



CPSP

CANADIAN PAEDIATRIC
SURVEILLANCE PROGRAM

2017 Results

CANADIAN PAEDIATRIC
SURVEILLANCE PROGRAM



Public Health
Agency of Canada

Agence de la santé
publique du Canada

Canadian
Paediatric
Society



Société
canadienne
de pédiatrie



Mission

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

Canadian Paediatric Surveillance Program Annual Results

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

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CPSP Surveillance in Action

Public health surveillance is an essential tool that involves the detection, deduction, and dissemination of information regarding emerging issues affecting children and youth.

Example: Medical assistance in dying

Following the Carter v. Canada decision (Supreme Court of Canada, 2015), Bill C-14 was passed in June 2016 allowing medical assistance in dying (MAID) for competent adults under specific circumstances. An independent review of mature minors and their potential eligibility for MAID was commissioned by Parliament. There were no Canadian data on the demand for MAID by mature minors.



Detection

The CPSP issued a one-time survey to 2,700 participating paediatricians and subspecialists asking how often Canadian paediatricians engage in exploratory conversations about or receive explicit requests for MAID.



Deduction

Paediatricians reported exploratory discussions about and explicit requests for MAID from both minors and parents on behalf of minor children.

Discussions and explicit requests from parents outnumbered those by minors by more than 5:1.

A large proportion of discussions and requests for MAID from parents involved an infant or neonate.



Dissemination

Survey results were shared with the Council of Canadian Academies providing critical evidence to inform the independent report to Parliament.

Survey results were central to the Canadian Paediatric Society Position Statement on MAID.

Survey results garnered significant national and local media coverage.

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Foreword

Federal Minister of Health

The Honourable Ginette Petitpas Taylor, P.C., M.P.



The Government of Canada is committed to supporting child health. That's why I'm proud that the Public Health Agency of Canada collaborates with the Canadian Paediatric Society to support the Canadian Paediatric Surveillance Program.

Monitoring rare and emerging childhood diseases, conditions, and public health issues is fundamental to our ability to advance early detection and treatment to support the health of young Canadians across the country.

The evidence and data produced by the Canadian Paediatric Surveillance Program provides health professionals, researchers, and policy makers with the crucial information they need to do their work in improving the health and well-being of our children. It is also a trusted and valued public health resource within the federal health portfolio.

I'm impressed by the leadership that the Canadian Paediatric Society has shown in advancing children's health through the Canadian Paediatric Surveillance Program for more than 20 years. I would like to thank paediatricians and paediatric subspecialists for their efforts in producing this annual results report.

Chief Public Health Officer of Canada

Dr. Theresa Tam



Surveillance systems contribute vital information for describing and understanding health conditions as well as providing a foundation for evidence-based decision-making for prevention and treatment. The Canadian Paediatric Surveillance Program (CPSP) continues to play a key role in monitoring for less common paediatric disorders and emerging conditions. In the over 20 years of its operation, the CPSP has advanced our knowledge of these conditions and contributed to research and practice, improving health outcomes for young Canadians.

The CPSP is uniquely able to leverage the collective intelligence and insight of paediatricians and paediatric sub-specialists across the country, which facilitates timely identification of new and emerging threats and risks to child health. Extending its collaborative approach across borders, the CPSP also participates in the International Network of Paediatric Surveillance Units, which provides a platform for Canada and other countries to share and benefit from each other's experiences.

As Chief Public Health Officer of Canada, I am proud to present the Canadian Paediatric Society's Canadian Paediatric Surveillance Program 2017 Results report. This report demonstrates how effective and flexible the CPSP is in capturing diverse and complex mental and physical health issues, including mental health issues such as serious self-harm requiring hospital admission; communicable diseases such as Lyme disease and congenital Zika syndrome; and chronic diseases such as type 2 diabetes.

I would like to thank the Canadian Paediatric Society and its network of paediatricians and paediatric sub-specialists across the country for their support and dedication to the ongoing success of the CPSP. Your work supports us all as we work together to maintain and improve the health of Canadian children and youth.

President of the Canadian Paediatric Society

Dr. Michael Dickinson

As the President of the Canadian Paediatric Society (CPS) in 2017–2018, I had the opportunity to see firsthand how data generated from the CPSP played an important role in the formation of policies, educational material, and recommendations from both the CPS and public health authorities.



If we look at the one-time surveys the CPSP conducted in 2017, we can see how surveillance results are immediately taken into action. The results of the survey on providing care to children and youth from military families highlighted that professional development activities are needed to increase awareness of the unique issues facing this population. A new online educational module for clinicians was developed by the CPS, in partnership with Military Family Services, to provide this much-needed information.

The survey results on vaccine hesitancy and vaccine preventable diseases (VPDs) showed that respondents feel that 35% of the vaccine hesitant parents they have encountered, whose child had contracted a VPD, would still choose not to vaccinate in the future. We have a long way to go in reassuring parents that vaccines are safe and effective, and survey findings will be used to inform public education programs and educational modules for health care providers.

In the survey on medical cannabis use by children and youth, 68% of respondents who reported having encountered paediatric patients using cannabis for medical purposes, stated that less than half of their patients had benefited from its use. These results will be used to advocate for investments in research on the safety, efficacy, dosing, and potential indications for medical cannabis in the paediatric population.

None of this work would be possible without the collaboration and support of the Public Health Agency of Canada and the 2,700 paediatricians and subspecialists who dedicate time to diligently report cases and complete the detailed clinical questionnaires. On behalf of the CPS and the Board of Directors, I would like to sincerely thank you for your commitment to helping us advance knowledge on rare paediatric diseases.

CPSP Chair

Dr. Jonathon Maguire

As 2017 was drawing to a close, I found myself reflecting that the CPSP has once again had an impressive year. The CPSP Steering Committee and investigators worked hard to launch five new studies on the following topics: congenital Zika syndrome, complex regional pain syndrome, infantile and later-onset Pompe disease, type 2 diabetes, and self-harm requiring ICU admissions.



The foundation of the program remains solid and our fruitful collaboration with the Public Health Agency of Canada is stronger than ever. Not only do we continue to monitor for acute flaccid paralysis to ensure Canada remains polio-free, and to monitor for serious and life-threatening adverse drug reactions, but the CPSP demonstrated flexibility and responsiveness to emerging issues including congenital Zika syndrome and the use of medical cannabis in children and youth. Over the past year, under the excellent leadership of Dr. Charlotte Moore Hepburn, a balance was struck between surveillance of rare diseases and severe complications of more common ones. As we all know from experience, lack of information on rare diseases or severe complications is challenging for individual patients and their families. Being able to offer knowledge gained through CPSP surveillance helps families to better understand these conditions and provides evidence for physicians on appropriate evaluation and treatment. We have also advanced CPSP knowledge translation activities through integration with CPS working groups and policy experts. We hope that you enjoy the new format of this report which was designed to make CPSP results easier to understand than ever.

So, does your participation in CPSP surveillance make a difference? The answer is a resounding YES! For many conditions, the CPSP is the only available source of reliable information. The dedication and faithful reporting of more than 2,700 paediatricians and paediatric subspecialists have produced important data that continues to lead to important changes in clinical practice and public health policy. A big thank you is extended to members of the CPSP Steering Committee, new and seasoned CPSP investigators, and paediatricians and subspecialists across Canada. None of this would be possible without you!

Acknowledgements

The key strength of the Canadian Paediatric Surveillance Program 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 principal investigators who design studies and analyse the data to provide knowledge and educational solutions, or the guidance of the 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 and the Public Health Agency of 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 2017 from the Public Health Agency of Canada's Centre for Surveillance and Applied Research, Health Canada's Marketed Health Products Directorate's Patient Safety Section, and the following non-governmental sources:

- Genzyme
- The Chronic Pain Network, a Canadian Institutes for Health Research initiative
- The Hospital for Sick Children's Centre for Healthy Active Kids EAT, PLAY, THINK! Catalyst Grant in partnership with:
 - The Centre for Brain & Mental Health, The Hospital for Sick Children
 - The Fraser Mustard Institute for Human Development, University of Toronto
 - The Centre for Child Nutrition, Health and Development, University of Toronto

CPSP Steering Committee

Jonathon Maguire, MD (Chair)	Canadian Paediatric Society
Christine Armour, MD	Canadian College of Medical Geneticists (Liaison)
Peter Buck, DVM, MSc	Centre for Food-borne, Environmental and Zoonotic Infectious Diseases, Public Health Agency of Canada
Claude Cyr, MD	Canadian Paediatric Society
Marie Adèle Davis, MBA	Canadian Paediatric Society
Elizabeth Donner, MD	Canadian Association of Child Neurology (Liaison)
Ciarán Duffy, MB	Paediatric Chairs of Canada (Liaison)
Joanne Embree, MD	IMPACT (Immunization Monitoring Program ACTive) (Liaison)
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Jorge Pinzon, MD	Canadian Paediatric Society
Anne Rowan-Legg, MD	Canadian Paediatric Society
Miriam Santschi, MD	Canadian Paediatric Society
Jill Starkes, MD	Canadian Paediatric Society

The CPSP would like to extend a sincere thank you to Dr. Claude Cyr who completed a six-year term on the Steering Committee as a representative for the Canadian Paediatric Society. His dedication and expertise on the committee will be missed, and we wish him all the best in future endeavours.



About the Canadian Paediatric Surveillance Program



Overview

The Canadian Paediatric Surveillance Program 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 over 2,700 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.
- The CPSP 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 Steering Committee, composed of representatives from the Public Health Agency of Canada, the Canadian Paediatric Society, former CPSP investigators, academic clinicians from diverse specialties, and community paediatricians.
- Each month, CPSP participants from across Canada receive a form listing the current conditions under study. Participants notify the program if they have seen any cases or have “nothing to report.”

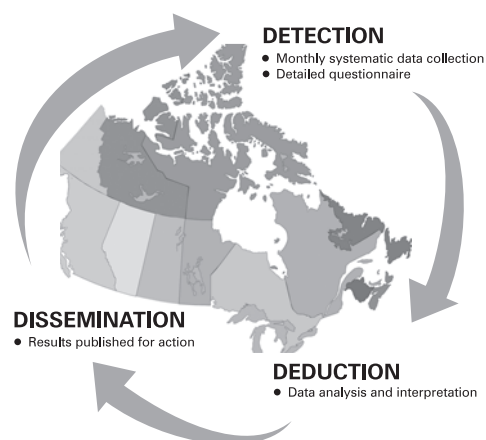
CPSP Quick Facts

Did you know?

- The CPSP celebrated its 20th anniversary in 2016.
- The CPSP is comprised of over 2,700 dedicated paediatricians and paediatric subspecialists.
- Since its inception, the CPSP has studied 69 rare conditions/diseases and initiated 46 one-time surveys.
- Over 60 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 2017, 78% of participants committed to receiving their monthly forms electronically.

Figure 1 – Surveillance process summary

Pan-Canadian health surveillance



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

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 2017

Provinces/territories	Reporting rates (%) [*]	Number of participants [†]
Alberta (AB)	82	376
British Columbia (BC)	78	282
Manitoba (MB)	84	115
New Brunswick (NB)	88	30
Newfoundland and Labrador (NL)	79	50
Northwest Territories (NT)	100	2
Nova Scotia (NS)	89	87
Nunavut (NU)	100	2
Ontario (ON)	81	1,046
Prince Edward Island (PE)	96	9
Quebec (QC)	76	602
Saskatchewan (SK)	83	66
Yukon (YT)	100	1
Canada	80	2,668

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

[†] The total number of individual CPSP participants is over 2,700. However, in this table, the number of CPSP participants in Canada is calculated based on both individual and group reporting. When a group designate responds to the CPSP on behalf of group members, it is counted as one response.

TABLE 2 – National initial response rates 2013–2017

Reporting year	Reporting rates (%)
2013	82
2014	81
2015	82
2016	79
2017	80

TABLE 3 – 2017 detailed questionnaire completion rates as of June 4, 2018

Studies/conditions	Reported cases [*]	Pending	% Completion rate
Acute flaccid paralysis	36	2	95
Adverse drug reactions – serious and life-threatening	44	8	85
Avoidant/restrictive food intake disorder	151	24	86
Childhood Lyme disease	19	1	95
Complex regional pain syndrome in Canadian children and youth	16	4	80
Congenital Zika syndrome in infants in Canada	≤ 5	0	100
Incidence trends of type 2 diabetes, medication-induced diabetes, and monogenic diabetes in Canadian children	147	29	84
Infantile and later-onset paediatric Pompe disease (glycogen storage disease type II)	≤ 5	0	100
Listeria in the newborn and early infancy	0	0	—
Medically serious self-harm in youth requiring ICU admission	80	20	80
Rh sensitization	45	5	90
Severe microcephaly	40	6	87
Total number of cases (all studies)	580	99	85

^{*} Excluding duplicate and excluded cases

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, diagnosis, treatments, and outcomes for rare childhood conditions.

Established in 1998, INOPSU now includes 16 paediatric surveillance units among its membership. Full member countries are Australia, Canada, Netherlands, New Zealand, Switzerland, United Kingdom, and Wales. Affiliate members are: Germany, Belgium, Scotland, Portugal, Ireland, and Greece/Cyprus as well as the British Ophthalmology Surveillance Unit, the British Neurology Surveillance Unit, and the UK Obstetrics Surveillance System.



Incredibly, 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.

