a formal confirmation of the provided Long COVID diagnosis.

After dealing with the challenges of navigating the healthcare system, a small number of parents (often those who sought care for their child outside of Canada) became deeply involved in Long COVID support groups, advocacy work, and even pro-bono legal initiatives to advocate for Long COVID awareness and proper care, especially for children. As they became more involved in advocacy work, they heard many stories from other parents who faced similar challenges in receiving a diagnosis, including being dismissed by healthcare providers and being pushed towards psychiatric or psychosomatic explanations for their child's symptoms.

Only a small number of **healthcare providers** involved in this study actively diagnosed children with Long COVID. For those who were providing diagnoses to children as a general or family physician, their diagnostic approach primarily involved examining children's symptoms, going through the process of exclusion (i.e., ruling out other conditions), and conducting a standard workup (e.g., routine bloodwork, chest x-rays, or ultrasounds, etc.). For children experiencing gastrointestinal symptoms, the diagnostic process would also include an abdominal ultrasound. Following their diagnostic process, several mentioned that they would often refer children to a pediatrician or pediatric respirologist to confirm the diagnosis.

Several **researchers and subject matter experts** spoke to the challenges associated with diagnosing Long COVID, particularly in children. These challenges included the lack of a clear definition and diagnostic criteria for Long

COVID, the symptomatic overlap with other conditions, and the broader lack of information and awareness of Long COVID.

Although **healthcare providers** were challenged by the lack of a clear definition for Long COVID, many expressed no clear preference for what a Long COVID definition should include, and most were unable to recall which definition they used in their workplace. This neutral stance often held for researchers, except for one, who expressed a dislike for the WHO definition as they felt it did not guide clinicians in providing a diagnosis. Instead, they preferred the 2024 National Academies of Sciences, Engineering, and Medicine (NASEM) definition,[38] which they believed to be more comprehensive. Aside from the lack of a clear definition, many expressed frustrations with the lack of clear diagnostic criteria (i.e., biomarkers) for Long COVID. Without clear biomarkers, healthcare workers had to ask child patients diagnostic questions to arrive at a diagnosis. An accurate diagnosis was reliant on patients understanding the questions being asked, but unfortunately, they were phrased in a way that children could not easily understand.

> *The WHO definition from 2023 for [diagnosing] Long COVID is the poorest definition that [we've] had in five years. It's weak. It doesn't help the clinician to distinguish any kind of disease. The 2024 NAESM definition, which is the same for children and adults, makes way more sense. But it's super complex for the clinician [providing a diagnosis] because the evidence is so poor, so they have a lot of trouble helping these kids.* – Researcher from Quebec
>
> *2024 NASEM Long COVID Definition*[38]
> *Long COVID (LC) is an infection-associated chronic condition (IACC) that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems. LC manifests in multiple ways. A complete enumeration of possible signs, symptoms, and diagnosable conditions of LC would have hundreds of entries. Any organ system can be involved, and LC patients can present*
>
> - *with single or multiple symptoms, such as shortness of breath, cough, persistent fatigue, post-exertional malaise, difficulty concentrating, memory changes, recurring headache, lightheadedness, fast heart rate, sleep disturbance, problems with taste or smell, bloating, constipation, and diarrhea.*
> - *single or multiple diagnosable conditions, such as interstitial lung disease and hypoxemia, cardiovascular disease and arrhythmias, cognitive impairment, mood disorders, anxiety, migraine, stroke, blood clots, chronic kidney disease, postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), mast cell activation.*
>
> *The research hasn't gotten us to a place where we have a solid answer or access to any kind of diagnostic testing or biomarkers. We definitely hang our hats on diagnostic testing. Not having any kind of positive test obviously hinders any kind of treatment. So, in an overwhelmed healthcare system, people are left without anything to do because the tests are normal.* – Physiotherapist from Alberta

Many **healthcare providers** also noted the challenges that symptomatic overlap posed in their ability to provide Long COVID diagnoses to children. Specifically, symptoms could overlap with other viral infections, psychiatric conditions, or natural and hormonal changes in teenagers (e.g., muscle and joint pain, changes in skin texture, mood fluctuations). The unspecific nature of Long COVID symptoms made it difficult for healthcare providers to distinguish between those that were related to Long COVID and those that were not. It could also lead to Long COVID being dismissed as purely psychiatric or psychosomatic.

Finally, the broad lack of knowledge and awareness of Long COVID – both among the public and among healthcare providers – was noted as a significant challenge. Both **healthcare providers and researchers** felt that there was a lack of knowledge of Long COVID in the medical community, largely due to the lack of available research. This situation often impacted the ability of healthcare providers to identify, diagnose, and treat Long COVID. As such, many suggested there may be an opportunity for large-scale training of healthcare providers who diagnose and treat Long COVID to improve their knowledge and diagnostic skills.

2.3.4 Post-Diagnosis and Treatment Plan for Long COVID

Parents who were satisfied with their experience of receiving a diagnosis for their child were often satisfied with any follow-up care and treatment that was offered. Those who had negative experiences and struggled to receive a diagnosis for their child often had additional negative experiences with follow-up care.

Drivers of Satisfaction

There were several factors that influenced parental satisfaction with the information and treatment plan they received from healthcare providers for their children. These factors were often related to the perceived knowledge levels of healthcare providers and the provider's willingness to validate the experiences of children. That said, parental satisfaction appeared to ultimately be tied to the severity of their child's Long COVID case.

The perceived knowledge that healthcare professionals had about Long COVID was a significant driver of satisfaction among parents. Many parents acknowledged the challenges faced by both the healthcare industry and the public during the pandemic with regard to the limited information available about Long COVID, specifically around Long COVID treatment and outcomes. However, there were several parents who praised the healthcare professionals who worked with their children for their knowledge levels (particularly given the circumstances) of Long COVID, and for their efforts to stay up to date with the latest guidance and research. A number of parents also felt comforted by their healthcare provider's openness to consider and explore the information they found by doing personal research into the condition. A number of participants who were able to access care from a doctor or specialist associated with a children's hospital tended to display higher levels of comfort in the care they received because of the doctor's expertise in children's health.

Generally, it seemed that healthcare providers' willingness or propensity to acknowledge and validate the symptoms and experiences of children with Long COVID was related to their knowledge about Long COVID. Parents who felt that their healthcare provider had relatively high levels of knowledge and awareness were often those who felt that the provider listened to and validated their child's experience. Several parents recalled very positive experiences where the healthcare professionals were kind and empathetic, and took great care to understand the experiences of their child.

Although the perceived knowledge levels of healthcare professionals, as well as their willingness to validate the symptoms and experiences of children, were often drivers of satisfaction across the board, the severity of the Long COVID case was often the ultimate factor that determined parental satisfaction with the quality of care and treatment their child received. Parents who were more satisfied with the information and treatment plan their healthcare provider offered were often those who had children with milder cases of Long COVID, particularly those that did not involve complex symptoms and only required minimal follow-up care.

> *We were really satisfied. I think we felt supported, even when we went to the walk-in clinic instead of the family doctor. I really feel like we had our need met. I know that's not the case for other people, but I thought [the doctors] navigated it the best they could. We got the best care for [our child].* – Parent from Alberta, 4-year-old child

There were only a few parents of children with moderate or severe symptoms who reported positive experiences with the information and/or treatment plan provided by healthcare professionals. Positive experiences were often only reported by parents later in their journey of accessing healthcare (i.e., following their challenges of receiving a diagnosis) and due to their close relationships with one or multiple healthcare providers.

Two children who experienced some of the most severe cases of Long COVID eventually found a doctor (based in the United States, in both cases) who agreed to take them on as patients and work with them. The parents of these two children reported extremely positive experiences with these doctors, in comparison to the more negative experiences they had with Canadian healthcare professionals. These positive experiences were largely attributed to the attitude and effort undertaken by the American doctors to understand their child's symptoms and experiences. They often spoke directly to the child to ensure the child felt heard and validated. Additionally, these doctors were perceived as having very high levels of knowledge about Long COVID and were often involved in "cutting edge" research and clinical trials.

Drivers of Dissatisfaction

The drivers of dissatisfaction with the information and treatment plan provided by healthcare professionals were often also related to their perceived knowledge and attitudes towards Long COVID. Several parents felt that the healthcare professionals caring for their child had limited knowledge and understanding of Long COVID, specifically as it related to the available treatment options and the long-term trajectory or outcomes for the condition. They expressed that they would have felt more comfortable managing their child's condition if they had received clear information from their healthcare providers about the specific steps they needed to take to resolve their child's symptoms. There was some recognition, as previously mentioned, of the knowledge gap related to Long COVID in the healthcare field. However, some parents felt that healthcare professionals did not make enough of an effort to seek out information and resources through different channels, such as Long COVID research that existed outside of Canada.

> *As a parent, it would've been great if [the doctors] could be like, "do these five steps and your kid is going to be better." That would've given a bit more peace of mind. But I understand that there wasn't really any available solution, and I guess we had to accept the fact that it was uncharted territory.* – Parent from Saskatchewan, five-year-old child

Additionally, like their experience in receiving a Long COVID diagnosis for their child, numerous parents felt that healthcare providers were often dismissive in terms of their attitude towards the child and their symptoms. There were some instances where healthcare providers were unwilling to engage with the child directly (and only spoke to the parent) or were unwilling to take the time to understand the symptoms and experiences of the child. For some, this also involved symptoms being brushed off as psychosomatic or as requiring psychiatric treatment. For other parents, this took the form of feeling as though healthcare professionals were "trying to get rid of them" as opposed to seeing through their child's treatment plan and recovery. A minority of parents also mentioned a "rushed bedside manner" among healthcare providers during follow-up visits at the hospital, at their specialist's office, or at their family doctor's office.

> *We had a horrendous experience with a pediatric neurologist, where she refused to acknowledge my daughter in the room. She went on to be very ignorant of the history of my child. She did not want to connect with our pediatrician to [understand] why we were there. She was fifteen minutes late to the appointment, so that just gave us ten minutes to chat. And here was my child, who wasn't able to walk and was in extreme pain with extreme fatigue.* – Parent from Alberta, 12-year-old child

Long wait times to access specialist care were the other main drivers of dissatisfaction with the care journey. Some parents reported having to wait weeks to access their family doctor, which resulted in some turning to walk-in clinics or emergency departments. The "lockdowns" introduced to manage the COVID-19 pandemic also presented barriers to accessing care from primary care physicians. Others reported having to wait weeks or even months after being referred to a specialist.

The lack of coordinated care among healthcare professionals was another challenge experienced by parents of children with more severe cases of Long COVID. Since these parents were largely dismissed by their family doctors, they had to personally take on the responsibility of coordinating care for their children. Because there was little interaction between different specialists or healthcare providers, parents had to retell their story every time they saw a different provider. They also had to take on the role of "piecing it all together."

Follow-Up Care and Treatment for Long COVID

The type of follow-up care and treatment received by children ranged quite widely and primarily depended on the severity of their symptoms.

Among children with mild symptoms, healthcare providers offered minimal advice or guidance related to treatment. As such, many parents relied on a combination of home remedies (e.g., hot water with honey and lemon, boiled garlic and ginger), over-the-counter pain relief (e.g., Advil, Tylenol), cold and flu medicine (e.g., cough syrup, Vicks VapoRub), vitamins (e.g., vitamin C and D), and lifestyle changes (e.g., staying hydrated, getting lots of sleep). In milder cases, these remedies tended to provide some relief to children, but none stood out to parents as being particularly effective. Generally, it was just a matter of the symptoms resolving over time. These children often did not require any follow-up care as their mild symptoms gradually faded over the course of a few months.

> *We would find different types of cough drops that would help her [sore] throat. We tried a bunch of different things, especially at night. I would put on a humidifier, and I found Vicks inserts for the humidifier. So, when she was congested, we would try a different repertoire of things, and it didn't always require Tylenol or Advil or ibuprofen. That seemed to mitigate some of the symptoms.* – Parent from Atlantic Canada, 8-year-old child

For those with moderate symptoms, there was more diversity in terms of the treatments attempted and received. The symptom management strategy was similar to that mentioned above, and included over-the-counter pain relief, vitamins, and lifestyle changes. However, there were quite a few children who received additional treatments during their visits to the emergency room (e.g., antibiotics, oxygen mask, IVIG). There were a handful of children who were prescribed inhaled corticosteroids (i.e., a puffer) that they could use as needed to help with their respiratory symptoms. Typically, treatments that children received in the hospital or that were prescribed (i.e., inhaled corticosteroids) were seen by the parents as being highly effective in alleviating their symptoms. There was one parent who took a more unconventional approach to treating their child's Long COVID: they used ivermectin that they acquired in Mexico after feeling unsatisfied with the guidance provided by Canadian healthcare providers.

Children with moderate symptoms often also sought out care and treatment through different channels, including psychiatrists to help manage the emotional and psychological impact of Long COVID; physiotherapists to help regain muscle and balance; and naturopaths to help guide any dietary changes and the use of vitamins or supplements. Additionally, a few of these children (particularly the younger ones) received follow-up care from their family doctor or a pediatric specialist, which often involved monthly appointments for blood work and monitoring.

For children with the most severe symptoms, their care and treatment journeys were often quite complex, involving many different channels. In some cases, their journey is ongoing to this day. These children often began their care journey seeking out guidance and treatment from various specialists (e.g., cardiologists, respiratory doctors), but parents often felt that these channels were unsuccessful in providing effective treatments that alleviated symptoms. Following these efforts, a few parents turned to different forms of care and treatment to manage their child's symptoms. This care included physiotherapy and chiropractic rehabilitation (e.g., traditional chiropractic care, hyperbaric oxygen therapy) for children with symptoms impacting their mobility (i.e., localized pain, POTS, extreme fatigue) to rebuild their strength and balance, or in some cases, to get them out of a wheelchair. Additionally, one parent mentioned different treatments that they tried, all of which were unsuccessful. Treatments included neurological therapy that used goggles and lights to try and address balance and sensory issues, and a psychoeducation program that focused on the mind–body connection. The parents thought the psychoeducation program was inappropriate given the ways in which it emphasized psychological symptoms. Finally, some mentioned using various medications to help manage symptoms and improve their child's quality of life, noting some success with certain medications (e.g., Florinef (Fludrocortisone) to treat POTS symptoms, Vyvanse (Lisdexamfetamine dimesylate) for noise and light sensitivity, Neurontin (Gabapentin) to alleviate pain).

It is important to note that for those with severe cases of Long COVID who continue to experience debilitating symptoms, these various avenues of care and treatment were used to manage their symptoms and improve their quality of life since they felt that there were no effective treatments available in Canada to eradicate or significantly alleviate symptoms.

> *We are at the point where we are just trying to improve her quality of life, which sucks. Like that's supposed to be the case for people who are at the end of their life or who have cancer. We're not actually able to solve any of her problems, we're just trying to make her life easier.* – Parent from Alberta, 12-year-old child

A few parents discussed their efforts to participate in clinical trials in the United States, hoping that the trials would address their children's symptoms. They expressed frustration and anger about the lack of similar research in Canada that explored treatment options and aimed to build a larger knowledge base about Long COVID, given the significant impact that it can have on the lives of children.

