



2016 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.

CPSP through the Ages

Proudly celebrating 20 years of surveillance into rare paediatric diseases/conditions

A recollection of notable studies and one-time surveys over the program's history

1997

Acute flaccid paralysis
Ongoing surveillance enables Canada to maintain certified polio-free status with the World Health Organization.

2000

Hemorrhagic disease of the newborn
Data from international surveillance units, including the CPSP, illustrated the merit and importance of intramuscular vitamin K prophylaxis.

2001

Necrotizing fasciitis
Results reinforced the statement from the National Advisory Committee on Immunization to include universal childhood immunization against varicella in the recommended vaccine schedule.

2003

Lap-belt syndrome
Results stimulated advocacy in all provinces and territories to ensure the adoption of proper car seat and booster seat legislation.

2004

Baby walkers
Data contributed to the total ban on the sale, import, and advertisement of baby walkers in Canada.

Medium-chain acyl-coenzyme A dehydrogenase (MCAD) deficiency
Results documented the efficacy of newborn blood-spot screening in identifying asymptomatic cases, supporting efforts to expand newborn screening programs across the country.

Renal stone disease associated with melamine-contaminated products
Following the outbreak of renal stones and/or acute renal failure in young infants in China associated with the consumption of powdered milk products contaminated with melamine, rapid emergency survey results confirmed that melamine contamination was not causing infant renal disease in Canada.

Neonatal hyperbilirubinemia
Findings from the initial 2002 study stimulated the creation of a Canadian Paediatric Society position statement advocating that all newborns should be evaluated for risk factors of hyperbilirubinemia and that levels should be measured before discharge. The study was repeated nine years later and far fewer cases were reported, suggesting the statement increased knowledge and contributed to this downward trend.

Childhood tuberculosis
Preliminary study results demonstrated that childhood tuberculosis disproportionately affects First Nations and Inuit children in specific areas and non-Canadian-born children.

Severe microcephaly
In conjunction with several international units, surveillance was swiftly initiated in June 2016 in response to the emerging public health concern associated with the link between microcephaly and Zika virus.

Medical assistance in dying (MAID)
To inform the independent review by Parliament on the issue of mature minors in Bill C-14 (Medical Assistance in Dying), survey results quantified how often Canadian paediatricians were receiving requests for MAID for minors.

2005

2008

2011

2013

2016

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Foreword

Federal Minister of Health

The Honourable Jane Philpott

Tracking and studying emerging health conditions and rare childhood diseases are crucial to improving early diagnosis and treatment.



It is because of the Canadian Paediatric Surveillance Program that we have reliable data on a wide range of serious infectious diseases, genetic conditions, rare neurologic illnesses, emerging sources of injury risk and other issues affecting the health of young Canadians. These data have enabled health professionals, researchers and policy makers to develop public health and treatment strategies to improve the health of our children.

I would like to extend my sincere gratitude and congratulations to the Canadian Paediatric Society and the more than 2,500 paediatricians and paediatric subspecialists for 20 years of contribution to the Canadian Paediatric Surveillance Program. Your collective efforts have created a valuable resource here in Canada and around the world.

Your commitment to surveillance is helping improve the health and well-being of children. The Government of Canada is proud to work with the Canadian Paediatric Society and its members to contribute to a healthier future for our children and youth.

Chief Public Health Officer of Canada

Dr. Theresa Tam

Robust surveillance systems are a cornerstone of public health.



The Canadian Paediatric Surveillance Program (CPSP) has been delivering valuable data to researchers and health professionals over the last 20 years, and providing insight into rare diseases, their risk factors, preventive practices, and intervention effectiveness.

The CPSP increases awareness and education within the medical community and among the public, related to less common paediatric disorders, as well as emerging threats and risks to children's health. In the past year, CPSP's rapid implementation of surveillance in response to the arrival of Zika virus in the Americas is a prime example of the program's flexibility and value to Canada during a global public health emergency.

The CPSP also supports Canada's participation in international paediatric surveillance efforts through the International Network of Paediatric Surveillance Units, for which we can be particularly proud.

On the CPSP's 20th anniversary, we celebrate the expansion of the CPSP's capacity in data collection, reporting, and analysis of more than 90 conditions and issues. The CPSP's findings have helped improve child health in Canada and provide the public health community with up-to-date information on health issues facing young Canadians today.

President of the Canadian Paediatric Society

Dr. Jonathan Kronick

As the President of the Canadian Paediatric Society (CPS), I am proud that the Canadian Paediatric Surveillance Program celebrated its twentieth anniversary in 2016. The program has grown tremendously over the past two decades and serves as an important vehicle to conduct national surveillance on rare diseases or rare complications of more common disorders.



The ability of the CPSP to bring together study investigators from across paediatric disciplines and from across Canada has been inspiring. The CPSP Resident Research Grant, launched in 2015, has been a wonderful addition to the program, enabling residents and trainees to work in collaboration with mentors and gather data on important paediatric concerns. The first winners of the grant focused on serious ATV-related injuries and death (see page 30).

The CPS has recently identified the following key strategic priorities: First Nations, Inuit, and Métis health; mental health; social paediatrics; early childhood learning; and paediatric drugs. As the CPS outlines specific objectives for each of these strategic priorities, I strongly invite study teams to come forward with related proposals for either CPSP multi-year studies or one-time surveys to strengthen efforts in these areas.

On behalf of the CPS and the Board of Directors, I would like to take this opportunity to thank the Public Health Agency of Canada for its ongoing collaboration and support of the CPSP. I would also like to thank the thousands of CPSP participants who contribute to the program on various fronts. We are fortunate to have a robust paediatric surveillance program such as the CPSP in Canada!

CPSP Chair

Dr. Jonathon Maguire

The Canadian Paediatric Surveillance Program was busy again in 2016 tackling important public health issues and emerging concerns facing Canadian children and youth. The CPSP undertook three new multi-year surveillance studies and four one-time surveys on topics frequently in the media spotlight. In addition, the program launched the first-ever resident competition to build capacity in Canadian paediatric surveillance and undertook a comprehensive privacy review.



CPSP one-time surveys allowed us to understand the implications of new laws on medical assistance in dying from the perspective of Canadian paediatricians (see page 34). With Canada's commitment to resettle 25,000 refugees from Syria before the end of December 2016, a one-time survey provided important information on physical and mental health issues facing Syrian refugee children and youth (see page 32).

In response to the global Zika virus health crisis, the CPSP launched a multi-year study on severe microcephaly to gain a better understanding of the epidemiology and etiology of severe microcephaly (see page 28). Efforts were coordinated with paediatric surveillance units across the world to ensure consistency of case definitions and protocols, allowing for international comparison of results. To more fully understand the spectrum of illness caused by the Zika virus, the CPSP will be launching a second surveillance study in 2017 specifically on congenital Zika syndrome.

In addition to meeting the paediatric surveillance needs of the Public Health Agency of Canada, the CPSP continues to receive numerous high-caliber proposals from dedicated paediatric study teams across Canada, demonstrating the value of the CPSP to its stakeholders. I would like to thank the CPSP Steering Committee members for their expertise and commitment to the program in adjudicating these proposals. Upcoming surveillance studies will provide high-quality Canadian data to inform Canadian child health policy and state-of-the-art clinical practice. I would also like to personally thank the paediatricians of Canada for their ongoing dedication to the program. Without the paediatricians who faithfully respond on a monthly basis and complete detailed clinical questionnaires, none of this work would be possible. As they say, it takes a village to raise a child. Working together, the CPSP will continue to provide important data to improve the health and well-being of Canada's children.

Acknowledgements

The key strength of the Canadian Paediatric Surveillance Program (CPSP) is its commitment to improve the health of children and youth in Canada and around the world. This focus would not be possible without the participation of Canadian paediatricians, subspecialists, and other health care providers in the monthly collection of information on rare paediatric conditions, the 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 2016 from the Public Health Agency of Canada's Centre for Chronic Disease Prevention, Health Canada's Therapeutic Effectiveness and Policy Bureau, and the following non-governmental sources:

- 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)
Ciaran Duffy, MB	Paediatric Chairs of Canada
Krista Jangaard, MD	Canadian Paediatric Society
Melanie Laffin Thibodeau, BCom	Canadian Paediatric Society
Juan Andrés León, MD, MSc	Centre for Chronic Disease Prevention, Public Health Agency of Canada
Dorothy Moore, MD	IMPACT (Immunization Monitoring Program ACTIVE) (Liaison)
Charlotte Moore Hepburn, MD	Canadian Paediatric Society
Paul Muirhead, LL.M.	Consultant
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Jennifer Pennock, MSc	Centre for Immunization and Respiratory Infectious Diseases, Public Health Agency of Canada
Jorge Pinzon, MD	Canadian Paediatric Society
Anne Rowan-Legg, MD	Canadian Paediatric Society
Dorcas Taylor, MSc*	Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada

* In 2016, Yogesh Choudhri and Sarah McDermott replaced Dorcas Taylor who is on assignment.

The CPSP extends a sincere thank you to Dr. Dorothy Moore for her dedication to the CPSP Steering Committee and valuable expertise, especially in the area of infectious diseases. Dr. Moore joined the Steering Committee in 2009 as the representative for IMPACT. The Steering Committee wishes her all the very best in her retirement and 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 2,500 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 about 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)

Process

- The full surveillance process is summarized in Figure 1 and includes the three “Ds” of surveillance: detection, deduction, and dissemination.
- Individual researchers 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.”
- Participants who have seen a case are sent a detailed clinical questionnaire to complete and return to the CPSP.

