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Evaluation of the Canadian Paediatric Surveillance Program

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EVALUATION OF THE CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

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EXECUTIVE SUMMARY

The Canadian Paediatric Surveillance Program

Initiated in 1996 by Health Canada and the Canadian Paediatric Society (CPS), the Canadian Paediatric Surveillance Program (CPSP) has grown from a pilot program monitoring three paediatric conditions to a mature surveillance system involving over 2350 reporting paediatricians/paediatric subspecialists and an annual average of 10 low frequency but high impact childhood disorders investigated to date. CPSP undertakes national surveillance of paediatric diseases/conditions that have a low incidence (< 1000 cases per year) but carry an increased risk of significant long-term disability and death as well as substantial economic costs to society.

A Steering Committee is responsible for reviewing research proposals according to scientific and public health criteria. Once a new condition has been accepted for surveillance, program participants, i.e. reporting paediatricians, receive a summary of the protocol and the case definition. They report all cases of the condition, as well as suspect and probable cases, seen within the previous month (or submit a nil report, if none was seen) on standard reporting forms. Those clinicians who report cases are then asked to provide more details by completing a follow-up questionnaire. Duplicate cases are identified during this follow-up process. Case ascertainment is verified through comparison with data from other programs, such as the Canadian Institute for Health Information.

By 2003, it was felt necessary to undertake an evaluation of the CPSP and its stated objectives. Consequently, an Expert Advisory Group (EAG) was established in the spring of that year to collaborate with the CPSP Working Group and Steering Committee on such a review and to make recommendations in light of the conclusions. The objectives of the review were as follows:

- to determine how well the CPSP is achieving its objectives;
- to assess the costs and effectiveness of the program in comparison with other similar surveillance programs;
- to assess how well the CPSP functions relative to CDC (U.S. Centers for Disease Control and Prevention) criteria for surveillance programs;
- to afford CPSP participants and researchers the opportunity to provide feedback;
- to determine whether the CPSP is meeting the needs of various target groups, including researchers and paediatricians;
- to assess the "public health worth" of the CPSP: Does the information it collects have the potential to change public health policies?
- to assess the effectiveness of the CPSP Steering Committee;
- to identify opportunities for improvement.

The evaluation comprised three components: establishment of an EAG to provide oversight; feedback from CPSP participants and others by means of anonymous questionnaires; and assessment of the CPSP using criteria for evaluating public health systems developed by the CDC.

The response rates to the survey questionnaires were 47% for CPSP participants, 45% for investigators, 71% for Steering Committee members and 46% for public health professionals. The survey data were used to assess how well the CPSP is meeting the needs of various target groups and to answer the questions posed by the CDC's guidelines on evaluation.

Overall, the EAG concluded that the CPSP has met its current objectives. It has initiated programs of national scientific significance and developed an effective surveillance system to monitor the health of Canadian children. Some important results over the past eight years include the improved reporting rate of acute flaccid paralysis; confirmation of the need for administration of intramuscular vitamin K to newborn babies for

prevention of hemorrhagic disease, in accordance with CPS guidelines; establishment of Canadian incidence of Smith-Lemli-Opitz syndrome; and information on vitamin-D deficiency rickets and neonatal hyperbilirubinemia to guide policy development. One-time surveys have been used to investigate the extent of injuries associated with baby walkers and lap belts. Surveillance results from the program have clear implications for treatment, prevention and public health measures. Of the public health professionals surveyed, 71% had used CPSP information to guide the planning, implementation and evaluation of programs. Of the investigators, 95% reported that their research project could not have been undertaken without national case ascertainment, and 68% felt that it would not have been possible without the CPSP.

The CPSP also has an important educational function. Paediatricians' awareness of the low frequency childhood disorders under surveillance has increased through participation in the program, and CPSP results are disseminated through various channels: highlights and articles are published in journals such as *Paediatrics and Child Health and Canada Communicable Disease Report*, bi-annual educational resource articles are circulated, an Annual Report is produced, and oral and poster presentations are made at scientific meetings. More than 60% of paediatricians responding to the survey reported that the study protocols and bi-annual resource articles were helpful, and clinicians who had previously reported a case to the CPSP were twice as likely to report that study-related materials had changed their clinical practice.

Not only does the CPSP provide a mechanism for national collaborative research (of the 11 studies monitored in 2002, six had co-investigators from different centres), it also actively promotes liaison with similar surveillance systems in other countries through the International Network of Paediatric Surveillance Units. Survey responses indicated that 65% of investigators believed that CPSP results provided information to allow partnership with researchers in other countries.

There is overwhelming evidence that the CPSP is a timely, cost-effective epidemiological tool that carries out a core Health Canada surveillance function and does so very successfully. It demonstrates high sensitivity and response rates, provides an invaluable tool in collaborative research, is recognized internationally as a high-quality program – and achieves all this on a small budget. It is a necessary program with no apparent alternative. The financial savings achieved through increased awareness and education, and thus earlier detection and treatment of patients, are likely to be considerable. An international comparison of its operating costs with those of other national surveillance programs proved impossible, as each unit functions differently.

Use of the CDC framework has demonstrated that the CPSP employs its resources wisely to maintain a surveillance/research tool that is clearly extremely useful, is simple, acceptable (e.g. 83% response rate for the year 2002) and sensitive (as shown through comparison with data from other sources). With regard to the program's influence on public health policy, 88% of public health professionals surveyed had heard of the program, and 86% of these were aware of its results; 32% used the results to evaluate public policy; 47% used them as a basis for future research; 70% for uses such as guiding immediate action; and 60% for continuing professional development.

In summary, the EAG concluded that the CPSP represents excellent value for money, an achievement that was seen as exceptional and unsurpassed by any comparable program known to the group. Furthermore, the CPSP represents an important collaborative tool for surveillance, research and policy development. It is a robust program, with a strong economical infrastructure, a well-established national collaborative network, a rapid real-time reporting rate and a high degree of sensitivity and predictive value.

Surveillance, per se, is not a therapeutic intervention. Surveillance is "knowledge transfer" in action. Information collected by the CPSP provides scientific evidence to advance clinical practices and guide public health actions. CPSP's legacy will be best remembered in the lives saved and the lives prolonged by clinical and social prevention/interventions derived from CPSP studies.

OVERVIEW OF THE CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

The Canadian Paediatric Surveillance Program (CPSP), a joint project of Health Canada's Centre for Infectious Disease Prevention and Control and the CPS, was established in 1996 to monitor diseases and conditions in Canadian children that have low frequency but high morbidity and mortality. The Steering Committee of the CPSP requests proposals from the paediatric research community on medical conditions that require surveillance. Once a study has been accepted, the paediatricians participating in CPSP submit monthly reporting forms on which they have recorded the number of new cases of the condition seen in the previous month. The CPSP is an active surveillance program and, accordingly, participants must return the monthly report form even if they have not seen a case. Once a case has been identified, the participant is asked to complete a detailed reporting form providing investigators with case-specific data.

Mission Statement

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.

Program Objectives

Mechanism

- To maintain and improve a national and collaborative population-based surveillance system to monitor health in Canadian children and youth.

High impact surveillance

- To perform surveillance on childhood disorders that are high in disability, morbidity, mortality and economic costs to society, despite their low frequency (less than 1000 cases per year).
- To provide a platform for population-based surveillance to look at special populations and regional variations.

Knowledge transfer

- To advance knowledge, enhance understanding and improve prevention, treatment and health care planning related to high impact childhood disorders.
- To disseminate important surveillance results to health professionals, policy-makers and the general public in order to contribute to the health and well-being of Canadian children, through collaborative efforts.

Emergency response

- To provide an infrastructure that allows rapid and efficient access to surveillance to respond to urgent paediatric public health emergencies.

International opportunities

- To participate in the International Network of Paediatric Surveillance Units (INoPSU) promoting "global village" surveillance that can result in an acceleration of the acquisition of timely information for public health decisions.

Program History

Founded in 1996 – A Pilot Program

In 1995, a small working group from the CPS and Health Canada was formed to set up a national paediatric surveillance program modelled on the British Paediatric Surveillance Unit. After several months of planning and consultation, a joint pilot program for

the surveillance of low frequency, high impact paediatric diseases and conditions was established, which commenced activity in January 1996. Three conditions were selected for the pilot program: acute flaccid paralysis (AFP), congenital rubella syndrome (CRS), and group B streptococcal infection (GBS). AFP was selected because even though Canada and the rest of the Americas were certified polio-free in 1994, there remained a risk of wild polio importation from polio-endemic regions to Canada. The CPSP provided a means of monitoring suspected cases of paralytic poliomyelitis and confirming the elimination of indigenous wild poliovirus transmission. CRS surveillance monitored progress towards the goal of eliminating indigenous rubella infection during pregnancy by the year 2000. The GBS study offered the challenge of gathering much needed information on the incidence of this infection in Canada.

The pilot study highlighted the importance of sending quarterly reminders to non-responding participants. Three reminders were sent for the first two months, whereas no reminders were sent for the final two months of the year, and this resulted in much higher response rates, of 89% and 88% for January and February, as compared with 61% and 64% for November and December. The pilot phase enabled the CPSP to evolve into a smoother, more efficient infrastructure as a result of the experience gained throughout the year.

The Emerging Years (1997-2000)

The CPSP continued to grow and build in 1997 with the addition of three new diseases to the program: Creutzfeldt-Jakob disease (CJD), hemorrhagic disease of the newborn, and neural tube defects. At the same time, surveillance of GBS was discontinued, as a number of other studies were initiated following the publication of guidelines for the management of GBS during pregnancy and delivery.

While no new studies were added to the CPSP in 1998, surveillance of neural tube defects concluded when final study results indicated that case ascertainment was incomplete. In retrospect, it became clear that establishing a network of collaborators is of prime importance when studying the occurrence of conditions that involve a number of health care professionals. To ensure that case ascertainment is complete, all collaborators must be involved. In this case, extending the list of participants to include other subspecialties, such as obstetricians and geneticists, would have ensured that case ascertainment results were more complete.

The program continued to evolve, becoming more self-directed, and in the summer of 1998 a call was issued for research proposals. The call was successful, six new studies being approved for inclusion in the program pending confirmation of financial support and ethical approval: anaphylaxis, cerebral edema in diabetic ketoacidosis, idiopathic interstitial lung disease, perinatal hemochromatosis, pyridoxine-dependent status epilecticus, and vitamin D-deficiency rickets. With more than 2100 paediatricians participating in the program, the CPSP became the largest paediatric surveillance unit in the world. By 1999 and 2000, the CPSP had gained recognition among paediatric researchers as a timely epidemiological tool. As a result, many different paediatric subspecialties embarked on new surveillance projects: anaphylaxis, hemolytic uremic syndrome, neonatal herpes simplex virus infection and Smith-Lemli-Opitz syndrome. This variety of conditions is important in keeping paediatricians highly interested and motivated to participate in the program. As well, the variety shows the great versatility of the CPSP as an epidemiological tool.

From three studies in the inaugural year to nine by 2001 and a total of 24 conditions under surveillance since its inception, today nearly 2350 paediatricians and paediatric subspecialists participate monthly, representing a child population under 18 years of age

of approximately 7.5 million. Since 1999, the initial monthly response rate has averaged 82%, with a completion rate of 95% for the follow-up, detailed questionnaire on case reports.

Surveillance at Work

CPSP Steering Committee

During 1996, a Steering Committee was established to ensure that the CPSP would be developed to serve the health needs of Canadian children and youth as well as the research needs of the health care community whose prime concern is the care and health of children. Membership on the Steering Committee includes representation from the CPS, the Centre for Infectious Disease Prevention and Control and the Centre for Healthy Human Development of Health Canada, the Federal/Provincial Advisory Committee on Epidemiology, Chief Medical Officers of Health, and the Assembly of Canadian University Paediatric Department Heads. Also included are liaison representatives from various organizations, such as the Canadian Association of Child Neurology and the Canadian College of Medical Geneticists. A lay person representing the discipline of bioethics was also added. Past and present members of the CPSP Steering Committee members are listed in Appendix 1.

The Process

The CPSP is designed to study low incidence, high impact childhood disorders (less than 1000 cases per year) or rare complications of more common diseases of such low frequency that national data collection is required to generate a sufficient number of cases to derive meaningful results. When the CPSP Steering Committee reviews new study proposals, preference is given to studies that have strong public health importance or could not be undertaken in any other way. All studies must conform to high standards of scientific rigour and practicality.

Upon initiation of a new study, program participants receive a summary of the protocol, including the case definition and a brief description of the condition. In addition to providing a uniform basis for reporting, this approach serves to educate and increase awareness of unusual or rare conditions. The initial reporting form, listing the conditions currently under surveillance, is mailed monthly to practising Canadian paediatricians and relevant paediatric subspecialists, and health care providers (Figure 1). Respondents are asked to indicate, against each condition, the number of new cases seen in the previous month or to submit a "nil" report. A nil report is very important in active surveillance because the CPSP cannot simply assume that no reply means no cases. Participants report all cases meeting the case definitions, including suspect or probable cases where there is some doubt about reporting. This sometimes leads to duplicate reports but avoids missed cases. Duplicate cases are identified during case follow-up. Respondents who do not reply every month receive quarterly reminders. As well, information, including the monthly compliance rates and the number of cases reported, is mailed quarterly to all participants to keep them informed of progress. Case ascertainment is monitored and verified by investigating duplicate reports and comparing data with the following programs or centres:

- Canadian Association of Paediatric Health Centres
- Canadian Paediatric Decision Support Network
- IMPACT (Immunization Monitoring Program ACTive) centres
- Notifiable Diseases Reporting System, Centre for Infectious Disease Prevention and Control, Health Canada
- Hospital Discharge Abstract Database, Canadian Institute for Health Information

One-time Survey Questions

The CPSP was expanded to allow investigators a cost-effective tool to survey participants on a one-time basis in order to identify the prevalence of a problem or to answer a specific question. In 2002, the Injury and Child Maltreatment Section, Health Surveillance and Epidemiology Division of the Centre for Healthy Human Development at Health Canada, with the cooperation and support of the Product Safety Bureau, Healthy Environments and Consumer Safety Branch, posed a question to better understand the frequency and extent of injuries associated with baby

Figure 1: Initial Reporting Form

Canadian Paediatric Surveillance Program

John Doe, MD
1234 Some Street
Somewhere ON A1A 1A1

February 2003
999999

100001

Conditions currently under study

(Please ensure that cases of statutorily notifiable diseases are reported to the appropriate public health authority.)

