CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

2021 Results

CPSP
CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

Public Health Agency of Canada
Agence de la santé publique du Canada

Canadian Paediatric Society
Société canadienne de pédiatrie

Mission

To contribute to the improvement of the health of children and youth in Canada by national surveillance and research into childhood disorders that are high in disability, morbidity, mortality, and economic costs to society, despite their low frequency.

Canadian Paediatric Surveillance Program Annual Results

Surveillance is integral to the practice of public health. Public health surveillance, as defined by the World Health Organization, includes the systematic collection, collation, and analysis of data coupled with the timely dissemination of information for assessment and public health response. Integral to its public health mandate, the Canadian Paediatric Surveillance Program (CPSP) is committed to sharing valuable information obtained through its active surveillance of rare diseases and uncommon conditions in children and youth in Canada. Key results of CPSP multi-year studies and one-time surveys are published in this annual report. These results highlight important findings and inform health professionals, researchers, and policy makers in developing strategies to improve the health of children and youth in Canada.

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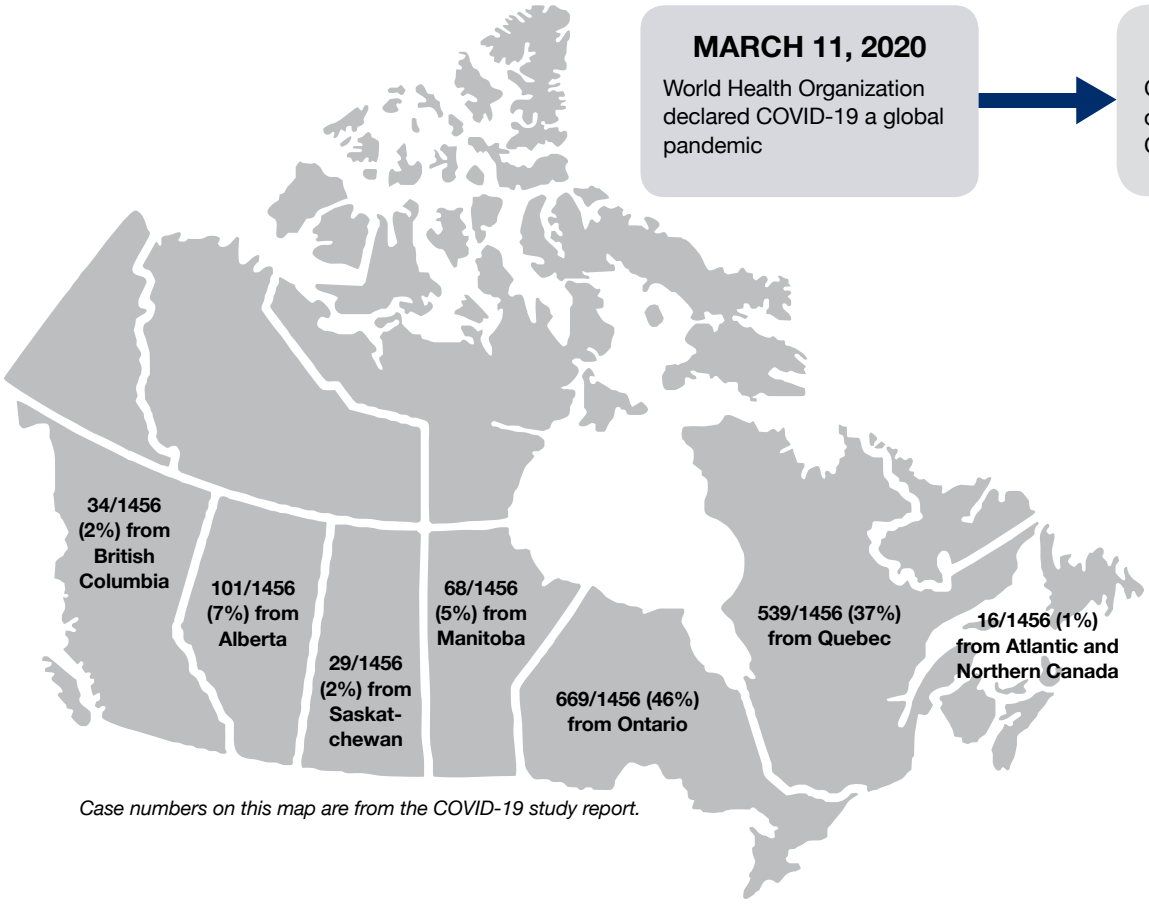
Importance of Public Health Surveillance During a Pandemic

MARCH 11, 2020

World Health Organization declared COVID-19 a global pandemic

MARCH 2020

CPSP mobilized for surveillance of severe acute COVID-19 in Canadian paediatric population



Case numbers on this map are from the COVID-19 study report.

DETECTION

APRIL 2020 to MAY 2021

- Data collection on severe acute SARS-CoV-2 infection to assess severity and risk factors
- Weekly (vs monthly) electronic data collection from 2,800 participants
- Online reporting for rapid case capture and analysis of clinical data
- Case definition expanded to include paediatric inflammatory multisystem syndrome (PIMS)

DEDUCTION

APRIL 2020 to DECEMBER 2021

- Near real-time analysis of 572 cases hospitalized with SARS-CoV-2 infection, 405 cases hospitalized with PIMS, and 505 non-hospitalized cases with SARS-CoV-2 infection with chronic condition/less than 1 year of age
- See page 23 for COVID-19 study results

DISSEMINATION

APRIL 2020 to DECEMBER 2021

PUBLIC HEALTH OFFICIALS

- Provided near real-time data to public health officials to inform clinical care and public health recommendations

PUBLIC HEALTH ALERTS

- COVID-19 and skin changes in children and youth
- Acute inflammatory illness in children and youth
- Myocarditis/pericarditis after COVID-19 vaccination

ADVERSE DRUG REACTION TIPS

- Remdesivir authorized with conditions for treatment of severe COVID-19 symptoms
- Recall of hand sanitizers posing health risks
- Cough and cold during COVID-19 pandemic
- Chloroquine and hydroxychloroquine and COVID-19
- No scientific evidence that ibuprofen worsens COVID-19 symptoms

PUBLICATIONS

- Characteristics of children admitted to hospital with acute SARS-CoV-2 infection in Canada in 2020 (Canadian Medical Association Journal)
- Canadian Paediatric Surveillance Program commentary on hospitalizations from COVID-19 among children in Canada (CPSP website)

PRESENTATIONS

- Canadian Paediatric Society 2020 Virtual Learning Session
- IDWeek 2021 Virtual Conference
- Pediatric Academic Societies 2021 Annual Meeting
- American College of Rheumatology Convergence 2021 Annual Meeting
- CanCOVID Virtual Speaker Series 2021

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Foreword

Federal Minister of Health

The Honourable Jean-Yves Duclos, P.C., M.P.

It is my pleasure to introduce the *Canadian Paediatric Surveillance Program 2021 Results*. This report highlights a year of studies of rare and emerging diseases and conditions that have significant impacts on children and youth in Canada. It also marks 25 years of collaboration between the Canadian Paediatric Society, Health Canada, and the Public Health Agency of Canada through the Canadian Paediatric Surveillance Program (CPSP), working together on over 83 multi-year surveillance studies, and more than 55 one-time surveys, to inform efforts to reduce risks, prevent disease, and improve diagnosis and treatment.

I would like to commend the Canadian Paediatric Society for their commitment to the well-being of children and youth in Canada and congratulate them on a successful year of work. The success of these studies would not be possible without the dedication of the 2,800 paediatricians and subspecialists from across Canada who continually contributed case reports to the CPSP despite the added burden of the COVID-19 pandemic. Your commitment continues to strengthen our national surveillance at a time when the importance of quality surveillance has never been clearer to Canadians.

The Government of Canada remains committed to supporting the physical and mental health of children and youth as we find our way through the global pandemic. The CPSP was among the first key sources of surveillance data to provide us with an understanding of the direct effects of COVID-19 on young people. Now it offers the opportunity to inform our understanding of some of the wider impacts of the pandemic on children and youth.

I am thankful for the leadership and commitment of the paediatricians, paediatric subspecialists, and all of those who make the CPSP possible. Your work continues to help researchers, decision makers and health professionals to improve public health policy, programming and clinical practice.

Chief Public Health Officer of Canada

Dr. Theresa Tam

For the past 25 years, the Canadian Paediatric Surveillance Program (CPSP) has been instrumental in providing Canada with surveillance data on rare diseases and emerging conditions in children and youth. The COVID-19 pandemic has shown us the importance of having robust surveillance data to gain a deeper understanding of emerging public health issues as well as to support evidence-informed decision-making. Throughout the pandemic, the CPSP has increased our understanding of the burden, prevention and treatment of existing and emerging diseases in Canadian children and youth that are occurring alongside SARS-CoV-2 infection, such as multisystem inflammatory syndrome in children (MIS-C).

This year's report includes a number of studies on the indirect impacts of COVID-19 on a range of diseases affecting children and youth, in addition to rare conditions, which have a disproportionate societal and economic burden. CPSP studies encompass diverse and complex mental and physical health issues, potentially exacerbated by COVID-19, such as admission to hospital for anorexia nervosa and impacts of the pandemic on children with medical complexity. The CPSP also continues to monitor other rare diseases and conditions, such as congenital syphilis, serious and life-threatening events associated with recreational cannabis use, and micronutrient deficiencies associated with autism spectrum disorder.

I would like to thank those involved in the CPSP and the Canadian Paediatric Society for their continued efforts to support the health of Canadian children and youth. The CPSP is possible because of the dedication of 2,800 paediatricians and paediatric sub-specialists across the country who provide accurate and up-to-date reporting. The valuable data generated has allowed health professionals and researchers to better inform patients and decision makers, and has helped to improve public health practices and policies for Canadians. Communities also benefit as reports like this help us to better understand how the needs of diverse children and youth vary across the country.

As Canada's Chief Public Health Officer, I am pleased to present the Canadian Paediatric Society's *Canadian Paediatric Surveillance Program 2021 Results* report. I am proud of the 25-year partnership between the Public Health Agency of Canada, Health Canada and the CPSP, which has provided continued support to surveillance and research in Canada, and has encouraged awareness within the medical community and the public.

President of the Canadian Paediatric Society

Dr. Ruth Grimes

As the President of the Canadian Paediatric Society, I am pleased to see how the Canadian Paediatric Surveillance Program (CPSP) continued to provide rich and timely data to support the Society's work in priority areas in 2021. I would like to thank our government partners at the Public Health Agency of Canada and Health Canada for their continued support and collaboration.

In addition to the study on COVID-19 and multisystem inflammatory syndrome in children, the CPSP continued to track some of Canada's most pressing paediatric health concerns during the past year. One example is the CPSP study on serious and life-threatening adverse events related to recreational cannabis, the results of which continue to support the need for stronger measures to protect children and youth from accidental exposures or ingestion. The interim study results on page 44 show that the majority of serious adverse events are in children and youth who consumed cannabis edibles, often found in the home in the form of gummy bears or chocolate. As a Society, we must continue to advocate for stronger rules and regulations around the sale of cannabis edibles, and ensure that Canadians are made aware of the harm these products may cause to children and youth.

A CPSP study on congenital syphilis that began in June 2021 is confirming the grim fact that this condition is no longer one of the past and that case numbers are on the rise. Within the first six months of the study launch, a significant number of cases were reported (page 21). This information reinforces the message that, while there is a need for public health surveillance related to the pandemic, we must not forget about other real threats to child health.

I would like to extend a sincere thank you to my colleagues across the country for your support and commitment to the CPSP. The Program would not succeed without your dedicated reporting and completion of detailed questionnaires. I urge you to continue to follow the CPSP studies and to report, even if you have not encountered any cases. As a national society advocating for the health and well-being of children and youth, surveillance data helps support our work in so many different ways.

Chair of the Canadian Paediatric Surveillance Program

Dr. Catherine Farrell

As the COVID-19 pandemic remained front and centre for global public health surveillance efforts in 2021, I am enormously proud of the many important contributions made by the Canadian Paediatric Surveillance Program (CPSP). Through the efforts of our committed investigators and our network of dedicated participants, we have generated valuable information to enable evidence-based decision making for the medical community, the public health community, as well as Canadian families.

Thanks to the hard work of our 2,800 participants, who reported weekly on cases of both acute paediatric COVID-19 and multisystem inflammatory syndrome in children between April 2020 and May 2021, our study team and our public health partners had compelling data to analyze and summarize in a timely fashion (page 23). Not only was this weekly analysis made available to public health officials at the highest levels, this work also led to the publication of one of the 25 most read articles in the *Canadian Medical Association Journal* in 2021. In addition, this CPSP publication received over 200 independent media mentions in the seven days following its release, demonstrating the high degree of interest in our high-quality surveillance findings. Congratulations to all for this exceptional contribution to public health surveillance.

Of course, we all know that the effects of COVID-19 on children and youth in Canada were felt far beyond the acute inpatient hospital setting. In response, the CPSP was deployed to explore the many ways young people have been impacted by the pandemic. I invite you to read the preliminary summary on the study of first-time hospitalizations for anorexia nervosa during the pandemic on page 27. The report clearly supports the need for children and youth to have timely access to mental health and community supports during these difficult times, and for specific investments in care for eating disorders. The two one-time surveys in 2021, one on identifying child maltreatment during virtual medical appointments (page 48) and one on the impacts of the pandemic on children with medical complexities (page 50), reveal some of the other unintended consequences that children and youth have experienced in the past 18 months.

I would like to take this opportunity to thank my colleagues across the country for your continued support of the CPSP. Despite unprecedented demands on our time and energy as health care providers over the past two years, you have once again demonstrated your strong commitment to public health surveillance and to providing the best possible care for our youngest citizens.

Acknowledgements

The key strength of the Canadian Paediatric Surveillance Program (CPSP) is its commitment to improve the health of children and youth in Canada and around the world. This focus would not be possible without the participation of Canadian paediatricians, subspecialists, and other health care providers in the monthly collection of information on rare paediatric conditions, the investigators who design studies and analyse the data to provide knowledge and educational solutions, or the guidance of the Scientific Steering Committee members. We thank them all.

We also thank IMPACT (Immunization Monitoring Program ACTive) centres for their role in verifying the acute flaccid paralysis study data and for their support of the CPSP.

The strong partnership between the Canadian Paediatric Society, the Public Health Agency of Canada, and Health Canada allows the Program to grow in Canada and to take a leadership role on the international scene.

Funding

Funding for the CPSP is required to support Program management. The surveillance Program is funded through a combination of government support and unrestricted grants from Canadian charities, research institutions, hospitals, and corporations. All funding is provided to maintain and expand the Program.

We gratefully acknowledge the financial support received in 2021 from the Public Health Agency of Canada's Centre for Surveillance and Applied Research, Health Canada's Marketed Health Products Directorate, and the following non-governmental sources:

- Alberta Children's Hospital Research Institute
- Bethanys Hope Foundation
- CHEO Research Institute
- Children's Hospital Research Institute of Manitoba sponsored studies grant from Novo Nordisk Inc.

Canadian Paediatric Surveillance Program Scientific Steering Committee

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The CPSP Scientific Steering Committee would like to extend a sincere thank you to Dr. Krista Jangaard, who completed a six-year term on the Committee as a representative of the Canadian Paediatric Society. Her dedication and expertise on many complex issues, especially related to neonatology, will be greatly missed by the Committee and we wish her all the best in her future endeavours.

The Committee also extends a warm thank you to Dr. Carsten Krueger, who recently completed a three-year term as the inaugural resident representative on the Scientific Steering Committee. His contributions to the Committee were extremely valuable and we wish Dr. Krueger all the best in his paediatric career.

About the Canadian Paediatric Surveillance Program

Overview

The Canadian Paediatric Surveillance Program (CPSP) is a joint project of the Public Health Agency of Canada and the Canadian Paediatric Society that contributes to the improvement of the health of children and youth in Canada by national surveillance and research into childhood disorders that are high in disability, morbidity, and economic costs to society, despite their low frequency. The CPSP gathers data from approximately 2,800 paediatricians and paediatric subspecialists each month to monitor rare diseases and conditions in Canadian children.

Objectives

- Maintain an active national surveillance system that monitors low-frequency, high-impact conditions and diseases in Canadian children and youth
- Involve paediatricians, paediatric subspecialists, and other medical professionals in related disciplines in the surveillance of rare conditions that are of public health and medical importance
- Generate new knowledge into rare childhood disorders to facilitate improvements in treatment, prevention, and health-care planning
- Respond rapidly to public health emergencies relevant to Canadian children and youth by initiating rapid one-time surveys and new studies
- Participate in international paediatric surveillance efforts through the International Network of Paediatric Surveillance Units (INOPSU)

Surveillance

- The full surveillance process is summarized in Figure 1 and includes the 3Ds of surveillance: detection, deduction, and dissemination.
- Health surveillance can be defined as: the tracking of any health event or health determinant through the continuous collection of high-quality data (detection); the integration, analysis, and interpretation of the data (deduction) into surveillance products; and the dissemination of those surveillance products to those who need to know (dissemination).

Process

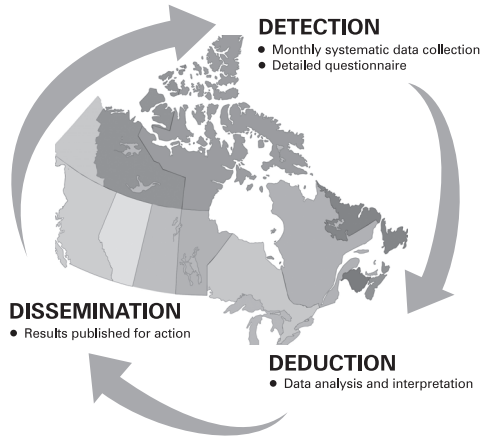
- Study teams from across Canada are encouraged to submit proposals for new studies or one-time surveys that meet the "criteria for submission," available on the CPSP website at www.cpsp.cps.ca/apply-proposez/criteria-for-inclusion-of-studies.
- The CPSP Scientific Steering Committee then reviews the proposals on a biannual basis and selects those of highest medical and public health importance. Proposals are evaluated against set criteria and are subject to comprehensive feedback from the multidisciplinary Scientific Steering Committee, composed of representatives from the Public Health Agency of Canada, the Canadian Paediatric Society, former CPSP investigators, academic clinicians from diverse specialties, and community paediatricians.
- Each month, CPSP participants from across Canada receive a form listing the current conditions under study. Participants notify the Program if they have seen any cases that meet the case definitions or have "nothing to report." Participants are encouraged to report all cases, including suspect or probable cases. This sometimes leads to duplicate reporting but avoids missed cases.
- Participants who have seen a case are sent a detailed clinical questionnaire to complete and return to the CPSP.
- Once the detailed questionnaire is returned to the CPSP, it is stripped of all unique identifiers and sent to the investigators for data analysis. All notifications of potential cases are assessed against the case definition. Duplicates or cases that don't meet the case definition are excluded.

CPSP Quick Facts

Did you know?

- The CPSP celebrated its 25th anniversary in 2021.
- The CPSP is comprised of approximately 2,800 dedicated paediatricians and paediatric subspecialists.
- Since its inception, the CPSP has studied 83 rare conditions/diseases and initiated 55 one-time surveys.
- Over 80 peer-reviewed manuscripts on study/survey results have been published in high-impact journals.
- The average monthly response rate is 80%.
- The average detailed questionnaire response rate varies between 80 to 90%.
- By December 2021, 97% of participants had committed to receiving their monthly forms electronically.