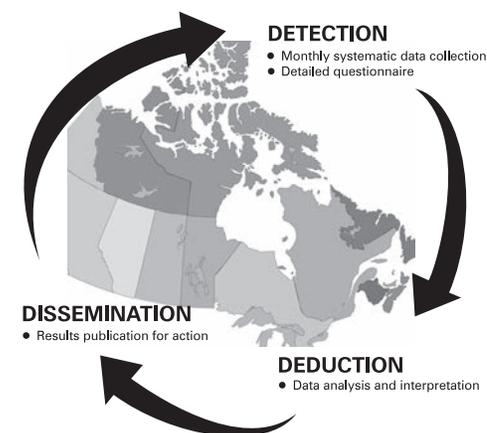
CPSP Quick Facts

Did you know?

- The CPSP celebrated its 20th anniversary in 2016.
- The CPSP is comprised of over 2,500 dedicated paediatricians and paediatric subspecialists.
- Since its inception, the CPSP has studied 65 rare conditions/diseases and initiated 42 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 2016, 72% of participants committed to receiving their monthly forms electronically.

Figure 1 – Surveillance process summary

Pan-Canadian health surveillance



- 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 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 2016

Provinces/territories	Reporting rates (%)*	Number of participants†
Alberta (AB)	78	352
British Columbia (BC)	73	272
Manitoba (MB)	82	117
New Brunswick (NB)	81	29
Newfoundland and Labrador (NL)	83	52
Northwest Territories (NT)	93	90
Nova Scotia (NS)	100	3
Nunavut (NU)	83	3
Ontario (ON)	77	1007
Prince Edward Island (PE)	98	9
Quebec (QC)	74	589
Saskatchewan (SK)	70	59
Yukon (YT)	100	1
Canada	78	2583

* 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 2500. 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 2012–2016

Reporting year	Reporting rates (%)
2012	84
2013	82
2014	81
2015	82
2016	78

TABLE 3 – 2016 detailed questionnaire completion rates as of May 1, 2017

Studies/conditions	Reported cases*	Pending	% Completion rate
Acute flaccid paralysis	72	5	94
Adverse drug reactions – serious and life-threatening	49	10	83
Avoidant/restrictive food intake disorder	150	20	88
Childhood Lyme disease	58	11	84
Childhood tuberculosis	81	7	92
Hypoglycemia in low-risk term newborns	21	2	91
<i>Listeria</i> in the newborn and early infancy	7	0	100
Rh sensitization	25	6	81
Severe microcephaly	30	5	86
Total number of cases (all studies)	493	66	88

* Excluding duplicate and excluded cases

International Network of Paediatric Surveillance Units

On August 16, 2016, the International Network of Paediatric Surveillance Units (INOPSU) held its 9th Scientific and Executive Committee meeting in Vancouver, British Columbia. The INOPSU executive chose the meeting venue to align with the Congress of the International Pediatric Association (IPA) to allow for leading scientists and faculty from around the world to attend both forums.

The theme of the meeting was “Aligning for IMPACT: The power of international surveillance.” Scientific programs included: Outcomes in the Surveillance of Rare Paediatric Diseases (session 1) and Optimizing Zika Virus Surveillance (session 2).

The first session highlighted the importance of integrated knowledge translation in paediatric surveillance, and included excellent presentations by Michael Sgro (CPSP) on severe neonatal hyperbilirubinemia, Shazhan Amed (CPSP) on non-type 1 diabetes mellitus, Elizabeth Elliott (Australian Paediatric Surveillance Unit [APSU]) on fetal alcohol syndrome, Yvonne Zurynski (APSU) on early-onset eating disorders, and Christoph Rudin (Swiss Paediatric Surveillance Unit) on the impact of surveillance studies in Switzerland.

The second session provided the opportunity for Australia, the United Kingdom, Canada, and New Zealand to showcase how their units were able to rapidly respond to an epidemiological emergency, launching similar studies on congenital Zika syndrome and/or severe microcephaly within a very short time. Representatives from each participating unit presented their projects, emphasizing the value of aligned international case definitions and data capture to facilitate high quality data pooling and international comparison.

The scientific session also included the launch of the Danielle Grenier Prize, an award that recognizes excellence in paediatric surveillance research and knowledge translation. We congratulate Yvonne Zurynski, winner of the inaugural honour.



Dr. Yvonne Zurynski (APSU), winner of the Danielle Grenier Prize, presented by Dr. Luc Charette



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 2,500 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 statement on neonatal hyperbilirubinemia and a practice point on pulse oximetry screening.

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.

“For the past 20 years, the CPSP has been an important collaborative asset for research, health policy development, and the active surveillance of less common paediatric disorders. The hundreds of Canadian paediatricians and paediatric subspecialists who participate monthly in the program ensure that the CPSP is an effective way to foster continuing medical education on a wide spectrum of clinical conditions that might otherwise go largely unrecognized.”

Bryce Larke, MD, Professor of Pediatrics, University of Alberta, Edmonton, 1975–2001; Chief Medical Officer of Health, Whitehorse, Yukon, 2001–2008; CPSP Steering Committee member, 2004–2010



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

Surveillance Studies in 2016

Acute flaccid paralysis

Ongoing study since January 1996



Shalini Desai

Principal investigator

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Co-investigator

Caron-Poulin L

Question

Did Canada maintain its polio-free status in 2016?

Importance

- Acute flaccid paralysis (AFP) surveillance is essential to monitor for polio in light of ongoing transmission of wild poliovirus in a few countries around the world.
- Canada conducts AFP surveillance in the under 15 years of age population in accordance with World Health Organization (WHO) recommendations.

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 CPSP and Canada's Immunization Monitoring Program ACTIVE (IMPACT) based in 12 tertiary care centres.

2016 Results

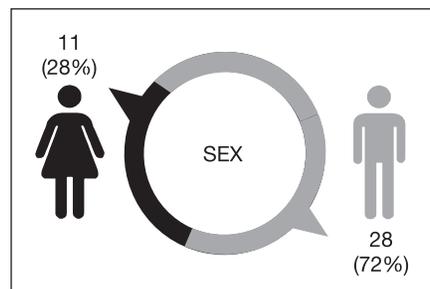
Note: due to reporting delay, this report represents a snapshot as of April 18, 2017.

Confirmed cases

- In total, 72 cases of AFP were reported to the Public Health Agency of Canada: 21 (29%) cases were from the CPSP network and 51 (71%) cases were from IMPACT.
- All AFP cases were adjudicated against the national AFP and polio case definitions.
- At the time of analysis, 39 cases were confirmed as meeting the AFP case definition; none were assessed to be polio.
- The average time from case onset to reporting was 78 days (range: 8 to 314).

Demographics

- There were 28 (72%) males and 11 (28%) females.
- Cases ranged in age from younger than 1 year to 14 years, with a mean of 7 years (95% CI 5.5–8.5) and a median of 5.9 years.



Presentation

- Hospitalization: all 39 (100%) cases were hospitalized and length of stay ranged from 1 to 105 days with a mean of 18 days (95% CI 9.8–26.2) and a median of 7.5 days.
- Vaccinations: 25 (64%) cases were up-to-date for their polio vaccinations, 9 (23%) were under-vaccinated, and the remaining 5 (13%) had no vaccination information recorded.
- Diagnoses: 18 (46%) cases were Guillain-Barré syndrome and 12 (31%) cases were transverse myelitis. The remaining 9 (23%) cases were diagnosed as: acute disseminated encephalomyelitis, acute motor/sensory axonal neuropathy, acute flaccid myelitis, acute and transient infectious process of unknown etiology, tick paralysis, and chronic inflammatory demyelinating polyneuropathy.
- No stool samples were positive for polio.
- Stool samples identified *Campylobacter*, enteroviruses, coxsackieviruses, and *Salmonella*.

Treatment and outcomes

- Of the 35 (90%) cases that had outcome documented at the time of initial report, 3 (9%) cases fully recovered and 32 (91%) cases partially recovered with residual weakness.
- Thirteen (33%) cases had clinical outcome reported at least 60 days after onset of paralysis or weakness: 7 (54%) cases had fully recovered and 6 (46%) cases had partially recovered.

Number of cases	Incidence rate [*]	% with adequate stool sample ^{2†}	% with 60-day follow-up [‡]
39	0.67	36%	33%

* 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 this study is ongoing, reporting delays occur and therefore numbers are expected to change.
- Canada's inability to meet the WHO defined incidence target for AFP may indicate under-reporting.
- Stool samples in patients with AFP are sometimes difficult to obtain due to the nature of their symptoms that can include constipation. Additionally, rapid availability of advanced diagnostic testing often identifies the diagnoses 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 2016.



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.



Publication and dissemination

Acute flaccid paralysis in Canadian youth, 1996 to 2014. Rotondo J, Desai S, Beaulieu M, Booth TF. Canadian Journal of Neurological Sciences Conference: 51st Annual Congress of the Canadian Neurological Sciences Federation, Quebec City, in June 2016 (oral presentation)

Acknowledgements

The investigators would like to thank everyone who participated in collecting the data. They would also like to acknowledge the excellent work of Jenny Rotondo, Susan Squires, Jenne Cunliffe, 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



Margaret Zimmerman

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 2016?