Acute flaccid paralysis (AFP) – including Guillain-Barré syndrome (stool culture important)

CHARGE association/syndrome (CAS) –

Congenital rubella syndrome (CRS) – including congenital rubella infection

Necrotizing fasciitis (NF) –

Neonatal herpes simplex virus infection (HSV) – infant 60 days or less

Neonatal hyperbilirubinemia – severe (NHS) – < 60 days (total bili > 425 micromol/L or exchange transfusion)

Prader-Willi syndrome (PWS) –

Vitamin D deficiency rickets (VDDR) –

If you have no new cases to report for any of these conditions, please check this box. ☐

If new cases have been seen, please complete the section below listing the study, and the Date of birth/Sex for each case.

Study	**Date of birth/Sex**	**Comment**
e.g. AFP		xxxx

Complete and return this form in the enclosed self-addressed envelope or fax to: (613) 526-3332.

Thank you for your cooperation.

100-2204 Walkley Road, Ottawa ON K1G 4G8 —- Tel.: (613) 526-9397, ext. 239; Fax: (613) 526-3332

walkers in Canada. A total of 1214 paediatricians returned the survey, representing a 53.4% response rate. A second survey question, in early 2003, verified that paediatricians see children with lap-belt syndrome at some point during their hospitalization and confirmed the need for a follow-up study.

Commitment to Patient Confidentiality

With increased concerns about the protection of individual privacy, an important issue for paediatric surveillance has become the need to balance the goal of data collection for the common good against the need for confidentiality. While health-related surveillance existed for centuries, the rapidly increasing technological ability to link, analyze and disseminate data is an important consideration. CPSP Steering Committee members have affirmed their commitment to maintaining patient confidentiality, and only non-nominal patient information is requested to track reports and eliminate duplicates. The CPSP ensures the privacy and the non-labelling of individuals, localities, and provinces in either rare encounters of a condition or localized outbreaks, stating that only pan-Canadian national data are used in presentations and publications.

Funding

Health Canada has provided funds to the CPSP through two contracts awarded to the CPS by the Science Directorate of Public Works and Government Services Canada. The contract's "scientific authority" resides with the Division of Surveillance and Risk Assessment of the Centre for Infectious Disease Prevention and Control, Population and Public Health Branch, Health Canada.

CPSP Contract, 1997-2000: The first contract, in the amount of $630,762.86, was awarded for three fiscal years, April 1, 1997, to March 31, 2000. The second and third years of the contract stipulated that "the Contractor will be paid its costs reasonably and properly incurred in the performance of the Work, less all revenues generated by the Contractor (CPS) for the program". The contract funded "core costs", which included labour, database and accounting support, and day-to-day operating expenses. As well, the contract provided a 12% administrative fee attributable to labour and direct operating expenses.

Three amendments increased the funding to $829,589.19, and extended the duration of the contract to November 30, 2000. Amendments assigned a Medical Affairs Officer to the program, commencing October 1, 1999, working one full day per week (or two half-days per week). It also provided for the support services of the Executive Director, commencing April 1, 2000, working 3.75 hours per week. The amendments covered the costs of conducting a survey of CPSP participants on the use of e-mail and Internet services, and hosting the inaugural meeting of the International Network of Paediatric Surveillance Units (INoPSU) in conjunction with the CPS annual meeting in June 2000.

CPSP Contract, 2000-2005: A second contract was awarded to the CPS for a period of four years and four months, commencing on December 1, 2000, and terminating on March 31, 2005. The contract is a "firm price contract" for the total expenditure of $1,570,974.00 (including GST).

Surveillance Results – Making a Difference (2001 to the present)

With many concluding studies and a well-established infrastructure, analysis and interpretation of results revealed important medical and public health issues needing dissemination and action. For example,

- with the introduction of active paediatrician-based reporting through the CPSP, the AFP reporting rate improved from 0.5 to 0.97 per 100 000 children and reached the World Health Organization's targeted rate for a country free of wild poliovirus. The Pan American Health Organization commended the CPSP on its success in identifying, reviewing, and investigating all AFP cases;
- results of the hemorrhagic disease of the newborn (HDNB) study reinforced the CPS guidelines on the administration of intramuscular vitamin K to newborn babies. An international comparison of the incidence of late HDNB (1995-2000) for Canada, Australia, New Zealand,

Switzerland, Germany and Britain showed Canada to have the lowest rate (0.37 per 100 000);

- the rarity of subacute sclerosing panencephalitis cases (two in four years) is a tribute to both the success of the measles immunization program and the safety of the measles vaccine;
- the anaphylaxis study documented for the first time that it was not a rare disorder and that it affected the entire Canadian paediatric population from age 1 month to 17 years; it also illustrated the need for increased public health measures to improve both recognition and prompt treatment of anaphylaxis;
- because of increased awareness in the paediatric milieu, the results of the Smith-Lemli-Opitz syndrome (SLO) study established a Canadian incidence, identified three new DHCR7 mutations, and were crucial in securing National Institutes of Health funding for a multi-centre international study on prenatal screening for SLO in Ontario and British Columbia;
- the vitamin D deficiency rickets study confirmed many cases in Canada and reinforced the CPS guidelines on the importance of vitamin D supplementation of all breastfed infants and children;
- the neonatal hyperbilirubinemia study identified a large number of newborns with severe disease and an educational need for improving their initial diagnostic laboratory evaluation;
- the adaptability of the CPSP as an epidemiological tool allows one-time surveys to determine the prevalence of a problem or to answer a specific question on practice experience, as highlighted by the surveys on baby walker and lap-belt syndrome injuries. Both of these will have product safety implications.

International Network of Paediatric Surveillance Units (INoPSU)

In August 1998, during the 22nd International Congress of Paediatrics in Amsterdam, the International Network of Paediatric Surveillance Units (INoPSU) was established1. The founding units were Australia, United Kingdom, Canada, Germany, Latvia, Malaysia, the Netherlands, New Zealand, Papua New Guinea, and Switzerland. The CPSP invited INoPSU to host its first scientific meeting during the CPS annual meeting in June 2000, affording Canadian paediatricians an excellent opportunity to benefit first-hand from this research dissemination. CPSP attended the second INoPSU meeting in April 2002 in York, England, at which time Canada (Dr. Victor Marchessault) was acclaimed the new convenor effective April 2003 and Andrea Medaglia, CPSP Senior Coordinator, the new secretary. The mission and aims of INoPSU are provided in Appendix 2.

The CPSP has promoted national programs and international studies and comparisons at

- The International Paediatric Association (IPA) meeting in Beijing, China, September 2001
- Royal College of Paediatrics and Child Health meeting in York, England, April 2002
- Canadian National Immunization Conference in Victoria, British Columbia, December 2002
- Child and Youth Health 2003: 3rd World Congress, Vancouver, British Columbia, May 2003
- The Irish and American Paediatric Society, Ottawa, Ontario, September 2003
- European Society of Paediatric Research meeting in Bilbao, Spain, September 2003
- Europaediatrics 2003 meeting in Prague, The Czech Republic, October 2003

The CPSP has assumed a leadership role in developing and submitting a formal proposal to the IPA for a scientific session on INoPSU at the meeting in Cancun, August 2004.

CPSP EVALUATION

The CPSP decided to undertake an evaluation of the surveillance program to determine whether it meets its objectives. Other, similar, paediatric surveillance systems operating in Australia and Britain have already conducted or are considering an evaluation. The Australian Paediatric Surveillance Unit (APSU) commenced operations in May 1993 and was modelled on the British Paediatric Surveillance Unit. In 1997, the APSU formally evaluated its program to assess whether it fulfilled stated objectives2 and conformed to guidelines developed by the U.S. Centers for Disease Control and Prevention (CDC) for evaluating surveillance systems3. The APSU evaluation concluded that the support of professional paediatric bodies, the simplicity of the reporting scheme, the low workload for clinicians, and the educational value and relevance for clinical practice accounted for the high compliance within these schemes. The APSU is interested in redoing its program evaluation in conjunction with CPSP. The British Paediatric Surveillance Unit has expressed interest in undertaking a similar program evaluation early in 2004.

Objectives of the Evaluation

The objectives were as follows:

- To determine how well the CPSP is achieving its objectives and goals;
- To assess the costs and effectiveness of the program in comparison with other similar surveillance programs;
- To assess how well the CPSP functions relative to CDC criteria for surveillance programs;
- To afford CPSP participants and researchers the opportunity to provide feedback;
- To determine whether the CPSP is meeting the needs of various target groups, including researchers and paediatricians;
- To assess the "public health worth" of the CPSP: Does the information collected by the CPSP have the potential to change public health policies?
- To assess the effectiveness of the CPSP Steering Committee;
- To identify opportunities for improvement.

Methods

The evaluation process consisted of the following components:

- The establishment of an Evaluation Working Group comprising members of the CPSP Working Group, two members of the CPSP Steering Committee and an epidemiologist hired "on contract";
- The development of logic models to gather background material, to identify critical questions and to illustrate short- and long-term outcomes;
- The establishment of an EAG to oversee the evaluation and formulate recommendations;
- A mail-out of questionnaires to CPSP participants, principal investigators, CPSP Steering Committee members and public health policy makers;
- Data analysis using the CDC criteria for evaluating public health surveillance systems as a template.

Development of Logic Models

The evaluation process was initiated with the development of logic models to gather background material and identify critical questions. Most programs share common elements, and a logic model is a diagram of these common elements, showing what the program is supposed to do, with whom and why. Components are groups of closely related activities in a program. Activities are the operations the program conducts to work toward its desired outcomes. Target

groups are the individuals, groups or communities at whom the program's activities are directed. Outcomes are the changes the program hopes to achieve. These are differentiated between short-term and long-term outcomes. Development of the logic models for the CPSP evaluation was guided by the program evaluation tool kit produced by the Ottawa-Carleton Health Department4. Logic models were established to illustrate short- and long-term outcomes in three key areas: the initiation of a study (Figure 2), the surveillance process (Figure 3) and the impact of information dissemination (Figure 4).

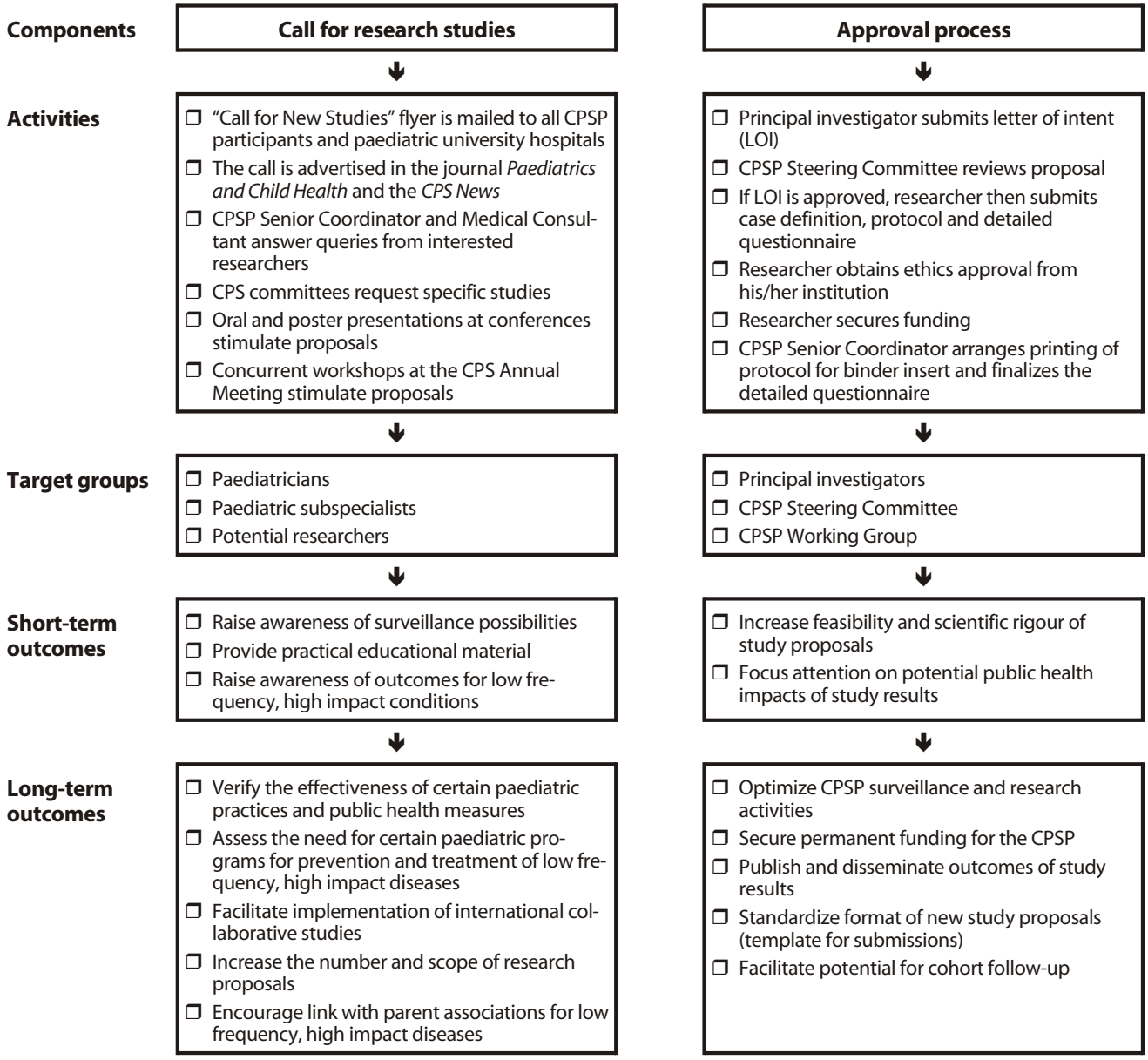
Establishment of the Expert Advisory Group

An EAG was formed in the spring of 2003 to collaborate with the CPSP Evaluation Working Group and the Steering Committee on the evaluation objectives, the design of the evaluation methodology, review of the findings, and development of recommendations. The members of the EAG are listed in Appendix 3. The terms of reference of the EAG were as follows:

- To provide advice on the evaluation objectives in concert with the CPSP Working Group;
- To provide advice on the design of the evaluation methodology in collaboration with the CPSP Working Group and the CPSP Steering Committee;
- To provide advice on the four questionnaires (CPSP participants, CPSP principal investigators, CPSP Steering Committee members and public health policy makers);
- To participate in conference calls as required;
- To attend one face-to-face meeting to review the findings of the surveys and to make recommendations;
- To seek clarification and additional information on CPSP as needed;
- To submit a final report to the CPSP Steering Committee outlining the strengths and weaknesses, including recommendations for improvement.

