CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

2024 Results













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 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.

Suggested citation

Canadian Paediatric Surveillance Program 2024 Results. Ottawa (ON): Canadian Paediatric Society; 2025.

Project manager

Melanie King, Manager, Surveillance

Scientific review

Catherine Farrell, MD, Chair, CPSP Scientific Steering Committee Sam Wong, MD, Medical Affairs Director, CPSP and Canadian Paediatric Society

Scientific and translation review

Evelyne D. Trottier, MD, Canadian Paediatric Society Representative, CPSP Scientific Steering Committee

Translation

Dominique Paré, C. Tr., Traduction Le bout de la langue inc.

Layout and design

John Atkinson, Fairmont House Design

Editing and production

Una McNeill, CPSP Consultant



The terms "surveillance" and "research" are often used interchangeably as the differences between them may not be well understood. While these terms have a lot in common, there are key differences between the two. Surveillance refers to the ongoing collection, analysis, and dissemination of health data to monitor disease trends and identify public health issues in realtime, allowing for immediate response. Research involves more in-depth studies to generate new knowledge and understanding about health issues, often with the goal of informing future interventions. Essentially surveillance is about collecting information for action now, while research is about building a broader knowledge base for the future.

Public Health Surveillance vs. Research

What are the key differences?

| | SURVEILLANCE | RESEARCH | |
|--------------------|--|---|--|
| Definition | "Public health surveillance is the continuous and systematic collection, orderly consolidation and evaluation of pertinent data, with prompt dissemination of results to those who need to know, particularly those who are in a position to take action." | Research is "an undertaking intended to extend knowledge through a disciplined inquiry and/or systematic investigation." ² | |
| Goal | To guide public health policy and action | To generate new knowledge | |
| Process | Requires "3D" integration (detection, deduction, and dissemination) | Does not require "3D" integration | |
| Driver | Driven by government duty to promote and protect public health | Driven by desire to generate new knowledge | |
| Rigour | Sacrifices precision to achieve timeliness ("pragmatic") | Focuses on absolute accuracy ("rigorous") | |
| Data Collection | Usually involves standard, broadly accepted methods of data collection Usually involves standard method can involve experimental, non-trainmethods of data collection | | |
| Ethics | Supported by principles of public health ethics — Research ethics board approval generally not required | Supported by principles of medical and research ethics — Research ethics board approval generally required | |
| Hypotheses | Generates hypotheses | Tests hypotheses | |



Examples of how the Canadian Paediatric Surveillance Program turns surveillance into action:

A study on severe neonatal hyperbilirubinemia (2002–2004) informed the 2007 Canadian Paediatric Society (CPS) position statement recommending all newborns be evaluated for hyperbilirubinemia and for bilirubin to be measured after birth. The study was repeated in 2011–2013, showing a decrease in incidence of severe neonatal hyperbilirubinemia after the introduction of the guidelines.

Since its launch in 1996, active surveillance of acute flaccid paralysis demonstrates Canada's polio-free status remains intact.

Results of the nonmedical (recreational) cannabis use study (2018–ongoing) informed the CPS's submission to the legislative review of the Cannabis Act. Recommendations from the review in 2024 included the need for child-resistant cannabis packaging as well as public health messaging on safe cannabis storage and the risks to children from accidental exposure. Two studies on non-type 1 diabetes mellitus (2006–2008 and 2017–2019) supported CPS and Public Health Agency of Canada efforts to promote healthy active living.

The lap-belt syndrome study (2003–2005) provided data that led to advocacy in all provinces and territories to ensure the adoption of proper car restraint and booster seat legislation.

The wheeled baby walker survey released in 2002 contributed to the ban on selling, importing, and advertising baby walkers in Canada.

The data collected through the congenital syphilis study (2021–2023) contributed to the revised CPS position statement released in March 2024.



² Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2018. http://www.pre.ethics.gc.ca/eng/documents/tcps2-2018-en-interactive-final.pdf



Table of Contents

| Foreword | 4 |
|--|----|
| Message from the Federal Minister of Health | 4 |
| Message from the Interim Chief Public Health Officer of Canada | 5 |
| Message from the President of the Canadian Paediatric Society | 6 |
| Message from the Chair of the Canadian Paediatric Surveillance Program | 7 |
| Acknowledgements | 8 |
| Funding | 8 |
| Canadian Paediatric Surveillance Program Scientific Steering Committee | 9 |
| About the Canadian Paediatric Surveillance Program | 10 |
| Overview | 10 |
| Objectives | 10 |
| Surveillance | 10 |
| Process | 10 |
| Limitations of surveillance | 11 |
| Response rates | |
| Glossary of terms in study results | 12 |
| International Network of Paediatric Surveillance Units | 13 |
| Surveillance Studies in 2024 | |
| Acute flaccid paralysis | 14 |
| Acute life-threatening harms related to illicit/non-medical use of opioids, stimulants, or sedatives | 17 |
| Adverse drug reactions – serious and life-threatening | 19 |
| Adverse events related to virtual care | |
| Fetal alcohol spectrum disorder diagnosis in school-age children | 23 |
| Hyperglycemic hyperosmolar state | |
| Hypoglycemia during treatment of acute lymphoblastic leukemia (final report) | 27 |
| Post-COVID-19 condition (long COVID) (final report) | 30 |
| Serious and life-threatening events associated with non-medical (recreational) | |
| cannabis use in Canadian children and youth | 33 |
| One-Time Surveys | |
| Adverse drug events related to paediatric medication compounding | 36 |
| Adverse events associated with lithium use | 38 |
| Adverse events associated with the use of appearance and performance-enhancing drugs | |
| and substances among children and adolescents | |
| Publications 2021–2024 | 43 |
| Published papers related to studies and one-time surveys | |
| CPSP Highlights published in Paediatrics & Child Health | |
| Presentations in 2024 | 46 |
| New Study and One-Time Survey Opportunities | 48 |

Foreword



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

Message from the Federal Minister of Health

The Honourable Marjorie Michel, P.C., M.P.

The Canadian Paediatric Surveillance Program (CPSP) 2024 Results annual report summarizes a year of ongoing monitoring of rare and emerging childhood conditions and adverse events in Canada. It features research and key studies that highlight health impacts on children and youth, including on the risks that substance-related harms can pose to children.

All children and youth should be able to get the care they need. Up-to-date data on paediatric conditions and health events is essential to achieving this objective. Data collection and research provide health professionals, researchers, and policy makers with the tools they need to support the health of children and youth in Canada.

Thank you to the thousands of health care providers, paediatricians, and paediatric subspecialists across the country who consistently shared data and insights to inform this program. I also commend the experts from the Canadian Paediatric Society, Health Canada, and the Public Health Agency of Canada for their collaboration on this important work. Together, we can provide a better quality of life for those who are the future of this country.





Message from the Interim Chief Public Health Officer of Canada

Dr. Howard Njoo

For over 25 years, the Public Health Agency of Canada, Health Canada, and the Canadian Paediatric Society have supported surveillance and research in Canada. The *Canadian Paediatric Surveillance Program 2024 Results* provides valuable insights into the state of child and youth health in Canada and makes vital contributions to the health of future generations.

Public health professionals need timely and reliable public health data to identify, monitor, and understand emerging and rapidly evolving health issues and trends. Timely and accurate data allow us to better prepare for health challenges and ultimately contribute to optimal health for all people in Canada.

I would like to thank the thousands of health care providers and paediatric experts across the country who contribute not only their time and effort, but also their invaluable expertise and insights to the monthly reporting for the Canadian Paediatric Surveillance Program.

This year, the report examines a number of studies related to substance use harms and safety.

This includes ongoing monitoring of serious and life-threatening events associated with non-medical use of cannabis, as well as the illicit/non-medical use of opioids, stimulants, or sedatives. The report also provides critical insights into adverse events related to drug and substance use among children and youth, including lithium use, appearance- and performance-enhancing products, and paediatric medication compounding. These studies highlight the importance of monitoring and addressing the health impacts of substance use, especially among vulnerable populations.

The report also enhances our understanding of acute and chronic conditions affecting children, such as post-COVID-19 condition, fetal alcohol spectrum disorder, acute flaccid paralysis, hyperglycemic hyperosmolar state, and hypoglycemia during treatment of acute lymphoblastic leukemia.

I congratulate the Canadian Paediatric Society on the release of the *Canadian Paediatric Surveillance Program 2024 Results* report. It provides a critical source of data on rare and emerging childhood conditions and adverse events. The insights in this report make a meaningful contribution to public health in Canada, both now and in shaping the health of future generations.



Message from the President of the Canadian Paediatric Society

Dr. Johanne Harvey

As president of the Canadian Paediatric Society (CPS), and as an adolescent medicine specialist practising in Quebec, I am proud to participate in the Canadian Paediatric Surveillance Program (CPSP). The Program provides new and necessary information on rare childhood disorders, or rare complications of more common conditions, to facilitate improvements in treatment, prevention, and health care planning. Thanks to its long-standing and well-developed infrastructure, the CPSP can respond rapidly to emerging public health issues relevant to Canadian children and youth by quickly initiating one-time surveys and new surveillance studies.

The CPS recently identified three strategic priorities for 2024 to 2027: Child and youth mental health, environmental health, and paediatric workforce. As the CPS outlines specific objectives for each of these strategic priorities, the CPSP can also play a role. I strongly invite teams of investigators to come forward with related proposals for either CPSP multi-year studies or one-time surveys to strengthen efforts in these priority areas.

I would like to thank my fellow colleagues for taking the time to report to the CPSP, and I encourage all members of the CPS to remain active participants and to continue to use the results generated from our surveillance studies to improve care and inform advocacy. Finally, on behalf of the CPS and its Board of Directors, thank you to the Public Health Agency of Canada and Health Canada; we are grateful for your continued support and collaboration.



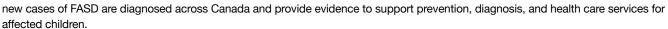
Message from the Chair of the Canadian Paediatric Surveillance Program

Dr. Catherine Farrell

The Canadian Paediatric Surveillance Program (CPSP) had another successful year in 2024, tackling important public health issues and emerging concerns facing children and youth in Canada. This work is only possible thanks to my fellow colleagues who continue to faithfully report to the CPSP on a monthly basis. Their dedication to the Program is essential to its continued success.

The foundation for collaboration remains strong between the Canadian Paediatric Society and the Public Health Agency of Canada in support of the CPSP's national surveillance. The Program continues to monitor for serious and life-threatening adverse drug reactions, as well as serious and life-threatening events associated with non-medical cannabis use. Ongoing surveillance on acute flaccid paralysis in children demonstrates that Canada remains polio free. This surveillance remains essential given global mobility and the presence of circulating polio virus in a number of countries.

Due to an increasing number of youth suffering life-threatening overdoses, in late 2024, the CPSP launched a new study on acute life-threatening harms related to the non-medical use of opioids, stimulants, and sedatives. Another newly launched study on fetal alcohol spectrum disorder (FASD) diagnosis in school-age children aims to improve our understanding of how





I invite you to read the final study results on post-COVID-19 condition (long COVID) and hypoglycemia during treatment of acute lymphoblastic leukemia that are included in this annual report. In addition, the three surveys that were sent to participants in 2024 all focused on adverse events related to medications and natural health product use in children (lithium, compounded medications, and appearance- and performance-enhancing drugs and substances). Studying these rare but significant events provides an excellent opportunity to raise awareness of these issues amongst paediatricians.

I would like to extend my sincere gratitude to the members of the CPSP Scientific Steering Committee, the Canadian Paediatric Society, and CPSP investigators. I would also like to thank the Public Health Agency of Canada for its commitment to public health surveillance and advancing knowledge on rare and emerging paediatric conditions.