The CPSP is looking forward to the next INOPSU meeting in 2020. During INOPSU meetings, member countries have the opportunity to 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.

Surveillance Studies in 2017

Acute flaccid paralysis

Ongoing study since January 1996



Robert Pless

Principal investigator

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? Question

Did Canada maintain its polio-free status in 2017?

! Importance

- Acute flaccid paralysis (AFP) surveillance is the cornerstone of monitoring for polio, in light of ongoing transmission of wild poliovirus in a few countries around the world.
- Canada conducts AFP surveillance in children under 15 years of age, in accordance with World Health Organization (WHO) recommendations and standards of practice.

➔ Methodology

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

Case definition

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

Unique to this study

Cases are captured through both the Canadian Paediatric Surveillance Program (CPSP) and Canada's Immunization Monitoring Program ACTive (IMPACT) based in 12 tertiary care paediatric centres.

✓ Results – January to December 2017

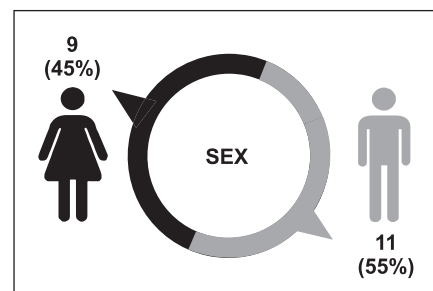
Note: Due to reporting delay, this report represents a snapshot as of February 5, 2018 for cases that occurred between January 1, 2017 and December 31, 2017.

Confirmed cases

- In total, 32 cases of AFP were reported to the Public Health Agency of Canada: 13 (40%) cases were reported through the CPSP network and 19 (60%) cases were reported through IMPACT.
- All AFP cases were adjudicated against the national AFP and polio case definitions.
- At the time of analysis, 20 cases were confirmed as meeting the AFP case definition; none were assessed to be polio.
- The average time from case onset to reporting was 55 days (range: 8 to 189).

Demographics

- There were 11 (55%) males and 9 (45%) females.
- Cases ranged in age from younger than 1 year to 14 years, with a mean of 6.3 years (95% CI 3.9–8.8) and a median of 4.8 years.



Presentation

- Hospitalization: All 20 (100%) cases were hospitalized and length of stay ranged from 1 to 24 days with a mean of 11 days (95% CI 7.3–14.8) and a median of 10 days.
- Vaccinations: 13 (65%) cases were up-to-date for their polio vaccinations.
- Diagnoses: 12 (60%) cases were Guillain-Barré syndrome. The remaining eight (40%) cases were diagnosed as: acute disseminated encephalomyelitis, Bell's palsy, transverse myelitis, non-inflammatory disease, and chronic inflammatory demyelinating polyneuropathy.
- No stool samples were positive for polio.

Treatment and outcomes

- Of the 13 (65%) cases that had outcome documented at the time of initial report, all had partially recovered with residual weakness.
- Nine (45%) cases had the clinical outcome reported at least 60 days after the onset of paralysis or weakness; all of these cases had either fully or partially recovered.

TABLE 1 – Measure of Canada's performance against WHO AFP surveillance performance indicators in 2017 ¹			
Number of cases	Incidence rate*	% with adequate stool sample ^{2†}	% with 60-day follow-up [‡]
20	0.34	20%	45%

* Target is 1.0 AFP case per 100,000 population in those less than 15 years of age

† Target is at least 80% of confirmed cases have adequate stool sampling

‡ Target is at least 80% have follow-up examination for residual paralysis at least 60 days after onset

Study limitations

- As with any voluntary reporting surveillance system, the CPSP recognizes that reporting on minimum incidence rates can have limitations, including under-representation of the disease/condition in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, such as pending test results or travel and immunization history, may not have been available at the point of care and therefore may be absent from the surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that allow Canada to maintain its polio-free status.
- Stool samples in patients with AFP are sometimes difficult to obtain due to the nature of the patient's symptoms, including constipation. Additionally, rapid availability of advanced diagnostic testing often identifies the diagnosis prior to the collection of the stool sample.

Conclusions

- There was sufficient evidence to suggest that no polio cases occurred in Canada even though Canada did not meet the WHO performance indicators for national AFP surveillance in 2017.

Anticipated study impact

- Canada's polio-free status remains intact.
- In its efforts to continue to support the Polio Endgame Strategy and strengthen AFP surveillance, Canada is updating the protocol for the investigation of AFP and the national case definition for polio.

Acknowledgements

The investigators would like to thank everyone who participated in collecting the data. They would also like to acknowledge the excellent work of Shalini Desai, Anada Silva, Jenne Cunliffe, Susan Squires, and Marc-André Beaulieu.

1. Detailed information on WHO surveillance performance indicators can be found at <http://polioeradication.org/polio-today/polio-now/surveillance-indicators/>

2. Adequate stool sample refers to one stool sample taken within 14 days of paralysis onset.

Adverse drug reactions – serious and life-threatening

Ongoing study since January 2004



Sally Pepper

Principal investigator

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? Question

What serious and life-threatening events suspected to be related to adverse drug reactions (ADRs) in children and youth were reported in 2017?

! Importance

- Only a minority of prescribed pharmaceuticals on the market in North America have been tested in paediatric patients, and most of them are used without the benefits 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 ongoing monitoring of the benefit-risk profile of health products used in children.

➔ Methodology

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

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 (immunoglobulin) products, 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

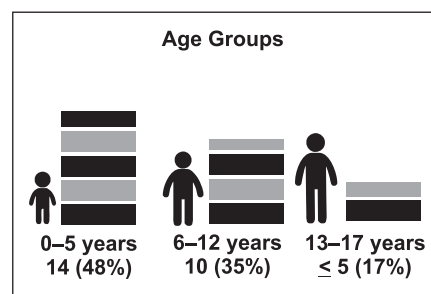
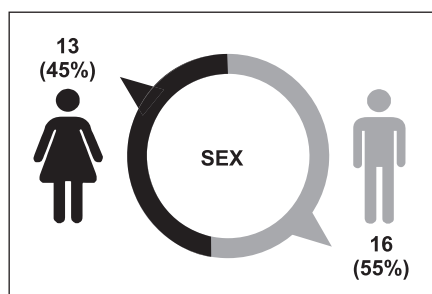
Unique to this study

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

✓ Results – January to December 2017

Confirmed cases

- At the time of analysis, the study confirmed 29 suspected paediatric ADR cases in 2017.
- In fewer than five reports, more than one product was suspected of causing the adverse reaction.
- The classes of health products (as classified using the Anatomical Therapeutic Chemical (ATC) classification system) most frequently



suspected of causing the adverse reaction(s) were the following: antibacterials for systemic use (eight reports) and antiepileptics (six reports).

- Antivirals for systemic use, antineoplastic agents, analgesics, corticosteroids for systemic use, vitamins, blood substitutes and perfusion solutions, antihypertensives*, immunosuppressants, anti-inflammatory and anti-rheumatic products, muscle relaxants, natural health products, drugs for obstructive airways disease, and anaesthetics were each involved in fewer than five case reports.

* Includes guanfacine, an alpha 2a adrenergic receptor agonist that has an indication for the treatment of attention deficit hyperactivity disorder

Demographics

- Patient sex was male in 16 (55%) cases and female in 13 (45%) cases.
- Reported age ranges were as follows: 14 (48%) involved children up to 5 years of age, 10 (35%) involved children aged 6 to 12 years, and the remaining cases were aged 13 to 17 years.

Presentation

- The 29 cases were classified as serious according to the following criteria (more than one cause for classification was provided in 11 reports): 7 cases were considered to be life-threatening, 19 cases required hospitalization, fewer than 5 cases reported disability, and 12 cases were considered to be medically important (defined as a case that may not be immediately life-threatening or result in death/hospitalization but may jeopardize the patient or require intervention to prevent one of these other outcomes from occurring).
- Fewer than five deaths were reported.
- The majority of the adverse reaction reports described skin and subcutaneous tissue disorders. This finding is consistent with the trend seen with all reports received through the CPSP since 2004.
- The majority of the reports described reactions generally documented in the approved Canadian product monograph (CPM) or other drug information references.

Treatment and outcomes

- The outcome was known in most of the 29 cases, with the majority of patients (20/29, 69%) having fully recovered.

Study limitations

- All adverse reactions (ARs) to health products are considered suspicions as a definite causal association often cannot be determined. The true incidence of ARs is unknown because ARs remain under-reported and total patient exposure is unknown.
- As with any voluntary reporting surveillance system, the CPSP recognizes that reporting on minimum incidence rates can have limitations, including under-representation of ARs in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, such as laboratory investigations, pre-existing medical conditions, and relevant components of the diagnostic assessment, may not have been available at the point of care and therefore may be absent from the surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that will allow for a better understanding of serious and life-threatening paediatric adverse drug reactions.

Conclusions

- The class of health product most frequently suspected of causing adverse reaction(s) reported in 2017 was antibacterials for systemic use, followed by antiepileptics. Since the implementation of the CPSP surveillance for adverse reactions in 2004, these two classes, along with psychoanaleptics, have been the most frequently associated with suspect products.

TABLE 1 – Suspect health products in 2017

Class of health product	Name of health product
Anaesthetics	Propofol
Analgesics	Acetaminophen/chlorpheniramine/ dextromethorphan/ pseudoephedrine*, fentanyl
Antibacterials	Amikacin, amoxicillin, amoxicillin/ clavulanic acid, ceftriaxone, co-trimoxazole*, piperacillin/ tazobactam*, vancomycin
Antiepileptics	Carbamazepine, oxcarbazepine, phenobarbital, phenytoin, valproic acid
Antihypertensives	Guanfacine
Anti-inflammatory and anti- rheumatic products	Ketorolac
Antineoplastic agents	Asparaginase, bleomycin
Antivirals	Acyclovir, zidovudine
Blood substitutes and perfusion solutions	Potassium phosphates
Corticosteroids for systemic use	Dexamethasone
Drugs for obstructive airways disease	Salbutamol
Immunosuppressants	Infliximab
Muscle relaxants	Rocuronium
Natural health products	Oil of wintergreen
Other therapeutic agents	Deferiprone, diazoxide
Vitamins	Vitamin D

* Combination product containing two or more active ingredients

- Amoxicillin and carbamazepine continue to be the most frequently reported suspect drugs in the antibacterial and antiepileptic classes respectively. Although no reports of psychoanaleptics that met the study criteria were received in 2017, methylphenidate remains the most frequently reported drug in this class based on cumulative data from previous years.

Anticipated study impact

- Health Canada recognizes the need to strengthen information related to paediatric health, as the use of medications to treat children is increasing, and the safety and efficacy of these medications may be significantly different in paediatric patients than in adult patients.^{1,2} The ongoing sharing of safety information through voluntary reporting of adverse drug reactions 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.

Acknowledgements

The assistance of Lynn Macdonald is greatly appreciated.

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Avoidant/restrictive food intake disorder

January 2016 to December 2017 – Final report



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Co-investigators

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? Question

What is the minimum incidence of avoidant/restrictive food intake disorder (ARFID) in the Canadian paediatric population?

! Importance

- ARFID is an eating disorder first described in the *Diagnostic and Statistical Manual of Mental Disorders – 5th edition* (DSM-5) associated with significant medical and psychiatric comorbidity.
- ARFID presents with the key clinical features of avoiding or restricting food intake without distorted cognitions about weight and shape as seen in patients with anorexia nervosa.
- Incidence estimates of ARFID range from 6 to 14% in tertiary care paediatric eating disorder centres; however, there are no data on the incidence of ARFID in community settings.
- Limited information exists on the diagnosis, clinical features, course, and treatment of ARFID in children and adolescents.

↪ Methodology

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

Case definition

Any child or adolescent from age 5 up to the patient's 18th birthday, seen in the previous month with a newly diagnosed eating or feeding disturbance (e.g., apparent lack of interest in eating or food, avoidance based on the sensory characteristics of food, concern about aversive consequences of eating), as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:

- Significant weight loss (or failure to achieve expected weight gain or faltering growth in children)
- Significant nutritional deficiency
- Dependence on enteral feeding or oral nutritional supplements
- Marked interference with psychosocial functioning

Exclusion criteria

The feeding or eating disturbance is:

- A result of lack of available food
- A result of culturally sanctioned practice
- Attributed to anorexia nervosa or bulimia nervosa
- Associated with abnormalities in the way in which the young person perceives his/her body weight or shape
- Explained by another medical or mental disorder, so that if treated, the feeding or eating disturbance will go away

✓ Results – January 2016 to December 2017

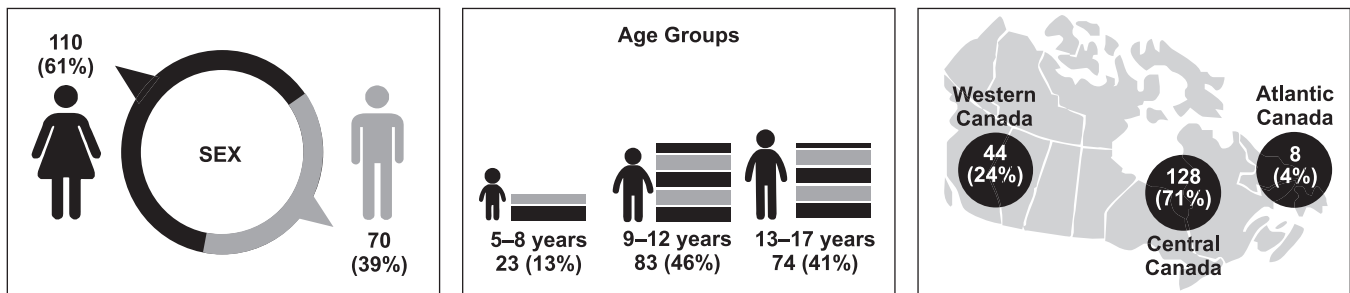
Confirmed cases

- At the time of analysis, 180 cases were confirmed over 24 months.