Notably, a very small number of parents turned to Long COVID clinics to seek care for their children. In these cases, healthcare providers either did not offer the clinic option to parents, were not aware of any Long COVID clinics for children, or advised parents that their child's symptoms were not severe enough to attend. The few who did report negative experiences found that they had more knowledge about Long COVID than the clinic's professionals.

Healthcare providers and researchers were relatively mixed in their perspectives on how to treat Long COVID. Most noted that treatment was quite specific and generally symptom-based – especially for pharmacological treatments – with healthcare providers suggesting treatment options that would alleviate a specific symptom. As such, they were largely unable to identify any specific treatment options or plans that worked "better" than others, but they were able to provide some insight into the treatment options they would suggest to address certain symptoms.

From the **perspective of researchers**, subject matter experts, and those working in a Long COVID support group or advocacy capacity, treatment approaches and options that solely work to alleviate specific symptoms were insufficient. They frequently mentioned the knowledge and research gap that existed about Long COVID, specifically regarding the available treatment options and potential long-term outcomes. However, some believed that the challenges faced by the healthcare system in addressing Long COVID were not unique and reflected its general inability to address and treat complex health conditions. As such, a few mentioned the need for further government investment in medical research about Long COVID, especially Long COVID in children, as the general lack of knowledge and expertise on Long COVID is compounded in the case of children. They also expressed a need for the development of care models for those experiencing Long COVID.

> *I'll hear from my patients, "my physician believes I have Long COVID, but doesn't know anything about it and doesn't know what to do." The first step is that awareness piece, to be willing to diagnose it. But now, we're lacking in the information about it. You don't have to be a specialist to at least know where to direct your patients or have guidance about what to do.* – Physiotherapist from Alberta

For some parents who had children with severe cases of Long COVID and who worked in an advocacy capacity, there was an emphasis on leveraging the research (e.g., clinical trials) and treatments (e.g., tilt table tests, microclot tests) that were available in the United States and abroad, and ensuring they were available and accessible for parents and children in Canada. However, some researchers were hesitant to adopt treatment modalities from other countries, and even questioned their efficacy, noting their more relaxed regulatory processes within the medical field.

2.4 Information Needs for Long COVID

Parents generally felt that they were more informed about Long COVID nowadays than they were at the start of their child's Long COVID journey. The information needs of parents tended to be fairly consistent and centred around identifying the underlying causes of their child's symptoms; managing and treating symptoms and underlying causes; and understanding the longer-term impact of Long COVID on their child's physical health and development. Parents also generally relied on a mix of information provided to them by their healthcare providers and through their own online research. There were nuances in how parents satisfied their information needs that were partly driven by the severity of their child's Long COVID case and the level of responsiveness from healthcare professionals they interacted with.

During the onset of their child's Long COVID symptoms, parents tended to prioritize "looking for answers" given that symptoms were flu-like but persisted over time or were combined with less typical flu-like symptoms. Some parents wanted to rule out a more serious condition, which may explain why a few turned to hospital emergency rooms as their first point of contact with the healthcare system. Most participants had little prior knowledge of Long COVID and had not heard of anyone in their social circle being affected by it. Some had never heard of the condition before it was mentioned to them by healthcare providers in the lead-up to a formal diagnosis. There were a couple of instances where participants were prompted to seek care because their family members mentioned Long COVID.

Once parents received a Long COVID diagnosis for their child, they had greater information needs and wanted a deeper understanding of the condition, symptom management, treatment options and recovery trajectory, and its longer-term impact on physical health and development. Parents relied on healthcare providers who gave the diagnosis as well as providers who were part of the management and recovery journey as key sources of information. Most felt that their healthcare providers were able to effectively address their questions. They rated their healthcare providers positively regarding their ability to offer information about Long COVID, to review treatment options, and to provide information that was consistent with what other healthcare providers were providing. Ratings were lower from parents who believed they were not provided information on Long COVID support groups, though it is worth noting that not all parents felt the need to use support groups. A few parents explained these lower ratings, pointing out that there was limited understanding of Long COVID at the time, which in turn limited what healthcare professionals could offer. A small number felt that the healthcare providers they encountered were not very knowledgeable about Long COVID and displayed little interest in learning more to support parents. These were often the same parents who felt that their healthcare provider was dismissive, as reported above.

All parents complemented the information they obtained from their healthcare providers with their own personal online research. Many parents noted that they were in the habit of supplementing health information offered by their healthcare provider with their own research and information, even if it was a simple Google search to validate the information they received. There was added impetus to learn more because of the newness of COVID-19 and Long COVID. As might be expected, the level of research conducted by participants varied based on the severity of their child's Long COVID case, as well as their satisfaction with and their trust in the healthcare provider's handling of their child's case.

Parents of children with more severe Long COVID and/or those who felt their children's care needs were not met by healthcare providers were more likely to conduct extensive research online. They turned to numerous sources including guidance offered by health ministries and public health agencies and information on well-known health information sites such as the Mayo Clinic. A few parents who had a background in health read the latest published scientific studies on Long COVID in children. These parents were also most active in online social media groups for parents in general or for parents of children with Long COVID. They appreciated hearing about the experiences of other parents navigating this newer condition, and were especially interested in learning about various management and treatment protocols that appeared to work. Several parents shared the treatment protocols they found online with their healthcare providers if they felt that their healthcare providers were not being proactive in offering ideas. Some participants were pleased that their healthcare providers were at least open to exploring some of the options.

Overall, these participants had higher levels of knowledge about Long COVID. The main information gaps they identified were related to the limited number of scientific studies on Long COVID in children.

In contrast, parents of children who had less severe cases and/or who reported more positive experiences with healthcare providers appeared to have conducted less in-depth online research about Long COVID. They simply recalled conducting a general "Google" search and reading as much information as they could around the time their children were first diagnosed. They generally found the information of limited use as it either confirmed what their healthcare provider said or it came in the form of too many search results to sift through. Participants were thus more inclined to focus on the information offered by their healthcare providers. As their children's symptoms alleviated, they were less motivated to conduct additional research. A few had read posts or threads about the experiences of other parents whose children were affected by Long COVID. They found it helpful to compare these experiences to their own, and in some ways, were comforted knowing that their children were not alone in being affected by Long COVID. They were less active in support groups on social media. These participants did not report any major informational gaps, though they said they would appreciate more information about the longer-term impact of Long COVID in children.

As alluded to in previous sections, **healthcare providers and researchers** felt that, at the time of the study, there was limited scientific evidence about Long COVID, the efficacy of COVID-19 vaccination, clinical guidelines for diagnosis, and treatment protocols for children. They saw a great need to address these informational gaps over time, which would in turn result in children and their families receiving higher quality care. Most stayed current on the latest published research in medical journals and the official guidance being issued by health authorities. They saw a need to continue raising awareness about PCC conditions among healthcare professionals and to offer CPD opportunities for professionals interested in receiving specialist training.

> *I would look on different medical journal websites, to see what was coming out of the United States and some of their forefront hospitals, but obviously the [United] States is different in terms of healthcare. I was also really trying to get the best Canadian perspective I could, but I also realize that it's a worldwide pandemic.* – Parent from Alberta, 5-year-old child

3. The Patient Journey for Multisystem Inflammatory Syndrome

3.1 Profile of Study Participants with MIS-C

Age and Pre-Long COVID Health Status of Study Participants

MIS-C incidence in the general population is lower compared to Long COVID; however, this study captured a small number of parents whose children had been affected by MIS-C. Children with MIS-C tended to be younger, with none over the age of 11 years at the time of diagnosis. Participant demographic characteristics are presented in Table 9. There was one case where multiple children in the same household experienced MIS-C.

Table 9. Demographic characteristics of children who were affected by MIS-C

Demographic characteristics	Participants (n=11)
Age at time of diagnosis (years)	
Infants and toddlers (2 or younger)	2
Preschool-aged children (3 to 5)	3
School-age children (6 to 11)	6
Gender	
Female	5
Male	6
Region	
Ontario	4
Quebec	4
Western and Northern regions	3

All parents described their children as being “normal,” “healthy,” and “active” prior to their SARS-CoV-2 infection that led to MIS-C. One parent reported that their child had ongoing kidney issues, while the rest reported no ongoing or pre-existing health conditions (Table 10).

Table 10. Pre-existing health conditions among children with MIS-C

Pre-existing health condition	Participants (n=11)
None	9
Allergies or asthma	1
Genetic or kidney issues	1

SARS-CoV-2 Infection and VOC Predominance Period

Most parents reported that their child had at least one confirmed or suspected SARS-CoV-2 infection (7 among 11 children). Some children had two (2 among 11 children) or ≥ 4 infections (2 among 11 children). This research captured the experiences of children who were infected with different COVID-19 variants of concern (VOCs), with 7 among 11 children getting infected during the pre-Omicron predominance period (Table 11).

Table 11. Timing of SARS-CoV-2 infection that led to MIS-C symptoms

Timing of SARS-CoV-2 infection and circulating VOC	Number of children with Long COVID
Wild type VOC – Pre-March 2021	6
Alpha/Beta/Gamma VOC – April to June 2021	0
Delta VOC – July to December 2021	1
Omicron VOC and sublineages – January 2022 to present	4

3.2 Living with MIS-C

MIS-C Symptoms Experienced

There were patterns regarding the symptoms that children with MIS-C experienced, both in terms of their initial SARS-CoV-2 infection and the ways in which their symptoms evolved leading up to their MIS-C diagnosis.

At the time of their initial SARS-CoV-2 infection, children's symptoms were described as "mild" and similar to those associated with the common cold or flu, such as nasal congestion, headache, fatigue, and fever. There was only one child who experienced more severe symptoms with their initial SARS-CoV-2 infection, including a "croup-like cough" and difficulty breathing, which persisted and became part of their MIS-C symptomology. However, for most children, these initial symptoms tended to either resolve over the course of a few days or remain consistently mild until the onset of more severe symptoms, which typically emerged within one to three weeks after the initial SARS-CoV-2 infection.

The MIS-C symptoms that emerged over time tended to be considerably more severe in nature, as reported by parents. Most parents reported that their children relapsed and experienced more severe symptoms, which included acute gastrointestinal symptoms (e.g., diarrhea, abdominal pain, vomiting); shortness of breath or difficulty breathing; body numbness, swelling, and aches; as well as some symptoms typically associated with the initial SARS-CoV-2 infection, such as fatigue, headache, and cough. In the more severe cases of MIS-C, parents reported that their children experienced skin rashes, mucocutaneous inflammation signs, and low blood pressure. The severity of symptoms experienced by different age groups is shown in Table 12.

Table 12. MIS-C symptom severity experienced by different age groups

Age at time of MIS-C diagnosis (years)	MIS-C symptom severity		
	Mild	Moderate	Severe
Infants and toddlers (2 or younger)	0	0	2
Preschool-aged children (3 to 5)	1	2	0
School-age children (6 to 11)	3	2	1
Total	4	4	3

The Impact of MIS-C Symptoms

Like the impact of Long COVID, the impact of MIS-C on the child was explored across three dimensions: physical, psychosocial, and day-to-day activities.

Parents reported that MIS-C symptoms tended to impact their child's physical health. This physical impact took several forms, including discomfort related to gastrointestinal symptoms, and occasionally associated weight loss; difficulty breathing due to respiratory symptoms, which often led to difficulties sleeping; and for some, physical pain or discomfort related to other symptoms (e.g., chest pain, headaches, cough). The physical impact of MIS-C was often greater than Long COVID, given the inherent severity of MIS-C symptoms that resulted in hospitalization.

The severity of MIS-C symptoms had implications for the mental health of children. For children who were younger and/or had not been in the hospital before, their experience was described by parents as "traumatizing" and involved significant stress or anxiety for the child due to the unfamiliar environment. For children who were older, the psychosocial impact tended to revolve around their inability to socialize, either because they were in the hospital for an extended period of time (i.e., up to ten days) or because they reduced their social interactions after being discharged to avoid reinfection. Though more severe than Long COVID, MIS-C symptoms tended to be less prolonged, with symptoms resolving over the course of four to six weeks in many cases (Table 13). Parents of children affected by MIS-C were thus more likely to focus on the physical impact of their condition rather than the psychosocial impact.

Table 13. MIS-C symptom duration

Length of symptoms post MIS-C diagnosis	Number of children with MIS-C
≤ 2 months	4
3–6 months	4
7–11 months	2
≥ 12 months	1

The impact on children's day-to-day lives was substantial during the peak of their symptoms, which eventually led to hospitalization. Children were unable to engage in their typical activities, such as attending school, playing video games, or participating in sports or other extracurricular activities. In most cases, this only lasted a few weeks, until symptoms started to ease, and the child began gradually returning to a normal functioning state.

> *It was really hard for him, being away from school and not able to see his friends or play his video games. It's hard when your kid is too sick to even be online or play his video games. But that all seem to resolve within a couple months, over the summer.* – Parent from British Columbia, 9-year-old child

Parents' psychosocial health was impacted because of the emotional and psychological burden of having a child experiencing pain or significant discomfort. Several parents mentioned the fear and anxiety they experienced about their child's symptoms, particularly those related to potentially more severe underlying issues. For example, they worried about whether chest pains were related to underlying cardiac issues or whether swollen hands and feet were related to underlying kidney issues. A few parents also mentioned feeling scared and often "helpless" while their child was being treated in the hospital.

> *The challenge for us, [as parents], was completely emotional and mental because there was nothing we could do at that point in time. He was being treated and was completely at the hands of the [healthcare] professionals, so there was very little we could do other than crying and dealing with it emotionally.* – Parent from Ontario, 2-year-old child.

3.2.3 Current Well-being and Future Outlook for MIS-C

Parents indicated that nearly all children who experienced MIS-C had fully recovered and no longer experienced any symptoms, except for one who was still experiencing some respiratory symptoms at the time of this research. For most children, their symptoms tended to resolve after one to seven months.

Parents were “cautiously optimistic” about their child’s future and expressed minimal concern about the potential long-term impact on their health, given their lack of symptoms and their return to “normal.” However, there were a few who expressed concern about the long-term impacts of MIS-C, specifically if their child would have any lingering cardiac or respiratory side-effects.

3.3 Seeking Solutions for MIS-C

3.3.1 Overview of Care Journeys

In comparison to the Long COVID healthcare journey, the typical healthcare journey for children with MIS-C was quite uniform across the board with fewer stages along the care journey. There were only two notable variations to this journey, which mainly differed based on the initial point of care:

1) For most parents, their first and primary point of care was the hospital, which they visited after their child’s initial SARS-CoV-2 infection when their symptoms became unmanageable or concerning. These children were then admitted to the hospital and received treatment for varying amounts of time that ranged from 48 hours to 10 days.
2) For a smaller number of parents, the first point of care was their family doctor at the time of their child’s initial infection. Their doctor suggested that they visit the hospital if symptoms worsened or became unmanageable. Parents in these circumstances ended up visiting the hospital a few weeks later, where their child was admitted and received treatment.

