Beyond counting cases: public health impacts of national Paediatric Surveillance Units

D Grenier, E J Elliott, Y Zurynski, R Rodrigues Pereira, M Preece, R Lynn, R von Kries, H Zimmermann, N P Dickson and D Virella

Arch. Dis. Child. 2007;92;527-533; originally published online 11 Dec 2006; doi:10.1136/adc.2006.097451

REVIEW

Beyond counting cases: public health impacts of national Paediatric Surveillance Units

D Grenier, E J Elliott, Y Zurynski, R Rodrigues Pereira, M Preece, R Lynn, R von Kries, H Zimmermann, N P Dickson, D Virella

Arch Dis Child 2007;**92**:527–533. doi: 10.1136/adc.2006.097451

Paediatric Surveillance Units (PSUs) have been established in 14 countries and facilitate national, prospective, active surveillance for a range of conditions, with monthly reporting by child health specialists. The International Network of Paediatric Surveillance Units (INoPSU) was established in 1998 and facilitates international collaboration among member PSUs and allows for sharing of resources, simultaneous data collection and hence comparison of data from different geographical regions. The impact of data collected by PSUs, both individually and collectively as members of INoPSU, on public health outcomes, clinical care and research is described.

For many uncommon but important paediatric conditions we lack national data on incidence, disease burden and short-term outcomes. We also lack evidence of the impacts of preventive public health measures on disease rates and outcomes. To address these important information gaps, Paediatric Surveillance Units (PSUs) have been established in 14 countries. All are based on the model developed by the British Paediatric Surveillance Unit. All PSUs facilitate national, prospective, active surveillance for a range of conditions, with monthly reporting by child health specialists. For each case reported, clinicians subsequently provide clinical and epidemiological data. This method provides considerable advantages over traditional passive reporting systems, including timeliness and increased rates of reporting and ascertainment.[1]

The International Network of Paediatric Surveillance Units (INoPSU) was established in 1998. INoPSU facilitates international collaboration among member PSUs and allows for sharing of resources, simultaneous data collection and hence comparison of data from different geographical regions (table 1).[2] Over 150 studies have been facilitated by INoPSU members on a range of infectious and vaccine preventable diseases, genetic and metabolic conditions, childhood injuries and mental health disorders. Over 10 000 paediatricians, servicing a population of >56 million children aged <15 years, contribute data to PSUs each month.

In this paper we describe the impact of data collected by PSUs, both individually and collectively as members of INoPSU, on public health outcomes, clinical care and research.

See end of article for authors' affiliations

Correspondence to: Professor Elizabeth Elliott, Australian Paediatric Surveillance Unit, Level 2, Research Building, The Children's Hospital at Westmead, Locked Bag 4001, Westmead, NSW 2145, Australia; Elizabe2@chw.edu.au

Accepted 27 November 2006
Published Online First 11 December 2006

METHODS

INoPSU has 14 member countries as described in table 2. Further details are available at http://www.inopsu.com. Members communicate through sharing annual reports, a bi-annual conference and the INoPSU website. Most communication is informal, for example when one unit seeks opinion or advice from other units when developing a new surveillance study. Often, one PSU acts as a catalyst for international collaboration by initiating a study that is later adopted by other PSUs.

All PSUs use a similar surveillance method and the quality and completeness of data collected depends on the monthly participation of clinicians. Each month a report card listing up to 16 different conditions is sent to practising paediatricians and other child health specialists. Average monthly card return rates are high (81.4%) and reflect the value with which clinicians regard this activity (table 2). This high response rate is an important achievement because many PSUs are in contact with over 1000 clinicians every month. To facilitate high participation rates some units have changed from postal to e-mail reporting or have introduced web-based reporting. Because case ascertainment is unlikely to be complete with any system, use of additional sources of cases, such as laboratory surveillance systems, is encouraged, when appropriate and available, to maximise case finding.

RESULTS

Table 3 summarises the outcomes of a selection of surveillance studies, their impact on public health policy and clinical practice, and their role in stimulating further research. Study outcomes have been categorised into seven main areas:

- monitoring public health interventions,
- informing the development of new screening policy,
- highlighting international differences that impact on local public health policy,
- describing the epidemiology and features of child mental health disorders,
- facilitating molecular epidemiological studies,

Abbreviations: CRS, congenital rubella syndrome; FAS, fetal alcohol syndrome; HUS, haemolytic uraemic syndrome; INoPSU, International Network of Paediatric Surveillance Units; MSBP, Munchausen syndrome by proxy; PIND, progressive intellectual and neurological deterioration; PSU, Paediatric Surveillance Unit; vCJD, variant Creutzfeldt-Jakob disease

Table 1 The aims of INoPSU

Primary aim:

- To enhance communication and collaboration between national Paediatric Surveillance Units and child health researchers worldwide

Secondary aims include:

- Collecting simultaneous or sequential, standardised data from two or more countries to:
  - document and compare epidemiology on rare and/or emerging disorders;
  - provide educational information to paediatricians to facilitate early diagnosis and appropriate management of rare conditions;
  - develop uniform diagnostic criteria;
  - establish international cohorts for future research, including molecular epidemiological studies; and
  - mount a response to epidemiological emergencies.
- Disseminating information on rare diseases to INoPSU members, community and parent-support groups, and relevant authorities to inform clinical practice, policy development, and educational and public health initiatives
- Sharing information about the surveillance process and facilitating evaluation of units and development of new units

- guiding paediatric clinical practice policy, and
- identifying and quantifying product safety hazards.