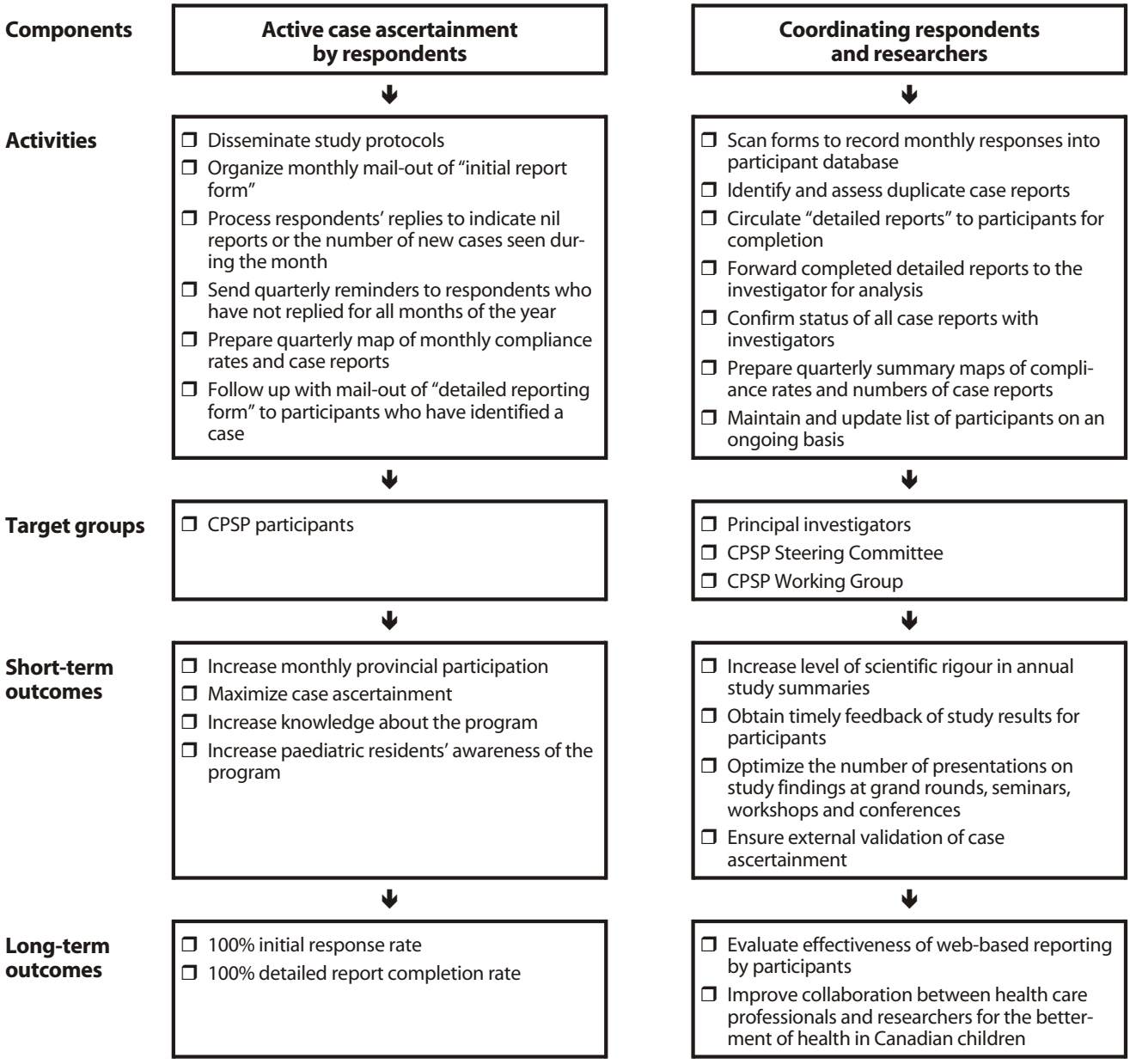
The EAG met for a one-day, face-to-face meeting on September 18, 2003, at which members of the CPSP Evaluation Working Group presented an overview of the program together with findings from the surveys. One half day was given to the EAG for deliberation and formulation of recommendations. The Chair of the EAG presented the final report to the Steering Committee at its meeting in November 2003.

Figure 2: Logic model for the initiation of a study



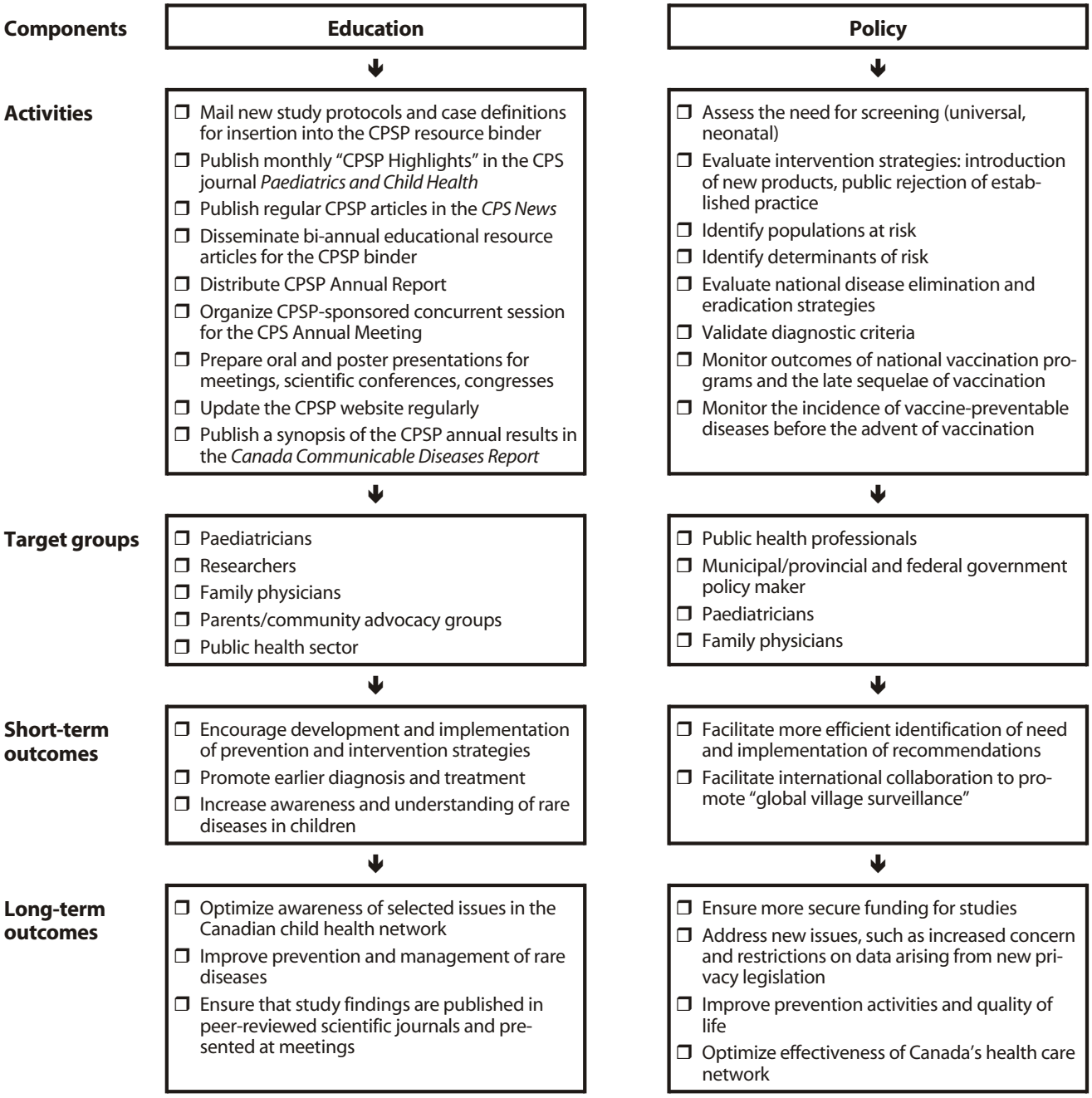
Steps taken to achieve short- and long-term outcomes are listed in Appendix 4.

Figure 3: Logic model of the surveillance process



Steps taken to achieve short- and long-term outcomes are listed in Appendix 4.

Figure 4: Logic model of the impact of information dissemination



Steps taken to achieve short- and long-term outcomes are listed in Appendix 4.

Survey Instruments

Questionnaires, each tailored to its respective group (see Appendix 5), were sent to paediatricians participating in the CPSP (n = 2326), principal investigators (n = 56), current and past Steering Committee members (n = 34) and public health professionals (n = 56), including decision-makers at Health Canada, Chief Medical Officers of Health, provincial epidemiologists, the Working Group on Polio Eradication, and non-governmental organizations. The questionnaires were adapted from those used in APSU's evaluation and incorporated qualitative and quantitative measures of how well the CPSP meets its purpose and objectives.

Criteria for Analysis

The data obtained from the survey were analyzed according to CDC criteria (Table 1) for evaluating public health surveillance systems. Alternative sources of data were used to validate case ascertainment and to assess the sensitivity of the CPSP.

Table 1: CDC criteria for evaluating public health surveillance systems

Describe the surveillance system to be evaluated
Describe the public health importance of the health-related event under surveillance
Describe the purpose and operation of the system
Describe the resources used to operate the system
Gather credible evidence regarding the performance of the surveillance system
Indicate the level of usefulness
Describe system attributes
Simplicity
Flexibility
Data quality
Acceptability
Sensitivity
Positive predictive value
Representativeness
Timeliness
Stability

Results

Questionnaires

The response rates to the questionnaires were as follows: 1105 participants (47%), 24 investigators (45%), 24 Steering Committee members (71%) and 26 public health professionals (46%). A detailed summary of the survey results can be found in Appendix 6.

Analysis by CDC Framework

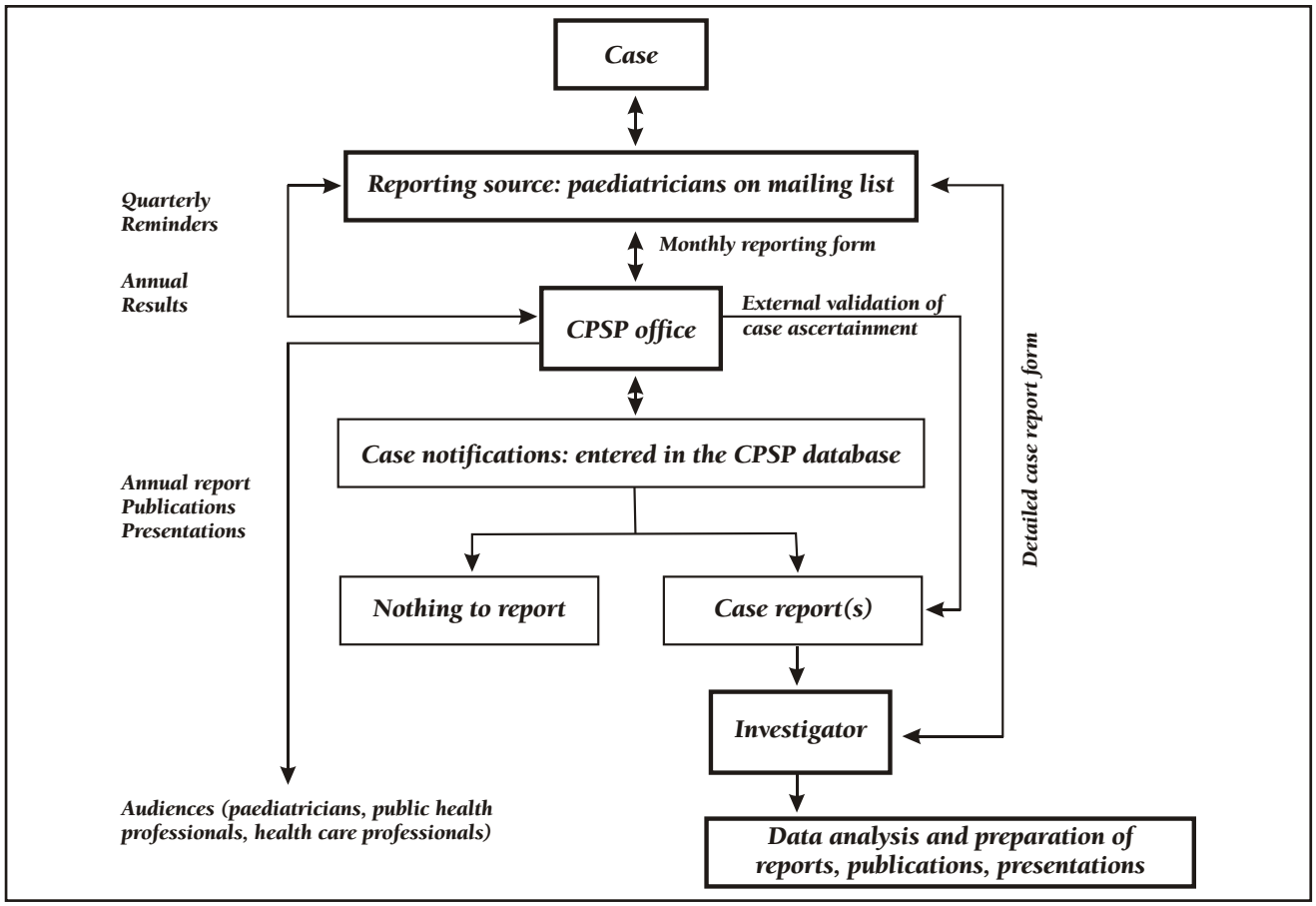
Public health importance: Steering Committee members assess new research proposals according to six criteria, as follows:

- rarity – fewer than 1000 cases per year
- paediatric and public health importance
- scientific importance
- uniqueness
- quality of proposal
- workload for paediatricians

Two criteria relate to the rarity of the disorders and their public health importance. Disorders considered for study are of such low incidence or prevalence that national case ascertainment is needed (less then 1000 cases per year). The criterion that assesses public health importance is also tied into the scientific importance criterion in that, together, they ensure that study outcomes clearly address a public or paediatric health issue and are of demonstrated scientific interest and importance.