Importance

- Only a minority of prescribed pharmaceuticals on the market in North America have been tested in paediatric populations, and most of them are used without the benefits of adequate guidelines for safety or efficacy.
- Post-marketing surveillance is essential for early 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.

2016 Results

Confirmed cases

- At the time of analysis, the study confirmed 28 suspected paediatric ADR cases in 2016.
- In 12 reports, more than one product was suspected of causing the adverse reaction.
- Table 1 lists the 37 suspect health products described in the 28 reports, sorted by the number of reports received per individual product.
- The most reported products in 2016 were amoxicillin, co-trimoxazole, ibuprofen, lamotrigine, propofol, sevoflurane, and valproic acid.
- The class of health products (as classified using the Anatomical Therapeutic Chemical classification system) most frequently suspected of causing the adverse reaction(s) were: antibacterials for systemic use (seven reports), antiepileptics (six reports), anti-inflammatory and anti-rheumatic products (four reports), analgesics, psychoanaleptics, immunosuppressants (three reports)

each); and anaesthetic agents and anti-hypertensives* (two reports each). Alimentary tract products, antiseptics/disinfectants, beta-blocking agents, diagnostic test agents, and other therapeutic agents were involved in one report each.

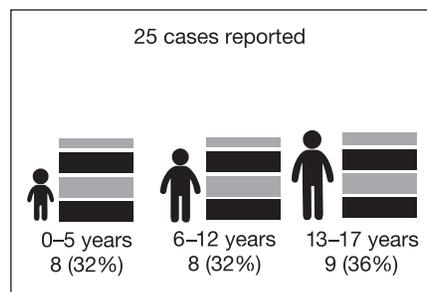
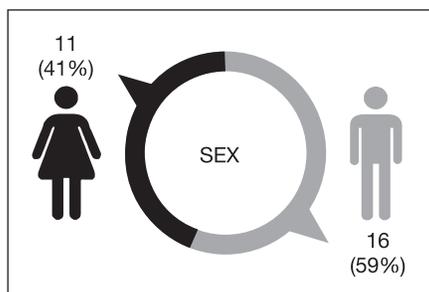
* Includes one report for guanfacine, an alpha 2 adrenergic receptor agonist which has an indication for the treatment of attention deficit hyperactivity disorder and one report for clonidine used in a growth hormone stimulation test

Table 1 – Suspect health products in 2016	
Suspect health product	# of cases
Amoxicillin, co-trimoxazole*, ibuprofen, lamotrigine, propofol, sevoflurane, valproic acid	2 each
Acetaminophen, acetylsalicylic acid, acyclovir, antiepileptic (unspecified), cefprozil, ceftriaxone, chlorhexidine, ciprofloxacin, clonazepam, clonidine, cyclosporine, dextroamphetamine, diazoxide, esomeprazole, fluoxetine, guanfacine, infliximab, l-arginine, leuprolide, levetiracetam, meloxicam, methylphenidate, morphine, mycophenolate mofetil, oxcarbazepine, phenobarbital, sotalol, sulfasalazine, tacrolimus, vancomycin.	1 each

* Combination product containing two active ingredients

Demographics

- Patient sex was male in 59% (16/27) of cases and female in 41% (11/27) of cases.
- Age ranges (where identified) varied as follows: 32% (8/25) involved children up to 5 years of age, 32% (8/25) were in children aged 6–12 years, and 36% (9/25) involved adolescents aged 13–17 years.



Presentation

- The 28 cases were classified as serious according to the following criteria (more than one reason for seriousness was provided in 11 reports): 8 cases were considered to be life-threatening, 18 cases required hospitalization, and 15 cases were considered to be medically important (defined as a case that may not be immediately life-threatening or results in death/hospitalization but may jeopardize the patient or require intervention to prevent one of these other outcomes from occurring).
- No deaths were reported in 2016.
- The majority of the adverse reaction reports described skin and subcutaneous 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).
- There were three reports of reactions not specifically listed in the CPMs of the suspect products.

Treatment and outcomes

- The outcomes for the 28 cases were as follows: 18 (64%) patients recovered, 4 (14%) patients were considered to be recovering/issue resolving, 2 (7%) patients were described as not recovering/issue not resolving, and the outcome was unknown in 4 (14%) cases.

Study limitations

- Adverse reactions (ARs) to health products are considered to be suspicions, as a definite causal association often cannot be determined. Spontaneous reports of ARs cannot be used to estimate the incidence of ARs because ARs remain underreported and patient exposure is unknown.

Conclusions

- In 2016, the most reported products suspected to have caused an adverse reaction(s) were amoxicillin, co-trimoxazole, ibuprofen, lamotrigine, propofol, sevoflurane, and valproic acid.
- Since the beginning of the study in 2004, antibacterials for systemic use, psychoanaleptics, and antiepileptics have been among the health products most frequently suspected of causing adverse reaction(s).

Anticipated study impact

- 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.

Avoidant/restrictive food intake disorder

January 2016 to December 2017



Debra Katzman

Principal investigators

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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 a newly defined eating disorder in the *Diagnostic and Statistical Manual of Mental Disorders – 5th edition (DSM-5)*, associated with significant medical and psychiatric comorbidity.
- ARFID captures 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, no data exist on the incidence of ARFID in community samples.
- 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

2016 Results

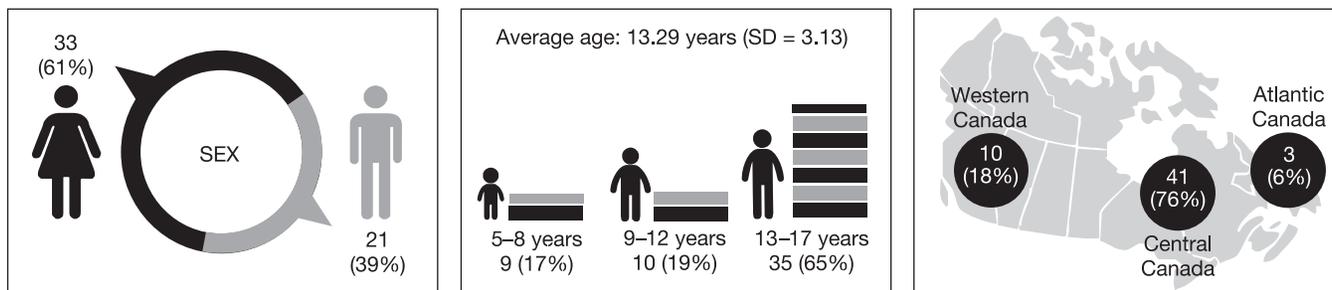
Confirmed cases

- At the time of analysis, 54 cases were confirmed.

Demographics

- There were 33 (61%) females and 21 (39%) males.
- The average age of cases was 13.29 years (SD = 3.13). Age ranges were as follows: 9 (17%) 5–8 years, 10 (19%) 9–12 years, and 35 (65%) 13–17 years.

- Cases were from Western Canada (10; 18%), Central Canada (41; 76%), and Atlantic Canada (3; 6%).
- The majority (76%) of cases were White; nine additional population groups were reported.



Presentation

- The average length of illness prior to diagnosis was 35 months (SD = 36).
- The most common abnormal eating behaviours reported were: 46 (85%) cases with food avoidance; 46 (85%) who were eating, but not eating enough; 43 (80%) who were not initiating eating or seeking out food as expected; and 41 (76%) with apparent lack of interest in eating or food.
- Cases presented with clinical signs including: 32 (59%) with marked interference with psychosocial functioning, 30 (56%) with failure to achieve expected weight gain, 27 (50%) with significant weight loss, 19 (35%) with dependence on enteral feeding or oral nutritional supplements, 11 (20%) with faltering growth, and 13 (24%) with significant nutritional deficiency.
- The most common psychiatric comorbidities seen among reported cases were: 29 (54%) with anxiety, 9 (17%) with attention-deficit/hyperactivity disorder, and 6 (11%) with depression.

Treatment and outcomes

- At the time of the report, ARFID cases were receiving the following treatments: 42 (78%) medical monitoring as an outpatient, 32 (59%) nutritional counselling by a dietician, 24 (44%) psychoeducation, 22 (41%) family therapy, and 16 (30%) individual therapy.
- Hospitalization occurred in 22 (41%) cases. Of those hospitalized, the most common reasons for hospitalization were: 7 (32%) with food refusal and 5 (23%) with severe weight loss/medical instability.

Study limitations

- Paediatricians may lack awareness of and comfort with applying the DSM-5 criteria to a relatively newly recognized eating disorder in children and adolescents.
- Children and youth in remote/rural areas may not have timely access to a paediatrician for proper diagnosis.

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 were 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.
- 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

ARFID & medical monitoring: A focus on pediatric eating disorders. Katzman DK, Norris ML. Ontario Community Outreach Program for Eating Disorders Annual Network Meeting, Toronto, in December 2016 (oral presentation)

Acknowledgements

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

Childhood Lyme disease

July 2014 to June 2017



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Co-investigators

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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.
- Disease burden is high in children; particularly in boys aged 5 to 9 years.
- Accurate estimates of the burden of illness in Canada are not available although incidence 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.