Monitoring public health interventions

Surveillance studies can be used to monitor incidence rates of vaccine-preventable diseases, effectiveness of vaccination programs, and occurrence of vaccine-associated adverse effects. In some countries, PSUs are the primary source of national data supplied to the WHO, allowing governments to fulfil their obligations to the global polio eradication initiative and to obtain certification as ''polio-free''.[3]

Sharing of study protocols among four countries enabled comparison of data on infants hospitalised with pertussis. PSU data showed that many affected infants were too young to be vaccinated according to their country's vaccination schedules, and that many acquired pertussis from their parents, another adult or an adolescent[4 5] (personal communication from Associate Professor Cameron Grant, NZPSU). A German study confirmed that a single dose of acellular pertussis vaccine protects against hospitalisation for pertussis.[5] This information and approval of an acellular pertussis vaccine for adults, informed changes to vaccination schedules. In the Netherlands, the recommended age for first vaccination was decreased from 3 to 2 months.[6] In Australia, the vaccination schedule now recommends vaccination of adolescents at 15–17 years of age[4] and a trial of vaccination at birth has been initiated (personal communication from Professor Peter McIntyre, National Centre for Immunisation Research and Surveillance, Australia).

Surveillance for *Haemophilus influenzae* type b infections attests to the success of a combined vaccine in dramatically reducing disease rates, mortality and morbidity caused by this bacterium.[7] Surveillance of subacute sclerosing panencephalitis by several PSUs confirmed this condition is now very rare in countries with measles vaccination programs, and that it is not a complication of measles vaccination.[8 9]

Surveillance of congenital rubella syndrome (CRS) by five PSUs showed that although the two-dose MMR vaccination regimen in place since the 1990s has been very successful in decreasing disease rates, congenital rubella still occurs.[10 11] In Australia and Canada, most children with CRS are born to immigrant mothers with incomplete or interrupted immunisation programs, or to unvaccinated mothers who travelled overseas during pregnancy to countries where rubella is still prevalent.[10 11] However, some affected children are born to mothers who missed school-based rubella vaccination or experienced primary vaccine failure.[11] These results have several implications. Given increasing world migration rates, ongoing surveillance programs to detect importations of rubella into developed countries should be supported. Educational campaigns are necessary to raise awareness and ensure high (>85%) uptake for primary MMR vaccination. More importance should be placed on checking rubella antibody status, and vaccinating rubella-susceptible women, particularly immigrants.[10 11]

Several PSU studies have provided data on vaccine-preventable diseases prior to the availability and/or introduction of a new vaccine. Although varicella is perceived to be a benign childhood infection, studies from five PSUs documented serious complications, for example encephalitis, cerebellar ataxia and necrotising fasciitis,[12 13] and the need for hospitalisation and surgical procedures in some children.[14] The effects of varicella infection in utero and in the neonatal period have also been documented.[15] As varicella vaccines have become more widely used, surveillance studies have been re-activated to provide current information and allow documentation of changes in disease rates and rates of serious complications of varicella.

Surveillance of invasive pneumococcal infections provided evidence on the inpatient burden of pneumonia, septicaemia

Table 2 Members of INoPSU

Paediatric Surveillance Unit	Year founded	Population <15 years old (millions)	Participating clinicians (number)	Card return rate (%)	Questionnaire return rate (%)
Australian Paediatric Surveillance Unit (APSU)	1993	3.9	1100	93	86
British Paediatric Surveillance Unit (BPSU)	1986	12.7	2550	93	93
Cyprus-Greece Paediatric Surveillance Unit (CGPSU)	2001	1.28	110	100	100
Canadian Paediatric Surveillance Program (CPSP)	1996	7.5	2335	83	96
German Paediatric Surveillance Unit (ESPED)	1992	12	462*	98	95
Irish Paediatric Surveillance Unit (IPSU)	1996	1.5	150	85	80
Latvian Paediatric Surveillance Unit (LPSU)	1996	0.4	22	80	85
Malaysian Paediatric Surveillance Unit (MPSU)	1994	7.7	395	75	‡
Netherlands Paediatric Surveillance Unit (NSCK)	1992	3.0	692	95	70
New Zealand Paediatric Surveillance Unit (NZPSU)	1997	0.8	208	93	‡
Papua New Guinea Paediatric Surveillance Unit (PNGPSU)	1996	2.0	40	79	‡
Portuguese Paediatric Surveillance Unit (PPSU)	2001	1.4	1800	35	66
Swiss Paediatric Surveillance Unit (SPSU)	1995	1.3	38†	100	96
Welsh Paediatric Surveillance Unit (WPSU)	1994	0.58	133	96	‡

*Reporting by heads of hospital departments; †reporting by heads of paediatric clinics; ‡questionnaire response rate not available.

and meningitis and supported the development of new vaccination policies.[16]

