

# The Canadian Paediatric Surveillance Program: Celebrating 15 years of successful paediatric surveillance



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Surveillance is a key component of the practice of medicine, which enables the tracking and studying of conditions (1,2). The Canadian Paediatric Surveillance Program (CPSP), an innovative epidemiological real-time tool modelled after the British Paediatric Surveillance Unit, was established in 1996 under the visionary collaboration of the late Dr Victor Marchessault, Executive Director of the Canadian Paediatric Society, and Dr Philippe Duclos, formerly with the Health Promotion and Chronic Disease Prevention Branch of the Public Health Agency of Canada (PHAC). The program has been in operation for 15 years and, to date, has studied 45 conditions and confirmed more than 5000 cases. The present article describes the CPSP, highlighting the successes and challenges, to illustrate the importance and advantages of national and international collaboration on surveillance.

## WHAT IS THE CPSP?

The CPSP is a joint project of the PHAC and the Canadian Paediatric Society (CPS). This pan-Canadian active surveillance network provides the opportunity for more than 2500 practicing clinical paediatricians and paediatric subspecialists to participate, on a voluntary basis, in the study of paediatric diseases and conditions affecting children and youth, which are relatively low in frequency but high in disability, morbidity, mortality and economic costs to society. Often, national data are required to generate a sufficient number of cases to derive meaningful information. Many of these cases are rare conditions and 'orphan diseases', for which research funding is often difficult to secure.

## HOW DOES THE CPSP WORK?

### Steering committee

A multidisciplinary expert steering committee with representation from groups, including the CPS, PHAC, the Paediatric Chairs of Canada and liaison representatives from various paediatric subspecialties and the Canadian Immunization Monitoring Program, ACTive, oversee the program and review each new study proposal. Preference is given to studies that have strong medical importance and/or are of public health importance, and in which this methodology is most appropriate. The program started with three conditions under surveillance on the monthly report form, never exceeded 12, and has averaged 10 conditions during a one-year period.

### Reporting process

On initiation of a new study, CPSP participants across the country receive a summary of the protocol in the mail, including the case definition and a brief description of the condition. The background information serves to educate and increase awareness of conditions under surveillance, and helps to provide a uniform basis for reporting.

The CPSP uses a two-tiered reporting process. On the initial mailed monthly reporting form, participants are asked to record the number of new cases of the conditions seen in the past month, including 'nil' reports. Once a case has been reported, participants are asked to complete a detailed questionnaire, separately mailed, providing investigators with non-nominal, clinical case-specific data for analysis. Quarterly reminders are sent to participants who do not reply every month.

Over the 15-year duration of the program, the CPSP national reporting rate has averaged 80% of those eligible to report, and the response rate for completion of detailed questionnaires has been 94%. This participation rate illustrates that paediatricians are enthusiastic about participating in such a program.

## WHAT ARE THE SPECIAL CHARACTERISTICS OF THE CPSP?

The CPSP has special characteristics that make data collection and management feasible. First, the CPSP selects only rare diseases – defined as having a rate of less than 1000 cases per year. Second, only relatively severe conditions are chosen and, hence, patients have a high probability of being referred to paediatricians. Finally, the number of participating paediatricians is also relatively small (approximately 2500). These three factors contribute to make the processing of reports, quality verification and data preparation for analysis manageable. Given the relatively small number of paediatricians in Canada, prodding them for follow-up or clarification of a response on information collected is not difficult. Also, because of the nature of the conditions investigated (ie, rare, unusual, serious and complex), it is highly likely that a paediatrician would remember cases they have seen during the month before reporting. By having an average of 10 conditions under study concurrently, use of participants' time can be minimized and research opportunities optimized. This passive/active surveillance system provides more comprehensive summative national clinical data collected directly by the treating paediatricians and obtained in a more real-time fashion than

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occurs with administrative database sources such as national hospitalization discharge, laboratory or billing data from provincial health insurance plans.

The program also provides an infrastructure that allows for rapid, inexpensive and efficient transmission of information. In response to a public health emergency, new targets can be rapidly selected and added to the monthly surveillance form, alerting paediatricians of the issue and recommending for investigation and management. The data collected from these alert targets can be used to inform public health responses to these conditions. Dr Robert McMurtry, who performed an external review in 2003 (3-5), perceived the CPSP as unique in Canada because of this function.

### WHAT IS THE IMPACT OF THE CPSP?

One of the most important successes of the CPSP is the creation of a Canadian national network of collaborative active surveillance that includes paediatricians from all regions of Canada. Such a network is crucial in helping to determine the burden of rare diseases and conditions in children and youth, and to identify risk and protective factors.