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 2024 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:

- The Hospital for Sick Children, Division of Endocrinology, internal research funds of Dr. Jill Hamilton
- University of Toronto, Elizabeth Arbuthnot Dyson Fellowship, awarded to Dr. Paul MacDaragh Ryan

Canadian Paediatric Surveillance Program Scientific Steering Committee

Catherine Farrell, MD Canadian Paediatric Society (Chair)
Jill Borland Starkes, MD Canadian Paediatric Society

Peter Buck, DVM, MSc Centre for Food-borne, Environmental and Zoonotic Infectious Diseases,

Public Health Agency of Canada Paediatric Chairs of Canada (Liaison)

Canadian Paediatric Society

Canadian Association of Child Neurology (Liaison)

Canadian Paediatric Society (incoming)

Canadian College of Medical Geneticists (Liaison) (incoming)

Canadian Paediatric Society

Meghan Grainger, BSc Centre for Surveillance and Applied Research, Public Health Agency of Canada

Megan Harrison, MDCanadian Paediatric SocietyMelanie King, BACanadian Paediatric Society

Joanna Lazier, MD Canadian College of Medical Geneticists (Liaison) (outgoing)

Shaun Morris, MD IMPACT (Immunization Monitoring Program ACTive)

Stevie O'Brien, JD Consultant (incoming)

Paul Dancey, MD

Alison Eaton, MD

Karen Forbes, MD

Marie Adèle Davis. MBA

Elizabeth Donner, MD Evelyne Doyon-Trottier, MD

Jay Onysko, MA

Centre for Surveillance and Applied Research, Public Health Agency of Canada

Christina Ricci, MPH

Centre for Surveillance and Applied Research, Public Health Agency of Canada

Chelsea Ruth, MD Canadian Paediatric Society

Miriam Santschi, MD Canadian Paediatric Society (outgoing)
Patrick Seitzinger, MD Canadian Paediatric Society (Resident)

Sam Wong, MD Canadian Paediatric Society

Dr. Miriam Santschi completed an eight-year term on the CPSP Scientific Steering Committee as a representative of the Canadian Paediatric Society. The members of the Committee will greatly miss Dr. Santschi and would like to extend their sincere thanks for her dedication to the Program and her valuable expertise. We wish her all the very best in her future endeavours.





The CPSP Scientific Steering Committee would like to express its gratitude to Dr. Joanna Lazier who served on the Committee as a representative of the Canadian College of Medical Geneticists. Her stewardship and guidance, especially on issues of medical genetics, were very much appreciated by the Committee. We wish her great success in her future pursuits.

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 2700 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).

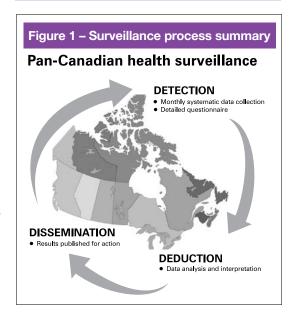
Process

- 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/criteriafor-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.

CPSP Quick Facts

Did you know?

- The CPSP celebrated its 28th anniversary in 2024.
- The CPSP is comprised of approximately 2700 dedicated paediatricians and paediatric subspecialists.
- Since its inception, the CPSP has studied 89 rare conditions/diseases and initiated 62 one-time surveys.
- Over 100 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 2024, 98% of participants had committed to receiving their monthly forms electronically.



- 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.

- It is important to note that CPSP studies use non-identifiable 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 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:

- The results presented in this annual report are provisional. At the time when investigators are asked to prepare study reports, some clinical questionnaires may still be pending. Once pending questionnaires are analyzed, study conclusions may change. Especially for preliminary study reports, the distribution of cases by province/territory may not be representative of the study's final results.
- 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.
- Reporting on minimum incidence rates can under-represent events in the population. For example, some cases may not be included in the surveillance totals because they presented to family doctors or other health care practitioners and not to paediatricians, while others may live in rural or remote areas and 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.
- Studies may only collect data on the patient/family's self-declared race/ethnicity/Indigenous identity if approved by a research ethics board and, as of 2023, only if the reporting physician's practice setting already systematically collects this data.
- During 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 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 2024

| Provinces/territories | Reporting rates (%)* | Number of participants [†] |
|---------------------------|----------------------|-------------------------------------|
| Alberta | 85 | 355 |
| British Columbia | 82 | 319 |
| Manitoba | 89 | 96 |
| New Brunswick | 70 | 35 |
| Newfoundland and Labrador | 77 | 43 |
| Northwest Territories | _ | <5 |
| Nova Scotia | 89 | 79 |
| Nunavut | _ | <5 |
| Ontario | 84 | 1014 |
| Prince Edward Island | 94 | 12 |
| Quebec | 77 | 484 |
| Saskatchewan | 87 | 62 |
| Yukon | _ | <5 |
| Canada | 82 | 2508 |

^{*} 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. According to CPSP privacy policy, some values have been suppressed.

TABLE 2 – National initial response rates 2020–2024

| Reporting year | Reporting rates (%) |
|----------------|---------------------|
| 2020 | 81 |
| 2021 | 80 |
| 2022 | 80 |
| 2023 | 83 |
| 2024 | 82 |

[†] The total number of individual CPSP participants is approximately 2700. 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 3 - 2024 detailed questionnaire completion rates as of April 8, 2025*

| Studies/conditions | Notifications of potential cases | Pending | % completion rate |
|--|----------------------------------|---------|-------------------|
| Acute flaccid paralysis [†] | 57 | 1 | 98 |
| Acute life-threatening harms related to illicit/non-medical use of opioids, stimulants, or sedatives | 7 | 1 | 86 |
| Adverse drug reactions – serious and life-threatening | 7 | 3 | 57 |
| Adverse events related to virtual care | _ | _ | _ |
| Fetal alcohol spectrum disorder diagnosis in school-age children | 17 | 4 | 77 |
| Hyperglycemic hyperosmolar state | 11 | 0 | 100 |
| Hypoglycemia during treatment of acute lymphoblastic leukemia | _ | _ | _ |
| Post-COVID-19 condition (long COVID) | 21 | 2 | 91 |
| Serious and life-threatening events associated with non-medical (recreational) cannabis use in Canadian children and youth | 48 | 7 | 85 |
| Total number of cases (all studies) | 177 | 19 | 89 |

^{*} 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. According to CPSP privacy policy, some values have been suppressed.

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

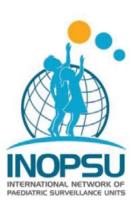
Met case definition: Cases verified as meeting the case definition, excluding duplicate case reports, cases failing to meet the case definition, cases pending verification, and cases reported from Quebec from institutions without project-specific research ethics board approval

[†] Includes case notifications from Quebec from centres with project-specific research ethics board approval. For all other studies, case notifications from Quebec were excluded.

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.

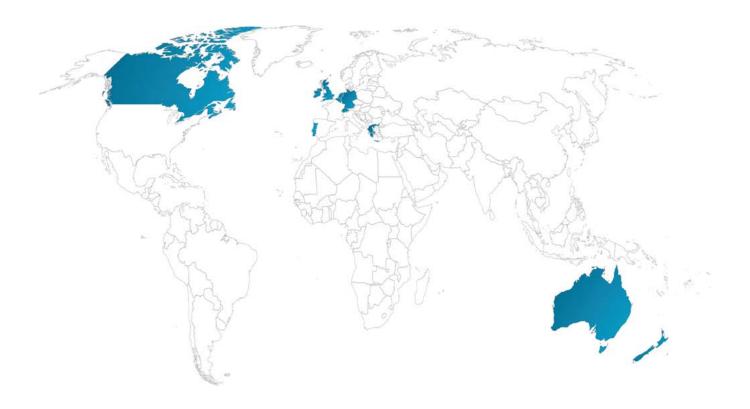
Established in 1998, INOPSU's membership includes many paediatric surveillance units from around the world, from Canada to New Zealand. Many of the paediatric surveillance units have been collecting data on rare childhood conditions for 20 years or more. Over 300 rare conditions have been studied to 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 2024

Acute flaccid paralysis

Study duration: Ongoing study since January 1996



Principal investigator (interim)

Marina I. Salvadori, MD, FRCPC, Senior Medical Advisor, Infectious Diseases and Vaccination Programs Branch, Public Health Agency of Canada; marina.salvadori@phac-aspc.gc.ca

Co-investigator Nicole Salem

Marina Salvadori



Question

Did Canada maintain its polio-free status in 2024?



Importance

- Poliomyelitis is targeted for eradication, with only two countries having ongoing wild poliovirus transmission, as well as several
 countries experiencing outbreaks of vaccine-derived polio. 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 https://cpsp.cps.ca/surveillance/study-etude/acute-flaccid-paralysis.

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 13 paediatric tertiary care 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 2024

Note: This report represents a snapshot as of February 4, 2025. There may be uncaptured cases in this report due to reporting delays. The total AFP case counts for 2020 to 2024 have been updated with all the confirmed cases that have been reported and are presented in Table 2.

| TABLE 1 – AFP cases in 2024 | | | | |
|---|---|---|---|----|
| Reported Duplicates Excluded Pending Met case definition* | | | | |
| 50 | 2 | 8 | 8 | 32 |

^{*} 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 Centre mère-enfant Soleil—CHU de Québec—Université Laval.

| TABLE 2 – Annual comparison of AFP cases 2020–2024 | | | | |
|--|--|--|--|--|
| Year Total cases | | | | |
| 32 | | | | |
| 34 | | | | |
| 28 | | | | |
| 10 | | | | |
| 2020 30 | | | | |
| | | | | |

Cases that met the case definition

- At the time of analysis, 32 cases were verified as meeting the AFP case definition in 2024; none were assessed as meeting the
 polio case definition. Twenty-eight of 32 cases (88%) were reported through an IMPACT centre.
- The median time from case onset of paralysis to reporting to the Public Health Agency of Canada was 56 days (IQR 30.8–206.5).

Demographics

- Where sex was reported, 18/30 (60%) were female and 12/30 (40%) were male.
- Cases ranged in age from one month old to 14.6 years, with a median age of 5.8 years.

Presentation and diagnosis

- All 32 (100%) cases were hospitalized. The median length of hospital stay was 8 days (IQR 6.0–13.0).
- Nearly half (15/32, 47%) of the cases were diagnosed with Guillain-Barré syndrome.
 The most common other causes included transverse myelitis and acute disseminated encephalomyelitis. No cases had a missing or unknown final diagnosis.
- For cases eligible for vaccination based on age and had vaccination status recorded, 23/30 (77%) reported being up-to-date for their polio vaccinations, based on routine vaccination schedules within their jurisdiction.
- Only 9/32 (28%) cases had stool samples submitted for viral testing; 6 (67%) of those 9 cases were taken within 14 days of paralysis onset. No stool samples were positive for polio.



- Thirty of the 32 (94%) cases had an outcome documented at initial report, of which 24 (80%) reported a full or partial recovery.
- Fourteen cases had a clinical outcome reported at least 60 days after the onset of paralysis or weakness, representing 45% of the cases eligible for follow up (excludes cases where no follow-up was conducted based on a full recovery at the initial assessment). Of the cases with follow-up, 11 (79%) cases reported a full recovery. No fatalities were reported at the initial or follow-up assessment.

| TABLE 3 – Measure of Canada's performance against WHO AFP surveillance performance indicators in 2024 ¹ | | | | | |
|--|------|-------|-------|--|--|
| Number of cases Incidence rate* % with adequate stool sample ^{†§} % with 60-day follow-up ^{‡§¶} | | | | | |
| 32 | 0.51 | 18.8% | 45.2% | | |

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

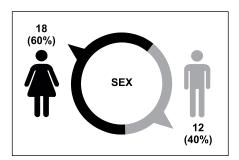
Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- Canada's performance on the WHO surveillance indicators should be interpreted with caution. Canada, like many other countries that have achieved polio elimination, does not consistently meet the recommended performance indicators for AFP surveillance for a number of reasons, including:
 - Availability of rapid diagnostic testing and imaging often leads to a final diagnosis prior to the collection of stool, and outcome at 60 days may not be available or may be deemed not applicable by the clinician.
 - Retrospective data collection is periodically conducted to increase the sensitivity of reporting. As such, case-level surveillance
 data are extracted following the clinical encounter during which stool samples may not have been obtained and follow-up may
 not have been arranged, or information was not available at the time of reporting.
 - Stool samples in patients with AFP are sometimes difficult to obtain due to the nature of the patient's symptoms, including constipation.



Conclusions

- Although Canada did not meet the WHO performance indicators for national AFP surveillance in 2024, there was sufficient evidence
 to suggest that no polio cases occurred in Canada.
- 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.
- 1. Detailed information on WHO surveillance performance indicators can be found at https://polioeradication.org/what-we-do/surveillance-indicators/



[†] 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

Toses deemed not applicable for follow-up based on a full recovery or fatal outcome at initial assessment are excluded from the denominator



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 paralysis: A call for clinical vigilance. Salem N, Grudeski E, Booth TF, Bhagat D, Salvadori MI. *Paediatr Child Health* 2024 Dec 15;30(1):6–7. doi: 10.1093/pch/pxae100. eCollection 2025 Feb

Acknowledgements

The investigators would like to thank everyone who participated in collecting the data. They would also like to acknowledge the excellent work of Sagikaa Rajakumar, Disha Bhagat, and Kristyn Franklin from the Public Health Agency of Canada.