Parents generally expressed high levels of satisfaction with the quality of care they received, mentioning supportive, proactive, and knowledgeable healthcare workers, as well as prompt diagnosis and treatment. The only challenges mentioned were related to larger structural issues within the entire healthcare system at that time, namely the strain being placed on healthcare facilities due to the COVID-19 pandemic and the shortage of healthcare workers.

3.3.2 The Journey Leading up to a MIS-C Diagnosis

For MIS-C cases, the first point of care was either the hospital emergency room or, for a smaller number of parents, a family physician. Parents who initially sought care from their family doctor did so at the time of their child’s SARS-CoV-2 infection, before MIS-C symptoms began to emerge. At this stage, they tended to be seeking guidance on how to manage their child’s symptoms. However, parents reported that the family doctor was relatively limited in what they could do in these circumstances, and instructed them to monitor symptoms and visit the emergency department if symptoms became unmanageable. The emergency department was often where parents would later receive a diagnosis for their child.

For others, the initial point of care was the hospital emergency room, given their concern about the rapid progression of their child’s symptoms. In these cases, children’s symptoms included those associated with COVID-19 (e.g., shortness of breath, fever, fatigue), and were accompanied by others that parents were concerned about, such as skin rashes, acute GI problems, inflammation of hands and feet, and hypotension.

Given that the hospital was either the initial or the secondary point of care, and the severity of symptoms at the time of the hospital visit, most children received their diagnosis upon being admitted to the hospital.

3.3.3 MIS-C Diagnosis Experiences

In most cases of MIS-C, the diagnosis was provided by an emergency room physician or other hospital staff (e.g., pediatrician). The time between the beginning of MIS-C symptoms and receiving a diagnosis was relatively short, often within two to four weeks, given that the severity of symptoms often led families to seek out medical care once they realized symptoms were not resolving.

Compared to the experiences of parents that had children with Long COVID, the diagnostic process for parents of children with MIS-C was significantly smoother. This was primarily because the symptoms, or diagnostic markers, of MIS-C were easier to identify. MIS-C was also easier to identify earlier in the pandemic when there was less information or clarity about the link between COVID-19 and MIS-C among children.

Given the ease with which parents were able to receive diagnoses for their children, they tended to reflect on the diagnostic process as being positive despite the circumstances. Parents often attributed their positive experiences to the knowledge levels of healthcare providers and their child’s prompt diagnosis.

However, following their child’s diagnosis, parents’ emotions were somewhat mixed. There was often fear or nervousness, as MIS-C was an unfamiliar condition with relatively severe symptoms. However, parents typically felt some relief, as the diagnosis provided an explanation for their child’s symptoms and a path forward. The concern that parents felt following their child’s diagnosis was often eased somewhat by the empathy, expertise, and quality of care provided by those working with their child. A minority of parents, particularly those whose children had received the COVID-19 vaccines prior to diagnosis, were shocked or surprised that their child developed MIS-C despite being vaccinated.

3.3.4 MIS-C Post-Diagnosis and Treatment Plan

All children with MIS-C were admitted to the hospital following their diagnosis, where they were monitored and received treatment.

The treatment plan offered by healthcare professionals was somewhat uniform for the children with MIS-C, typically involving a hospital stay of between five to ten days for most. Although, two participants with slightly milder symptoms were admitted only for 24–48 hours. During their stay in the hospital, it was common for children to receive corticosteroids, antibiotics, intravenous immunoglobin (IVIG), and low-dose aspirin. A minority of children, often those with slightly more serious symptoms, were also treated with an oxygen mask, new onset dialysis, and/or mechanical ventilation. Parents believed that the treatments their child received in the hospital were highly effective in reducing their symptoms. Further, parents observed a significant decrease in the severity of their child’s symptoms before they were discharged from the hospital.

The visible impact of the treatments, combined with the expertise and empathy of healthcare providers, contributed to parents’ trust in the treatment plan and gave them a notably positive healthcare experience. As such, parents did not need to reach out to other formal channels for care or guidance. Instead, they relied on informal support networks, such as extended family, to help manage care needs for their children.

> *I think everything was [effective]. I don’t know what made the most difference, because I don’t have that type of knowledge. I just know that the combination of all treatments worked and was very effective.* – Parent from Ontario, 7-year-old child
>
> *After [the healthcare providers] administered his IV, he started to feel a little bit better. We were very happy that he was getting the correct treatment, as opposed to just trying to wait it out at home. I can’t speak ill at all about the people who treated our son. I felt that he got the care that he needed, at the right time, and the right diagnosis.* – Parent from British Columbia, 9-year-old child

Once discharged from the hospital with significantly reduced symptoms, children were taken home to be monitored. Children often attended follow-up appointments to monitor any residual symptoms, which cleared over the subsequent month or two. Appointments typically involved check-ups and routine bloodwork. Parents were appreciative of the fact that their children were being monitored. They also reported few healthcare access issues.

There were only a handful of children with MIS-C who were attending school at the time, and these children typically received some level of support from their school. The support provided by their school typically took the form of accommodations, providing the child with take-home materials, giving them the option to attend class virtually, or assisting with their return to school once their symptoms began to resolve by providing condensed learning plans.

> *We kept her out of school until she fully recovered, so there was home schooling involved. [The school] sent her modules to study and there was access to some classes online through her iPad. The school was supportive and [understanding] and when she did go back to school, she was fully integrated back into the school system.* – Parent from Ontario, 7-year-old child

3.4 Information Needs for MIS-C

Parents knew very little about MIS-C prior to their children being diagnosed with the condition. As reported above, their lack of familiarity resulted in anxiety at the time of diagnosis. Though participants felt more informed about the condition because their children had been affected by it, several still did not feel very knowledgeable about the condition itself and its effects on children.

The information gaps were not because healthcare providers were unresponsive to parents' questions or because of the relative newness of MIS-C. Rather, a few parents admitted that they felt somewhat overwhelmed by the situation and found it difficult to process all the information that they received about the condition. Most participants solely relied on their child's health team for information, or in one case, healthcare professionals within their extended family. They generally felt comfortable with the level of information they were provided and saw little need to seek additional information.

There were a couple of parents who turned to online sources for information about MIS-C. The severity of their children's condition prompted them to seek out as much information as they could about the immediate effects of the symptoms on their child's physical health. They did not encounter issues finding information. Instead, the challenge was being able to digest all the information and filtering out untrustworthy sources.

4. COVID-19 Vaccination Status and Attitudes Towards Vaccination

4.1 COVID-19 Vaccination Status Among Children and Adolescents with Long COVID

At the time of the research, 13 participants were unvaccinated, 8 were partially vaccinated, and 33 had received at least a primary series (i.e., two doses) of the COVID-19 vaccine (Table 14). The vaccination status of children and adolescents varied, with some having received five or more vaccines. There was no difference in vaccine uptake between the pre-Omicron and Omicron periods.

Healthcare workers who participated in this research were mostly unable to recall the exact number of vaccines that their adolescent patients with Long COVID had received; however, they thought that most patients had received at least a primary series, and that a smaller number of patients had received up to six vaccines. Healthcare workers often mentioned that it was rare for children to have not received any COVID-19 vaccines, and only occasionally recalled one or two patients who were unvaccinated.

Table 14. Vaccination status and vaccine timing among children affected by Long COVID

COVID-19 vaccination variable	Number of children with Long COVID
COVID-19 vaccine status	
Unvaccinated	13
1 dose	8
2 doses	14
3 doses	6
≥ 4 doses	13
Timing of COVID-19 vaccination	
Unvaccinated	13
Vaccinated before Long COVID diagnosis only	15
Vaccinated after Long COVID diagnosis only	13
Vaccinated before and after Long COVID diagnosis	13

The timing of their vaccination relative to their Long COVID diagnosis also varied (Table 14), but vaccine timing was influenced by the vaccine availability for their age group at the time. In Canada, the COVID-19 vaccine only became available for children 5 to 11 years old in November 2021[35] and for children under 5 years old in July 2022.[36] As such, children who were younger (i.e., under 5 years) or those who developed Long COVID earlier in the pandemic (i.e., prior to November 2021) were often unvaccinated prior to their Long COVID diagnosis, given the unavailability of the vaccine at that time. In comparison, those who were slightly older or developed Long COVID later were more likely to have received at least a primary series prior to their initial SARS-CoV-2 infection, or at least prior to their Long COVID diagnosis. However, there were still some parents who chose to not get their children vaccinated, even once the vaccines became available for their respective age group.

Overall, two-thirds of parents of children and adolescents with long COVID reported that they received information and resources about COVID-19 vaccination and were given the opportunity to make an informed decision.

Comparison of Vaccine Journeys for Long COVID in Children and Adolescents

The qualitative nature of this study means that it is not possible to draw any definitive conclusions regarding the impact of COVID-19 vaccination on various health outcomes for children and adolescents affected by Long COVID. This area will be addressed more fully by examining the complementary quantitative results from the open-link survey under a separate cover.

However, by exploring the outcomes of children affected by Long COVID in this study, a qualitative comparison was made between the experiences of children who were unvaccinated, those who received at least some of their vaccine doses prior to diagnosis, and those who were vaccinated following their diagnosis.

The vaccination status and timing of vaccination varied across children and adolescents affected by Long COVID, as discussed above. However, the vaccination status and timing of vaccination seemed to have little to do with the range of symptoms experienced, the severity of symptoms (as reported by parents), or the health outcomes of children (e.g., the amount of time it took for symptoms to resolve, for those no longer experiencing symptoms).

There were unvaccinated children with had mild cases of Long COVID who made a complete recovery within 4–6 months. There were other unvaccinated children though who had moderate to severe Long COVID and continued to experience symptoms. Similarly, there were children who had received multiple doses of a COVID-19 vaccine (often the primary series vaccine) prior to their diagnosis, experienced very mild symptoms, and made a prompt recovery. Other vaccinated children experienced severe symptoms. A few of the most severe cases of Long COVID were among those who had received at least one vaccine dose prior to their diagnosis. As such, there were no discernable patterns in symptoms or outcomes that emerged based on vaccination status and timing.

4.2 COVID-19 Vaccination Status Among Children with MIS-C

Most children had received at least two doses of a COVID-19 primary series vaccine. Several also received booster doses. There were three children who were unvaccinated.

This research included children who received at least one COVID-19 vaccine dose before their MIS-C diagnosis, those who were unvaccinated at the time of their MIS-C diagnosis but were vaccinated after, and those who were vaccinated both before and after their MIS-C diagnosis (Table 15). Those who were older at the time of their infection were more likely to have received at least a COVID-19 primary series vaccine, as were those who were infected with later variants of SARS-CoV-2.

Table 15. Vaccination status and vaccine timing among children affected by MIS-C

COVID-19 vaccination status variable	Number of children affected by MIS-C
COVID-19 vaccine status	
Unvaccinated	4
1 dose	0
2 doses	3
3 doses	3
≥ 4 doses	1
Timing of COVID-19 vaccination	
Unvaccinated	4
Vaccinated after MIS-C diagnosis only	4
Vaccinated before MIS-C diagnosis only	1
Vaccinated before and after MIS-C diagnosis	2

Comparison of the Vaccine Journey for MIS-C in Children

The qualitative nature of this study, along with the very small number of cases, means that it is not possible to draw any conclusions about the impact of COVID-19 vaccination on the health outcomes of children affected by MIS-C.

Despite these limitations, a qualitative examination was conducted that compared the experiences of unvaccinated children, those who were vaccinated before their diagnosis or both before and after diagnosis, and those who were vaccinated after their diagnosis only. No discernable patterns in the self-reported severity of infection, types of symptoms, and recovery trajectory emerged.

4.3 Drivers of COVID-19 Vaccine Uptake and Hesitancy

Most parents who took part in the study had their children vaccinated with at least a primary series of the COVID-19 vaccine. Comfort levels with the primary series and booster doses varied between parents and over time. That said, the underlying factors that drove uptake and hesitancy were fairly consistent as shown in Table 16.

Table 16. Drivers of vaccine uptake and vaccine hesitancy

Driver	Explanation of driver
Drivers of vaccine uptake	
Vaccine confidence	• Belief in the protection offered by the COVID-19 vaccines
Motivation	• Desire to follow public health messaging on COVID-19 vaccination • A pro-vaccination and pro-science stance
Trust	• Trust in public health and healthcare professionals
Drivers of vaccine hesitancy	
Safety concerns	• Immediate adverse side effects • Longer term side effects • Perceived lack of evidence on safety due to the newness of the COVID-19 vaccines • Hearing stories of others being affected by adverse side effects • Unsure how a child weakened from PCC would react to vaccination
Efficacy concerns	• Experience of becoming infected with COVID-19 and developing PCC despite being vaccinated diminished confidence in the vaccine's efficacy
Practical issues	• Child ineligible for COVID-19 vaccination at the height of public health messaging about vaccination
Declining perceived disease risk	• Perceived reduced risk of a SARS-CoV-2 infection as time went on • Belief in child having acquired "natural immunity" from previous SARS-CoV-2 infections
Social processes	• Lack of health professional recommendations on COVID-19 vaccine boosters

From the beginning of the vaccine rollout, some parents had very few concerns about the COVID-19 vaccines and vaccinating their children. They followed the strong public health guidance at the time, vaccinating their children and themselves, to ensure they had a layer of protection against the SARS-CoV-2 virus. They displayed high levels of trust towards public health officials and healthcare professionals, and a subset of participants stressed that they "believed" in vaccination and science in general.

> *We didn't have any concerns or hesitations about the vaccine. We knew we didn't want our kids to get COVID, especially because [their grandparents] are getting older. It was important to keep everyone safe and do what was needed to be responsible citizens, for ourselves but also for the people around us.* – Parent from Alberta, 6-year-old child

At the same time, there were instances where parents were hesitant about vaccinating their children against COVID-19. Their hesitation was mainly related to concerns about the COVID-19 vaccine's safety. The speed with which the vaccine was developed and the "newness" of the vaccine resulted in many parents questioning the safety of the COVID-19 vaccine in children. They contrasted the COVID-19 vaccine to vaccines recommended as part of the immunization schedules for children. Participants had higher levels of confidence in the safety of childhood vaccines because they had been researched and studied over a longer period. These participants stressed that they were not "anti-vaxxers." Some expressed concerns over the immediate side effects of the vaccine. These concerns were heightened among parents who personally experienced an adverse reaction to the COVID-19 vaccine or if they heard of similar reactions happening to their family and friends. The risk of potential longer term adverse effects from COVID-19 vaccination was also a source of concern for some parents. Some parents strongly believed that these adverse reactions will only be identified over time.