Figure 1 – Surveillance process summary



- It is important to note that CPSP studies use anonymized data from patient charts; the study investigators have no direct contact with individual patients.
- The study team is responsible for data analysis, and for ensuring that a solid knowledge translation plan is in place to disseminate the results in a timely and effective manner.
- Study results are published annually and acted upon to improve the health of children and youth in Canada. For example, CPSP study results help to warn of emergent public health issues, identify safety hazards, mobilize knowledge on rare diseases/conditions, and inform new policies and guidelines.

Limitations of surveillance

As with any voluntary reporting surveillance system, the CPSP recognizes that its surveillance has some limitations, including the following:

- Reporting on minimum incidence rates can under-represent events in the population.
- Some cases may present to family doctors or other health care practitioners and not to paediatricians.
- Surveillance totals may not include some children, such as those who live in rural or remote areas who are less likely to receive timely specialist care.
- Some data elements (e.g., laboratory investigations, pre-existing medical conditions) may not be available in the patient chart at the time of reporting and therefore may be absent from the surveillance totals. Every effort is made to ensure complete data capture and to handle missing data appropriately in the data analysis.
- At the time when investigators are asked to prepare study reports for the CPSP Annual Results, some clinical questionnaires may still be pending. Once pending questionnaires are analyzed, study conclusions may change.
- Data from Quebec are incomplete. Due to Quebec legislation, cases reported from that province can only be included in the data analysis when reported from a centre with project-specific research ethics board approval.
- Since the start of the COVID-19 pandemic, with the unprecedented demands being placed on front-line health care providers, it is possible that some cases may have gone unreported.

Despite these limitations, surveillance serves an important purpose and provides rich clinical data that allows for a better understanding of the rare childhood diseases/conditions under study.

Response rates

The CPSP's average national monthly response rate is 80% and the average detailed questionnaire completion rate varies between 80 to 90%.

TABLE 1 – Initial response rates (%) and number of participants for 2021

Provinces/territories	Reporting rates (%)*	Number of participants†
Alberta (AB)	82	382
British Columbia (BC)	84	318
Manitoba (MB)	78	117
New Brunswick (NB)	82	37
Newfoundland and Labrador (NL)	86	48
Northwest Territories (NT)	—	<5
Nova Scotia (NS)	88	88
Nunavut (NU)	—	<5
Ontario (ON)	82	1074
Prince Edward Island (PE)	87	9
Quebec (QC)	74	574
Saskatchewan (SK)	75	71
Yukon (YT)	—	<5
Canada	**80**	**2715**

* The CPSP national monthly reporting rate averages 80%. Every effort is made to maximize reporting, and annual response rates are subject to change due to delays in reporting.

† The total number of individual CPSP participants is approximately 2,800. However, in this table, the number of CPSP participants in Canada is calculated based on both individual and group reporting. When a group designate responds to the CPSP on behalf of group members, it is counted as one response.

TABLE 2 – National initial response rates 2017–2021

Reporting year	Reporting rates (%)
2017	83
2018	79
2019	82
2020	82
2021	80

TABLE 3 – 2021 detailed questionnaire completion rates as of August 20, 2022*

Studies/conditions	Notifications of potential cases	Pending	% Completion rate
5q spinal muscular atrophy	10	1	90
Acute flaccid paralysis†	11	1	91
Adverse drug reactions – serious and life-threatening	11	6	46
Congenital syphilis	99	13	87
COVID-19†‡	733	—	—
First-time hospitalizations for anorexia nervosa during the COVID-19 pandemic	100	19	81
Frequency and impact of PANDAS/PANS diagnosis	47	3	94
Micronutrient deficiencies and autism spectrum disorder	28	7	75
Optic nerve hypoplasia and septo-optic dysplasia	<5	—	—
Paediatric-onset leukodystrophies	19	6	74
Paediatric pulmonary thromboembolism	18	6	67
Serious adverse events related to cannabis used for medical purposes	<5	—	—
Serious and life-threatening events associated with non-medical (recreational) cannabis use in Canadian children and youth	49	16	67
Severe vaping-related illness and injury	<5	—	—
Total number of cases (all studies)	**1136**	**79**	**81**

* The numbers in this table were compiled later than those contained in the individual study reports and hence may differ because of delayed case reporting or case analysis.
† Includes case notifications from Quebec from centres with project-specific research ethics board approval. For all other studies, case notifications from Quebec were excluded.
‡ The data collection methodology for this study was different, as described in the study report, and as such, the completion rate is not presented.

Glossary of terms in study results

Reported: Notifications of potential cases received by the CPSP

Duplicates: Cases reported by more than one participant

Excluded: Cases not meeting the case definition and cases reported from Quebec institutions without project-specific research ethics board approval

In mid-2018, the CPSP became aware of a change in Quebec legislation that affected the ability of the Program to collect detailed information from physicians who practise in that province. The Ministère de la Santé et des Services sociaux approved the continued collection of CPSP case notifications (including date of birth and sex) from paediatricians and subspecialists in Quebec. More detailed case-level information for CPSP studies may also be collected in Quebec from institutions with project-specific research ethics board approval. Therefore, cases notified by Quebec participants after August 1, 2018 are included in the data analysis only if they are reported from an institution with CPSP project-specific research ethics board approval.

Pending: Detailed questionnaires not received or not yet verified as meeting the case definition

Met case definition: Cases verified as meeting the case definition, excluding duplicate case reports, cases failing to meet the case definition, cases pending verification, and cases reported from Quebec from institutions without project-specific research ethics board approval

International Network of Paediatric Surveillance Units

The CPSP offers an opportunity for international collaboration with other paediatric surveillance units worldwide, through the International Network of Paediatric Surveillance Units (INOPSU). The network provides a successful and easily accessible platform for international surveillance. No other network enables international comparisons of demographics, diagnoses, treatments, and outcomes for rare childhood conditions.

Established in 1998, INOPSU's membership includes many paediatric surveillance units from around the world, from Canada to New Zealand. Many of the paediatric surveillance units have been collecting data on rare childhood conditions for 20 years or more. Over 300 rare conditions have been studied to date, including rare infectious and vaccine-preventable diseases, mental health disorders, child injuries, and immunological conditions. The network encompasses approximately 10,000 child health care providers who voluntarily contribute data on these rare diseases every month.

Joint collaborative studies are seen as an important method of advancing the knowledge of uncommon childhood disorders around the world. For example, collaborative work is taking place to combine the data from the CPSP's congenital Zika syndrome and severe microcephaly studies with data from similar national surveillance projects conducted in the United Kingdom, Australia, and New Zealand.

During INOPSU meetings, member countries can highlight their surveillance program activities, explore innovative study ideas of interest to the network, discuss knowledge translation and joint publication opportunities, as well as strategize on how best to maintain active engagement of participants.

More information on INOPSU can be found at www.inopsu.com.

Surveillance Studies in 2021

5q spinal muscular atrophy

Study duration: January 2020 to December 2021 – Final report

Jean K. Mah

Principal investigator
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Co-investigators
Price T, Hodgkinson V, Innes M, Korngut L, Parboosingh J

Questions

- What is the minimum incidence of 5q spinal muscular atrophy (SMA) in children in Canada?
- What is the age at onset of symptoms and the age at time of genetic confirmation of disease?
- What therapeutic interventions are used in the treatment of children with SMA across Canada?

Importance

- SMA is the leading genetic cause of infant death and the second most common autosomal recessive disorder in Canada.
- SMA types 1, 2, and 3 are childhood onset diseases. Patients with SMA type 1 present before 6 months of age, with severe muscle weakness, hypotonia, and areflexia leading to progressive feeding and respiratory insufficiency. Sadly, if untreated, affected infants are never able to sit, and often die before their second birthday. Patients with SMA type 2 are symptomatic before 18 months of age. They may be able to sit but are unable to stand or walk unassisted; orthopedic and respiratory complications are common and the condition can be associated with reduced life expectancy. Patients with SMA type 3 present after 18 months of age with the ability to walk unassisted; progressive weakness may result in loss of independent ambulation, but a normal life span can be expected.
- A growing number of effective therapies for SMA, such as nusinersen, are now available. Understanding the minimum incidence, disease presentation, and current care practices will help inform strategies to improve the standard of care for children with SMA in Canada.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/concluded-studies.

Case definition

Any patient with a new genetically confirmed case of SMA (type 0 – 3) from birth to 18 years of age. The majority (96%) of 5q SMA cases are due to homozygous deletion of exon 7 (and exon 8) of the SMN1 gene; mutations of one SMN1 allele plus a deletion or mutation of SMN1 on the other allele can be found in the remaining 3–4% of cases.

Exclusion criteria

Excludes patients with other causes of developmental delay, hypotonia, or weakness (such as genetic or acquired causes of myopathies, muscular dystrophies, neuropathies, neuromuscular junction transmission defects, and central nervous system disorders) or non-5q SMA (such as distal SMA, SMA with respiratory distress, and other genetic or acquired motor neuron diseases).

Unique to this study

This study aims to estimate the minimum annual incidence of SMA using multiple sources, including a) the Canadian Paediatric Surveillance Program (CPSP); b) molecular genetics laboratories in Canada; and c) the Canadian Neuromuscular Disease Registry.

Results – January 2020 to December 2021

TABLE 1 – 5q SMA cases from January 1, 2020 to December 31, 2021					
Year	**Reported**	**Duplicates**	**Excluded**	**Pending**	**Met case definition***
2020	24	3	0	10	11
2021	14	2	0	5	7
Total	**38**	**5**	**0**	**15**	**18**

* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

Cases that met the case definition

At the time of analysis, 18 cases were verified as meeting the case definition for 5q SMA from January 1, 2020 to December 31, 2021. An additional 15 cases were pending verification.

Demographics

- The median age of cases was 11 months (interquartile range [IQR] 4–21).
- Patient sex was male in the majority of cases.
- The geographic distribution of cases was: 10/18 (56%) cases from Ontario and the remaining cases from Atlantic Canada and Western Canada.

Presentation and diagnosis

- Diagnosis was confirmed by genetic testing in all 18 (100%) cases.
- In 14/18 (78%) cases there was no known family history of SMA.
- Half of the cases (9/18, 50%) were SMA type 1 and the other half were SMA type 2 or 3.
- Five of the 18 (28%) cases were initially asymptomatic, and were diagnosed shortly after birth by SMA newborn screening or targeted genetic testing prompted by positive family history.
- The majority of symptomatic SMA type 1 cases were diagnosed at 5 to 6 months of age, with a mean of three months between symptom onset and diagnosis.
- The majority of symptomatic SMA type 2 cases were diagnosed between 9 to 22 months of age, with a mean of eight months between symptom onset and diagnosis.
- The majority of symptomatic SMA type 3 cases were diagnosed between 22 to 42 months of age, with a mean of 18 months between symptom onset and diagnosis.
- The most common presenting symptoms included hypotonia in 12/14 (86%) cases and delayed motor milestones in 10/14 (71%) cases. Muscle weakness was reported in 7/14 (50%) cases.

Treatment and outcomes

Of the 14 cases with treatment information available, 12 (86%) symptomatic cases received nusinersen as initial treatment. Treatment for the remaining four cases was unspecified.

Study limitations

Limitations common to all CPSP studies are listed on page 11.

Conclusions

- Analysis of the pending cases is ongoing. Once analysis is complete, the observed minimum incidence rate of SMA in children in Canada will be ascertained from the CPSP data.
- On average, diagnosis was delayed after the onset of symptoms by three months for SMA type 1, by eight months for type 2, and by 18 months for type 3.
- At least two thirds (12/18, 67%) of the SMA cases received nusinersen as initial treatment.

Anticipated study impact

- All cases were followed in multidisciplinary clinics and received supportive services for SMA. Further details on patient function, health status, and access to health services will be examined.
- Early recognition of SMA and newborn screening may reduce diagnostic delay and enable early treatment. Study results will contribute to improving the care and health outcomes of children with SMA by helping to inform health system planning and to optimize access to effective novel therapies.

Publication and dissemination

5q Spinal Muscular Atrophy Canadian Paediatric Surveillance Program 2020 Results. Price T, Hodgkinson V, Innes M, Korngut L, Parboosingh J, Mah JK. Canadian Neurological Sciences Federation's Congress, Toronto, in October 2021 (poster presentation)

5q Spinal Muscular Atrophy Canadian Paediatric Surveillance Program 2020–2021 Results. Price T, Hodgkinson V, Innes M, Korngut L, Parboosingh J, Mah JK. Canadian Neurological Sciences Federation's Congress, Montreal, in June 2022 (poster presentation)

Acknowledgements
The investigators thank the Alberta Children's Hospital Research Institute, University of Calgary, for funding support.

Acute flaccid paralysis

Study duration: Ongoing study since January 1996

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Question

Did Canada maintain its polio-free status in 2021?

Importance

- Poliomyelitis is targeted for eradication, with only two countries having ongoing wild poliovirus transmission. Acute flaccid paralysis (AFP) surveillance is the cornerstone of monitoring for polio and is critical for documenting the absence of poliovirus circulation required for countries to declare polio-free status.
- Canada conducts AFP surveillance in children under 15 years of age, in accordance with World Health Organization (WHO) recommendations and standards of practice.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

Acute onset of focal weakness or paralysis characterized as flaccid (reduced tone) without other obvious cause (e.g., trauma) in a child less than 15 years of age. Transient weakness (e.g., post-ictal weakness) does not meet the case definition.

Unique to this study

Cases are captured through both the Canadian Paediatric Surveillance Program (CPSP) and Canada's Immunization Monitoring Program ACTive (IMPACT) based in 12 tertiary care paediatric centres. Of the cases reported from Quebec, only AFP cases reported by Quebec IMPACT centres are eligible for data analysis in this report.

Results – January to December 2021

Note: Due to reporting delays, this report represents a snapshot as of March 1, 2022. The total AFP case counts for 2017 to 2021 have been updated with all the confirmed cases that have been reported and are presented in Table 2.

TABLE 1 – AFP cases in 2021

Reported	Duplicates	Excluded	Pending	Met case definition*
8	0	2	0	6

* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis, unless reported from a centre with project-specific research ethics board approval. Cases reported through the following centres were included in the data analysis for this report: CHU Sainte-Justine, Montreal Children's Hospital, and CHU de Québec-Université Laval and Centre mère-enfant Soleil.

TABLE 2 – Annual comparison of AFP cases 2017–2021

Year	Total cases
2021	6
2020	30
2019	36
2018	73
2017	32

Cases that met the case definition

- In total, eight reports of sudden onset muscle weakness in children younger than 15 years of age were provided to the Public Health Agency of Canada. All reports were made through IMPACT.
- At the time of analysis, six cases were verified as meeting the AFP case definition in 2021; none were assessed as meeting the polio case definition.
- The median time from case onset of paralysis to reporting was 103.5 days and the average was 93 days (range: 35– 123).

Demographics
Cases ranged in age from 1 year to 13 years, with a median of 6.0 years and a mean of 7.2 years.

Presentation and diagnosis
- All six cases (100%) were hospitalized. Length of stay was known for five cases, which ranged from 2 to 27 days, with a median of 4 days and a mean of 9 days.
- Diagnoses reported for the cases include Guillain-Barré syndrome, myelitis, and ataxia. The most frequent diagnosis was Guillain-Barré syndrome.
- Fewer than five cases were reported to be up-to-date for their polio vaccinations.
- Zero cases had stool sample submitted for viral testing.

Treatment and outcomes
- Five of the six cases (83%) had outcomes documented at initial report, and all five had either fully recovered or partially recovered with residual weakness.
- Fewer than five cases had clinical outcomes reported at least 60 days after the onset of paralysis or weakness.

TABLE 3 – Measure of Canada's performance against WHO AFP surveillance performance indicators in 2021[1]

Number of cases	Incidence rate*	% with adequate stool sample†[2]§	% with 60-day follow-up‡§
6	0.10	0%	50%

* Per 100,000 population in those less than 15 years of age - target is 1.0 AFP case per 100,000 population less than 15 years of age
† Target is at least 80% of cases have adequate stool sampling within 14 days of paralysis onset
‡ Target is at least 80% have follow-up examination for residual paralysis at least 60 days after onset
§ Percentage should be interpreted with caution due to the small number of cases

Study limitations
- Limitations common to all CPSP studies are listed on page 11.
- Delays in reporting due to operational demands of the COVID-19 pandemic may have affected the number of cases reported in 2021.
- Stool samples in patients with AFP are sometimes difficult to obtain due to the nature of the patient's symptoms, including constipation. Additionally, rapid availability of advanced diagnostic testing often identifies the diagnosis prior to the collection of the stool sample.

Conclusions
- Although Canada did not meet the WHO performance indicators for national AFP surveillance in 2021, there was sufficient evidence to suggest that no polio cases occurred in Canada.
- It will be important to strengthen AFP case reporting activities that were affected by the COVID-19 pandemic, as operational demands related to the COVID-19 pandemic are eased.
- AFP surveillance in Canada is conducted through a sensitive and active surveillance system that allows prompt and appropriate investigation of AFP cases to detect polio. Polio is a reportable disease in every province and territory, and is nationally reportable.

Anticipated study impact
Canada's polio-free status remains intact, as assessed annually by Canada's National Certification Committee for Polio Eradication.

Publication and dissemination
Acute flaccid myelitis in Canada, 2018 to 2019. Dickson C, Ho Mi Fane B, Squires SG. *Can Commun Dis Rep* 2020 Oct 1;46(10):349–53. doi: 10.14745/ccdr.v46i10a07

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1. Detailed information on WHO surveillance performance indicators can be found at https://polioeradication.org/polio-today/polio-now/surveillance-indicators/
2. Adequate stool sample refers to one stool sample taken within 14 days of paralysis onset.

Adverse drug reactions – serious and life-threatening

Study duration: Ongoing study since January 2004

Sally Pepper

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Question

What serious and life-threatening events suspected to be related to adverse drug reactions (ADRs) in children and youth were reported in 2021?

Importance

- Only a minority of prescribed pharmaceuticals on the market in North America have been tested in paediatric patients, and many of them are used without the benefit of adequate and/or specific guidance on safety or efficacy in this population.
- Post-marketing surveillance is essential for detection of ADRs and contributes to the ongoing monitoring of the benefit-risk profile of health products used in children.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

Serious and life-threatening adverse drug reactions* in an infant or child up to the age of 18 years, associated with the use of prescription, non-prescription, biological products (immunoglobulin), complementary medicines (including herbals), and radiopharmaceutical products.

* Noxious and unintended severe response to a drug, which occurs at any dose and results in emergency observation, hospitalization, persistent or significant disability, or death

Exclusion criteria

Reactions to medical devices, blood products (platelets, red cells and single-donor plasma), vaccines, poisonings or self-administered overdoses

Unique to this study

Significant results for the ADR study contribute to the monthly ADR Tips distributed by the Canadian Paediatric Surveillance Program (CPSP).

Results – January to December 2021

TABLE 1 – ADR cases in 2021

Reported	Duplicates	Excluded	Pending	Met case definition*
7	0	2	0	5

* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

Cases that met the case definition

- At the time of analysis, five suspected serious and/or life-threatening paediatric ADR cases were verified as meeting the case definition in 2021. Reporting and verification delays related to the pandemic contributed to the low case count for 2021.
- In a small number of cases, more than one product was suspected of causing the adverse reactions..