Demographics

- There were 110 (61%) females and 70 (39%) males.

- The average age was 13.0 years (SD = 3.2). The number of children (%) in each age range was as follows: 23 (13%) 5 to 8 years, 83 (46%) 9 to 12 years, and 74 (41%) 13 to 17 years.
- Geographic location was reported as follows: 44 (24%) cases from Western Canada, 128 (71%) cases from Central Canada, and 8 (4%) cases from Atlantic Canada.
- The majority of cases, 142 (79%), were White; 10 additional population groups were reported.



Presentation

- The average length of illness prior to diagnosis was 34 months (SD = 40.5).
- The most common abnormal eating behaviours reported were: 148 (82%) cases with food avoidance, 129 (72%) cases with a loss of appetite or little or no desire to eat, 126 (70%) cases with an apparent lack of interest in eating or food, 160 (89%) cases were eating but not eating enough, 128 (71%) cases were eating but avoiding certain foods, and 129 (72%) cases were not initiating eating or seeking out food as expected.
- Cases presented with clinical signs including: 116 (64%) with marked interference with psychosocial functioning, 104 (58%) with significant weight loss, 103 (57%) with failure to achieve expected weight gain, 60 (33%) with dependence on enteral feeding or oral nutritional supplements, 52 (29%) with faltering growth, and 47 (26%) with significant nutritional deficiency.
- The most common psychiatric comorbidities seen among reported cases were: 87 (48%) with anxiety, 24 (13%) with attention deficit hyperactivity disorder, 19 (11%) with depression, 16 (9%) with autism spectrum disorder, and 13 (7%) with obsessive-compulsive disorder.

Treatment and outcomes

- At the time of the report, ARFID cases were receiving the following treatments: 151 (84%) medical monitoring, 117 (65%) nutritional counselling by a dietician, 94 (52%) psychoeducation, 94 (52%) family therapy, and 61 (34%) individual therapy.
- Hospitalizations had occurred in 71 (39%) cases. Of those hospitalized, the most common reasons for hospitalization were: 16 (23%) for medical instability, 16 (23%) for weight or growth concerns, and 9 (13%) for food refusal.

Study limitations

- As with any voluntary reporting surveillance system, the Canadian Paediatric Surveillance Program (CPSP) recognizes that reporting on minimum incidence rates can have limitations, including under-representation of the disease in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, such as social history, past psychiatric illness, and relevant components of the diagnostic assessment, may not have been available at the point of care and therefore may be absent from the surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that will allow for a better understanding of Canadian-specific epidemiology on ARFID in children and youth.
- Paediatricians may lack awareness of and comfort with applying the DSM-5 criteria to a relatively newly recognized eating disorder in children and adolescents.

Conclusions

- At present, a significant period of time elapses between the onset of symptoms and receiving a diagnosis of ARFID. Improvements in the identification of ARFID are necessary to accelerate access to appropriate treatment.
- Each of the DSM-5 diagnostic criteria for ARFID was reported in this study.
- The majority of patients with ARFID were female; however, a higher percentage of males with ARFID was reported than is found in older adolescents and adults with anorexia nervosa and bulimia nervosa.
- Patients presented with high rates of mental health co-morbidity.
- The majority of children and adolescents were in treatment, most commonly outpatient medical monitoring.



Anticipated study impact

- This study will be the first to establish the minimum incidence of ARFID in children and adolescents in Canada.
- Study results will advance the knowledge of Canadian clinicians and relevant stakeholders to facilitate early diagnosis and management of ARFID that may lead to policy, educational, and public health initiatives.



Publication and dissemination

Are all paediatric feeding and eating disorders created equal? Working with patients who have avoidant/restrictive food intake disorder. Katzman DK, Norris M. Canadian Paediatric Society Annual Conference, Vancouver, in June 2017 (oral presentation)

Acknowledgements

We would like to thank Karizma Mawjee, MA for her help with the CPSP ARFID study.

Childhood Lyme disease

July 2014 to June 2017 – Final report



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? Question

What is the epidemiology of Lyme disease in Canadian children?

! Importance

- Lyme disease is a multi-system illness caused by the tick-borne bacterium *Borrelia burgdorferi*.
- Symptoms often present in the weeks following a tick bite with the characteristic erythema migrans rash, or later, with heart, joint, skin, or nervous system illness representing disseminated Lyme disease.
- Accurate estimates of the burden of illness in Canadian children are not available. The incidence of Lyme disease is expected to increase as the vector tick populations spread further into parts of southern Ontario, Quebec, Nova Scotia, New Brunswick, and Manitoba.

➡ Methodology

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

Case definition

A patient less than 16 years of age with Lyme disease, meeting the following criteria:

Confirmed Lyme disease – Patient fulfills one of two conditions:

1. Clinical evidence of illness with laboratory confirmation
 - a. Isolation of *Borrelia burgdorferi* from an appropriate clinical specimen
 - OR
 - b. Detection of *B burgdorferi* DNA by PCR in appropriate tissues
2. Clinical evidence of illness with a history of residence in, or visit to, an endemic area* and with laboratory evidence of infection
 - Positive serologic test using the two-tiered serological approach (i.e., ELISA followed by Western blot assays)

Probable Lyme disease – Patient fulfills one of two conditions:

1. Clinical evidence of illness without a history of residence in, or visit to, an endemic area* and with laboratory evidence of infection
 - Positive serologic test using the two-tiered serological approach (i.e., ELISA followed by Western blot assays)
2. Clinician-observed erythema migrans without laboratory evidence but with history of residence in, or visit to, an endemic area*

Exclusion criteria

- Confirmation of infection with a non-tick-borne disease, which fully explains symptoms
- Cases diagnosed by methods and/or laboratories not recommended by the Public Health Agency of Canada or the US Centers for Disease Control and Prevention

* An endemic area is defined as a locality in which reproducing populations of *Ixodes scapularis* or *Ixodes pacificus* tick vectors are present and transmission of *B burgdorferi* occurs at the location.

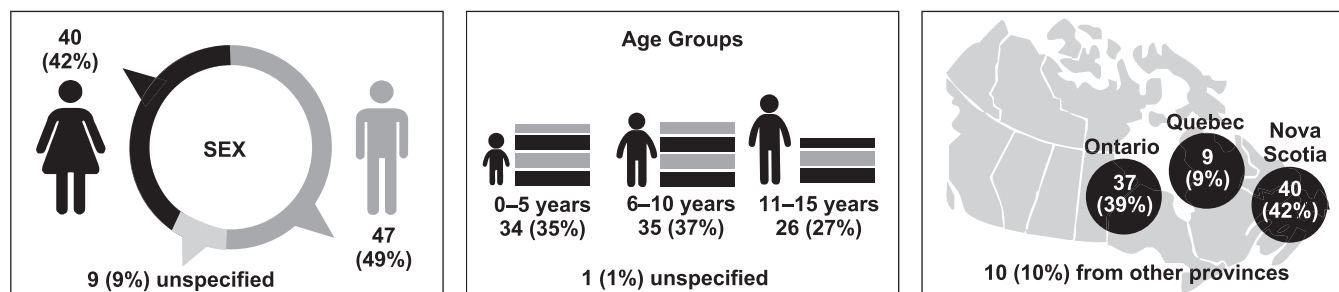
✓ Results – July 2014 to June 2017

Confirmed cases

- Of the 108 cases reported to the Canadian Paediatric Surveillance Program (CPSP), 96 cases met the case definition: 34 for *confirmed* Lyme disease and 62 for *probable* Lyme disease.

Demographics

- The median age of cases at diagnosis was 7 years. Age ranges were reported as follows: 34 (35%) aged 0 to 5 years, 35 (37%) aged 6 to 10 years, 26 (27%) aged 11 to 15 years, and in 1 (1%) case age was unknown.
- No significant gender difference was seen. Where sex was recorded, 47 (49%) were male and 40 (42%) were female. Sex was not recorded for nine (9%) cases.
- Eighty-one percent of cases were from two provinces: 40 (42%) from Nova Scotia and 37 (39%) from Ontario. Nine (9%) cases were reported from Quebec and the remaining 10 cases were from British Columbia, Alberta, Manitoba, New Brunswick, and Newfoundland and Labrador.



Presentation

- Most diagnoses (66, 69%) were made during the main May to October tick activity season.
- Manifestations of Lyme disease were as follows: 25 (26%) cases were early Lyme disease (i.e., a single erythema migrans [EM] lesion), 15 (16%) cases were early disseminated Lyme disease (i.e., multiple EM, neurological and/or cardiac symptoms), and 56 (58%) cases were late disseminated Lyme disease (arthritis).

Treatment and outcomes

- Sixty-four (67%) cases recovered following one course of antibiotic treatment (the most common included amoxicillin, doxycycline, and ceftriaxone).
- In 13 (14%) cases a second course of antibiotics was given.
- In 19 (20%) cases treatment and outcome were unknown or not indicated.

Study limitations

- As with any voluntary reporting surveillance system, the CPSP recognizes that reporting on minimum incidence rates can have limitations, including under-representation of the disease in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Lower than expected reporting of Lyme disease occurred, potentially due to the diagnosis being made by non-CPSP practitioners.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, including exposure risk, were not available in many cases. This may be due to the delay between patient consultation and questionnaire completion as well as the delay between infection exposure and the development of clinical manifestations of Lyme disease. Data elements missing from the charts are absent from the surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that will allow us to better understand the Canadian-specific epidemiology and the impact of childhood Lyme disease.

Conclusions

- Over the three year study period, 96 cases of Lyme disease were reported from eight provinces with 81% of cases from Nova Scotia and Ontario.
- The median age of reported cases was 7 years.
- Late disseminated Lyme disease (arthritis) was a common presentation in this cohort of Canadian children. This may be due to the fact that consultant paediatricians are more likely to see later manifestations of Lyme disease than acute Lyme disease, which would be handled in the acute care setting.

Anticipated study impact

- Study results will lead to a better understanding of the spectrum of clinical presentation of Lyme disease among children in Canada, as well as the diagnostic methods and treatments used.
- Study results allow for further identification of geographical risk areas for Lyme disease, and permit targeted disease prevention strategies in those regions where front-line medical practitioners most need information on the appropriate diagnosis and treatment of Lyme disease.

Publication and dissemination

Lyme disease: An emerging infectious disease in Canada. Langley J. Canadian Paediatric Society Annual Conference, Vancouver, in June 2017 (oral presentation)

Complex regional pain syndrome in Canadian children and youth

September 2017 to August 2019



Krista Baerg

Principal investigator

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Co-investigators

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? Question

- What are the minimum incidence and geographic distribution of complex regional pain syndrome (CRPS) in the Canadian paediatric population?
- What are the pathways of referral, clinical presentation, diagnostic interventions, and recommended interventions by paediatricians and pain specialists?

! Importance

- CRPS is a chronic severe pain condition that involves peripheral, central, and autonomic nervous system and immune system mechanisms. It results in greater functional impairment and symptoms than other chronic pain conditions. The persistent and severe pain results in psychological, physical, and neurological structural and functional changes.
- CRPS is a rare condition and few interventions have been formally evaluated in the paediatric population.

↻ Methodology

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

Case definition

A patient presenting between the ages of 2 and 18 years (up to the 18th birthday) with a new diagnosis of CRPS, meeting the following International Association for the Study of Pain clinical diagnostic criteria:

1. Continuing pain, which is disproportionate to any inciting event
2. Reports at least one symptom in at least three of the following four categories:
 - **Sensory:** hyperesthesia and/or allodynia
 - **Vasomotor:** temperature asymmetry and/or skin color changes and/or skin color asymmetry
 - **Sudomotor/Edema:** edema and/or sweating changes and/or sweating asymmetry
 - **Motor/Trophic:** decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin)
3. Displays at least one sign at time of evaluation in at least two of the following four categories:
 - **Sensory:** hyperalgesia (to pinprick) and/or allodynia (to light touch and/or temperature sensation and/or deep somatic pressure and/or joint movement)
 - **Vasomotor:** temperature asymmetry ($>1^{\circ}\text{C}$) and/or skin color changes and/or asymmetry
 - **Sudomotor/Edema:** edema and/or sweating changes and/or sweating asymmetry
 - **Motor/Trophic:** decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin)

Exclusion criteria

Presence of another diagnosis that better explains the signs and symptoms

Unique to this study

The following are the Canadian paediatric pain clinics and the nominated representatives that have been engaged as site champions for the duration of the study:

- Marie-Joëlle Doré-Bergeron, MD, FRCPC, CHU Ste-Justine
- Sheri Findlay, MD, McMaster Children's Hospital
- Pablo M. Ingelmo, MD, McGill University Health Centre
- Christine Lamontagne, MD, FRCPC, Children's Hospital of Eastern Ontario
- Tim Oberlander, MD, FRCPC, BC Children's Complex Pain Service
- Raju Poolacherla, MD, London Health Sciences Centre, Victoria Hospital
- Kathy Reid, RN, NP, Stollery Children's Hospital
- Adam Spencer MD, MSc, FRCPC, Alberta Children's Hospital
- Jennifer Stinson, RN, PhD, The Hospital for Sick Children



Results – September to December 2017

Confirmed cases

- Fewer than five cases were confirmed at the time of analysis; however, 21 potential cases had been signalled to the Canadian Paediatric Surveillance Program (CPSP).