Acute life-threatening harms related to illicit/ non-medical use of opioids, stimulants, or sedatives

Study duration: October 2024 to September 2027



Matthew Carwana

Principal investigators

Matthew Carwana, MD, MPH, FRCPC, FAAP, Paediatrician, BC Children's Hospital; Clinical Assistant Professor, University of British Columbia; Investigator, BC Children's Hospital Research Institute; matthew.carwana@cw.bc.ca

Nicholas Chadi, MD, MPH, FRCPC, FAAP, Adolescent and Addiction Medicine, Centre hospitalier universitaire Sainte-Justine; Clinical Associate Professor, Department of Paediatrics, Université de Montréal; nicholas.chadi.med@ssss.gouv.gc.ca

Eva Moore, MD, MSPH, FRCPC, FAAP, Adolescent Medicine Physician, BC Children's Hospital; Clinical Associate Professor, Department of Paediatrics, University of British Columbia; eva.moore@cw.bc.ca

Co-investigators

Richard Bélanger, Daniel Brody, Sara Citron, Jessica Foulds, Camille Fournier, Sarah Gander, Christina Grant, Laurie Horricks, Karen Leslie, Charlotte Moore Hepburn, Tatiana Sotindjo, Laurence Truchon, Trisha Tulloch

Collaborator

Bridget Maloney-Hall



Questions

- What is the minimum incidence of toxicity related to illicit/non-medical use of opioids, stimulants and sedatives in children and adolescents in Canada?
- What are the most common co-morbidities and features of presentations that paediatric providers should be aware of?



Importance

Overdose from illicit drug toxicity is the leading cause of death for adolescents in British Columbia, and of increasing concern elsewhere in Canada. Epidemiology for this condition, including detailed patient demographics, co-morbidities, and treatment outcomes, are lacking.



Methodology

The complete protocol can be accessed at https://cpsp.cps.ca/surveillance/study-etude/acute-life-threatening-harms-related-to-illicit-non-medical-use-of-opioids-stimulants-or-sedatives.

Case definition

Any patient less than 18 years of age (up to their 18th birthday) requiring any of the following:

- Emergency department care, hospitalization, or admission to an intensive care unit (ICU)
- Resuscitation (e.g., naloxone) outside of hospital*

Due to either of the following:

- Use of an illicit/non-prescription opioid, stimulant, or sedative substance
- Non-medical use of a prescription opiate (e.g., codeine, hydromorphone, oxycodone), stimulant (e.g., psychostimulant), or sedative
 drug (e.g., benzodiazepine, barbiturate) (e.g., using prescription medication in a manner other than as prescribed, using prescription
 medication prescribed to someone else)

Exclusion criteria

- A condition due to inadvertent exposure to another person's substances (e.g., child accidentally ingesting an adult's substance)
- A condition resulting from use of an illicit substance during pregnancy/breastfeeding (information already captured elsewhere)
- · A condition resulting from indicated use of medications prescribed to the patient for medical purposes
- · A condition arising from accidental misuse of medications prescribed to the patient for medical purposes
- · A condition resulting solely from the use of alcohol, cannabis, vaping, cigarettes, and/or tobacco products
- * Children and adolescents who experienced a critical toxicity incident and received only emergency resuscitation outside of hospital at the time of the incident (e.g., community-based naloxone administration) are eligible for this study when they present for a first health care visit following resuscitation in the community.

Unique to this study

- This is the only known national surveillance study among paediatric providers for adolescents with harms related to illicit substance use in Canada.
- This is the first study to collect patient demographics, including co-morbidities, at a national level.



Results - October to December 2024

| TABLE 1 – Cases of acute life-threatening harms related to illicit/non-medical use of opioids, stimulants, or sedatives from October 1 to December 31, 2024 | | | | | | |
|---|---|--|--|--|--|--|
| Reported | Reported Duplicates Excluded Pending Met case definition* | | | | | |
| 10 1 2 2 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 cases met the case definition from October 1, 2024 to December 31, 2024 and two cases were pending verification.

Demographics

As per Canadian Paediatric Surveillance Program (CPSP) policy, data elements with fewer than five cases cannot be presented.

Presentation and diagnosis

All of the reported cases (5/5, 100%) had at least one concurrent mental health disorder (e.g., mood disorder, anxiety disorder, attention deficit hyperactivity disorder).

Treatment and outcomes

As per CPSP policy, data elements with fewer than five cases cannot be presented.

Study limitations

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



Conclusions

- At the time of analysis, this study had only just launched. More time is required before conclusions can be drawn. Data collection will
 continue until September 2027.
- From the limited data available, patients presenting with overdose syndromes have high rates of co-occurring mental health conditions.



Anticipated study impact

This study will allow clinicians and policy makers to co-develop overdose interventions alongside youth to mitigate harms and improve health outcomes.

Acknowledgements

Thank you to the CPSP team, particularly Melanie King, for all of the support with the study.

Adverse drug reactions – serious and life-threatening

Study duration: Ongoing study since January 2004



Principal investigator
Sally Pepper, BScPhm, RPh, Patient Safety Section, Marketed Health Products Directorate, Health Canada; sally.pepper@canada.gc.ca

Sally Pepper



Question

What serious and life-threatening events suspected to be related to adverse drug reactions (ADRs) in children and youth were reported in 2024?



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 https://cpsp.cps.ca/surveillance/study-etude/adverse-drug-reactions-serious-and-life-threatening.

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 2024

| TABLE 1 – ADR cases in 2024 | | | | | |
|--|---|----|----|----|--|
| Reported Duplicates Excluded Pending Met case definition | | | | | |
| 9 | 0 | <5 | <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 suspected serious or life-threatening paediatric ADR reports were verified as meeting the case definition in 2024.

| TABLE 2 – Annual comparison of ADR cases 2020–2024 | | | |
|--|----|--|--|
| Year Total cases | | | |
| 2024 | <5 | | |
| 2023 | 9 | | |
| 2022 11 | | | |
| 2021 | 5 | | |
| 2020 | 9 | | |

 Consistent with the trend seen in previous years, the health product class (using the Anatomical Therapeutic Chemical classification system) most frequently suspected of causing the adverse reactions in 2024 was antibacterials.

Demographics

A 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 due to the small number of cases reported in 2024.

Study limitations

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

- The class of health products most frequently suspected of causing adverse reactions in 2024 was antibacterials.
- Since the implementation of the CPSP surveillance for adverse reactions in 2004, the product classes most frequently associated with suspect products have been antibacterials for systemic use, antiepileptics, and psychoanaleptics. The most frequently reported suspect drugs in these classes are amoxicillin, carbamazepine, and methylphenidate respectively. No reports meeting the study criteria were received in 2024 for antiepileptics and psychoanaleptics.



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 safety and efficacy in the paediatric population are limited.^{1, 2}
 The 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 ADRs 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.

^{1.} Klassen TP, Hartling L, Craig JC, et al. Children are not just small adults: the urgent need for high-quality trial evidence in children. *PLoS Medicine* 2008;5(8):1180-2

^{2.} Abi Khaled L, Ahmad F, Brogan T, et al. Prescription medicine use by one million Canadian children. Paediatr Child Health 2003;8(A):6A-56A

Adverse events related to virtual care

Study duration: February 2023 to January 2025



Ellen Goldbloom

Principal investigators

Ellen Goldbloom, MD, FRCPC, Deputy Chief Medical Information Officer, Ambulatory Care Medical Director, Paediatric Endocrinologist, Children's Hospital of Eastern Ontario; Associate Professor, Department of Paediatrics, University of Ottawa; Clinical Investigator, CHEO Research Institute; egoldbloom@cheo.on.ca

Shelley Vanderhout, PhD, Scientist, Learning Health Systems, Trillium Health Partners; shelley vanderhout@thp.ca

Co-investigators

Dominic Allain, Imaan Bayoumi, Jill Chorney, Megan Cooney, David Creery, Janet Curran, Tammie Dewan, Olivier Drouin, Gary Garber, Sarah Hall, Michael Hill, Brenden Hursh, Sara Jassemi, Kristopher Kang, Jim King, Patricia Li, Lillian Lim, Julia Orkin, Dawn Pickering, Hasu Rajani, Phillippe Robaey, Daniel Rosenfield, Anne Rowan-Legg, Sumeet Sadana, Holden Sheffield, Sam Wong, Kelley Zwicker

Collaborators

Kim Courtney, Christine Kouri, Alex Petiguan, Martha Pinheiro-Maltez, Cecile Rousseau, Julianna Saoud



Questions

- What is the burden and nature of recognized adverse events (AEs) suspected to be related to the provision of virtual care in the Canadian paediatric population?
- Is there any association between clinical and sociodemographic characteristics and the likelihood of an AE related to virtual care?



Importance

- Though there are benefits to providing virtual care, it is unknown whether virtual care leads to adverse medical outcomes that would not occur if care was delivered in person.
- Results of this surveillance may help paediatricians, public health authorities, and health care systems make evidence-informed decisions to guide care delivery recommendations and programs for children and adolescents receiving care virtually.



Methodology

The complete protocol can be accessed at https://cpsp.cps.ca/surveillance/study-etude/adverse-events-related-to-virtual-care.

Case definition

Any patient less than 18 years of age (up to their 18th birthday) presenting with a new AE associated with harm that the reporting physician suspects is related to virtual care, including:

- Misdiagnosis: The limitations of virtual care in patient assessment results in incorrect, missed, or delayed diagnosis.
- Emergency without the ability to respond: The virtual care provider identifies an emergency clinical or social situation but is not able to provide timely emergency care.

Exclusion criteria

- · AEs not deemed to be related to virtual care
- · Near misses and no-harm incidents
- · Event due to connectivity issues that interfered with patient care but did not result in harm
- · AEs related to breach of privacy



Results - January to December 2024

| TABLE 1 – AEs related to virtual care cases in 2024 | | | | | |
|---|---|---|---|----|--|
| 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 for AEs related to virtual care in 2024.

Demographics

As per Canadian Paediatric Surveillance Program (CPSP) policy, 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 reported in 2024.

Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- This study will not capture unrecognized AEs nor AEs not recognized as being related to virtual care.
- AEs were reported based on the suspicion that they are related to virtual care; however, the determination of causation may not be
 possible.
- This study is collecting data on AEs causing harm that are recognized by paediatricians/subspecialists who are CPSP participants and not those recognized by patients, families/caregivers, or other health care providers.



Conclusions

- AEs suspected to be related to virtual care in children presenting to paediatricians and paediatric subspecialists do not appear to be frequent in Canada thus far, based on 23 months of surveillance data.
- If case ascertainment is correct and the incidence of these AEs is truly low, when the virtual care modality is being selected in appropriate circumstances, virtual care could be offered to provide patient- and family-centred care. Conversely, data collection techniques may not have completely captured AEs related to virtual care; further studies with different reporting mechanisms may help clarify this question.



Anticipated study impact

Results will contribute to the evidence base on paediatric virtual care and will help inform guidelines outlining the safe use of virtual care in paediatric practice, including when and for whom virtual care is not an adequate replacement for in-person care.

Acknowledgements

We would like to acknowledge and thank all of the physicians who reported cases to this CPSP study and provided data.

Fetal alcohol spectrum disorder diagnosis in school-age children

Study duration: November 2024 to October 2026



Principal investigators

Adam Probert, MSc, Senior Epidemiologist, Lifespan, Chronic Diseases and Conditions Division, Public Health Agency of Canada; adam.probert@phac-aspc.gc.ca

Sabrina Eliason, MD, FRCPC, Medical Director, Paediatric FASD Clinic, Glenrose Rehabilitation Hospital; Assistant Clinical Professor, Department of Paediatrics, University of Alberta; President, Developmental Paediatrics Section, Canadian Paediatric Society; sabrina.eliason@albertahealthservices.ca

Christine Loock, MD, FRCPC, Associate Professor, Department of Paediatrics, Faculty of Medicine, University of British Columbia; Executive Member, Social Paediatrics Section, Canadian Paediatric Society; cloock@cw.bc.ca

Co-investigators

Sarah Palmeter, Gurpreet Salh, Michael Sgro, Melissa Tremblay, Leigh Wincott

Questions

- How is fetal alcohol spectrum disorder (FASD) diagnosed among children aged 6 to 12 years, including clinical guidelines used, involvement of other health professionals, as well as the services and supports provided?
- · What is the minimum incidence of paediatrician-diagnosed FASD in children aged 6 to 12 years in Canada, how does it vary by age, sex, and location, and what are the common concurrent diagnoses?