Informing the development of new screening policies

HIV/AIDS surveillance by five PSUs confirms that most children now acquire the virus from their mother through perinatal exposure.[17–19] PSUs have documented trends in disease frequency and outcome over time. Early surveillance showed that maternal HIV infection was frequently acquired through intravenous drug use or receipt of contaminated blood products, that HIV was rarely diagnosed antenatally, that maternal infection was often identified only when children developed an AIDS-related condition and that there were substantial rates of HIV transmission from mother to infant.[17–19] Recent surveillance shows that the most common means of maternal acquisition of HIV infection is now through heterosexual contact. Earlier (antenatal) diagnosis allows uptake of interventions (anti-retroviral agents, elective caesarean section and avoidance of breastfeeding) and has led to lower transmission rates.[18–20] These findings informed the development and implementation of national policy in the UK, and more recently in New Zealand, supporting the introduction of routine HIV screening during pregnancy.[18]

Studies on invasive group B streptococcal disease provided national epidemiological data in five countries (UK, Canada, Germany, Netherlands, Portugal). All studies reported the higher frequency and severity of early-onset compared with late-onset disease, and supported the development of guidelines that advocate either universal screening in late pregnancy or screening based on identifiable risk factors.[21–23] One ongoing study is assessing the clinical impact of one of these guidelines.[24]

Rates of neonatal herpes simplex infection reported through the Canadian and Australian PSUs are considerably lower than rates reported in the USA.[25 26] PSU data highlight the importance of HSV-1 in congenital and neonatal infections. HSV-1 predominates in Australia and Canada, whereas HSV-2 is responsible for most neonatal infections in the USA.[26] PSU studies highlight the fact that many women are unaware of their infection prior to delivery and that, despite early and intensive treatment with antiviral medications, many newborns have disseminated disease with a high fatality rate.[27 28] These results have implications for screening, vaccine program development, community education and management.

Highlighting international differences that impact on local public health policy

Using the same case definition, seven PSUs monitored the association between Shiga toxin-producing *Escherichia coli* (STEC) and haemolytic uraemic syndrome (HUS) (table 3). HUS is endemic in Australia, UK, Canada, Latvia, New Zealand, Portugal and Switzerland, and outbreaks were reported in the UK, Canada and Australia. Diarrhoea-associated HUS was acquired through ingestion of contaminated food (mettwurst, meat pies) or well water, swimming in contaminated sea water and environmental contamination at a kindy farm where the public can interact with the animals.[29–31] Although *E coli* O157 was the organism most commonly implicated, there was considerable geographic heterogeneity. In particular, *E coli* O157 was rare in Australia where *E coli* O111:H− (an organism not isolated in any other country) predominated.[31] Data from these studies supported public health measures to raise awareness of the disease and promote means to minimise the risk of acquisition, enhance diagnostic services, and improve food handling and manufacturing practices.[31]

In 1997 the BPSU implemented surveillance of progressive intellectual and neurological deterioration (PIND) in response to the emergence of variant Creutzfeldt-Jakob disease (vCJD). Canada, which at that time was free of bovine spongiform encephalitis, served as a comparison country. Both units used the same case definition and over a 7 year period six cases of vCJD were identified through the BPSU but none in Canada.[32 33] Results highlighted the numerous causes of PIND in childhood and the large number of cases for which a specific diagnosis could not be found even after extensive investigations and review by a panel of experts.[32 33] Similarly, 21% of cases of childhood dementia identified in Australia were idiopathic, indicating the need for further research and improved diagnostic services.[34]

Describing the epidemiology and features of child mental health disorders

Little is known about the epidemiology of many uncommon child mental health disorders and PSUs have generated data to address this knowledge gap. These studies have raised awareness of child mental health conditions, identified the need for education of paediatricians regarding their diagnosis and management, and highlighted the need for improved access to multidisciplinary diagnostic and management services. The move by PSUs to monitor mental health disorders is important because they are increasing in incidence in paediatric practice worldwide.

The early onset eating disorder studies from Australia and Canada showed that children aged 5–13 years with eating disorders present with significant weight loss (average 6–7 kg) or failure to gain weight, psychological problems and medical complications, including bradycardia, hypothermia and hypotension.[35] Although early onset eating disorder mainly affects girls, a significant proportion of patients (14% in Canada and 25% in Australia) are boys, particularly in the younger age groups. Many children do not meet the DSM-IV diagnostic criteria for anorexia nervosa, indicating the need for establishing pre-adolescent diagnostic criteria.[35]

The Australian study of conversion disorder described its epidemiology and clinical features. Over half of the children identified had multiple conversion symptoms, most commonly disturbance of voluntary motor function, sensory symptoms, pseudoseizures or respiratory problems. In many children antecedent stressors were identified, including family conflict or a personal history of mental health problems, predominantly depression and anxiety.[36] This study highlighted the chronicity of conversion disorder, its burden on families and health professionals, and the need for a multidisciplinary approach to ensure timely diagnosis and appropriate management.