> *I mean, [the COVID vaccine] was definitely a concern for a lot of parents, just [because] it was so new. People were either on one side or the other about getting their children vaccinated, because there was limited information about the strength of the vaccine and the long-term effects of the vaccine. So, we were on the fence at first, but I think it was common sense for us because it was approved by Health Canada. There was no way they would approve something that would not be beneficial for children, short term, or long term.* – Parent from British Columbia, 4-year-old child

For many parents who expressed concerns, the perceived safety risks of COVID-19 vaccines outweighed the benefits that were being shared by their healthcare providers and by public health professionals. These parents were motivated to give their children a layer of protection against SARS-CoV-2 infection. Interestingly, very few parents viewed the COVID-19 vaccines as a way to treat or mitigate the chances of re-developing PCC.

A very small number of parents admitted to feeling that they had no choice but to vaccinate their children, despite their concerns about safety. They felt pressured into vaccinating their children by the dominant pro-vaccine discourse that emerged early in the COVID-19 pandemic in order to access essential services and activities for their children. Only a small number of participants had not vaccinated their children at all, primarily because their children were too young to receive the COVID-19 vaccine at the height of the vaccination campaign. There were only two cases where children were unvaccinated due to parents' strongly held belief that COVID-19 vaccines were not safe. In both of these instances, misinformation about the vaccine (e.g., suspicion that the vaccines were a means of government control) that was found readily on the internet appeared to play a role in their decision to not vaccinate their child.

Uptake of COVID-19 booster doses was lower than the primary series, and the reasons behind this were multi-faceted. Some participants who had vaccinated their children prior to their emergence of PCC symptoms and who tended to be more hesitant towards the vaccine to begin with, questioned the efficacy of the COVID-19 vaccine when their children were infected with SARS-CoV-2 (see Section 4.4 for more details).

Others believed that the primary vaccine series, combined with the various SARS-CoV-2 infections and PCC their children had experienced, provided enough protection against future SARS-CoV-2 infections. There was a reluctance to keep vaccinating their children against COVID-19 indefinitely. The newness of the COVID-19 vaccine was again partly the reason for this, but there was also a broader aversion to frequent vaccination. The latter point was also evident when many parents noted that their children did not receive the annual seasonal flu shot. Participants preferred their children fight off illnesses such as the flu via their "natural" immunity. There was an aversion to continually injecting their children with a foreign substance, especially children who were younger.

Many parents grew increasingly less concerned about their children contracting COVID-19 again as time went on. This sentiment was most apparent among parents whose children had experienced less severe cases of Long COVID and made a full recovery. There was a broader belief that the worst of the COVID-19 virus was behind us, and many had not been prompted by their family doctor to give a booster dose to their children. Indeed, a few participants said they would be more motivated to vaccinate their children with a COVID-19 booster in the future if it was recommended by public health and/or if there was a reported increase in the severity of symptoms from a SARS-CoV-2 infection. Parents were of the general belief that COVID-19 does not pose a strong health risk to their children.

> *I likely wouldn't get my child vaccinated again. COVID's not a thing anymore. There's no danger, there's no risk. Like, I just don't think there's any need for anyone to get a COVID vaccine now unless they have extreme comorbidities or are extremely immunocompromised.* – Parent from Ontario, 5-year-old child

For participants, whose children had not made a full recovery from PCC, attitudes towards COVID-19 boosters were mixed. Some parents were reluctant to give their children a booster because they were concerned about how their children's weakened immune systems would react. They did not want to risk aggravating their children's PCC or having them contract another SARS-CoV-2 infection. In contrast, others viewed the COVID-19 boosters as a preventative measure to protect against future SARS-CoV-2 infections. They were thus highly motivated to stay on top of the COVID-19 booster vaccinations. A few of the children who were still experiencing a severe case of Long COVID continued to adopt other recommended public health measures for preventing the spread of COVID-19. A small number of parents shared the challenges their children had faced when practicing self-isolation or wearing masks in public. In one extreme case, a young person was being bullied in school for wearing his mask as other children in the school lacked understanding and empathy towards his Long COVID condition.

With the exception of a very small number of participants, most parents reported that their healthcare provider left it to them to decide whether or not to give their children the COVID-19 vaccine. This choice given to parents was seen as a departure from past vaccination approaches. Parents believed that in the past, there had been more consensus around vaccines and parents just followed the recommended childhood immunization schedules. Almost all parents reported that their children were fully up to date with their childhood vaccines, even though they could not always name the vaccines their children received and had never questioned whether or not to vaccinate their children.

The research findings from the **healthcare provider** interviews were in line with the findings reported above on parents' experiences and attitudes. Those in primary care and those with experience administering the COVID-19 vaccines to children reported that many of the children and young people seen by their clinic received at least one dose of the primary series and then uptake dropped off with the booster shots. Uptake among children was generally weaker compared to uptake among their adult patients. Vaccine safety was the main concern healthcare providers encountered when speaking to parents hesitant about vaccinating their children with a COVID-19 vaccine. Parents were concerned about the potential side effects arising from fast COVID-19 vaccine development. Healthcare providers felt that parent concerns were partly fueled by vaccine misinformation that was widely accessible online during the pandemic. There was also a sense that parents were fatigued with the various pandemic-related public health measures. Some parents may have felt "fed up" and thus less motivated to comply with the recommendations to vaccinate their children against COVID-19.

Healthcare providers generally had a pro-vaccine stance. That said, there was one participant who had experienced some initial hesitation around vaccine safety and another who felt that healthcare workers had no choice but to get vaccinated. Those in primary care settings who encountered vaccine-hesitant parents provided them with information and reassured them about the benefits of vaccination. Healthcare providers used different strategies to reassure parents, ranging from offering information from reputable sources to focusing on the benefits of COVID-19 vaccination in mitigating the effects of a SARS-CoV-2 infection and allowing children to participate in day-to-day activities (e.g., attending school). Interestingly, they were less likely to approach the topic from the perspective of the vaccine playing a role in preventing PCC. They recommended parents vaccinate their children against COVID-19, but ultimately, because of the context of the COVID-19 pandemic and heightened concerns about vaccine safety, they left the choice of vaccination up to parents.

4.4 Perceived Efficacy of COVID-19 Vaccines Against PCC

Parents and healthcare providers generally did not feel comfortable speculating what role the COVID-19 vaccine played in children's experience of PCC.

At best, some parents of children affected by Long COVID "chose to believe" that the vaccine helped by mitigating the severity of their child's SARS-CoV-2 infection. These parents had internalized the public health messaging that vaccination does not prevent a SARS-CoV-2 infection but mitigates the severity of symptoms, yet it was impossible for them to prove this point. One young person imagined that he would blame himself for not doing everything he could to prevent Long COVID if he had *not* been immunized. He was thus grateful that he had vaccinated himself even though he ended up being affected by a severe case of Long COVID and had taken a "gap year" to recover.

> *I'm a big believer that when you do take a vaccine, whether it's for COVID or the flu, it does lessen the potential effects, compared to if you hadn't had it. So, if she hadn't had the vaccines, maybe her health would be extremely poor right now. I believe that it helped minimize some of the symptoms.* – Parent from Alberta, 7-year-old child

There were several parents who were disappointed and shocked that their children developed PCC despite being vaccinated prior to being diagnosed. These parents pointed out that they themselves or their friends had also been vaccinated yet "everyone got COVID." These first-hand experiences thus resulted in the strongly held belief that the COVID-19 vaccine "does not work" and validated, where applicable, pre-existing hesitations towards the vaccine. No one suggested that the COVID-19 vaccines contributed to their children's SARS-CoV-2 infection or PCC diagnosis. Many parents, especially those with children who had more severe and prolonged PCC, shared how "scary" and upsetting it was to see their children's physical health and quality of life deteriorate. It was apparent that for some parents, the worst-case scenario following a SARS-CoV-2 infection had happened, and therefore, they were not at all inclined to entertain how the COVID-19 vaccine had played a mitigating role.

> *He got [Long COVID] after being vaccinated twice. He hasn't had [COVID] since, so maybe it's stopped another infection, but I don't have that answer. I'm just disappointed that he had Long COVID, and for such a long time, even though he was vaccinated.* – Parent from British Columbia, 8-year-old child

Only a small number of parents had experiences of vaccinating their children *following a* PCC diagnosis. An even smaller number had been motivated to vaccinate their children as a way to treat Long COVID. This small group reported that they had not seen a marked improvement in their child's symptoms following vaccination.

Similarly, **healthcare providers** had little to offer in terms of explaining how the COVID-19 vaccines improved health outcomes for children and young people who experienced PCC. Some felt unable to comment because they did not have a large enough PCC caseload to arrive at any conclusions or because they had not consulted the scientific literature on the matter. A small number offered that they had not seen any noticeable benefits of COVID-19 vaccination in relation to PCC symptoms in children and young adults. There were a couple of instances where providers questioned the efficacy of COVID-19 vaccines in reducing the risk of PCC. They pointed out that there is a lack of scientific evidence on this topic and that the vaccine can only reduce the severity of an infection, which PCC is unrelated to. These findings further explain why healthcare providers tended to advise parents about the protection that COVID-19 vaccines provide against SARS-CoV-2 infection and not against PCC specifically.

> *The vaccine isn't really able to make a difference with Long COVID, because getting COVID in and of itself is the problem. You can have people with mild or asymptomatic COVID end up with Long COVID, so it has*

> *nothing to do with how sick you get. Whereas the vaccines are to prevent severity, so they can't really touch Long COVID.* – Physiotherapist from Alberta

4.5 Information Needs About COVID-19 Vaccination

The sources of information that parents turned to regarding the COVID-19 vaccines were only briefly covered in the interviews. Parents generally reported that healthcare providers gave them a great deal of information about COVID-19 vaccines. That said, information regarding COVID-19 or the impact of the COVID-19 vaccine on PCC specifically appeared to be rarely sought out by parents, nor was it proactively offered by healthcare providers. Many parents simply referred to the plethora of information that was available when vaccines became available for children.

There were only a small number of parents who discussed the pros and cons of COVID-19 vaccines for their PCC-affected children with their healthcare providers. These parents shared positive experiences about these interactions since they were able to ask their provider questions, hear the provider's recommendation, and arrive at a decision that felt right for their child.

Conclusion

Canadian data regarding the prevalence and incidence of PCC in children and adolescents remain scarce. However, PCC seems to be less frequent in children and adolescents compared to adults. Vaccination appears to be an important preventative measure against COVID-19 severe outcomes. The protection conferred by hybrid immunity is now very relevant given most individuals have already experienced one or more SARS-CoV-2 infections.

A recent Canadian study shared that COVID-19 vaccination protects against long COVID, adding to protection against COVID-19 disease. COVID-19 vaccination prevented Long COVID during the pre-Omicron period and reduced the risk by more than half post-Omicron among healthcare workers in Quebec.[39] With most of the population now vaccinated and infected, repeated booster doses may add little incremental value against Long COVID. This observation warrants further investigation among children and adolescents, and confirmation by others given the important public health, vaccine program, and cost implications. Specifically, more research is needed to better understand the impact of vaccination and newer variants on PCC prevalence and symptoms in children and adolescents.

The findings of this POR suggest that PCC appears to pose major burdens at the individual and health system levels, affecting key domains, including health, function, health services use, and the economy, and it is critical that governments understand the magnitude of this burden and plan accordingly. Currently, there are several government-funded initiatives aimed at supporting people with PCC. A multifaceted approach, including one that incorporates human centered design, will be needed to maximize access to diagnostic care for PCC, and to improve education and training for health care professionals.

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Appendix

A.1 Qualitative Recruitment Screeners

COVID-19 Post-Acute Conditions Recruitment Screener – Parents

INTRODUCTION

Hello, my name is ______________ from Ipsos, a national market research and public opinion firm. We are conducting a research study about COVID-19 post-acute conditions in children and adolescents (from birth through 19 years old) who have received a diagnosis of Long COVID and/or MIS-C from a physician/health care professional between 2021-2024 in Canada and looking for participation from parents/legal guardians to understand their experiences and perspectives. This research is being commissioned on behalf of Public Health Agency of Canada (PHAC) and Health Canada.

To be eligible for the survey, you must be 19 years of age or younger and have received a diagnosis of Long COVID and/or MIS-C from a physician/health care professional, or be a parent/legal guardian of a child or adolescent age 19 years or younger with a diagnosis of Long COVID and/or MIS-C from a physician/health care professional.

This study will involve participation in an interview lasting approximately 60 minutes. The interview will be held online, using MS Teams. As a token of our appreciation for your participation, we would like to offer an honorarium of $200.

Would you be interested in participating in this research?

Yes CONTINUE
No THANK AND TERMINATE (No problem, have a good day)

PROVIDE BELOW PRIVACY NOTICE TO ALL PARTICIPANTS

The personal information you provide is protected in accordance with the Privacy Act and is being collected under the authority of section 4 of the Department of Health Act and section 3 of the Public Health Agency of Canada Act. The information you provide will not be linked with your name on any document including the consent form or the discussion form. In addition to protecting your personal information, the Privacy Act gives you the right to request access to and correction of your personal information. You also have the right to file a complaint with the Office of the Privacy Commissioner if you feel your personal information has been handled improperly. For more information about these rights, or about our privacy practices, please contact ve.covid-19.ev@phac-aspc.gc.ca.

ELIGIBILITY

Now, I would like to ask you a few questions to see if you qualify for the study.

1. Are you a parent and/or legal guardian of a child or adolescent (from birth through 19 years old) who have received a **diagnosis of Long COVID and/or MIS-C** from a physician/health care professional between 2021-2024 in Canada?

   Yes **CONTINUE**
   No **THANK AND TERMINATE** (Thanks for your interest. Unfortunately, you do not qualify for the study)

2. Has your child/adolescent been diagnosed by a physician/healthcare provider with any of the following?
   Long COVID **CONTINUE**

   [IF NEEDED: History of confirmed or probable SARS-CoV-2 infection, usually three months from the onset of COVID-19, presenting with symptoms lasting at least two months with no other explanation]
   Multisystem Inflammatory Syndrome in Children (MIS-C) **CONTINUE**
   [IF NEEDED: A serious complication of SARS-CoV-2 infection characterized by a hyperinflammatory response, with illness onset typically 4−6 weeks after infection]
   Both Long COVID and MIS-C **CONTINUE, RECRUIT FOR EITHER IDI SEGMENT**
   None of the above **THANK AND TERMINATE** (Thanks for your interest. Unfortunately, you do not qualify for the study)

3. Was your child/adolescent hospitalized or treated in pediatric health centers between 2021 and 2024 in Canada for Long COVID and/or MIS-C?