Demographics

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

Presentation, treatment, and outcomes

While specific information on this study cannot be presented at the current time due to the small number of cases, available literature on CRPS suggests the following:

- A diagnosis of CRPS relies on history and clinical examination; there is no definitive diagnostic test or pathognomonic findings.
- Patients present with unusual features such as spontaneous pain, altered sensation resulting in pain (e.g., allodynia and hyperalgesia), and pain outside the distribution of a peripheral nerve.
- Pain is often not responsive to opioids or nonsteroidal anti-inflammatory drug (NSAID) medications.
- Physiotherapy is the cornerstone of treatment for CRPS.

Study limitations

- As with any voluntary reporting surveillance system, the CPSP recognizes that reporting on minimum incidence rates can have limitations, including under-representation of the disease/condition in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, such as social history or special investigations, may not have been available at the point of care and therefore may be absent from the surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that will allow for a better understanding of the Canadian-specific epidemiology and the impact of CRPS.



Conclusions

- At the time of analysis, fewer than five cases of CRPS were confirmed.



Anticipated study impact

- Study results will help determine the minimum incidence of CRPS and highlight current resource needs in Canada.
- The study will help identify patient demographics, triggers, or risk factors associated with CRPS.
- Results will be used to promote early recognition and treatment to benefit patient recovery.



Publication and dissemination

Canadian surveillance study of complex regional pain syndrome in children and youth. Baerg K, Tupper S, Finley A. Chronic Pain Network Annual Meeting, Hamilton, in September 2017 (poster presentation)

Acknowledgements

Thanks to all the collaborating Canadian paediatric pain clinics, the CPSP, and CPSP participants. We gratefully acknowledge funding for this study from the Chronic Pain Network.

Congenital Zika syndrome in infants in Canada

March 2017 to February 2019



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? Question

What is the minimum incidence of infants born with congenital Zika syndrome (CZS) in Canada and what is the spectrum of clinical manifestations and abnormalities seen in these infants?

! Importance

- In October 2015, an increased incidence of microcephaly was noted in northeastern Brazil. Further investigations noted an increase in severe microcephaly and other neurological disorders among newborns born to mothers with Zika virus infection.
- While severe microcephaly was the first major congenital anomaly linked with Zika virus infection during pregnancy, a wide range of congenital anomalies have been described. As a result of the spectrum of clinical manifestations and abnormalities seen in infants born to Zika virus-infected mothers, the term congenital Zika syndrome has been developed. Importantly, some newborns born to mothers infected with Zika virus have neurological abnormalities with a normal head circumference.
- Surveillance for CZS in Canada through the Canadian Paediatric Surveillance Program (CPSP) started in March of 2017. This project is complementary to the CPSP surveillance for severe microcephaly.

↻ Methodology

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

Case definition

An infant less than 12 months of age who presents with the following criteria:

- Microcephaly, defined as head circumference less than two standard deviations for gestational age and sex according to the standardized reference percentile*
OR
- Other congenital anomalies and malformations consistent with congenital Zika syndrome including malformations of the central nervous system, such as intracranial calcifications, structural brain or eye abnormalities, or other congenital central nervous system-related abnormalities (not explained by another etiology†)
AND
- A maternal history that includes an epidemiologic linkage‡ to Zika virus OR a positive or inconclusive Zika virus laboratory test
OR
- An infant with a positive or inconclusive Zika virus laboratory test

* If there is a case of severe microcephaly suspected to be associated with Zika virus then a questionnaire for the severe microcephaly study and the congenital Zika syndrome study should be completed (i.e., if the case meets both case definitions).

† Other etiologies that should be considered include other congenital infections such as syphilis, toxoplasmosis, rubella, cytomegalovirus, varicella zoster, parvovirus B19, and herpes simplex virus. An assessment of potential genetic and other teratogenic causes of the congenital anomalies should also be considered.

‡ Epidemiological linkage means: travelled to, or resided in, an area with active Zika virus transmission during her pregnancy; OR had unprotected sex during pregnancy with a partner who resided in, or traveled to, an area with active Zika virus transmission.

Unique to this study

There is currently a CPSP study underway examining the incidence and epidemiology of severe microcephaly in Canada. For cases of severe microcephaly suspected to be associated with Zika virus, CPSP participants are asked to report using both the severe microcephaly questionnaire AND the CZS questionnaire. There is cross-representation of principal and co-investigators on the research teams to ensure that all cases are appropriately identified and analyzed.



Results – March to December 2017

Confirmed cases

- Since data collection was initiated, fewer than five cases of CZS have been identified in Canada.

Demographics

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

Presentation, treatment, and outcomes

While specific information on this study cannot be presented at the current time due to the small number of cases, available literature demonstrates that CZS consists of:

- Severe microcephaly in which the skull has partially collapsed
- Decreased brain tissue with a specific pattern of brain damage, including subcortical calcifications
- Damage to the structures of the eye, including but not limited to macular scarring and focal pigmentary retinal mottling
- Congenital contractures
- Hypertonia

Studies show that among completed pregnancies with laboratory evidence of infection with Zika virus, about 6% of fetuses or infants had evidence of Zika-associated birth defects. Among pregnant women with Zika virus infection in the first trimester, about 11% of fetuses or infants had evidence of Zika-associated birth defects.

Study limitations

- As with any voluntary reporting surveillance system, the CPSP recognizes that reporting on minimum incidence rates can have limitations, including under-representation of the disease/condition in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, for example pending test results, parental travel history, physical examination, and relevant components of the diagnostic assessment, may not have been available at the point of care and therefore may be absent from the surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that will allow us to better understand the Canadian-specific epidemiology and impact of Zika virus.



Conclusions

- CZS is rare in Canada. According to the Public Health Agency of Canada, as of December 1, 2017, 544 travel-related cases and 4 sexually transmitted cases of Zika virus infection have been reported in Canada since cases started being detected in October 2015. A total of 37 cases have been reported among pregnant women. Thus far, fewer than five cases of CZS have been reported in this CPSP study.
- This CPSP study will continue until February of 2019 with data analyzed quarterly to identify any key epidemiologic findings.



Anticipated study impact

- While CZS has been rare thus far in Canada, this study will provide valuable clinical and epidemiological information on cases that may occur following maternal infection via travel, sexual transmission, or other modes.
- These data will supplement any other data collected via provincial or territorial reportable disease programs.

Incidence trends of type 2 diabetes, medication-induced diabetes, and monogenic diabetes in Canadian children

June 2017 to May 2019



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? Question

- What are the minimum incidence and the 10-year minimum incidence trends of non-type 1 diabetes mellitus (NT1DM) and its subtypes (type 2 diabetes [T2D], medication induced diabetes [MID], and monogenic diabetes) in Canada?
- What are the childhood-onset T2D risk factors, clinical characteristics, and diabetes-related complications, as well as differences in approaches to treatment across Canada?

! Importance

- Childhood-onset T2D is on the rise. With access to Canadian data on T2D incidence in children and youth from 2006 to 2008, this second Canadian Paediatric Surveillance Program (CPSP) surveillance study will provide national incidence trend data over a 10-year period.
- This surveillance study will produce the first-ever 10-year incidence trends for other forms of NT1DM including MID and monogenic diabetes.

➡ Methodology

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

Case definition

A new or revised* diagnosis of non-type 1 diabetes (NT1DM) in a patient less than 18 years of age with clinical features that are **not** consistent with classic type 1 diabetes (defined as a child with symptomatic acute hyperglycemia).

* A revised diagnosis occurs when a child previously diagnosed with type 1 diabetes mellitus receives a "revised" diagnosis of non-type 1 diabetes based on clinical progression and/or results of investigations.

Diabetes is defined based on the Canadian Diabetes Association Guidelines:

- Fasting plasma glucose (FPG) ≥ 7.0 mmol/L[†] or
- Random plasma glucose ≥ 11.1 mmol/L[†] or
- Two-hour plasma glucose ≥ 11.1 mmol/L[†] after a standard oral glucose tolerance test

† Requires a second, confirmatory test if child is asymptomatic

Clinical features suggestive of non-type 1 diabetes mellitus are listed below:

- a) Obesity (body mass index >95 th percentile for age and gender)
- b) Family history of type 2 diabetes in a first- or second-degree relative(s)
- c) Belonging to a high-risk ethnic group (e.g., Indigenous, Black, Latin American, South-Asian)
- d) A history of exposure to diabetes *in utero* (diagnosed before or during pregnancy)

- e) *Acanthosis nigricans*
- f) Polycystic ovarian syndrome
- g) Diabetes in a person with a syndrome often associated with type 2 diabetes (Prader-Willi syndrome)
- h) Diabetes in a non-obese patient with at least one first-degree relative with diabetes
- i) Diabetes diagnosed in a neonate/infant less than 6 months of age
- j) Minimal or no insulin requirement with a normal or near normal A1c level (4–6%) one year after diagnosis
- k) A diagnosis of diabetes while on medical therapy with a known diabetogenic medication (e.g., glucocorticoids, L-asparaginase, cyclosporine, tacrolimus, atypical antipsychotic, anticonvulsant)

Exclusion criteria

Do not report patients with cystic fibrosis-related diabetes, pregnant teenagers with gestational diabetes, and patients in critical care settings requiring **short-term** insulin therapy for stress hyperglycemia.

Unique to this study

- To produce the most accurate incidence estimate of childhood-onset T2D, this study will also use data from the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) to identify new cases of childhood-onset T2D seen by participating primary care providers (e.g., family physicians) that would not be reported by paediatricians or paediatric endocrinologists.
- Reporting physicians have the option of accessing free specialized pancreatic autoantibody testing accessed via the Barbara Davis Center for Childhood Diabetes (Denver, Colorado) if they feel that the additional testing would help with the classification of diabetes subtype, and they do not have access to this testing via their provincial laboratory services. This part of the study is not conducted through the CPSP and requires patient consent.



Results – June to December 2017

Confirmed cases

- At the time of analysis, 108 cases were confirmed for the first six months of reporting.

Demographics

- There were 57 (53%) females and 51 (47%) males.
- Population groups were indicated for 105 cases with the majority of cases being from the following groups: 40 (38%) Indigenous, 25 (24%) White, and 10 (10%) South Asian (Bangladeshi, Punjabi, Sri Lankan, Indian).
- The provincial/territorial breakdown was as follows: 53 (49%) from Western Canada, 46 (43%) from Central Canada, and 9 (8%) from Atlantic Canada.

Presentation

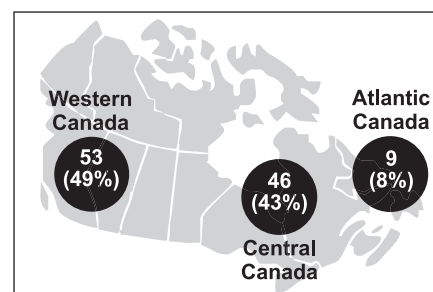
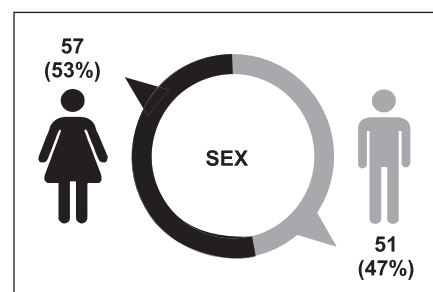
- Based on the 98 cases where the reporting physician made a clinical diagnosis of diabetes subtype, 70 (71%) cases were T2D, 15 (15%) were MID, and 4 (4%) were confirmed or suspected monogenic diabetes. There were 9 (9%) cases where the diagnosis of a diabetes subtype was unknown or unconfirmed.
- Fifty-six cases were assigned a final classification of diabetes subtype by the research team. Of these 56 cases, 82% were confirmed as T2D, 7% were MID, and 11% of cases were classified as 'indeterminate'.
- Polyuria was present at diagnosis in 45/93 (48%) cases and polydipsia in 40/93 (43%) cases; 41/93 (44%) cases were asymptomatic. Diabetic ketoacidosis (DKA) was described in 10 cases. Fewer than five cases each presented with a hyperglycemic hyperosmolar state (HSS) or combined DKA and HHS.

Treatment and outcomes

- At this early stage in surveillance, treatment and outcome data cannot be reported.

Study limitations

- As with any voluntary reporting surveillance system, the CPSP recognizes that all new cases of paediatric NT1DM in Canada may not be captured; therefore, a minimum incidence estimate for NT1DM and its subtypes will be calculated. The case capture for this study will be optimized by reviewing CPCSSN electronic medical record data from primary care physicians across Canada and identifying any new cases of childhood-onset T2D that were not reported via the CPSP.
- Case level surveillance data are extracted from patient medical charts following the clinical encounter; therefore, some data elements not collected as part of routine care may be absent from the surveillance totals and, in some cases, insufficient clinical information is provided to accurately assign a diagnosis of diabetes subtype. However, surveillance serves an important purpose and provides rich clinical data that will allow for a better understanding of Canadian-specific epidemiology and the impact of T2D, MID, and monogenic diabetes in Canadian children.