The system: The purpose and objectives of the surveillance system were stated in the Overview of the CPSP .The population under study is Canadian children up to and including 18 years of age. Studies range in duration from one to nine years, with an average of two to three years. The reporting source is

Figure 5: CPSP reporting process



paediatricians/subspecialists on the CPSP mailing list. Case ascertainment is monitored and verified by investigating duplicate reports and comparing data with the programs or centres listed on page 3.

Figure 5 is a simplified flow chart of the surveillance system. The data collected for each condition under study are summarized annually for the CPSP Annual Report. Other educational resources include monthly "*CPSP Highlights*" in the CPS journal *Paediatrics and Child Health*; regular CPSP articles in the *CPS News*; bi-annual educational resource articles for the CPSP binder; CPSP-sponsored concurrent sessions at the CPS annual meetings; oral and poster presentations for meetings, scientific conferences, and congresses; regular updates to the CPSP website; and a synopsis of the CPSP annual results in the *Canada Communicable Disease Report*.

Resources used to operate the system: The CPSP is funded by a contract awarded by Public Works and Government Services Canada on behalf of Health Canada to the CPS. The contract includes the salaries of the CPSP Senior Coordinator (full-time), Medical Affairs Officer (part-time), CPSP Administrative Assistant/Clerk (full-time), the cost of the scientific Steering Committee, postage, printing and other administrative costs. The funding covers the cost of maintaining the CPSP database, used to maintain the names of participants and their response information. The funds received from Health Canada are also used to promote the program both nationally – to increase participation and awareness of its contribution to public health – and internationally – to encourage collaboration with other paediatric surveillance programs. Lastly, the funds are used to provide practical information and education concerning the conditions under study, to give feedback to the participants, but also to alert them to significant findings in a timely manner.

Usefulness:

- *Does the system detect trends signalling changes in the occurrence of disease?*

  The surveillance system is not designed to detect outbreaks or epidemics as they occur. There is an inherent delay in reporting, as monthly reporting forms are sent to participants at the end of each month. The research studies do monitor trends in disease incidence, management and outcome over time, as many studies run for multiple years.

- *Does the system provide estimates of the magnitude of morbidity and mortality related to the health problem under surveillance?*

  Detailed assessment of acute and chronic morbidity associated with the conditions under study is available from the clinical information collected. This type of information is often not available from other sources. Study results have provided Canadian baseline incidence for haemolytic uremic syndrome comparable to the Australian data. The true incidence in Canada is often not known for some conditions under study, such as CHARGE association/syndrome and necrotizing fasciitis. The surveillance program provides a unique opportunity to investigate the epidemiology of these conditions.

  Follow-up cohort studies have been undertaken for three CPSP studies.

- *Does the system stimulate epidemiological research likely to lead to control or prevention?*

  Data collected for the study on neonatal herpes simplex virus infection can be used as pre-vaccine baseline data to define the burden of illness in Canada, promote prevention, develop program strategies and enhance future research. The one-time survey question on lap-belt injuries confirmed that lap-belt syndrome occurs and that study data are needed to determine, first, whether these injuries are frequent enough to necessitate a review of child restraints in motor vehicles and, second, whether prevention strategies need to be re-evaluated.

- *Does the system identify risk associated with disease and/or lead to identification of prevention strategies?*

  Preliminary results from the study on vitamin D-deficiency rickets have identified a subset of Canadians who are at particular risk of nutritional rickets. Further study is needed to assist with the development of public health policies to prevent nutritional rickets in children living

in Canada. The study on congenital rubella syndrome identified the need for standing orders for vaccination of all rubella-susceptible women in the immediate postpartum period.

- *Does the system lead to improved clinical practice by health care providers who are the constituents of the surveillance system?*

  Seventeen percent of responding clinicians reported using the educational materials to change clinical practice. Clinicians who had previously reported a case to the CPSP were twice as likely to report that study-related materials changed their clinical practice. Sixty-eight percent found that study protocols were helpful, and 62% found the biannual educational resource articles helpful. Eighty percent of clinicians were aware of the CPSP Annual Report. To date, publications containing CPSP data or describing the system include 28 peer reviewed articles, two annotations, 37 posters, and 27 CPSP Highlights.

- *Has the system led to changes in public health policy?*

  Twenty-three (88%) of the public health professionals who responded to the survey had heard of the CPSP prior to this evaluation. Of those who had heard of the program, 86% (n = 18) were aware of results. Approximately 32% (n = 6) used the results to evaluate public policy, 47% (n = 9) used them to provide a basis for future research, 71% (n = 14) for guidance in the planning, implementation and evaluation of programs, 70% (n = 14) for other uses, such as guiding immediate action of public health importance, and 60% (n = 12) used them for continuing professional development and maintenance of competence.

- *Has the CPSP provided a mechanism for national collaborative research?*

  Of the 11 studies on the monthly reporting form in 2002, six had co-investigators from a different centre.

  Ninety-five percent of investigators felt that their research question could not have been answered without national case ascertainment, and 68% felt that their research could not have been undertaken nationally (i.e. through another mechanism) without the CPSP.

  International collaborative research opportunities are available through INoPSU. Sixty-five percent of investigators felt that the CPSP provided information to enable possible collaboration with investigators from other INoPSU countries.

System attributes:

- *Simplicity*

  The reporting process for the CPSP is simple (Figure 5). The monthly reporting form is easy to complete and only requires that clinicians indicate the number of cases, if any, seen in the previous month. Reporting forms are postage-paid. Paid postage seems to be an incentive to returning the forms: only 41% said that they would return the form if it was not postage-paid.

  Ninety-six percent of respondents returned most or all monthly reporting forms and almost half reported at least one case; of these, 47% reported more than one. The follow-up study questionnaire was considered easy to complete by 80% of those who had reported a case. Eighty-three percent felt that the case-specific information was generally available. There were comments about the amount of detailed information required and the length of study questionnaires. Difficult access to hospital records hindered timely completion.

- *Flexibility and timeliness*

  Changes to the monthly reporting form can occur in a one-month period for urgent public health issues. Researchers have an alternative to the monthly reporting format. Periodic surveys can be sent to clinicians with just one question. The most recent survey question had a response rate of 53%. The amount of time between first submission of a new study proposal and implementation is, on average, 10 months.

  Ninety-two percent of clinicians were willing to report cases by telephone or fax if an important public health reason were to be provided. Interest has been expressed in using an

electronic format for reporting. A large proportion of respondents (67%) stated that they would be willing to respond monthly by e-mail or a web-based tool.

- *Acceptability*

  The overall initial response rate has increased since the program began in 1996 and was at 83% in 2002. The voluntary completion rate for detailed questionnaires is much higher, at 95% for 2002.

  Ninety percent of those who reported a case did not hesitate to provide clinical information for research conducted through the CPSP. At the time of the survey, nine conditions were on the monthly reporting form. Seventy percent of respondents thought that the number of conditions on the form should stay the same. Ten percent of clinicians had considered conducting a study through the CPSP. The majority of investigators (94%) stated that their CPSP study met their stated study objectives.

- *Sensitivity*

  Sensitivity refers to the proportion of cases of a disease (or other health-related event) detected by a surveillance system. Only 3% of respondents who had known of a case returned the form without reporting it, and an even smaller number (2%) knew of a case but did not return the form. To estimate the sensitivity of the CPSP, cases were ascertained from alternative sources. With the exception of cases of hepatitis C virus infection, the sensitivity ranged from 89% to 100% (congenital rubella syndrome, cerebral edema in diabetic ketoacidosis, Creutzfeldt-Jakob disease, acute flaccid paralysis).

  - Congenital rubella syndrome (CRS)

    From January 1996 to December 2002, there were nine new cases of CRS in Canada: eight (89%) were reported to the CPSP and to the Notifiable Diseases Reporting System (NRDS), while one was reported to NDRS only in 1996. Additionally, another case was reported to the CPSP only. Since 1997, the CPSP has notified provincial authorities of all CRS case reports because it is a statutorily notifiable disease in Canada.

    Sensitivity: 89%

  - Cerebral edema in diabetic ketoacidosis (CE-DKA)

    From July 1999 to June 2001, 23 cases of CE-DKA were reported to CPSP. The investigators excluded eight additional cases that were reported to CPSP because they did not meet the case definition. CPSP case ascertainment was compared with cases reported to the Hospital Discharge Abstract Database of the Canadian Institute of Health Information (CIHI): only 13 cases identified by the CPSP were also identified by the CIHI database. The investigators undertook a chart review of all cases of CE-DKA at three paediatric hospitals. A health record technologist re-abstracted information from original records. The accuracy of administrative and demographic data was 95% or higher. Furthermore, the agreement for most responsible diagnosis ranged from 75% to 96%. The investigators had previously reported an 83% accuracy in discharge codes for CE-DKA that were used for the CIHI database.

    Sensitivity: 100%

  - Creutzfeldt-Jakob disease (CJD)

    One case of iatrogenic Creutzfeldt-Jakob disease was reported to the CPSP during the duration of the study, from July 1999 to June 2001. This case was reported to the CPSP by five separate paediatricians and was also reported to the Canadian CJD-Surveillance System of Health Canada.

    Sensitivity: 100%

  - Acute flaccid paralysis (AFP)

    The AFP reporting rate has improved since the introduction of paediatrician-based reporting through the CPSP from 0.5 cases per 100 000 children less than 15 years in 1996 (30 cases) to 1.04 cases per 100 000 in 2000 (61 cases). Forty three (43) cases were reported to the

CPSP in 2002. All cases were hospitalized; accordingly, case-ascertainment was compared with cases ascertained by IMPACT and by the Hospital Discharge Abstract Database using the ICD-10 diagnostic codes for Guillain-Barré syndrome, poliomyelitis, late effects of poliomyelitis and "other" demyelinating diseases of the central nervous system, which includes transverse myelitis. The results proved to be inconclusive because many of the cases were coded improperly. AFP was declared a "disease under national surveillance", all cases to be reported through the CPSP, in 2000. No cases of AFP have been reported to the NDRS independent of the cases ascertained by the CPSP since AFP became a condition under national surveillance.

Sensitivity: 100%

- Hepatitis C virus infection (HCV)

  During the surveillance period from February 2001 to January 2003, 58 cases of HCV infection were reported to the CPSP. During the same period, approximately 358 cases were reported to the NDRS. It is important to note that the NDRS results include cases up to 19 years of age, whereas CPSP cases are only up to 18 years of age. The CPSP Working Group and the Steering Committee identified problems with "buy-in" of this study by CPSP participants at the study proposal stage. Problems with buy-in affect case ascertainment because participants are reluctant to report cases. Solutions to the problem were suggested to the principal investigator and were implemented before the study was initiated. However, case ascertainment remained problematic throughout the duration of the study.

  Sensitivity: 16%

- Positive predictive value

  Positive predictive value (PPV) is the proportion of cases reported to CPSP that actually have the health-related event under surveillance. The PPV was calculated in three ways to examine the impact that duplicates and errors had on the rate. Duplicate reports are encouraged because they measure the high degree of acceptance and participation in the program by the participants, an important aspect of active surveillance. However, the inclusion and exclusion of duplicates generate different estimates of PPV. Table 2 shows all cases reported to the CPSP from 1999 to 2002, their status as of August 2003, and the three PPV calculations. With the most liberal method (PPV3), all conditions except two had a PPV above 70%.

Table 2: Positive predictive value (PPV) of cases reported to the CPSP (January 1999 to December 2002)

		Valid reports (*n*)	Invalid reports (*n*)					
Conditions under surveillance	**Total reports**	**Confirmed**	**Duplicates**	**Discards**	**Pending (*n*)**	**PPV1 (%)**	**PPV2 (%)**	**PPV3 (%)**
Acute flaccid paralysis (AFP)	402	218	149	28	7	54	86	91
Anaphylaxis	747	645	7	69	26	86	87	87
CHARGE association/syndrome	137	78	38	20	1	57	79	85
Cerebral edema in diabetic ketoacidosis	44	23	12	9	0	52	72	80
Congenital rubella syndrome (CRS)	17	5	7	5	0	29	50	71
Creutzfeldt-Jakob disease (CJD)	5	1	4	0	0	20	100	100
Hepatitis C virus infection	115	58	15	25	17	50	58	63
Hemolytic uremic syndrome (HUS)	228	140	64	24	0	61	85	89
Hemorrhagic disease of the newborn	8	1	1	5	1	13	14	25
Necrotizing fasciitis	43	24	13	4	2	56	80	86
Neonatal herpes simplex virus infection	103	45	37	16	5	44	68	80
Neonatal hyperbilirubinemia	79	47	10	17	3	59	68	72
Neonatal liver failure/ perinatal hemochromatosis	22	10	6	6	0	45	63	73
Progressive intellectual and neurological deterioration (PIND)	99	61	14	24	0	62	72	76
Smith-Lemli-Opitz syndrome	86	35	32	19	0	41	65	78
Subacute sclerosing panencephalitis	3	2	1	0	0	67	100	100
Vitamin D-deficiency rickets	33	24	5	3	1	73	86	88

PPV1, all valid reports/total reports.
PPV2, all valid reports/(total reports – duplicates).
PPV3, all valid reports + duplicates/total reports.