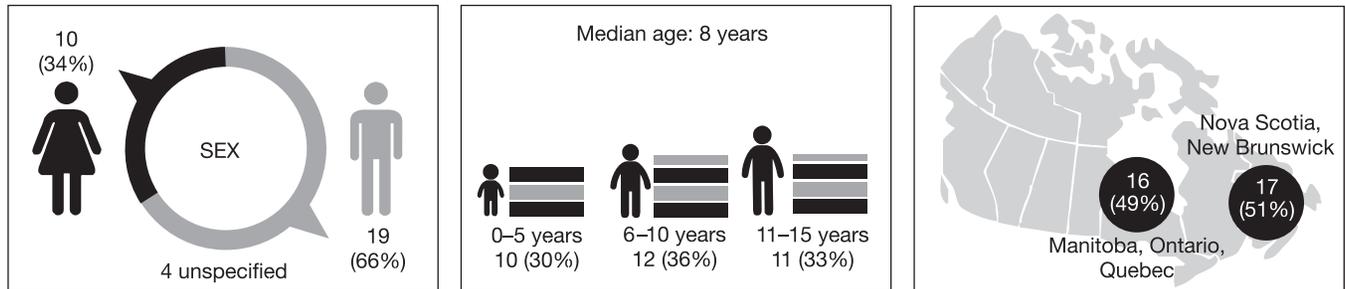
2016 Results

Confirmed cases

- At the time of analysis, 33 cases fulfilled the case definition as either confirmed or probable Lyme disease.

Demographics

- The median age of cases at diagnosis was 8 years. Age ranges were reported as follows: 10 (30%) 0–5 years, 12 (36%) 6–10 years, and 11 (33%) 11–15 years.
- Where sex was recorded, 66% (19/29) were male and 34% (10/29) were female. Sex was not reported for four cases.
- Cases were reported from the following provinces: 16 cases from Manitoba, Ontario, and Quebec; and 17 cases from Nova Scotia and New Brunswick (provinces are grouped for reporting purposes due to numbers being below the reporting threshold).
- Almost all cases (31; 94%) had a history including travel to a known area of Lyme disease risk in Canada.



Presentation

- The majority of the diagnoses (21; 64%) were made during the main May to October tick activity season.
- Manifestations of Lyme disease were as follows: 6 (18%) cases of early Lyme disease (i.e., a single erythema migrans [EM] lesion), 9 (27%) cases of early disseminated Lyme disease (multiple EM, neurological and/or cardiac symptoms), and 21 (64%) cases of late disseminated Lyme disease (arthritis).
- Ten (30%) cases had non-specific manifestations of headache and/or fever.
- Multiple manifestations were reported for 18 (55%) cases.

Treatment and outcomes

- Fifteen (45%) cases recovered following antibiotic treatments comprising courses of amoxicillin, doxycycline, or ceftriaxone for two to three weeks.
- Nine (27%) cases had persistent manifestations (arthritis or fatigue), and received further antibiotic treatment.
- Outcomes were unknown for nine (27%) cases.

Study limitations

- It was hoped that more detailed information on exposure risk could be obtained but this has often been impractical given the time difference between patient consultation and questionnaire completion.
- The number of patients for which information is available so far is low although this supports the numbers of reports in national surveillance. The lower than anticipated number could be due to patients with early Lyme disease being diagnosed and managed by family practitioners rather than paediatricians.

Conclusions

- In 2016, 33 cases of confirmed and probable Lyme disease were reported from five provinces (Manitoba, Ontario, Quebec, New Brunswick, and Nova Scotia).
- The median age of confirmed cases was 8 years and 66% of cases were male.
- A high percentage of cases showed manifestations of late disseminated Lyme disease (arthritis). Delayed diagnosis and treatment may explain a few of these cases, but for many cases, manifestations of late disseminated Lyme disease were the only reported manifestations, so it is possible that arthritis occurs more rapidly in children than in adults.

Anticipated study impact

- Study results will help define the spectrum of clinical presentation of Lyme disease among children in Canada, as well as the diagnostic methods and treatments used.
- Results will identify the most frequently reported locations of Lyme disease risk and sites of exposure to infected ticks. This will provide valuable information to inform targeted disease prevention strategies to at-risk populations in Canada.
- This study will help identify regions in Canada where front-line medical practitioners most need information on the appropriate diagnosis and treatment of Lyme disease. It will also help to describe the most common clinical presentations of Lyme disease in children in Canada. This information will facilitate timely and accurate identification and treatment of Lyme disease.

Childhood tuberculosis

October 2013 to September 2016 – Final report



Ian Kitai

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Question

What is the epidemiology and clinical presentation of childhood tuberculosis (TB) in Canada and what variability exists in diagnosis, microbiology, treatment, and treatment outcomes?

Importance

- The importance of understanding the epidemiology and clinical history of childhood TB in Canada is underlined by: changes in immigration patterns from tuberculosis endemic regions; an increase in immunocompromised children due to underlying disease, treatment, or transplants; and rapidly changing patterns of microbial resistance.
- At present, there is little detailed population-based information about the incidence, clinical presentation, methods of diagnosis, and response to treatment of paediatric TB in Canada.

Methodology

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

Case definition

Any new active or retreatment case of TB disease in patients under the age of 15 years

Proven TB disease

1. Laboratory-confirmed

Isolation of *M tuberculosis* complex from any clinical specimen: Positive culture **OR** positive nucleic acid amplification test (NAAT), specifically *M tuberculosis*, *M africanum*, *M canetti*, *M caprae*, *M microti*, *M pinnipedii* or *M bovis* (excluding *M bovis* BCG strain)

2. Clinically confirmed

Probable intrathoracic	Probable extrapulmonary – non-pleural
Signs and symptoms, histology suggestive of TB or close contact with an infectious source case	Signs and symptoms, histology or findings on diagnostic radiology consistent with TB
Chest radiography consistent with intrathoracic TB disease	
and at least one of the following: <ul style="list-style-type: none">• A positive clinical response to anti-TB treatment• Documented exposure to active case of infectious <i>M tuberculosis</i>• Immunological evidence of <i>M tuberculosis</i> infection: Positive TB skin test (TST) or positive interferon gamma release assay (IGRA)	

Presumed TB disease

Treatment for suspected TB disease at any site with at least three anti-TB drugs

Cases are identified as “New” or “Re-treatment” based on the following criteria:

- **New active case of tuberculosis disease:** No documented evidence or history of previously active tuberculosis.
- **Re-treatment case of tuberculosis:**
 1. a) Documented evidence or adequate history of previously active TB that was declared cured or treatment completed by current standards, and

- b) At least a six-month interval since the last day of previous treatment and
 - c) Diagnosis of a subsequent episode of TB that meets the active TB case definition.
- OR
- 2. a) Documented evidence or adequate history of previously active TB that cannot be declared cured or treatment completed by current standards, and
 - b) Inactive disease for six months or longer after the last day of previous treatment and
 - c) Diagnosis of a subsequent episode of TB that meets the active TB case definition

Exclusion criteria

- Isolation of another pathogen, including atypical mycobacteria
- Patient arriving in Canada on TB treatment for presumed TB but for whom treatment is stopped because subsequent work-up in Canada suggests no TB
- Patient with latent TB (TST- or IGRA-positive but no clinical or radiologic abnormality)

Unique to this study

In addition to paediatricians, select non-paediatricians who manage childhood TB were enrolled for the duration of the study. Collection of follow-up data is conducted at six month intervals, until six months after treatment completion.

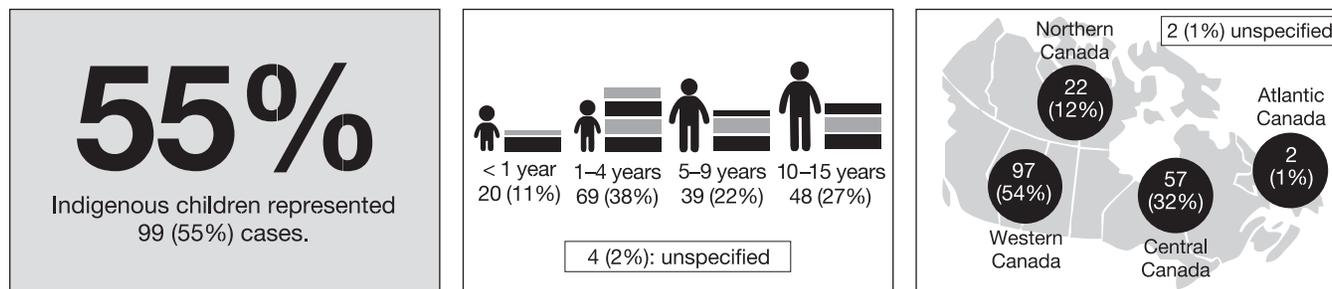
 **Results – From October 2013 to September 2016**

Confirmed cases

- At the time of analysis, 180 cases were confirmed. Analysis is ongoing and thus totals shown below may not sum to 180. Additional cases remain to be confirmed and added.

Demographics

- Age ranges were reported as follows: 20 (11%) were under 1 year of age, 69 (38%) 1–4 years, 39 (22%) 5–9 years, 48 (27%) 10–15 years, and 4 (2%) cases were of unknown age.
- There were 88 (49%) males, 87 (48%) females, and in 5 (3%) cases sex was not indicated.
- Province/territory of residence was reported as follows (Saskatchewan data was unavailable at the time of report): 10 (6%) from British Columbia, 23 (13%) from Alberta, 64 (36%) from Manitoba, 34 (19%) from Ontario, 23 (13%) from Quebec, 2 (1%) from Atlantic Canada, 22 (12%) from Nunavut, and for 2 (1%) cases location was unknown.
- Confirmed cases were from the following population groups: 68 (38%) First Nations; 39 (22%) Canadian-born, non-Indigenous; 30 (17%) Inuit; 1 (<1%) Indigenous, unspecified; 11 (6%) Canadian-born, unspecified; 29 (16%) non-Canadian born; and 2 (1%) unknown.
- Indigenous children represented 99 (55%) cases.
 - Of the First Nations children, 54/68 (79%) lived on reserve and 61/68 (90%) resided in Manitoba.
 - Of the Inuit children, 20/30 (67%) lived in Nunavut and 10/30 (33%) lived in Quebec.
 - Twelve (12%) Indigenous children had latent TB infection treatment previously, compared to 4/68 (6%) of the non-Indigenous cases.