Conclusions

- The second CPSP surveillance study for NT1DM has been successfully operationalized. In the first six months, 22 cases have been reported, on average, per month. If reporting rates remain the same, it is expected that approximately 550 cases of NT1DM will be reported by the end of the surveillance period, with the majority of these cases being childhood-onset T2D.

Anticipated study impact

- Study results will provide minimum incidence rates and trends in childhood-onset NT1DM and its subtypes based on Canada's unique ethnic, cultural, and geographic characteristics.
- Results will help define childhood-onset T2D risk factors, clinical characteristics, and diabetes-related complications, as well as differences in approaches to treatment across Canada.
- By largely replicating the first CPSP study on NT1DM, this subsequent study can help determine whether the 'face' of childhood-onset T2D is changing related to demographics, clinical presentation, and severity — information that is critical to designing prevention and treatment programs that meet the specific needs of the populations affected.

Acknowledgements

Thank you to members of the CPSP and the Canadian Pediatric Endocrine Group (CPEG) for diligently reporting cases and completing case report forms. We also thank the Public Health Agency of Canada for providing the funding to support this work.

Infantile and later-onset paediatric Pompe disease (glycogen storage disease type II)

October 2017 to September 2019



Eugenio Zapata
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Principal investigators

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Co-investigators

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? Question

- What is the clinical presentation of infantile and later-onset paediatric Pompe disease in Canada?
- What are the minimum incidence and minimum prevalence of infantile-onset and juvenile-onset paediatric Pompe disease in Canadian children and adolescents?

! Importance

- The main manifestations in congenital and adult-onset Pompe disease have been characterized, but it is critical to delineate the symptoms and clinical characteristics of infantile and juvenile-onset paediatric Pompe disease to facilitate prompt management and treatment of these unique conditions.
- The incidence and prevalence of infantile and juvenile-onset paediatric Pompe disease in Canadian children and adolescents are unknown.
- Raising awareness among Canadian paediatricians about infantile and juvenile-onset Pompe disease in Canadian children and adolescents is important to ensure that the disease is considered appropriately in the differential diagnosis for children presenting with proximal weakness, hypotonia, respiratory insufficiency, and/or high serum creatine kinase.

↻ Methodology

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

Case definition

A patient (new or previously diagnosed) of less than 18 years old meeting the following criteria:

1. **Genetic criteria:** Pathogenic mutations affecting both GAA genes (encodes the acid alpha-glucosidase protein) as determined by sequence analysis or deletion/duplication analysis
AND/OR
2. **Biochemical criteria:** Measurement of acid alpha-glucosidase (GAA) enzyme activity performed on one or more of:
 - Dried blood spot GAA enzyme activity assay
 - Whole blood GAA enzyme activity assay
 - Skin biopsy (fibroblast culture) GAA enzyme activity assay
 - Muscle biopsy GAA enzyme activity assay

Exclusion criteria

Clinical evidence of proximal muscle weakness without genetic or biochemical confirmation of disease

Unique to this study

Although Canadian Paediatric Surveillance Program (CPSP) studies classically capture minimum incidence rates, this study also aims to capture the prevalence of infantile and later-onset paediatric Pompe cases in Canada.

Results – October to December 2017

Confirmed cases

- To date fewer than five cases have been reported to the CPSP.

Demographics

- As per CPSP policy, case numbers and data elements for five cases or fewer cannot be presented.

Presentation, treatment, and outcomes

While specific information on this study cannot be presented at the current time due to the small number of reported cases, available literature demonstrates that:

- Children with Pompe disease have a deficiency of the lysosomal enzyme acid alpha-glucosidase (GAA). The clinical spectrum ranges from the severe, infantile-onset form, to the milder juvenile phenotype that presents later in childhood.
- Infants with Pompe disease exhibit severe hypotonia, weakness, cardiomyopathy, poor feeding, and respiratory failure.
- Many patients with later-onset Pompe disease experience long delays in diagnosis.
- Enzyme replacement therapy can improve essential function and quality of life and support longer survival for patients with both infantile and later-onset Pompe disease.

Study limitations

- As with any voluntary reporting surveillance system, the CPSP recognizes that reporting on minimum incidence rates, and in this study prevalence rates, can have limitations, including under-representation of the disease/condition in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, for example signs and symptoms prior to diagnosis, laboratory results, and relevant components of the diagnostic assessment, may not have been available at the point of care and therefore may be absent from the surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that will allow us to better understand the Canadian-specific epidemiology and the impact of infantile and later-onset Pompe disease.

Conclusions

- To date, fewer than five cases have been reported to the CPSP.

Anticipated study impact

- Study results will be submitted for publication in a peer-reviewed journal.
- Following analysis of the data, final results may be distributed to all provinces and territories.
- Study results will be disseminated to key stakeholder organizations, including the Canadian Association of Pompe and Muscular Dystrophy Canada, to help inform their efforts.

Acknowledgements

We would like to thank Rhiannon Hicks, BSc for all her help with the CPSP Pompe study.

Listeria in the newborn and early infancy

May 2015 to April 2017 – Final report



Tobias R. Kollmann

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? Question

- What is the age-specific minimum incidence of neonatal listeriosis in Canada?
- What maternal and perinatal risk factors are associated with early- versus late-onset listeriosis in Canada?
- What factors are associated with more severe outcomes (i.e., neonatal intensive care unit admission and/or death)?

! Importance

- Listeriosis is associated with high morbidity and mortality, especially in the newborn period.
- The epidemiologic factors associated with early-onset infection are well characterized, but those contributing to late-onset infection of the newborn are not well defined.
- Currently, empiric antibiotic coverage is the standard of care for neonatal listeriosis. The age at which *Listeria* is no longer a risk, and when empiric antibiotics to cover *Listeria* are no longer necessary for suspected sepsis, are not clear.
- Knowledge of evidence-based criteria for choice of antibiotics for *Listeria* during early life is essential to developing evidence-based treatment guidelines and advancing antimicrobial stewardship.

➡ Methodology

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

Case definition

New patient less than six months of age, meeting the following criteria:

- 1) Definitive
 - Positive culture of *Listeria* from a usually sterile site, such as blood, CSF or pleural fluid; or
 - Positive culture of *Listeria* from the placenta in the presence of compatible clinical features of listeriosis (sepsis, meningitis, respiratory distress, etc.).
- 2) Probable
 - Positive PCR for *Listeria* from a usually sterile site or the placenta in the presence of compatible clinical features of listeriosis (sepsis, meningitis, respiratory distress, etc.).

Unique to this study

- Since there is ongoing surveillance for invasive listeriosis within the Infectious Diseases Prevention and Control Branch of the Public Health Agency of Canada (PHAC), the role of PHAC in this project is to provide an aggregated national number of paediatric cases reported to PHAC through routine surveillance during the period of study. The national case count provided by PHAC excludes any cases in the province of Quebec; due to legal restrictions, Quebec is not currently participating in the ongoing national surveillance program.
- If the number of paediatric cases per year reported through the Canadian Paediatric Surveillance Program (CPSP) does not match the number of cases reported to PHAC through ongoing routine surveillance, the principal and co-investigators have access to other existing networks, including the Paediatric Investigators Collaborative Network on Infections in Canada (PICNIC) and other informal networks of health professionals in Canada, to identify missing cases.
- Together, this overlapping approach ensured complete coverage of the entire newborn population in Canada over the years of the study.



Results – May 2015 to April 2017

Confirmed cases

- Over the 24 months of the study, eight cases of laboratory-confirmed listeriosis were reported in newborns and infants.

Demographics

- Due to the small number of confirmed cases, no clear association with race/ethnicity, birth mode, or feeding mode has been detected.

Presentation

- Of the eight cases of neonatal listeriosis reported, six were early-onset.
- The early-onset cases presented as septic on the day of birth (median time at presentation: 0.5 hours, range: 0–2 hours of life).
- All early-onset cases had bacteremia.
- Early-onset cases were associated with maternal fever in almost all cases.
- Late-onset cases presented between day of life 9 and 20.
- None of the late-onset cases had obvious risk factors captured by the study questionnaire.

Treatment and outcomes

- All of the early-onset cases needed intensive care unit (or neonatal intensive care unit) admission. Mortality was reported in fewer than five cases.
- No mortality was associated with reported cases of late-onset listeriosis.

Study limitations

- Considering the low number of cases reported, risk factors and outcomes for late-onset cases could not be described.
- As with any voluntary reporting surveillance system, the CPSP recognizes that reporting on minimum incidence rates can have limitations, including under-representation of the disease/condition in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, such as pending laboratory results or components of the diagnostic assessment, may not have been available at the point of care and therefore may be absent from the surveillance totals. However, our overlapping approach to surveillance should have captured most cases; surveillance as outlined in this study serves an important purpose and provides rich clinical data that will allow us to better understand neonatal listeriosis.



Conclusions

- Based on the Canadian birth cohort of ~370,000 per year, and the reported incidence of neonatal listeriosis in the United Kingdom and the United States (5/100,000 live births and 8.6/100,000 respectively), a total of 19 to 30 cases of neonatal listeriosis were expected per year in Canada.
- The fact that only eight cases were reported over the 24 months of this CPSP surveillance study (confirmed through PHAC's surveillance program) suggests that the incidence of neonatal listeriosis in Canada is much lower than expected (~1/100,000 live births).
- Given the small number of cases to date, it is difficult to draw firm conclusions about underlying risk factors or outcomes of late listeriosis. Findings are in keeping with the published literature for early-onset listeriosis.
- Because sporadic food-borne *Listeria* outbreaks may continue to occur, ongoing surveillance and re-evaluation of early-onset *Listeria* sepsis should continue.



Anticipated study impact

- The ability to capture cases through the CPSP and PICNIC and compare counts with those obtained through PHAC's routine surveillance (invasive listeriosis is a nationally notifiable disease) indicates that current measures to capture cases in Canada are working well. This model of surveillance may be useful for other, rare neonatal and/or paediatric infections.
- The data from this study suggest that empiric therapy for neonatal listeriosis may benefit from re-evaluation in the face of lower than expected incidence. In addition, empiric therapy for listeriosis for infants older than 4 weeks of age may not be required as no cases of listeriosis were detected in this age group over the study period.



Publication and dissemination

Listeriosis in neonates and infants in Switzerland and Canada. Huang S, Abu Raya B, Jost M, Bortolussi R, Bettinger J, Grabowski J, Lacaze T, Robinson J, Posfay-Barbe K, Mäusezahl M, Kollmann TR. International Network of Paediatric Surveillance Units (INoPSU) 10th Scientific Conference, Glasgow, Scotland in March 2018 (oral presentation)

Acknowledgements

We wish to thank members of PICNIC, the Public Health Agency of Canada, and the CPSP participants for their contributions to this project.

Medically serious self-harm in youth requiring ICU admission

January 2017 to December 2018



Daphne Korczak

Principal investigator

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Co-investigators

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? Question

- What is the minimum incidence rate of children and adolescents (less than 18 years of age) admitted to the intensive care unit (ICU) for medically serious self-inflicted injury?
- What are the patterns of presentation, including demographics and psychiatric and medical history, encountered in these cases?

! Importance

- Suicide is the second leading cause of death among Canadian youth (15 to 19 years of age), representing almost 30% of all deaths in this age group in 2014.
- For every adolescent that dies by suicide, it is estimated there are 20 to 40 suicide attempts. However, there is little information available regarding the suicide attempts.
- Youth who make near-fatal suicide attempts – such as those requiring ICU level care – may closely approximate those who die by suicide, highlighting the need to further understand these suicide attempts.

➔ Methodology

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

Case definition

A new patient less than 18 years of age (up to the 18th birthday) meeting **BOTH** of the following criteria:

1. A confirmed or suspected self-harm or suicide attempt (any form of self-poisoning or self-injury regardless of the degree of intent to die)
AND
2. Admitted to an intensive care unit at any time during a hospital admission (for any duration)

Exclusion criteria

Accidental poisoning (e.g., intoxication) or injury

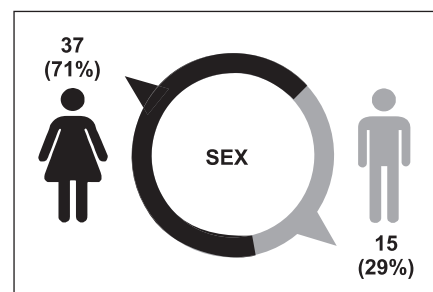
✓ Results – January to December 2017

Confirmed cases

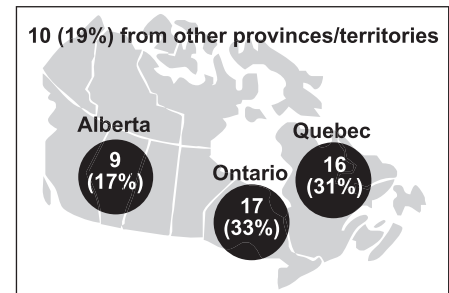
- At the time of analysis, 52 cases were confirmed.

Demographics

- The mean age of the confirmed cases was 15.41 years (range: 11.17 – 17.92 years of age).
- Almost three quarters of these adolescents were females. There were 37 (71%) females and 15 (29%) males.
- The majority of cases were White (31/51, 61%) and born in Canada (34/52, 65%).
- Seventy percent of the youth were living with their biological parent(s): 22/51 (43%) with one parent and 14/52 (27%) with both parents.