TABLE 2 – Suspect health products in 2021	
Class of health product	**Name of health product**
Antidiarrheals, intestinal anti-inflammatory/anti-infective agents	Sulfasalazine
Antiepileptics	Phenytoin
Antihistamines for systemic use	Rupatadine
Antineoplastic agents	Trametinib
Drugs for obstructive airway disease	Formoterol/budesonide*
Psychoanaleptics	Escitalopram
Psycholeptics	Risperidone

* Combination product containing 2 or more active ingredients

Demographics

- Patient sex was male in the majority of cases.
- Cases were reported from each of the following age ranges: 6 to 12 years, and 13 to 17 years.

Presentation and diagnosis

- All cases were classified as serious according to the following criteria (more than one cause for classification was provided in some of the reports): life-threatening; hospitalization; required intervention to prevent damage or permanent impairment; and medically important (defined as a case that may not be immediately life-threatening or result in death/hospitalization but may jeopardize the patient or require intervention to prevent one of these other outcomes from occurring).
- The adverse reactions presented as disorders from the following categories: cardiac disorders; immune system disorders; nervous system disorders; respiratory, thoracic and mediastinal disorders; and skin and subcutaneous tissue disorders. Based on the small number of reports, trends in reporting for the study year 2021 cannot be determined. From the time of initiation of the study in 2004 until 2021, the majority of the adverse reactions have presented as skin and subcutaneous tissue disorders.
- The majority of the reports described reactions generally documented in the approved Canadian product monograph or other drug information references.

Treatment and outcomes

- No deaths were reported.
- The outcome was known in all cases, with patients experiencing either a full recovery or reporting that the reaction was resolving.

Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- Reporting and verification delays related to the pandemic contributed to the low case count for 2021.
- All adverse reactions to health products are considered as "suspected," as a definite causal association often cannot be determined. The true incidence of adverse reactions is unknown because they remain under-reported and total patient exposure is unknown.

Conclusions

Since the implementation of the CPSP surveillance for adverse reactions in 2004, the product classes most frequently associated with suspected ADRs have been antibacterials for systemic use, antiepileptics, and psychoanaleptics. The most frequently reported suspect drugs in these classes have been amoxicillin, carbamazepine, and methylphenidate, respectively. No reports meeting the study criteria were received in 2021 for these three drugs.

Anticipated study impact

- Health Canada recognizes the need to strengthen information related to paediatric health, as medication safety and efficacy may be significantly different for children than adults, and data on medication safety and efficacy in the paediatric population are limited.[1, 2] The ongoing sharing of safety information through voluntary reporting of ADRs from various sources, such as the CPSP, is valuable to Health Canada as it contributes to ongoing monitoring of the benefit-risk profile of health products used in children and can thus result in the implementation of risk mitigation measures.
- In acknowledgement of the importance of safety information provided by ADR reporting, Health Canada has implemented Vanessa's Law, an amendment to the Food & Drugs Act that requires certain health care institutions to identify and report serious adverse drug reactions and medical device incidents to the federal regulator (for more information, visit: www.canada.ca/en/health-canada/services/drugs-health-products/medeffect-canada/adverse-reaction-reporting/mandatory-hospital-reporting/education/module-1.html). A key objective of mandatory reporting is to improve the quality and quantity of serious ADR reports, and to expand on the real-world data available to monitor the safety of health products used in children.

Acknowledgements

The assistance of Heather Morrison is greatly appreciated.

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Congenital syphilis

Study duration: June 2021 to May 2023

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Questions

- What are the maternal sociobehavioural risk factors associated with infants born with congenital syphilis (CS)?
- How are paediatricians recognizing, diagnosing, and managing infants with CS?

Importance

- CS has become increasingly common and can have irreversible consequences if the diagnosis is missed.
- Understanding the barriers preventing women from engaging in prenatal care is crucial to preventing CS.
- Understanding the patterns of presentation, as well as current patterns in the diagnosis and management of CS, can inform physician education efforts.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

Any neonate, infant, or child <4 years old with a new diagnosis of confirmed or probable CS in the last month.

Confirmed congenital syphilis (requires one of the following)

1. Identification of *Treponema pallidum* in the infant/child's specimen by polymerase chain reaction or fluorescent antibody examination
2. Reactive serology from venous blood in an infant that is four-fold greater than the maternal serology collected near the time of birth
3. Reactive serology from venous blood in an infant that persists beyond their second birthday

Probable congenital syphilis

1. Infant born to a mother who had untreated or inadequately treated syphilis at delivery, regardless of findings in the infant

OR BOTH OF THE FOLLOWING:

2. An infant or child with a reactive treponemal test result
3. One of the following additional criteria:
   a. Clinical signs of CS on physical examination
   b. Evidence of CS on radiographs of long bones
   c. Abnormal cerebrospinal fluid cell count or protein without other cause
   d. Reactive treponemal immunoglobulin M (IgM) (19S-IgM antibody test or IgM enzyme-linked immunosorbent assay)

Unique to this study

This study was designed in conjunction with the Sexually Transmitted and Blood-Borne Infections Surveillance Division of the Public Health Agency of Canada.

Results – June to December 2021

TABLE 1 – CS cases from June 1 to December 31, 2021

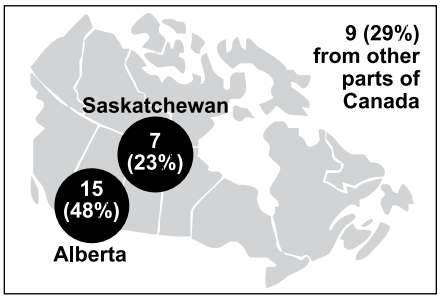
Reported	Duplicates	Excluded	Pending	Met case definition*
84	0	0	53	31

* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

Cases that met the case definition

At the time of analysis, 31 cases of CS were verified as meeting the case definition from June 1 to December 31, 2021. At the time of publication, 53 cases were pending verification.

Demographics



- The geographic distribution of cases was: 15/31 (48%) from Alberta, 7/31 (23%) from Saskatchewan, and the remaining 9/31 (29%) from elsewhere in Canada. One quarter of cases (7/28, 25%) were from rural postal codes.
- The median maternal age was 24 years (range 17–38).
- The most common reported sociobehavioural risk factors of mothers with affected children were substance use (19/31, 61%) and housing insecurity (10/31, 32%). "Unknown" responses were common for other risk factors, as high as 93% (28/30).
- Of mothers with reported substance use, 42% (8/19) used methamphetamines and 32% (6/19) used fentanyl.
- Maternal coinfections were common, with 52% (15/29) of mothers having at least one. Chlamydia was the most common (11/29, 38%) maternal coinfection.
- None of the congenital syphilis cases indicated that the mother had immigrated to Canada in the last 10 years. However, numerous (12/31, 39%) "unknown" responses were reported.

Presentation and diagnosis

- Many mothers of affected children (9/31, 29%) had no documented prenatal care.
- Most mothers (22/30, 73%) had syphilis screening in pregnancy, and of the 21 who had positive serology in pregnancy, only 67% (14/21) received treatment.
- Most neonates with CS (22/31, 71%) had normal physical exams, but 50% (15/30) had abnormal long bone X-rays.

Treatment and outcomes

- Most neonates (27/31, 87%) with confirmed or probable CS started treatment within their first week of life.
- All of the affected neonates received at least 10 days of aqueous penicillin G, the treatment of choice for CS.
- In 46% (13/28) of cases, there were no complications documented at the time of reporting.

Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- Many potential maternal sociobehavioural risk factors were unknown to reporting physicians.

Conclusions

- Housing insecurity and substance use in pregnancy were common risk factors of mothers of children with CS; however, the presence of other potential sociobehavioural risk factors was often not known by reporting paediatricians.
- Most affected infants identified by this study were diagnosed and treated early.

Anticipated study impact

- The data gathered will help inform public health strategies for preventing CS.
- Study results may inform an upcoming Canadian Paediatric Society position statement on CS, as well as Public Health Agency of Canada discussions on the revision of the national case definition for CS.
- Next steps include exploring maternal barriers to engaging in prenatal care with congenital infection specialists.

COVID-19

Study duration: April 2020 to May 2021 – Final report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Questions

- What is the spectrum of disease, and what are risk factors for severe disease, from severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection in children in Canada?
- What is the spectrum of disease, and what are the clinical features of paediatric inflammatory multisystem syndrome (PIMS)/multisystem inflammatory syndrome in children (MIS-C) temporally associated with coronavirus disease 2019 (COVID-19)?

Importance

- COVID-19 is caused by SARS-CoV-2, a novel coronavirus that spread rapidly around the world in 2020 causing a global public health emergency. While severe disease in children is less common than in adults and the elderly, the spectrum of acute illness and the comorbid conditions that increase the risk for severe disease, remain poorly understood.
- SARS-CoV-2 has also been associated with a post-infectious hyperinflammatory syndrome referred to as both PIMS and MIS-C. Little is known about this important, but rare, complication of SARS-CoV-2 infection in children. There is an urgent need to refine current diagnostic approaches as well as to better understand the response to current therapies.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/concluded-studies.

Case definition
Any new patient less than 18 years of age (up to the 18th birthday) who meets one of the following three case definitions:

1) HOSPITALIZED with acute COVID-19 (i.e., microbiologically confirmed SARS-CoV-2)
2) HOSPITALIZED with paediatric inflammatory multisystem syndrome (PIMS)/Kawasaki disease temporally associated with COVID-19, defined as:
   - Persistent fever (>38 degrees Celsius for 3 or more days) and elevated inflammatory markers (C-reactive protein [CRP], erythrocyte sedimentation rate [ESR], or ferritin)

AND one or both of the following:
- Features of Kawasaki disease (complete or incomplete)
- Toxic shock syndrome (typical or atypical)

AND
- No alternative etiology to explain the clinical presentation

IMPORTANT NOTE: Patients should be reported regardless of SARS-CoV-2 status

3) NON-HOSPITALIZED with acute COVID-19 (i.e., microbiologically confirmed SARS-CoV-2) AND at least one of the following chronic comorbid conditions:
- < 12 months of age
- Obesity
- Congenital heart disease
- Immunocompromising medications (high-dose steroids,* chemotherapy, biologics, immunomodulators)
- Solid organ transplant
- Primary or secondary immunodeficiency
- Sickle cell disease or other chronic hematologic condition
- Tracheostomy
- Inflammatory bowel disease or other chronic gastrointestinal or liver disease
- Asthma
- Chronic lung disease
- Chronic renal disease
- Solid tumor or hematologic malignancy
- Bone marrow transplant
- Chronic neurologic or neurodevelopmental condition
- Diabetes
- Chronic rheumatologic or autoimmune disease
- Genetic/metabolic disease

* Equivalent to at least 2 mg/kg or 20 mg/day of prednisone for at least two weeks

Unique to this study

Unique aspects of this study include three separate case definitions, weekly surveillance using entirely electronic data capture, and the size and scope of the co-investigator team.

Results – April 2020 to May 2021

Note: This report includes 2020 cases notified before February 2, 2021.

TABLE 1 – COVID-19 cases from April 1, 2020 to May 31, 2021

Year	Reported	Duplicates	Excluded	Pending	Met case definition‡
2020*	960	150	79	0	731
2021†	840	77	38	0	725
Total	**1800**	**227**	**117**	**0**	**1456**

* April 1 to December 31, 2020
† January 1 to May 31, 2021
‡ Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis, unless reported from a centre with project-specific research ethics board approval. Cases reported through the following centres were included in the data analysis for this report: CHU Sainte-Justine, Montreal Children's Hospital, CHU de Sherbrooke, and CHU de Québec-Université Laval and Centre mère-enfant Soleil.

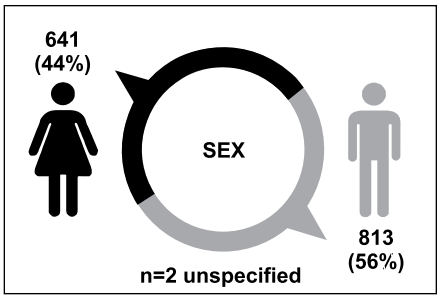
Cases that met the case definition

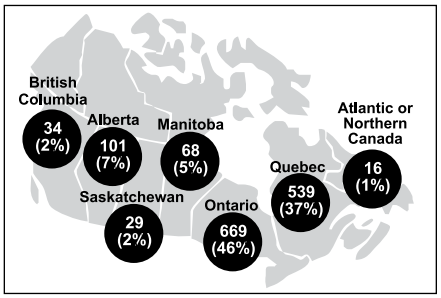
- In total, 1456 cases met at least one study case definition between April 1, 2020 and May 31, 2021. This includes 572 cases hospitalized with confirmed SARS-CoV-2 infection, 405 cases hospitalized with PIMS, and 505 non-hospitalized cases with confirmed SARS-CoV-2 infection who either had a chronic comorbid condition or were less than 1 year of age.
- Twenty-six cases simultaneously met the case definitions for hospitalized patients with SARS-CoV-2 infection and PIMS.

Demographics

- The median age of hospitalized cases with SARS-CoV-2 infection was 3.2 years (interquartile range [IQR] 0.3–13.4), while the median age of hospitalized cases with PIMS was 5.4 years (IQR 2.5–9.8).
- Among non-hospitalized cases with SARS-CoV-2 infection, 332/505 (66%) were younger than 1 year of age, while 189/505 (37%) had a known chronic comorbid condition.

- Across all case definitions, 813/1454 (56%) cases were male while 641/1454 (44%) were female (n=2 unspecified).
- Across all case definitions, the geographic distribution of cases was as follows: 669/1456 (46%) from Ontario, 539/1456 (37%) from Quebec, 101/1456 (7%) from Alberta, 68/1456 (5%) from Manitoba, 34/1456 (2%) from British Columbia, 29/1456 (2%) from Saskatchewan, and 16/1456 (1%) from Atlantic or Northern Canada.





Presentation and diagnosis

- Overall, 240/572 (42%) of hospitalized cases with SARS-CoV-2 infection and 68/405 (17%) of hospitalized PIMS cases had known chronic comorbid conditions.
- Among hospitalized cases with SARS-CoV-2 infection, 361/572 (63%) were admitted for care related to symptoms of COVID-19, 198/572 (35%) were admitted for care unrelated to COVID-19, and 13/572 (2%) were admitted for social/humanitarian or infection control purposes.
- The most common symptoms among hospitalized and non-hospitalized cases with SARS-CoV-2 infection were fever (613/916, 67%), cough (372/916, 41%), and runny nose (359/916, 39%).
- The most common clinical features among hospitalized PIMS cases were gastrointestinal symptoms (e.g., abdominal pain, diarrhea, or vomiting; 311/405, 77%), rash (288/405, 71%), and bilateral bulbar conjunctival injection without exudate (285/405, 70%).
- Among PIMS cases with echocardiograms performed (n=391), 190 (49%) had recorded abnormalities.

Treatment and outcomes

- Among hospitalized cases with SARS-CoV-2 infection, 120/572 (21%) received steroids, 33/572 (6%) received remdesivir, and 10/572 (2%) received biologics.
- The most common treatments for PIMS cases were immunoglobulin (382/405, 94%), aspirin (365/405, 90%), and steroids (271/405, 67%).
- Admission to an intensive care unit was required by 105/572 (18%) hospitalized cases with SARS-CoV-2 infection and 127/405 (31%) hospitalized PIMS cases.
- Some form of respiratory or hemodynamic support was required by 144/572 (25%) hospitalized cases with SARS-CoV-2 infection and 116/405 (29%) hospitalized PIMS cases.
- Across all case definitions, six children were reported to have died, none of whom had PIMS.

Study limitations

Limitations common to all Canadian Paediatric Surveillance Program studies are listed on page 11.

Conclusions

- SARS-CoV-2 has affected children in Canada, with nearly 1000 hospitalizations (572 cases hospitalized with confirmed SARS-CoV-2 infection, 405 cases hospitalized with PIMS) successfully captured during the study period through the CPSP.
- Data from these hospitalizations has provided insight on the clinical presentation of SARS-CoV-2 infection and PIMS, in addition to risk factors for severe disease and outcomes within specific age groups.
- Data from non-hospitalized children with SARS-CoV-2 infection further contribute to the understanding of the clinical presentation and severity among different groups, defined by age and presence of comorbidities.

Anticipated study impact

These data will continue to inform both clinical care and policy-related decisions about children and COVID-19 in Canada.

Publication and dissemination

Canadian Paediatric Surveillance Program commentary on hospitalizations from COVID-19 among children in Canada [Internet]. Kakkar F, Moore Hepburn C, Drouin O, Morris SK; on behalf of the Canadian Paediatric Surveillance Program COVID-19 study team. Ottawa: Canadian Paediatric Society; 2020 Sep. Available from: https://www.cpsp.cps.ca/uploads/publications/CPSP_COVID-19_Commentary_September_2020.pdf

Characteristics of children hospitalized with acute SARS-CoV-2 infection in Canada in 2020. Drouin O, Moore Hepburn C, Farrar DS, Baerg K, Chan K, Cyr C, Donner EJ, Embree JE, Farrell C, Forgie S, Giroux R, Kang KT, King M, Laffin M, Luu TM, Orkin J, Papenburg J,

Pound CM, Price VE, Purewal R, Sadarangani M, Salvadori MI, Top KA, Viel-Thériault I, Kakkar F, Morris SK, for the Canadian Paediatric Surveillance Program COVID-19 Study Team. *CMAJ* 2021 Sep 27;193:E1483–93. doi: 10.1503/cmaj.210053

COVID-19, the road to recovery: Preliminary results of the CPSP study. Morris S, Tam T, Korczak D. Canadian Paediatric Society Virtual Learning Session, in September 2020 (oral presentation and panel discussion)

Characteristics of children hospitalized with acute SARS-CoV-2 infection in Canada. Drouin O, Moore Hepburn C, Farrar DS, Kakkar F, Morris SK, for the Canadian Paediatric Surveillance Program COVID-19 study group. Pediatric Academic Societies Annual Meeting, virtually, in May 2021 (poster presentation)

COVID-19: Year two. Drouin O, Langley J, Allen U. Child and youth health lecture. Canadian Paediatric Society Annual Conference, virtually, in June 2021 (oral presentation)

Disease severity and clinical manifestations of SARS-CoV-2 infection among infants over the first year of the pandemic in Canada. Piché-Renaud PP, Panetta L, Farrar DS, Moore Hepburn C, Drouin O, Kakkar F, Morris SK, for the Canadian Paediatric Surveillance Program COVID-19 Study Team. IDWeek 2021 Virtual Conference, in September/October 2021 (poster presentation)

Epidemiology, clinical features, and severity of paediatric inflammatory multisystem syndrome temporally associated with SARS-CoV-2 infection in hospitalized children in Canada: A Canadian Paediatric Surveillance Program national prospective study. El Tal T, Morin MP, Morris SK, Farrar DS, Berard R, Kakkar F, Moore Hepburn C, Haddad E, Scuccimarri R, Yeung R, for the Canadian Paediatric Surveillance Program COVID-19 study group. American College of Rheumatology Convergence Annual Meeting, virtually, in November 2021 (poster and recorded oral presentation)

Epidemiology and outcomes of children with SARS-CoV-2 in Canada. Findings from a prospective pan-Canadian study. Drouin O. CanCOVID Speaker Series, virtually, in December 2021 (oral presentation)

Acknowledgements
The investigators thank paediatricians and paediatric subspecialists across Canada for reporting cases for this study. Significant numbers of cases were reported on a weekly basis, and we gratefully recognize the extra effort that was required of CPSP participants to report cases, especially during busy pandemic times.

First-time hospitalizations for anorexia nervosa during the COVID-19 pandemic

Study duration: September 2021 to August 2023

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Questions

- What is the minimum incidence rate of first-time hospitalizations for anorexia nervosa (AN) among children and adolescents during the COVID-19 pandemic, as compared to the three years prior to the pandemic?
- What are the clinical features and COVID-19 pandemic risk factors associated with hospital admissions for a first presentation of a primary diagnosis of AN during the COVID-19 pandemic?