Importance

- This study will improve understanding about how and where new cases of FASD are diagnosed in children in Canada and how diagnostic practices may influence the prevalence of this disorder. The information collected can support the development of guidelines and early intervention and/or prevention strategies related to FASD.
- Determining the incidence of FASD is key, as the information cannot be gathered from population-based surveys or derived effectively from health administrative data. Comparable international paediatric surveillance programs in Australia, New Zealand, and Britain have conducted analogous studies of FASD within their membership in the International Network of Paediatric Surveillance Units.



Methodology

The complete protocol can be accessed at https://cpsp.cps.ca/surveillance/study-etude/fetal-alcohol-spectrum-disorder-diagnosis-inschool-age-children.

Case definition

Any new diagnosis of FASD in children aged 6 to 12 years (up to their 13th birthday), using recognized/established FASD diagnostic guidelines

Unique to this study

The clinical questionnaire for this study was based on a study by the Australian Paediatric Surveillance Unit, thus facilitating international comparisons of the findings.



Results - November to December 2024

| TABLE 1 - Cases of FASD diagnosis in school-age children from November 1 to December 31, 2024 | | | | |
|---|------------|----------|---------|----------------------|
| Reported | Duplicates | Excluded | Pending | Met case definition* |
| 20 | 1 | 6 | 5 | 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, eight cases met the case definition between November 1, 2024 to December 31, 2024 and an additional five cases were pending verification.

Demographics

Cases ranged in age from 9 to 12 years.

Presentation and diagnosis

All of the verified cases had confirmed prenatal alcohol exposure, and the diagnosis was made employing the Canadian FASD Guidelines.

Treatment and outcomes

Among cases, the most common types of services and support provided for the patients were psychology/counselling, educational support, and respite/mentor/community support.

Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- It is possible that there might not be sufficient access to paediatric care in some areas of the country, leading to under-reporting.
 Early monitoring of the geographic distribution of case reports and follow-up with non-responsive CPSP paediatricians in under-represented areas might mitigate this issue.
- The CPSP does not include family physicians; therefore, any cases initially diagnosed and managed by family physicians will not be captured. Yet, as the Canadian diagnosis guidelines are targeted towards paediatricians making the FASD diagnosis, this may not be a concern.



Conclusions

With only two months of data collection in 2024, conclusions are not available at this stage of the study. Data collection will continue until October 2026.



Anticipated study impact

- Studies like this contribute to increasing awareness about FASD and providing needed evidence to support prevention, diagnosis, and health care services.
- Information collected by this study may be used to support the development of a potential Canadian Paediatric Society (CPS)
 position statement, and other knowledge translation activities related to FASD diagnosis. If variation in diagnostic practices,
 standards, and norms is found, this information could be used to inform the development of educational tools (e.g., CPS Annual
 Conference seminars and/or workshops) on FASD case identification and diagnosis.
- Information on racialized and Indigenous groups can help identify potential factors related to inequities regarding FASD diagnosis across populations.



Publication and dissemination

New CPSP study on fetal alcohol spectrum disorder. Canadian Paediatric Society. CPS news: Fall-Winter 2024: https://cps.ca/uploads/publications/cpsnews-fall-winter-2024.pdf

Acknowledgements

We would like to acknowledge and thank all of the physicians who reported cases to this CPSP study and provided data. We would also like to thank Dr. Tracey Tsang and Dr. Elizabeth Elliot of the Australian Paediatric Surveillance Unit for their assistance in developing the clinical questionnaire.

Hyperglycemic hyperosmolar state

Study duration: June 2023 to May 2025



Principal investigators

Paul MacDaragh Ryan, MB, BCh, BAO, PhD, Paediatrics Resident, Department of Paediatrics, University of Toronto, The Hospital for Sick Children; paul.ryan@sickkids.ca

Jill Hamilton, MD, MSc, FRCPC, Head, Division of Endocrinology, The Hospital for Sick Children; Professor, Department of Paediatrics, University of Toronto; Senior Associate Scientist, SickKids Research Institute; iill.hamilton@sickkids.ca

Co-investigators

Shazhan Amed, Elizabeth Sellers

Collaborators

Ereny Bassilious, Tracey Bridger, Stasia Hadjiyannakis, Andrea M. Haqq, Andrew Helmers, Josephine Ho, Mona Jabbour, Munier Nour, Mona Patel, Teresa Pinto



Questions

- What is the minimum annual incidence of hyperglycemic hyperosmolar state (HHS) in children and adolescents across Canada?
- What are the populations that are most at risk for HSS, and what are the precipitating factors?
- What degree of morbidity and mortality is associated with HHS?
- What are the relative contributions of the different types of diabetes to cases of HHS?
- How frequently is HHS the first presentation of diabetes in children and adolescents?



Importance

- · Cases of HHS in the literature are relatively few, but frequently carry high morbidity or even mortality.
- HHS is a likely under-recognized hyperglycemic emergency, which may be confused for hyperosmolar diabetic ketoacidosis, and the
 implications of delayed or failed recognition are not known.
- This is the first surveillance study of its kind to attempt estimation of the minimum annual incidence of HHS in children and adolescents.



Methodology

The complete protocol can be accessed at https://cpsp.cps.ca/surveillance/study-etude/hyperglycemic-hyperosmolar-state.

Case definition

Any patient less than 18 years of age (up to the 18th birthday), with or without a prior diagnosis of diabetes, presenting to hospital with hyperglycemic hyperosmolar state (HHS), defined as:

- Serum glucose concentration of >33 mmol/L
- Serum osmolality of >320 mOsm/kg
- · Absence of significant acidosis:
 - Serum bicarbonate concentration of >15 mEq/L
 - Arterial/capillary pH of >7.30 or venous pH of >7.25

This case definition aligns with the current Diabetes Canada diagnostic criteria for HHS with one important amendment: ketosis is **NOT** an exclusion factor. The rationale for including ketosis is that the original HHS definition was based on adult presentation, and it is well demonstrated that more than 40% of children and adolescents with type 2 diabetes present with ketones (even if not acidotic).



Results - January to December 2024

| TABLE 1 – Hyperglycemic hyperosmolar state cases in 2024 | | | | |
|--|------------|----------|---------|----------------------|
| Reported | Duplicates | Excluded | Pending | Met case definition* |
| 11 | 1 | 5 | 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, a total of five cases met the case definition of HHS across Canada from January 1, 2024 to December 31, 2024.

Demographics

- Of the five cases, the majority were male, with a mean age at onset of 12.4 years (SD 4.4 years), and a minority population predominance.
- Pre-existing comorbidities included diabetes, developmental issues or intellectual disability, seizures, obesity, and sleep apnea.

Presentation and diagnosis

- Identified triggers of illness included infection/dehydration and trauma/surgery.
- The most common presentations were altered level of consciousness, or Glasgow Coma Scale <13, and polyuria. Additional signs
 on presentation included polydipsia, nausea/vomiting, and acanthosis nigricans.
- Mean venous pH was 7.32 (SD 0.04), mean serum glucose was 39.8 mmol/L (SD 6.1), mean serum bicarbonate was 24.4 mEq/L (SD 7.8), and mean serum osmolarity was 377.4 mOsm/kg (SD 34.8).

Treatment and outcomes

- Initial bolus and further rehydration intravenous fluid volumes (range 10–20 ml/kg) and compositions were heterogenous, but all children were started on an insulin infusion at some point during hospital admission.
- · Main complications reported during admission included hypokalemia, hyperkalemia, and impaired renal function.
- Most of the children required paediatric intensive care unit admission and hospital length of stay data was variable but revealed a
 mean admission duration of 21.8 days (SD 21.2).
- There were no mortalities at the time of discharge.

Study limitations

- Limitations common to all CPSP studies are listed on page 11.
- The present study excludes all cases reported from within Quebec due to provincial privacy legislation.
- · The low number of reported cases may limit the generalizability of conclusions garnered from this study.



Conclusions

- Although HHS remains a relatively uncommon hyperglycemic emergency amongst children in Canada and no mortalities were
 recorded in this period, presentations were severe, generally including significantly altered level of consciousness and requirement
 for intensive care unit level of care.
- Although several additional reports of cases of hyperosmolar hyperglycemia were received over the reporting period, these
 represented cases of hyperosmolar diabetic ketoacidosis in children with type 1 diabetes.
- Children of minority ethnicity were disproportionately over-represented.
- · Similarly, those with developmental delay, neurodevelopmental issues, or intellectual disabilities were also reported more commonly.
- Data collection will continue for a further 6 months, to a total of 24 months.



Anticipated study impact

- It is hoped that the study results may inform prospective clinical practice guidelines, providing Canada-specific information on the
 presentation, management, and rates of complications of HHS in children and adolescents.
- Additionally, this work may highlight individual populations who are most at risk of developing HHS, allowing implementation of
 preventative measure.



Publication and dissemination

Hyperglycaemic hyperosmolar state: No longer an endocrine crisis exclusive to adulthood. Ryan PM, Sellers EAC, Amed S, Hamilton JK. *Paediatr Child Health* 2023 Nov 7;29(2):81–3. doi: 10.1093/pch/pxad073. eCollection 2024 May

Acknowledgements

We wish to acknowledge the excellent work of Ms. Melanie Laffin, former Senior Manager Surveillance, Canadian Paediatric Society, and Ms. Christina Ricci, Epidemiologist, Public Health Agency of Canada, in progressing this study to launch.

Hypoglycemia during treatment of acute lymphoblastic leukemia

Study duration: October 2022 to September 2024 - Final report



Mary Jiang

Principal investigators

Mary Jiang, MD, FRCPC, Paediatric Endocrinology Fellow, Children's Hospital of Eastern Ontario, University of Ottawa; MJiang@cheo.on.ca

Alexandra Ahmet, MD, FRCPC, Paediatric Endocrinologist, Children's Hospital of Eastern Ontario, Associate Professor of Paediatrics, University of Ottawa; AAhmet@cheo.on.ca

Scott Somerville, MD, FRCPC, Paediatric Endocrinologist, Children's Hospital of Eastern Ontario; SSomerville@cheo.on.ca

Co-investigators

Mylene Bassal, Andrea Ens, Hannah Geddie, Paul Gibson, Geneviève Goulet, Melissa Harvey, Ara Healey, Caroline Laverdière, Paola Luca, Seth D. Marks, John Mitchell, Arati Mokashi, Constadina Panagiotopoulos, Angela Punnett, Isabelle Rousseau-Nepton, David Saleh, Judith Simoneau-Roy, Matthew Speckert, Richelle Waldner, Daphne Yau

Questions

- What is the minimum incidence of a first episode of biochemically proven hypoglycemia while being treated for acute lymphoblastic leukemia (ALL)?
- What is the frequency of a first episode of symptomatic hypoglycemia while being treated for ALL?
- What is the timing of onset of hypoglycemia associated with treatment for ALL and its duration?
- What are the management strategies for hypoglycemia associated with treatment for ALL?



Importance

- Likely under-appreciated, a recently recognized adverse event associated with standard ALL treatment is hypoglycemia. Two
 medications that have been found to be associated with hypoglycemia are asparaginase (most commonly in the form of L- and
 peq-asparaginase) and 6-mercaptopurine (6-MP).
- Hypoglycemia places children at risk of decreased level of consciousness, seizures, and possibly negative neurocognitive sequelae, especially in younger children.



Methodology

The complete protocol can be accessed at https://cpsp.cps.ca/surveillance/study-etude/hypoglycemia-and-all.

Case definition

Any patient less than 18 years of age (up to the 18th birthday) with a **first known** episode of biochemically proven hypoglycemia via laboratory serum glucose sample (if not available, then point-of-care) with blood glucose level below 3.0 mmol/L during chemotherapy for acute lymphoblastic leukemia (ALL) (all agents and protocols)

Exclusion criteria

Patients who have had a previous documented episode of biochemical hypoglycemia during chemotherapy for ALL (blood glucose <3.0 mmol/L)

Unique to this study

The study team will be collaborating with the Cancer in Young People in Canada program (CYP-C) to clearly identify the denominator of patients with ALL who were treated with the various forms of asparaginase during the study period.