SUMMARY REPORT OF THE EXPERT ADVISORY GROUP

Dr. R.Y. McMurtry
Chair, Expert Advisory Group for the Evaluation of the Canadian Paediatric Surveillance Program

Preamble

The EAG was created in the spring of 2003 and convened on September 18, 2003. In preparation for the one-day meeting, extensive background material was pre-circulated to the members of the EAG. In addition, a preparatory meeting was held on May 30, 2003, attended by the Chair of the EAG. Finally, the Chair submitted the CPSP Program Evaluation Summary Report to the CPSP Steering Committee on November 21, 2003, presenting the findings of the EAG emanating from the September 18 meeting. This document is the final step in the review process of the EAG.

Overall Comments

The EAG was unanimous in its opinion that the CPSP program represents excellent value for money. The achievement in this respect was seen as excellent and unsurpassed by any comparable program known to the EAG. The CPSP was seen as representing an important collaborative tool for surveillance, research and policy development. In this role, it was perceived as unique in Canada. In other words, without the CPSP an important activity could not continue, unless a much larger investment were made to replace it.

The core activity of providing surveillance of low frequency, high impact conditions affecting children has created a network that reaches into all parts of Canada. This not only generates crucial information about these conditions (CPSP programs are "on target") but it is also a mechanism to provide important public health information quickly and inexpensively on a national basis. Examples include the work on hemorrhagic disease of the newborn, confirming the Canadian recommendation of vitamin K as the gold standard for prevention, and on baby walker injuries, confirming the need for a commercial product safety ban on these devices.

The EAG was impressed by the survey of clinicians (paediatricians), which affirmed a change in practice pattern by some and a high degree of recognition by all. The publications generated by the program also received accolades. The CPSP is encouraged to increase its reach to include nurse practitioners and northern communities and territories.

Finally the EAG underlined the importance of providing more evidence of impact on public health policy and clinical practice. Annual evaluation of the effectiveness of the Steering Committee was also recommended.

Program Objectives

The CPSP has done well with regard to its current objectives. It has initiated programs of national scientific significance and developed an effective surveillance system to monitor the health of Canadian children in relation to low frequency, high impact conditions.

Nonetheless, there may be an advantage to rewording the program objectives to reflect emerging priorities and new realities (e.g. changes in federal leadership, positive changes in federal/provincial/territorial relations).

Some specific wording for the program objectives was suggested as follows:

- to identify important disease conditions for surveillance in order to support paediatricians and public health officials in their role of

contributing to the health and well-being of Canadian children;

- to ensure a strong infrastructure, and to maintain and improve a national and collaborative population-based surveillance system to monitor health in Canadian children;
- to facilitate research into low frequency, high impact childhood disorders for the advancement of knowledge, the enhancement of understanding, and the improvement of treatment, prevention and health care planning.

The EAG commended the CPSP on performing its core function so well and emphasized that important additional roles, such as responding to public health emergencies and international collaboration, may require additional resources.

Evaluation Objectives

The evaluation process was seen as exemplary, and the EAG was impressed with the surveys of the four stakeholder groups and the CDC framework. The responses to the latter were well done and contained both quantitative and qualitative information of value. The logic frameworks provided an interesting context. However, the program *goals* were not seen as serving CPSP well and could be deleted without ill consequence.

The case in support of the excellent value for money represented by the CPSP might be strengthened, especially in view of the new federal fiscal reality that will likely be similar to the Program Review of 1994-95. The EAG is convinced that the case for CPSP's importance can be made and, furthermore, that an effort to duplicate the essential work of the program by another means would be considerably more expensive.

Strategic Issues and Conclusions

The events of 2003 have been characterized by large-scale change and high impacts. All provinces east of Alberta held elections in that year, and new governments were elected in Ontario, Quebec, and Newfoundland and Labrador. Most observers feel that, together with the change in federal leadership, a more collaborative approach at federal/provincial/territorial forums can be anticipated. In addition, a significantly negative economic impact was felt from SARS (severe acute respiratory syndrome) and the case of one animal with BSE (bovine spongiform encephalopathy). Both were low frequency, high impact events, and accordingly both underscore the importance of public health and the crucial need for surveillance.

In the reviewers' opinion, the asset that the CPSP represents is relevant to these realities. It is a national program and an important mechanism for surveillance of human health as observed in the health and well-being of one of the most vulnerable populations in Canada, our children.

CONCLUSIONS AND NEXT STEPS

The objectives of the evaluation process are revisited with reference to the evidence collected and the recommendations made by the EAG.

How well has the CPSP achieved its objectives and goals?

- **Infrastructure**

  In seven years, the CPSP has grown substantially in scope and experience. From an initial pilot project involving three conditions since its inception in 1996, the program has expanded to involve almost 2350 paediatricians or paediatric subspecialists monitoring 22 childhood conditions of national importance. An important component of the CPSP infrastructure is the Steering Committee, responsible for evaluating proposals from investigators. Responses from the survey have shown that 90% of investigators had received written feedback on their proposal from the Steering Committee, and 100% of these found the feedback useful. The EAG has suggested that there be annual evaluation of the Steering Committee's effectiveness, possibly through assessment of *outcomes achieved* vis-à-vis *outcomes desired*, as set out in an action plan. The Steering Committee's membership should also be reviewed on an ongoing basis.

- **Surveillance and research**

  The CPSP has been recognized for its success in identifying and investigating all cases of acute flaccid paralysis, has been able to confirm the importance of giving intramuscular vitamin K to newborn babies for the prevention of hemorrhagic disease of the newborn, and has established incidence rates for important emerging paediatric conditions. One-time surveys have been used to investigate the extent of injuries associated with baby walkers and lap belts. CPSP surveillance results have implications for treatment, prevention and public health measures – for example, the need for vaccination of all rubella-susceptible women in the immediate postpartum period, as demonstrated by the results of the CRS study. Seventy-one percent (71%) of those surveyed had used CPSP information to guide the planning, implementation and evaluation of programs.

- **Awareness and education**

  To increase physicians' awareness and promote their active participation, the CPSP publishes regular "CPSP Highlights" in the journal *Paediatrics and Child Health* of the CPS, articles in the *CPS News*, bi-annual educational resource articles, an Annual Report and a synopsis of the annual results in the *Canada Communicable Disease Report*. Of note is the fact that the *Paediatrics and Child Health* journal is sent to 15 500 paediatricians and family physicians in Canada. The CPSP prepares poster and oral presentations for meetings and scientific conferences, and organizes a CPSP concurrent session during the CPS annual meeting. More than 60% of surveyed respondents found the CPSP study protocols and the bi-annual educational resource articles to be helpful; 70% were aware of, or made use of, the "CPSP Highlights". Clinicians who had previously reported a case to the CPSP were twice as likely to report that study-related materials had changed their clinical practice.

- **Timely responding**

  The ability to respond quickly to public health emergencies involving children and youth is limited by the inherent delay in reporting by means of monthly forms. Nevertheless, there are possible options available for speeding up the reporting process. Survey results showed that 92% of clinicians were willing to report cases by telephone or fax if there was an important public health reason, and 67% would be willing to respond monthly by e-mail or using a web-based application. CPSP one-time survey questions proved to be an innovative and effective mode of information collection with great public health potential.

- **International collaboration**

  The work of the CPSP has been recognized internationally by the PanAmerican Health Organization and the National Institutes of

Health in the United States, which funded a researcher's participation in a multi-centre international study. CPSP representatives actively participate in INoPSU meetings, and collaborative projects with INoPSU countries are both encouraged and ongoing. Survey responses indicated that 65% of investigators believed that the CPSP provided information to allow partnership with investigators from other INoPSU countries.

Overall, the extensive EAG review concluded that the CPSP has met its current objectives. It has initiated programs of national scientific significance and developed an effective surveillance system to monitor the health of Canadian children with respect to low frequency, high impact conditions. Health Canada has an obligation to report on conditions such as poliomyelitis and measles; the EAG determined that the CPSP is not only carrying out core surveillance but it is also doing so very successfully.

What are the costs and effectiveness of the CPSP in comparison with other, similar, surveillance programs?

The CPSP is a timely epidemiological tool that offers excellent value for money: it carries out a core function in national surveillance, demonstrates high sensitivity and response rates, provides an invaluable tool in collaborative research, is recognized internationally as a high-quality program – and accomplishes all this on a small budget. It is a necessary program with no apparent alternative. If it were cancelled and had to be re-started from scratch, the CPSP would be more expensive and cumbersome, especially if each province and territory were asked to undertake the surveillance. In addition, reporting by paediatricians is voluntary, a factor that influences the cost-effectiveness of CPSP. Almost all investigators (95%) reported that their research project could not have been undertaken without national case ascertainment, and 68% felt that it would not have been possible without the CPSP.

The EAG felt that, although an international comparison of CPSP operating costs with those of the other national paediatric surveillance units proved impossible given the different functioning of each unit, it could be argued that financial savings can occur through increased awareness and education resulting in earlier detection and treatment of patients with these conditions.

How well does the CPSP function relative to CDC criteria for surveillance programs?

Use of the CDC framework has demonstrated that the CPSP employs its resources wisely to maintain a surveillance/research tool that is useful, is simple (monthly report forms, pre-paid return postage), acceptable (83% average response rate) and sensitive. It provides a mechanism for collaborative research and has the potential to influence public policy.

Feedback from CPSP participants and researchers

The survey results have been used to evaluate the success of the CPSP in relation to the attributes of the CDC framework, and they have also shown that there is a high level of awareness of the program not only among investigators and participating paediatricians but also among public health professionals (88.5%).

Does the CPSP meet the needs of its various target groups?

In its review, the EAG noted that the program is meeting the needs of researchers and paediatricians. Other groups that would benefit from the information available through the CPSP include primary care physicians and nurse practitioners in Northern Canada and, to some extent, the general public and different levels of government.

Does the information collected by the CPSP have the potential to change public policies?

Most of the studies conducted by the CPSP have had implications for public health policies. For instance, identifying targeted, at-risk populations for vitamin D-deficiency rickets and neonatal hyperbilirubinemia

is a prerequisite for the formulation of new public health policies in this area, and one-time surveys to determine the extent of injuries associated with the use of products for children can be the impetus for change in health policy. Nearly a third of public health professionals who responded to the survey used CPSP results to evaluate public policy, 47% to provide a basis for future research, and 71% for guidance in the planning, implementation and evaluation of programs. The EAG emphasized the importance of documenting tangible changes in public policy resulting from CPSP studies.

How effective is the Steering Committee?

Through the years, the CPSP Steering Committee revised and improved the study inclusion criteria and process. Researchers are now required to clearly outline from the onset the medical and public health expected outcomes of their proposed study and to defend their proposal in oral presentations to the Steering Committee. The ensuing follow-up discussions are always very fruitful in improving end results.

Next Steps

The evaluation identified several challenges for future action that the CPSP Steering Committee needs to consider and prioritize. Important issues to explore include the following:

- **Potential for emergency response**

  To explore its potential as an emergency response mechanism to public health threats, the CPSP should develop an urgent response protocol for fast-tracking a problem that would enable paediatricians to respond within 24 hours. Concomitantly, an urgent response protocol should be developed to explore electronic data reporting within this context.

- **Ability to capture the unique entity of northern Canada**

  Because of the paucity of paediatricians who practise in the Northwest Territories, Nunavut and the Yukon, the CPSP participant list should be expanded to include nurse practitioners and family physicians who provide front-line health care to children in these regions. In addition, the EAG suggested that CPSP should undertake the surveillance of diseases/conditions unique to the North and to the health of First Nation's, such as juvenile diabetes, suicide and substance abuse, and hearing disability.

- **Increased capability of knowledge transfer to specific target audiences**

  CPSP has the potential to educate and change clinical practice and initiate public health action. It should continue its efforts and build on that potential. Surveillance is "knowledge in action". However, to reach this goal, a dissemination action plan must be tailored to ensure that educational materials suit the needs of specific target groups. Different venues and innovative approaches to ensure that this information is transferred will improve the health of children and youth affected by these low frequency, high impact conditions/diseases.

- **International cooperation and collaboration**

  CPSP should encourage Canadian researchers to undertake collaborative studies with member countries of INoPSU and assume a leadership role in supporting other countries in establishing paediatric surveillance units, as the British unit did for Canada.

- **Ongoing commitment to, and participation in, the program**

  To maintain high interest in the paediatric milieu, the CPSP should regularly issue a call for new studies to all, including CPS Committees and Sections and all Paediatric Chairs of Canada. Another avenue to explore would be the encouragement of different government departments to work together in initiating new study proposals. The launch of a bursary for a study led by a young researcher is an endeavour that would go a long way towards promoting the CPSP.

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APPENDIX 1

Membership of the CPSP Steering Committee

Current:

Garth Bruce, MD	Canadian Paediatric Society
Rick Cooper, MD	Paediatric Chairs of Canada
Marie Adèle Davis, MBA	Canadian Paediatric Society
Gilles Delage, MD	Canadian Paediatric Society
Jo-Anne Doherty, MSc	Health Canada
Danielle Grenier, MD	Canadian Paediatric Society
Richard Haber, MD	Canadian Paediatric Society
Susan King, MD	Canadian Paediatric Society
Simon Levin, MD	Canadian Association of Child Neurology
Catherine McCourt, MD	Health Canada
Andrea Medaglia	Canadian Paediatric Society
Paul Muirhead, LL.M.	Consultant
Jeffrey Scott, MD	Council of Chief Medical Officers of Health
Anne M. Summers, MD	Canadian College of Medical Geneticists
Paul Varughese, MD	Health Canada
Wendy Vaudry, MD	IMPACT (Immunization Monitoring Program ACTive)
Lynne J. Warda, MD	Canadian Paediatric Society
Lonnie Zwaigenbaum, MD	Canadian Paediatric Society

Past:

Ronald Barr, MD	Canadian Paediatric Society
Rodney Bergh, MD	Canadian Paediatric Society
Monique Douville-Fradet, MD	Advisory Committee on Epidemiology
Frank R. Friesen, MD	Canadian Paediatric Society
Jack Holland, MD	Paediatric Chairs of Canada
Miriam Kaufman, MD	Canadian Paediatric Society
Daniel Keene, MD	Canadian Association of Child Neurology
Arlene King, MD	Health Canada
Robert Brian Lowry, MD	Canadian College of Medical Geneticists
Victor Marchessault, MD*	Canadian Paediatric Society
Nicole Menzies	Canadian Paediatric Society
Angus Nicoll, MD	British Paediatric Surveillance Unit
Paul Sockett, PhD	Health Canada
Richard Stanwick, MD	Canadian Paediatric Society
Lamont Sweet, MD	Advisory Committee on Epidemiology
John Waters, MD*	Council of Chief Medical Officers of Health
John Watts, MD	Canadian Paediatric Society

*deceased

APPENDIX 2

Mission and Aims of INoPSU

Mission

The mission of INoPSU is the advancement of knowledge of uncommon childhood infections and disorders and the participation of paediatricians in surveillance on a national and international basis so as to achieve a series of benefits.