Munchausen syndrome by proxy (MSBP) involves behaviours by care givers to deliberately mislead the doctor, including fabrication, exaggeration or falsification of information regarding their child's illness, or physical interference to create or worsen symptoms and signs. British and Australian PSU studies estimate an incidence of MSBP of 0.5/100 000 children aged <15 years. Children with MBPS place considerable demand on health resources because they often require multiple admissions and many doctors are involved in their care.[37] The condition is exceedingly difficult to recognise and caution is needed when clinicians are faced with seemingly unexplained signs and symptoms in children.[37]

Facilitating molecular epidemiological studies

Studies of Rett, Prader-Willi and Smith-Lemli-Opitz syndromes and the CHARGE association have estimated national incidence rates for these rare genetic disorders.[38–40] Surveillance studies have enabled establishment of cohorts that will be followed longitudinally to assess disease prognosis, have enabled researchers to investigate genotype–phenotype correlations and have highlighted the advantage of early genetic confirmation of the diagnosis for ensuring early access to multidisciplinary

Table 3 Impacts of paediatric surveillance unit studies

Study	Impact	Participating PSU
Acute flaccid paralysis	Confirmed absence of wild poliovirus and presence of vaccine-associated paralytic polio; contributed to WHO eradication and accreditation program	APSU, BPSU, CPSP, NZPSU, SPSU
Haemophilus influenzae type B infection	Documented success of Hib vaccination programs including with use of combined pentavalent vaccine	APSU, ESPED, NSCK
Pertussis infection in infants	Informed changes to vaccination schedules; identified need to review age of first vaccination and for targeted adult/adolescent vaccination	APSU, BPSU, CGPSU, NSCK, NZPSU
Pneumococcal infection	Documented disease burden and supported universal vaccination programs	ESPED, NZPSU
Congenital rubella syndrome (CRS)	Documented persistence of CRS despite good vaccine coverage, and identified need for targeted vaccination for susceptible women (eg, immigrants, non-immune, pre-conception and postpartum)	APSU, BPSU, CPSP, NZPSU, SPSU, NSCK
Subacute sclerosing panencephalitis	Confirmed disease is rare in countries with well implemented measles vaccination programs and is associated with wild measles virus infection	APSU, BPSU, CPSP, ESPED
Congenital varicella, neonatal varicella, complications	Supported need for universal vaccination, use of antiviral therapy and education for community and health professionals regarding infection in pregnancy	APSU, BPSU, CPSP, ESPED, SPSU
Neonatal herpes simplex virus infection	Confirmed HSV-1 is most prevalent type in Australia and Canada, incidence is lower in these countries than in the USA and disease is often severe. Identified need for effective screening; development of vaccines against HSV-1 and 2	APSU, BPSU, CPSP, SPSU
HIV/AIDS, perinatal exposure to HIV	Supported recommendations for use of anti-retroviral agents, caesarean section and bottle feeding in infected mothers. Confirmed benefit of antenatal diagnosis and supported recommendation of universal prenatal screening in some countries	APSU, BPSU, LPSU, NSCK, NZPSU
Invasive group B streptococcal disease	Recommend development of national prevention guidelines and screening (universal or based on risk factors) in late pregnancy	BPSU, CPSP, ESPED, NSCK, PPSU
PIND and childhood dementia	Identified cases of variant CJD in the UK but not in Canada but no trend to increased rate over time. Although PIND has many aetiologies, many cases are idiopathic; all are highly demanding of health services	APSU, BPSU, CPSP
Early onset eating disorder (<13 years old)	Confirmed need for pre-adolescent diagnostic criteria. Substantial proportion of boys identified aged $\leqslant$9 years	APSU, BPSU, CPSP, NSCK
Conversion disorder	First national study; described clinical features, disease burden, co-morbidity and risk of recurrence	APSU
Munchausen syndrome by proxy	Identified large disease burden, feelings of isolation in clinicians and need for multidisciplinary support for diagnosis and management	APSU, BPSU
Rett syndrome, Prader-Willi syndrome, SLOS	Described molecular epidemiology and genotype-phenotype correlations; established research cohorts for longitudinal, intervention and other studies	APSU, BPSU, CPSP
CHARGE association	Identified the complexity of CHARGE, its overlap with other syndromes and the need for future health resources, and facilitated genetic studies	APSU, CPSP
Medium chain acyl CoA dehydrogenase deficiency	Confirmed the value of neonatal tandem mass spectrometry screening for early identification of disease	BPSU, NSCK
Vitamin K deficiency bleeding	Confirmed most cases are late onset and related to underlying liver disease; a high proportion of cases receive no or incomplete prophylaxis	APSU, BPSU, CPSP, ESPED, NZPSU, SPSU, NSCK
Fetal alcohol syndrome	Identified need for universal diagnostic criteria, specialised services, education of health professionals and the community, and prevention	APSU, NZPSU
Haemolytic uraemic syndrome	Described geographic variation in aetiology, highlighting the need for new diagnostic tests. Supported preventative measures, eg education, hygiene regulations for kindy farms and legislation regarding food production*	APSU, BPSU, CPSP, LPSU, NZPSU, PPSU, SPSU
Chemistry set poisoning	Resulted in amended legislation in the UK regarding packaging and provision of information	BPSU
Reye syndrome	Recommended ban of aspirin in paediatric and youth populations	BPSU, ESPED
Baby walkers	Supported ban on sale, re-sale, advertisement and importation of baby walkers in Canada	CPSP
Lap-belt syndrome	Resulted in call for age- and size-appropriate use of restraints for children in motor vehicles	CPSP, APSU