Presentation

Disease location

- Intrathoracic: 160/180 (89%); 111 (minimum) with pulmonary involvement. Other sites included pleura (15 cases) and intrathoracic nodes.*†
- Extrathoracic: 36/180 (20%); including 22 central nervous system (CNS), 5 miliary, 5 extrathoracic lymph nodes, and other sites including pericardium, abdominal, and bone.*
 - Almost half (17/36; 47%) of the extrathoracic cases were in children 10–15 years old.
 - CNS involvement was mostly seen in Indigenous children (17/22; 77%).

Microbiology

- There was one case of *Mycobacterium bovis*; all other cases were *Mycobacterium tuberculosis*.
- Positive cultures were obtained in 58/139 (42%) cases in which respiratory culture was attempted.†
- The age ranges of children with positive cultures were as follows: 5/14 (36%) <1 year of age, 18/53 (34%) 1–4 years, 11/30 (37%) 5–9 years, 23/40 (58%) 10–15 years, and 1/2 (50%) age unreported.

* Sites are not mutually exclusive, and therefore not additive

† Some intrathoracic cases are awaiting definitive classification

‡ Sputum, gastric aspirate, or bronchoalveolar lavage

Drug resistance

- There were two cases of multi-drug-resistant TB (one microbiologically proven and one clinical based on sensitivities of the source case).
- There were two cases of single-drug resistance (isoniazid and streptomycin).

Treatment and outcomes

- Treatment: 138/149 (93%) cases had received directly observed therapy.
- Hospitalization: admission was required in 93/163 (57%) cases. The median length of stay was 14 days (IQR: 7–21). Of those hospitalized, 11 (12%) were admitted to the ICU.
- Medication: 18/169 (11%) cases had adverse reactions requiring a change in medications from one or more drugs, most commonly attributed to pyrazinamide (12 cases) and isoniazid (5 cases).
- No deaths were reported.

Study limitations

- Diagnosis of TB in children is complex and management extends over many months, making data collection challenging.
- The physician making the initial diagnosis and reporting the case to the CPSP is often not the same physician managing the ongoing care of the patient, thus obtaining follow-up data can be challenging.



Conclusions

- Childhood TB is disproportionately found in First Nations and Inuit children and non-Canadian-born children.
- The majority of children with pulmonary involvement had negative cultures, while rates of extrathoracic cases in older children/adolescents were higher than previously described.
- Low rates of drug resistance were found.
- Adverse reactions to treatment occurred in 11% of children.



Anticipated study impact

- This is the first nation-wide prospective study of childhood TB in Canada and it demonstrates significant regional variation in incidence, disease site, and severity in specific groups, particularly in Indigenous children.
- Results will be used to inform policy-level decisions regarding the prevention, detection, and treatment of TB in Canadian children, and to strengthen interventions for Indigenous and foreign-born children.



Publication and dissemination

Midpoint results of national surveillance of childhood tuberculosis. Giroux R, Jamal A, Kitai I, Consunji-Araneta R, Baikie M, Morris SK & the CPSP Childhood TB Study Group. Pediatric Academic Societies Annual Meeting, Baltimore, in April–May 2016 (poster presentation)

Midpoint results of national surveillance of childhood tuberculosis. Giroux R, Jamal A, Kitai I, Consunji-Araneta R, Baikie M, Morris SK & the CPSP Childhood TB Study Group. Canadian Paediatric Society Annual Conference, Charlottetown, in June 2016 (poster presentation)

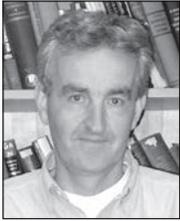
Preliminary results of national surveillance of childhood tuberculosis in Canada. Giroux R, Montgomery-Soong A, Consunji-Araneta R, Kitai I, Morris SK & the CPSP Childhood TB Study Group. International Union against Tuberculosis and Lung Disease-NAR Meeting, Vancouver, in February 2017 (oral & poster presentations)

Acknowledgements

Thank you to all co-investigators for their contributions and to our three students: Ryan Giroux, Alaina Jamal, and Aaryn Montgomery-Song. Thanks are also extended to the Centre for Global Child Health at SickKids and PHAC.

Hypoglycemia in low-risk term newborns

April 2014 to March 2016 – Final report



Michael Flavin

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Co-investigators

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? Question

How common is significant hypoglycemia in unmonitored term newborns, and what characteristics occur with high frequency in this group?

! Importance

- Neonatal hypoglycemia is a significant health issue, with the potential to cause neurodevelopmental impairment. Monitoring protocols allow prompt diagnosis in high-risk newborns.
- The incidence of hypoglycemia in low-risk term newborns is unknown. Delayed diagnosis in this group may increase morbidity.
- Detailed investigation of cases may identify common characteristics that could help define monitoring protocols that could capture additional at-risk groups.

➔ Methodology

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

Case definition

Any otherwise healthy neonate less than 96 hours (4 days) old with all of the following:

- Term gestation: 37–42 weeks
- Birth weight: 2500–3999 grams
- Hypoglycemia, defined as whole blood or serum glucose <2.0 mmol/L
- Hypoglycemia treated with IV dextrose

Exclusion criteria

Neonate being monitored for hypoglycemia because of known risk factors, i.e., maternal diabetes (gestational or pre-gestational), growth restriction, macrosomia, or important neonatal illness

✓ Results – April 2014 to March 2016

Confirmed cases

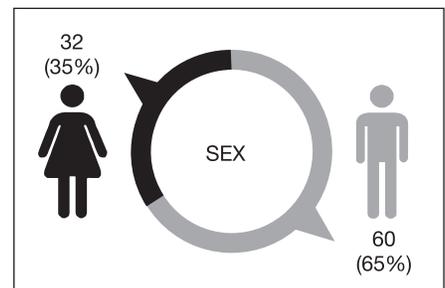
- At the time of analysis, 92 cases were confirmed.

Demographics

- There were 60 (65%) males and 32 (35%) females.
- The most highly represented population groups were White with 46/77 (60%) cases and First Nations with 6/77 (8%).
- Delivery by emergency Caesarean section occurred in 32/86 (37%) cases.

Presentation

- Prior feeding issues were identified in 22/81 (27%) cases, the great majority of which related to disinterest in feeding.
- The most frequent reasons for blood glucose measurement were jitteriness in 33 (36%) cases and major signs (defined as seizure, apnea, or cyanosis) in 18 (20%) cases.



- Most (69%) newborns with major signs presented after 6 hours of age. In comparison, only 33% of those without major signs presented after 6 hours of age ($p=0.008$). Newborns presenting with major signs had significantly lower glucose levels (median: 0.8 mmol/L, interquartile range [IQR]: 0.5) compared to those without major signs (median: 1.6 mmol/L, IQR: 0.7 [$p = 0.001$]).
- Fifty-seven of 73 (78%) infants had at least one potential perinatal stress indicator (emergency Caesarian section, meconium, brief resuscitation, or cord artery pH < 7.10). Cases with a stress indicator were more likely to have had early hypoglycemia (≤ 6 hours) compared to cases without a stress indicator ($p = 0.02$).
- In 23/91 (25%) cases, birth weight was <10th centile using Kramer's growth chart.

Treatment and outcomes

- In 47 (51%) cases, the infant had a work-up for hypoglycemia. An underlying diagnosis or compounding factor was present in 31 cases. Endocrine causes predominated in 17 cases, 14 of which had hyperinsulinism.
- In 13 (14%) cases the infant had a brain MRI and 10 were abnormal. At least four cases were compatible with hypoglycemic brain injury.
- Neurodevelopmental concern at discharge was reported in 17 (19%) cases.

Study limitations

- Hypoglycemia may have gone unnoticed by caregivers in newborns presenting with subtle signs (i.e., poor feeding). This may have decreased the total number of cases reported.
- While this study highlights potential risk factors for hypoglycemia and its morbidities, other data sources are needed to provide denominators to calculate risk.



Conclusions

- Hypoglycemia in low-risk newborns appears to be uncommon but is associated with a relatively high rate of neurodevelopmental concern at discharge.



Anticipated study impact

- Widespread adoption of Kramer's norm-based standards for small for gestational age would improve timely diagnosis of significant hypoglycemia in term newborns.
- Several aspects may require further study. For example, the data suggest that inclusion of certain perinatal stress indicators in risk assessment may capture a group at risk for early hypoglycemia.



Publication and dissemination

Hypoglycemia in unmonitored term newborns. Flavin M, Osiovich H, Coughlin K, Gregoire K, Hu L, León JA, Ray J, Sgro M, Gallipoli A, Grewal K. Neonatal Update 2016, London UK, in November 2016 (poster presentation)

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 2017 (poster presentation)

Acknowledgements

We acknowledge the expertise of Helen Coo in data analysis.