Aims

- to facilitate communication and cooperation between existing national paediatric surveillance units;
- to assist in the development of new units;
- to facilitate sharing of information and collaboration among researchers from different nations and scientific disciplines;
- to share information on current, past and anticipated studies and their protocols, and on conditions that have been nominated for surveillance but are not selected;
- to encourage the use of identical protocols to potentially enable simultaneous or sequential collection of data on rare paediatric disorders in two or more countries;
- to share and distribute information of educational benefit to constituent units, notably on study and surveillance methodologies;
- to share school techniques and models of evaluation for units;
- to peer review and evaluate existing and proposed units;
- to identify rare disorders of mutual interest and public health importance for cooperative surveys through each national unit;
- to collaborate with and provide information to other groups, such as parent support groups, interested in rare childhood diseases;
- to respond promptly to international emergencies concerning rare childhood conditions to which national and international studies can make a contribution in terms of science or public health.

APPENDIX 3

Membership of the Expert Advisory Group

Dr. Robert McMurtry (Chairperson)
University of Western Ontario

Dr. Margaret Berry
Montreal Children's Hospital

Dr. Jeff Davis
Wisconsin Division of Public Health

Dr. Philippe Duclos
World Health Organization

Dr. Monika Naus
BC Centre for Disease Control

APPENDIX 4

Logic Model Outcomes

Initiation of a research study

	Call for research studies	Approval process
Short-term outcomes	❒ Raise awareness of surveillance possibilities ■ Call for new studies flyer ■ Letters to paediatric department heads ■ Flyers announcing new and concluded studies ■ PCH – July/Aug. 2001 (Call for studies) ■ News – Jan. 2003 (New study suggestions) ■ *CPSP Results 2002* – Call for new studies ❒ Provide practical educational material ■ PCH – Jan. 2002 (HSV) ■ PCH – Mar. 2001 (HCV) ■ Educational resources (CE-DKA) ■ PCH – July 2002 (baby walker survey) ■ PCH – Oct. 2002 (vitamin K) ■ PCH – Feb. 2003 (CRS) ❒ Raise awareness of outcomes of rare conditions ■ Posters (public health implications – CPS annual meeting, Calgary 2003) ■ PCH – Jan. 2003 and Sept 2001 (genetics) ■ PCH – Dec. 2001 (NLF-PH)	❒ Increase feasibility and scientific rigour of study proposals ■ SC study inclusion criteria checklist ■ PCH – Nov. 2001 (surveillance case definitions and clinical diagnoses) ❒ Focus attention on potential public health impacts of study results ■ SC study inclusion criteria checklist ■ PCH – Nov. 2001 (surveillance case definitions and clinical diagnoses)
Long-term outcomes	❒ Verify the effectiveness of certain paediatric practices and public health measures ■ Vitamin K guidelines ❒ Assess the need for certain paediatric programs for prevention and treatment of rare diseases ■ Vitamin D recommendations ❒ Improve treatment and management for patients with rare paediatric conditions ■ CAS, CE-DKA, SLO, kernicterus resources ❒ Facilitate implementation of an international collaborative study ■ EOED and PIND ■ News – May/June 2003 (EOED) ❒ Increase the number and scope of research proposals ■ 3-6-10 studies (1996-2002) ■ News – Sept. 2001 (research opportunities) ❒ Encourage link with parent associations for rare diseases ■ CAS, CE-DKA, PWS, SLO	❒ Optimize CPSP surveillance and research activities ■ ADR monitoring ❒ Secure permanent funding for the CPSP ■ Letters of support ■ Contacts – CPS meetings with HC and other organizations ❒ Publish and disseminate outcomes of study results ■ Annual reports, posters, CPSP Highlights in PCH ■ Concurrent sessions – Apr. 2002, Apr. 2003 (News and PCH) ❒ Standardize format of new study proposals (template for submissions) ■ Format for submissions ❒ Facilitate potential for cohort follow-up ■ CAS, HSV, SLO

ADR: Adverse drug reactions; **AR**: Annual report (*CPSP Results*); **CAS**: CHARGE association/syndrome; **CE-DKA**: Cerebral edema in diabetic ketoacidosis; **CPS**: Canadian Paediatric Society; **CPSP**: Canadian Paediatric Surveillance Program; **CRS**: Congenital rubella syndrome; **EOED**: Early-onset eating disorder; **HC**: Health Canada; **HCV**: Hepatitis C virus infection; **HSV**: Herpes simplex virus infection; **News**: *CPS News*; **NF**: Necrotizing fasciitis; **NLF-PH**: Neonatal liver failure/perinatal hemochromatosis; **PCH**: *Paediatrics and Child Health*; **PIND**: Progressive intellectual and neurological deterioration; **PWS**: Prader-Willi Syndrome; **SC**: Steering Committee; **SLO**: Smith-Lemli-Opitz syndrome.

Logic model outcomes – surveillance process

	Canvassing participants	Coordinating respondents and researchers
Short-term outcomes	❒ Increase monthly response rate nationally ■ News – Jan. 2001 (monthly reporting) ■ News – Nov. 2001 (nil reporting) ■ News – Jan. 2002 (monthly form winner) ■ News – May 2002 (detailed form winner) ■ PCH – Feb. 2001 (complete or toss-in bin?) ■ Flyers (Aug. 2002 +++) ❒ Increase monthly response rate provincially ■ Maps ■ Chairs of Paediatric Departments (letters) and SK department chairs re. response ■ SC members – NL, QC and SK ❒ Increase knowledge about the program ■ PCH – May/June 2001 ■ PCH – Nov. 2002 (polio eradication) ❒ Increase paediatric residents' awareness of the program ■ All residents are CPS members and so receive News, PCH and annual meeting material	❒ Increase level of scientific rigour in annual study summaries ■ Changes in AR format ■ SC editorials (ANAP, HCV, NTD) ❒ Obtain more timely feedback of study results for participants ■ PCH – Dec. 2000 (AFP stool cultures) ■ Baby walker survey results ❒ Increase the number of presentations on study findings at grand rounds, seminars, workshops and conferences ■ List available on Web ■ Concurrent session 2002 (ANAP, CE?DKA) ■ Concurrent session 2003 (CAS, PWS, SLO) ■ Subspecialty meetings (ANAP, CAS, CE?DKA, PIND, SLO) ❒ Ensure external validation of case ascertainment ■ News – Jan. 2001 ■ CPSP Results (Acknowledgements)
Long-term outcomes	❒ 100% initial response rate ■ Improved response (AR table) ❒ 100% detailed report completion rate ■ Improved rate (AR table)	❒ Evaluate effectiveness of web-based reporting by participants ■ E-mail response survey ■ News – Mar. 2002 (new Web site) ■ Web site (protocols, case definitions, educational articles) ❒ Improve collaboration between health care professionals and researchers for the betterment of health in Canadian children ■ increased awareness through study protocols, case definitions, and resource articles

AFP: Acute flaccid paralysis; **ANAP**: Anaphylaxis; **AR**: Annual report (*CPSP Results*); **CAS**: CHARGE association/ syndrome; **CE-DKA**: Cerebral edema in diabetic ketoacidosis; **CPS**: Canadian Paediatric Society; **CPSP**: Canadian Paediatric Surveillance Program; **NL**: Newfoundland and Labrador; **NTD**: Neural tube defects; **PCH**: *Paediatrics and Child Health*; **PIND**: Progressive intellectual and neurological deterioration; **PWS**: Prader-Willi Syndrome; **QC**: Quebec; **SC**: Steering Committee; **SK**: Saskatchewan; **SLO**: Smith-Lemli-Opitz syndrome.

Impacts of information dissemination

	Education	Policy
Short-term outcomes	❒ Encourage development and implementation of prevention and intervention strategies ■ Vitamin K, vitamin D, hyperbilirubinemia ❒ Promote earlier diagnosis and treatment ■ Educational resources (CAS, CE-DKA, SLO) ■ Encourage development and implementation of prevention and intervention strategies ■ CRS, vitamin K, baby walker survey, lap-belt syndrome survey ■ News – Sept. 2000 (vaccines safety) ■ PCH – Mar. 2003 (hyperbilirubinemia) ■ PCH – Dec. 2002 (rickets) ■ PCH – July 2003 (lap-belt syndrome) ❒ Increase awareness and understanding of rare diseases in children ■ PCH – Sept. 2002 (AFP) ■ PCH – Feb. 2002 (new web site) ■ PCH – Jan. 2003 (genetics) ■ News – Jan. 2003 (binder and MOC credits) ■ News – March 2002 (new Web site)	❒ Facilitate more efficient and rapid uptake of recommendations ■ PCH – Oct. 2002 (vitamin K) ■ Poster at CPS annual meeting – June 2002 (vitamin K) ■ PCH – Jan. 2001 (post-partum rubella vaccination) ■ Poster at Canadian National Immunization Conference – Dec. 2002 (CRS) ■ CPS annual meeting 2003 – public health implications of the CPS ❒ Facilitate international collaboration to promote "global village surveillance" ■ News – Nov. 2000 (INoPSU meeting) ■ Poster – International Paediatric Association meeting, Sept. 2001, Beijing, China (CPSP – An epidemiological tool in action) ■ Poster – INoPSU meeting, Apr. 2002, York, England (CRS) ■ Presentations – Royal College of *Paediatrics and Child Health* meeting, Apr. 2002, York, England (CE-DKA and PIND) ■ PCH – Feb. 2003 (CRS) ■ Poster – Irish American Meeting, Sept. 2003, Ottawa – global village
Long-term outcomes	❒ Optimize awareness of selected issues in the Canadian Health Network (CHN) ■ CPSP hyperlinked in CHN Web site, as well as in INoPSU Web site ❒ Improve prevention and management of rare diseases ■ NF, SLO, CAS, ANAP ❒ Ensure study findings are published in peer-reviewed scientific journals and presented at meetings (also see main publication/ presentations list) ■ CPSP annual reports ■ PCH – Apr. 2003 (concurrent session) ■ PCH – Apr. 2002 (concurrent session) ■ News – May 2001 (annual report) ■ News – Mar. 2001 (PCH May/June, surveillance issue)	❒ Ensure more secure funding for studies ■ Letters of support ■ CPS meetings with HC ❒ Address new issues, such as increased concerns and restrictions on data arising from new privacy legislation ■ News – Nov 2002 (confidentiality and surveillance) ■ PCH – Oct. 2001 (commitment to patient confidentiality) ■ Ethics workshop – Nov. 2000 ■ Legal issues (delay in ADR study) ❒ Improve prevention and quality of life ■ Baby walker survey ■ Lap-belt syndrome

ADR: Adverse drug reactions; **AFP**: Acute flaccid paralysis; **ANAP**: Anaphylaxis; **CAS**: CHARGE association/ syndrome; **CE-DKA**: Cerebral edema in diabetic ketoacidosis; **CPS**: Canadian Paediatric Society; **CPSP**: Canadian Paediatric Surveillance Program; **CRS**: Congenital rubella syndrome; **HC**: Health Canada; **INoPSU**: International Network of Paediatric Surveillance Units; **MOC**: Maintenance of certification; **News**: *CPS News*; **NF**: Necrotizing fasciitis; **PCH**: *Paediatrics and Child Health*; **PIND**: Progressive intellectual and neurological deterioration; **SLO**: Smith-Lemli-Opitz syndrome.

APPENDIX 5

Survey Questionnaires

Canadian Paediatric Surveillance Program Evaluation Survey – Public Health

The Canadian Paediatric Society and Health Canada are evaluating the Canadian Paediatric Surveillance Program (CPSP).

The purpose of this survey is to determine how well the CPSP interfaces with public health professionals to achieve its objectives.

Q1. The broad category that best describes your area of work is (circle one number):

1 PUBLIC HEALTH (POLICY DEVELOPMENT) **2** INFECTIOUS DISEASE MONITORING

3 NON-GOVERNMENTAL AGENCY **4** OTHER – please specify: _____

Q2. How much of your total involvement in health has to do with children and youth?

1 < 25% **2** 24-49% **3** 50-74% **4** 75-100%

Q3. Had you heard of the Canadian Paediatric Surveillance Program prior to receiving this questionnaire?

1 YES **2** NO

If NO, you do not need to answer any further questions. THANK YOU FOR YOUR TIME.
Please return this survey to the CPSP in the envelope provided. For information on the CPSP, go to: www.cps.ca/english/cpsp

Q4. Listed below are some of the information sources that publish CPSP study findings and program updates. Please indicate, for each information source, whether you have received or accessed the source (circle one number for each information source).

	NEVER	SOME	OFTEN	DON'T RECEIVE OR ACCESS
a. CPS JOURNAL *PAEDIATRICS AND CHILD HEALTH*	1	2	3	4
b. *CPS NEWS*	1	2	3	4
c. CPSP ANNUAL REPORT (RESULTS)	1	2	3	4
d. CONCURRENT SESSION AT THE CPS ANNUAL MEETING	1	2	3	4
e. SCIENTIFIC MEETINGS, CONFERENCES AND CONGRESSES	1	2	3	4
f. CPSP WEBSITE (http://www.cps.ca/english/cpsp)	1	2	3	4
g. *CANADA COMMUNICABLE DISEASE REPORT*	1	2	3	4

Q5. Are you aware of the results of CPSP studies?