Importance

- AN is a serious mental illness with significant, life-threatening medical and psychiatric morbidity and mortality.
- The COVID-19 pandemic has had significant impact on new cases of children and adolescents with AN across Canada and globally.
- Paediatricians across Canada are seeing increased numbers of children and adolescents with AN presenting to their practices. The exact cause of this increase is unknown.
- This study will address an important and timely paediatric health issue with significant scientific and public health importance by providing valuable data on the incidence, clinical characteristics, severity, and key individual, family system, and other pandemic-related factors thought to drive the observed increase in the number and severity of children and adolescents with AN presenting to hospital for care.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

Any patient 11 to 18 years of age (up to their 18th birthday) hospitalized with a primary admitting diagnosis of AN for the first time.

As defined in the *Diagnostic and Statistical Manual for Mental Disorders*, Fifth Edition (DSM-5), a diagnosis of AN requires all three of the following criteria:

1. Restriction of energy intake relative to requirements leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.
2. Intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.
3. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Exclusion criteria

1. Patients hospitalized for weight loss and/or malnutrition, however the:
   a) patient has another DMS-5 diagnosis of an eating disorder (e.g., avoidant restrictive food intake disorder, bulimia nervosa, binge eating disorder)

b) patient's presentation is explained by another medical condition or mental disorder
c) cause of weight loss is indeterminate/uncertain
d) patient has had previous admission(s) to hospital for AN

2. Patients admitted to a partial hospital or day treatment program

3. Patients admitted for a primary reason other than AN

Results – September to December 2021

TABLE 1 – Cases of first-time hospitalizations for AN during COVID-19 pandemic from September 1 to December 31, 2021				
Reported	**Duplicates**	**Excluded**	**Pending**	**Met case definition***
118	1	29	47	41

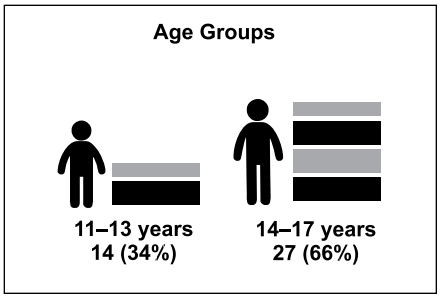
* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

Cases that met the case definition

At the time of analysis (February 25, 2022), 41 cases were verified as meeting the case definition from September 1 to December 31, 2021. An additional 47 cases were pending verification.

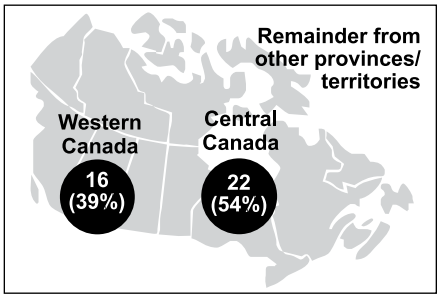
Demographics

- The majority of cases were female (over 90%).
- Cases ranged in age between 11 and 17 years. The mode was 16 years. The majority of cases (27/41, 66%) were aged 14 to 17 years and the rest (14/41, 34%) were aged 11 to 13 years.
- Geographic location was reported as follows: 22/41 (54%) cases were from Central Canada, 16/41 (39%) cases were from Western Canada, and the remainder were from other provinces/territories.
- The majority of cases (25/41, 61%) were admitted to a general paediatric ward and 9/41 (22%) were admitted to a specialized paediatric eating disorders unit.



Presentation and diagnosis

- The COVID-19 pandemic was identified by the reporting physician as a precipitating factor in the development of AN in 20/41 (49%) cases.
- The COVID-19 pandemic was identified by the reporting physician as having precipitated the hospitalization in 15/41 (37%) cases.



Study limitations

- Limitations common to all CPSP studies are listed on page 11
- This is a preliminary analysis of a newly launched study and some centres may not yet have reported all of their cases.
- The methodology is reliant on children and their families accessing paediatric medical care and the diagnosis being made accurately and appropriately in this setting.
- Recognizing that this study is cross sectional, it will not provide information about the medical and psychiatric treatment responses, long-term health service usage, and prognosis.

Conclusions

- The COVID-19 pandemic was identified to be a precipitating factor in the development of AN in almost 50% of children and adolescents reported to the study.
- The COVID-19 pandemic was identified as having precipitated the hospitalization in more than a third of cases.
- The majority of hospitalized patients with a first-time diagnosis of AN were female, 14 to 17 years old, and admitted to a general paediatric unit.

Anticipated study impact

- This study will establish a minimum incidence of first-time hospitalizations for AN in children and adolescents in Canada during the pandemic.

- This study will provide needed information on the clinical presentation and potential precipitating factors of first-time hospitalizations for AN in children and adolescents during the pandemic.
- Study results will provide important data that will facilitate the implementation of prevention strategies and best ways to adapt, modify, and deliver needed services to support children and adolescents with AN and their families during this pandemic and in the case of future public health emergencies.

Publication and dissemination

Surge on surge: Eating disorders and the COVID pandemic, Vyver E, Katzman DK, Canadian Paediatric Society Grand Rounds, virtually, March 16, 2021 (oral presentation)

Acknowledgements
Thank you to all the collaborating Canadian paediatric eating disorder programs, the CPSP, and CPSP participants. We gratefully acknowledge funding for this study from the CPSP. We also thank the Public Health Agency of Canada for their contributions and support of this work.

Frequency and impact of PANDAS/PANS diagnosis

Study duration: December 2019 to November 2021 – Final report

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Question

What is the frequency and impact of applying the diagnostic label of PANDAS (paediatric autoimmune neuropsychiatric disorders associated with streptococcal infection)/PANS (paediatric acute-onset neuropsychiatric syndrome) in children in Canada?

Importance

- PANDAS/PANS is an acute, debilitating neuropsychiatric syndrome with significant impacts on children, families, and health care utilization.
- There are challenges in the application of the current PANDAS/PANS diagnostic criteria and the true frequency of the diagnosis is unknown.
- Practice patterns related to the clinical assessment, diagnosis, and treatment of paediatric patients diagnosed with PANDAS/PANS in Canada are poorly understood.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/concluded-studies.

Case definition

Any child between the ages of 3 years and 18 years (up to the 18th birthday), seen in the previous month who has received* the diagnostic label of PANDAS or PANS.

* The diagnosis was given by any health care provider (generalist, specialist, subspecialist, allied health care provider, or complementary/alternative health care provider) or a family member.

Unique to this study

- Unlike traditional Canadian Paediatric Surveillance Program (CPSP) studies that identify and examine characteristics associated with a specific and confirmed disease or condition, this study attempts to define the minimum incidence of children who have received the diagnostic label of PANDAS or PANS (as applied by a medical professional or by a family member). It is the diagnostic label, and not the diagnosis, per se, that is under active study.
- This study included targeted outreach to certain specialist/subspecialist groups (including child psychiatrists, paediatric neurologists, and paediatric rheumatologists) as well as specialized clinics known to be referral centres for suspected PANDAS/PANS cases.

Results – December 2019 to November 2021

Note: These results are a snapshot as of May 2, 2022 and should be considered preliminary. Due to reporting delays, more cases are expected to be included in the study's final analysis.

TABLE 1 – Cases of PANDAS/PANS diagnosis from December 1, 2019 to November 30, 2021

Year	Reported	Duplicates	Excluded	Pending	Met case definition‡
2019*	12	0	0	1	11
2020	39	0	3	4	32
2021†	48	1	3	3	41
Total	**99**	**1**	**6**	**8**	**84**

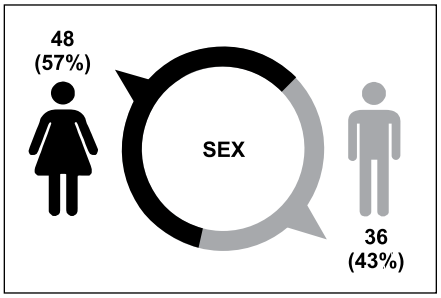
* December 1 to 31, 2019
† January 1 to November 20, 2021
‡ Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis, unless reported from a centre with project-specific research ethics board approval. Cases reported through the following centres were included in the data analysis for this report: CHU Sainte-Justine, Montreal Children's Hospital, CHU de Sherbrooke, and CHU de Québec-Université Laval and Centre mère-enfant Soleil.

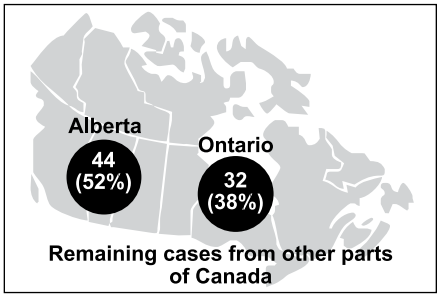
Cases that met the case definition

At the time of analysis, 84 cases with the diagnostic label of PANDAS/PANS were verified as meeting the case definition between December 1, 2019 and November 30, 2021. An additional eight cases were pending verification.

Demographics

- Over half (48/84, 57%) of cases were female.
- The mean age of cases was 9.4 years (SD=3.12).
- Most cases were from Alberta (44/84, 52%) and Ontario (32/84, 38%).





Presentation and diagnosis

- Of the 84 cases, 59 (70%) had one or more pre-existing conditions, with the most common being anxiety/depression (24/84, 31%).
- Most cases presented with at least one neuro-behavioural symptom (e.g., anxiety, depression, hyperactivity) (81/84, 96%) or obsessive-compulsive symptom (e.g., checking/counting, ordering/list making/rituals) (62/84, 74%) and/or abnormal movement (e.g., choreiform movements, tics) (34/84, 40%).
- The most frequently reported symptoms were: emotional lability (67/84, 80%), irritability (63/84, 75%), and anxiety (60/84, 71%).
- In 77% (63/82) of cases, the pace of symptom onset was gradual, with a reported progression from no symptoms to severe symptoms over a period of greater than 48 hours.
- In the majority of cases, there was no microbiologically confirmed group A streptococcal (GAS) infection or other documented infection, either at symptom onset (61/73, 84%; 67/77, 87%) or at the time of symptom exacerbation (58/70, 83%; 45/69 65%).
- Additional medical evaluations commonly completed were bloodwork (i.e., any of complete blood count, erythrocyte sedimentation rate, C-reactive protein, antinuclear antibodies; 56/84, 67%), neuroimaging (i.e., computerized tomography or magnetic resonance imaging of the head; 20/84, 24%), and electroencephalogram (17/84, 20%).

Treatment and outcomes

- Approximately three quarters (52/68, 76%) of cases reported having had five or more health care visits since the onset of symptoms, and over one quarter (24/78, 31%) of cases were involved with more than five different health care providers.
- Significant negative impacts since symptom onset were reported in the following domains: new or increased intra-family stress, mental health concerns, or conflict (54/84, 64%); school absences (43/84, 51%); and withdrawal from social activities/friends (33/84, 39%).
- Eighty-two percent (69/84) of cases received at least one course of antibiotics, which were most frequently prescribed for treatment of GAS infection (41/84, 49%) and prophylaxis for GAS infection (20/84, 24%).
- The most common anti-inflammatory/immune modulating treatment prescribed was non-steroidal anti-inflammatory drugs (42/84, 50%).

- Psychological treatment and psychotropic medication were provided in 54% (45/84) and 38% (32/84) of cases, respectively.
- In forty-one percent (33/81) of cases, there was a significant discrepancy in the degree of certainty about the diagnosis of PANDAS/PANS, with patients' families feeling more certain about the diagnosis than the reporting physicians.

Study limitations

Limitations common to all CPSP studies are listed on page 11.

Conclusions

- There was high health care utilization among patients who received a diagnostic label of PANDAS/PANS, including a significant number of health care visits, diagnostic tests, treatments (including antibiotics in the absence of documented GAS infection), as well as care by multiple health care providers.
- Psychological therapies and psychotropic medications for behavioural or mental health symptoms were not consistently prescribed to patients with a PANDAS/PANS diagnosis.
- Results suggest a high level of discordance in diagnostic certainty between clinicians and families.

Anticipated study impact

- This study improves the understanding of how frequently the PANDAS/PANS diagnosis is being applied to children in Canada and helps to describe the clinical features of children receiving the diagnosis and the associated burden for children, families, health care providers, and the health care system.
- Study results will impact awareness, education, and clinical practice related to PANDAS/PANS.

Micronutrient deficiencies and autism spectrum disorder

Study duration: January 2020 to December 2022

Laura Kinlin

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Questions

- Among children and youth with autism spectrum disorder (ASD) in Canada, what is the minimum incidence of specific micronutrient deficiencies (vitamin A deficiency/xerophthalmia; scurvy; severe, symptomatic vitamin D deficiency; and severe iron deficiency anemia)?
- What clinical characteristics, use of health care services, and health complications are associated with micronutrient deficiencies in children and youth with ASD in Canada?

Importance

- The incidence of micronutrient deficiencies in children and youth with ASD in Canada is unknown.
- Better understanding the burden of serious micronutrient deficiencies in children and youth with ASD will inform anticipatory guidance, screening, and prevention strategies in this population.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

All children and youth less than 18 years of age (up to their 18th birthday) with autism spectrum disorder **AND** a new diagnosis of one or more of the following micronutrient deficiencies:

- Vitamin A deficiency/xerophthalmia
- Scurvy
- Severe, symptomatic vitamin D deficiency
- Severe iron-deficiency anemia

The patient's autism spectrum disorder must have been diagnosed by a general paediatrician, developmental paediatrician, psychiatrist, or psychologist. Definitions for the micronutrient deficiencies and laboratory reference ranges can be found in Appendix 1 of the study protocol.

Results – January to December 2021

TABLE 1 – Micronutrient deficiency and ASD cases in 2021

Reported	Duplicates	Excluded	Pending	Met case definition*
28	1	6	13	8

* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

Cases that met the case definition

- At the time of analysis (January 2022), eight children and youth with micronutrient deficiency and ASD were verified as meeting the case definition from January 1 to December 31, 2021. An additional 13 cases were pending verification.

- The majority of patients met the case definition for only one of the four micronutrient deficiencies under surveillance; however, some patients had more than one of the deficiencies. Among the eight patients, there were 12 diagnoses of micronutrient deficiency.
- Each of the four specific micronutrient deficiencies under surveillance was reported in fewer than five patients. Scurvy and severe iron deficiency anemia were the most commonly reported, with vitamin A deficiency/xerophthalmia and severe, symptomatic vitamin D deficiency reported less frequently.

Demographics
- All patients (8/8) were male, which may reflect that ASD is more common in males than females.
- The median age of patients was 5.5 years (range 1.8–9.8 years).

Presentation and diagnosis
- All patients (8/8, 100%) were deemed to have a restricted diet/limited food repertoire. In all cases (8/8, 100%), the reporting physician attributed the restricted diet/limited food repertoire to the patient himself/herself (e.g., picky eater, unwilling to try new foods).
- For the majority of patients, the total number of different foods in the patient's diet was less than 10.
- Nearly all of the patients (7/8, 88%) were reported as being non-verbal (i.e., using no spoken language or only a few spoken words).
- Very few patients had medical conditions other than ASD, and none had food allergies/intolerances diagnosed by a medical professional.
- It was uncommon for patients to be receiving vitamins, herbals and/or supplements at the time of micronutrient deficiency diagnosis.
- Nearly all of the patients (6/8, 75%) had a height and weight measured at the time of micronutrient deficiency diagnosis. Based on the reporting physician's classification of weight status or growth measurements, most patients (5/8, 63%) were of normal/healthy weight.
- In all patients (8/8, 100%), the micronutrient deficiency was first diagnosed by a general paediatrician.

Treatment and outcomes
- Most patients (6/8, 75%) were admitted to hospital either for investigations leading to diagnosis of their micronutrient deficiency, or for management. The median duration of admission was nine days (range 4–18 days).
- Of the six patients admitted to hospital, a minority underwent an invasive procedure as part of their diagnostic workup (e.g., bone marrow aspiration, general anesthetic for imaging).
- All patients (8/8, 100%) were treated via administration of enteral vitamins. Other additional treatments were sometimes used.
- No deaths or serious, permanent sequelae were reported, although the timing of reporting may limit respondents' ability to comment on long-term effects of micronutrient deficiencies.

Study limitations
- Limitations common to all Canadian Paediatric Surveillance Program (CPSP) studies are listed on page 11.
- Given the relatively small number of reported cases and the relatively brief duration of surveillance, these results should be interpreted with caution; this CPSP study will continue until December 2022.

Conclusions
- From January to December 2021, eight children and youth with ASD were verified as meeting the case definition for one or more of the following micronutrient deficiencies: vitamin A deficiency/xerophthalmia; scurvy; severe, symptomatic vitamin D deficiency; or severe iron deficiency anemia. Follow-up of pending cases is ongoing.
- These eight patients with micronutrient deficiency and ASD suggest that:
  - Very restricted diet/limited food repertoire is common in cases of micronutrient deficiency, and this dietary restriction is related to the preferences and choices of the child or youth.
  - Weight status and micronutrient status are not synonymous; a child or youth with a micronutrient deficiency may not be underweight.
  - Hospital admission is not uncommon in children and youth with ASD and micronutrient deficiency.

Anticipated study impact
- This study is the first to evaluate the minimum incidence of micronutrient deficiencies in children and youth with ASD in Canada.
- Ongoing surveillance will help to identify clinical characteristics, use of health care services, and health complications associated with micronutrient deficiencies in children and youth with ASD.
- Results will inform anticipatory guidance, screening, and prevention strategies in this population.

Publication and dissemination
Micronutrient deficiencies in autism spectrum disorder: A macro problem? Kinlin LM, Birken CS. *Paediatr Child Health* 2021 Jun 5;26(7):436-7. doi: 10.1093/pch/pxab032. eCollection 2021 Nov

Acknowledgements
We are grateful to Melanie Laffin Thibodeau and Melanie King, for their assistance with study coordination and management. We recognize the ongoing demands associated with the COVID-19 pandemic and sincerely thank physicians who reported cases, for their time and effort.

Optic nerve hypoplasia and septo-optic dysplasia

Study duration: November 2021 to October 2022

Brandy Wicklow

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Questions

- What is the minimum incidence of optic nerve hypoplasia (ONH) and septo-optic dysplasia (SOD) in children from 0–17 years of age in Canada?
- What are the prenatal risk factors for developing ONH?
- What is the incidence of pituitary hormone dysfunction (PHD) at diagnosis in patients with ONH/SOD and what is the specific pattern of hormone deficiency?
- What risk factors are associated with the presence of PHD at diagnosis of ONH/SOD?

Importance

- A better understanding of the incidence and risk factors associated with ONH and SOD in children, as well as the presence of PHD, will inform clinical guidance, screening, and prevention strategies.
- PHD is a common finding in children with SOD and can be associated with significant morbidity if not detected early.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

Optic nerve hypoplasia (ONH) and septo-optic dysplasia (SOD) diagnoses are along a continuum. Patients are classified as having ONH when hypoplasia of the optic nerves is an isolated finding and as SOD when there are two or more of the following findings: hypoplasia of the optic nerves, pituitary hormone dysfunction (PHD), and/or midline abnormalities of the brain. A case of ONH can progress into a case of SOD, or clinical evidence of PHD can lead to a diagnosis of SOD, if ONH is present on ophthalmologic examination or magnetic resonance imaging (MRI).

