

The CPSP: An active surveillance program protecting and promoting the health of Canadian children and youth



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In 2016, the Canadian Paediatric Surveillance Program (CPSP) celebrates its 20th anniversary. The CPSP is a national voluntary surveillance system that collects rich clinical and public health data regarding childhood disorders that are high in disability, morbidity, mortality and/or economic costs to society, despite their low frequency.

The CPSP was established in 1996 under the visionary joint leadership of the late Dr Victor Marchessault, Executive Vice-President of the Canadian Paediatric Society, and Dr Philippe Duclos, who was serving as Chief of the Division of Immunization, Laboratory Centre for Disease Control, Health Canada. The late Dr Danielle Grenier, a member of the inaugural CPSP team, tirelessly supported the CPSP as the Director of Medical Affairs for the Canadian Paediatric Society and is, in large part, responsible for the program's past and current success.

The CPSP also benefits from its participation in the International Network of Paediatric Surveillance Units (INOPSU), a large network of 12 countries with similar surveillance systems, that collaborate on study protocols and publications, thus facilitating global comparison on key public health priority subjects.

Over the past two decades, the CPSP has had an impressive record, both generating new knowledge and translating that knowledge into new practices and policies that improve the outcome for Canada's youngest and most vulnerable citizens. This work would not be possible without the dedication of the 2500 paediatricians and paediatric subspecialists who voluntarily report to the program. Over the past 20 years, the CPSP's national monthly reporting rates have averaged 80%, and the response rate for completion of detailed questionnaires is near 90%.

The CPSP is led by a multidisciplinary expert Steering Committee that reviews and oversees each new study proposal. Preference is given to studies that have strong medical and public health importance. In 2011, the CPSP offered the possibility to complete the monthly reports online and, to date, 72% of participants engage in electronic reporting.

A selection of notable studies (conducted over the program's history) and one-time surveys are described in Table 1:

TABLE 1
Selected notable studies

Study/one-time survey	Main findings	Public health/clinical practice importance
Baby walker injuries (survey, 2005)	The survey identified 132 children under the age of 18 months with injuries associated with baby walkers.	Data contributed to the total ban in Canada on the sale, import, and advertisement of baby walkers.
Exposure to liquid detergent capsules (survey, 2014)	The survey identified 54 children who suffered injuries after exposure to liquid detergent packets; 25 were admitted to hospital and six were admitted to ICU.	Results confirmed the need to advocate for better packaging regulations around hazardous agents such as liquid detergent pods.
Hemorrhagic disease of the newborn (HDNB) (1997–2000)	Following concerns in Germany, the United Kingdom, Sweden, and Australia that the use of oral vitamin K may be associated with an increased incidence of late HDNB, the CPSP undertook a four-year study. Only five cases were confirmed in Canada where guidelines state that intramuscular vitamin K injection is the gold standard for prevention of HDNB.	Results confirmed the recommendation in the CPS statement that intramuscular vitamin K injection is the "gold standard" for prevention of HDNB.
Inhalation of e-cigarettes and ingestion of e-liquid (survey, 2015)	Physicians reported 220 cases. For inhalation cases, most were male, 15–19 years, seeking treatment for vomiting, cough, throat irritation, or acute nicotine toxicity in an outpatient setting. For ingestion cases, most were male, 1–4 years, presenting to an emergency department with vomiting or respiratory distress.	Results substantiated the CPS recommendations that the government should make it illegal to buy, possess or use any form of e-cigarette, or other 'vaping' device, if under the legal age to purchase conventional tobacco products.