1 YES – please specify: _____

2 NO

Q6.	**Have you used information from research conducted through the CPSP:**		
	(Circle one number for each answer.)	**YES**	**NO**
	a. to evaluate public policy?	1	2
	b. to provide a basis for future research?	1	2
	c. to guide the planning, implementation and evaluation of programs?	1	2
	d. for other uses, such as guiding immediate action of public health importance?	1	2
	e. for continuing professional development and maintenance of competence?	1	2

Q7. Do you have suggestions for future CPSP studies?

1 YES – please specify: _____

2 NO

Q8. Please provide any comments or suggestions for ways the CPSP could be improved to meet public health objectives.

Thank you for taking the time to complete this survey.
Please return to the CPSP in the enclosed envelope.

Canadian Paediatric Surveillance Program Investigators' Evaluation Survey

The Canadian Paediatric Society and Health Canada are evaluating the Canadian Paediatric Surveillance Program (CPSP).

The purpose of this survey is to determine how well the CPSP interfaces with public health professionals to achieve its objectives.

Q1. You are/were the:

1 CPSP PRINCIPAL INVESTIGATOR **2** CPSP CO-INVESTIGATOR

Q2. Investigators for your study were from:

1 ONLY ONE CENTRE **2** DIFFERENT CENTRES

Q3. When you were developing your proposal, did you:

	YES	NO
a. have informal conversations and/or meetings with CPSP staff?	**1**	**2**
If yes, was this useful?	**1**	**2**
b. receive written feedback from the CPSP Steering Committee?	**1**	**2**
If yes, was this useful?	**1**	**2**
c. receive independent reviewers' comments?	**1**	**2**
If yes, was this useful?	**1**	**2**

Q4. Could your research have been completed with meaningful results without national case ascertainment?

1 YES – please describe: _____

2 NO **3** DON'T KNOW

Q5. Could your research study have been undertaken nationally without the CPSP (i.e., through another mechanism)?

1 YES **2** NO

Q6. Has surveillance through the CPSP resulted in a modification of your original case definition?

1 YES **2** NO

Q7. As you are aware, to ensure high-response rates from paediatricians, the CPSP recommends short questionnaires.

a. Did the questionnaire for your study provide adequate information to fulfill your study aims?

1 YES **2** NO

b. Could you have obtained adequate information with a shorter questionnaire?

1 YES **2** NO

c. The CPSP staff identifies duplicate cases and does not forward questionnaires to subsequent reporting physicians. Would you like to receive duplicate detailed reporting forms?

1 YES **2** NO

Q8. Did your CPSP study meet your stated study objectives?

1 YES **2** NO – please specify: _____

Q9. **Is or was your CPSP study worthwhile in terms of:**

(Circle one number for each statement.)	STRONGLY DISAGREE	MILDLY DISAGREE	NEITHER AGREE NOR DISAGREE	MILDLY AGREE	STRONGLY AGREE
a. your professional development?	1	2	3	4	5
b. contributing to medical literature?	1	2	3	4	5
c. evaluating current medical management/policy?	1	2	3	4	5
d. informing future medical management/policy?	1	2	3	4	5
e. contributing to prevention policy?	1	2	3	4	5

Q10. **As a researcher, how often do you review your CPSP study data?**

1 AS QUESTIONNAIRES ARRIVE 2 QUARTERLY 3 ANNUALLY 4 STUDY COMPLETION

Q11. **Have you published your completed study results?**

1 YES 2 NO – please specify: _____

Q12. **Do you think the CPSP fee for doing a study was reasonable?**

1 YES 2 NO

Q13. **Did the CPSP provide information to enable possible collaboration with investigators from other International Network of Paediatric Surveillance Units (INoPSU)?**

1 YES 2 NO

Q14. **List ways in which the CPSP could improve the study approval process:**

Q15. **List ways in which the CPSP could increase awareness of the research opportunity that the surveillance program provides:**

Q16. **Please list the advantages/disadvantages of case ascertainment through the CPSP as compared to other alternatives.**

Advantages:

Disadvantages:

Q17. **Any further comments?**

Thank you for taking the time to complete this survey.
Please return to the CPSP in the enclosed envelope.

Canadian Paediatric Surveillance Program Participants' Evaluation Survey

The Canadian Paediatric Society and Health Canada are evaluating the Canadian Paediatric Surveillance Program (CPSP).

The purpose of this survey is to determine how well the CPSP interfaces with public health professionals to achieve its objectives.

Section 1

Q1. **CPSP provides program participants with study protocols, case definitions and biannual educational resource articles. How useful is this material (circle one number for each type of material)?**

Study protocols (case definitions)	**1** NO HELP AT ALL **2** SLIGHTLY HELPFUL **3** FAIRLY HELPFUL **4** VERY HELPFUL	**Biannual educational resource articles**	**1** NO HELP AT ALL **2** SLIGHTLY HELPFUL **3** FAIRLY HELPFUL **4** VERY HELPFUL

Q2. **Have the study-related materials changed your clinical practice (circle a number)?**

1 YES – please specify: _____

2 NO

Q3. **Listed below are some of the information sources that publish CPSP study findings and program updates. Please indicate, for each information source, whether you have received or accessed the source (circle one number for each information source).**

	NEVER	SOME	OFTEN	DON'T RECEIVE OR ACCESS
a. CPS JOURNAL *PAEDIATRICS AND CHILD HEALTH*	1	2	3	4
b. *CPS NEWS*	1	2	3	4
c. CPSP ANNUAL REPORT (*RESULTS*)	1	2	3	4
d. CONCURRENT SESSION AT THE CPS ANNUAL MEETING	1	2	3	4
e. SCIENTIFIC MEETINGS, CONFERENCES AND CONGRESSES	1	2	3	4
f. CPSP WEBSITE (http://www.cps.ca/english/cpsp)	1	2	3	4
g. *CANADA COMMUNICABLE DISEASE REPORT*	1	2	3	4

Q4. **What proportion of the CPSP monthly forms that you have received have you returned (circle one number)?**

1 ALL **2** MOST **3** SOME **4** NONE

Q5. **Would you return the form if it was *not* postage-paid?**

1 YES **2** NO

Q6. **Do you think the number of conditions on the form should:**

1 INCREASE **2** STAY THE SAME **3** DECREASE

Q7. **Are you aware that the CPSP collects only non-nominal, non-identifiable data?**

1 YES **2** NO

Q8. **Have you ever known of a case but returned the form without reporting it?**

1 YES **2** NO

Q9. **Have you ever known of a case and *not returned* the form?**

1 YES **2** NO

Q10. Have you considered conducting a study through the CPSP?

1 YES – please specify condition: _____
2 NO

Q11. The broad category that best describes your clinical practice is:

1 GENERAL PAEDIATRICS 2 SUBSPECIALTY PAEDIATRICS – please specify: _____

Q12. Do you report as:

1 AN INDIVIDUAL PARTICIPANT 2 A MEMBER OF A GROUP

Q13. Would you be willing to report cases by phone/fax if an important public health reason was provided?

1 YES 2 NO

Q14. Do you have access to e-mail?

1 YES 2 NO

Q15. Would you be willing to respond monthly by e-mail or web-based tool?

1 YES 2 NO

Q16. Do you have any other comments or suggestions for improving the CPSP?

Q17. How many cases have you reported to the CPSP?

1 0 CASES 2 1 CASE 3 2 CASES 4 ≥ 3 CASES – How many? _____

IF YOU NEVER REPORTED A CASE to the CPSP, you do not need to answer any further questions.
Please return this survey to the CPSP in the envelope provided
THANK YOU FOR YOUR TIME.

Section 2 Please complete only if you have ever reported cases to the CPSP

Q1. Was the questionnaire easy to complete?

1 YES 2 NO – please specify study: _____

Q2. Was the case-specific data generally available?

1 YES 2 NO – please specify study: _____

Q3. Do you have any hesitation providing clinical information to research conducted through the CPSP?

1 YES – please specify study: _____ 2 NO

Q4. Do you have any comments or suggestions for improving response time for questionnaires?

Thank you for taking the time to complete this survey.
Please return to the CPSP in the enclosed envelope.

Canadian Paediatric Surveillance Program
Steering Committee Evaluation Survey

The Canadian Paediatric Society and Health Canada are evaluating the Canadian Paediatric Surveillance Program (CPSP).

The purpose of this survey is to determine how well the Steering Committee functions to achieve its ojectives.

Q1. Are you a current or past Steering Committee member?

1 PAST **2** CURRENT

Q2. Which group do you represent? (circle one number)

1 CPS MEMBER **2** HEALTH CANADA **3** PROVINCIAL PUBLIC HEALTH
4 ACADEMIC **5** OTHER

Q3. Are meetings twice a year adequate to decide on projects and review the previous year's program?

1 YES **2** NO

Q4. How would you rate the format of the meetings?

	VERY USEFUL	USEFUL	NOT USEFUL
a. PRESENTATIONS OF PROPOSALS	**1**	**2**	**3**
b. REVIEW OF LETTERS OF INTENT	**1**	**2**	**3**
c. PRESENTATION OF STUDY FINAL RESULTS	**1**	**2**	**3**

Q5. Are the meeting arrangements adequate?

1 YES **2** NO – please specify: _____

Q6. How would you rank the mix of committee members in relation to providing feedback to investigators?

1 POOR **2** FAIR **3** GOOD **4** EXCELLENT

Q7. Is there an agency or group that is not currently represented on the committee that should have a seat?

1 YES – please specify: _____
2 NO

Q8. Do you find the meeting materials adequate and appropriate?

1 YES **2** NO

Q9. Do you review the study proposal and complete the study inclusion criteria evaluation form prior to the meeting?

1 YES **2** NO

Q10. Are the criteria for study inclusion appropriate?

1 YES **2** NO – please specify: _____

Q11. How would you rank the process for study inclusion?

1 POOR **2** FAIR **3** GOOD **4** EXCELLENT

Q12. **How would you rank the quality of the proposals that are submitted?**

1 POOR **2** FAIR **3** GOOD **4** EXCELLENT

Q13. **In your opinion, do the majority of study proposals fit the aims/objectives of the CPSP?**

1 YES **2** NO – please specify: _____

Q14. **Does the committee chair allocate enough time for group discussion on each research proposal?**

1 YES **2** NO

Q15. **Does a live presentation by the principal investigator improve your understanding of the proposed study and impact on your decision to approve/disapprove?**

1 YES **2** NO

Q16. **Does the group discussion following proposed study presentations provide you with additional insight?**

1 YES **2** NO

Q17. **What suggestions do you have for improving participation rates?**

Q18. **Do you have any suggestions for improving the working of the Steering Committee?**

Q19. **Do you have any other comments or suggestions for improving the CPSP?**

Thank you for taking the time to complete this survey.
Please return to the CPSP in the enclosed envelope.

APPENDIX 6

Survey results

Participants

Response rate: 47.5% (1105/2326)

Section 1

Q1. CPSP provides program participants with study protocols, case definitions and biannual educational resource articles. How useful is this material (circle one number for each type of material)?

	No Help at all	Slightly Helpful	Fairly Helpful	Very Helpful
Study protocol *n* = 1043	69 (6.6%)	267 (25.6%)	444 (42.6%)	263 (25.3%)
Biannual educational resource articles *n* = 934	64 (6.9%)	292 (31.2%)	385 (41.1%)	193 (20.8%)

Q2. Have the study-related materials changed your clinical practice?

	***n* = 1019**
Yes	170 (16.7%)
No	858 (83.3%)

Comment	*n* (%)
Increase alertness/awareness	62 (47%)
Diagnostic criteria	17 (13%)
Specimens/testing	8 (6%)
Management/therapy	7 (5%)
Education	2 (1%)
Miscellaneous responses	36 (27%)

Q3. Level of awareness/use of CPSP information sources

	Never	Some	Often	Don't Receive or Access
CPSP Highlights in the CPS journal *Paediatrics and Child Health** (*n* = 1075)	59 (5.5%)	227 (21.1%)	742 (69.0%)	47 (4.4%)
CPS News (CPSP article)* (*n* = 1044)	141 (13.5%)	354 (33.9%)	441 (42.2%)	108 (10.3%)
CPSP Annual Report (Results) (*n* = 1056)	160 (15.2%)	460 (43.6%)	385 (36.5%)	51 (4.8%)
Concurrent session at the CPS annual meeting* (*n* = 1028)	446 (43.4%)	339 (33.0%)	86 (8.4%)	157 (15.3%)
Scientific meetings, conferences and congresses (*n* = 1043)	295 (28.3%)	481 (46.1%)	174 (16.7%)	93 (8.9%)
CPSP Website (*n* = 1042)	441 (42.3%)	353 (33.9%)	103 (9.9%)	145 (13.9%)
Canada Communicable Disease Report (*n* = 1044)	304 (29.1%)	444 (42.5%)	149 (14.3%)	147 (14.1%)

** sent to CPS non-members*

Q4. What proportion of the CPSP monthly forms that you have received have you returned?

	***n* = 1099**
All	749 (68.1%)
Most	304 (27.7%)
Some	36 (3.3%)
None	11 (1.0%)

Q5. Would you return the form if it was not postage-paid?

	***n* = 1079**
Yes	438 (40.6%)
No	641 (59.4%)

Q6. Do you think the number of conditions on the form should?

	***n* = 1045**
Increase	204 (19.5%)
Stay the same	732 (70.0%)
Decrease	109 (10.4%)

Q7. Are you aware that CPSP collects only non-nominal, non-identifiable data?

	***n* = 1086**
Yes	776 (71.3%)
No	312 (28.7%)

Q8. Have you ever known of a case but returned the form without reporting it?

	***n* = 1101**
Yes	37 (3.4%)
No	1064 (96.6%)

Q9. Have you ever known of a case and not returned the form?

	***n* = 1100**
Yes	20 (1.8%)
No	1080 (98.2%)

Q10. Have you considered conducting a study through the CPSP?