All patients less than 18 years of age (up to their 18th birthday) with a new diagnosis of any one of the following:

1. Isolated ONH*
2. SOD, defined as two or more of the following findings:
   a) ONH
   b) PHD†
   c) Midline abnormalities of the brain (including agenesis of the septum pellucidum and/or corpus callosum on brain imaging)
3. PHD† in a patient known to have ONH
4. ONH reported as a component of a complex genetic syndrome

* ONH is defined as hypoplasia of the optic nerves confirmed by an ophthalmologist's evaluation indicating the presence of the double ring sign on direct ophthalmoscopy and/or nerve diameter <1.5 mm and/or MRI findings reported by a paediatric radiologist.

† PHD is defined as one or more of the following hormone deficiencies, based on laboratory testing supported by clinical symptoms and physical examination:
- Growth hormone (GH)
- Adrenocorticotropic hormone (ACTH)
- Thyroid stimulating hormone (TSH)
- Antidiuretic hormone (ADH)
- Luteinizing hormone (LH)
- Follicular stimulating hormone (FSH)

Exclusion criteria
ONH thought to be associated with other postnatal events such as retinopathy of prematurity

Results – November to December 2021

TABLE 1 – ONH and SOD cases from November 1 to December 31, 2021				
Reported	**Duplicates**	**Excluded**	**Pending**	**Met case definition***
<5	0	0	<5	<5

* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

Cases that met the case definition
At the time of analysis, fewer than five cases were verified as meeting the case definition for ONH and SOD from November 1 to December 31, 2021. Of note, surveillance was active for only two months in 2021.

Demographics
As per Canadian Paediatric Surveillance Program (CPSP) policy, case numbers and data for fewer than five cases cannot be presented.

Presentation and diagnosis, treatment, and outcomes
Specific information on this study cannot be presented at this time due to the small number of cases.

Study limitations
Limitations common to all CPSP studies are listed on page 11.

Conclusions

- Fewer than five cases were reported and verified as meeting the case definition for ONH and SOD in the first two months of this study.
- More time is required before conclusions can be drawn. A greater number of cases will allow for a better understanding of the minimum incidence and risk factors associated with ONH and SOD in children in Canada.

Anticipated study impact

- The study will provide Canadian-specific data regarding the incidence rates of ONH and SOD in children and will identify risk factors associated with PHD.
- Study results will inform clinical guidance, screening, and prevention strategies.

Paediatric-onset leukodystrophies

Study duration: December 2019 to November 2022


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Questions

- What is the minimum incidence of paediatric-onset leukodystrophies (LD) in Canada?
- What are the patterns of presentation, clinical features, comorbidities, and diagnostic journeys of children and youth with different types of LD?

Importance

- Determining the minimum incidence of paediatric-onset LD in Canada will provide information that will help with more effective planning of services to children and youth with this condition, and help families and health care practitioners more effectively advocate for this vulnerable group of patients.
- By determining the proportion of children with each specific LD, diagnostic protocols and educational programming can be developed to enhance clinical care.
- This study will be foundational for the development of national and international collaborative studies on the natural history and pathobiology of LD, which will serve as a step towards future therapeutic developments.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

All children and youth less than 18 years of age (up to their 18th birthday) with a new diagnosis of a leukodystrophy, defined as a genetically* determined disorder characterized by primary involvement of the white matter. Disorders characterized as leukodystrophies include, but are not limited to, the following (non-exhaustive list):

- Pol-III related disorders (4H syndrome (hypomyelination, hypodontia, and hypogonadotropic hypogonadism))
- 18q minus syndrome
- X-linked adrenoleukodystrophy (X-ALD)
- Adult-onset leukodystrophy with neuroaxonal spheroids and pigmented glia (including hereditary diffuse leukoencephalopathy with spheroids, HDLS, and pigmentary type of orthochromatic leukodystrophy with pigmented glia, POLD)
- Aicardi-Goutières syndrome (AGS)
- Alexander disease (AxD)
- Autosomal dominant leukodystrophy with autonomic disease (ADLD)
- Canavan disease
- Cerebrotendinous xanthomatosis (CTX)
- Chloride ion channel 2 (CIC-2) related leukoencephalopathy with intramyelinic oedema
- eIF2B related disorder (vanishing white matter disease or childhood ataxia with central nervous system hypomyelination (CACH))
- Fucosidosis
- Globoid cell leukodystrophy (Krabbe disease)
- Hypomyelination with atrophy of the basal ganglia and cerebellum (H-ABC)
- Hypomyelination with brainstem and spinal cord involvement and leg spasticity (HBSL)

- Hypomyelination with congenital cataract (HCC)
- Leukoencephalopathy with brainstem and spinal cord involvement and lactate elevation (LBSL)
- Leukoencephalopathy with thalamus and brainstem involvement and high lactate (LTBL)
- Megalencephalic leukoencephalopathy with subcortical cysts (MLC)
- Metachromatic leukodystrophy (MLD) and its biochemical variants
- Oculodentodigital dysplasia
- Pelizaeus-Merzbacher disease (PMD)
- Pelizaeus-Merzbacher-like disease (PMLD)
- Peroxisomal biogenesis disorders (including Zellweger, neonatal adrenoleukodystrophy, and infantile Refsum)
- Polyglucosan body disease (PGBD)
- RNAse T2 deficient leukoencephalopathy
- Sialic acid storage disorders (Salla disease, infantile sialic acid storage disease and intermediate form)
- Single enzyme deficiencies of peroxisomal fatty acid beta oxidation (including only D-bifunctional protein deficiency; sterol carrier protein X (SCPx) deficiency; peroxisomal acyl-CoA-oxidase deficiency)
- Sjögren-Larsson syndrome
- SOX10-associated PCWH: peripheral demyelinating neuropathy, central dysmyelinating leukodystrophy, Waardenburg syndrome, and Hirschsprung disease

* For information on the availability of and access to genetic testing in your region, refer to the list of study principal investigators/co-investigators at the beginning of the study protocol and contact the one who is located closest to your practice.

Results – January to December 2021

TABLE 1 – Paediatric-onset LD cases in 2021

Reported	Duplicates	Excluded	Pending	Met case definition*
21	0	0	8	13

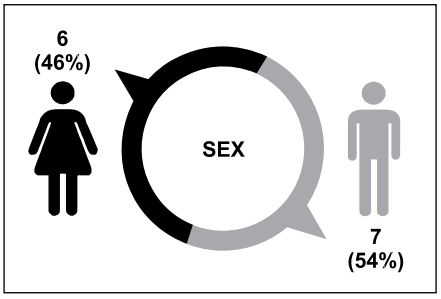
* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

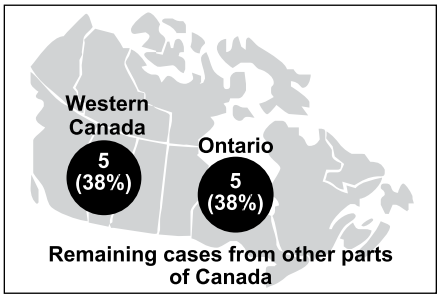
Cases that met the case definition

At the time of analysis, a total of 13 new cases of paediatric-onset LD were verified as meeting the case definition from January 1 to December 31, 2021. An additional eight cases were pending verification.

Demographics

- Patient sex was reported as 7/13 (54%) males and 6/13 (46%) females.
- The geographic distribution of cases was 5/13 (38%) from Ontario, 5/13 (38%) from Western Canada, and the remaining cases from other parts of Canada.





Presentation and diagnosis

- The most common symptoms at presentation included the following: abnormal muscle tone (6/13, 46%), feeding issues (6/13, 46%), global developmental delay (5/13, 38%), and developmental regression (5/13, 38%). Fewer than five cases had seizures or behavioural changes. Multiple symptoms were seen in the majority of patients at presentation.
- The following LD diagnoses were reported: metachromatic leukodystrophy, globoid cell leukodystrophy (Krabbe disease), multiple sulfatase deficiency, Pelizaeus-Merzbacher disease, X-linked adrenoleukodystrophy, mitochondrial leukoencephalopathy, Cockayne syndrome, and *TUBB4A*-related leukodystrophy.
- LD diagnoses were made most frequently via whole exome sequencing. The remaining cases were diagnosed using chromosomal microarray, single gene testing, family history.
- LD diagnoses were made on average 13.5 months after presentation to medical attention.

Study limitations

- Limitations common to all Canadian Paediatric Surveillance Program (CPSP) studies are listed on page 11.
- Due to COVID-19 restrictions, in-person patient visits and access to diagnostic tests may have been limited.

Conclusions

- After presenting to medical attention, diagnosis of more common peadiatric-onset LD took an average of 13 months. While patients with paediatric-onset LD received indicated health care services once they presented to medical attention, early diagnosis allows for optimal management. Disease-specific treatments (e.g., bone marrow transplant, gene therapy), where available, can be provided once a genetic diagnosis is obtained.
- These conditions continue to be challenging to manage for both the patient and the health care provider due to the patient's medical and psychosocial complexity, lack of resources, lack of awareness of clinical care guidelines, and the need for multiple subspecialists.

Anticipated study impact

- Study results will assist with developing knowledge translation activities to educate child health care providers about the types of LD, the various presentations, and the needs of children with LD. Increasing awareness about the current diagnostic journey of children and youth with LD, may lead to improvements in timely diagnosis and the early implementation of potential therapies.
- The collaboration of interested paediatricians and subspecialists from across the country in this study may set the foundation for expanding the Canadian Paediatric Genetically-determined White Matter Diseases Network and creating LD centres of excellence across Canada, in collaboration with health care decision makers. Ultimately, this work may lead to the development of a prospective Canadian LD registry to study longitudinal cohorts and determine natural history, morbidity, and mortality rates of LD.
- Study results could contribute to the development of standardized clinical management guidelines for LD relevant to the Canadian population.

Paediatric pulmonary thromboembolism

Study duration: January 2020 to December 2022

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Principal investigators

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Questions

- What is the minimum incidence of pulmonary thromboembolism in the Canadian paediatric population, and what are the associated demographics and geographic distribution?
- What is the clinical presentation of paediatric pulmonary thromboembolism, and what are the risk factors and short-term outcomes?
- What diagnostic modalities and therapeutic interventions are chosen by clinicians?

Importance

- Pulmonary thromboembolism is a rare but life-threatening event, with very little known about the epidemiology and presenting characteristics in the paediatric population.
- Variability exists in diagnosis and management.
- Improved knowledge of the incidence, presentation, and risk factors can help to promote early detection and diagnosis, and improve management and outcomes.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

Any patient up to their 18th birthday+ with a new diagnosis of confirmed or suspected pulmonary thromboembolism. Pulmonary thromboembolism is defined as in situ thrombus or embolism, including fragments and fat embolism, situated anywhere in the pulmonary arterial circulation from the right ventricle (RV), through the outflow tract, to the peripheral and subsegmental regions of the pulmonary arteries. Report patients including, but not limited to, asymptomatic patients, post-operative patients, pregnant or recently pregnant patients, and deceased patients.

Confirmed pulmonary thromboembolism – patient fulfills one of four criteria:

1. Pulmonary thromboembolism diagnosed on computerized tomography (CT) pulmonary angiography **OR** conventional pulmonary angiography **OR** magnetic resonance imaging/magnetic resonance pulmonary angiography
2. Ventilation–perfusion (V/Q) scan reporting high probability of pulmonary thromboembolism
3. Echocardiogram demonstrating thrombus in the RV **OR** outflow tract **OR** main pulmonary artery/branch pulmonary arteries **OR** in transit
4. Pulmonary thromboembolism identified on autopsy

Suspected pulmonary embolism – patient fulfills one of two criteria:

1. Clinical suspicion of pulmonary thromboembolism **AND** V/Q scan reporting intermediate probability of pulmonary thromboembolism
2. Clinical suspicion of pulmonary thromboembolism **AND** echocardiogram demonstrating RV dysfunction with no other explanation

Unique to this study

Initially this study was limited to patients up to their 16th birthday. An amendment was accepted by the research ethics board to allow for broadening the case definition to include patients up to their 18th birthday, with retrospective reporting allowed for cases identified since study onset.

Results – January 2020 to December 2021

TABLE 1 – Paediatric pulmonary thromboembolism cases from January 1, 2020 to December 31, 2021*				
Reported	**Duplicates**	**Excluded**	**Pending**	**Met case definition†**
35	0	6	19	10

* Because of the rarity of this condition, the decision was made to present the data for both 2020 and 2021, to allow for the presentation of some study results in this interim report.

† Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

Cases that met the case definition

At the time of analysis, 10 cases of paediatric pulmonary thromboembolism were verified as meeting the case definition from January 1, 2020 to December 31, 2021. An additional 19 cases were pending verification.

Demographics

- Cases were predominantly female (9/10, 90%) and between the ages of 11 to 18 years (8/10, 80%).
- At least one risk factor was present in 8/10 (80%) patients; none had a history of thromboembolic disease.

Presentation and diagnosis

- Almost all cases were symptomatic (9/10, 90%), most commonly presenting with tachycardia (6/10, 60%) and/or tachypnea (5/10, 50%).
- The most common diagnostic modality used was CT pulmonary angiogram (6/10, 60%).

Treatment and outcomes

- The majority of cases (8/10, 80%) were treated medically, all (8/8, 100%) of which were treated with either unfractionated or low molecular weight heparin.
- Fewer than five deaths were reported during the study period and none were attributed to treatment complications.

Study limitations

Limitations common to all Canadian Paediatric Surveillance Program (CPSP) studies are listed on page 11.

Conclusions

- Adolescents accounted for the majority of paediatric pulmonary thromboembolism cases in Canada.
- Individual risk factors were variable, but at least one risk factor was almost always present.
- Systemic anticoagulation was the most commonly administered therapy.

Anticipated study impact

- This study will provide Canadian-specific data on the epidemiology, presentation, and outcomes of paediatric pulmonary thromboembolism, and how clinicians diagnose and manage this condition.
- This information may be useful for the development of a practice point for clinicians.

Acknowledgements

Thank you to Julien Gallant, Research Coordinator, Department of Paediatric Critical Care, IWK Health Centre, for his involvement in this study's start-up, analysis, and reporting.

Serious adverse events related to cannabis used for medical purposes

Study duration: December 2019 to November 2022

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Principal investigators

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Collaborators

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Questions

- What are the clinical characteristics of serious adverse events (SAEs) related to cannabis used for medical purposes in children, including indications for use and concomitant medications?
- How were SAEs associated with intentional cannabis exposure identified and managed?
- What are the outcomes following SAEs related to cannabis or cannabis products used for medical purposes (with or without a medical authorization) in children and adolescents in Canada?

Importance

- While Health Canada has not approved any product containing cannabinoids for use by children or youth, cannabis for medical purposes is currently used for a variety of conditions, including nausea and vomiting in children with cancer, drug-resistant seizure disorders, and refractory spasticity.
- There is little real-world Canadian data on SAEs in children using cannabis or cannabis products for medical purposes and limited knowledge about associated products, indications, and adverse events.
- There is also limited scientific evidence on the clinical characteristics, management, and outcomes following SAEs in children and youth exposed to cannabis or cannabis products used for medical purposes.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

Any serious or life-threatening adverse event* in a child up to 18 years of age related to the intentional use of cannabis for medical purposes.† Report an adverse event even if there is not certainty it is related to the use of cannabis. Include any cannabis product from a licensed producer or private producer (home grown) such as dried cannabis to be smoked or vaporized, oils to be ingested or applied topically, and cannabis products taken by any other route of administration.

* A serious or life-threatening adverse event is defined as a noxious and unintended severe response to a drug which occurs at any dose and results in emergency observation, hospitalization, persistent or significant disability, or death.

† Cannabinoids or cannabis used for medical purposes is defined as intentional cannabis use for any self-reported (or parent reported) health reasons, with or without physician authorization.

Exclusion criteria

- Adverse events resulting from non-medical cannabinoid/cannabis use
- Adverse events resulting from accidental/unintentional cannabinoid/cannabis exposure (even if being used for medical purposes by another individual in the home)

Results – January to December 2021

TABLE 1 – SAEs related to cannabis used for medical purposes cases in 2021				
Reported	**Duplicates**	**Excluded**	**Pending**	**Met case definition***
<5	0	0	0	<5

* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

Cases that met the case definition
Fewer than five cases were verified as meeting the case definition in Canada from January 1 to December 31, 2021.

Demographics
As per Canadian Paediatric Surveillance Program (CPSP) policy, case numbers and data for fewer than five cases cannot be presented.

Presentation, diagnosis, treatment, and outcomes
Specific information on this study cannot be presented due to the small number of cases.

Study limitations
Limitations common to all CPSP studies are listed on page 11.

Conclusions

- Fewer than five cases were reported and verified as meeting the case definition for this study in 2021.
- This study will continue until November 2022 and case reporting will be encouraged and promoted on social media via the Canadian Paediatric Society and the Canadian Childhood Cannabinoids Clinical Trials (C4T).

Anticipated study impact

- This study will provide Canadian-specific paediatric data on the clinical characteristics, management, and outcomes of patients following SAEs related to the use of cannabis and cannabis products for medical purposes.
- The information from this study will be shared directly with Health Canada and may be adapted for professional and public education materials.

Acknowledgements
The investigators would like to thank the physicians who reported cases for this study.

Serious and life-threatening events associated with non-medical (recreational) cannabis use in Canadian children and youth

Study duration: September 2018 to August 2022

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Collaborator

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Questions

- What is the minimum incidence of serious and life-threatening events associated with non-medical use of cannabis in children and youth in Canada?
- What are the clinical presentations and associated medical needs of children and youth presenting with serious and life-threatening events related to non-medical cannabis exposure?
- Are there changes in the incidence of serious and life-threatening events during the four-year period following cannabis legalization?

Importance

- There are currently limited scientific data quantifying the impact of cannabis legalization and regulation on the health of children and youth in Canada.
- Data provided by this study will be used to assess the health impacts of cannabis legalization and regulation in the paediatric population and to inform policy, legislation and regulations, as well as public education and awareness communications.

Methodology

The complete protocol can be accessed at www.cpsp.cps.ca/surveillance/current-studies.

Case definition

Any child or adolescent less than 18 years of age (up to the 18th birthday) presenting with a new health condition or a deteriorating chronic/previously diagnosed condition resulting in either hospitalization (inpatient, intensive care unit, psychiatric), permanent disability, or death, which was likely primarily caused by the use of cannabis for non-medical (recreational) purposes.

This includes either intentional or unintentional exposure to cannabis in a child or adolescent, or a condition resulting from use by another individual, such as a friend or a parent/caregiver, who is under the influence of cannabis.

Exclusion criteria

- A condition resulting from cannabis use for non-medical purposes during pregnancy/breastfeeding
- A condition resulting from cannabis use for medical purposes

Results – January to December 2021

TABLE 1 – Serious and life-threatening events associated with non-medical cannabis use cases in 2021

Reported	Duplicates	Excluded	Pending	Met case definition*
53	0	4	16	33

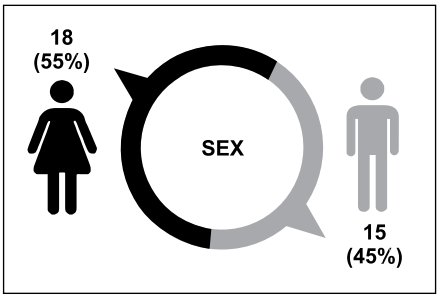
* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis.