Results - October 2022 to September 2024

| TABLE | TABLE 1 – Hypoglycemia during treatment of ALL cases from October 1, 2022 to September 30, 2024 | | | | |
|-------------------|---|------------|----------|---------|----------------------|
| Year | Reported | Duplicates | Excluded | Pending | Met case definition* |
| 2022† and 2023 | 10 | 0 | 0 | 0 | 10 |
| 2024 [‡] | 7 | 1 | 0 | 1 | 5 |
| Total | 17 | 1 | 0 | 1 | 15 |

^{*} 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 15 cases were confirmed to have met the case definition from October 1, 2022 to September 30, 2024. One case was pending verification.

Demographics

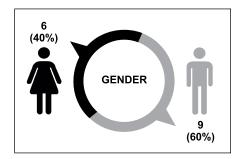
- Most cases were of male gender (9/15, 60%).
- The median age at presentation was 5.31 years (IQR 2.67–7.83).
- The median body mass index percentile was 43% (IQR 27-98).
- Two thirds of cases (10/15, 67%) were from Western Canada.

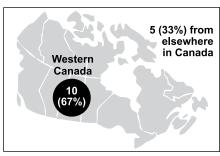
Presentation and diagnosis

- Almost half of the cases presented as inpatients (7/15, 47%), a third presented in the outpatient oncology clinic (5/15, 33%), and the remaining cases presented to the emergency department or presented at home.
- Of those who documented presence or absence of symptoms, half of the patients were asymptomatic (7/14, 50%) and hypoglycemia was found on routine bloodwork. Half presented with symptoms (7/14, 50%), including altered level of consciousness, seizure, tremor/jitteriness, diaphoresis, hunger, nausea, fatigue, and dizziness. The most common symptom was tremors/jitteriness (5/7, 71%).
- Just over half of the patients had multiple occurrences of hypoglycemia (8/15, 53%). Almost all patients required treatment to prevent subsequent hypoglycemia (see *Treatment and outcomes* below).
- Most patients were not on steroids at the time of their hypoglycemic episode but had
 previous steroid exposure (11/15, 73%). Of those who had previous steroid exposure,
 almost all cases had received dexamethasone (10/11, 91%) and, in over half of those cases, more than 14 days had elapsed since
 last steroids (6/11, 55%).
- The median presenting blood glucose was 2.6 mmol/L (IQR 2.3–2.9). More than half of the patients (9/15, 60%) had laboratory venous glucose sample rather than point-of-care testing for the presenting blood glucose level. One third of patients had a critical sample drawn (5/15, 33%).
- Nine patients had hypoglycemia within 40 days of peg-asparaginase exposure (9/15, 60%).
- Six patients had hypoglycemia within seven days of 6MP completion (6/15, 40%).
- No patients had a glucagon stimulation test to evaluate the etiology of hypoglycemia.
- Hypoglycemia occurred a median of 17 days (range 9–38) following peg-asparaginase exposure, lasting a median duration of 7.5 days (range 1–89).
- Hypoglycemia occurred a median of 51 days (range 2–697) following initiation of the most recent 6MP course, lasting a median duration of 1 day (range 1–389).

Treatment and outcomes

- Almost all patients required some form of intervention for their hypoglycemia (14/15, 93%). Six patients had ongoing treatment at the time of reporting (6/14, 43%).
- Of those who had completed treatment at the time of reporting (8/14, 57%), the median days receiving treatment was 2 days (range 1–8).
- Two thirds of patients required enteral glucose (e.g., juice, snacks, nasogastric feeds) to treat their hypoglycemia (10/15, 67%). Six patients required IV dextrose (6/15, 40%), while other patients required different treatments for hypoglycemia (e.g., cornstarch, changing timing of 6MP).
- · For patients admitted to the hospital, hypoglycemia was not reported to prolong hospitalization for any patients.





[†] October 1 to December 31, 2022

[‡] January 1 to September 30, 2024

Study limitations

- Limitations common to all Canadian Paediatric Surveillance Program studies are listed on page 11.
- This study is limited to gathering data from patients who have biochemically proven hypoglycemia. Therefore, the study will not be
 able to capture the true incidence of hypoglycemia including symptomatic or asymptomatic patients for whom a blood glucose
 was never drawn.
- In hospitalized patients, hypoglycemia may be masked by the use of glucose containing intravenous fluids.
- It is difficult to define hypoglycemia using a single glucose value as it also depends on the history of disorders that may cause
 hypoglycemia, the patient's current clinical condition, on the availability of energy sources, and ongoing energy demands. Therefore,
 the definition used in the study (<3.0 mmol/L) may not capture all cases.



Conclusions

- Hypoglycemia is a rare but significant adverse drug reaction in ALL treatment.
- Half of the patients with hypoglycemia during treatment of ALL were asymptomatic at presentation, although severe symptoms, including altered level of consciousness and seizure, were reported. This result highlights the importance of screening to allow for management and prevention of severe hypoglycemia.
- Hypoglycemia following peg-asparaginase administration can present later and last longer compared to previously reported hypoglycemia with L-asparaginase. Etiology of hypoglycemia following peg-asparaginase appears to be most likely due to hyperinsulinism in the context of elevated insulin levels.
- Hypoglycemia due to 6-MP can occur at any point during therapy.
- Almost all patients required intervention to treat hypoglycemia.
- Our study suggests that clinicians need to be aware of hypoglycemia as a possible side effect of ALL therapy and should consider screening for hypoglycemia in children exposed to asparaginase and/or 6-MP.
- Given that hypoglycemia can present at various times during therapy, at minimum, families should be educated about the risk of
 hypoglycemia with ALL therapy and of symptoms that should prompt them to seek medical attention. Clinicians might also consider
 educating caregivers about treatment of mild to moderate hypoglycemic symptoms with sugar-containing fluids at symptom onset
 and prior to seeking medical attention.
- More research is needed to determine true incidence and etiology of hypoglycemia to help inform future guideline development.



Anticipated study impact

- This study will provide insight into the scope of this iatrogenic side effect in children undergoing ALL therapy.
- Study results may inform clinical guidance, screening, and strategies to prevent hypoglycemia during ALL therapy, as well as help to
 promote increased recognition of this adverse drug reaction.



Publication and dissemination

Hypoglycemia during treatment of acute lymphoblastic leukemia. Jiang M, Ahmet A. *Paediatr Child Health* 2023 May 15;28(5):305–6. doi: 10.1093/pch/pxad019. eCollection 2023 Aug

Hypoglycemia during treatment of acute lymphoblastic leukemia – A Canadian Paediatric Surveillance Program study. Jiang MR, Somerville S, Duan LX, Ens A, Geddie H, Gibson P, et al. 19th Annual Canadian Pediatric Endocrine Group Annual Scientific Meeting, London, Ontario, in February 2025 (oral presentation)

Acknowledgements

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

Post-COVID-19 condition (long COVID)

Study duration: September 2022 to August 2024 - Final report



Anu Wadhwa

Principal investigators

Anu Wadhwa, MD, MEd, FRCPC, University of Toronto, The Hospital for Sick Children; anupma.wadhwa@sickkids.ca

Shaun Morris, MD, MPH, FRCPC, FAAP, University of Toronto, The Hospital for Sick Children; shaun.morris@sickkids.ca

Sanjay Mahant, MD, FRCPC, University of Toronto, The Hospital for Sick Children; sanjay.mahant@sickkids.ca

Co-investigators

Rebecca Barmherzig, Michelle Barton, Jared Bullard, Malini Dave, Claire De Souza, Marie-Joëlle Doré-Bergeron, Leah Ethier, Anne Fuller, Jo-Anna Hudson, Charles Hui, Christos Karatzios, Kirk Leifso, Charlotte Moore Hepburn, Nisa Mullaithilaga, Nancy Nashid, Rupeena Purewal, Stanley Read, Christina Ricci, Sima Saleh, Katia Sinopoli, Alena Tse, Sze Man Tse, Otto Vanderkooi, Mumtaz Virji, Jacquie Wong, Peter Wong, Rae Yeung

Questions

- What is the minimum incidence of long COVID in children and youth in Canada?
- What are the demographics and characteristics of children and youth who present with long COVID?
- What are the clinical characteristics of this condition at presentation? Specifically, what are the symptoms at presentation (including duration) and the impact on the child's participation in daily activities?



Importance

- There is scant data regarding the incidence and clinical characteristics of long COVID in children and youth in Canada and the full extent of the burden of this illness in children in Canada is unclear.
- Based on early reports and clinical experiences managing children with long COVID, the health care services use for each patient can be significant.
- A better understanding of the extent and nature of this new condition in children is required so that health care systems may best support their recovery.



Methodology

The complete protocol can be accessed at https://cpsp.cps.ca/surveillance/study-etude/post-covid-19-condition.

Case definition

Any patient less than 18 years of age (up to the 18th birthday) who meets both of the following criteria:

1) Experiencing one or more new or persistent symptoms after recovery from acute COVID-19 (proven by laboratory testing and/or highly suspected based on clinical history)

AND

2) Symptom(s) have persisted for at least eight weeks



Results - September 2022 to August 2024

| TABLE 1 – Post-COVID-19 condition cases from September 1, 2022 to August 31, 2024 | | | | | |
|---|----------|------------|----------|---------|----------------------|
| Year | Reported | Duplicates | Excluded | Pending | Met case definition* |
| 2022 [†] | 21 | 0 | 3 | 2 | 16 |
| 2023 | 47 | 0 | 9 | 6 | 32 |
| 2024 [‡] | 23 | 0 | 3 | 3 | 17 |
| Total | 91 | 0 | 15 | 11 | 65 |

^{*} 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.

[†] September 1 to December 31, 2022

[‡] January 1 to August 31, 2024

Cases that met the case definition

At the time of analysis, 65 cases were verified as meeting the case definition for long COVID from September 1, 2022 to August 31, 2024. An additional 11 cases were pending verification.

Demographics

- Long COVID cases were reported from four provinces, with 86% of cases from Ontario.
- Of the 65 cases, 34 (52%) were female and 31 (48%) were male.
- In 48 cases (74%), the population group reported was White.
- Cases ranged in age from 3 to 17 years, with a median age of 12 years.

Presentation and diagnosis

- At least one co-morbid condition was reported in 44 cases (68%). Common co-morbidities included the following: anxiety (n=17), attention deficit hyperactivity disorder (ADHD) (n=10), depression (n=10), and allergies (n=9).
- None of the confirmed cases experienced hospitalization from multisystem inflammatory syndrome in children (MIS-C).
- Most patients (57/65, 88%) experienced a mild acute COVID-19 illness managed at home, while 6/65 cases (9%) were either seen in the emergency room or hospitalized during their acute illness.
- The most common persisting symptoms were fatigue (n=57), headache (n=39), light-headedness (n=36), brain fog (n=31), myalgia (n=31), and sleep disturbance (n=29).
 Of the 57 cases (88%) reporting fatigue, 43 (75%) experienced post-exertional fatigue.
- Long COVID cases presented to paediatric care a median of nine months after the onset of symptoms.
- Of the 57 cases who had microbiological testing to diagnose acute COVID-19, 36 were by rapid antigen testing and 16 by polymerase chain reaction (PCR).
- Most cases (55/65, 85%) had received two or more doses of a COVID-19 vaccine. Eight of these cases (15%) had onset of long COVID before their first vaccine dose. In 35/55 cases (64%) the patient had two doses or more of a COVID-19 vaccine prior to the onset of long COVID and, in 7/55 cases (13%), the patient had three or more doses before onset.
- In 21 cases (32%), the patient had at least one COVID-19 vaccine dose after the onset of long COVID; however, most families reported no effect of the vaccination on long COVID symptoms or were unsure if there had been any effect.

Treatment and outcomes

- The management of these 65 children and adolescents with long COVID included sleep hygiene measures (n=48), psychological/mental health support (n=42), rehabilitation strategies (e.g., physiotherapy, occupational therapy) (n=41), referral to additional specialists (n=41), and adjustment in school programming (n=20). The most common referrals were to psychiatry, chronic pain, and cardiology.
- There were various impacts on daily activities for children diagnosed with long COVID. The vast majority of patients (60/65, 92%) reported decreased involvement in physical activities, while 55 patients (85%) reported negative impacts on school performance, and 63 patients and their family members (97%) reported feelings of distress due to long COVID symptoms. Notably, 15 patients (23%) reported a decrease in the ability to perform self-care activities (e.g., dressing, bathing).