	***n* = 1068**
Yes	101 (9.5%)
No	967 (90.5%)

Study suggestions (n = 56)

- ❒ abdominal wall defects
- ❒ acetaminophen toxicity
- ❒ agenesis of the corpus callosum
- ❒ animal bites
- ❒ apnea of prematurity
- ❒ autism/autism spectrum disorders
- ❒ Barth syndrome
- ❒ Batten disease
- ❒ bilirubin encephalopathy
- ❒ brachial paralysis injury
- ❒ child abuse
- ❒ chronic idiopathic urthicaria in children
- ❒ congenital diaphragmatic hernia
- ❒ congenital varicella
- ❒ coronary events on stimulants
- ❒ cytomegalovirus (CMV)
- ❒ death attributable to anorexia nervosa
- ❒ fetal alcohol syndrom
- ❒ firearms related injuries
- ❒ fragile X in girls
- ❒ Friedreich ataxia/spinal amyotrophy
- ❒ Gilles de la Tourette syndrome
- ❒ glycogenesis type IV
- ❒ haemolytic disease of the newborn
- ❒ herpes zoster/varicella immunization
- ❒ histiocytic disorders

- ❒ HIV in-vitro exposure
- ❒ HIV/hepatitis
- ❒ hyponatremia
- ❒ interstitial lung disease/emphysema
- ❒ iron deficiency anaemia in preschoolers/toddlers
- ❒ Kawasaki disease
- ❒ listeria neonatal infection
- ❒ long QT interval/arrhythmia
- ❒ maternal lupus & cardiac arrhythmias
- ❒ migraine
- ❒ myocarditis
- ❒ Munchausen by proxy
- ❒ neonatal diabetes
- ❒ neurological outcome of hypernatremic dehydration
- ❒ obesity in children
- ❒ omphalitis
- ❒ palliative care treatment
- ❒ performance enhancing drugs in teens
- ❒ portal and renal vein thrombosis
- ❒ pyridoxine deficiency
- ❒ rubella panencephalitis
- ❒ Rubenstein-Taybi syndrome
- ❒ shaken baby syndrome
- ❒ SIDS
- ❒ sleep apnea
- ❒ sudden deaths in Prader Willi Syndrome
- ❒ type 1 diabetes/hyperlipidemia
- ❒ unexplained pain
- ❒ white matter disease in aboriginal children
- ❒ withdrawal of life sustaining treatment in newborns

Q11. Identify the broad category that describes your clinical practice.

	***n* = 1091**
General paediatrics	606 (55.5%)
Subspecialty paediatrics	485 (44.5%)

Sub speciality (*n* = 465)**	***n* (%)**
Developmental/behavioural	61 (13%)
Neonatology	59 (12%)
Emergency medicine	41 (9%)
Allergy/asthma	32 (7%)
Endocrinology	25 (5%)
Neurology	23 (5%)
Haematology/oncology	23 (5%)
Infectious diseases	22 (4%)
Cardiology	22 (4%)
Genetics	21 (4%)
Adolescent medicine	16 (3%)
Respiratory	13 (2%)
Miscellaneous (reported less than 10 times)	107 (23%)

*** self selected*

Q12. Do you report as:

	***n* = 1089**
Individual	1019 (93.6%)
Member of a group	70 (6.4%)

Q13. Would you be willing to report cases by phone/fax if an important public health reason was provided?

	***n* = 1085**
Yes	996 (91.8%)
No	89 (8.2%)

Q14. Do you have access to email?

	***n* = 1089**
Yes	980 (90.0%)
No	109 (10.0%)

Q15. Would you be willing to respond monthly by email or web-based tool?

	***n* = 1081**
Yes	727 (67.3%)
No	354 (32.7%)

Q16. Comments

Not presented in this document

Q17. How many cases have you reported to the CPSP?

***n* = 1086**	***n* (%)**
No cases	574 (53%)
One case	269 (25%)
Two cases	151 (14%)
Three or more cases	92 (8%)

Section 2: Participants who have previously reported

Q1. Was the questionnaire easy to complete?

	***n* = 466**
Yes	372 (79.8%)
No	94 (20.2%)

Comments

***n* = 105**	***n* (%)**
Questionnaire too detailed/time consuming	40 (38%)
Had to complete chart review	21 (20%)
Case already report/questionnaire completed	8 (7%)
Miscellaneous responses	36 (4%)

Q2. Was the case-specific data generally available?

	***n* = 451**
Yes	373 (82.7%)
No	78 (17.3%)

Comments – similar to those provided for Q1.

Q3. Do you have any hesitation providing clinical information to research conducted through the CPSP?

	***n* = 471**
Yes	39 (8.3%)
No	432 (91.7%)

Comments

***n* = 22**	***n* (%)**
Need for consent	5 (23%)
Query about ethics approval	3 (13%)
Miscellaneous	14 (64%)

Public health professionals

Response rate: 46% (26/56)

Q1. The broad category that best describes your area of work is:

	***n* = 26**
Public health	13 (50.0%)
Infectious diseases	10 (38.5%)
Non-governmental Agency	0
Other*	3 (11.5%)

** did not specify*

Q2. How much involvement in health of children and youth?

	***n* = 26**
< 25%	10 (38.5%)
25-49%	8 (30.8%)
50-74%	5 (19.2%)
75-100%	3 (11.5%)

Q3. Had you heard of the CPSP prior to receiving this questionnaire?

	***n* = 26**
Yes	23 (88.5%)
No	3 (13.0%)

Q4. Information Sources

	Never	**Some**	**Often**	**Don't Receive or Access**
CPS journal *Paediatrics and Child Health* (*n* = 23)	2 (8.7%)	7 (30.4%)	14 (60.9%)	
CPS News (*n* = 23)	9 (39.1%)	4 (17.4%)	10 (43.5%)	
CPSP Annual Report (Results) (*n* = 23)	6 (26.1%)	3 (13.0%)	14 (60.9%)	
Concurrent session at the CPS Annual Meeting (*n* = 23)	16 (69.6%)	3 (13.0%)	1 (4.3%)	2(13.0%)
Scientific meetings, conferences and congresses (*n* = 23)	9 (39.1%)	11 (47.8%)	2 (8.7%)	1(4.3%)
CPSP Website (*n* = 23)	8 (34.8%)	9 (39.1%)	6 (26.1%)	
Canada Communicable Disease Report (*n* = 23)	1 (4.3%)	5 (21.7%)	17 (73.9%)	

Q5. Are you aware of the results of CPSP studies?

	***n* = 21**
Yes	18 (85.7%)
No	3 (14.3%)

Current selection: q3 = 1

Q5 Awareness of CPSP Studies

- ❑ all of the last 3 years
- ❑ anaphylaxis, AFP
- ❑ annual reports/sought out study
- ❑ by feedback and survey
- ❑ for AFP
- ❑ CPS journal
- ❑ HSV neonatal
- ❑ IMPACT
- ❑ through discussions with colleagues
- ❑ vaccination guide
- ❑ via rapports

Q6. Have you used information from research conducted through the CPSP?

	Yes	**No**
To evaluate public policy (*n* = 19)	6 (31.6%)	13 (68.4%)
To provide a basis for future research (*n* = 19)	9 (47.4%)	10 (52.6%)
To guide the planning, implementation and evaluation of programs (*n* = 21)	15 (71.4%)	6 (28.6%)
For other uses, such as guiding immediate action of public health importance (*n* = 20)	14 (70.0%)	6 (30.0%)
For continuing professional development and maintenance of competence (*n* = 20)	12 (60.0%)	8 (40.0%)

Q7. Suggestions for future studies:

	***n* = 20**
Yes	2 (10.0%)
No	18 (90.0%)

Q8. Comments

PUBLISH IN CJPH

Investigators

Response rate: 45% (24/53)

Q1.

	***n* = 24**
CPSP PI	9 (37.5%)
CPSP Co-Invest	15 (62.5%)

Q2. Investigators for your study were from:

	***n* = 24**
Only one centre	4 (16.7%)
Different centres	20 (83.3%)

Q3. CPSP involvement during proposal development

	Yes	**No**
Have informal conversations and/or meetings with CPSP staff (*n* = 21)	18 (85.7%)	3 (14.3%)
Useful	16 (100.0%)	
Receive written feedback from the CPSP Steering Committee (*n* = 19)	17 (89.5%)	2 (10.5%)
Useful	15 (100.0%)	
Receive independent reviewers' comments (*n* = 18)	12 (66.7%)	6 (33.3%)
Useful	11 (100.0%)	

Q4. Could research have been completed with meaningful results without national case ascertainment?

	***n* = 23**
Yes	
No	22 (95.7%)
Don't know	1 (4.3%)

Q5. Could research have been undertaken nationally without the CPSP (i.e., through another mechanism)?

	***n* = 22**
Yes	7 (31.8%)
No	15 (68.2%)

Q6. Has surveillance through the CPSP resulted in a modification of your original case definition?

	***n* = 22**
Yes	4 (18.2%)
No	18 (81.8%)

Q7a. Did the questionnaire for your study provide adequate information to fulfill your study aims?

	***n* = 23**
Yes	20 (87.0%)
No	3 (13.0%)

Q7b. Could you have obtained adequate information with a shorter questionnaire?

	***n* = 23**
Yes	2 (8.7%)
No	21 (91.3%)

Q7c. The CPSP staff identifies duplicate cases and does not forward questionnaires to subsequent reporting physicians. Would you like to receive duplicate detailed reporting forms?

	***n* = 23**
Yes	9 (39.1%)
No	14 (60.9%)

Q8. Did your CPSP Study meet your stated study objectives?

	***n* = 119**
Yes	18 (94.7%)
No	1 (5.3%)

Specify: DATA COLLECTION NOT STARTED
PROGRAM IN STUDY DESIGN
PROBLEM IN STUDY DESIGN
STILL ONGOING

Q9. CPSP study worthiness

	Strongly disagree	Mildly disagree	Neither agree nor disagree	Mildly agree	Strongly agree
Your professional development (*n* = 21)			2 (9.5%)	6 (28.6%)	13 (61.9%)
Contributing to medical literature (*n* = 21)				7 (33.3%)	14 (66.7%)
Evaluating current medical management/policy (*n* = 21)			1 (4.8%)	10 (47.6%)	10 (47.6%)
Informing future medical management/policy (*n* = 21)			4 (19.0%)	5 (23.8%)	12 (57.1%)
Contributing to prevention policy (*n* = 21)			8 (38.1%)	4 (19.0%)	9 (42.9%)

Q10. As a researcher, how often do you review your CPSP study data?

	***n* = 22**
As questionnaires arrive	11 (50.0%)
Quarterly	8 (36.4%)
Annually	3 (13.6%)
Study completion	

Q11. Have you published your completed study results?

	n* = 22
Yes	6 (27.3%)
No	16 (72.7%)

** not reflective of individual studies as investigators and co-investigators responded from the same study*

Comments: ABSTRACT, MANUSCRIPT ABSTRACTS/MANUSCRIPT
DATA UNDER ANALYSIS
DRAFT SENT IN
IN PROGRESS
INCOMPLETE
NOT COMPLETED
NOT YET COMPLETE
ONLY CPSP ANNUAL RPT
WILL BE SUBMITTING

Q12. Do you think the CPSP fee for doing a study was reasonable?

	***n* = 17**
Yes	13 (76.5%)
No	4 (23.5%)

Fee Comments: TOO HIGH

Q13. Did the CPSP provide information to enable possible collaboration with investigators from other INoPSU?

	***n* = 20**
Yes	13 (65.0%)
No	7 (35.0%)

Steering Committee members

Response rate: 71% (24/34)

Q1. Are you current or past member?

	***n* = 24**
Past	9 (37.5%)
Current	15 (62.5%)

Q2. Which group do you represent?

	***n* = 24**
CPS member	12 (50.0%)
Health Canada	3 (12.5%)
Provincial PH	2 (8.3%)
Academic	1 (4.2%)
Other*	6 (25.0%)

** did not specify*

Q3. Are meetings twice a year adequate to decide on projects and review the previous year's program?

	***n* = 23**
Yes	21 (91.3%)
No	2 (8.7%)

Q4. Rate the format of the meetings

	Very Useful	**Useful**	**Not Useful**
Presentations of proposals (*n* = 23)	19 (82.6%)	3 (13.0%)	1 (4.3%)
Review of letters of intent (*n* = 23)	14 (60.9%)	9 (39.1%)	
Presentation of study final results (*n* = 22)	16 (72.7%)	5 (22.7%)	1 (4.5%)

Q5. Are the meeting arrangements adequate?

	***n* = 23**
Yes	23 (100.0%)
No	

Q6. How would you rank the mix of committee members in relation to providing feedback to investigators?

	***n* = 22**
Poor	
Fair	2 (9.1%)
Good	9 (40.9%)
Excellent	11 (50.0%)

Q7. Is there an agency that is not currently represented on the committee that should have a seat?

	***n* = 23**
Yes	4 (17.4%)
No	19 (82.6%)

Q8. Do you find the meeting materials adequate and appropriate?

	***n* = 23**
Yes	23 (100.0%)
No	

Q9. Do you review the study proposal and complete the study inclusion criteria form prior to the meeting?

	***n* = 21**
Yes	18 (85.7%)
No	3 (14.3%)

Q10. Are the criteria for study inclusion appropriate?

	***n* = 22**
Yes	20 (90.9%)
No	2 (9.1%)

Q11. How would you rank the process for study inclusion?

	***n* = 23**
Poor	
Fair	2 (8.7%)
Good	17 (73.9%)
Excellent	4 (17.4%)

Q12. How would you rank the quality of the proposals that are submitted?

	***n* = 23**
Poor	
Fair	3 (13.0%)
Good	17 (73.9%)
Excellent	3 (13.0%)

Q13. In your opinion, do the majority of study proposals fit the aims/objectives of the CPSP?

	***n* = 22**
Yes	22 (100.0%)
No	

Q14. Does the committee chair allocate enough time for group discussion on each research proposals?

	***n* = 22**
Yes	22 (100.0%)
No	

Q15. Does a live presentation by the principal investigator improve your understanding of the proposed study and impact on your decision to approve/disapprove?

	***n* = 22**
Yes	20 (90.9%)
No	2 (9.1%)

Q16. Does the group discussion following presentations provide you with additional insight?

	***n* = 23**
Yes	23 (100.0%)
No	

Q18.

NOTHING TO DECLARE MOVE TO TOP

DRAWS INCENTIVES, EMAIL FORM

Q19.

SEEMS TO WORK WELL

WORKING FINE