Cases that met the case definition

- In total, 53 cases of serious and life-threatening events associated with non-medical use of cannabis among children and youth were reported through the Canadian Paediatric Surveillance Program (CPSP) in 2021.
- At the time of analysis, 33 of these cases were verified as meeting the case definition in 2021. In comparison, 10 cases met the case definition from September to December 2018, 38 cases in 2019, growing to 50 cases in 2020.

Demographics

- Patient sex was female in 18 cases (55%, 95 CI 37–71) and male in 15 cases (45%, 95 CI 29–63).
- The mean age was 7.7 years with a median age of 5.5 years. The majority of cases were 12 years of age and younger (24/33, 73%, 95 CI 55–86).



Presentation and diagnosis

- Again this year, the most common primary presentation was poisoning/intoxication (12/33, 36%, 95 CI 21–54). In the majority of these poisoning/intoxication cases, children aged 12 years and younger had ingested cannabis in edible form (10/12, 83%, 95 CI 48–96). Cannabis-infused gummies were the most frequently reported form of edible cannabis ingested.
- Other case presentations included neurologic problems such as seizure and altered level of consciousness (11/33, 33%, 95 CI 19–51) and cannabis use disorder (DSM-5) (7/33, 21%, 95 CI 10–39). In 8/33 cases (24%, 95 CI 12–42) more than one primary presenting condition was reported.
- Cases from unintentional exposure to cannabis (20/33, 61%, 95 CI 43–76) were found exclusively among children aged 12 years and younger, while cases from intentional exposure (9/33, 27%, 95 CI 14–45) were found exclusively among youth aged 13 years and older. In the remaining four cases, the intent was either unknown or unspecified.
- Overall, more than two-thirds of cases (23/33, 70%, 95 CI 52–83) had ingested cannabis in edible form. However, the majority of cases related to youth aged 13 years and older (8/9, 89%, 95 CI 41–99) had inhaled cannabis by smoking or vaping.
- Consistent with data from previous years, the majority of cases involved cannabis from unknown (23/33, 70%, 95 CI 11–83) or illegal (8/33, 24%, 95 CI 12–42) sources, as reported by the reporting physician. The reported source of cannabis could not be verified.

Treatment and outcomes

- The vast majority of cases were hospitalized (30/33, 91%, 95 CI 74–97): 26/33 cases (79%, 95 CI 70–90) were admitted as inpatients and 6/33 cases (18%, 95 CI 8–36) were admitted to the intensive care unit.
- Physical treatment was received by 22/33 cases (67%, 95 CI 49–81), by diverse modalities, such as intravenous fluids, ventilation assistance, or neurologic investigations/care. Twelve cases (36%, 95 CI 21–54) received mental health treatment (e.g., psychiatry consultation, referral to a social, addiction or youth worker), either exclusively or in addition to physical treatment.

Study limitations

Limitations common to all CPSP studies are listed on page 11.

Conclusions

- Serious and life-threatening events associated with non-medical use of cannabis are occurring among children and youth in Canada, with 33 cases meeting the case definition in 2021. More than two thirds of these cases (23/33, 70%) had ingested cannabis in edible form.
- The most common primary case presentation was poisoning/intoxication (12/33, 36%), the majority of which involved children 12 years and younger and cannabis in edible form (10/12, 83%). This trend will continue to be monitored as the study continues.
- More time is required to determine the impact of cannabis legalization and regulation on child and adolescent health. While the vast majority of cases of serious and life-threatening events associated with non-medical use of cannabis were reported to have involved cannabis from illegal or unknown sources (31/33, 94%), legal edible cannabis products only became available for purchase in late December 2019.

Anticipated study impact

- This study will provide Canadian-specific data on the impact of cannabis legalization and regulation on the health of children and youth. These data may also be used to inform policies, legislation, and regulations related to cannabis for non-medical purposes.
- The information from this study may also be adapted to develop public education and awareness communication materials.

Acknowledgements

Thank you to Sieara Plebon-Huff, Health Canada, and Anna-Maria Frescura, Public Health Agency of Canada, for their involvement in the analysis of the data relating to this project and the writing of this preliminary report.

Severe vaping-related illness and injury

Study duration: February 2021 to January 2022

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Questions

- What is the minimum incidence of severe vaping-related illness or injury among children and youth?
- What are the clinical characteristics, product-level and substance-specific risk factors, comorbidities, and treatment outcomes of children and youth with severe vaping-related illness or injury?

Importance

- According to the 2020–2021 Canadian Tobacco and Nicotine Survey, 14.4% of adolescents 15 to 19 years of age reported vaping in the past 30 days, similar to the proportion reported in the 2019–2020 survey.
- Gaining a better understanding of the specific risk factors and patterns of illness and injury related to vaping products is essential for the development of effective preventive and regulatory measures.

Methodology

The complete protocol can be accessed at www.cpcp.cps.ca/surveillance/current-studies.

Case definition

Any patient less than 18 years of age (up to 18th birthday) requiring emergency department care, hospitalization, or admission to an intensive care unit (ICU) due to an illness or injury associated with any of the following:

1. Inhalation of aerosol from a vaping device (e.g., acute pulmonary injury, serious gastrointestinal symptoms, central nervous system activation/depression, acute nicotine toxicity or withdrawal)
2. Malfunction of a vaping device (e.g., burn, trauma to the eye, hand, and/or face)
3. Ingestion of a vaping substance (e.g., e-liquid with or without nicotine and/or flavours, tetrahydrocannabinol [THC] oil, hash oil)

Exposure to vaping devices/products/substances may be either **intentional** or **unintentional** and includes both primary (i.e., direct use/inhalation) and/or secondary exposures (i.e., exposure to another person's vaping aerosol or injury caused by another person using a vaping device).

Vaping devices include any type of electronic cigarette or similar device that aerosolizes a solid or liquid substance (vaping substance) which may contain some or all of the following: nicotine, cannabis, flavouring agents, and other chemicals.

Unique to this study

- This study follows two previous Canadian Paediatric Surveillance Program (CPSP) one-time surveys on vaping-related illness and injury conducted in 2015 and 2019.
- Study investigators will cross-validate study findings with hospital discharge data obtained from the Canadian Institute for Health Information.

Results – February to December 2021

TABLE 1 – Severe vaping-related illness and injury cases from February 1 to December 31, 2021

Reported	Duplicates	Excluded	Pending	Met case definition*
<5	0	0	0	<5

* Due to Quebec legislation, any cases notified by Quebec participants were counted in the "Reported" column, but detailed case information was not collected and these cases were excluded from the data analysis, unless reported from a centre with project-specific research ethics board approval. Cases reported through the following centres were included in the data analysis for this report: CHU Sainte-Justine, Montreal Children's Hospital, and CHU de Sherbrooke.

Cases that met the case definition
Fewer than five cases were verified as meeting the case definition in Canada from February 1 to December 31, 2021.

Demographics
As per CPSP policy, case numbers and data for fewer than five cases cannot be presented.

Presentation, diagnosis, treatment, and outcomes
Specific information on this study cannot be presented at this time due to the small number of cases.

Study limitations
- Limitations common to all CPSP studies are listed on page 11.
- Cases of severe vaping-related illness or injury that might have presented to outpatient clinics or other non-hospital settings may not have been captured by this study. Similarly, vaping-related illnesses or injuries that did not meet the CPSP case definition of "severe" would also not be captured.

Conclusions

- Very few cases of severe vaping-related injury or illness were reported since study inception, contrasting with the 2015 and 2019 one-time CPSP surveys on vaping-related illness or injuries for which 35 and 88 cases were reported, respectively. Of note, these two previous surveys had slightly different case definitions and also included a small proportion of cases seen in outpatient settings.
- Co-investigators and providers based in several major paediatric centres across the country confirmed very low case numbers of severe vaping-related illness or injury at their centres and noted anecdotally that there seems to have been a decrease in case numbers over the past year.
- Potential explanations for the lower-than-expected case numbers in this study may include an actual decrease in the incidence of vaping-related illness or injury, changes in provincial and federal vaping policies and regulations, increased monitoring and control of vaping products by resellers and manufacturers, and changes in access and use of vaping products by children and youth in the context of the COVID-19 pandemic.

Anticipated study impact

- Given the rapidly evolving landscape of vaping products across the country and high rates of youth vaping, this study has the potential to help identify emerging health hazards associated with vaping products.
- Study results may support the need for further research to measure the impact of vaping-related health risks among children and youth.
- Continuing to collect details on individual cases, including product-level and substance-related information, even in low numbers, may help inform ongoing changes in vaping-related policies and public health preventive measures.

Acknowledgements
The investigators would like to thank the physicians who reported cases for this study.

One-Time Surveys

Identifying child maltreatment during virtual medical appointments

October 2021

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Principal investigators

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Co-investigators

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Questions

- Are Canadian paediatricians identifying child maltreatment in virtual medical appointments?
- How is child maltreatment identified in virtual medical appointments and what are the enabling factors?
- Do virtual medical appointments affect paediatricians' perceived ability to identify child maltreatment?

Importance

- Child maltreatment is an important cause of morbidity and mortality in paediatrics.
- During the COVID-19 pandemic, concerns have emerged regarding potential missed cases of child maltreatment. Evidence of increased hospital admissions related to child maltreatment suggests an increased incidence of child maltreatment despite a documented decline in reports to child protective services.
- Paediatricians play an important role in the identification of child maltreatment. Due to the COVID-19 pandemic, many medical appointments have shifted from in-person appointments to virtual care. The effect of this shift on the identification of child maltreatment is currently unknown.

Methodology

A one-time survey was sent to paediatricians and paediatric subspecialists through the Canadian Paediatric Surveillance Program (CPSP). The survey tool can be accessed at www.cpsp.cps.ca/surveillance/one-time-surveys.

Results

The survey response rate was 34% (928/2770). Of the total number of responses, 76% (704/928) were eligible to be included in the analysis. The remaining responses (n=224) were excluded, because the survey was incomplete, the respondent indicated that s/he did not provide any virtual care, or the respondent had never reported a case of child maltreatment.

Respondents

- The average amount of time respondents had been in independent practice was 17.5 years.
- Most respondents (486/700, 69%) had no experience with virtual care prior to the pandemic.

Identification of child maltreatment

- Prior to the pandemic, 6% (45/704) of respondents had reported at least one case of child maltreatment to child protection authorities following a virtual appointment.
- Since the start of the pandemic, 11% (78/700) of respondents reported at least one case of child maltreatment to child protection authorities following a virtual appointment.

- The number of cases of child maltreatment reported to authorities following a virtual appointment was significantly associated with the number of years the respondent had been in medical practice (p=0.026) but not with the respondent's volume of virtual appointments or prior experience with virtual appointments (p=0.735 and p=0.127, respectively).
- Respondents reported a total of 143 cases to a child protective service following a virtual medical appointment. In nearly one quarter of those cases (34/143, 24%), the physician required a subsequent in-person appointment prior to reporting the case to child protective services.
- The most common factors mentioned by respondents that triggered concern about possible child maltreatment during virtual appointments included the presence of significant social stressors, such as financial difficulty and the home environment, and parental capacity, such as cognitive capacity/mental health and addictions.
- Of the factors that triggered concern, nearly one third (166/524, 32%) were clear disclosures from patients (children/youth), during the virtual appointment.
- No respondents identified the virtual physical exam as contributing to identifying child maltreatment.

Difficulty identifying child maltreatment during virtual appointments

- Identifying child maltreatment was rated as slightly or much more difficult during virtual appointments by 69% (481/700) of respondents.
- There was no significant association between the perceived difficulty of identifying cases of child maltreatment during a virtual appointment and the number of child maltreatment cases reported by the respondent (Cramér's V=0.096).
- The largest barrier to identifying child maltreatment in virtual medical appointments was a lack of interaction with the patient (251/596, 42%), including the inability to perform a physical examination (214/596, 36%). Another issue identified was privacy and confidentiality in a virtual setting, as some physicians felt unsure whether the patient had a private space for their virtual appointment (58/596, 10%). The benefit of being able to observe the family in their own home environment was appreciated by 7% (39/596) of responding physicians.
- Concerns that a case of child maltreatment had been identified late, or missed, following a virtual care appointment were reported by 32% (207/648) of respondents, with 4% (28/704) commenting on a known case of clear harm to a child within their practice.

Survey limitations

- Limitations common to all CPSP surveys are listed on page 11.
- CPSP one-time survey data is collected from multiple respondents and duplicate cases cannot be identified; therefore, it is possible that some of the cases of possible or confirmed child maltreatment identified during a virtual appointment were counted more than once.

Conclusions

- The majority of survey respondents felt that identifying child maltreatment was more difficult during virtual appointments than in person, with barriers notable for a lack of interaction, physical exam, and confidential spaces.
- The number of years in medical practice may be an important mitigating factor.
- Social factors, parental capacity, and clear disclosures from patients constituted the majority of reports to child protective services. The virtual physical exam was not influential in any case.
- This survey reveals that virtual care may be an important factor in missed cases of child maltreatment and that the provision of virtual care presents challenges in the timely identification of child maltreatment.

Anticipated survey impact

- This work is the first step in developing an approach to help physicians to identify child maltreatment during a virtual care appointment.
- Given concerns about the difficulty identifying child maltreatment during virtual appointments, survey results may inform policy decisions about whether there is a need to prioritize a return to in-person services for the paediatric population.

Acknowledgements
Thank you to the CPSP for the survey opportunity through the Resident Surveillance Grant.

Impacts of the COVID-19 pandemic on children with medical complexity

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Question

What are the impacts of the COVID-19 pandemic on children with medical complexity (CMC) and their families?

Importance

- As a direct consequence of COVID-19 pandemic restrictions, CMC have experienced multiple disruptions in their care, including disruption of medical and specialist care, therapy and rehabilitative services, home care, respite services, and education.
- This is the first known survey in Canada designed to explore the specific effects and adverse outcomes associated with the disruption of services to CMC during the pandemic.

Methodology

A one-time survey was sent to paediatricians and paediatric subspecialists through the Canadian Paediatric Surveillance Program (CPSP). The survey tool can be accessed at www.cpsp.cps.ca/surveillance/one-time-surveys.

Results

The survey response rate was 28% (784/2826), with 69% (540/784) of respondents indicating that they provide care to CMC. The following results pertain only to the 540 respondents who provided care to CMC.

Impact of pandemic-related health care delivery disruptions

- Sixty-seven (12%) respondents reported having encountered a CMC with an adverse health outcome due to a COVID-19 pandemic-related disruption in health care delivery in the past 12 months. These respondents reported 546 events, with a median number of three events per respondent (interquartile range [IQR] 1–10).
- Respondents reported the following adverse health outcomes for CMC as being due to a COVID-19 pandemic-related disruption in health care delivery: 26/540 (5%) reported patients requiring hospital admission, 22/540 (4%) reported patients with a loss of physical or developmental gains, 12/540 (2%) reported patients requiring extended hospital stays, and 6/540 (1%) saw patients admitted to an intensive care unit.
- Other adverse health outcomes seen by respondents included the following: delayed presentation to health care or deferral of care because of the perceived risk of exposure to SARS-CoV-2 at a tertiary care centre, observed slowing of developmental gains, reduced provision of health surveillance, delays in accessing elective procedures, and challenges associated with hospital visitation policies.
- Disruption of the supply of medication and equipment for CMC was reported by 12% (64/540) of respondents.
- Respondents also reported that CMC experienced interruptions in family caregiving (252/540, 47%) and home care delivery (218/540, 40%).

Perceived benefits of COVID-related changes in health care delivery to CMC

- Importantly, 47% (253/540) of respondents observed a benefit to CMC due to COVID-19 pandemic-related changes in health care delivery.

- Perceived benefits included the increased availability of virtual care and its associated benefits (e.g., reduced travel time and costs associated with hospital visits), health system changes that support the provision of virtual care (e.g., development of specific billing codes, supportive technology), and the reduction in seasonal respiratory illness.

Education and school supports

- Some respondents (78/540, 14%) reported that they had seen CMC who were excluded from in-person learning as compared to peers without medical complexity who were given the option to attend class.
- Reasons for exclusions included public health advice that precluded their attendance (e.g., advice on the management of aerosol-generating medical procedures [n=6] or CMC being residents in long-term care facilities), the absence of in-school behaviour supports, challenges associated with maintaining safe and appropriate transportation, individual physician recommendations (discouraging school attendance), and limitations in terms of maintaining necessary physical distancing or mask wearing in the school setting.
- Almost two thirds of respondents (357/540, 66%) reported that CMC receive health care services at school. Very few respondents (45/540, 8%) reported that services were transferred from school to home and/or community during periods of virtual learning.

Survey limitations

- Limitations common to all CPSP surveys are listed on page 11.
- Paediatricians may be unaware of all aspects of a child's life, as evidenced by the high number of respondents who did not complete the full survey.
- The survey did not include the experience of family caregivers, who are best placed to describe their children's experiences.

Conclusions

- CMC experienced adverse health outcomes related to the direct and indirect effects of the COVID-19 pandemic.
- The COVID-19 pandemic has interrupted family caregiving, home care services, access to education, and other essential supports for CMC and their families.
- Canadian paediatricians observed benefits associated with structural changes related to the COVID-19 pandemic, including the expansion of virtual care and the reduced incidence of non-COVID-19 respiratory illnesses.

Anticipated survey impact

- This study can inform pandemic and non-pandemic health policy and planning for CMC, including service design and delivery across acute, home, and community care sectors.
- Results may help inform education policy and service planning for children with CMC.

Acknowledgements
The investigators thank the CPSP Scientific Steering Committee and, in particular, Melanie Laffin Thibodeau.

Maintenance of Certification Section 3 Credit Case Vignettes

Note: Multiple choice questions for these Maintenance of Certification (MOC) Section 3 case vignettes will be available in the fall of 2022 via the Canadian Paediatric Society's online learning portal, Pedagogy. For more information on Pedagogy visit www.cps.ca/en/ecme.

References: Available upon request from the Canadian Paediatric Surveillance Program

Congenital syphilis

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Clinical vignette

A 21-year-old woman, gravida 1 parity 0, presents to hospital in labour. It is determined that she has had no prenatal care, has been living in the shelter system, and has been exchanging sex for methamphetamine and money. Investigations for sexually transmitted and blood-borne infection reveal: negative HIV serology, antibody to hepatitis B surface antigen (HBsAb) protective, hepatitis B surface antigen (HBsAg) negative, hepatitis C virus (HCV) antibody negative, and urine nucleic acid amplification test (NAAT) positive for chlamydia. Her syphilis serology is CMIA (chemiluminescent microparticle immunoassay) reactive with a rapid plasma reagin (RPR) of 1:128. She does not endorse any systemic symptoms but has a painless chancre on her cervix. Her baby is born and estimated to be 33 weeks gestational age with a birthweight of 2100 grams. On exam, the neonate has a diffuse macular rash with peeling of the palms and soles, as well as diffuse lymphadenopathy and hepatosplenomegaly. Complete blood count reveals leukopenia and thrombocytopenia.

The neonate is investigated for suspected congenital syphilis, and the diagnosis of congenital syphilis is supported by a positive neonatal RPR of 1:512, positive *Treponema pallidum* polymerase chain reaction (PCR) on nasal secretions, cerebrospinal fluid (CSF) venereal disease reference laboratory (VDRL) positivity at 1:4, and bilateral periosteal reaction. The baby is treated with 10 days of intravenous aqueous penicillin G in consultation with an infectious diseases physician. During the hospital stay, both ophthalmology and audiology were consulted and exams were completed on the infant.

