EVALUATION OF THE CANADIAN PEDIATRIC SURVEILLANCE PROGRAM

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CPSP Evaluation Process

Process
- Followed WHO directives
- Determined clear concise objectives to:
  - provide opportunity for feedback
  - assess scientific and public health worth
  - address strengths and weaknesses
  - identify opportunities for improvement

Background Program Materials
- Logic models for short- and long-term outcomes
- Initiation of a study
- Impact of information dissemination
- Anonymous surveys

Evaluation Advisory Group Membership
Chair
- Dr. Robert McMurtry
- Former Assistant Deputy Minister, Health Canada
- Former Dean of Medicine, University of Western Ontario

Members
- Dr. Margaret Barry
- Neurologist and CPSP participant
- Dr. Jeff Davis
- Chief Medical Officer, Wisconsin, USA
- Dr. Philippe Duches, Project Leader, Immunization Safety, WHO
- Dr. Monica Naus
- Epidemiologist, BC Centre for Disease Control
- Chair, National Advisory Committee on Immunization

Functions
- Reviewed all data independently
- Interviewed key people
- Produced a final assessment summary with recommendations
- Presented evaluation findings to the CPSP Steering Committee and discussed next steps

CPSP Anonymous Surveys

CDC Criteria*
- Simplicity
- Flexibility and timeliness
- Data quality
- Acceptability
- Sensitivity
- Positive predictive value
- Representativeness
- Stability

CPSJ Surveys
- 2,928 participants - 48%
- 53 investigators - 45%
- 24 Steering Committee members - 71%
- 56 public health professionals - 46%

CPSP Surveys
- 60% of a SARS outbreak in the larger province

Survey Feedback

Participants
- Flexibility and Timeliness
  - Initial report can be altered within days
  - Average implementation time is 10 months
  - Specific survey question is an option
  - 41% would return form if not postage-paid
  - 67% favourable to e-mail/fax response
  - 92% would respond by phone/fax for a public health emergency

Acceptability
- 83% monthly response rate
- 95% voluntary completion of detailed questionnaires
- 95% had no hesitation in providing clinical information
- 70% felt that 11 conditions under surveillance was an adequate number
- 10% had considered conducting a CPSP study
- 92% would respond by phone/fax for a public health emergency

Sensitivity
- 83% of cases were captured
- 80% were aware of CPSP annual results
- 68% knew study protocols useful
- 62% knew educational resources helpful
- 17% of clinicians said materials changed their clinical practice

Public Health Professionals
- 95% - national announcement needed to answer research questions
- 88% - national study possible only with the CPSP
- 94% - CPSP study met their research objectives
- 05% - studies had co-investigators from different centres encouraging collaborative national research

Usefulness
- 90% - 100% were pleased with the CPSP administration
- 88% - 90% found study protocols useful
- 80% of respondents agreed that case-specific information was generally available
- 92% felt it was too hard/hard to complete but were still willing to complete

Positive Predictive Value
- 94% - CPSP study met their research objectives
- 89% - congenital rubella syndrome
- 83% - Creutzfeldt-Jakob disease
- 80% - hepatitis C virus infection
- 71% - hepatitis virus infection

Recommendations and Next Steps

Expert Advisory Group Conclusions
- Exemplary evaluation process
- Robust program unique in Canada
- Strong economical infrastructure
- Well-established national collaborative network
- Rapid real-time reporting rate
- High degree of sensitivity and predictive value
- 'CPSP a gem, a light under a bushel' - Dr. Robert McMurtry

Expert Advisory Group Recommendations
- Continue essential surveillance on uncommon high impact paediatric diseases and conditions
- Reach out to other health-care professionals
- Explore potentials for quick response to a public health emergency
- Transfer high-quality study results to relevant target audiences
- To promote effective use in policy development
- To provide research evidence-based knowledge for use in decision-making
- Secure long-term financial support
- Pervasive in essential advisory role

The CPSP gratefully acknowledges all program participants and study investigators for their active role in helping to advance research and knowledge on uncommon diseases.