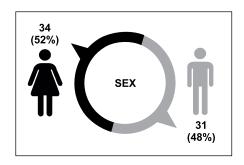
Study limitations

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



Conclusions

- These findings represent the results from 24 months of voluntary reporting surveillance by paediatricians and paediatric subspecialists.
- Children and youth are presenting to paediatricians across Canada with multiple persistent symptoms after acute COVID-19. Common persistent symptoms include fatigue, light-headedness, headache, brain fog, myalgia, and sleep disturbance.
- The majority of long COVID cases reported to date experienced a mild acute COVID-19 illness.
- The impact on daily activities for children was significant, with almost all reporting a decrease in physical activities and over 85% reporting a negative impact on school performance. A smaller but notable percentage (23%) reported a decrease in the ability to perform self-care activities.
- The management of patients with long COVID included multiple strategies addressing physical and mental health.







Anticipated study impact

- The study results will increase our understanding of the incidence, clinical characteristics, and impact on daily activities of this new condition in children and youth in Canada.
- A better understanding of the extent and nature of long COVID in children and youth is required so that health care systems may better support their recovery.



Publication and dissemination

Persistent symptoms after COVID-19 in children: Long COVID syndrome or long pandemic syndrome? Wadhwa A, Barmherzig R. Canadian Adolescent Medicine Rounds, virtual, in September 2022 (oral presentation)

Post-COVID-19 condition in children and youth in Canada: A Canadian Paediatric Surveillance Program study. Wadhwa A, Ricci C, Morris S, Mahant S (on behalf of the CPSP Long COVID study team). Health Canada Science Forum, Ottawa, in February 2023 (poster presentation)

Post-COVID-19 condition in children: The long and the (not so) short of it. Wadhwa A, Barmherzig R, Fuller A. SickKids Pediatric Update, Toronto, in May 2023 (oral presentation)

What do we know about long COVID in children and youth? Wadhwa A, Fuller A. Canadian Paediatric Society Annual Conference, Halifax, in May 2023 (oral presentation)

Post-COVID-19 condition in children: The long and the (not so) short of it. Wadhwa A. University Health Network Citywide Infectious Diseases Rounds, virtual, in October 2023 (oral presentation)

Post-COVID-19 condition in children: The long and the (not so) short of it. Wadhwa A. Long COVID Web Webinar Series, virtual, in January 2024 (oral presentation)

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

Study duration: Ongoing since September 2018



Richard Bélanger

Principal investigators

Richard E. Bélanger, MD, Department of Paediatrics, Centre mère-enfant Soleil—CHU de Québec—Université Laval; richard.belanger.med@ssss.gouv.qc.ca

Christina Grant, MD, Professor, Division of Adolescent Medicine, Department of Paediatrics, McMaster University; chgrant@mcmaster.ca

Co-investigators

Hanan Abramovici, Amy Acker, Seth D. Ammerman, Nathalie Gingras, Stephanie Jack, Charlotte Moore Hepburn, Shahid Perwaiz, Sieara Plebon-Huff, Robert Yates

Collaborator

Dirk Huyer, MD, Chief Coroner for Ontario



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 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 https://cpsp.cps.ca/surveillance/study-etude/serious-and-life-threatening-events-associated-with-non-medical-recreational-cannabis-use-in-canadian-children-and-youth.

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 2024

| TABLE 1 – Cases of serious and life-threatening events associated with non-medical use of cannabis in 2024 | | | | |
|--|------------|----------|---------|----------------------|
| Reported | Duplicates | Excluded | Pending | Met case definition* |
| 50 | 0 | 2 | 14 | 34 |

^{*} 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, 50 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 2024.
- At the time of analysis, 34 of these cases were verified as meeting the case definition in 2024 and 14 cases were pending verification.
- In comparison, in previous years of the study, the annual number of cases that met the case definition ranged from 21 to a high of 50 in 2020.

| TABLE 2 – Annual comparison of cases of serious and life-threatening events associated with non-medical use of cannabis 2020–2024 | | | |
|---|-------------|--|--|
| Year | Total cases | | |
| 2024 | 34 | | |
| 2023 | 21 | | |
| 2022 | 28 | | |
| 2021 | 34 | | |
| 2020 | 50 | | |

Demographics

- Patient sex was female in 17/34 cases (50%, 95 Cl 33–67) and male in 17/34 cases (50%, 95 Cl 33–67).
- The mean age was 6.5 years with a median age of 5.7 years. Most cases were among children 12 years of age and younger (30/34, 88%, 95 Cl 72–96).

Presentation and diagnosis

- Like in previous years, the most common primary presentation was unintentional poisoning/intoxication (27/34, 79%, 95 Cl 62–90), followed by cannabis-related disorders (8/34, 24%, 95 Cl 12–41). Some of these cases included multiple primary presentations (6/34, 18%, 95 Cl 8–35).
- Almost all of the unintentional poisoning/intoxication cases were children aged 12 years and younger (26/27, 96%, 95 Cl 76–100), and most cases involved cannabis in edible format (23/27, 85%, 95 Cl 65–95).
- Overall, 29/34 cases (85%, 95 CI 68–94) ingested cannabis in an edible format, including candies, chocolates, cookies, gummies, and home-baked goods.
- In the majority of cases the cannabis was from an unknown source (28/34, 82%, 95 Cl 65–92), as reported by the reporting physician. Multiple products from different sources may be reported for a single case.
- Where known by the reporting physician, the cannabis was most commonly acquired by a friend (9/22, 41%, 95 Cl 22–63) or by a parent or caregiver (8/22, 36%, 95 Cl 19–59).

Treatment and outcomes

- All cases required hospitalization, with a mean length of stay of 1.1 days.
- Physical treatment, such as intravenous fluids, supplementary oxygen, and patient monitoring, was received by 24/34 cases (71%, 95 CI 53–84).
- The presence of cannabinoids was qualitatively verified for 13/34 cases (38%, 95 Cl 23–56).

Study limitations

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



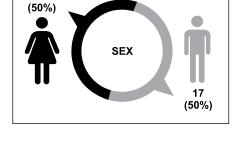
Conclusions

- Serious and life-threatening events associated with non-medical use of cannabis are occurring among children and youth in Canada, with 34 cases meeting the case definition in 2024. Most of these cases involved ingestion of cannabis in edible formats.
- More data is required to determine the impact of cannabis legalization and regulation on child and adolescent health. In most cases
 of serious and life-threatening events associated with non-medical use of cannabis, the cannabis was from an unknown source.
 Efforts to raise awareness surrounding the distinction between legal and illegal cannabis will help to ensure that this key piece of
 information is accurately captured in this study.
- The most common primary case presentation was unintentional poisoning/intoxication, largely involving children 12 years and younger and cannabis in edible formats. This trend continues to be monitored and highlights the importance of public education and awareness surrounding safe storage of cannabis to avoid accidental cannabis exposures in children.



Anticipated study impact

This study will continue to provide Canadian-specific data on the impact of cannabis legalization and regulation on the health of
children and youth. These data are used to inform policies, legislation, and regulations related to cannabis used for non-medical



purposes. To date, study results have contributed to the Canadian Paediatric Society's submission to the legislative review of the *Cannabis Act* and to the <u>final recommendations</u> by the Expert Panel on the legislative review of the *Cannabis Act*.

• The information from this study may also be adapted to develop public education and awareness communication materials.



Publication and dissemination

Serious and life-threatening events associated with non-medical cannabis use in Canadian children and youth. Grant C, Plebon-Huff S, Perwaiz S, Abramovici H, Bélanger RE. *Paediatr Child Health* 2023 Jun 26;29(1):3–4. doi: 10.1093/pch/pxad036. eCollection 2024 Feb

Acknowledgements

Thank you to Sieara Plebon-Huff, Health Canada, for her involvement in the analysis of the data relating to this project and the writing of this annual report.

One-Time Surveys

Adverse drug events related to paediatric medication compounding

September 2024



Charlotte Moore Hepburn

Principal investigator

Charlotte Moore Hepburn, MD, FRCPC, FAAP, Medical Director, Child Health Policy Accelerator, Department of Paediatrics, The Hospital for Sick Children; Faculty Paediatrician, Division of Paediatric Medicine, The Hospital for Sick Children; Associate Professor, Department of Paediatrics, University of Toronto School of Medicine; Adjunct Faculty, Institute of Health Policy, Management and Evaluation, University of Toronto; Co-Chair, Paediatric External Reference Group, Office of Paediatric Therapeutic Policy, Health Canada; charlotte.moorehepburn@sickkids.ca

Co-investigators

Geert 't Jong, Catherine Litalien, Derek McCreath



Questions

- How frequently do practising paediatricians consider a compounding-related adverse drug event (ADE) as a cause of unexplained treatment failure or toxicity?
- · How frequently do practising paediatricians identify and report ADEs related to paediatric medication compounding?



Importance

- When paediatric drug formulations are unavailable, compounding serves as a common and essential practice. While many
 safeguards are in place to optimize the quality and safety of compounded products, the practice is associated with potential errors
 and intrinsic risks.
- Many paediatric prescribers may be unaware of how frequently their prescriptions require compounding before dispensing and administration.
- Paediatricians must consider, identify, and report compounding-related ADEs if compounding-related errors are to be identified and managed appropriately.
- Canada lags behind comparable jurisdictions in terms of commercializing manufactured paediatric formulations. Increasing access to
 commercially-prepared, child-friendly formulations will decrease reliance on compounded products with the ultimate goal of
 improving safety and efficacy of paediatric pharmacotherapy.



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.

Unique to this survey

- This survey was developed in collaboration with, and reviewed by, paediatric pharmacist colleagues, as well as the Goodman Pediatric Formulations Centre of CHU Sainte-Justine.
- This survey complements ongoing work of the Canadian Paediatric Society (CPS), including the development of the forthcoming CPS
 Position Statement on Paediatric Formulations.



Results

- The survey received 887 responses (out of a total 2555 CPSP participants), for a survey response rate of 35%.
- The majority of respondents (852/880, 97%) reported being aware of the practice of paediatric medication compounding.

- While 69% (606/881) of respondents reported being aware that the practice of compounding was associated with an increased
 risk of ADEs, only 26% (230/882) reported ever considering an ADE associated with medication compounding as a possible cause
 of otherwise unexplained treatment failure and/or drug toxicity over the course of their entire career.
- In total, 57 respondents reported that they had identified at least one compounding-related ADE over the previous 12 months, culminating in a total of 69 ADEs. Of those who reported having identified at least one compounding-related ADE, 12 respondents (12/57, 21%) reported identifying two or more ADEs.
- The most common drug class associated with compounding-related ADEs was sedatives/analgesics/muscle relaxants, accounting for 14% (10/69) of the ADEs reported.
- Of the ADEs reported, 12% (8/69) required hospitalization, 10% (7/69) required an emergency department visit, and 9% (6/69) required intensive care.
- A minority of ADEs (8/69, 12%) were known to be reported to any authority or regulatory body.
- Analysis of the compounding-related ADEs reported is ongoing.

Survey limitations

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



Conclusions

- Despite compounding serving as a common and essential practice in paediatrics, a majority of respondents reported never having
 considered an ADE associated with compounding as a possible cause for otherwise unexplained treatment failure and/or toxicity.
 Education is necessary to ensure that compounding-related ADEs are appropriately identified and managed.
- ADEs related to medication compounding can be serious, with some patients requiring emergency department visits, hospitalization, or ICU-level care. Ensuring that Canadian children have access to commercially-available, child-friendly formulations is a child health priority.
- A minority of ADEs related to compounding are reported to health authorities or regulatory bodies. Investing in systems and
 processes to ensure all clinically significant ADEs are appropriately reported is essential to optimize medication safety.



Anticipated survey impact

- This work will add valuable Canadian-specific data to forward broader education and advocacy initiatives related to paediatric
 medication access, including efforts to advance Health Canada's Pediatric Drug Action Plan and the National Priority List of Pediatric
 Drugs.
- The publication and dissemination of these findings will complement the forthcoming CPS Position Statement on Paediatric Formulations (planned publication in 2025).
- International dissemination of results is planned with submission of the data to the European Paediatric Formulation Initiative Conference in September 2025.



Publication and dissemination

Publications, presentations, and targeted dissemination of findings to Health Canada's Centre for Policy, Pediatrics and International Collaboration will take place in 2025.

Acknowledgements

The investigators wish to thank the dedicated members of the CPS Drug Therapy Committee for their review of the survey tool and their valuable feedback on the project.