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TABLE 1 – CONTINUED
Selected notable studies

Study/one-time survey	Main findings	Public health/clinical practice importance
Lap-belt syndrome (2003–2005)	The study identified 28 cases of lap-belt syndrome (injuries associated with seat belts that were not properly fitted leading to abdominal or thoracolumbar spine injuries) in a two-year period; paraplegia developed in 25% of confirmed cases.	Results stimulated advocacy in all provinces and territories to ensure the adoption of proper car seat and booster seat legislation.
Necrotizing fasciitis (NF) (2001–2003)	The study identified varicella as the most frequent risk factor among patients with group A streptococcal-related NF infection.	Results supported the statement by the National Advisory Committee on Immunization (NACI) to include universal childhood immunization against varicella in the recommended vaccine schedule.
Neonatal hyperbilirubinemia – severe (2002–2004)	The initial study identified 258 confirmed cases over a two-year period.	Results stimulated the CPS position statement advocating for all newborns to be evaluated for risk factors of hyperbilirubinemia and for bilirubin to be measured before discharge.
(2011–2013)	A follow-up study identified 90 cases of severe hyperbilirubinemia.	Results revealed that an infant was 3.5 times more likely to be diagnosed with severe neonatal hyperbilirubinemia from 2002 to 2004 than from 2011 to 2013. Introduction of the CPS guidelines and improved awareness of severe neonatal hyperbilirubinemia likely made positive contributions to this trend.
Severe iron-deficiency anemia (IDA) (2009–2011)	The study identified 201 confirmed cases, many with significant health outcomes, such as developmental delay, heart failure, cerebral thrombosis and supraventricular tachycardia, requiring admission to an intensive care unit.	Results confirmed that severe IDA is associated with substantial morbidity and may be preventable. Modifiable feeding practices include: (1) cow's milk consumption greater than 500 mL per day; (2) daytime bottle use beyond 12 months of age; and (3) bottle use in bed. These feeding practices should be highlighted in future recommendations for public health and primary care providers.
Vaccine hesitancy (survey, 2015)	Physicians reported that the most common concerns expressed by vaccine-hesitant parents were autism (64%), too many vaccines (62%), weakened immune system (52%) and vaccine additives (51%).	Results indicated that three variables predicted greater success in avoiding vaccine non-compliance: (1) using a presumptive ("We have to do some shots") versus participatory ("What do you want to do about shots?") approach to initiate vaccination discussions; (2) using personal endorsement to address parental resistance; and (3) having positive discussions with parents about vaccination.
Vitamin D-deficiency rickets (2002–2004)	The initial study identified over 100 infants and children. Clinically significant morbidity at diagnosis was observed, including hypocalcemic seizures, delayed motor milestones and fractures. Lack of vitamin D supplementation in infants/children with risk factors for vitamin D deficiency (including exclusive breast-feeding, darker skin and Northern latitude) was identified as the main reason for prevention failure.	Results supported the CPS recommendation that children who are exclusively breast-fed should receive vitamin D supplementation.
(survey, 2015)	More than a decade later, a one-time survey demonstrated that vitamin D-deficiency rickets and severe symptomatic vitamin D deficiency remains a problem for infants and children in Canada and are linked to serious health outcomes, including seizures, fractures, delayed developmental milestones, cardiorespiratory failure, and even death.	Results supported the need for heightened professional and public education on the risk of vitamin D-deficiency rickets in Canada and the need for supplementation for prevention. These results suggest that new strategies to facilitate vitamin D supplementation (other than home-based daily administration) may be needed for eradication of the disease in Canada.

CPSP Canadian Paediatric Society

The CPSP is a valuable research platform, advancing knowledge relating to rare paediatric conditions, and conditions of public health importance. The future of the CPSP is exciting and full of promise, as the program commits to the continued pursuit of timely, tangible, high-impact studies that change both clinical practice and public policy.

Details regarding the above studies and surveys, among others, can be found at www.cpsp.cps.ca/surveillance/concluded-studies and www.cpsp.cps.ca/surveillance/one-time-surveys.

The Canadian Paediatric Surveillance Program (CPSP) is a joint project of the Canadian Paediatric Society and the Public Health Agency of Canada, which undertakes the surveillance of rare diseases and conditions in children and youth. For more information, visit our website at www.cpsp.cps.ca.