   Yes **RECORD**
   No **RECORD**

4. What is your relationship with the child/adolescent?

   Parent
   Legal Guardian
   Grandparent
   Other family members
   Unrelated
   Other, please specify: ____

5. In which age category does your child/adolescent who had Long COVID/MIS-C belong?
   < 6 months
   6-23 months
   2-4 years
   5-11 years
   2-15 years
   16-17 years
   18-19 years

6. **Since January 2020, Has your child/adolescent had a COVID-19 infection or suspected infection?**
   Yes
   No
   Do not know

7. **[ONLY ASK IF ANSWERED ‘YES’ IN Q6]** During your child/adolescent’s COVID-19 infection(s) or suspected infection(s), did they receive a positive test for COVID-19 from a PCR test or rapid antigen test?
   [IF NEEDED: PCR test is often used in health care settings. It is sent to a lab and produces the most accurate result. Rapid antigen test is often called a rapid test, which produces a result within minutes]

   Yes **[RECORD AS COVID-19 CONFIRMED CASE]**
   No **[RECORD AS COVID-19 SUSPECTED CASE if Q6=YES or Do not know]**
   Don’t remember **[RECORD AS COVID-19 SUSPECTED CASE if Q6= YES or Do not know]**
   Don’t know **[RECORD AS COVID-19 SUSPECTED CASE if Q6= YES or Do not know]**
   Never have been tested **[RECORD AS COVID-19 SUSPECTED CASE if Q6= YES or Do not know]**

Prefer not to answer

8. **[ONLY ASK IF ANSWERED '16-17 or 18-19 YEARS' IN Q5]** We may also be interested in talking to your adolescent to hear about their experiences, challenges, and needs with Long COVID/MIS-C. Would you be open to your adolescent taking part in the study?
   [IF RELUCTANT/IF ASKED, EXPLAIN: We are asking this because sharing how they have personally been affected by Long COVID or MIS-C will contribute to research that can help improve the care and support adolescents receive in the future]

Yes	**RECORD**
No	**RECORD**
Maybe/Will decide after taking part in the interview myself	**RECORD**

9. What is your child/adolescent's current COVID-19 vaccination status?

4 doses total or more	**CONTINUE**
3 doses total	**CONTINUE**
2 doses total	**CONTINUE**
1 dose	**CONTINUE**
0 dose: ineligible/didn't receive for a medical reason	**CONTINUE**
0 dose: unvaccinated	**CONTINUE**

FOR Q1-Q9, IF THE PERSON DOESN'T KNOW THE ANSWER OR PREFERS NOT TO ANSWER, THANK AND TERMINATE: Unfortunately, we do need answers to these questions to see if you qualify for the study. As such, we can't proceed, but we thank you for your interest.

QUALITY SCREENING

10. Have you participated in a market research study such as one that involved a focus group or an interview in the past six months?

Yes	**THANK AND TERMINATE** (Thanks for your interest. Unfortunately, you do not qualify for the study)
No	**CONTINUE**

11. How many interviews or focus groups have you attended in the last five years?

______ **IF 5 TIMES OR MORE OR DOES NOT WANT TO SAY/DOES NOT KNOW, THANK AND TERMINATE** (Thanks for your interest. Unfortunately, you do not qualify for the study) **OTHERWISE CONTINUE**

QUOTAS

It is important that our study is inclusive and captures the perspectives and experiences of parents/legal guardians from different backgrounds. So, I have some questions about who you are.

12. What type of area do you live in?

Urban	
Suburban	
Rural or remote	
Prefer not to answer	**THANK AND TERMINATE** (Thanks for your interest. Unfortunately, you do not qualify for the study)

REFER TO QUOTAS IN SPECIFICATION TABLE AND RECRUIT ACCORDINGLY

13. Which province or territory do you live in?
    Alberta
    British Columbia
    Manitoba
    Newfoundland and Labrador
    Northwest Territories
    Nova Scotia
    Nunavut
    Ontario
    Prince Edward Island
    Quebec
    Saskatchewan
    Yukon
    Outside of Canada **THANK AND TERMINATE** (Thanks for your interest. Unfortunately, you do not qualify for the study)
    Prefer not to answer **THANK AND TERMINATE** (Thanks for your interest. Unfortunately, you do not qualify for the study)

REFER TO QUOTAS IN SPECIFICATION TABLE AND RECRUIT ACCORDINGLY

14. Do you identify as First Nations, Métis and/or Inuk (Inuit)?

    Yes – First Nations (includes status and non-status individuals)
    Yes – Métis
    Yes - Inuk (Inuit)
    Yes - Multiple Indigenous Identities
    No
    Prefer not to answer
    IF YES TO INDIGENOUS AT Q14, SKIP TO Q15 AND GO TO Q16
    REFER TO QUOTAS IN SPECIFICATION TABLE RE: INDIGENOUS PEOPLES AND RECRUIT ACCORDINGLY

15. Which of the following best describes the racial or ethnic community that you belong to? We recognize that this list of racial or ethnic identifiers may not exactly match how you would describe yourself. Please identify/select all that apply to you.
    Black (African, Afro-Caribbean, African descent)
    East/Southeast Asian (e.g. Chinese, Korean, Japanese, Taiwanese, Filipino, Vietnamese, Cambodian, Thai, Indonesian, other East/Southeast Asian descent)
    Latino/Latina (e.g. Latin American, Hispanic descent)
    Middle Eastern and North African (e.g. Arab, Algerian, Egyptian, West Asian descent (e.g. Iranian, Israeli, Lebanese, Turkish, Kurdish, etc.)
    South Asian (e.g., Afghan, Indian, Pakistani, Bangladeshi, Sri Lankan, etc.)
    White European
    Other, please specify: ____
    Prefer not to answer
    REFER TO SPECIFICATION TABLE RE: RACIALIZED COMMUNITIES, OTHERWISE RECRUIT A MIX

16. What is your gender?
    IF NEEDED: Gender refers to your current gender, which may be different from sex assigned at birth and may be different from what is indicated on legal documents.
    Woman
    Man
    Transgender
    Two-spirit

Prefer to self-describe: ___________
Prefer not to answer
AIM FOR A MIX

17. Which of the following categories best describes your age?
    Under 18
    18 to 29
    30 to 39
    40 to 49
    50 to 59
    60 to 69
    70 to 79
    80 or older
    Prefer not to answer
    AIM FOR MIX

18. Which of the following categories best describes your total annual household income before taxes?

Under $20,000
$20,000 to $39,999
$40,000 to $59,999
$60,000 to $79,999
$80,000 to $99,999
$100,000 to $149,999
$150,000 and above
Don't know
Prefer not to answer
AIM FOR MIX AND REFER TO FINAL BULLET POINT IN QUOTAS IN THE SPECIFICATION TABLE AND RECRUIT ACCORDINGLY [LESS THAN $39,999 IS LOWER INCOME]

TECHNOLOGY

I'm now going to ask you some questions to see if you have what technology is needed to take part in an interview.

19. Do you have access to a computer/laptop, or telephone, which you would be able to use to participate in an online interview?
    Yes **RECORD**
    No **RECORD**

20. During the discussion, you will be audio- and video-taped. This taping is being done to assist us with our report writing. The recording is never used for any other purposes. Do you consent to be recorded?
    Yes **RECORD**
    No **RECORD**

21. Will you need any accommodations to take part in an interview?
    Yes **WRITE IN AND CONTINUE:** ____________________________
    No

22. Our client contacts at PHAC and Health Canada would like to observe the online interviews. Your last name will not be disclosed though. Do you consent to being observed during the interview?
    Yes **RECORD**
    No **RECORD**

INVITATION

[READ TO STAND-BY RESPONDENTS]

Thank you for answering my questions. We would like to place you on our standby list as we have reached the number of people that we need in a similar situation to yours. This means that if there is an opening, we will then call you back and see if you are available to take part. May I please have a daytime contact number, an evening contact number an email address, if you have one, so that we can contact you as soon as possible if an opening becomes available? [RECORD CONTACT INFO]

[READ TO SCREENED IN RESPONDENTS]

Thank you for taking the time to complete these questions – you qualify to take place in one of these interviews which will take place on [DATE @ TIME]

As a reminder, we will call or email you a day or two before the interview to confirm your participation. If for any reason you are not able to attend, please call us at [INSERT CONTACT]. All those who participate will receive an honorarium of $200. Can I confirm that you are willing to attend?

Can I get your name, phone number, and email address so we confirm all the details?
IF REFUSED: Unfortunately, we do need this information to finalize your participation in the study. Would you like to change your mind about providing these details?

IF THEY CHANGE THEIR MIND, PROCEED
IF NOT, THANK AND TERMINATE

NAME: ____
PHONE NUMBER: ____
EMAIL ADDRESS: ____

Thank you very much!

COVID-19 Post-Acute Conditions Recruitment Screener – Primary Health Care Providers

INTRODUCTION

Hello, my name is ______________ from Ipsos Canada, one of the largest research consultancies in Canada. We are conducting a research study about Post-acute COVID-19 Conditions (PCC) in children and adolescents (from birth through 19 years old) who was diagnosed and treated for Long COVID or Multisystem Inflammatory Syndrome in Children (MIS-C) between 2021-2024 in Canada.

PHAC and Health Canada are seeking your participation in in-depth interviews exploring Post-acute COVID-19 Conditions (PCC) associated with COVID-19 Vaccine Impact and Effectiveness among Children and adolescents in Canada. We're looking for your help, expertise, and thought leadership as a physician to ensure that your views and experiences, as well as the views and experiences of children and families, are well represented in the research findings and considered in the design and execution of future vaccination programs.

To address the research objectives, we are looking to speak with several audiences, including Health care providers who have diagnosed or treated a patient under the age of nineteen with Long COVID and/or MIS-C.

The interview will take about 45 – 60 minutes and will be conducted by telephone or using Microsoft Teams, whichever you prefer, and scheduled at a time most convenient for you. Your participation is voluntary and confidential. As a token of our appreciation for your participation, we would like to offer an honorarium of $500.

Would you be interested in participating in this research?

Yes	**CONTINUE**
No	**THANK AND TERMINATE**

*PROVIDE BELOW PRIVACY NOTICE TO ALL PARTICIPANTS

The personal information you provide is protected in accordance with the Privacy Act and is being collected under the authority of section 4 of the Department of Health Act and section 3 of the Public Health Agency of Canada Act. The information you provide will not be linked with your name on any document including the consent form or the discussion form. In addition to protecting your personal information, the Privacy Act gives you the right to request access to and correction of your personal information. You also have the right to file a complaint with the Office of the Privacy Commissioner if you feel your personal information has been handled improperly. For more information about these rights, or about our privacy practices, please contact ve.covid-19.ev@phac-aspc.gc.ca.

IF ASKED EXPLAIN: Other audiences we are speaking to include:

- Parents of children and adolescents (from birth through 19 years old), as well as adolescents between the ages of 16 and 19 years of age, who have been diagnosed with Long COVID and/or MIS-C during our study period (2021-2024).
- Researchers and academics whose area of study and/or expertise relates to Long COVID and/or MIS-C, particularly in children and adolescents.
- Representatives from Long COVID support groups, such as: interventions or caregiver supports group, Covid Long Haulers Support Group and other associations, patient support and advocacy groups, parents' groups, community mental health services, and rehabilitative care.

ELIGIBILITY SCREENER

Now, I would like to ask you a few questions to see if you qualify to attend.

1. Are you currently employed as a Health Worker in Canada?
   [**IF NEEDED:** A Health Worker is any staff within the health care system. This includes paid work of at least 20 hours per week. The definition includes physicians, nurses, allied health professionals, and auxiliary health workers such as: community care and hospital staff (personal support workers, cleaning or laundry personnel, patient transporters, catering staff, medical waste handlers etc.)]

   Yes **CONTINUE**
   No **THANK AND TERMINATE**

2. Were you employed as a health worker during 2021-2024?

   Yes **CONTINUE**
   No **THANK AND TERMINATE**

3. In what capacity are you employed as a health worker?

Target Sub-group	
General/Family Physician	**QUALIFIES AS PRIMARY CARE PROVIDER**
General Pediatrics	
Specialist Physician	
Nurse (licensed practical nurse, nurse practitioner, registered nurse)	
Occupational therapist	**QUALIFIES AS ALLIED HEALTH**
Pharmacist	
Physiotherapist	
Social Worker	
Pedo-psychiatrist	
Other:	**THANK AND TERMINATE**
Prefer not to answer	

4. Have you ever diagnosed a patient under the age of nineteen with Long COVID and/or Multisystem Inflammatory Syndrome in Children (MIS-C)?

   Yes, Long COVID
   Yes, Multisystem Inflammatory Syndrome in Children (MIS-C)
   Both, MIS-C and long COVID
   No **THANK AND TERMINATE PHYSICIANS , CONTINUE IF NURSE OR ALLIED HEALTH**

5. Do you currently have, or have you previously had patients under the age of nineteen with Long COVID? [**IF NEEDED:** Long COVID is the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation (including but not limited to shortness of breath, cognitive dysfunction (brain fog), and fatigue).

   Yes
   No **[TERMINATE IF NO TO Q5 AND Q6 IF NURSE OR ALLIED HEALTH WORKER, CONTINUE IF PHYSICIAN]**
   Don't Know
   Prefer not to answer

6. Do you currently have, or have you previously had patients under the age of nineteen with Multisystem Inflammatory Syndrome in Children (MIS-C)? [**IF NEEDED:** Multisystem Inflammatory Syndrome in Children (MISC) is a rare but serious complication of COVID-19 involving inflammation of two or more organs (including the heart, lungs, gastrointestinal tract, hematologic system, kidneys, nervous system, musculoskeletal system, skin, or eyes.)]

   Yes
   No **[TERMINATE IF NO TO Q5 AND Q6 IF NURSE OR ALLIED HEALTH WORKER, CONTINUE IF PHYSICIAN]**
   Don't know
   Prefer not to answer

7. Have you worked or are you currently working in Long COVID clinics?

   Yes
   No
   Prefer not to answer

8. At your workplace, do you (or delegated health care workers) administer COVID-19 vaccinations to pediatric patients?
   Yes, to all or almost all pediatric patients
   Yes, with some pediatric patients
   No, never
   Prefer not to answer

QUALITY SCREENING QUESTIONS

9. Have you participated in a market research study in the past six months?

Yes	**THANK AND TERMINATE**
No	**CONTINUE**

10. How many interviews (or focus groups) have you attended in the last five years?
    THANK AND TERMINATE IF MORE THAN 4

STUDY SPECIFIC SCREENER

11. Which setting best describes your current workplace?

    Children hospital
    University Hospital Centre
    Other Hospital setting: Specify : ____________
    Long COVID clinics
    Other Clinic setting
    Community setting
    Telehealth
    Academic Health Science Centre (AHSC)
    Older Adult Care Facility setting
    Other [WRITE IN: ____________] **THANK AND TERMINATE**
    RECRUIT GOOD MIX

12. Which of the following best <u>describes your place/area of practice</u> ?

    Urban
    Suburban
    Rural or remote
    Prefer not to answer **THANK AND TERMINATE**
    REFER TO QUOTAS IN SPECIFICATION TABLE AND RECRUIT ACCORDINGLY

13. What is your current COVID-19 vaccination status?

    Completed primary vaccine series and 2 additional doses/second booster: 4 doses total or more
    Completed primary vaccine series and 1 additional dose/first booster: 3 doses total
    Completed primary series: received a second dose in a 2-dose series: 2 doses total
    Completed primary series: 1-dose vaccine series (Janssen (Johnson & Johnson))
    Partially vaccinated: received the first vaccine dose in a 2-dose series
    Unvaccinated: didn't receive any COVID-19 vaccine
    Ineligible for any COVID-19 vaccine: didn't receive any COVID-19 vaccine for medical reason
    Prefer not to answer **THANK AND TERMINATE**

DEMOGRAPHICS

It is important that our study captures the perspectives and experiences of health workers from different backgrounds. So, I have some questions about who you are.