- Most cases were from three provinces: 17 (33%) from Ontario, 16 (31%) from Quebec, and 9 (17%) from Alberta. Fewer than five cases each were reported from British Columbia, Saskatchewan, Manitoba, New Brunswick, Nova Scotia, Newfoundland and Labrador, and the Northwest Territories.



Presentation

- Although the majority of cases reported were females, the majority of the deaths were of males (71%).
- Among females, the most common method of self-inflicted injury was overdose ingestion (70%) compared with hanging among males (33%).
- The most common precipitating events associated with suicide attempts (both fatal and non-fatal) were the following: in 28/51 (55%) cases it was family conflict, in 13/51 (26%) cases it was conflict with peer(s), and in 12/51 (24%) cases it was loss of a romantic relationship.
- In 14 (27%) cases, the parents/caregivers were aware that their child was considering suicide.
- Of those with a previous suicide attempt(s), 91% (20/22) were female.

Treatment and outcomes

- Overall, there were seven deaths in the sample, with six as the result of hanging.
- Of the 45 surviving cases that were discharged from the ICU, 31 (69%) were referred for follow-up with a psychiatrist and 35 (78%) with a mental health professional. Five cases or fewer received no follow-up.
- Females were more likely than males to have received a psychiatric diagnoses (26/31, 84%) and to be under the care of a psychiatrist or other mental health professional (24/27, 89%) prior to ICU admission.
- Of those cases that received treatment during the ICU admission, 23/51 (45%) received ventilation, 12/51 (24%) received hemodynamic support, and 14/51 (28%) used an antidote as part of treatment. Fewer than five cases each required dialysis or surgery.

Study limitations

- As with any voluntary reporting surveillance system, the Canadian Paediatric Surveillance Program recognizes that reporting on minimum incidence rates can have limitations, including under-representation of the disease in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas or adolescents treated in adult settings.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, such as psychiatric or family history, may not have been available at the point of care and therefore may be absent from surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that will allow for a better understanding of medically serious self-harm in youth requiring ICU admission.



Conclusions

- These findings are consistent with epidemiologic data that observe a gender paradox in youth suicide in which females demonstrate a higher rate of suicide attempts, while males display a higher rate of suicide mortality.



Anticipated study impact

- The present study seeks to extend current knowledge by providing greater detail on the personal and psychiatric history, situational factors, and management of adolescents following a near-fatal suicide attempt.

Acknowledgements

We would like to sincerely thank Rae Dopko from the Public Health Agency of Canada for her assistance with data analysis.

Rh sensitization

June 2016 to May 2018



Michael Sgro

Principal investigator

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Co-investigators

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? Question

What is the current incidence of Rh sensitization and Rh disease-associated neonatal severe hyperbilirubinemia in Canada?

! Importance

- Rh sensitization occurs when women whose red blood cells are Rh(D)-antigen negative develop anti-Rh(D) antibodies either during a previous pregnancy in which the fetus is Rh(D) positive or by exposure to Rh antigens from blood products/transfusion.
- Neonates born to Rh-sensitized mothers may present with severe jaundice, anemia, and death from acute or chronic bilirubin encephalopathy or brain damage resulting from severe neonatal hyperbilirubinemia.
- Several recent studies have found severe hyperbilirubinemia to be associated with other developmental delays such as autism, speech delay, and global developmental delay, even without concomitant choreoathetotic cerebral palsy.
- Rh disease is now considered rare in countries where Rh prophylaxis is used and the blood type and Rh sensitization status of the mother is usually known at the time of a delivery.

➡ Methodology

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

Case definition

Any infant 60 days of age or less with Rh(D) sensitization fulfilling ALL of the following criteria:

- Mother is Rh negative (D-negative)
- Mother has positive antibody screen due to anti-D. (This must be a maternal allo-anti-D, not passive anti-D from Rh(D) immunoglobulin (RhoGAM))
- Cord or infant blood group is Rh positive (D-positive)

✓ Results – January to December 2017

Confirmed cases

- At the time of analysis, 15 cases were confirmed.

Demographics

- Confirmed cases were from British Columbia, Alberta, Ontario, Quebec, Nova Scotia, and Newfoundland.
- Maternal country of birth was reported as Canada in eight cases. The remaining cases were born to mothers from South and West Asia or the maternal country of birth was unknown.

Presentation

- The average gestational age was 36.5 weeks (range: 35–40).
- The average age at presentation was 2.8 hours.
- The average hemoglobin at presentation was 133.8 g/L (range: 65–192 g/L).
- The average peak micro bilirubin (MBR) level was 81.9 $\mu\text{mol/L}$ (range: 35.8–267 $\mu\text{mol/L}$).

Treatment and outcomes

- The average number of phototherapy hours was 129.
- Fourteen cases did not receive exchange transfusion and for one case it was not known.

Study limitations

- Antibody reports obtained prenatally are sent to the obstetrician therefore there is a potential that positive results may not have been seen by a paediatrician if the infant remains well.
- As with any voluntary reporting surveillance system, the Canadian Paediatric Surveillance Program (CPSP) recognizes that reporting on minimum incidence rates can have limitations, including under-representation of the disease/condition in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, such as pending test results or family history, may not have been available at the point of care and therefore may be absent from the surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that will allow us to better understand Rh sensitization.



Conclusions

- Rh disease continues to exist in Canada.
- Despite current public health measures in place across Canada, additional work must be done to prevent Rh disease, noting factors including changes in immigration patterns, Rh immunoglobulin (RhoGAM) refusal, and Rh sensitization prior to 28 weeks gestation.



Anticipated study impact

- The study will identify risk factors associated with severe neonatal hyperbilirubinemia, including the contribution of Rh disease to severe neonatal hyperbilirubinemia in Canada.
- Study results will help to understand how best to identify Rh disease, given current immigration patterns as well as other causes of inadequate Rh prophylaxis.



Publication and dissemination

Rh sensitization in Canada is not obsolete. Baker JM, Campbell DM, Bhutani VK, Sgro M. *Paediatr Child Health* 2017;22(4):238–9

Acknowledgements

The investigators would like to thank Aidan Campbell for the assistance with the data entry.

Severe microcephaly

June 2016 to May 2018



Chantal Nelson

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Collaborators: Evans J, Tataryn J

? Question

What are the epidemiology and minimum incidence of severe microcephaly in Canada and are there cases of Zika virus-associated microcephaly in Canada?

! Importance

- Congenital microcephaly is an anomaly of the central nervous system that begins *in utero*. It is a condition in which an infant's head is significantly smaller than the heads of other children of the same age and sex at the time of birth.
- In early 2015, there was an increase in the number of microcephaly cases reported in Brazil. The increased incidence in Brazil, followed by similar experiences in other countries, was subsequently linked to an outbreak of Zika virus.
- Given the frequent travel of Canadians to Zika endemic regions, it is critical to monitor for microcephaly in Canada, both to establish baseline rates and understand the potential association with Zika virus infection.
- Surveillance for severe microcephaly in Canada through the Canadian Paediatric Surveillance Program (CPSP) started in June of 2016. This project is complementary to the CPSP surveillance for congenital Zika syndrome (CZS).

↪ Methodology

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

Case definition

Any new patient less than 12 months of age, with a head circumference measurement less than three standard deviations below the mean (0.13th centile) for gestational age and sex, based on the sex-specific World Health Organization growth parameters:

- Female term infant with a head circumference of less than 30.3 cm
- Male term infant with a head circumference of less than 30.7 cm
- Preterm infant (less than 38 weeks' gestation), as per INTERGROWTH-21st study standards

Unique to this study

Given the significant international interest in this issue, the CPSP has partnered with the International Network of Paediatric Surveillance Units to align research questions and data definitions. Parallel studies are ongoing in the United Kingdom, Australia, and New Zealand, and multi-national data will be collated and compared at the completion of this surveillance project. This partnership represents the largest international research collaborative investigating the epidemiology of severe microcephaly.

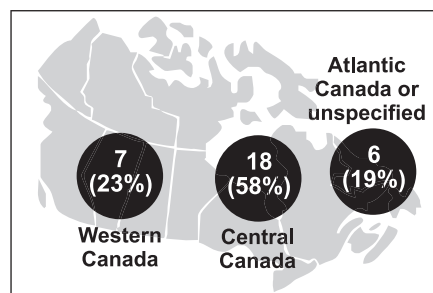
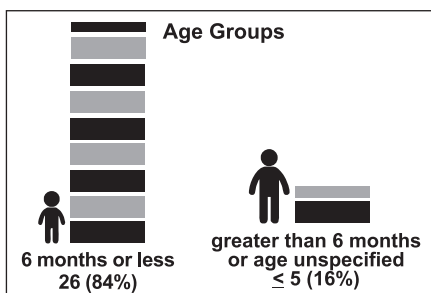
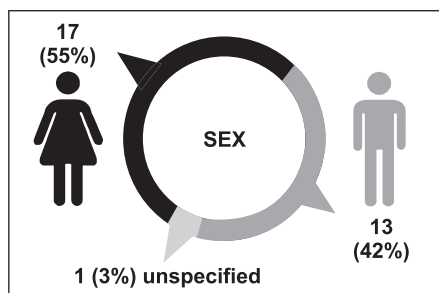
✓ Results – January to December 2017

Confirmed cases

- At the time of analysis, 31 cases of severe microcephaly were confirmed.

Demographics

- There were 17 (55%) females, 13 (42%) males, and 1 (3%) was not specified.
- Age groups were reported as follows: 26 (84%) were 6 months or less and the remaining cases were greater than 6 months or the age was unspecified.
- Seven (23%) cases were from Western Canada, 18 (58%) from Central Canada, and the remaining cases were from Atlantic Canada or location was unspecified.



Presentation

- The majority of infants were singleton births with an average gestational age at birth of 37.7 (± 1.7) weeks.
- The average head circumference at birth for all infants was 28.8 (± 1.2) cm.

Treatment and outcomes

- The suspected causes of microcephaly were varied and included: 11 (36%) genetic causes, 15 (48%) other/unknown causes, and the remaining cases were due to ischemia or infection.
- To date, fewer than five cases of Zika-associated microcephaly have been reported.

Study limitations

- The case definition of severe microcephaly is restrictive and therefore only the most serious cases of the condition are captured.
- This study captures only live-born infants which may underestimate the impact of severe microcephaly.
- As with any voluntary reporting surveillance system, the CPSP recognizes that reporting on minimum incidence rates can have limitations, including under-representation of the disease/condition in the population. It is possible that some groups of children were missed, for example those who live in rural or remote areas, as they may be less likely to receive timely specialist care.
- Case level surveillance data are extracted from patient charts following the clinical encounter. Data elements, such as pending laboratory results or components of the diagnostic assessment, may not have been available at the point of care and therefore may be absent from the surveillance totals. However, surveillance serves an important purpose and provides rich clinical data that will allow for a better understanding of the Canadian-specific epidemiology (including etiology, when known) of severe microcephaly.



Conclusions

- To date, fewer than five cases of Zika-associated microcephaly have been reported.



Anticipated study impact

- There are no case-level national data on microcephaly in Canada. This study will provide valuable clinical and epidemiological information on severe microcephaly.
- Data collection will continue until the end of May 2018 with data analyzed quarterly to examine any epidemiological findings.



Publication and dissemination

Small bite, big problem: Understanding severe microcephaly in Canada. Nelson CRM, Demarsh A, Miller SP, Morris SK, Moore Hepburn C, Bitnun A, Moore A, Shevell M, Evans J, Tataryn J. *Paediatr Child Health* 2017; 22(8):504-5

One-Time Surveys

Cannabis for medical purposes among Canadian children and youth

January 2017



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? Question

What are Canadian paediatricians' views, knowledge, and experiences regarding cannabis use for medical purposes among children and youth?

! Importance

- Cannabis use for medical purposes has gathered growing interest from the public through reports of its purported benefits.
- Since 2001, Health Canada allows health practitioners to authorize cannabis for medical purposes, regardless of the patient's age.
- The Canadian Paediatric Society's 2016 Position Statement *Is the medical use of cannabis a therapeutic option for children?* reports there is insufficient data on the efficacy and safety of cannabis use for the paediatric population, and recommends only potential exceptional therapeutic use in specific cases by skilled clinicians.

➔ 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.

✓ Results

The survey response rate was 31% (877/2,816).

Paediatricians' experiences

- In the year preceding the survey, half (50%, 419/835) of respondents had encountered patients who had used cannabis for medical purposes, either authorized or not authorized.
- The vast majority of respondents who encountered a child or youth using cannabis for medical purposes in the preceding year reported having seen five or fewer cases.
- Among respondents who reported having seen patients aged 12 years and older who used unauthorized cannabis for medical purposes in the preceding year, a substantial number (22%, 45/204) saw more than five cases.
- Among respondents reporting having encountered paediatric patients using cannabis for medical purposes in the past year, 68% (218/321) reported that less than half of their patients had benefited from its use, and 15% (47/318) stated that the majority of their patients had experienced adverse effects.
- More than one third (38%, 316/835) of respondents had been asked by a parent or by an adolescent patient to authorize cannabis for medical purposes within the prior year.
- Only 34 respondents reported having authorized cannabis for a child or youth in the past year.

