Canadian Paediatric Surveillance Program: A developmental check-up

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Just as children are born, grow and develop, so too do programs. In 1996, as a medical officer of health, I attended the first steering committee meeting in Ottawa to witness the birth of the Canadian Paediatric Surveillance Program (CPSP), a new overseas cousin to the now 10-year-old British program. Little did I, and others at the meeting, realize how much time and attention this new baby would require.

The CPSP, like any developing infant, required nurturing. As it grew, the number of surveillance activities increased. It started slowly with the reporting of three paediatric infectious diseases with important public health implications: acute flaccid paralysis as part of polio surveillance, congenital rubella syndrome and neonatal group B streptococcal infection. As the CPSP gained experience, it extended its reach to undertake surveillance of up to 10 conditions simultaneously. It has now been involved with a total of 24 important paediatric conditions covering areas such as infectious diseases, injuries, genetic disorders, metabolic conditions and neurological problems (Table 1). At first, the CPSP had to actively seek out conditions for surveillance, but as its reputation grew, an increasing number of investigators came forward with proposed studies. At the last steering committee meeting, a list of 30 proposed new CPSP studies was presented to the group.

As the program approached seven years of age, Health Canada and the Canadian Paediatric Society decided that a developmental check-up was needed to see if the CPSP was maturing according to expectations. Assessing the CPSP's adaptability to respond effectively to the changing Canadian health care delivery environment was also deemed essential.

An internal CPSP evaluation team was created to supervise the evaluation, and a public health epidemiologist was contracted to assist in the process. An external international advisory group was formed with expertise in paediatrics, surveillance, public health and policy development to provide input into the objectives and methodology of the evaluation. A review of the literature indicated that only one other national paediatric surveillance unit, the Australian Paediatric Surveillance Unit, had undergone a formal evaluation, based primarily on the criteria used by the Centers for Disease Control and Prevention for evaluation of a surveillance program (1,2). This, together with other literature on the evaluation of public health programs, served as references to develop and implement an evaluation process (3). Evaluation objectives were created with the emphasis placed on ensuring feedback from program participants who were frontline paediatricians, researchers and public health policy makers. Survey questions were sent to over 2469 participants. The survey included specific questions, but also allowed respondents the opportunity to provide suggestions on how the program could be improved. In addition, a review of the health conditions that had undergone surveillance was performed to see how accurately the program was able to detect the true number of events.

The expert advisory group met with the evaluation team for a full day to receive and review the results of the evaluation. The advisory group then caucused separately to review their analysis and provide both immediate verbal and later written comment on the CPSP.

While the results of the evaluation, the recommendations from the expert group and the proposed changes to the CPSP will be provided to readers in the months ahead through posters, articles and published manuscripts, some key points are worth noting.

It is clear that the CPSP has developed into an effective infrastructure for national collaborative surveillance and research into paediatric conditions. These conditions, although occurring at a low frequency, may have a high impact on society in terms of morbidity, mortality and cost. It is an excellent value for the money and it is unique in Canada as an ongoing collaborative tool for surveillance and research that provides supporting evidence for policy development. The reach of the program extends beyond Canada as the program continues to provide surveillance results and to collaborate on common surveillance activities with 13 other members of INoPSU (International Network of Paediatric Surveillance Units) (4). Most importantly, the CPSP, through its surveillance activities, provides evidence that can be used to guide actions to improve children's health, such as improved clinical recognition and management or beneficial changes in policy development. Several examples include the work on vitamin D deficiency rickets, hemorrhagic disease of the newborn due to problems with vitamin K administration, and injuries due to baby walkers.

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TABLE 1
Timeline (by end date) of Canadian Paediatric Surveillance Program studies

Studies	Start date	End date	Total confirmed cases to December 2003
Group B streptococcal infection	Jan-96	Dec-96	178
Neural tube defects	Jan-97	Dec-98	107
Creutzfeldt-Jakob disease	Jan-97	Jun-99	1
Hemorrhagic disease of the newborn	Jan-97	Dec-00	5
Subacute sclerosing panencephalitis	Jan-97	Dec-00	3
Cerebral edema in diabetic ketoacidosis	Jul-99	Jun-01	23
Progressive intellectual and neurological deterioration	Jul-99	Jun-01	59
Anaphylaxis	Jan-00	Jun-01	732
Hemolytic uremic syndrome	Apr-00	Mar-02	140
Smith-Lemli-Opitz syndrome	Jan-00	Dec-02	35
Hepatitis C virus infection	Feb-01	Jan-03	58
Neonatal liver failure/perinatal hemochromatosis	Feb-01	Jan-03	10
Necrotizing fasciitis	Sep-01	Aug-03	37
Neonatal herpes simplex virus infection	Oct-00	Sep-03	58
Neonatal hyperbilirubinemia – severe	Jul-02	Jun-04	48
Vitamin D deficiency rickets	Jul-02	Jun-04	20
CHARGE association/syndrome	Sep-01	Aug-04	78
Acute flaccid paralysis	Jan-96	Dec-04	354
Congenital rubella syndrome	Jan-96	Dec-04	9
Prader-Willi syndrome	Jan-03	Dec-04	9
Osteogenesis imperfecta	Jan-04	Dec-04	–
Early-onset eating disorders	Mar-03	Feb-05	23
Lap-belt syndrome	Sep-03	Aug-05	1
Adverse drug reactions – serious and life-threatening	Jan-04	Dec-05	–

The potential to contribute to many other significant public health issues has already been documented by the older British Paediatric Surveillance Unit (5).

One conclusion from the evaluation is that should the CPSP cease to exist, Canada would likely need to invest more time, effort and dollars in creating issue-specific surveillance tools. These tools would be necessary to respond when concerns arise about new or existing low-frequency but high-impact conditions.

What of the CPSP's future? Well, the expert advisory group recognized that while continuing to perform ongoing surveillance activities among paediatricians across Canada, the program must start to reach out to other health care professionals, particularly those among the First Nations who are involved in child care delivery. The group recommended that the potential for a quick response to urgent paediatric public health issues, as exemplified by the snapshot survey of baby walker injuries, be explored. A key recommendation was that the CPSP needs to ensure that the high quality paediatric and public health evidence found during its work is targeted to clinicians, administrators and policy makers in a manner that promotes effective use in policy development.

As my mother used to say, the future is what you make of it. The CPSP has had a great childhood and has developed the attributes that will enable it to contribute even more to children in Canada and the world. Now it will be up to all those participating in the CPSP to respond to the results and recommendations of the evaluation to ensure that it achieves its potential.

REFERENCES

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