

The opportunity

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

Track record

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

Themes of interest

Including examples of successful CPSP studies

- Rare diseases (including genetic, metabolic, or rare acquired conditions)
- Congenital myotonic dystrophy
- Medium-chain acyl-coenzyme A dehydrogenase deficiency
- Rare complications of more common diseases
 - Adrenal suppression with glucocorticoid therapy
 - Serious adverse events associated with complementary and alternative medicine
- Emerging infections
- COVID-19
- Lyme disease
- · Threats to public health and safety
- Vaping
- Neonatal abstinence syndrome
- Serious/life-threatening use of opioids, stimulants, and sedatives

Study success factors

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

Study impact

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

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

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

Public health promotion and education:

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

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

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