A kindy farm is an open farm where children can interact with the animals. PIND, progressive intellectual and neurological deterioration; SLOS, Smith-Lemli-Opitz syndrome.

care.[40 41] Demonstrating the extent of health service usage by affected children has helped to justify establishment of new models of health service delivery.[42] Members of cohorts have also consented to participate in additional research including case–control and randomised controlled trials.[43 44] Surveillance for Smith-Lemli-Opitz syndrome and CHARGE association identified significant behavioural and co-morbid diagnoses in older children, with implications for planning of future health resources.[41 45 46] PSUs also provided data on the burden of medium chain acyl CoA dehydrogenase deficiency that informed the implementation of tandem mass spectrometry for neonatal screening.[47 48]

Guiding paediatric clinical practice policy

Publication of an alleged link between intramuscular vitamin K administration in newborns and later childhood cancer led several countries to alter their prevention policy and recommend oral vitamin K as an alternative for prevention of vitamin K deficiency bleeding. Publicity surrounding this allegation led some parents to refuse consent for vitamin K. Surveillance studies in seven countries (table 3) subsequently confirmed an increased number of patients, some with intracranial bleeding and severe neurological sequelae.[49 50] International comparison showed that the lowest incidence rates of such complications occur in countries using predominantly intramuscular vitamin K, confirming this as the most effective route of administration and leading to revision of practice guidelines.[50 51]

Surveillance of Reye syndrome by the BPSU commenced in 1981 following reports of an association with the consumption of aspirin.[52] This led to a ban on aspirin use in children aged <12 years. Subsequent monitoring demonstrated an almost total elimination of Reye syndrome in this age group in the UK. However, when cases continued to be reported in children aged >12 years, the ban was extended to cover all children aged <16 years.[53]

Studies of fetal alcohol syndrome (FAS), conducted in Australia and New Zealand, suggested under-diagnosis of this condition. The APSU study showed that Indigenous children were over-represented, about one third were in foster care and almost half had an affected sibling, indicating missed prevention opportunities.[54] The APSU study prompted two surveys of health professionals that indicated lack of knowledge about FAS diagnosis and management, fear of stigmatising the child or family, and uncertainty about the appropriate advice to give to women regarding alcohol use in pregnancy.[54 55] The study highlighted the need for review of prevention policy including the content of National Health and Medical Research Council Australian Guidelines for alcohol use in pregnancy, development of educational materials for health providers and the community, and review of diagnostic and management models used internationally. Representatives from the APSU study team are in a unique position to influence those responsible for policy on prevention, education and research through membership of the Inter Governmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders in Australia, convened by the Ministerial Council on Drugs Strategy. Other PSUs have shown interest in developing surveillance studies on FAS.

An NZPSU study demonstrated that bronchiectasis was most common in Pacific Islander children and also more common in Maori children than those of European ethnicity. The study highlighted the need for earlier and more effective treatment of lower respiratory disease in disadvantaged children.[56]

Identifying and quantifying product safety hazards

PSUs have been used to document rare injuries in children. A British study of poisoning by toy chemistry sets identified problems with packaging and led to amendments to the European Union legislation on toy safety and instructions on the packages.[57] A Canadian study identified that injuries from baby walkers continued to occur despite a voluntary ban on their sale from 1988. This led the Canadian government to prohibit the sale, advertisement and importation of baby walkers from 2004.[58] Another Canadian study documented the severity of lumbar spine fractures and spinal cord injuries in children aged 2–15 years who were inappropriately restrained in motor vehicles by lap-only belts. In this study, 25% of children became paraplegic following injury and children aged 5–8 years were at higher risk. Advocacy for optimal restraint use in motor vehicles and use of booster seats in older children led to legislation changes in some Canadian jurisdictions.[59] A study of serious seatbelt injuries based on the Canadian study is currently under way in Australia.

DISCUSSION

Active, national surveillance facilitated by PSUs is an important, versatile and relatively cheap epidemiological tool. PSUs facilitate research in children and provide new national data on the epidemiology, diagnosis, management and short-term outcome of a wide range of uncommon, but high impact and often neglected, conditions. They complement data derived from alternative sources. Surveillance allows practising paediatricians to participate in, and contribute to, research and evaluation efforts. High participation rates by paediatricians around the world reflect the importance with which they regard this activity.

The formation of INoPSU has been important for facilitating international cooperation and collaboration between PSUs, developing new surveillance methods, and enabling international comparison of study results. It has allowed us to identify geographic differences in disease aetiology, management, prevention and outcome and these data inform local health policy. The network continues to expand: new PSUs are under development in Trinidad-Tobago and Argentina. Furthermore, the surveillance methodology developed by PSUs has been used to create specialty surveillance units including the British Neurological Surveillance Unit and the UK Obstetric Surveillance System.

As we have demonstrated, surveillance by INoPSU members allows us to monitor the impact of established public health policy and provides new and timely data to inform the development of new policy. This information also impacts on health service planning, guides national legislation pertaining to injury prevention in children and young people, informs the development of screening programs, and provides insights into genetic epidemiology. Surveillance units are able to respond quickly to recognition of emerging diseases of public health importance (for example vCJD in the UK) by rapidly initiating studies to generate national data. For most conditions studied PSUs have compiled the only national data, and in many cases PSU studies have generated hypotheses that have catalysed future research.