Provider awareness

- Just over half (51%, 441/874) of respondents reported being aware that Canadian physicians can authorize cannabis use for medical purposes for a child and 61% (534/873) for youth.

- A clear majority of respondents said they had no knowledge or minimal knowledge regarding the following topics: 76% (636/837) on why cannabis may be authorized for medical purposes to a child/youth (conditions, reasons, expected benefits), 89% (744/834) on what cannabis products may be authorized for medical purposes to a child/youth (formulations, dosages), and 90% (752/832) on how cannabis can be authorized for medical purposes to a child/youth (provincial policies, monitoring for efficacy and side effects, information to provide).

Personal beliefs

- Nearly half (46%, 403/873) of respondents believe that there are appropriate indications to support the authorization of cannabis for medical purposes for children and youth.
- Among respondents who said they believe that there are appropriate indications to support the authorization of medical cannabis in children and youth, the majority identified the following indications, almost exclusively for refractory symptoms not responding to first-line agents: 96% (354/369) palliative care, 76% (277/367) epilepsy, 75% (275/367) chronic pain, and 50% (180/360) spasticity. The conditions receiving the least support by paediatricians as indications for authorizing cannabis to children/youth were: 28% (102/366) acute pain, 14% (52/364) anxiety, and 6% (22/363) attention deficit hyperactivity disorder.
- Respondents reported the following as the most common factors that may lead them to refrain from authorizing cannabis use for medical purposes to children/youth: 82% (685/828) the state of evidence regarding cannabis efficacy, 79% (655/828) cannabis dosing and toxicity, 79% (650/828) concerns regarding the long-term impact of its use, and 62% (517/828) concerns for abuse and dependence.

Survey limitations

- The majority of respondents were urban and academic paediatricians, a group of health care providers that manage the most complex and severe health issues in children and youth.
- The survey response rate was 31%; the survey results may under or over represent the knowledge and/or experiences of Canadian paediatricians.
- Some findings are limited due to incomplete responses from the survey respondents for certain data elements. Denominators in the report may vary according to the number of survey respondents who replied to each question.
- This survey data was gathered prior to the publication of the pivotal study evaluating the use of cannabidiol (CBD) to treat epilepsy among children with Dravet syndrome reported in the *New England Journal of Medicine* in the spring of 2017.¹

Conclusions

- Paediatricians in Canada frequently encounter questions about cannabis use for medical purposes, and certain patient populations employ cannabis, both authorized and unauthorized, for medical use.
- Not surprisingly, Canadian paediatricians have little knowledge about authorizing cannabis use for medical purposes for children and youth. Paradoxically, they have a fairly positive view regarding cannabis use for medical purposes for certain conditions, despite the lack of solid scientific evidence regarding its safety and efficacy.
- Of concern are the results showing a significant proportion of paediatricians are willing to consider a number of indications for medical cannabis without current evidence for efficacy and safety. This may reflect paediatricians encountering very difficult clinical situations where there are limited therapeutic options available for their patients.
- Expected legalization of cannabis for non-medical purposes is likely to influence personal and medical views of cannabis and the experiences of clinicians who responded.

Anticipated survey impact

- Survey results will be used to highlight the need for training and continuing medical education for paediatricians on cannabis use for medical purposes among children and youth.
- Survey results will also be used to inform public education efforts about what is known regarding cannabis for medical indications.
- Survey results will be used to advocate for investments in research to investigate the safety, efficacy, dosing, and potential indications for cannabis for medical use in children and youth.

Publication and dissemination

Canadian paediatricians' views and knowledge about cannabis use for medical purposes among children and adolescents. Bélanger RE, Grant C, Côté M, Donner E, Breakey V, Laflamme J, Pinard A-M, Rieder M. Canadian Paediatric Society Annual Conference, Quebec City, in May/June 2018 (poster presentation)

Acknowledgements

Many thanks to Mr. Eric Demers for his timely assistance in analyzing the data set and to Myriam Côté, medical student, Université de Montréal, who participated in the coordination of the survey, its analysis, and the dissemination of survey results.

1. Devinsky O, Cross JH, Laux L, Marsh E, Miller I, Nabbout R, Scheffer IE, Thiele EA, Wright S, Cannabidiol in Dravet Syndrome Study Group. Trial of Cannabidiol for Drug-Resistant Seizures in the Dravet Syndrome, *N Engl J Med* 2017 May 25;376(21):2011-2020

Chlorhexidine gluconate antiseptics and chemical skin injuries (including burns) in neonates

May 2017



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? Question

Have any cases of chemical skin injuries (including burns) associated with chlorhexidine gluconate (CHG) occurred in neonates in Canada?

! Importance

- Chemical skin injuries associated with the use of chlorhexidine gluconate solutions (both alcohol and aqueous based) for skin antisepsis prior to invasive procedures in neonatal patients have been reported to foreign regulatory agencies. However, no Canadian cases were found in either the Canada Vigilance Database (CVD) or in the medical literature.
- Antisepsis prior to invasive procedures is mandatory in all patients. Antisepsis is especially important in premature infants, where nosocomial infections and septicemia are leading causes of death.
- National guidelines concerning the type of antiseptic that should be used in preterm and term infants younger than 2 months of age are lacking.
- Data are needed to help guide the potential development of national guidelines for antisepsis in this population and to inform possible future regulatory risk mitigation measures.

↻ 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.

✓ Results

The survey response rate was 30% (829/2,741).

Respondents

- Respondents reported the following areas of practice: 462 (56%) general paediatricians, 354 (43%) subspecialists (including 41 neonatologists), and 13 (2%) did not specify.
- Of the total number of respondents, 308 (67%) general paediatricians and 178 (50%) subspecialists indicated that their practice involved hospitalized neonates.
- The majority of respondents whose practice involved hospitalized neonates, (321/486, 66%) practised in urban centres.

Use of CHG solutions

- Of the 486 respondents who saw neonates in hospital, 366 (75%) reported that they used CHG antiseptics prior to procedures.
- Forty-six percent (223/486) did not know what type of CHG solutions they used and the others reported use of both alcohol and aqueous solutions in both single and multi-use formulations of CHG.
- There was no predominant use of any single product.

Chemical skin injuries

- Given the nature of responses, it is estimated that a maximum of 128 cases of serious chemical skin injuries due to CHG were seen by respondents over the last five years. (One-time survey methodology does not allow for ruling out duplicate cases).

- It is estimated that a maximum of 66 cases of serious chemical skin injuries due to CHG were seen over the last 12 months.
- Clinical details of the 66 cases seen over the last 12 months were reported as follows:
 - Seventy-seven percent (51/66) of injuries occurred in neonates less than 32 weeks gestation and 77% (43/56) of birth weights were between 500 to 1,000 grams.
 - Eighty-five percent (52/61) of neonates involved were less than 2 weeks old.
 - Use of CHG alcohol solutions was reported in 39% (22/56) of cases versus aqueous CHG in 27% (15/56) of cases. Respondents did not recall the type of solution used in 34% (19/56) of cases.
 - The formulations of CHG used were reported as follows: 56% (31/55) single-swab, 20% (11/55) multiple-use solution, and 35% (19/55) did not recall.
 - Ninety-two percent (48/52) of cases required wound care and pain control while five cases or fewer involved either skin grafting or other invasive therapeutic procedures.
 - There was no interruption in care in 77% (27/35) of cases, but 29% (10/35) of cases reported either sepsis or prolongation of hospitalization.
 - A fatal outcome was reported in fewer than five cases.

Support for national guidelines

- Of the 816 who responded to the question on guideline development, 277 (34%) said they would deem guideline development useful.
- Of note, of the general paediatricians who answered this question, 44% (202/462) deemed that guidelines would be useful compared to only 21% (75/354) of subspecialists.

Survey limitations

- The one-time survey did not allow for the collection of specific details of cases per year, therefore trends cannot be determined.
- Survey participation is voluntary and subject to recall bias. Therefore, the full extent of these injuries in neonates in Canada could not be ascertained. However, until this survey, none had been reported to Health Canada.
- Some findings are limited due to incomplete responses from the survey respondents for certain data elements. Denominators in the report may vary according to the number of survey respondents who replied to each question.



Conclusions

- Although no cases of skin burns in neonates had previously been reported in Canada, the respondents of this survey reported a maximum of 128 cases.
- The majority of the cases that occurred in the last 12 months were in preterm infants, less than 32 weeks gestation, and within the first two weeks of life.
- Both alcohol and aqueous-based, as well as single and multiple-use CHG solutions, were implicated in these injuries.
- There is some interest in treatment guideline development for antiseptics use in neonates.



Anticipated survey impact

- Survey results will increase the awareness of the occurrence of this risk following antiseptics in neonates, and thus hopefully prevent or minimize its occurrence.
- Survey results provide initial evidence to guide development and implementation of risk minimization measures.

Acknowledgements

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Providing care to children and youth from military families

October 2017



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? Question

What are the current knowledge and experience among Canadian paediatricians in the provision of health care for children and youth from military families?

! Importance

- Over 64,000 children and youth in Canadian military families experience unique circumstances such as frequent relocations within and across provinces, parental deployment, and family separation.
- This set of stressors may negatively affect access to, and continuity of, health care because military family members must access health services through provincial and territorial health care systems.
- Reports by the Department of National Defence and Canadian Forces Morale and Welfare Services identify concerns with military families' access to medical and mental health care.
- The recent Canadian Paediatric Society position statement *Caring for Children and Youth from Canadian Military Families: Special Considerations* (2016) highlighted issues relevant to this population and this survey provides new data on Canadian paediatricians' experiences caring for children/youth from military families.

➡ 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.

✓ Results

The survey response rate was 28% (774/2,799).

Respondents

- Respondents reported the following areas of practice: 418 (54%) general paediatricians, 345 (45%) paediatric subspecialists, and 11 (1%) other/no response.
- Practice settings reported included (some participants practice in more than one setting): 603 (78%) urban, 134 (17%) suburban, and 91 (12%) rural/remote.

Provider awareness

- A minority of respondents (17%, 127/773) correctly responded that the federal military health care system does not provide health care to children/youth from military families; 83% were incorrect or unsure.
- Nearly half of paediatricians (48%, 368/770) reported not having cared for a child/youth from a military family in the preceding year, and 21% (163/770) were unsure.
- The majority of respondents (87%, 671/773) did not routinely inquire as to whether a parent was in the military, and 23% (180/776) said that finding out a parent was in the military would not inform that child's care any differently.

Needs assessment

- More than half of respondents (57%, 430/755) did not feel adequately prepared to care for children and youth from military families.

- Nearly all respondents (98%, 753/766) said they had not received any specific training related to caring for military families.
- A significant proportion (74%, 563/764) expressed interest in expanding their knowledge of health-related risks for children and youth in military families and 47% (356/764) were interested in accessing information and resources on services available to military families.

Survey limitations

- Children/youth from military families may have difficulty accessing paediatricians, and hence may not be seen by the surveyed group.
- Many Canadian paediatricians do not practise primary care, and may not be aware of the challenges that military families face accessing health care.
- The survey response rate was low at 28%, and hence may not be an accurate representation of the knowledge or experience of Canadian paediatricians.
- Some findings are limited due to incomplete responses from the survey respondents for certain data elements. Denominators in the report may vary according to the number of survey respondents who replied to each question.

Conclusions

- The majority of Canadian paediatricians are unaware that children and youth in military families receive health care in the provincial or territorial health care systems, and 21% were unclear whether they had provided health care to a child from a military family in their practice in the previous year.
- The vast majority of paediatricians have not received any special training or education on caring for children and youth in military families.
- Improved military family literacy among Canadian paediatricians is needed.

Anticipated survey impact

- The Department of National Defence is currently developing a new national Comprehensive Military Family Plan to inform the delivery of services to military personnel and their families. Survey results, in conjunction with other published data, could contribute to national policy recommendations on health care access for military families.
- Survey results will help inform professional development activities to increase awareness of the issues facing children and youth in military families and identify the need for resources available to military families.
- An on-line educational module for clinicians is already under development at the Canadian Paediatric Society in partnership with Military Family Services.

Publication and dissemination

Calling for a medical home for Canadian military families. Cramm H, Mahar A, MacLean C, Rowan-Legg A, Tam-Seto L. 2018 Family Medicine Forum Conference, Toronto, in November 2018 (oral presentation)

Current knowledge and needs of Canadian paediatricians delivering healthcare to children and youth in military families. Cramm H, Mahar A, MacLean C, Rowan-Legg A, Tam-Seto L. Canadian Association of Health Services and Policy Research Conference, Montreal, in May 2018 (oral presentation)

Vaccine hesitancy and vaccine-preventable diseases

August 2017



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? Question

- In the preceding 12 months, how often and what types of vaccine-preventable diseases (VPDs) have been seen by paediatricians whereby the patient or a sibling was not vaccinated or vaccination was delayed by parental choice?
- What contributed to vaccine hesitancy among parent(s) with a child who had contracted a VPD?
- Are paediatricians using a formal strategy to discuss future vaccinations or vaccinations for siblings with vaccine-hesitant parent(s) caring for a child who had contracted a VPD?

! Importance

- Despite decades of accumulated scientific evidence supporting the safety and effectiveness of vaccines, surveys have shown that a small proportion of the Canadian public is not confident in routine childhood immunization.
- This phenomenon has been termed “vaccine hesitancy” by the World Health Organization and its prevalence poses an urgent threat to public health.
- At present, there is limited knowledge regarding effective interventions to address vaccine hesitancy.