14. Can I take your age?
    Under 18 **THANK AND TERMINATE**
    18-34
    35-44
    45-54
    55-64
    65 and over
    RECRUIT MIX ON AGE

15. What is your province or territory of residence?

Alberta
British Columbia
Manitoba
Newfoundland and Labrador
Northwest Territories
Nova Scotia
Nunavut
Ontario
Prince Edward Island
Quebec
Saskatchewan
Yukon
Outside of Canada **THANK AND TERMINATE**

REFER TO QUOTAS IN SPECIFICATION TABLE AND RECRUIT ACCORDINGLY

16. Do you identify as First Nations, Métis and/or Inuk (Inuit)?

Yes – First Nations (includes status and non-status individuals)
Yes – Métis
Yes - Inuk (Inuit)
Yes - Multiple Indigenous Identities
No
Prefer not to answer
IF YES TO INDIGENOUS AT Q16, SKIP TO Q18, OTHERS ASK Q17

17. Which of the following best describes the racial or ethnic community that you belong to? We recognize that this list of racial or ethnic identifiers may not exactly match how you would describe yourself. Please select all that apply to you.

Black (African, Afro-Caribbean, African descent)
East/Southeast Asian (e.g. Chinese, Korean, Japanese, Taiwanese, Filipino, Vietnamese, Cambodian, Thai, Indonesian, other East/Southeast Asian descent)
Latino/Latina (e.g. Latin American, Hispanic descent)
Middle Eastern and North African (e.g. Arab, Algerian, Egyptian, West Asian descent (e.g. Iranian, Israeli, Lebanese, Turkish, Kurdish, etc.)
South Asian (e.g., Afghan, Indian, Pakistani, Bangladeshi, Sri Lankan, etc.)
White European
Other, please specify: ____
Prefer not to answer
AIM FOR A MIX

18. What is your gender? Gender refers to your current gender, which may be different from sex assigned at birth and may be different from what is indicated on legal documents.

Woman
Man
Transgender
Two-spirit
Prefer to self-describe:___________
Prefer not to answer

AIM FOR A MIX

TECHNOLOGY SCREENING

19. Do you have access to a computer or laptop at home or work, which you would be able to use to participate in an online interview?
    Yes
    No

20. Do you have access to high-speed internet at home or work, which you would be able to use to participate in an online interview?
    Yes
    No

21. Does your computer/laptop have a working webcam that you can use for the session?
    Yes
    No

22. During the discussion, you will be audio- and video-taped. This taping is being done to assist us with our report writing. The recording is never used for any other purposes. Do you consent to be recorded?
    Yes **CONTINUE**
    No **THANK AND TERMINATE**

23. Our client contacts at PHAC would like to observe the online interviews. Your last name will not be disclosed though. Do you consent to being observed during the interview?
    Yes **RECORD**
    No **RECORD**

CONFIRMATION

[READ TO STAND-BY RESPONDENTS]
Thank you for answering my questions. We would like to place you on our stand-by list as we have reached the number of people that we need in a similar situation to yours. This means that if there is an opening, we would then call you back and see if you are available to take part. May I please have a daytime contact number, an evening contact number an email address, if you have one, so that we can contact you as soon as possible if an opening becomes available? [RECORD CONTACT INFO]
[READ TO SCREENED IN RESPONDENTS]

Thank you for taking the time to complete these questions – you qualify to take place in one of these interviews which will take place on [DATE @ TIME]
Can I get your name, phone number, and email address so we confirm all the details? [IF REFUSED - THANK & TERMINATE]

NAME: ____
PHONE NUMBER: ____
EMAIL ADDRESS: ____
Thank you for very much for your participation!

A.2 Qualitative Discussion Guides

COVID-19 Post-Acute Conditions Qualitative Research Adolescents and Parents Discussion Guide

INTRODUCTION

- Introduce moderator and thank participant

- Explain purpose and logistics:
  - We are interviewing you today to hear about your/your family's story about your child developing long COVID/MIS-C after contracting a COVID-19 infection.
  - You are one of many young people/families we are speaking to on behalf of the Public Health Agency of Canada.
  - The information that you share with us today will help the Public Health Agency better understand your experience, and the experiences of others in similar circumstances, to inform their decision-making.
  - The session is being recorded for analysis purposes. These recordings remain in our possession and will not be released to anyone who is not working on the study.
  - Please note that anything you say during this interview will be held in the strictest confidence. We do not attribute comments to specific people. Our report will summarize the findings from all the interviews but does not mention anyone by name. The report can be accessed through the Library and Archives Canada.
  - Observers are watching the sessions live because they are really interested in your opinions.
  - This interview may include questions that bring up strong emotions (e.g., anger, sadness, discomfort), but I want to stress that you only need to provide as much detail as you feel comfortable with and we can move past questions, if needed.

- Let's start off with an introduction, tell me a bit about your family – who is in your household and where do you live.
- And can you tell me a bit about yourself/your child that developed long COVID/MIS-C? PROBE FOR UNDERLYING HEALTH CONDITIONS:
- How would you describe your/your child's health prior to contracting long COVID/MIS-C?
- Did you/your child have any ongoing medical conditions prior to contracting long COVID/MIS-C?

  PROMPT IF NEEDED AND CODE BASED ON ANSWERS GIVEN
  - Immunosuppression or autoimmune condition
  - Chronic heart disease
  - High blood pressure
  - Asthma
  - Chronic lung disease (not asthma)
  - Obesity
  - Diabetes (Type 1 or Type 2)
  - Kidney disease
  - Liver disease
  - Asplenia
  - Cancer
  - Blood disorder
  - Rheumatological disorder
  - Neurological condition
  - Dementia
  - HIV

    - TB
    - Depression
    - Anxiety

HISTORY OF COVID INFECTION AND LONG COVID/MIS-C

I want to start off by understanding the timeline of what happened. I'd like you to tell me about your/your child's experience with COVID-19, as well as the timeline leading up to your/your child's diagnosis with Long COVID/MIS-C.

- Since January 2020, did you/your child have a confirmed or suspected COVID-19 infection?
    - **IF YES:** How many confirmed or suspected COVID-19 infections have you/your child had? One? Multiple?
    - Can you tell me when these infections occurred? PROBE FOR MONTH AND YEAR
    - How severe were your/your child's symptoms during the infection(s)?
- When did you/your child first started experiencing/presenting symptoms of long COVID/MIS-C? PROBE FOR MONTH AND YEAR
- How long did you/your child experience symptoms before being diagnosed? PROBE FOR # OF WEEKS
- Roughly, when did you/your child receive the diagnosis of COVID/MIS-C?PROBE FOR MONTH AND YEAR
- Who provided the diagnosis?
- How did you/your child feel about the diagnosis?
- Did you/your child receive a COVID-19 vaccine?
    - IF YES: When did your child receive their first COVID-19 vaccine? Was it after or before they started experiencing symptoms? PROBE FOR MONTH AND YEAR AND CODE
        - Before March, 2021 (Wild type VOC)
        - April, 2021, to June, 2021 (Alpha/Beta/Gamma VOCs)
        - July, 2021, to December, 2021 (Delta VOC)
        - January 2022 to present (Omicron VOC)

SPECTRUM OF SYMPTOMS

Now I want to hear the full story of what happened, starting with the symptoms that you/your child started experiencing during INSERT MONTH AND YEAR.

- Can you tell me about the symptoms of Long COVID/MIS-C that you/your child experienced <u>at the time of diagnosis?</u> [CODE USING TABLE, PROMPT IF NEEDED]
- How severe were the symptoms? (e.g., manageable, serious, requiring hospitalization, life-threatening)
- How long did the symptoms last?
- How did the symptoms change over time? Were there any symptoms that got better/worse over time?
- And what symptoms of Long COVID/MIS-C are you/your child <u>experiencing now</u>? [CODE USING TABLE, PROMPT IF NEEDED]
- How severe are the symptoms? (e.g., manageable, serious, requiring hospitalization, life-threatening)
- IF NOT EXPERIENCING SYMPTOMS: When did you/your child fully recover from Long COVID/MIS-C? How long were you experiencing symptoms after your diagnosis was confirmed? PROBE FOR # OF WEEKS

	Experienced at time of diagnosis	Experiencing now
Long COVID		
Unusual fatigue		
Unusual shortness of breath		
Palpitation		
Unusual headaches		
Sore throat		
Cough		
Nausea		
Diarrhea		
Unusual abdominal pain		
Constipation		
Sleep problems		
Cognitive problems, such as: Memory loss Lack of concentration Difficulty thinking or concentrating		
Muscle aches and joint pains		
Altered taste or smell		
Appetite loss		
Skin rash		
Hair loss		
Post-exertional malaise		
Unusual light-headedness		
Unusually fast heart rate		
MIS-C		
Rash		
Conjunctival injection		
Mucocutaneous inflammation signs (oral, hands or feet)		
Hypotension or shock		
Features of myocardial dysfunction, pericarditis, valvulitis,		
Coronary abnormalities (including ECHO findings)		
Elevated troponin/N-terminal pro-brain natriuretic peptide (NT-proBNP)		
Evidence of coagulopathy (by prothrombin time, partial thromboplastin time, elevated D-dimer)		
Acute gastrointestinal problems (diarrhea, vomiting or abdominal pain)		
Elevated markers of inflammation such as C-reactive protein, erythrocyte sedimentation rate or procalcitonin		
No other obvious microbial cause of inflammation, including bacterial sepsis, staphylococcal or streptococcal shock syndromes.		
Kawasaki disease		

- Which symptoms were the most challenging for…
  - You/your child?
  - Your family/yourself as a caregiver?
- Did you/your child experience any social or emotional challenges related to their symptoms, or during your/their experience with Long COVID/MIS-C? Please elaborate.
- Can you tell me about your/your child’s current health status regarding Long COVID/MIS-C? Recovered? Improving? Worsening?

ACCESS TO CARE AND TREATMENT

My next set of questions are about your/your and your child's journey of accessing care and treatment for long COVID/MIS-C. I am interested in all the different treatments and types of care or support that you/ you and your child tried and/or received.

- Did you/your child reach out to a doctor or healthcare provider about experiencing symptoms of Long COVID/MIS-C?
    - What prompted you/you and your child to reach out?
    - What were your specific needs at this time?
    - Did you find it difficult during your/your child's illness to access a primary care provider?
    - What made it difficult? What could've made it easier?
- Did you/your child go to a Long COVID clinic or hospital? Please elaborate.
    - IF LONG COVID CLINIC:
        - How many times? Do you recall the approximate date of your visit(s)? PROBE FOR MONTH AND YEAR
        - Can you tell me about the quality of care you/your child received at this facility? Were your/your child's needs met? Did you/you and your child experience any challenges?
        - What did you do next? How did you/your child feel at this point?
        - IF HOSPITAL: Tell me a bit more about this experience.
            - Were you admitted to the hospital or the intensive care unit (ICU)?
            - Do you remember the date of admission(s)? How long was your stay?
            - Can you tell me about the quality of care you/your child received at this facility? Were your/your child's needs met? Did you/you and your child experience any challenges?
            - What did you do next? How did you/your child feel at this point?
- How satisfied were you with the overall quality of care received during your/their Long COVID/MIS-C Illness, on a scale of 1 to five (1 – very dissatisfied, 5 – very satisfied)?
    - Can you explain your rating?
    - What were some of the challenges that you experienced?
    - Is there anything that could've been different that would've increased your level of satisfaction?
- Did you/ you and your child seek out care/support/guidance from anywhere else? PROBE FOR PROBE FOR DIFFERENT TYPES OF HEALTHCARE, SUPPORT GROUPS OR OTHER COPING/RECOVERY STRATEGIES USED & REPEAT BELOW PROBES AS NEED.
    - Why did you choose to seek out care/support/guidance from here?
    - Can you tell me about the quality of care/support/guidance that you/you and your child received?
    - Were you/your child's needs met? Did you/your child experience any challenges?
- Did you receive any support from your/your child's school? What kind of support? Was it helpful/unhelpful?
- Did you receive any support from support/advocacy groups? What kind of support? Was it helpful/unhelpful?
- Of all the different types of care/support/guidance you received, which was the most helpful? Which was the least helpful? Why?
- Moving on slightly… Can you tell me about any treatments that you/your child received or are currently receiving for Long COVID/MIS-C? [PROBE FOR LISTED TREATMENTS AND CODE IN TABLE BELOW]

LONG COVID		
	Previously Received	Currently Receiving
Treatment with corticosteroids		
Treatment with antibiotics		
Treatment with lopinavir/ritonavir		
Treatment with monoclonal antibodies		
Intravenous immunoglobulin (IVIG) and glucocorticoids		
Intensive care unit (ICU) Care		
New onset dialysis		
Mechanical ventilation		
Oxygen mask or High flow oxygen		
MIS-C		
Treatment with corticosteroids		
Treatment with antibiotics		
Treatment with lopinavir/ritonavir		
Treatment with monoclonal antibodies		
Intravenous immunoglobulin (IVIG) and glucocorticoids		
Anti-inflammatory drugs		
Low dose aspirin		
Intensive care unit (ICU) Care		
New onset dialysis		
Mechanical ventilation		
Oxygen mask or High flow oxygen		

- Of all the treatments that you/your child received, or are currently receiving, which one(s) were the most effective? Which were the least effective? Please elaborate.

For my next few questions, I'm going to walk you through some scale questions. I'd like you to indicate on a scale of one to seven (1 – not at all, 7 – to a very great extent) how much this event or situation has happened to you/your family since your/their Long COVID/MIS-C diagnosis.