Despite the fact that PSUs provide important data to inform public health initiatives, clinical practice and research agendas, no PSU has ongoing core funding. PSUs rely predominantly on time-limited government and competitive research funding. INoPSU has no current funding. The success of individual PSUs and INoPSU depends on the dedication and commitment of key individuals who ensure the continuation of this important work, often under difficult circumstances. However, national surveillance is essential for low frequency conditions and INoPSU members will continue to provide high quality evidence that contributes to improved health for children and young people.

ACKNOWLEDGEMENTS

The authors wish to acknowledge all PSU support staff, study investigators, and clinicians who report cases. Funders and supporters

of the following PSUs are also gratefully acknowledged. APSU: Australian Government Department of Health and Ageing; National Health and Medical Research Council (NHMRC) Enabling Grant No. 402784; NHMRC Practitioner Fellowship No. 457084 (EE); Discipline of Paediatrics and Child Health and Faculty of Medicine, University of Sydney; Royal Australasian College of Physicians. NZPSU: The New Zealand Ministry of Health and the Paediatric Society of NZ. CPSP: The Public Health Agency of Canada and the Canadian Paediatric Society. BPSU: The Department of Health; The Royal College of Paediatrics and Child Health. NSCK: Dutch Paediatric Society; TNO Quality of Life. SPSU: Swiss Federal Office of Public Health; The Swiss Paediatric Association. PPSU: The Portuguese Society of Paediatrics; GSK Foundation-Portugal.

Authors' affiliations

D Grenier, Canadian Paediatric Surveillance Program, University of Ottawa and Children's Hospital of Eastern Ontario, Ottawa, Canada
E J Elliott, Australian Paediatric Surveillance Unit, The Children's Hospital at Westmead, Westmead, Australia
Y Zurynski, Australian Paediatric Surveillance Unit and The University of Sydney, Sydney, Australia
R Rodrigues Pereira, Dutch Paediatric Surveillance Unit, Netherlands Institute for Applied Sciences (TNO) Quality of Life, Leiden, The Netherlands
M Preece, R Lynn, British Paediatric Surveillance Unit, Royal College of Paediatrics and Child Health, London, UK
R von Kries, German Paediatric Surveillance Unit, Institute for Social Paediatrics and Adolescent Medicine, Munich, Germany
H Zimmermann, Swiss Paediatric Surveillance Unit, Swiss Federal Office of Public Health, Division of Communicable Diseases Vaccinations Section, Bern, Switzerland
N P Dickson, New Zealand Paediatric Surveillance Unit, Department of Women's and Children's Health, Dunedin School of Medicine, University of Otago, New Zealand
D Virella, Portuguese Paediatric Surveillance Unit, Lisbon, Portugal

Competing interests: None.

All authors are contributing clinicians and investigators of the International Network of Paediatric Surveillance Units