Listeria in the newborn and early infancy

May 2015 to April 2017



Tobias R. Kollmann

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? Question

- What is the age-specific 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, is 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 CPSP does not match the number of cases reported to PHAC through ongoing routine surveillance, the principal and co-investigators may use their existing networks to search for any missing cases. These networks may include the Paediatric Investigators Collaborative Network on Infections in Canada (PICNIC) and other informal networks of health professionals in Canada.



Results – May 2015 to December 2016

Note: this study is ongoing until April 2017 and analysis is not completed. Due to small case numbers, this report pertains to 20 months of data versus 12 months.

Confirmed cases

- At the time of analysis, eight cases were confirmed over 20 months.

Demographics

- To date, 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 and two were late-onset.
- All of the six early-onset cases presented as septic on the day of birth.
- Of the late-onset cases, one case became symptomatic (septic) on day of life (DOL) 9 and the other presented with seizure on DOL 20.
- Early-onset cases were associated with maternal fever in five out of the six cases.
- Neither of the two late-onset cases had obvious risk factors captured by the study questionnaire.

Treatment and outcomes

- All of the early-onset cases required intensive care.
- Two of the six early-onset cases died.
- Both late-onset cases survived the episode, but in one case, the infant had permanent sequelae (hemiplegia).

Study limitations

- Considering the low number of cases reported, risk factors and outcomes for late-onset cases cannot be described at this point.



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 eight cases were reported over 20 months of this surveillance study (with similar findings through PHAC's surveillance program) suggests that the incidence of neonatal listeriosis may be lower than expected in Canada.
- 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.



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 ongoing study seem to suggest that empiric therapy for neonatal listeriosis may benefit from re-evaluation in the face of lower than expected incidence.

Acknowledgements

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

Rh sensitization

June 2016 to May 2018



Michael Sgro

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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 the 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 – From June to December 2016

Confirmed cases

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

Demographics

- Confirmed cases were from Ontario, Alberta, and Quebec.
- Maternal country of birth: six were reported to be Canadian born and one was unknown.

Presentation

- The average gestational age was 36.5 weeks (range: 35–38 +6 days).
- The average age at presentation was 10.5 hours.
- The hemoglobin average was 141 g/L (range: 101–200 g/L).
- The peak micro bilirubin (MBR) level was 283 $\mu\text{mol/L}$ (range: 29–338 $\mu\text{mol/L}$).

Treatment and outcomes

- The average number of phototherapy hours was 960.
- Two cases received exchange transfusion and five did not.

Study limitations

- Antibody reports prenatally are sent to the obstetrician therefore there is the potential that the results may not be seen by a paediatrician if the infant is well.



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 triggers or 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 and other causes of inadequate Rh prophylaxis.

Acknowledgements

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Severe microcephaly

June 2016 to May 2018



Chantal Nelson

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Question

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

Importance

- Microcephaly is a congenital anomaly of the central nervous system wherein an infant's head is significantly smaller than the heads of other children of the same age and sex.
- There has been an increase in the number of microcephaly cases reported globally, linked to an outbreak of Zika virus. While the increase was primarily documented in early 2015 in South America, understanding this outbreak was complicated by the fact that limited baseline epidemiologic information about microcephaly exists.
- Given the possible modes of transmission of Zika virus and the frequent travel of Canadians to warmer climates, baseline epidemiologic data on severe microcephaly is essential to effectively monitor for this important, emerging public health threat. Surveillance of severe microcephaly in Canada was initiated on June 1, 2016.

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.

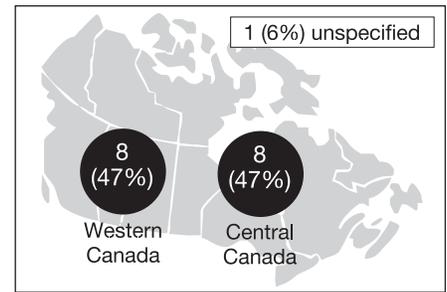
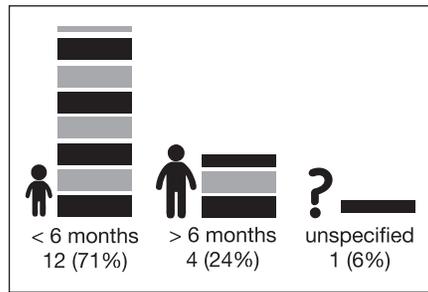
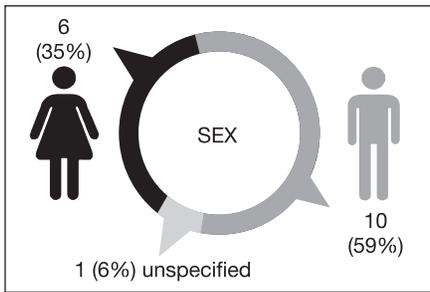
Results – From June to December 2016

Confirmed cases

- At the time of analysis, 17 cases of severe microcephaly were confirmed.

Demographics

- There were 10 (59%) males, 6 (35%) females, and for 1 (6%) sex was not reported.
- Age groups were reported as follows: 12 (71%) less than 6 months, 4 (24%) greater than 6 months, and 1 (6%) unspecified.
- Eight (47%) cases were from Western Canada, 8 (47%) from Central Canada, and 1 (6%) was unspecified.



Presentation

- All 17 cases were singleton births with an average gestational age at birth of 38.2 (± 1.6) weeks.
- The average head circumference at birth for all cases was 30.4 (± 1.6) cm.

Treatment and outcomes

- The suspected causes of microcephaly were varied and included: genetic causes, ischemic causes, infection, and other/unknown causes.
- To date, no cases reported as part of the study are suspected to be caused by Zika virus.

Study limitations

- The case definition of severe microcephaly is restrictive, and therefore allows data collection for only the most severe cases.
- This study captures only live-born infants which underestimates the impact of severe microcephaly.
- Some infants may not see a paediatrician (or paediatric subspecialist) which can affect the capture of severe microcephaly cases in this study.

Conclusions

- Of the 17 confirmed cases to date, none have been attributed to the Zika virus.

Anticipated study impact

- This study will provide valuable baseline incidence and etiologic information on severe microcephaly in Canada.
- The study allows for near real-time monitoring of Zika virus-associated severe microcephaly in the country.
- Study results and international collaboration will enable more effective monitoring for Zika virus and other emerging public health threats associated with severe congenital microcephaly, in both Canada and other similar jurisdictions.

One-Time Surveys

All-terrain vehicle (ATV) serious injuries and death

October 2016



Peter Gill

CPSP Resident Research Grant award recipients

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? Question

What is the burden of ATV-related serious injury and death in children and youth in Canada, and how familiar are CPSP participants with ATV-related legislation and health promotion practices?

! Importance

- ATVs are a leading cause of serious paediatric injury in children and youth.
- In Canada, 36% of ATV-related injury hospitalizations occur in children aged 5 to 19 with 15 to 21% of ATV-related fatalities in those under the age of 16, usually due to head trauma.
- Certain Canadian provinces (e.g., Quebec) have implemented safety legislation, including age restrictions, mandatory safety training, and helmet use.
- Jurisdictions with more stringent ATV-safety legislation have been shown to have reduced injury rates in the short term.

↻ Methodology

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

✓ Results

The survey response rate was 32% (904/2793).

Respondents

- Respondents reported the following areas of practice: 497 (55%) general paediatricians, 364 (40%) paediatric subspecialists, 29 (3%) emergency physicians, and 14 (2%) intensive care paediatricians.
- Practice settings reported included (some participants practice in more than one setting): 95 (11%) rural/remote, 142 (16%) suburban, and 733 (81%) urban.
- Cases were reported by 80 (9%) participants.
- Seventy-eight of the participants who reported cases indicated their location as follows: 6 (8%) from British Columbia, 12 (15%) from Alberta, 9 (12%) from Saskatchewan, 6 (8%) from Manitoba, 26 (33%) from Ontario, 15 (19%) from Quebec, and 4 (5%) from Atlantic Canada.

ATV-related injuries/deaths

- There were 181 cases of serious and/or fatal ATV-related injuries reported, including six deaths.
- Deaths were reported from participants in British Columbia, Alberta, Saskatchewan, and Quebec.
- ATV-related injury/death occurred most frequently between the months of May and August with 48% (71/147) in July/August and 25% (37/147) in May/June.

Demographics

- There were 133/170 (78%) males and 37/170 (22%) females.
- Age ranges were as follows: 11 (6%) 1–4 years, 40 (22%) 5–9 years, 82 (45%) 10–14 years, and 48 (27%) 15–19 years. No cases were reported in children aged 12 months and under.

Presentation

- At the time of ATV-related injury/death, 83% (139/167) of cases were using the ATV for recreation. Other activities reported included: 6 (4%) racing, 6 (4%) farming, 6 (4%) for transportation, and 10 (6%) were unsure.
- The location of injuries/death was reported in 167 cases as follows: 57 (34%) on private land, 32 (19%) on public land, 17 (10%) on First Nation's land, 0 (0%) at ATV parks, and in 61 (37%) cases location was unknown.
- ATV-related injury/death did not occur on roadways in 52% (87/167) of cases.
- Children and youth were the driver in 59% (99/168) of cases.