	To a very great extent	To a great extent	To a fairly great extent	To a moderate extent	To a small extent	To a very small extent	Not at all	Not applicable
IN THE PAST YEAR, to what extent do the PEOPLE who work with you and your family:								
Fully explain treatment choices to you and your family?	7	6	5	4	3	2	1	0
Provide opportunities for you and your family to make decisions about treatment?	7	6	5	4	3	2	1	0
Provide opportunities for you and your family to make decisions about COVID-19 vaccines primary series and booster doses?	7	6	5	4	3	2	1	0
Talk to you and your family about the results from assessments?	7	6	5	4	3	2	1	0

	To a very great extent	To a great extent	To a fairly great extent	To a moderate extent	To a small extent	To a very small extent	Not at all	Not applicable
Look at you and your family's "whole" emotional needs (e.g. mental, emotional, and social needs) instead of just physical needs?	7	6	5	4	3	2	1	0
Make sure that at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
Plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0
Give you and your family information that is consistent from person to person?	7	6	5	4	3	2	1	0
Help you and your family feel competent?	7	6	5	4	3	2	1	0
Provide a caring atmosphere rather than just give information to you and your family?	7	6	5	4	3	2	1	0
Provide enough time to talk so you and your family don't feel rushed?	7	6	5	4	3	2	1	0
Treat you and your family as an equal rather than just a patient or a parent?	7	6	5	4	3	2	1	0
Treat you and your family as individuals rather than as a "typical patient or parent" of a child with LONG COVID or MIS-C	7	6	5	4	3	2	1	0
IN THE PAST YEAR, to what extent does the healthcare facility (hospital/clinic) where you receive the majority of care related to Long COVID:								
Give you and your family information about the types of care or treatment offered at the healthcare facility, Long COVID clinic or in their community?	7	6	5	4	3	2	1	0
Have information available about Long COVID or MIS-C (e.g., causes, progression, future outlook)?	7	6	5	4	3	2	1	0
Provide opportunities for you and your family to obtain information about LONG COVID or MIS-C?	7	6	5	4	3	2	1	0
Provide information about COVID-19 vaccines and resources?	7	6	5	4	3	2	1	0
Provide advice on how to get information to contact support groups (e.g. Organization's parent resource library, support group, etc.)?	7	6	5	4	3	2	1	0
Have information available to you and your family in various forms, such as a booklet, kit, video, etc.?	7	6	5	4	3	2	1	0

- Is there anything that could've been better in your experience receiving care/seeking treatment? Please elaborate.

ACCESS TO KNOWLEDGE AND INFORMATION

I'd like us to move on and talk a bit about your knowledge related to Long COVID and MIS-C, and your experience accessing information.

- How informed do you feel about…
    - Long COVID/MIS-C
    - Effect of Long COVID/MIS-C on children/adolescents
    - COVID-19 vaccination against Long COVID and it's effectiveness of children/adolescents
- Where have you sought out information about Long COVID/MIS-C? Where have you sought out information about vaccination?
    - PROBE FOR: Healthcare providers (e.g., medical doctors, nurses, pharmacists), Alternative health providers (e.g., naturopaths, homeopaths), Family/friends, Medical associations, Public health (e.g., local public health clinic, PHAC, Health Canada), Ministry of Health, Social media, Local Community Services Center , Long COVID Clinics
- Tell me a bit more about your experience seeking out and accessing information on Long COVID/MIS-C and vaccinations.
    - Was it easy/difficult?
    - Were there specific topics that were harder to find information on?
    - What could've made this easier?
- Prior to your/your child's diagnosis, how much did you know about Long COVID/MIS-C? Can you tell me about if/how your knowledge levels have changed over time?

THE PERCIEVED EFFECTIVENESS OF THE COVID-19 VACCINE

You mentioned earlier that your child was vaccinated against COVID-19 prior to/after the onset of long COVID/MIS-C symptoms.

- Can I check how many doses of the COVID-19 vaccine you/your child received?

IF VACCINATED:

- Did you/your child receive and vaccine doses <u>before</u> the first COVID-19 infection/suspected infection?
    - IF YES: How many?
- Roughly, when did you/your child receive their last dose of the vaccine? PROBE FOR DATES AND CODE:
    - Before March, 2021 (Wild type VOC)
    - April, 2021, to June, 2021 (Alpha/Beta/Gamma VOCs)
    - July, 2021, to December, 2021 (Delta VOC)
    - January 2022 to present (Omicron VOC)
- Do you remember the brand of your/their most recent COVID vaccine?
    - IF NEEDED:
        - AstraZeneca Vaxzevria
        - Janssen Jcovden (Johnson & Johnson)
        - Pfizer (don't know which type)
        - Pfizer-BioNTech Comirnaty Monovalent (original)
        - Pfizer-BioNTech Comirnaty Bivalent (BA.1)
        - Pfizer-BioNTech Comirnaty Bivalent (BA.4/BA.5)
        - Pfizer-BioNTech Comirnaty Monovalent XBB.1.5
        - Moderna (don't know which type)
        - Moderna Spikevax Monovalent (original)
        - Moderna Spikevax Bivalent (BA.1)
        - Moderna Spikevax Bivalent (BA.4/BA.5)
        - Moderna Spikevax Monovalent XBB.1.5
        - Medicago Covifenz
        - Novavax Nuvaxovid

- When did you/your child receive the vaccines in relation to the diagnosis of Long COVID/MIS-C? Did you/they receive any vaccine doses before or after the diagnosis? IF YES: How many?
- How did you feel about getting vaccinated/getting your child vaccinated?
- Did you have any concerns or hesitations towards the COVID-19 vaccine?
    - Were there any concerns related to the safety or effectiveness of the vaccine?
    - Were there any concerns related to long COVID/MIS-C?
- What role, if any, did the COVID-19 vaccine play in your/your child's experience of long COVID/MIS-C?
- Did the COVID-19 vaccine lessen the symptoms of long COVID/MIS-C in any way or did it have another effect? What makes you say that?
- Do you/your child plan on receiving a COVID-19 booster (additional) dose in the future? Why/why not?

IF UNVACCINATED:

- If you don't mind me asking, can you tell me about the reasons why you/your child chose to not receive the COVID-19 vaccine?
- Do you think the COVID-19 vaccine would have played any role in your/your child's experience of long COVID/MIS-C?
- Do you/your child plan on receiving a COVID-19 vaccine in the future? Why/why not?
- Is there anything that would make you/your child more inclined to receive the vaccine in the future?

FOR ALL:

- Did you/your child receive the 2023/223 seasonal flu vaccine? Why is that?
- What about other vaccines? Have you/your child been vaccinated other diseases? Which ones? CODE THOSE APPLICABLE

	RECEIVED? Y/N
Chickenpox (Varicella)	
Diphtheria, Tetanus and Pertussis (DTaP) (Given to infants)	
Tetanus, Diphtheria and Pertussis booster (Tdap) (Given to adolescents)	
Haemophilus influenzae type b (Hib)	
Hepatitis B	
Human Papilloma Virus (HPV)	
Measles	
Meningococcal	
MMR (Measles, Mumps, Rubella)	
MMRV (Measles, Mumps, Rubella, Varicella)	
Mumps	
Pneumococcal	
Polio (IPV) (Poliomyelitis)	
Rotavirus	
Rubella	

- Did you have any concerns with these other vaccines compared to what you shared earlier with me about the COVID and flu vaccines? Why is that?
- What do you think about other public health measures… [IF NEEDED: Public Health Measures are interventions that can be used to help reduce the transmission of COVID-19 in communities]
    - Personal measures: self-monitoring, isolation, quarantine?
    - General recommendations: hand hygiene, non-medical mask use, physical distancing
    - Community measures: public messaging, education campaigns
    - Restrictive community measures limiting activities or access to resources, facilities, or institutions (e.g., 'lockdown' measures4)

- FOR EACH:
    - What do you think about these measures?
    - Do you agree/disagree with them?
    - Do you think these measures are effective in reducing the transmission of COVID-19.

IMPACT OF LONG COVID/MIS-C

Thank you for everything you shared with me so far. I want to better understand how your child's life has been affected by long COVID/MIS-C.

<u>MODERATOR TO USE DISCRETION WITH FOLLOWING QUESTIONS, ONLY ASK IF NOT ALREADY DISCUSSED IN PREVIOUS SECTIONS</u>

- In what ways, if any, did long COVID/MIS-C affect your child's physical health? Did this change over time?
- In what ways, if any, did long COVID/MIS-C affect your child's day-to-day activities? Did this change over time?
- In what ways, if any, did your child's behaviour change as a result of long COVID/MIS-C? Did this change over time?
- Did long COVID/MIS-C have an effect on your child's mental health? Did this change over time?
- What has been most difficult for your child?
- What about the effects of long COVID/MIS-C on your as a caregiver and your family's overall well-being? What has been the hardest thing for you and your family?

FINAL REFLECTIONS

I really appreciate everything that you have shared with me today. To finish off our interview…

- <u>ONLY IF NOT MENTIONED ALREADY:</u> How would you describe your/your child's health status in relation to long COVID/MIS-C – fully recovered, stable, deteriorating or something else?
    - IF FULLY RECOVERED: Is long COVID/MIS-C something that your child or you still think about? Do you have any concerns about longer term impact?
    - IF NOT FULLY RECOVERED: Do you feel optimistic or pessimistic that your child will recover in the future? What gives you hope/why are you pessimistic?
- Given everything that you/your family has gone through, what would you have done differently or wished that you knew from the beginning when your child first developed symptoms of long COVID/MIS-C?
- Are you glad or do you regret getting the COVID-19 vaccine/vaccinating your child against COVID-19? Why is that?
- What advice would you give to health authorities on how they can better support young people and their families affected by long COVID/MIS-C?

That is all the time we have for this today, but before we wrap things up, do you have any final comments or anything you feel we haven't addressed?

COVID-19 Post-Acute Conditions Qualitative Research Physicians Discussion Guide

INTRODUCTION

Introduce moderator and thank participant.

Explain purpose and logistics:

We are interviewing you today to hear about your experiences as a researchers, physicians or Allied health workers working and/or treating children and adolescents with Long COVID and/or Multisystem Inflammatory Syndrome in Children (MIS-C) in Canada.

We are conducting the interview on behalf of The Centre for Immunization Surveillance (CIS) of the Public Health Agency of Canada (PHAC) and Health Canada.

PHAC and Health Canada are seeking your participation in in-depth interviews exploring Post-acute COVID-19 Conditions (PCC) and COVID-19 vaccine impact and effectiveness among children and adolescents in Canada. We're looking for your help, expertise, and thought leadership to ensure that your views and experiences, as well as the views and experiences of children and families, are well represented in the research findings and considered in the design and execution of future vaccination programs.

The interview is part of a wider study where we are also speaking to families affected by Long COVID and / or MIS-C. The evidence gathered through the research will provide PHAC with a better understanding of what is happening on the ground in order to inform their decision-making.

The session is being recorded for analysis purposes. These recordings remain in our possession and will not be released to anyone who is not working on the study.

Please note that anything you say during this interview will be held in the strictest confidence. We do not attribute comments to specific people. Our report will summarize the findings from all the interviews but does not mention anyone by name. The report can be accessed through the Library and Archives Canada.

Observers are watching the sessions live because they are really interested in your opinions.

PLAN OF THE QUESTIONNAIRE

Plan of the Questionnaire	Researcher	Physician	Allied HW
	Research area: Long COVID/MIS-C Target population: 0-19 years old Research objectives Diagnostic/ therapeutic/Laboratory research/Other Key findings Impact of COVID-19 vaccination on Long COVID/MIS-C Perceptions of healthcare delivery and future improvements	Spectrum of clinical symptoms and diagnostic experiences and issues: Long COVID/MIS-C Target population: 0-19 years old Health care access and use, recovery trajectories and health disparities among children and adolescents with Long COVID/ MIS-C. Treatment Impact of COVID-19 vaccination on Long COVID/MIS-C Perceptions of healthcare delivery and future improvements	

Plan of the Questionnaire	Researcher	Physician	Allied HW
	Needs, Constraints and Recommendations Gaps to be addressed in future	Involvement of families in improving quality, equity, safety, and care experience Needs, Constraints and Recommendations Gaps to be addressed in future	
Employment status: screener questions (1-17Qs)	Let's start with an introduction: How long have you been in research and more specifically on Long COVID in children What is your area of research, your target audience	Let’s start off with an introduction: how long have you been practicing, where do you practice, what setting do you practice in and what is the patient profile of your practice.	
1. Characterize the spectrum of clinical symptoms, natural history, and distinct phenotypes identified as sequelae of SARS-CoV-2 infection among children and adolescents (defined as persons ≤ 19 years of age)		Patterns in the symptoms they witnessed	
2. Describe health care use, recovery trajectories and health disparities among children and adolescents with PCC or MIS-C.		Journey as a physician in diagnosis and treatment Sources of guidance/knowledge (formal and informal) Patient involvement Gaps to be addressed in future	
3. Understand the impact of PCC and MIS-C on health-related quality of life, behavioral health, and the impact on caregivers and family well-being, especially among disadvantaged groups.		Impact on their practice of treating patients with long COVID/MIS-C Involvement of families in direct care, care planning, and decision-making Clinician and staff practices that support family involvement Involvement of families in improving quality, equity, safety, and care experience Leadership commitment to family-centered care	
4. Assess COVID-19 vaccine uptakes, impact, and effectiveness (VE) against COVID-19-severe outcomes, post-COVID conditions (PCC) and Multisystem inflammatory syndrome in		COVID-19 vaccination: Uptake/ Patterns of vaccination in their patient groups, perceptions, hesitancy Impact Recommendations	

Plan of the Questionnaire	Researcher	Physician	Allied HW
children (MIS-C) among vaccine-eligible participants.			

OVERVIEW OF CASE LOAD AND SYMPTOMS

For all my questions today, I'd like you to focus on patient who were 19 or younger at the time of diagnoses.