Adverse events associated with lithium use

January 2024



Rachel Mitchell

Principal investigators

Rachel Mitchell, MD, FRCPC, Staff Psychiatrist, Department of Psychiatry, Sunnybrook Health Sciences Centre; Associate Scientist, Hurvitz Brain Sciences Program, Sunnybrook Research Institute; Assistant Professor, Department of Psychiatry, Temerty Faculty of Medicine, University of Toronto; rachel.mitchell@sunnybrook.ca

Charlotte Moore Hepburn, MD, FRCPC, FAAP; Medical Director, Child Health Policy Accelerator, Department of Paediatrics, The Hospital for Sick Children; Faculty Paediatrician, Division of Paediatric Medicine, The Hospital for Sick Children; Associate Professor, Department of Paediatrics, Temerty Faculty of Medicine, University of Toronto; Adjunct Faculty, Institute of Health Policy, Management and Evaluation, University of Toronto; Co-Chair, Paediatric External Reference Group, Office of Paediatric Therapeutic Policy, Health Canada; charlotte.moorehepburn@sickkids.ca

Simina Toma, MD, FRCPC; Staff Psychiatrist, Department of Psychiatry, Sunnybrook Health Sciences Centre; Assistant Professor, Department of Psychiatry, Temerty Faculty of Medicine, University of Toronto; simina.toma@sunnybrook.ca

Co-investigators

Jasmine Amini, Simran Dhaliwal, Maggie Dobbin, Geert 't Jong, Mathieu Lemaire, Tom McLaughlin, Michael Rieder, Ayal Schaffer, Sam Wong



Question

What is the frequency of adverse events (AEs) related to lithium use for paediatric bipolar disorder, as identified by paediatricians in Canada?



Importance

- Paediatric bipolar disorder (PBD) is associated with more severe symptomatology than adult-onset bipolar disorder (BD).
- Evidence to inform the treatment of PBD is limited, and at present, few treatment options exist. While lithium is the gold standard treatment for BD in adults, guidelines for its use in paediatric populations remain inconsistent.
- There is limited data on the incidence of AEs associated with lithium use in youth aged 18 years or less.



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

As per CPSP policy, case numbers and data for fewer than five cases have been suppressed. The survey was open for responses from CPSP members from February to April 2024. The response rate was 36% (917/2530).

Respondent demographics

- Of the total 917 respondents, 102 (11%) reported caring for at least one patient who had been prescribed lithium during their career
- Of the respondents who reported having cared for a patient prescribed lithium, the vast majority (97%) indicated that they would never (90/102, 88%) or rarely (9/102, 9%) independently initiate lithium therapy.

Total adverse events

- Approximately 30% of respondents who reported caring for at least one patient prescribed lithium during their career, reported having observed at least one AE associated with lithium use (33/102; 32%).
- The total number of AEs associated with lithium use reported by these 33 respondents was 56.

Federal drug safety reporting system (Health Canada)

Of the 33 respondents who reported observing at least one AE associated with lithium use, fewer than five reported an AE to a federal drug safety reporting system.

Reported adverse events

The following AEs associated with lithium use were observed by survey respondents.

| TABLE 1 – Reported adverse events associated with lithium use (n=56) | | | | |
|--|---------------------|--|--|--|
| Adverse event | Number of responses | | | |
| Thyroid abnormalities | 12 (21%) | | | |
| Lithium toxicity | 11 (20%) | | | |
| Gastrointestinal upset | 6 (11%) | | | |
| Rising creatinine due to diabetes insipidus | 6 (11%) | | | |
| Rising creatinine due to interstitial nephritis | <5 | | | |
| Intentional/non-accidental overdose | 5 (9%) | | | |
| Renal failure requiring dialysis | <5 | | | |
| Weight gain | <5 | | | |
| Acne | <5 | | | |
| Unintentional/accidental overdose | <5 | | | |
| Other | 5 (9%) | | | |

Outcomes of reported adverse events

Of the 56 AEs reported, 15 (27%) were associated with a significant negative outcome. Significant outcomes are outlined below.

| TABLE 2 – Outcomes of reported adverse events associated with lithium use (n=56)* | | | | |
|---|---------------------|--|--|--|
| Outcome of adverse event | Number of responses | | | |
| Hospitalization for medical care on a ward | 6 (11%) | | | |
| Hospitalization for medical care in the intensive care unit | <5 | | | |
| Hospitalization for psychiatric care | <5 | | | |
| Renal transplant | 0 | | | |
| Death | 0 | | | |
| Other | <5 | | | |
| No reply to question | 41 (73%) | | | |

^{*} Only 15 survey respondents answered this question; the percentage of each outcome was calculated using total AEs as the denominator.

Survey limitations

- Limitations common to all CPSP surveys are listed on page 11.
- This survey excluded AEs observed by non-paediatric providers (e.g., psychiatrists) who may more commonly prescribe lithium
 and encounter associated AEs. However, it was assumed that the more significant AEs associated with lithium therapy would not be
 independently managed by non-paediatric providers.
- Recall bias is a limitation, but it may be lower in this survey compared to other retrospective surveys due to the one-year reporting
 period and the rarity of lithium-related AEs in youth, which likely makes them more memorable to respondents.



Conclusions

- The type, frequency, and distribution of AEs among youth with BD who had been prescribed lithium were similar to those observed in adults with BD.
- Notwithstanding the survey limitations, the frequency of AEs for lithium in the paediatric population is relatively low and in keeping with, or lower than, AEs associated with other psychotropic medications used in children.
- Reporting of AEs among paediatricians to established drug safety systems is low. AE reporting is essential for drug safety monitoring and must be encouraged.



Anticipated survey impact

The results will contribute to the evidence base on lithium and paediatric bipolar disorder. These results will help inform the development of guidelines outlining the safety of lithium use in youth.



Publication and dissemination

Investigating the safety of lithium use for youth with bipolar disorder. Dobbin M, Moore Hepburn C, Amini J, Toma S, Dhaliwal S, King M, Wong S, Lemaire M, Schaffer A, Mitchell RHB. Statistics Canada and the Public Health Agency of Canada Health Data User Conference, Ottawa, in November 2024 (poster presentation)

Investigating the safety of lithium use for youth with bipolar disorder. Dobbin M, Moore Hepburn C, Amini J, Toma S, Dhaliwal S, King M, Wong S, Lemaire M, Schaffer A, Mitchell RHB. 24th World Congress of Psychiatry, Mexico City, Mexico, in November 2024 (poster presentation)

Acknowledgements

We would like to thank the paediatricians across Canada who completed this CPSP survey and contributed to the successful completion of this project.

Adverse events associated with the use of appearance- and performance-enhancing drugs and substances among children and adolescents

May 2024



Kyle Ganson

Principal investigators

Kyle Ganson, PhD, MSW, Assistant Professor, Factor-Inwentash Faculty of Social Work, University of Toronto; kyle.ganson@utoronto.ca

Debra K. Katzman, MD, Professor of Paediatrics, Division of Adolescent Medicine, Department of Paediatrics, The Hospital for Sick Children, University of Toronto; debra.katzman@sickkids.ca

Zahra Alebraheem, Jennifer Coelho, Camille Fournier, Christina Grant, Margo Lane, Simone Lebeuf, David Martens, Mark Norris, Ellie Vyver, Elisabeth York



Questions

- What are the adverse events associated with use of appearance- and performance-enhancing drugs and substances (APEDS) among adolescents in Canada, observed by paediatricians and paediatric subspecialists?
- How knowledgeable are paediatricians and paediatric subspecialists about APEDS and what are their screening practices?



Importance

- · APEDS are commonly used by adolescents. The use of APEDS has previously been linked with adverse events, including hospitalization and disability.
- No known research has explored adverse events from APEDS use among Canadian adolescents.



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.

Unique to this survey

For this survey, APEDS were defined as drugs, dietary supplements, and substances used for the purposes of improving athletic performance, increasing muscular development, and/or altering one's weight and appearance. APEDS occur in multiple forms, including legal natural health products, such as whey protein powders, creatine monohydrate, and amino acids, as well as illegal drugs, such as anabolic-androgenic steroids and selective androgen receptor modulators (SARMs). A list of APEDS was also provided to CPSP participants for reference and included, for example, amino acids/branched-chain amino acids (BCAAs), anabolic-androgenic steroids, energy drinks, pre-workout drinks or powders, and whey protein powders/protein shakes.



Results

Of the 2497 CPSP paediatricians and paediatric subspecialists sent the survey, 935 completed the survey for a response rate of 37%. Of the total survey responses, 78 surveys were removed during data cleaning due to the respondent reporting that they do not treat children and adolescents ages 10 to 18 years, resulting in a final analytic sample of 857 complete responses.

Adverse events from APEDS use

- Many paediatricians reported having seen a case of an adverse event associated with APEDS use in their adolescent patients in the previous 12 months (143/856, 17%). A total of 55 cases were reported on in detail.
- Over half of the cases with adverse events from APEDS use were 13 to 15 years of age (31/55, 56%), while 31% (17/55) were 10 to 12 years of age, and 13% (7/55) were 16 to 18 years of age. The majority identified as cisgender boys (49/55, 89%).

APEDS involved in adverse events

- Of the 55 cases reported, 40% (n=22) involved the use of whey protein powders or protein shakes and 29% (n=16) involved the use
 of pre-workout drinks or powders.
- In almost a quarter of cases, illegal APEDS (e.g., anabolic-androgenic steroids) were used (13/55, 24%).
- Slightly more than half of cases with adverse events involved only one APEDS (31/55, 56%), 20% (11/55) involved two, and 16% (9/55) involved three or more.

Description of cases

- Nearly a third of cases with adverse events had effects to the renal system (17/55, 31%), and a quarter had effects to the gastrointestinal system (14/55, 25%).
- While outpatient monitoring was the most common medical care provided (20/55, 36%), 16% (9/55) of cases were admitted to the hospital.
- The majority of cases had a full recovery (35/55, 64%), while 16% (9/55) had ongoing health issues, and for 20% (11/55) outcome
 was unknown/unreported.
- A medical or psychiatric comorbidity was reported in 20% (11/55) of cases.
- Over a third of the adverse events were formally reported to Health Canada (19/55, 35%).

Knowledge and screening practices of CPSP participants related to APEDS

- Of the 857 participating paediatricians and paediatric subspecialists, more than a quarter reported having no knowledge of APEDS (240/855, 28%).
- More than half of the respondents reported never screening for APEDS in routine practice (456/854, 53%).

Survey limitations

- Limitations common to all CPSP surveys are listed on page 11.
- It is possible that there were duplicate cases reported among CPSP participants.
- Given the overall low knowledge of APEDS among survey respondents, and the lack of formal screening for APEDS in routine
 practice, it is possible that there was a significant under-reporting of adverse events.



Conclusions

- Paediatricians and paediatric subspecialists from across Canada reported seeing a total of 55 cases of adolescents who experienced adverse effects related to APEDS consumption in the previous 12 months.
- The majority of these cases included dietary supplements, such as whey protein, which are widely regarded as harmless, and may be linked to negative outcomes, such as gastrointestinal and renal complications.
- Almost a quarter of the cases involved the use of illegal APEDS, such as anabolic-androgenic steroids, and one third of the cases
 that had an adverse event involved the use of two or more APEDS.
- The majority of cases were managed in outpatient settings and, while most patients experienced a full recovery, nine patients were admitted to hospital and nine had ongoing health issues.
- The survey also revealed a significant knowledge gap regarding APEDS among participating paediatricians and paediatric
 subspecialists, with more than a quarter reporting no knowledge of these substances. Additionally, more than half of survey
 respondents reported never screening for APEDS use during routine clinical practice.



Anticipated survey impact

- Overall, these survey findings underscore the need for enhanced research, education, and training for paediatricians and paediatric subspecialists in Canada on APEDS.
- To provide comprehensive care, healthcare providers must routinely inquire about APEDS use among adolescents and report adverse
 events to Health Canada.
- The data can help inform policymakers, healthcare professionals, and regulatory bodies, to strengthen safety standards, improve consumer education, and reduce harm from APEDS use among adolescents.

Publications 2021–2024

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.)