What a clinician needs to know

Congenital syphilis, once considered a "historical disease" has become increasingly common over the last decade, paralleling a shift in the demographic composition of adult syphilis cases. While men have consistently higher rates of syphilis than women, a rapid increase in cases among young women has led to an increase in the incidence of congenital syphilis from 0.26 per 100 000 notifiable disease reports in 2013 to 23.2 per 100 000 in 2019. In absolute terms, only a single case was reported in 2013, whereas 53 cases were reported in 2019 — the highest number since reporting began in 1993. Recognition and early treatment are required to prevent long-term physical and developmental sequelae. However, it is likely that many cases go undiagnosed due to missed opportunities for screening in the third trimester, false negative testing in the third trimester, and the frequently asymptomatic presentation of affected newborns.

Presentation and diagnosis

It is estimated that about 60% of neonates with congenital syphilis are asymptomatic at birth, but those that are symptomatic may have hepatosplenomegaly, lymphadenopathy, osteochondritis, rash that can include peeling of the palms and soles, and copious nasal secretions. Clinical suspicion of the possibility of congenital syphilis should begin before delivery, especially in situations where prenatal care has been limited. Each instance of congenital syphilis represents a shortcoming of our health care system — Congenital syphilis is preventable by ensuring that all pregnant women receive appropriate prenatal care, and specifically engaging women at higher risk of syphilis in screening and treatment.

Neonates born to women with untreated or inadequately treated syphilis during pregnancy, or who have signs on examination consistent with congenital syphilis, should be investigated as per the Canadian Paediatric Society practice point (https://cps.ca/documents/position/congenital-syphilis) with complete blood count, syphilis serology, lumbar puncture for cell count, biochemistry, and CSF VDRL, and long bone X-rays. There should be a low threshold for pursuing ophthalmological and audiological

examinations to screen for interstitial keratitis, chorioretinitis, and sensorineural hearing loss, as well as screening for other sexually transmitted and blood-borne infections that could be vertically co-transmitted.

The national definition of confirmed congenital syphilis requires: 1) the identification of *T. pallidum* by dark field microscopy or fluorescent antibody examination of a neonatal specimen; OR 2) reactive syphilis serology in an infant with clinical, laboratory, or radiographic evidence of congenital syphilis whose mother is without evidence of adequate treatment; OR 3) detection of *T. pallidum* DNA by PCR from a neonatal specimen. Many provinces have varying definitions of "probable congenital syphilis" though no national definition has been adopted to date. Serological diagnosis of syphilis uses the reverse algorithm in most jurisdictions. This consists of a screening CMIA followed by the RPR if the CMIA is reactive. The RPR is a surrogate of syphilis disease activity. Successful treatment typically results in a decrease in the RPR on follow-up testing. A four-fold drop in dilutions is indicative of successful treatment (for example, an RPR dropping from 1:128 to 1:32 is considered an adequate response).

Prevention, treatment, and management

Routine screening of pregnant women in the first trimester allows for the early detection and treatment of maternal syphilis with penicillin, which prevents vertical transmission to the fetus. Unfortunately, many of the hypothesized risk factors for having syphilis in pregnancy also contribute to difficulty engaging in prenatal care, such as substance use, housing insecurity, low income, rural and remote residence, as well as social stigma and discrimination. In turn, under-identification of infected women in pregnancy makes preventative efforts at a public health level challenging. Many health jurisdictions have implemented universal syphilis screening at delivery to identify any new infections or reinfections acquired after the first trimester screen in pregnancy.

Treatment of congenital syphilis is widely available and highly effective. The drug of choice is intravenous aqueous crystalline penicillin G for a total of 10 days, with a total daily dose of 50 000 units/kg/dose in divided doses whose frequency is based on the infant's age. Not all cases of congenital syphilis are cured with this regimen, and so follow-up with a health care provider experienced in the management of these children is crucial to ensure that they have an adequate drop in their RPR in response to treatment.

COVID-19 in infants

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Clinical vignette

A male infant born at 33 weeks of gestation was admitted to the neonatal intensive care unit (NICU) with respiratory distress. The mother reported no significant past medical history, and her only medications were prenatal vitamins. She reported not having received any doses of the COVID-19 vaccine. She tested positive for SARS-CoV-2 at the time of her hospital admission when she presented with preterm labour, spontaneous rupture of membranes in the setting of three days of upper respiratory tract illness symptoms associated with low-grade fevers. At the time of birth, the infant was found to have decreased tone, laboured breathing, and a heart rate of 90 beats per minute. Non-invasive ventilation was initiated and following improvement of his respiratory status and heart rate, he was switched to low-flow oxygen. Blood cultures were drawn at the time of NICU admission, and he was subsequently started on intravenous ampicillin and tobramycin. A SARS-CoV-2 polymerase chain reaction (PCR) test was done by nasopharyngeal swab and came back positive. The complete blood count showed mild neutropenia of 1.3 x 10^9/L, and a chest X-ray revealed airspace opacities in the left upper lobe. Intravenous dexamethasone of 0.15 mg/kg/day was initiated in the context of severe COVID-19. He subsequently improved and was weaned off the low-flow oxygen. The dexamethasone and intravenous antibiotics were stopped after a 10-day course. He was discharged at 36 weeks corrected gestational age after he was found to have adequate oral intake, weight gain, and no concerns about his respiratory status.

What a clinician needs to know

Presentation and diagnosis

Symptoms commonly associated with COVID-19 in infants include fever, coryza, cough (upper respiratory tract infection), and gastrointestinal symptoms such as decreased oral intake, vomiting, and diarrhea. Careful clinical evaluation and physical examination of infants presenting with these symptoms are important to rule out causes other than COVID-19, including pneumonia, bacteremia, meningitis, or other non-infectious diagnoses. Nasopharyngeal COVID-19 PCR testing, as per local testing policies, a chest X-ray, and other relevant investigations should be considered in infants presenting with the above symptoms, based on physical examination and clinical assessment.

Severe COVID-19 is generally uncommon in infants, especially when compared to adults and adolescents with comorbid conditions. However, some infants who are infected with SARS-CoV-2 can develop symptoms similar to bronchiolitis, including respiratory distress, and other features of severe COVID-19. Infants aged less than 1 year with COVID-19 may require hospital admission in this context, or secondary to other clinical concerns related to SARS-CoV-2 infection, such as febrile illness, decreased oral intake and dehydration, lethargy, or in rare cases, seizures. Evidence is evolving, but studies have found that risk factors for COVID-19 admission and severe disease in infants include preterm birth before 34 weeks of gestation, age less than 1 month, and comorbid conditions (such as congenital heart disease, neurodevelopmental conditions, and chronic lung disease). Preterm neonates are at higher risk of severe COVID-19, and in addition, SARS-CoV-2 infection has been shown to increase the rate of preterm birth and perinatal mortality in pregnant women. Although a low threshold for admission of infants aged less than 6 to 12 weeks who present with fever may explain their increased risk of hospitalization, a larger proportion of neonates aged less than 1 month admitted for COVID-19 present increased risk for features of severe disease compared to older infants, such as the need for respiratory support. Of note, evidence has also shown that pregnant women with COVID-19 were at increased risk.

Prevention, treatment, and management

Supportive measures such as nasal hygiene, acetaminophen for symptomatic relief, and ensuring adequate oral intake are typically the only treatment required for COVID-19 in infants, since the vast majority of infants experience mild disease from SARS-CoV-2 infection. However, in certain infants who develop respiratory distress and who are admitted to hospital for respiratory support, low-flow oxygen, non-invasive ventilation or mechanical ventilation, and a course of dexamethasone of 0.15 mg/kg/dose daily orally or intravenously (up to 6 mg per day) for five to ten days may be considered. Infants with a suspected pulmonary bacterial superinfection, especially younger neonates, may require a course of antibiotics.

Owing to limited data in children aged less than 12 years, antiviral agents against SARS-CoV-2 such as remdesivir or nirmatrelvir/ritonavir, or COVID-19 monoclonal antibodies such as sotrovimab or casirivimab plus imdevimab are generally not recommended in infants. In rare cases of infants who develop severe COVID-19, these agents may be considered on a case-by-case basis (typically owing to significant medical comorbidities). For such cases, consultation with a paediatric infectious diseases physician would be recommended.

In the absence of any COVID-19 vaccine approved for use in young infants, an important strategy to prevent SARS-CoV-2 infection in neonates is through maternal immunization. This approach has been well established for reducing the risk of other infections in the newborn, such as influenza, and has also shown to be effective in protecting infants less than 6 months of age against hospitalization from COVID-19.

First-time hospitalizations for anorexia nervosa during the COVID-19 pandemic

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Clinical vignette

A 15-year-old male is brought to the emergency department by his parents with a 16 kg weight loss over the past three months. He is a competitive swimmer and was well until March 2020. With the onset of the COVID-19-related lockdown, he started to "eat healthy," avoid high-calorie foods, exercise excessively, and spend more time on social media learning how to increase his muscle mass. His parents noted that he was quieter and more irritable. He reports that he was "lonely." He also describes being tired, dizzy, and constipated. On physical examination, he is pale and emaciated. His weight is 41 kg (3rd percentile; 72% of his treatment goal weight) and height is 173 cm (50th to 75th percentile). His orthostatic vital signs are heart rate of 36 beats per minute (bpm) (supine) and 50 bpm (standing), and blood pressure of 90/40 (supine) and 92/46 (standing). His oral temperature is 35.7°C. His extremities are acrocyanotic and his pedal pulses are diminished.

Investigations include a complete blood count (CBC) revealing a mild thrombocytopenia and neutropenia. Electrolytes, including calcium, magnesium, phosphate, and glucose, are normal. His urea is 7 mmol/L (2.8–7.0 mmol/L), creatinine is 96 µmol/L (40–69 µmol/L), aspartate aminotransferase (AST) is 75 U/L (<41 U/L) and alanine aminotransferase (ALT) is 73 U/L (< 29 U/L). An electrocardiogram (EKG) shows a junctional bradycardia with a heart rate of 35 bpm and no other abnormalities.

The patient is diagnosed with anorexia nervosa (AN) and hospitalized because of bradycardia, hypothermia, and significantly low body weight. The goals of the admission include medical stabilization, nutritional rehabilitation, weight restoration, and initiation of psychological treatment for his eating disorder.

What a clinician needs to know

Presentation and diagnosis

AN is a complex mental illness with significant medical and psychiatric morbidity. It has the highest mortality rate of any psychiatric disorder. The prevalence of AN is approximately 1% of the population with a peak onset in adolescence. The exact etiology of AN is unknown. Research suggests that many factors play a role in the development of AN, including both genetics and the environment.

The COVID-19 pandemic has had a significant impact on new cases of paediatric AN. The issues underlying the rise in cases are complex and may be associated with several factors including public health mitigation strategies, school closures, social isolation, and lack of structure and peer support.

Adolescents with AN often present with rapid weight loss, food restriction, intense fear of gaining weight/becoming fat, ritualized eating behaviors, body image disturbance, menstrual dysfunction in natal females (assigned female at birth), mood changes, poor self-esteem, and social withdrawal. Physical symptoms can include fatigue; cold intolerance; hair loss; lanugo hair; pale, dry, or yellowing skin; constipation; faltering growth; pubertal delay; and decreased ability to concentrate.

If AN is suspected, a thorough history and physical exam is indicated. Consideration should be given to other medical and psychiatric diagnoses, as well as the impact of social determinants of health, in the differential diagnosis. The diagnostic criteria for AN are outlined in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* and are divided into two subtypes: the restricting type and the binge-eating/purging type.

AN can affect every organ system. Acute medical complications include physiologic instability such as bradycardia, hypotension, orthostatic pulse and blood pressure changes, and low body temperature. The long-term impact of malnutrition can cause changes to brain structure and function, faltering growth, pubertal delay or interruption, and peak bone mass reduction.

There are no pathognomonic investigations to diagnose AN. Blood tests are recommended to rule out other causes of weight loss and to evaluate the impact of malnutrition on end-organ function. These tests include a CBC with differential; C-reactive protein (CRP); electrolytes including calcium, magnesium, and phosphate; glucose; urea; creatinine; liver function tests; estradiol or testosterone; and luteinizing hormone (LH), follicle-stimulating hormone (FSH), and thyroid-stimulating hormone (TSH). An EKG should be included with the initial investigations. Common abnormalities are neutropenia; transaminitis; elevated creatinine; and suppression of LH, FSH, estradiol or testosterone, and TSH. Electrolytes including calcium, magnesium, and phosphate are often normal at baseline in the restrictive type of AN but can become deranged (refeeding syndrome) during nutritional rehabilitation. Hypokalemia is common in the binge-eating/purging type of AN and should be closely monitored. The most common EKG abnormality is bradycardia, a physiologic response to malnutrition.

Prevention, treatment, and management
Early recognition and timely intervention are prognostic factors of AN. Adolescents with AN should be medically monitored for acute- and long-term consequences of this disorder. Malnutrition is a perpetuating factor for AN and therefore weight restoration is the first step in treatment. Medical monitoring includes measurement of weight, height, orthostatic heart rate, blood pressure, growth and development, and metabolic status. Family-based treatment is recommended as the first-line outpatient psychological treatment for medically stable adolescents. Hospitalization is reserved for adolescents with severe malnutrition and associated acute medical complications, mental health disorders that interfere with treatment, and acute suicidality.

For more information, consult the Position Paper of the Society of Adolescent Health and Medicine: Medical Management of Restrictive Eating Disorders in Adolescents and Young Adults (https://www.jahonline.org/article/S1054-139X(14)00686-7/fulltext) and the report of the Academy for Eating Disorders, Eating Disorders: A Guide to Medical Care (https://www.aedweb.org/resources/publications/medical-care-standards).

References: Available upon request from the Canadian Paediatric Surveillance Program

Identifying child maltreatment during virtual medical appointments

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Clinical vignette

An otherwise healthy 13-year-old girl is referred to you for ongoing abdominal pain. The pain has been chronic, lasting for several years, but has worsened over the past six months. Given the COVID-19-related public health restrictions, you see her for a virtual medical appointment, with her mother present. The girl's siblings are also present, playing in the background during the virtual appointment, since there is not a separate space in the home where the girl and her mother may speak privately. After taking a preliminary history, noting the pain's onset, location, quality, and exacerbating/alleviating factors, it is not clear what is causing this pain. You identify no significant "red flags," including no weight loss, no bilious emesis, no reported energy and appetite change, and an otherwise negative review of systems. You note that the girl is in no acute physical distress, but a physical examination is not possible given the virtual encounter. A confidential HEADSS assessment cannot be completed given the lack of privacy. You book her for an in-person assessment two weeks later, to complete the history in a private setting and to perform a physical exam. When she comes for her appointment and when you complete the HEADSS assessment, she discloses that there is physical and verbal abuse in the home. As such, you call the local child protective services team.

What a clinician needs to know

The COVID-19 pandemic has exacerbated psychosocial stress for some parents and families. Factors such as financial concerns, social isolation, loss of services, and school closures are drivers of this stress. Along with a rise in social stressors, some studies cite a rise in child maltreatment cases. While calls to child protective services have declined, calls to the Kids Help Phone have increased by 20%. As pandemic-related stressors evolve and persist, concerns related to an increased incidence of child maltreatment continue.

Virtual medical appointments pose a unique challenge for assessing children in the context of identifying maltreatment. However, there is no evidence-based approach to guide paediatricians when they have concerns about child maltreatment in the context of virtual care.

In October 2021, a Canadian Paediatric Surveillance Program one-time survey was conducted to explore the identification of child maltreatment during virtual medical appointments. The most commonly reported factors that led responding physicians to report a case of suspected child maltreatment to child protective services based on a virtual appointment included clear disclosure of abuse by the child and/or caregiver and social stressors, such as financial difficulty, the home environment, or isolation. Other factors that triggered concern related to parental capacity, such as cognitive capacity/mental health and addictions.

The major barriers to identifying possible child maltreatment during virtual medical appointments noted by survey respondents included not being able to see the child or interact directly with them because they may not be present during the appointment, and not being able to complete a physical examination. Another issue identified was privacy and confidentiality in a virtual setting, as many physicians felt unsure whether the patient had a private space for their virtual visit. Although some physicians reported completing virtual physical examinations, they did not contribute to any reports made to child protective services. About two thirds of responding physicians reported that it was more difficult to detect child maltreatment when providing virtual care.

Out of the possible cases of child maltreatment identified by respondents at a virtual appointment, nearly one quarter required an in-person follow-up visit before issuing a formal report to a child protective service. Concerns regarding a possible missed case or delays in the identification of child maltreatment were reported by 32% of respondents. Overall, this work suggests that paediatricians should be asking directly about risks for child maltreatment, after ensuring patient/caregiver privacy and confidentiality are protected in the virtual setting.

References: Available upon request from the Canadian Paediatric Surveillance Program

Paediatric inflammatory multisystem syndrome temporally associated with COVID-19

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Clinical vignette

A 10-year-old obese Black male presents to an emergency department with three days of fever, abdominal pain, diarrhea, rash, and red cracked lips. On examination he is febrile (39.5°C), tachycardic (153 beats/minute), hypotensive (90/46 mm/Hg) with a respiratory rate of 24 breaths/minute. His exam is notable for conjunctival injection without exudate and cracked erythematous lips. The dorsa of his hands and feet appear swollen and erythematous, and he has a diffuse maculopapular blanching erythematous rash across the back and spreading to the buttocks. Abdominal exam reveals abdominal distension, tenderness, and guarding.

Investigations are as follows:

- Complete blood count/differential: white blood cells 4.92×10^9/L, hemoglobin 90 g/L, platelet count 34×10^9/L, absolute neutrophil count 1.18×10^9/L, absolute lymphocytes count 1.08×10^9/L
- Alanine aminotransferase 54 U/L, aspartate aminotransferase 76 U/L, albumin 21 g/L
- Creatinine 98 µmol/L
- International normalized ratio (INR) 1.5, partial thromboplastin time (PTT) 47.2 seconds, fibrinogen 2.4 g/L, D-dimer 24.26 ng/mL
- C-reactive protein 201 mg/L, erythrocyte sedimentation rate 5 mm/hr, ferritin 3318.7 ng/mL, triglycerides 1.45 mmol/L
- Troponin 74.7 ng/L, N-terminal pro-brain natriuretic peptide (NT-proBNP) 7429.3 ng/L
- Nasal pharyngeal SARS-CoV-2 polymerase chain reaction (PCR) negative

Based on his history, physical exam, and laboratory findings, he is diagnosed with paediatric inflammatory multisystem syndrome temporally associated with COVID-19 (PIMS-TS) and admitted to the ward for the initiation of therapy.

What a clinician needs to know

Several names and case definitions have been used to describe a post-infectious inflammatory syndrome in paediatric patients temporally associated with COVID-19, including PIMS-TS and multisystem inflammatory syndrome in children (MIS-C).

Presentation and diagnosis

Patients with PIMS/MIS-C present with fever (>38°C for ≥3 days), unexplained by other causes. The clinical phenotypes of PIMS/MIS-C described to date include: 1) fever with hyperinflammation; 2) Kawasaki disease-like features, and 3) shock or shock-like states. In addition to features of Kawasaki disease and toxic shock syndrome, the cardiac, gastrointestinal, renal, and neurological systems may be affected. Patients presenting in all three clinical phenotypes can deteriorate rapidly and develop signs of hypotension and poor perfusion related to myocardial dysfunction.

A temporal association with COVID-19 is known, with cases of PIMS/MIS-C typically following two to six weeks after SARS-CoV-2 infection. The majority of affected children test negative on reverse transcription PCR for SARS-CoV-2 using nasopharyngeal swabs at the time of presentation with signs of PIMS/MIS-C, but the vast majority (80% to 100%) of affected children test positive for antibodies to SARS-CoV-2. Many case series have suggested that a disproportionally high number of Black and Latino children are affected by PIMS/MIS-C.