- Approximately, how many cases of long COVID in children and young people have you diagnosed? And how many of these cases are still "active" – by that I mean that the child or young person is still experiencing long COVID currently?
- And how many cases of MIS-C in children and young people have you diagnosed? And how many of these cases are still "active"?
- Do you recall when you first started diagnosing children and young people with long COVID? What about MIS-C? Can you share a specific date or was it…
  - Before March 2021 (**Wild type VOC**)
  - March 2021, to June 2021 (**Alpha/Beta/Gamma VOCs**)
  - July 2021, to November 2021 (**Delta VOC**)
  - December 2021 to present (**Omicron VOC**)

For my next questions, I want to better understand the profile of children and young people that you treated with long COVID and MIS-C.pref

- Were certain age groups impacted more than others? PROBE SEPERATELY IN RELATION TO LONG COVID AND MIS-C.
- What were the most common symptoms that you observed?
- Did the symptoms vary by age group?
- PROBE AND CODE BASED ON GRID BELOW

	0-4 YEARS	5-11 YEARS	12-17 YEARS	18-19 YEARS
Long COVID				
Unusual fatigue				
Unusual shortness of breath				
Palpitation				
Unusual headaches				
Sore throat				
Cough				
Nausea				
Diarrhea				
Unusual abdominal pain				
Constipation				
Sleep problems				
Cognitive problems, such as: Memory loss Lack of concentration Difficulty thinking or concentrating				
Muscle aches and joint pains				

	0-4 YEARS	5-11 YEARS	12-17 YEARS	18-19 YEARS
Altered taste or smell				
Appetite loss				
Skin rash				
Hair loss				
Post-exertional malaise				
Unusual light-headedness				
Unusually fast heart rate				
MIS-C				
Rash				
Conjunctival injection				
Mucocutaneous inflammation signs (oral, hands or feet)				
Hypotension or shock				
Features of myocardial dysfunction, pericarditis, valvulitis,				
Coronary abnormalities (including ECHO findings)				
Elevated troponin/N-terminal pro-brain natriuretic peptide (NT-proBNP)				
Evidence of coagulopathy (by prothrombin time, partial thromboplastin time, elevated D-dimer)				
Acute gastrointestinal problems (diarrhea, vomiting or abdominal pain)				
Elevated markers of inflammation such as C-reactive protein, erythrocyte sedimentation rate or procalcitonin				
No other obvious microbial cause of inflammation, including bacterial sepsis, staphylococcal or streptococcal shock syndromes.				
Kawasaki disease				

- On average, how long did your pediatric patients experience symptoms of long COVID/MIS-C?
- And did you notice any patterns in pre-existing chronic conditions in the cases of children and young people affected by long COVID/MIS-C? PROBE AND CODE

<u>LONG COVID</u>

- Immunosuppression or autoimmune condition
- Chronic heart disease
- High blood pressure
- Asthma
- Chronic lung disease (not asthma)
- Obesity
- Diabetes mellitus
    - Type 1
    - Type 2
- Kidney disease
- Liver disease

- Asplenia
- Cancer
- Blood disorder
- Rheumatological disorder
- Neurological condition
- Dementia
- HIV
- TB
- Depression
- Anxiety
- Arrythmias
- Stroke
- Blood clots
- Postural orthostatic tachycardia syndrome (POTS)
- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)
- Mast cell activation syndrome (MCAS)
- Fibromyalgia
- Connective tissue disorders
- Hyperlipidemia

<u>MIS-C</u>

- Immunosuppression or autoimmune condition
- Chronic heart disease
- High blood pressure
- Asthma
- Chronic lung disease (not asthma)
- Obesity
- Diabetes mellitus
  - Type 1
  - Type 2
- Kidney disease
- Liver disease
- Asplenia
- Cancer
- Blood disorder
- Rheumatological disorder
- Neurological condition
- Dementia
- HIV
- TB
- Depression
- Anxiety

To the best of your knowledge, what number of your pediatric patients with long COVID and/or MIS-C have a pre-existing chronic condition?

EXPERIENCES OF DIAGNOSIS

My next set of questions are about your experiences of diagnosing for long COVID and MIS-C in children and young people.

- Can you describe to me your approach for diagnosing long COVID/MIS-C and whether it evolved over time?

Thanks for that. I wanted to follow-up up on some items… USE PROBES BELOW BASED ON WHAT HAS / HASN'T EMERGED

- Are you familiar with the definitions for long COVID and MIS-C that have been offered by various health bodies? Which ones did you refer to? IF NEEDED PROMPT WITH DEFINITIONS:

- LONG COVID: Long COVID is an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.
    - "Continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation." (WHO)
    - "When the symptoms of COVID-19 persist for more than 12 weeks after the infection. The most common symptoms in children include fatigue; headaches; abdominal pain; sleep problems; shortness of breath; cognitive problems, such as: lack of concentration, difficulty thinking or concentrating; muscle aches and joint pains" (Government of Canada)
    - "Umbrella term for the wide range of physical and mental health consequences experienced by some patients that are present 4 or more weeks after SARS-CoV-2 infection." (CDC)

- MIS-C:
    - "Multisystem inflammatory syndrome in children (MIS-C) is a rare condition associated with SARS-CoV-2 (the virus that causes COVID-19), which usually occurs 2-6 weeks after a child is infected with SARS-CoV-2. The child's SARS-CoV-2 infection may be very mild or have no symptoms at all and may go unrecognized. MIS-C causes different body parts to become inflamed, including the heart, lungs, kidneys, brain, skin, eyes, or gastrointestinal tract. MIS-C can be serious, even deadly, but most children who are diagnosed with this condition get better with medical care. To meet a case ascertainment, according to the CDC, the patients must meet all inclusion criteria: Age <21 years; Subjective or documented fever (≥38.0°C); Illness with clinical severity requiring hospitalization or resulting in death; A more likely alternative diagnosis is not present; C-reactive protein ≥3.0 mg/dL (30 mg/L); New onset manifestations in ≥2 of the following categories: (a) Cardiac involvement indicated by left ventricular ejection fraction <55%; coronary artery dilatation, aneurysm, or ectasia; or troponin elevated above laboratory normal range or indicated as elevated in a clinical note (b) Mucocutaneous involvement indicated by rash, inflammation of the oral mucosa, conjunctivitis or conjunctival injection, or extremity findings; (c) Shock; (d) Gastrointestinal involvement indicated by abdominal pain, vomiting, or diarrhea; (e) Hematologic involvement indicated by platelet count <150,000 cells/µL or absolute lymphocyte count (ALC) <1,000 cells/µL; Meets laboratory criteria for SARS-CoV-2 infection or epidemiologic linkage criteria: (a) Positive viral test (i.e., NAAT/PCR or antigen) during hospitalization or within 60 days prior (b) Positive viral test (i.e., NAAT/PCR or antigen) in a post-mortem specimen (c) Detection of SARS-CoV-2 specific antibodies associated with current illness (d) Close contact with a confirmed or probable case of COVID-19 disease in the 60 days prior to hospitalization; Death certificate lists MIS-C as an underlying cause of death or a significant condition contributing to death" (CDC)

    - "Children and adolescents 0-19 years of age with fever for three or more days AND two of the following: rash or bilateral non-purulent conjunctivitis or mucocutenous inflammation signs (oral, hands, or feet); Hypotension or shock; Features of myocardial dysfunction, pericarditis, valvulitis, or coronary abnormalities (including ECHO findings or elevated troponin/N-terminal pro-brain netriuretic peptide); Evidence coagulopathy (by prothrombin time, partial thromboplastin time, elevated D-dimer); Acute gastrointestinal problems (diarrhea, vomiting or abdominal pain) AND Elevated markers of inflammation such as C-reactive protein, erythrocyte sedimentation rate or procalcitonin AND No other obvious microbial cause of inflammation, including bacterial sepsis, staphylococcal or streptococcal shock syndromes AND Evidence of COVID-19 (reverse transcription polymerase chain reaction; RT-PCR, antigen test or serology positive) or likely contact with patients with COVID-19." (Canada.ca)

What were some of the challenges, if any, that you experienced as a physician when diagnosing children and young people with long COVID and MIS-C?

- How did the types of challenges evolve?
- What challenges remain today? How can they be addressed?

THE PERCIEVED SAFETY AND EFFECTIVENESS OF THE COVID-19 VACCINE

I'd like to move on slightly to talk about the COVID-19 vaccine in relation to long COVID and MIS-C in children and adolescents.

- Do you or others in your workplace administer childhood vaccines?
- Can you estimate the number of pediatric patients in your workplace that have received at least one dose of the COVID-19 vaccine?
- Of your pediatric patients can you estimate the number of them who have received a COVID-19 vaccination prior to COVID-19 infection?
- Based on your professional experience, please share the number of vaccinations administered to each individual patient ≤ 19 years old who has experienced or is experiencing long COVID and/or MIS-C.
- What were some of the challenges that you experienced in discussing COVID-19 vaccination with parents and adolescents?
- What were some of the concerns or barriers to COVID-19 vaccine uptake among pediatric patients?
    - Lack of educational material in their preferred language to provide patients or caregiver(s) on COVID-19 vaccination for this age group ?
    - Patient or caregiver's concern about myocarditis or pericarditis after COVID-19 vaccination?
    - Patient or caregiver's concern about COVID-19 vaccine safety or other side effects?
    - Patient or caregiver's belief that the COVID-19 vaccine is not effective?
    - Patient or caregiver's belief that the COVID-19 infection not serious enough in this age group to justify vaccination?
    - Vaccine hesitancy; patient and caregivers concern about all immunizations
    - Anxiety or fear of needles?
    - Other?
    - I have not noted any barriers for this age group.

- Did you personally have any concerns about the safety of the COVID-19 vaccine for pediatric patients?
- How, if at all, did long COVID or MIS-C factor into your discussions?
- Did you recommend the COVID-19 vaccine as a prevention for long COVID/MIS-C or not really? Did you feel confident in providing this advice, including mentioning risk and benefits of vaccines, or not really? Why is that?

- Based on your pediatric patients, what impact, if any, did the COVID-19 vaccine have in preventing or mitigating the effects of…
    - Acute COVID-19
    - MIS-C
    - Long COVID

- Did you observe any differences of vaccine effectiveness in terms of…
    - Number of doses received
    - Type of variant (OMICRON VERSUS DELTA)
    - Severity of infection

- Can you estimate the number of your pediatric patients who have or had long COVID received at least 1 dose of the COVID-19 vaccine prior to their diagnosis? And what is the comparable number for MIS-C? PROBE FOR NUMBERS WHO RECEIVED 0 DOSES, 2 DOSES, 3 DOSES AND 4 OR MORE DOSES

- May I ask if you were personally vaccinated?

- How likely are you to recommend the COVID-19 vaccine to your pediatric patients, specifically to prevent long COVID and/or MIS-C? Can you please explain your reasoning?
    - Infection with SARS-CoV-2 virus is not frequent among children in this age group?
    - COVID-19 is not severe among children in this age group?
    - Concern that COVID-19 vaccine is not effective among children in this age group?
    - Concern that the COVID1-9 vaccine may not be effective against future variants of SARS-CoV-2?
    - Concerns about rapid development of COVID-19?
    - Limited long-term data of COVID-19 vaccinations in this age group?
    - Concern for myocarditis or pericarditis after COVID-19 vaccination?
    - Concerns for other side effects or adverse effects of administering COVID-19 vaccine in this age group?
    - Concern about negative reaction from caregiver(s)?
    - Other?

TREATMENT FOR LONG COVID/MIS-C

Thank you for everything you shared with me so far. I now want to turn to interventions for long COVID and MIS-C.

- In your experiences, which interventions did you find most effective for long COVID? What about for MIS-C? PROBE FOR BOTH PHARMALOGICAL AND NON-PHARMALOFICAL. CODE AS MENTIONED

	LONG COVID	MIS-C
PHARMA		
Antiviral drugs		
Steroids		
Antibiotics		
Hydroxychloroquine		
Monoclonal Antibody		
Convalescent Plasma		
Anticoagulation		
Treatment with antihistamines		
Treatment with naltrexone		
Treatment with metformin		
Treatment with IL-6 antagonist		
Treatment with IL-1 antagonist		
Treatment with kinase inhibitor		
COVID experimental treatment trial		
NON PHARMA		
Use of activity, movement, or exercise-based interventions		

	LONG COVID	MIS-C
Self-monitor of heart rate as part of an energy conservation strategy		
Use of breath training		
Use of occupational therapy interventions		
Use of social network interventions		
Use of dietary interventions		
Use of nutraceutical or amino acids		
Use of family-centered interventions		
Treat potentially modifiable symptoms according to their current evidence-based/credible practice guidelines for people without long COVID		
Use fluids and compression stockings		
Use mindfulness exercises (including neurofeedback, dynamic neural retraining system, or related mind/body training)		

- And typically how long did it take for pediatric patients to fully recover from long COVID and MIS-C?
- What measures do you believe should be used to prevent long COVID and/or MIS-C?
- In people who do not have COVID-19 and no active long COVID/MIS-C:
    - Use of ventilation (including mechanical, mixed-mode or natural)?
    - Use of air filtration (including HEPA, MERV-13, in-room HEPA filter air cleaners and DIY-type Corsi-Rosenthal Boxes)?
    - Use of UV (both far wavelength UV and upper room UV-C)?
    - Use masking for asymptomatic individuals in community settings?
    - Use of saline nasal rinses and oral gargling (either Neti pot or salt water)?
    - Use of mouthwash gargling (including cetylpyridium chloride, chlorhexadine or alcohol-based)?
    - Use of additional doses of vaccines authorized in Canada (including mRNA or protein-based)?
    - Use of primary series of vaccines authorized in Canada (including mRNA or protein-based)?

- In people with COVID-19 infection and active long COVID:
    - Use of vaccines authorized in Canada?
    - Use of nirmatrelvir/ritonavir?
    - Use of metformin?
    - Use of rest, pacing or exercise avoidance?
    - Use of prophylactic dose of anti-coagulation such as acetylsalicylic acid (ASA)?
    - Use of selective serotonin reuptake inhibitors (SSRIs) or serotonin and norepinephrine reuptake inhibitors (SNRIs)?
    - Use of diet interventions such as high anti-inflammatory diets?
    - In people with COVID-19 infection and active MIS-C:
    - Use of vaccines authorized in Canada?
    - Use of nirmatrelvir/ritonavir?
    - Use of metformin?
    - Use of rest, pacing or exercise avoidance?
    - Use of prophylactic dose of anti-coagulation such as acetylsalicylic acid (ASA)?
    - Use of selective serotonin reuptake inhibitors (SSRIs) or serotonin and norepinephrine reuptake inhibitors (SNRIs)?
    - Use of diet interventions such as high anti-inflammatory diets?

PERCEPTIIONS OF HEALTHCARE DELIVERY AND FUTURE IMPROVEMENTS

I really appreciate everything that you have shared with me today. To finish off our interview, I'd like to get your opinions overall on healthcare delivery for pediatric patients affected by long COVID/MIS-C.

- How would you rate the overall health service delivery in place for pediatric patients affected by long COVID/MIS-C?
    - What are some of the gaps?
    - How should these gaps be addressed in future?
- Are you aware of the human-centered design? [IF NEEDED: Human-Centered Design (HCD) is an approach that prioritizes the perspectives, experiences, challenges and needs of individuals.]
    - Do you feel that the HCD approach is being used in the treatment of children and young people with Long COVID and MIS-C? Why or why not?
- How confident do you feel as a physician in diagnosing and treating pediatric patients affected by long COVID/MIS-C?
- Are there any gaps in supports or training that would help you in future? PROBE IN RELATION TO:
    - COVID-19 vaccination in general
    - COVID-19 vaccination protocols on long COVID/MIS-C specifically
    - Treatment and recovery trajectories
    - Support options
- What's your preferred format for receiving additional guidance, training or information about these gaps?
- Thinking about the future…
    - Should patient navigators be used to support care for pediatric patients with long COVID and MIS-C?
    - In pediatric patients who had COVID-19 (confirmed or suspected) and are at risk of long COVID and/or MIS-C, should we do blood tests annually to establish COVID-19 reservoirs?
    - Should options for remote appointments (e.g., virtual, telephone) versus in-person appointments be used for pediatric patients with suspected or diagnosed long COVID and/or MIS-C for initial visit and ongoing care/rehab visits?
    - Should care for pediatric patients with suspected or diagnosed long COVID and/or MIS-C be provided in specialized long COVID clinics vs primary care or walk-in clinics?
- Was there anything else related to your experience of diagnosing and treating long COVID/MIS-C that you had hope to share with me today?
- What advice would you give to health authorities on how they can better support physicians who treat young people and their families affected by long COVID/MIS-C?