↻ 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.

✓ Results

The survey response rate was 33% (925/2,798).

Respondents reported the following areas of practice: the majority were general paediatricians (522, 56%), 42% were paediatric subspecialists, and 2% identified as “other” or did not indicate their area of practice.

VPDs

- Of the 925 respondents, 196 (21%) reported that they had seen a patient in the preceding 12 months who was diagnosed with a VPD whereby the patient or a sibling was not vaccinated or vaccination was delayed by parental choice.
- Of the paediatricians who indicated that they had seen a patient with a VPD, 77% (150/196) had seen between one and three of these patients in the preceding 12 months.
- The most commonly diagnosed VPDs were: 31% (60/196) pertussis, 27% (53/196) varicella, and 10% (20/196) pneumococcal disease.
- Fourteen percent (27/196) of respondents reported having seen more than one of the VPDs listed on the survey.
- The vast majority (94%) of paediatricians indicated that the VPD(s) was not acquired outside of Canada.

Vaccine-hesitancy

- The child's vaccination status against the VPD prior to contracting the VPD was reported as follows: 81% (156/192) had no immunization and 19% (36/192) had delayed immunization.
- The top three reasons for parental vaccine hesitancy expressed to participating physicians were: 44% (75/171) worried the risk of the vaccine was greater than the risk of the disease, 36% (61/171) were concerned about “too many vaccines,” and 32% (54/171) cited the risk of a weakened immune system.

Intervention strategies

- When asked about intervention strategies, 23% (41/181) of respondents reported that they had used a formal strategy or structured approach to discuss vaccination with the vaccine-hesitant parent(s) **prior** to the patient contracting a VPD. Fifty-seven percent (101/178) reported that a formal strategy was used **after** the patient contracted the VPD.
- Respondents indicated that their impression was that 35% (64/183) of vaccine-hesitant parents would not vaccinate in the future; 33% (60/183) of respondents were unsure.
- Seventy-nine percent (147/186) of respondents reported that they were aware of existing tools to manage vaccine hesitancy (e.g., Canadian Paediatric Society Practice Point *Working with vaccine-hesitant parents*). Of those who were aware of existing tools, 69% (100/145) had used the tools.

Survey limitations

- Acquiring specific information about the outcome of each case is not possible in a one-time survey.
- Many Canadian paediatricians do not practise primary care therefore not all children acquiring VPDs will be treated by a paediatrician or paediatric subspecialist.
- The cases presented in this survey include only children with VPDs who were seen by a paediatrician. Children with VPDs that are rare in the paediatric population (e.g., measles, meningococcal infection, and pertussis before the age of one) are most often treated by paediatricians. For VPDs that are more common among children (e.g., pneumococcal pneumonia, varicella, and rotavirus), generally only the most severe cases are referred to paediatricians for treatment.
- The survey response rate was 33% and hence, the results may not reflect the experience of all Canadian paediatricians.
- Bias may be present, as those who had seen a case of a VPD in a child of vaccine-hesitant parent(s) may be more or less likely to respond to a survey on this subject. In addition, case characteristics including vaccination history and reasons for vaccine refusal were not independently verified and may reflect respondent bias and recall error.
- Some findings are limited due to incomplete responses from the survey respondents for certain data elements. Denominators in the report may vary according to the number of survey respondents who answered each question.



Conclusions

- Despite sustained efforts to increase public awareness on the evidence of vaccine efficacy, one fifth of paediatricians who responded to the survey had seen at least one case of a child with a VPD and vaccine-hesitant parent(s) in the preceding 12 months.
- Structured approaches to guide paediatricians in conversations with vaccine-hesitant parents exist; however, the survey results demonstrate that a substantial number of respondents are either unaware of these tools (21%, 39/186) or are not using them (31%, 45/145).



Anticipated survey impact

- Adequate vaccine coverage is critical to avoiding the spread of vaccine-preventable disease and protecting vulnerable individuals from infection. Vaccine hesitancy poses a threat to acceptable vaccine coverage rates and therefore is a significant public health concern. Effective interventions are critical to addressing this phenomenon.
- These findings, particularly those regarding the specific concerns of vaccine-hesitant parents, may be used to inform public education programs and to assist health care providers, including paediatricians.
- These results will encourage continued interdisciplinary collaboration on the subject of vaccine hesitancy, focusing on enhanced communication skills, including awareness and use of evidence-based structured approaches to care in these challenging situations.

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Publications 2015–2017

Published 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.)

Acute flaccid paralysis

Performance of acute flaccid paralysis surveillance compared to WHO standards. Desai S, Smith T, Thorley BR, Grenier D, Dickson N, Altpeter E; SPSU Committee, Sabbe M, Elliott E, Zurynski Y. *J Paediatr Child Health* 2015;51(2):209–14

Guillain-Barré syndrome after immunization in Canadian children (1996–2012). Top KA, Desai S, Moore D, Law BJ, Vaudry W, Halperin SA, Bettinger JA for members of the Canadian Immunization Monitoring Program Active. *Pediatr Infect Dis J* 2015;34(12):1411–3

Acute flaccid paralysis surveillance: The need for ruling out polio infection. Rotondo J, Desai S, Pless R, Ahmad R, Squires S, Booth TF. *Paediatr Child Health* 2015;20(6):309–10

The polio eradication endgame: Why immunization and continued surveillance is critical. Booth TF, Grudeski E, McDermid A, Rotondo J. *CDCR* 2015;41(10):232–40

Adrenal suppression

Symptomatic adrenal suppression among children in Canada. Goldbloom EB, Mokashi A, Cummings EA, Abish S, Benseler SM, Huynh H, Watson W, Ahmet A. *Arch Dis Child* 2017 Apr;102(4):338–9

Early onset eating disorders

From questions to answers: Examining the role of pediatric surveillance units in eating disorder research. Katzman DK, Madden S, Nicholls D, Mawjee K, Norris ML. *Int J Eat Disord* 2017 Mar;50(3):259–65

Growth charts

Use of growth charts in Canada: A national Canadian Paediatric Surveillance Program survey. Lawrence S, Cummings E, Chanoine J-P, Metzger D, Palmert M, Sharma A, Rodd C. *Paediatr Child Health* 2015;20(4):185–8

Major depressive disorder

Major depressive disorder among pre-adolescent Canadian children: Rare disorder or rarely detected? Korczak DJ, Ofner M, LeBlanc J, Wong S, Feldman M, Parkin PC. *Acad Pediatr* 2017;17(2):191–7

Understanding presentation of very early onset MDD. Innes-Leroux E. *The Chronicle of Neurology & Psychiatry* 2017 Aug:1-2

Neonatal hyperbilirubinemia

Severe neonatal hyperbilirubinemia decreased after the 2007 Canadian guidelines. Sgro M, Kandasamy S, Shah V, Ofner M, Campbell D. *J Pediatr* 2016 Apr;171:43–7

Persistent albuminuria

Persistent albuminuria in children with type 2 diabetes: A Canadian Paediatric Surveillance Program study. Sellers EA, Hadjiyannakis S, Amed S, Dart AB, Dyck RF, Hamilton J, Langlois V, Panagiotopoulos C, Dean HJ. *J Pediatr* 2016 Jan;168:112–7

Respiratory syncytial virus infections

Respiratory syncytial virus infections in pediatric transplant recipients: A Canadian Paediatric Surveillance Program study. Robinson JL, Grenier D, MacLusky I, Allen UD. *Pediatr Transplant* 2015;19(6):659–62

Severe iron-deficiency anemia

Severe iron-deficiency anaemia and feeding practices in young children. Parkin PC, DeGroot J, Maguire JL, Birken CS, Zlotkin S. *Public Health Nutr* 2016;19(4):716–22

Surveillance

An innovative web based system for reporting rare diseases in paediatrics. Mukhi SN, Laffin Thibodeau M, Szijarto B. *Online J Public Health Informatics* 2015;7(2):e215

CPSP Highlights published in 2017 in *Paediatrics & Child Health*

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

Rh sensitization in Canada is not obsolete. Baker JM, Campbell DM, Bhutani VK, Sgro M. *Paediatr Child Health* 2017;22(4):238–9

Severe vitamin D deficiency: A persistent yet preventable problem among Canadian youth. Ward LM, Ladhani M, Zlotkin S. *Paediatr Child Health* 2017;22(1):43–4

Small bite, big problem: Understanding severe microcephaly in Canada. Nelson CRM, Demarsh A, Miller SP, Morris SK, Moore Hepburn C, Bitnun A, Moore A, Shevell M, Evans J, Tataryn J. *Paediatr Child Health* 2017;22(8):504–5

CPSP studies and one-time surveys that contributed to CPS position statements and practice points published in 2017

Medical aid in dying

Medical Assistance in Dying: A Paediatric Perspective. Davies D; Canadian Paediatric Society, Bioethics Committee. *Paediatr Child Health* 2018;23(2):125–30 (position statement)

Neonatal pulse oximetry screening

Pulse oximetry screening in newborns to enhance detection of critical congenital heart disease. Narvey M, Wong K, Fournier A; Canadian Paediatric Society, Fetus and Newborn Committee. *Paediatr Child Health* 2017;22(8):494–8 (practice point)

Severe microcephaly and congenital Zika syndrome

Zika virus: What does a physician caring for children in Canada need to know? Robinson JL; Canadian Paediatric Society, Infectious Diseases and Immunization Committee. *Paediatr Child Health* 2017;22(1):48–51 (practice point)

Presentations in 2017

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

National

ARFID

Are all paediatric feeding and eating disorders created equal? Working with patients who have avoidant restrictive food intake disorder. Katzman DK, Norris M. Canadian Paediatric Society Annual Conference, Vancouver, in June (oral)

Complex regional pain syndrome

Canadian surveillance study of complex regional pain syndrome in children and youth. Baerg K, Tupper S, Finley A. Chronic Pain Network Annual Meeting, Hamilton, in September (poster)

CPSP

News you can use: Hot off the press from the Canadian Paediatric Surveillance Program (CPSP). Gill P, Hui C, Richmond S. Canadian Paediatric Society Annual Conference, Vancouver, in June (oral)

Hypoglycemia

Hypoglycemia in unmonitored term newborns, Flavin M, Osiovich H, Coughlin K, Gregoire K, Hu L, León JA, Ray J, Sgro M, Gallipoli A, Barr L, Grewal K. James Low Research Day, Kingston, in March (poster)

Lyme disease

Lyme disease: An emerging infectious disease in Canada. Langley J. Canadian Paediatric Society Annual Conference, Vancouver, in June (oral)

Medical aid in dying

One year later: Medical assistance in dying (MAID) and what we've learned about requests concerning minors. Davies D, Shariff M. Annual Conference Online Self-Assessment Series based on presentations at the Canadian Paediatric Society Annual Conference, Vancouver, in June (online continuing medical education course)

Medical and mental health issue in Syrian refugees

Medical and mental health issues in Syrian refugees. Hui C, Pottie K, Audcent T, Barazzino T, Rashid M, Banerji A, Beiser M, Auger L, Rowan-Legg A, Moore Hepburn C. North American Refugee Health Conference, Toronto, in June (oral)

Severe hyperbilirubinemia

Severe hyperbilirubinemia (SH) in the newborn: Treatment, consequences and hematological considerations. Baker J, Sgro M. Canadian Paediatric Society Annual Conference, Vancouver, in June (oral)

Pulse oximetry screening

Canadian paediatricians' perceptions of neonatal pulse oximetry screening. Wong KK, Dow K. Canadian Paediatric Society Annual Conference, Vancouver, in June (poster)

Tuberculosis

Preliminary results of national surveillance of childhood tuberculosis in Canada. Giroux R, Montgomery-Soong A, Consunji-Araneta R, Kitai I, Morris SK & the CPSP Childhood TB Study Group. 21st Conference of the International Union against Tuberculosis and Lung Disease-North American Region Meeting, Vancouver, in February (oral & poster)

Results of national surveillance of childhood tuberculosis: 2013-2016. Giroux R, Montgomery-Song A, Consunji-Araneta R, Kitai I, Morris S. Canadian Paediatric Society Annual Conference, Vancouver, in June (poster)

International**Hypoglycemia**

Hypoglycemia in unmonitored term newborns in Canada. Flavin M, Osiovich H, Coughlin K, Gregoire K, Hu L, León JA, Ray J, Sgro M, Gallipoli A, Grewal K. Pediatric Academic Societies Annual Conference, San Francisco, in May (poster)



Canadian Paediatric Surveillance Program

New Study and One-Time Survey Opportunities

The opportunity

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

Track record

- The average monthly response rate from approximately 2,700 paediatricians is 80%.
- The average detailed questionnaire response rate varies from 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
 - Health hazards related to the consumption of energy drinks
- Emerging infections
 - Congenital Zika syndrome
 - Lyme disease
- Threats to public health and safety
 - Adverse events related to exposure to laundry detergent pods
 - All-terrain vehicle severe injury and death

Study success factors

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

Study impact

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

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

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

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

"As the Paediatric Chairs of Canada representative to the CPSP 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 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, Chief of Pediatrics, Children's Hospital of Eastern Ontario; Professor and Chairman, Department of Pediatrics, Faculty of Medicine, University of Ottawa; CPSP Steering Committee representative, Paediatric Chairs of Canada



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