5q spinal muscular atrophy

A study on the incidence and prevalence of 5q spinal muscular atrophy in Canada using multiple data sources. Price TR, Hodgkinson V, Westbury G, Korngut L, Innes MA, Marshall CR, et al. *Can J Neurol Sci* 2024 Sep;51(5):660–71. doi: 10.1017/cjn.2024.1. Epub 2024 Jan 5

Avoidant/restrictive food intake disorder

Incidence and age- and sex-related differences in the clinical presentation of children and adolescents with avoidant restrictive food intake disorder. Katzman DK, Spettigue W, Agostino H, Couturier J, Dominic A, Findlay SM, et al. *JAMA Pediatr* 2021 Dec 1;175(12):e213861. doi: 10.1001/jamapediatrics.2021.3861. Epub 2021 Dec 6

Button battery ingestions

Clinical features, management, and complications of paediatric button battery ingestions in Canada: an active surveillance study using surveys of Canadian paediatricians and paediatric subspecialists, Hudson AS, Carroll MW, *J Can Assoc Gastroenterol* 2024 Sep 28;7(6):416–22. doi: 10.1093/jcag/gwae032. eCollection 2024 Dec

Complex regional pain syndrome

Canadian surveillance study of complex regional pain syndrome in children. Baerg KL, Tupper SM, Chu LM, Cook N, Dick BD, Doré-Bergeron MJ, et al. *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, et al. *CMAJ* 2021 Sep 27;193:E1483–93. doi: 10.1503/cmaj.210053

Risk factors for severe COVID-19 in hospitalized children in Canada: A national prospective study from March 2020–May 2021. Farrar DS, Drouin O, Moore Hepburn C, Baerg K, Chan K, et al. *Lancet Reg Health Am* 2022 Nov;15:100337. doi: 10.1016/j. lana.2022.100337. Epub 2022 Aug 1

Clinical manifestations and disease severity of SARS-CoV-2 infection among infants in Canada. Piché-Renaud PP, Panetta L, Farrar DS, Moore Hepburn C, Drouin O, Papenburg J, et al. *PLoS ONE* 2022 Aug 24;17(8): e0272648. doi: 10.1371/journal.pone.0272648. eCollection 2022

Paediatric inflammatory multisystem syndrome in Canada: Population-based surveillance and role of SARS-CoV-2 linkage. El Tal T, Morin MP, Morris SK, Farrar DS, Berard RA, Kakkar F, et al. *Pediatr Res* 2023 Nov;94(5):1744–53. doi: 10.1038/s41390-023-02668-1. Epub 2023 Jun 5

Resource use and disease severity of children hospitalized for COVID-19 versus multisystem inflammatory syndrome in children (MIS-C) in Canada. Farrar DS, Moore Hepburn C, Drouin O, El Tal T, Morin MP, Berard R, et al. *Can Commun Dis Rep* 2023 Apr 1;49(4):103–12. doi: 10.14745/ccdr.v49i04a03

COVID-19 pandemic and children with medical complexity

The impact of the COVID-19 pandemic on children with medical complexity. Diskin C, Buchanan F, Cohen E, Dewan T, Diaczun T, Gordon M, et al. *BMC Pediatr* 2022 Aug 23;22(1):496. doi: 10.1186/s12887-022-03549-y

Identifying child maltreatment during virtual medical appointments

Identifying child maltreatment during virtual medical appointments through the COVID-19 pandemic: A physician-based survey. Lim-Reinders S, Ward M, Malic C, Keely K, Kang K, Jain N, et al. *Paediatr Child Health* 2023 Sep 28;29(1):23–8. doi: 10.1093/pch/pxad064. eCollection 2024 Feb

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 Oct;26(supplement_1):e79–80. doi: 10.1093/pch/pxab061.090

Listeria in the newborn and early infancy

Listeriosis in infants: Prospective surveillance studies in Canada and Switzerland. Abu-Raya B, Jost M, Bettinger JA, Bortolussi R, Grabowski J, Lacaze-Masmonteil T, et al. *Paediatr Child Health* 2021 Jun 19;26(7):e277–82. doi: 10.1093/pch/pxab035. eCollection 2021 Nov

Near-fatal self-harm

Near-fatal self-harm among Canadian adolescents. Mitchell RH, Ani C, Cyr C, Irvine J, Joffe AR, Skinner R, Wong S, et al. Can J Psychiatry 2022 Aug;67(8):598–607. doi: 10.1177/07067437211058602. Epub 2021 Nov 30

Non-type 1 diabetes

Incidence trends of type 2 diabetes mellitus, medication-induced diabetes, and monogenic diabetes in Canadian children, then (2006–2008) and now (2017–2019). Patel TJ, Ayub A, Bone JN, Hadjiyannakis S, Henderson M, Nour MA, et al. *Pediatr Diabetes* 2023 Nov 14;1–10. doi: 10.1155/2023/5511049. eCollection 2023

Paediatric pulmonary thromboembolism

Pediatric pulmonary thromboembolism: A 3-year Canadian Paediatric Surveillance Program study. Krmpotic K, Ramsay L, McMullen S, Chan AKC, Plint AC, Moorehead P. *J Thromb Haemost* 2024 May:1–6. doi: 10.1016/j.jtha.2024.01.005. Epub 2024 Jan 22

Providing care to children and youth from military families

Caring for children and youth from Canada's military families. Cramm H, Mahar A, Tam-Seto L, Rowan-Legg A. *Paediatr Child Health* 2022 May;27(2):88–92. doi: 10.1093/pch/pxab053. Epub 2021 Sep 13

Severe microcephaly and congenital Zika syndrome

Population-based surveillance of severe microcephaly and congenital Zika syndrome in Canada. Morris SK, Farrar DS, Miller SP, Ofner M, Bitnun A, Nelson CRM, et al. *Arch Dis Child* 2021 Sep;106(9):855–61. doi: 10.1136/archdischild-2020-320968. Epub 2021 Jan 8

Severe obesity and global developmental delay in preschool children

Severe obesity and global developmental delay in preschool children: Findings from a Canadian Paediatric Surveillance Program study. Gehring ND, Birken CS, Bélanger S, Bridger T, Chanoine JP, Gibson WT, et al. *Paediatr Child Health* 2023 May;28(2):107–12. doi: 10.1093/pch/pxac109. Epub 2022 Nov 12

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, et al. *Arch Dis Child* 2021 Dec;106(12):1165–70. doi: 10.1136/archdischild-2021-322092. Epub 2021 Aug 20

Vaping-related illness and injury

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. *Paediatr Child Health* 2021 Aug 23;27(1):43–9. doi: 10.1093/pch/pxab062. eCollection 2022 Mar

Opportunities and challenges in capturing severe vaping-related injuries among children and youth. Chadi N, Richmond SA, Tulloch T, Grant CN, Venugopal J, Moore Hepburn C. *Prev Med Rep* 2023 Mar 25;33:102186. doi: 10.1016/j.pmedr.2023.102186. eCollection 2023 Jun

CPSP Highlights published in Paediatrics & Child Health

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

Acute flaccid paralysis

Acute flaccid paralysis: A call for clinical vigilance. Salem N, Grudeski E, Booth TF, Bhagat D, Salvadori MI. *Paediatr Child Health* 2024 Dec 15;30(1):6–7. doi: 10.1093/pch/pxae100. eCollection 2025 Feb

Adverse events related to virtual care

A Canadian Paediatric Surveillance Program study to guide safe integration of virtual care for children. Vanderhout S, Rosenfield D, Goldbloom EB. *Paediatr Child Health* 2023 Sep 5;28(8):468–9. doi: 10.1093/pch/pxad059. eCollection 2023 Dec

First-time hospitalization for anorexia nervosa and COVID-19 pandemic

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

Hyperglycemic hyperosmolar state

Hyperglycaemic hyperosmolar state: No longer an endocrine crisis exclusive to adulthood. Ryan PM, Sellers EAC, Amed S, Hamilton JK. *Paediatr Child Health* 2023 Nov 7;29(2):81–3. doi: 10.1093/pch/pxad073. eCollection 2024 May

Hypoglycemia during treatment of acute lymphoblastic leukemia

Hypoglycemia during treatment of acute lymphoblastic leukemia. Jiang M, Ahmet A. *Paediatr Child Health* 2023 May 15;28(5):305–6. doi: 10.1093/pch/pxad019. eCollection 2023 Aug

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

Serious and life-threatening events associated with non-medical cannabis use

Serious and life-threatening events associated with non-medical cannabis use in Canadian children and youth. Grant C, Plebon-Huff S, Perwaiz S, Abramovici H, Bélanger RE. *Paediatr Child Health* 2023 Jun 26;29(1):3–4. doi: 10.1093/pch/pxad036. eCollection 2024 Feb

Presentations in 2024

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

Adverse events associated with lithium use

Investigating the safety of lithium use for youth with bipolar disorder. Dobbin M, Moore Hepburn C, Amini J, Toma S, Dhaliwal S, King M, Wong S, Lemaire M, Schaffer A, Mitchell RHB. Statistics Canada and the Public Health Agency of Canada Health Data User Conference, Ottawa, in November (poster)

Investigating the safety of lithium use for youth with bipolar disorder. Dobbin M, Moore Hepburn C, Amini J, Toma S, Dhaliwal S, King M, Wong S, Lemaire M, Schaffer A, Mitchell RHB. 24th World Congress of Psychiatry, Mexico City, Mexico, in November (poster)

Congenital syphilis

Overview of existing social and structural barriers. Bullard J. Taking Action on Congenital Syphilis in Canada: National Conference, Ottawa, in February (oral)

Congenital syphilis in Canada: Clinical and health-care related diagnosis and treatment findings of a Canadian Paediatric Surveillance Program study (June 2021-May 2023). Bullard J. Association of Medical Microbiology and Infectious Diseases Canada Conference, Vancouver, in April (oral)

COVID-19

Clinical features and severity of COVID-19 with respiratory virus coinfections versus SARS-CoV-2 monoinfection in hospitalized children: a Canadian national surveillance study. Di Chiara C, Farrar D, Bettinger JA, Campigotto A, Deeks S, Drouin O, et al. Canadian Paediatric Society Annual Conference, Vancouver, in June (poster)

Clinical features and severity of COVID-19 with respiratory virus coinfections versus SARS-CoV-2 monoinfection in hospitalized children: a Canadian national surveillance study. Di Chiara C, Farrar D, Bettinger JA, Campigotto A, Deeks S, Drouin O, et al. Pediatric Academic Societies Meeting, Toronto, in May (oral)

Clinical features and outcomes of children hospitalized in Canada for COVID-19 with comorbid neurologic and neurodevelopmental disorders. Huang R, Farrar DS, Donner EJ, Bettinger JA, Campigotto A, Di Chiara C, et al. Pediatric Academic Societies Meeting, Toronto, in May (oral)

Frequency and impact of PANDAS/PANS diagnosis

Demystifying PANDAS/PANS: A practical approach for paediatricians. Shouldice M, Yeh A. Canadian Paediatric Society Annual Conference, Vancouver, in June (oral)

Home-based phototherapy

Home-based phototherapy for neonatal hyperbilirubinemia: A one-time Canadian Paediatric Surveillance Program survey. Holyer K. Canadian Paediatric Society Annual Conference, Vancouver, in June (poster)

Medically serious self-harm in youth requiring ICU admission

Understanding and treating self-injurious behaviours in children with neurodevelopmental disorders. MacEachern S, Richardson A. Canadian Paediatric Society Annual Conference, Vancouver, in June (oral)

Micronutrient deficiencies in children and youth with autism spectrum disorder

Micronutrient deficiencies in children and youth with autism spectrum disorder: Findings from a national surveillance study. Kinlin L, Shouldice M. Canadian Paediatric Society Annual Conference, Vancouver, in June (poster)

Paediatric pulmonary thromboembolism

Spotting the clotting: a 3-year national surveillance study of paediatric pulmonary thromboembolism. Krmpotic K, Ramsay L. Canadian Paediatric Society Annual Conference, Vancouver, in June (poster)

Post-COVID-19 condition

Post-COVID-19 condition in children: The long and the (not so) short of it. Wadhwa A. Long COVID Web Webinar Series, virtual, in January (oral)

Severe/life-threatening opioid, stimulant, or sedative use

The time is now: How paediatricians can support adolescents with severe substance use disorder. Carwana M, Chadi N. Canadian Paediatric Society Annual Conference, Vancouver, in June (oral)

Transgender and gender-diverse children and youth care needs

An approach to gender-affirming care. Kadoura B, Mooney J. Canadian Paediatric Society Annual Conference, Vancouver, in June (oral)



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 2700 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
- Serious/life-threatening use of opioids, stimulants, and sedatives

Study success factors

- A disease 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.

"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 Paediatrics, Faculty of Medicine, University of Ottawa; Past CPSP Steering Committee representative, Paediatric Chairs of Canada





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

Canadian Paediatric Society

Manager, Surveillance
2305 St. Laurent Blvd., Suite 100
Ottawa ON K1G 4J8
Tel.: 613-526-9397, ext. 244
Fax: 613-526-3332
cpsp@cps.ca
www.cpsp.cps.ca