Any unwell child with unexplained high fever (≥3 days, and other causes excluded), particularly with any clinical sign suggesting Kawasaki disease, severe abdominal pain, or hypotension, should have appropriate screening investigations. PIMS/MIS-C should also be considered in patients with ≥5 days of unexplained fever without other clinical signs. Screening investigations should consist of routine laboratory tests for Kawasaki disease, troponin, NTproBNP (if available), electrocardiogram, and echocardiogram. If there is concern for hyperinflammation, consider additional work-up for an evolving picture of cytokine storm syndrome/macrophage activation syndrome, including values for ferritin, lactate dehydrogenase, fibrinogen, D-dimer, PTT, INR, and triglycerides. As PIMS/MIS-C is a diagnosis of exclusion, microbiologic testing should consist of bacterial cultures, viral swabs, and SARS-CoV-2 PCR. Where possible, SARS-CoV-2 serology should also be requested.

The differential diagnosis for PIMS/MIS-C is broad. The following diagnoses should be considered/excluded: Kawasaki disease, bacterial sepsis, toxic shock syndrome, severe acute COVID-19 or other viral infections, appendicitis, and other rheumatic disease (e.g., systemic juvenile idiopathic arthritis, vasculitis, or rheumatic disease complicated by macrophage activation syndrome). Other causes of prolonged fever/inflammation need to be considered during the work-up for PIMS/MIS-C.

Prevention, treatment, and management
For hospitalized patients, multidisciplinary team involvement is strongly advised (which may include general paediatrics, infectious diseases, rheumatology, immunology, intensive care, cardiology, and hematology/thrombosis services). For children at centres without a dedicated paediatric intensive care unit, referral to a tertiary care centre should be considered when they are presenting with hypotension/shock and/or features of macrophage activation syndrome/cytokine storm syndrome.

PIMS therapy consists of corticosteroids, intravenous immunoglobulin (IVIg), and aspirin. Corticosteroids may be given at a dose range of either 1 to 2 mg/kg/day orally or intravenously, as prednisone or methylprednisolone, respectively. For more severe organ-threatening disease or failure to improve with lower steroid doses, pulse intravenous methylprednisolone therapy can be administered at 10 to 30 mg/kg/day (maximum 1000 mg) as an infusion over one to three hours. Some patients require the initiation of a biologic medication such as interleukin-1 blockers. This should be done in collaboration with a paediatric rheumatologist. Anti-coagulation is indicated in a subset of patients. Guidance should be provided by hematology, as anticoagulation should be considered on an individual basis and practice patterns and guidance vary. The following risk factors should be considered: central venous catheterization, age >12 years, malignancy, intensive care unit admission, and/or an ejection fraction <35%.

Patients with PIMS/MIS-C should be followed by cardiology and rheumatology after discharge. Patients treated with corticosteroids or biologics often require two to three weeks or more of therapy, with tapering of medications guided by clinical and laboratory evaluations. All patients with PIMS/MIS-C who receive IVIg should remain on low-dose aspirin (3 to 5 mg/kg/day, maximum 81 mg/day) until a follow-up echocardiogram confirms normal coronary arteries in the subacute phase, 4 to 6 weeks post diagnosis and inflammatory markers return to normal. Cardiology follow-up is recommended, in accordance with guidance already in place for Kawasaki disease, with bloodwork, electrocardiogram, and echocardiogram suggested 7 to 14 days and four to six weeks post diagnosis. Further imaging and follow-up are dictated by the presence or absence of coronary artery aneurysms and/or myocardial dysfunction.

Publications 2018–2021

Peer-reviewed papers related to studies and one-time surveys

(For a complete list with hyperlinks, see www.cpsp.cps.ca/publications/published-papers-related-to-studies-and-one-time-surveys.)

Acute flaccid paralysis
Acute flaccid myelitis in Canada, 2018 to 2019. Dickson C, Ho Mi Fane B, Squires SG. *Can Commun Dis Rep* 2020 Oct 1;46(10): 349–53. doi: 10.14745/ccdr.v46i10a07

Adrenal suppression
Screening practices for paediatric asymptomatic adrenal suppression in Canada: Are we addressing this important risk? Goldbloom EB, Ahmet A. *Paediatr Child Health* 2020 Oct;25(6):389-93. doi: 10.1093/pch/pxy174. Epub 2019 Mar 30

All-terrain vehicle safety
All-terrain vehicle serious injuries and death in children and youth: A national survey of Canadian paediatricians. Gill PJ, McLaughlin T, Rosenfield D, Moore Hepburn C, Yanchar NL, Beno S. *Paediatr Child Health* 2019 Feb;24(1):e13–8. doi: 10.1093/pch/pxy059. Epub 2018 Jun 18

Avoidant/restrictive food intake disorder
Incidence and age- and sex-related differences in the clinical presentation of children and adolescents with ARFID: A Canadian Paediatric Surveillance Program study. *JAMA Pediatr* 2021 Dec 1;175(12):e213861. doi: 10.1001/jamapediatrics.2021.3861. Epub 2021 Dec 6

Complex regional pain syndrome
Canadian surveillance study of complex regional pain syndrome in children. Baerg KL, Tupper SM, Chu LM, Cooke N, Dick BD, Doré-Bergeron MJ, Findlay S, Ingelmo PM, Lamontagne C, Mesaroli G, Oberlander T, Poolacherla R, Spencer AO, Stinson J, Finley GA. *Pain* 2022 Jun 1;163(6):1060-9. doi:10.1097/j.pain.0000000000002482. Epub 2021 Sep 13

COVID-19
Characteristics of children hospitalized with acute SARS-CoV-2 infection in Canada in 2020. Drouin O, Moore Hepburn C, Farrar DS, Baerg K, Chan K, Cyr C, Donner EJ, Embree JE, Farrell C, Forgie S, Giroux R, Kang KT, King M, Laffin M, Luu TM, Orkin J, Papenburg J, Pound CM, Price VE, Purewal R, Sadarangani M, Salvadori MI, Top KA, Viel-Thériault I, Kakkar F, Morris SK, for the Canadian Paediatric Surveillance Program COVID-19 Study Team. *CMAJ* 2021 Sep 27;193:E1483-93. doi: 10.1503/cmaj.210053

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Population-based study of early-onset neonatal sepsis in Canada. Sgro M, Kobylianskii A, Yudin MH, Tran D, Diamandakos J, Sgro J, Campbell DM. *Paediatr Child Health* 2019 May;24(2):e66–73. doi: 10.1093/pch/pxy018. Epub 2018 Apr 24

E-cigarettes
E-cigarettes: A new hazard for children and adolescents. Richmond SA, Pike I, Maguire JL, Macpherson A. *Paediatr Child Health* 2018;23(4):255–9. Corrigendum: Epub 2020 May 29, doi: 10.1093/pch/pxaa060

Hypoglycemia
Hypoglycemia in unmonitored full-term newborns—a surveillance study. Flavin MP, Osiovich H, Coughlin K, Sgro M, Ray J, Hu L, León AJ, Gregoire K, Barr L, Gallipoli A, Grewal K. *Paediatr Child Health* 2018 Dec;23(8):509–14. doi: 10.1093/pch/pxy025. Epub 2018 Mar 10

Interim Federal Health Program
Interim Federal Health Program (IFHP): Survey of access and utilization by pediatric health care providers. Leps C, Monteiro J, Barozzino T, Bowry A, Rashid M, Sgro M, Suleman S. *Paediatr Child Health* 2021;26(supplement_1): e79–e80. doi: 10.1093/pch/pxab061.090

Lipid screening
Pediatric lipid screening and treatment in Canada: Practices, attitudes, and barriers. Khoury M, Rodday AM, Mackie A, Gill P, McLaughlin T, Harris KC, Wong P, McCrindle BW, Birken CS, de Ferranti S. *Can J Cardiol* September 2020;36(9):1545–9. doi: 10.1016/j.cjca.2020.05.035. Epub 2020 Jun 3

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Lyme disease in children: Data from the Canadian Paediatric Surveillance Program. Ogden NH, Gasmi S, Koffi JK, Barton M, Lindsay LR, Langley JM. *Ticks Tick Borne Dis* 2020 Mar;11(2):101347

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Procedural skill needs for Canadian paediatricians: A national profile. White J, Rowan-Legg A, Writer H, Chanchlani R, Gupta R. *Paediatr Child Health* 2020 Nov; pxaa103. doi: 10.1093/pch/pxaa103. Epub 2020 Nov 7

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Infants affected by Rh sensitization: A 2-year Canadian national surveillance study. Baker JM, Campbell DM, Pavenski K, Gnanalingam A, Hollamby K, Jegathesan T, Zipursky A, Bhutani V, Sgro M. *Paediatr Child Health* 2020 Mar 30;26(3):159-65. doi: 10.1093/pch/pxaa025

Self-harm
Near-fatal self-harm among Canadian adolescents. Mitchell RH, Ani C, Cyr C, et al. *Can J Psychiatry* 2021 Nov. doi:10.1177/07067437211058602. Epub ahead of print

Severe alcohol intoxication
Severe alcohol intoxication among Canadian youth: A two-year surveillance study. Acker A, Norris ML, Coo H, Santos A, Allain D, Dow K. *Paediatr Child Health* 2019 Nov;26(2):e82-8. doi: 10.1093/pch/pxz152. eCollection Apr-May 2021

Severe microcephaly and congenital Zika syndrome
Population-based surveillance of severe microcephaly and congenital Zika syndrome in Canada. Morris SK, Farrar DS, Miller SP, et al. *Arch Dis Child* 2021;0:1–7. doi: 10.1136/archdischild-2020-320968. Epub 2021 Jan 8

Tuberculosis
Epidemiology, clinical features, and outcomes of incident tuberculosis in children in Canada in 2013-2016: Results of a national surveillance study. Morris SK, Giroux RJP, Consunji-Araneta R, Stewart K, Baikie M, Kakkar F, Zielinski D, Tse-Chang A, Cook VJ, Fisher D, Salvadori M, Pernica J, Elwood K, Sauvé L, Hui C, Miners A, Alvarez GG, Al-Azem A, Gallant V, Grueger B, Lam R, Langley JM, Radziminski N, Rea E, Wong S, Kitai I. *Arch Dis Child* 2021 Aug 20; archdischild-2021-322092. doi: 10.1136/archdischild-2021-322092. Epub ahead of print

Vaping-related illness and injury
Vaping-related injury and illness among Canadian children and adolescents: A one-time survey of paediatric providers. Chadi N, Moore Hepburn C, Beno S, Richmond SA. *BMJ Paediatrics Open* 2020 Oct;4:e000840. doi:10.1136/bmjpo-2020-000840. Epub 2020 Oct 19

Acute injury or illness related to the inhalation of vaping aerosols among children and adolescents across Canada: A cross-sectional survey of Canadian paediatricians. Zutrauen S, Do MT, Ghandour L, Moore Hepburn C, Beno S, Richmond SA, Chadi N. *Paed Child Health* Aug 2021; pxab062. doi.org/10.1093/pch/pxab062. Epub ahead of print

CPSP Highlights published in *Paediatrics & Child Health*

(For a complete list with hyperlinks, see www.cpsp.cps.ca/publications/cpsp-highlights.)

Anorexia nervosa and COVID-19
Anorexia nervosa: A paediatric health crisis during the COVID-19 pandemic. Vyver E, Katzman DK. *Paediatr Child Health* 2021 Aug;26(5): 317–8. doi: 10.1093/pch/pxab031. Epub 2021 June 18

Micronutrient deficiencies and autism spectrum disorder
Micronutrient deficiencies in autism spectrum disorder: A macro problem? Kinlin LM, Birken CS. *Paediatr Child Health* 2021 Jun 5;26(7):436-7. doi: 10.1093/pch/pxab032. eCollection 2021 Nov

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Serious self-harm requiring intensive care unit admission: Understanding near-fatal suicide attempts. Korczak DJ, Skinner R, Dopko R. *Paediatr Child Health* 2019 Feb;24(1):58–9. doi: 10.1093/pch/pxy077. Epub 2018 Jul 25

Teething necklaces
Teething necklaces and bracelets pose significant danger to infants and toddlers. Abdulsatar F, Matsui D, Miller M, Taheri S. *Paediatr Child Health* 2019 May;24(2):132–3. doi: 10.1093/pch/pxy155. Epub 2018 Nov 7

Presentations in 2021

(For a complete list with hyperlinks, see www.cpsp.cps.ca/publications/presentations.)

5q spinal muscular atrophy
5q Spinal Muscular Atrophy Canadian Paediatric Surveillance Program 2020 Results. Price T, Hodgkinson V, Innes M, Korngut L, Parboosingh J, Mah JK. Canadian Neurological Sciences Federation's Congress, Toronto, in October (poster)

Complex regional pain syndrome
Canadian surveillance study of complex regional pain syndrome in children and youth. Baerg K, Tupper S, Chu L, Finley GA, and the CRPS Collaborator Group. Chronic Pain Network Annual Meeting, virtually, in March (oral and poster)

CRPS national results. Baerg, K. Pediatric Inpatient Research Network meeting, in April (oral)

Agreement of reported symptoms by patients and signs at evaluation assessed by health professionals: An evaluation from the Canadian surveillance study of complex regional pain syndrome in children. Chu LM, Tupper S, Finley A, McMahon C, Baerg KL. International Association for the Study of Pain Virtual World Congress, in June (poster)

Complex regional pain syndrome in Canadian children and youth: preliminary results. Baerg K, Tupper S, Finley AG. International Association for the Study of Pain Virtual World Congress, in June (poster)

Just how common is it? Results of the Canadian surveillance study for kids with complex regional pain syndrome. Baerg K. Pediatric Grand Rounds, University of Saskatchewan, virtually, in June (oral)

Complex regional pain syndrome in Canadian children and youth. Baerg K. Pediatric Pain, Patient & Community Partnership, and Research: Five Studies to Keep You in the Know, Children's Healthcare Canada Spark: Live Pain Theme Month, virtually, in November (oral)

COVID-19
Characteristics of children hospitalized with acute SARS-CoV-2 infection in Canada. Drouin O, Moore Hepburn C, Farrar DS, Kakkar F, Morris SK, for the Canadian Paediatric Surveillance Program COVID-19 study group. Pediatric Academic Societies Annual Meeting, virtually, in May (poster)

COVID-19: Year two. Drouin O, Langley J, Allen U. Child and youth health lecture. Canadian Paediatric Society Annual Conference, virtually, in June (oral)

Disease severity and clinical manifestations of SARS-CoV-2 infection among infants over the first year of the pandemic in Canada. Piché-Renaud PP, Panetta L, Farrar DS, Moore Hepburn C, Drouin O, Kakkar F, Morris SK, for the Canadian Paediatric Surveillance Program COVID-19 Study Team. IDWeek 2021 Virtual Conference, in September/October (poster)

Epidemiology, clinical features, and severity of paediatric inflammatory multisystem syndrome temporally associated with SARS-CoV-2 infection in hospitalized children in Canada: A Canadian Paediatric Surveillance Program national prospective study. El Tal T, Morin MP, Morris SK, Farrar DS, Berard R, Kakkar F, Moore Hepburn C, Haddad E, Scuccimarri R, Yeung R, for the Canadian Paediatric Surveillance Program COVID-19 study group. American College of Rheumatology Convergence Annual Meeting, virtually, in November (poster and recorded oral)

Epidemiology and outcomes of children with SARS-CoV-2 in Canada. Findings from a prospective pan-Canadian study. Drouin O. CanCOVID Speaker Series, virtually, in December (oral)

First-time hospitalizations for anorexia nervosa during the COVID-19 pandemic
Surge on surge: Eating disorders and the COVID pandemic, Vyver E, Katzman DK. Canadian Paediatric Society Grand Rounds, virtually, March (oral)

Interim Federal Health Program
Interim Federal Health Program (IFHP): Survey of access and utilization by pediatric health care providers. Leps C, Monteiro J, Suleman S. Canadian Paediatric Society Annual Conference, virtually, in June (poster)

Lipid screening
Child and adolescent lipid screening and management. Khoury M, Wong JP. Canadian Paediatric Society Annual Conference, virtually, in June (oral)

Severe obesity and global developmental delay
Severe obesity and global developmental delay in preschool children: Findings from a Canadian Paediatric Surveillance Program study. Gehring ND, Ball GDC, Belanger S, Bridger T, Chanoine JP, Gibson WT, Hadjiyannakis S, Haines J, Hamilton J, Haqq A, Henderson M, Ho J, Irvine B, Legault L, Luca P, Maguire J, McPherson A, Morrison K, Wahi G, Weksberg R, Zwaigenbaum L, Birken CS. University of Alberta's Pediatric Research Day, virtually, in April (poster)

Canadian Paediatric Surveillance Program

New Study and One-Time Survey Opportunities

The opportunity

- Benefit from the CPSP's well-established, timely, cost-effective, and internationally recognized surveillance platform.
- The CPSP is effective at monitoring low-frequency, high-impact diseases and conditions encountered by general paediatricians and paediatric subspecialists.

Track record

- The average monthly response rate from approximately 2,800 paediatricians is 80%.
- The average detailed questionnaire response rate varies between 80% to 90%.

Themes of interest

Including examples of successful CPSP studies

- Rare diseases (including genetic, metabolic, or rare acquired conditions)
  - Congenital myotonic dystrophy
  - Medium-chain acyl-coenzyme A dehydrogenase deficiency
- Rare complications of more common diseases
  - Adrenal suppression with glucocorticoid therapy
  - Serious adverse events associated with complementary and alternative medicine
- Emerging infections
  - COVID-19
  - Lyme disease
- Threats to public health and safety
  - Vaping
  - Neonatal abstinence syndrome
  - Teething necklaces and bracelets worn by infants and toddlers

Study success factors

- A study or condition with an incidence of less than 500 cases per year
- A multidisciplinary study team, with national representation
- Local champions who encourage study reporting at their institutions

Study impact

Knowledge translation: Studies have been published in high-impact, peer-reviewed journals; the CPSP is well known and recognized by prominent editorial boards.

Public health policies and legislation: Results have informed the total ban on baby walkers and the promotion of booster seats to prevent lap-belt syndrome.

Professional medical guidelines: Results have informed guidelines such as the Canadian Paediatric Society position statements on neonatal hyperbilirubinemia and medical assistance in dying.

Public health promotion and education: Results have informed efforts to prevent vitamin D deficiency rickets and the use of e-cigarettes in those under the legal age to use conventional tobacco products.

CPSP
CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

""As the Paediatric Chairs of Canada representative to the CPSP Scientific Steering Committee, I have witnessed the extraordinary ability of the CPSP to bring together study investigators from across paediatric disciplines and across Canada in the study of rare paediatric diseases. For conditions that are high in disability, morbidity, mortality, and economic costs to society, despite their low frequency, national surveillance to capture case-level data is essential. On behalf of the Scientific Steering Committee, I would like to extend a sincere thank you to the thousands of CPSP participants who contribute to the Program. We are truly fortunate to have such a robust paediatric surveillance program in Canada."

Ciarán M. Duffy, MB, BCh, MSc, FRCPC, FRCPI; Professor, Department of Pediatrics, Faculty of Medicine, University of Ottawa; Past CPSP Steering Committee representative, Paediatric Chairs of Canada

For more information, please call us at 613-526-9397 ext. 239, e-mail cpsp@cps.ca or visit www.cpsp.cps.ca.

For more information on the Canadian Paediatric Surveillance Program or to obtain a French version of this report, please contact:

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