REFERENCES

1 **Gazarian M**, Williams K, Chant K, *et al*. Evaluation of a national surveillance unit. *Arch Dis Child* 1999;**23**:128–31.
2 **Elliott E**, Nicoll A, Lynn R, *et al*. Rare disease surveillance: an international perspective. *Paediatr Child Health* 2001;**6**:251–60.
3 **Kelly H**, Brussen KA, Lawrence A, *et al*. Polioviruses and other enteroviruses isolated from faecal samples of patients with acute flaccid paralysis in Australia, 1996–2004. *J Paediatr Child Health* 2006;**42**:370–6.
4 **Elliott EJ**, McIntyre P, Ridley G, *et al*. A national study of infants hospitalised with pertussis in the acellular vaccine era. *Paediatr Infect Dis J* 2004;**23**:246–52.
5 **Juretzko P**, von-Kries R, Hermann M, *et al*. Effectiveness of acellular pertussis vaccine assessed by hospital-based active surveillance in Germany. *Clin Infect Dis* 2002;**35**:162–7.
6 **Neppelenbroek SE**, de Melker HE, Schellekens JFP, *et al*. *Severity of pertussis. Paediatric surveillance and notification study in the Netherlands in 1997*, RIVM-report no 128507006. Bilthoven: RIVM, 1999.
7 **Kalies H**, Verstraeten T, Grote V, *et al*. Four and one-half-year follow-up of the effectiveness of diphtheria-tetanus toxoids-acellular pertussis/Haemophilus influenzae type b and diphtheria-tetanus toxoids-acellular pertussis-inactivated poliovirus/H. influenzae type b combination vaccines in Germany. *Paediatr Infect Dis J* 2004;**23**:944–50.
8 **Campbell C**, Levin S, Humphreys P, *et al*. Subacute sclerosing panencephalitis: results of the Canadian Paediatric Surveillance Program and review of the literature. *BMC Pediatr* 2005;**5**:47–6.
9 **Miller C**, Andrews N, Rush M, *et al*. The epidemiology of subacute sclerosing panencephalitis in England and Wales 1990–2002. *Arch Dis Child* 2004;**89**:1145–8.
10 **Canadian Paediatric Society**. CPSP highlights. Congenital rubella syndrome—Time to act on missed prevention opportunities. *Paediatr Child Health* 2003;**8**:107–8.
11 **Forrest JM**, Burgess M, Donovan T. A resurgence of congenital rubella in Australia? *Commun Dis Intell* 2003;**27**:533–6.
12 **Davies HD**. Necrotising fasciitis. In: *Canadian Paediatric Surveillance Program 2003 results*. Ottawa: Canadian Paediatric Society, 2004:33–7. Available from http://www.cps.ca/English/surveillance/cpsp/studies/2003Results.pdf (accessed 21 February 2007).
13 **Ziebold C**, von-Kries R, Lang R, *et al*. Severe complications of varicella in previously healthy children in Germany: a 1 year survey. *Paediatrics* 2001;**108**:E79.
14 **Bonhoeffer J**, Baer G, Muehleisen B, *et al*. Prospective surveillance of hospitalisations associated with varicella-zoster virus infection in children and adolescents. *Eur J Paediatr* 2005;**164**:366–70.
15 **Forrest JM**, Mego S, Burgess MA. Congenital and neonatal varicella in Australia. *J Paediatr Child Health* 2000;**36**:108–13.
16 **Von-Kries R**, Seidler A, Schmidtt HJ, *et al*. Proportion of invasive pneumococcal infections in German children preventable by pneumococcal conjugate vaccines. *Clin Infect Dis* 2000;**31**:482–7.
17 **Duong DM**, Ades AE, Gibb DM, *et al*. Vertical transmission rates for HIV in the British Isles: estimates based on surveillance data. *BMJ* 1999;**319**:1227–9.
18 **Gibb DM**, Duong T, Tookey PA, *et al*. National Study of HIV in Pregnancy and Childhood Collaborative HIV Paediatric Study. Decline in mortality, AIDS, and hospital admissions in perinatally HIV-1 infected children in the United Kingdom and Ireland. *BMJ* 2003;**327**:1019–25.
19 **McDonald AM**, Li Y, Cruickshank MA, *et al*. Use of interventions for reducing mother-to-child transmission of HIV in Australia. *Med J Aust* 2001;**174**:449–52.
20 **Dickson N**, Paul C, Wilkinson L, *et al*. Estimates of HIV prevalence among pregnant women in New Zealand. *New Zealand Public Health Reports* 2002;**9**:17–19.
21 **Trijbels-Smeulders M**, Gerards LJ, Pasker-de Jong PCM, *et al*. Epidemiology of neonatal group B streptococcal disease in The Netherlands 1997–98. *Paediatr Perinat Epidemiol* 2002;**16**:334–41.
22 **Heath PT**, Balfour G, Weisner AM, *et al*. Group B streptococcal disease in UK and Irish infants younger than 90 days. *Lancet* 2004;**363**:292–4.
23 **Fluegge K**, Siedler A, Heinrich B, *et al*. Incidence and clinical presentation of invasive neonatal group B streptococcal infections in Germany. *Pediatrics* 2006;**117**:e1139–45.
24 **Neto MT**. Group B Streptococcus neonatal infection. In: Antsaklis A, ed. *Proceedings of the XIX European Congress of Perinatal Medicine*. Medimond: Atenas 2004:335–9.
25 **Kropp RY**, Wong T, Cormier L, *et al*. Neonatal herpes simplex infection in Canada: results of a 3-year national prospective study. *Paediatrics* 2006;**117**:1955–62.
26 **Freedman E**, Mindel A, Jones C. Epidemiological, clinical and laboratory diagnosis of neonatal herpes – an Australian perspective. *Herpes* 2004;**11**:38–40.
27 **Wong T**. Neonatal herpes simplex infection: In: *Canadian Paediatric Surveillance Program 2003 results*. Ottawa: Canadian Paediatric Society, 2004:34–7. Available from http://www.cps.ca/English/surveillance/cpsp/studies/2003Results.pdf (accessed 21 February 2007).
28 **Tookey P**, Peckham CS. Neonatal herpes simplex virus infection in the British Isles. *Paediatr Perinat Epidemiol* 1997;**10**:432–42.
29 **Lynn RM**, O'Brien SJ, Taylor CM, *et al*. Childhood hemolytic uremic syndrome, United Kingdom and Ireland. *Emerg Infect Dis* 2005;**11**:590–6.
30 **Proulx F**, Sockett P. Prospective surveillance of Canadian children with haemolytic uraemic syndrome. *Paediatr Nephrol* 2005;**20**:786–90.
31 **Elliott EJ**, Robins-Browne RM, O'Loughlin EV, *et al*. Nationwide study of haemolytic uraemic syndrome: clinical, microbiological and epidemiological features. *Arch Dis Child* 2001;**85**:125–31.
32 **Keene DL**, Sutcliffe T, Harman P, *et al*. Surveillance for progressive intellectual and neurological deterioration in the Canadian paediatric population. *Can J Neurol Sci* 2004;**31**:220–4.
33 **Devereux G**, Stellitano L, Verity C, *et al*. Variations in neurodegenerative disease across the UK: findings from a national study of progressive and neurological deterioration (PIND). *Arch Dis Child* 2004;**89**:8–12.
34 **Nunn K**, Williams K, Ouvrier R. The Australian Childhood Dementia Study. *Eur Child Adolesc Psychiatry* 2002;**11**:63–70.
35 **Morris A**, Madden S, Katzman D, *et al*. Early onset eating disorders in young children: first report from the APSU and CPSP studies. Abstracts of the 4th INoPSU Conference, London, 2006.
36 **Kozlowska K**, Nunn K, Rose D, *et al*. Conversion disorder in Australian paediatric practice. *J Am Acad Child Adolesc Psychiatry* 2007;**46**(1):68–75.
37 **Jureidini J**, Shafer A, Donald T. Munchausen by proxy syndrome: not only pathological parenting but problematic doctoring? *Med J Aust* 2003;**178**:130–2.
38 **Smith A**, Egan J, Ridley G, *et al*. Birth prevalence of Prader-Willi syndrome in Australia. *Arch Dis Child* 2003;**88**:263–4.
39 **Nowaczyk MJM**, Waye JS, Zeesman S, *et al*. Incidence of Smith-Lemli-Opitz syndrome in Canada: results of three-year population surveillance. *J Paediatr* 2004;**145**:503–5.
40 **Colvin L**, Fyfe S, Leonard S, *et al*. Describing the phenotype in Rett syndrome using a population database. *Arch Dis Child* 2003;**88**:38–43.
41 **Prasad C**, Marles S, Prasad AS, *et al*. Smith-Lemli-Opitz syndrome: new mutation with a mild phenotype. *Am J Med Genet* 2002;**108**:64–8.
42 **Moore H**, Leonard H, de Klerk N, *et al*. Health service use in Rett syndrome. *J Clin Neurol* 2005;**20**:42–50.
43 **Leonard H**, Fyfe S, Dye D, *et al*. Using genetic epidemiology to study Rett syndrome: the design of a case-control study. *Paediatr Perinat Epidemiol* 2000;**14**:85–95.
44 **Ellaway CJ**, Peat J, Williams K, *et al*. Medium-term open label trial of L-carnitine in Rett syndrome. *Brain Dev* 2001;**23**(Suppl 1):S85–9.
45 **Williams G**, Wilson M, Rose D, *et al*. The epidemiology and clinical features of the CHARGE association in Australian children 2000–2002. *Portuguese Paediatric Surveillance Unit Bulletin* 2004;**5**(1):17.
46 **Issekutz KA**, Graham JM Jr, Prasad C, *et al*. An epidemiological analysis of CHARGE syndrome: preliminary results from a Canadian study. *Am J Med Genet* 2005;**133**:309–17.