Provider awareness

- Eighty-four percent (604/722) of respondents were aware of the Canadian Paediatric Society position statement on preventing ATV-related injuries.
- Sixty-eight percent (486/720) of respondents were aware that ATVs should not carry passengers.
- Almost half (351/722; 49%) of respondents were aware that children and youth who drive ATVs should receive ATV-safety training courses and that they are mandatory in some provinces.
- Despite high levels of provider awareness, 86% (615/718) of respondents said they have never, or only occasionally, discussed ATV safety with their patients.

Survey limitations

- Gaining specific information about each case, and more importantly on the deaths, is not possible in a one-time survey.
- Some findings are limited due to incomplete responses for certain data elements from survey participants. For example, while the questions on physician demographics were complete in over 95% of surveys, questions regarding physician knowledge were not completed in 20 to 25% of surveys.



Conclusions

- Despite efforts to reduce injuries to Canadian children and youth related to ATVs, significant numbers of serious injuries and deaths still occur related to ATV use.
- ATV-related injuries and deaths in Canadian children during 2016 were most commonly in older children, serving as drivers, and riding for recreational purposes.
- Most physicians who reported cases (68%; 53/78) practised in regions without mandatory ATV-safety training for children, including Ontario, Alberta, Saskatchewan, and British Columbia. All but one death was reported by physicians practising in these provinces.



Anticipated survey impact

- Serious injuries and deaths related to ATVs are a significant issue in Canada that can be effectively addressed with a multi-dimensional response, including increasing parental and provider awareness of safety issues as well as legislation.
- Survey findings will be shared with the provinces and territories that may be considering specific ATV-related legislation to help reduce the number of ATV-related injuries and deaths in children and youth.
- Survey findings will be highlighted to Canadian paediatricians as many reported they did not discuss ATV safety with patients, even if they were aware of the Canadian Paediatric Society position statement on preventing ATV-related injuries.

Medical and mental health issues in Syrian refugee children and youth

August 2016



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Co-investigators

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Question

What was the experience of paediatricians and paediatric subspecialists in their delivery of care to refugee children and youth from Syria?

Importance

- Following the outbreak of civil war in Syria, and the ensuing humanitarian crisis, there has been a mass exodus from the country, with millions of people displaced for more than one year. While in transit, in refugee camps, or in neighbouring cities, individuals are often left without access to health care.
- Canada resettled over 40,000 refugees from Syria from November 2015 to February 2017; 50% of those welcomed were children.
- The health of migrant children has been shown to be at risk. Very little information on the health status of Syrian refugee children and youth has been published.
- To advance evidence-based care for refugee children and youth, and to inform provincial and federal health system planning for this unique and vulnerable population, information on the health status of Syrian refugee children and youth is required.

Methodology

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

Unique to this survey

Clinicians involved in the provision of care in refugee clinics, including those outside of the regular CPSP participant list, were invited to complete the survey.

Results

The survey response rate was 31% (856/2798).

Care of refugee children and youth from Syria

- Thirty-six percent (36%) of respondents (304/856) indicated that they had seen, assessed, or managed the care of Syrian children/youth over the past 12 months. Of these, 144 (47%) were general paediatricians, 137 (45%) were subspecialists, and 23 (8%) were other child health care providers.
- The majority of providers (62%) had cared for less than five refugee children and youth from Syria.

Health care needs

- A significant number of respondents reported encountering important medical and mental health disorders in the Syrian child and youth refugee population, including: non-infectious diseases such as failure to thrive/malnutrition and severe iron deficiency anemia (221; 73% of respondents), complex medical needs (160; 53% of respondents), psychosocial disorders such as post-traumatic stress disorder and anxiety/depression (110; 36% of respondents), and infectious diseases such as hepatitis B, cutaneous leishmaniasis, and strongyloides (31; 10% of respondents).

- Just less than half of respondents (143; 47%) were involved in the care of Syrian refugee patients admitted to hospital.
- Eighty-seven (29%) respondents cared for children who required urgent referral to a dentist. Of these, 28% had difficulty finding a dentist to accept the referral.

Interpretative services

- The majority of respondents (263; 87%) reported having access to interpretative services for the majority of cases.
- Of those with access to interpretative services, 67% of providers had access to professionally-trained interpreter services, 50 (19%) providers relied on non-professionally trained interpreters, and 32 (12%) providers relied on friends and family members for interpretative services.

Survey limitations

- This one-time survey was sent to paediatricians, paediatric subspecialists included in the CPSP platform, and to clinicians who care for refugees. The majority of refugee children and youth would likely not encounter a specialist, as routine health care supervision for healthy patients is managed predominantly by family physicians. Specialists more commonly see complex and severe conditions in any population. The CPSP does not allow for comprehensive population-based health measurement, and the results should not be interpreted as representative of the entire Syrian refugee population.
- 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 identification of mental health disorders is challenging given language barriers (and the need for interpretative services), and additional care barriers that arise from care delivered in a new cultural context. In addition, screening for mental health disorders is often inappropriate during a first clinical encounter, and many Syrian refugee families were very recently welcomed to Canada when this survey was administered.



Conclusions

- Paediatricians, paediatric subspecialists, and primary care refugee clinicians reported encountering a range of medical and mental health needs in their care of Syrian refugee children and youth. With access to the appropriate care, many of the most commonly encountered conditions are fully treatable.
- Paediatricians and paediatric subspecialists in a variety of clinical settings encountered Syrian refugee children and youth; therefore, education and training in refugee health is necessary for all health care providers, not only those practising in dedicated refugee clinics.
- Access to dental services and professional interpretative services was not optimal and may have compromised both the clinical outcomes and the integration of Syrian newcomers to Canada.



Anticipated survey impact

- Study results can inform physician education and training in refugee health for all medical providers. Evidence-based screening and management tools (including updated guidelines for health assessment of children and youth new to Canada), system navigation training, and cultural competency will enhance medical care for this vulnerable group.
- Data from this survey can also inform broader efforts to expand both dental care and professional interpretative services for all vulnerable Canadians, including but not limited to, the refugee population.

Acknowledgements

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Medical assistance in dying: Infants, children, and adolescents

May 2016



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? Question

How often are Canadian paediatricians engaging in exploratory conversations or receiving explicit requests for medical assistance in dying (MAID)?

! Importance

- Following the Carter versus Canada decision (Supreme Court of Canada 2015), Bill C-14 was passed in June 2016, allowing MAID for competent adults (18 years minimum) under specific circumstances.
- Inclusion of mature minors was debated. Although mature minors are not currently eligible for MAID, an independent review of this issue must be received by Parliament by December 2018.
- Medical aid in dying has been permitted in Quebec since December 2015 (Bill 52). Eligibility is limited to those 18 years of age and older.
- There are no Canadian data about requests for MAID by minors. Requests for MAID for minors also arise from parents.

↪ Methodology

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

Unique to this survey

A complementary survey designed to explore physician attitudes and beliefs with respect to MAID was developed and distributed to all Canadian Paediatric Society members. Academic analysis will be completed using both data sets.

✓ Results

The survey response rate was 40% (1050/2597).

Most respondents were general paediatricians (588; 56%). Various subspecialties represented the remaining portion of respondents, the largest percentage representing neonatology (62; 6%).

End-of-life or palliative care

- Just over one-third of participants reported they provide end-of-life or palliative care (370; 35%).
- Almost two-thirds of participants reported they have adequate access to palliative care (690; 66%).

Conversations directly with minor children

- Exploratory discussions with a minor(s) about MAID were reported by 35 participants, representing 60 patients in the following age ranges: 4 (7%) younger than 10 years of age, 11 (18%) 10–13 years, 40 (67%) 14–18 years, and 5 (8%) with age not stated.
- Nine participants recalled an explicit request(s) for MAID, representing 17 minors in the following age ranges: 1 younger than 10 years, 3 children 10–13 years, and 13 youth 14–18 years.

Conversations with parents, on behalf of minor children

- Exploratory discussions with parents about MAID were reported by 118 participants, representing 419 minor patients in the following age ranges: 157 (37%) neonates \leq 30 days, 70 (17%) infants 1–12 months, 144 (34%) children 1–13 years, and 48 (11%) youth 14–18 years.
- Forty-five participants recalled an explicit request(s) for MAID by 91 parents for children/youth in the following age ranges: 42 (46%) neonates \leq 30 days, 19 (21%) infants 1–12 months, 22 (24%) children 1–13 years, and 8 (9%) youth 14–18 years.

Survey limitations

- Patients may be counted multiple times (if a patient discussed MAID with more than one respondent).
- Some respondents submitted the cumulative incidence of discussions over their careers, not “within the last year.”



Conclusions

- CPSP participants from across Canada reported conversations about MAID and requests for MAID from both minors and parents.
- Discussions with parents and explicit requests from parents outnumbered those by minors by more than five to one.
- A large proportion of discussions and explicit requests from parents for MAID involved an infant and/or neonate.
- Discussions with minors and explicit requests from minors themselves are relatively rare.
- Of the exploratory conversations with minors, 15/60 (25%) children were under the age of 14 years and therefore unlikely to be considered mature minors in the current legal debate.



Anticipated survey impact

- Survey results will be shared with the Council of Canadian Academies, which is charged with the independent review of considering mature minors in the eligibility criteria for MAID. The results, following complete analysis, may inform future health legislation.
- Results will also inform the pending Canadian Paediatric Society position statement on medical assistance in dying.



Publication and dissemination

Headline news, Physician-assisted dying: Should kids ever be considered? Davies D, Shariff M, Emberley J. Canadian Paediatric Society Annual Conference, Charlottetown, June 2016 (oral presentation)

Acknowledgements

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Neonatal pulse oximetry screening

February 2016



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? Question

What are Canadian paediatricians' perceptions of neonatal pulse oximetry screening (NPOS) and to what extent is NPOS used in Canada?