Many of the studies have led to important medical and public health actions over the years such as the following:

- The wheeled baby walker survey (6) contributed to the total ban on the sale, import and advertisement of these walkers in Canada.
- The lap-belt syndrome study (7) led to changes in legislation requiring longer use of booster seats by children.
- The ongoing acute flaccid paralysis study (8) documented that Canada is free of endemic polio, a requirement needed to maintain its WHO certification status.
- The necrotizing fasciitis study (9) identified that varicella was the most frequent factor of group A streptococcal-related necrotizing fasciitis and supported introducing the universal childhood varicella immunization program.
- The vitamin D deficiency rickets study (10) confirmed the importance of reinforcing the current CPS recommendation that exclusively breastfed infants and children receive vitamin D supplementation.
- The medium-chain acyl-coenzyme A dehydrogenase deficiency study (11) documented the efficacy of newborn metabolic screening programs in detecting asymptomatic cases that allow for early preventive measures (the two reported deaths during the course of the study did not occur in jurisdictions with screening programs).
- The international adoption survey (12,13) determined that knowledge about screening methods varied significantly with important gaps for tuberculosis and hepatitis B, stimulating the implementation of continuing medical education programs in these areas.
- The severe neonatal hyperbilirubinemia study (14) confirmed that many cases were occurring in term newborns and contributed to the revision of the CPS guidelines on the management of neonatal hyperbilirubinemia.
- The non-type 1 diabetes mellitus study (15) determined that obesity/overweight was the predisposing factor in nearly all cases of type 2 diabetes mellitus in children and youth – information used for specific health promotion and disease prevention programs.

To date, more than 40 peer-reviewed articles on CPSP studies have been published, demonstrating the importance of the work of the investigators and the participants.

The CPSP also participates in the International Network of Paediatric Surveillance Units (INoPSU), which promotes collaboration and simultaneous or sequential target surveillance. The CPSP is currently assuming a leadership role in the INoPSU chairmanship with the Australian Paediatric Surveillance Unit. Collection of these data permits international comparisons that can result in an acceleration of timely information for the development of medical, educational and public health interventions (16) such as the following:

- Hemorrhagic disease of the newborn, in five national paediatric surveillance units, illustrated the merit and importance of intramuscular vitamin K prophylaxis (17).
- Congenital rubella syndrome, in five paediatric surveillance units, reaffirmed the importance of maintaining the universal two-dose rubella immunization strategy and standing orders for immunization of rubella-susceptible women in the immediate postpartum period (18).

### HOW HAS THE PROGRAM INNOVATED?

Because not all research questions warrant a complete study, the CPSP instituted one-time survey questions that may be added to the monthly mailouts to offer investigators the possibility of capturing a signal, documenting a change in pre- or postdisease knowledge, identifying the prevalence of a problem, or answering a specific question of clinical or public health relevance. In 2008, following the outbreak of renal stones and/or acute renal failure in association with the consumption of melamine-contaminated powdered infant formula in China, the PHAC used the CPSP to conduct a one-time survey to determine whether any Canadian infants had faced the same situation. Within 10 working days, a survey was sent out to the program's participants, and results were available within three weeks. The CPSP demonstrated the potential for the PHAC and CPS to work together to perform national emergency surveillance of a rare condition (renal stones/failure in infants, in this instance) quickly and inexpensively, to inform public health responses to disease management and prevention (19,20).

Over the years, the program has recognized the importance of providing educational materials and rapid dissemination of study results to health professionals, researchers, policy makers, politicians and the general public. Integral components of the program's current activities are the following: educational articles on conditions under study; the CPSP ADR Tips of the Month; the CPSP Highlights featuring clinical vignettes, learning points and a yearly quiz in *Paediatrics & Child Health*; and regular articles in *CPS News*, the bimonthly newsletter of the CPS. This multipronged approach is consistent with the recommended WHO surveillance definition of information for action (21).

### WHAT ARE THE CHALLENGES OF THE PROGRAM?

Like all surveillance programs, the CPSP has challenges. Of utmost importance is maintaining the quality and momentum of the program. For example, constant efforts are made to keep paediatricians interested and actively participating, both in terms of submitting proposals and completing the initial reporting forms and detailed questionnaires. The CPSP encourages participating paediatricians to keep track of surveillance activities for continuing professional educational credits with the Royal College of Physicians and Surgeons of Canada. Currently, the CPSP uses regular mail, but is in the process of establishing electronic reporting as an evolving surveillance methodology. This has the potential to improve response rates and the speed of responses,

and can facilitate communication back to participants. Nationally, the program needs to maintain a stable infrastructure and ensure long-term financing. On the international scene, the CPSP will, where possible, continue to support strong collaboration with other members of national paediatric surveillance units to conduct simultaneous or linked projects.

### WHAT CAN BE LEARNED FROM A PROGRAM LIKE THE CPSP?

A national network of active surveillance cannot be successful without well-connected and dedicated frontline participants, public health officials and study investigators. The CPSP is a live demonstration of exemplary collaboration between the PHAC and CPS. As a national specialty organization, the CPS brings program credibility to the participants and a track record of reliable managerial skills to the funding authorities. The emergency-response preparedness ability of the CPSP illustrates the importance of investing in a population-based surveillance tool. The multiple avenues used to provide timely dissemination of study results are added values and essential to translating epidemiological data into actions.

Population-based surveillance is of great importance in the advancement of knowledge regarding high-impact child and youth orphan disorders. The future of the CPSP is promising because the outcomes of studies have been timely, tangible and enduring medical and public health changes, including how practitioners care for children and youth, as well as government laws and prevention strategies that affect child and youth well-being and safety.

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*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.cps.ca/cpsp](http://www.cps.ca/cpsp).*