47 **Pollitt RJ**, Leonard JV. Prospective surveillance study of medium-chain CoA dehydrogenase deficiency in the United Kingdom. *Arch Dis Child* 1998;**79**:116–19.
48 **Hoffmann GF**, von Kries R, Klose D, *et al*. Frequencies of inherited organic acidurias and disorders of mitochondrial fatty acid transport and oxidation in Germany. *Eur J Pediatr* 2004;**163**:76–80.
49 **Cornelissen M**, Von Kries R, Loughnan P, *et al*. Prevention of vitamin K deficiency bleeding: efficacy of different multiple oral dose schedules of vitamin K. *Eur J Pediatr* 1997;**156**:126–30.
50 **McMillan DD**, Grenier D, Medaglia A. Canadian Paediatric Surveillance Program confirms low incidence of hemorrhagic disease of the newborn in Canada. *Paediatr Child Health* 2004;**9**:235–8.
51 **Schubiger G**, Berger TM, Weber R, *et al*. Prevention of vitamin K deficiency bleeding with oral mixed micellar phylloquinone: results of a 6 year surveillance in Switzerland. *Eur J Pediatr* 2003;**162**:885–8.
52 **Newton L**, Hall SM. Reye's syndrome in the British Isles: report for 1990/91 and the first decade of surveillance. *Commun Dis Rep CDR Rev* 1993;**3**:R11–6.
53 **Macdonald S**. Aspirin use to be banned in under 16 year olds. *BMJ* 2002;**325**:988.
54 **Elliott EJ**, Bower C. FAS in Australia: fact or fiction? *J Paediatr Child Health* 2004;**40**:8–10.
55 **Elliott EJ**, Payne J, Haan E, *et al*. Diagnosis of fetal alcohol syndrome and alcohol use in pregnancy: a survey of paediatricians' knowledge, attitudes and practice. *J Paediatr Child Health* 2006;**42**:698–703.
56 **Twiss J**, Metcalfe R, Edwards E, *et al*. New Zealand national incidence of bronchiectasis ''too high'' for a developed country. *Arch Dis Child* 2005;**90**:737–40.
57 **Mucklow ES**. Chemistry set poisoning. *Int J Clin Pract* 1997;**51**:321–3.
58 **Grenier D**, Doherty J, Macdonald D, *et al*. Canadian Paediatric Surveillance Program Evaluation: an excellent report card. *Paediatr Child Health* 2004;**9**:379–84.
59 **Cyr C**, Lemoine C, Santschi M. Lap-belt syndrome. In: *Canadian Paediatric Surveillance Program 2005 results*. Ottawa: Canadian Paediatric Society, 2006:38–9. Available from http://www.cps.ca/English/surveillance/cpsp/studies/2005Results.pdf (accessed 21 February 2007).