! Importance

- Critical congenital heart disease (CCHD) remains a leading cause of infant death and early diagnosis decreases morbidity, mortality, and disability.
- Current detection strategies, including prenatal ultrasound and newborn physical examination, are very helpful but there remains a diagnostic gap.
- NPOS has been shown to enhance the detection of CCHD by identifying levels of hypoxemia otherwise undetectable by clinical evaluation. While the American Academy of Pediatrics (AAP) endorsed NPOS in 2012, the status of screening in Canada is unknown.

↪ Methodology

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

✓ Results

The survey response rate was 25% (660/2601).

Of the 660 respondents, 405 (61%) were general paediatricians, 254 (38%) were paediatric subspecialists, and 1 was marked as other.

Care of newborns with CCHD

- Respondents indicated that, in the last two years, 190/518 (37%) of them had been involved in the care of newborns with CCHD not identified by prenatal ultrasound or newborn physical examination.
- Of these, 139 (73%) participants recalled cases diagnosed after discharge, 102 (54%) recalled cases requiring resuscitation, and 23 (12%) were involved in cases where the newborn died prior to intervention.

Provider awareness

- In total, 74% (389/524) of respondents were aware of NPOS.
- Of the 405 general paediatricians, 337 (83%) were aware of NPOS. Specifically, 216 (53%) were aware of the AAP NPOS protocol and 83 (20%) were performing NPOS.

Use of NPOS

- NPOS is being performed by 135 respondents.
- The majority (119; 88%) did so without a provincial program or were unaware of the existence of a provincial program in their province.
- Protocols that screened the right arm and one foot were used by 95 (70%) respondents.
- A paediatrician was called for abnormal results in 126 (93%) cases.

Support for NPOS and barriers

- A total of 380 respondents did not use NPOS or did not know if their centre screened. Of these: 243 (64%) supported developing NPOS at their centre, 119 (31%) were undecided if they were supportive of NPOS, and 18 (5%) were not supportive of NPOS.

- Barriers to NPOS were identified by 301 respondents and included: 141 (47%) identified the lack of a clear Canadian Paediatric Society (CPS) position statement on NPOS, 162 (54%) had concerns about false positives, and 123 (41%) cited insufficient nursing resources.

Availability of neonatal echocardiography services

- Neonatal echocardiography services were available to 77% (405/524) of respondents located either in their centre (54%) or in their city (23%).
- Of the respondents who perform NPOS, 52% (70/135) do not have echocardiography located within their city.
- Of those undecided or against developing NPOS, 81% (111/137) have echocardiography located within their city.

Survey limitations

- Not all respondents answered each question fully, resulting in varying denominators.



Conclusions

- Cases of CCHD presenting *in extremis* after newborn discharge remain a problem, thus providing an opportunity for NPOS to enhance the detection of CCHD.
- Most of the respondents are aware of NPOS but only a small percentage has implemented screening.
- Of the total respondents who did not use NPOS or were not aware if their centre screened, the majority (64%) were in support of developing NPOS at their centre.
- Echocardiography located in another city has not prevented respondents from performing NPOS.



Anticipated survey impact

- Survey results highlight the need for ongoing education and awareness of NPOS.
- Results will be used to inform a CPS position statement that addresses the utility of NPOS and that may influence implementation.

Acknowledgements

Many thanks to Laura Irving for her administrative support.

Publications 2014–2016

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* 2016 Nov 9. doi:10.1136/archdischild-2016-311223 [Epub ahead of print]

Adverse events following immunization

Canadian paediatricians' approaches to managing patients with adverse events following immunization: The role of the Special Immunization Clinic network. Top KA, Zafack J, De Serres G, Halperin SA. *Paediatr Child Health* 2014;19(6):310–4

Complementary and alternative medicine

Serious adverse events associated with pediatric complementary and alternative medicine. Zorzela L, Boon H, Mior S, Yager J, Gross A, Vohra S. *Eur J Integr Med* 2014;6(4):467–72

Concussion management

Concussion management by paediatricians: A national survey of Canadian paediatricians. Gordon KE, Do MT, Thompson W, McFaull S. *Brain Inj* 2014;28(3):311–7

Congenital cytomegalovirus infection

Congenital cytomegalovirus infection in Canada: Active surveillance for cases diagnosed by paediatricians. Vaudry W, Lee BE, Rosychuk RJ. *Paediatr Child Health* 2014;19(1):e1–5

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* 2016;17(2):191–7

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 2016 in *Paediatrics & Child Health*

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

The CPSP: An active surveillance program protecting and promoting the health of Canadian children and youth. Moore Hepburn C, Laffin Thibodeau M, on behalf of CPSP investigators. *Paediatr Child Health* 2016;21(5):263–4

Minor injuries... major implications: Watching out for sentinel injuries. Barrett R, Ornstein A, Hanes L. *Paediatr Child Health* 2016;21(1):29–30

Presentations in 2016

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

National

Acute flaccid paralysis

Acute flaccid paralysis in Canadian youth, 1996 to 2014. Rotondo J, Desai S, Beaulieu M, Booth TF. Canadian Journal of Neurological Sciences Conference: 51st Annual Congress of the Canadian Neurological Sciences Federation, Quebec City, in June (oral)

Avoidant/restrictive food intake disorder

ARFID & medical monitoring: A focus on pediatric eating disorders. Katzman DK, Norris ML. Ontario Community Outreach Program for Eating Disorders Annual Network Meeting, Toronto, in December (oral)

Neonatal sepsis

Early-onset neonatal sepsis in Canada: 2011–2012. Sgro M, Kobylanskii A, Sankaran K, Tran D, Yudin M, Campbell D. Canadian Paediatric Society Annual Conference, Charlottetown, in June (poster)

Early-onset neonatal sepsis in Canada: 2011–2012. Sgro M, Sankaran K, Yudin M, Kobylanskii A, Campbell D. International Congress of Pediatrics, Vancouver, in August (poster)

Periodic fever syndromes

Surveillance of periodic fever syndromes in Canada. Dancey P, Benseler S, Miettunen P, Turner L, Gattorno M, Laxer RM, Junker A. Canadian Paediatric Society Annual Conference, Charlottetown, in June (poster)

Physician-assisted dying

Headline news, Physician-assisted dying: Should kids ever be considered? Davies D, Shariff M, Emberley J. Canadian Paediatric Society Annual Conference, Charlottetown, in June (oral)

Sentinel injuries

Awareness of sentinel injuries amongst Canadian paediatricians: A CPSP one-time survey. Barrett R, Hanes L, Ornstein A. Canadian Paediatric Society Annual Conference, Charlottetown, in June (poster)

Severe alcohol intoxication

Severe alcohol intoxication in Canadian adolescents: 2-year surveillance data. Acker A, Dow K, Norris M, Allain D, Thomas K. Canadian Paediatric Society Annual Conference, Charlottetown, in June (poster)

Tuberculosis

Midpoint results of national surveillance of childhood tuberculosis. Giroux R, Jamal A, Kitai I, Consunji-Araneta R, Baikie M, Morris SK. Canadian Paediatric Society Annual Conference, Charlottetown, in June (poster)

Vaccine hesitancy

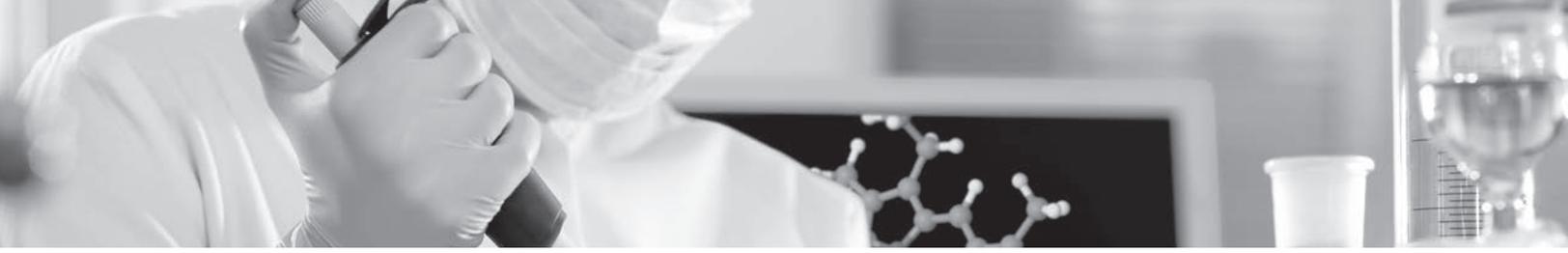
Physician response to vaccine hesitancy in paediatric care. Allan K, Tran D, Fallon B. International Congress of Pediatrics, Vancouver, in August (poster)

International**Neonatal hypoglycemia**

Hypoglycemia in unmonitored term newborns. Flavin M, Osiovich H, Coughlin K, Gregoire K, Hu L, León JA, Ray J, Sgro M, Gallipoli A, Grewal K. Neonatal Update 2016, London UK, in November (poster)

Tuberculosis

Midpoint results of national surveillance of childhood tuberculosis. Giroux R, Jamal A, Kitai I, Consunji-Araneta R, Baikie M, Morris SK & the CPSP Childhood TB Study Group. Pediatric Academic Societies Annual Meeting, Baltimore US, in April–May (poster)



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