Role of the Australian Paediatric Surveillance Unit in monitoring communicable diseases of childhood

Katrina Williams,[1] Elizabeth Elliott[2]

Abstract

The Australian Paediatric Surveillance Unit (APSU) conducts active national surveillance of conditions affecting children, including communicable diseases and their complications. By mailing over 900 clinicians each month the APSU gathers national information, not available from other sources, about the incidence, demographic and clinical features of these conditions. In some conditions APSU data supplements that available from existing schemes. The APSU has monitored 20 conditions to date. Eight of these are communicable diseases or their complications, two have a possible infectious aetiology and one frequently presents with infection. Since its inception in 1993 the return rate of monthly report cards by the mailing list has increased from 88 per cent to 94 per cent. Return rate of questionnaires for the communicable diseases studied ranged from 74 per cent to 100 per cent. Studies have enabled estimation of disease incidence, identification of risk factors and possible preventive strategies and provision of detailed clinical information. Although the APSU cannot serve a public health role by case identification and contact tracing it provides information that contributes to the communicable disease strategy for Australia. *Comm Dis Intell* 1998;22:283-287

ISSN 0725-3141
Volume 22
Number 13
24 December 1998

1. Assistant Director APSU, Lecturer, University of Sydney and Clinical Epidemiology Unit, New Children's Hospital, Sydney
2. Director APSU, Senior Lecturer, Department of Paediatrics and Child Health, University of Sydney, Consultant Paediatrician, New Children's Hospital, Sydney

Corresponding author, Dr Elizabeth J Elliott, Director, The Australian Paediatric Surveillance Unit, Level 2, Clinical Sciences Building, New Children's Hospital, PO Box 3515, Parramatta NSW 2124

Contents

Introduction

The APSU, modelled on a similar scheme in Britain,[1] was established in 1992 with the aims shown in Figure 1. Since May 1993 it has conducted active national surveillance of conditions affecting children, including selected communicable diseases and their complications. Some of these are vaccine preventable. All result in considerable morbidity or mortality. For most, no data has previously been available to allow estimation of national incidence or provide a picture of current management or outcome. For other conditions the APSU provides data additional to that available through existing schemes.

Figure 1. Aims of the APSU

Primary aim:

- To accurately document the number of Australian children with specific diseases (or complications of diseases), their geographic distribution, clinical features, current management and outcome

Secondary aims:

- To provide a mechanism for national collaborative research
- To issue updated clinical and diagnostic information to clinicians caring for children with specific conditions being studied
- To disseminate information acquired by the unit which will guide best practice, appropriate prevention strategies and optimal health resource allocation

Methods

Information about APSU activities and individual studies is available in the 1997 annual report.[2] Each month clinicians on the mailing list are sent either a reply-paid report card or an e-mail which they are asked to return, indicating either the number of cases of listed conditions they have seen in the previous month or that they have "nothing to report" (Figure 2). A principal investigator is identified for each condition, and each principal investigator is notified monthly by the APSU of positive case reports and provided with contact details for the reporting doctor. The principal investigator is then responsible for obtaining demographic and clinical data on the case from the reporting doctor by postal questionnaire; for collating, presenting and publishing data and for regular feedback of information to paediatricians and the APSU. No identifying patient details are requested by the APSU or the researcher. Duplicate reports are detected by a unique identifier code.

The mailing list comprises nearly 900 paediatricians, paediatric subspecialists and other clinicians who work predominantly with children (eg paediatric surgeons, ophthalmologists and community child health clinicians). The mailing list attempts to include all paediatricians and other doctors who see children with the type of rare and serious conditions monitored through the APSU and who can ascertain cases seen as both outpatients and hospital inpatients.

Individuals or organisations may apply to study a condition through the APSU and applications undergo a process of peer review and revision before being listed on the monthly report card. To satisfy the criteria for study, a condition must be sufficiently uncommon that the system is not over-burdened; must invariably result in referral to a paediatrician or related specialist and must provide information that satisfies the study aims and that is not available from other sources. Conditions are usually studied for three years, although provision for on-going study may be granted for diseases of public health significance and for those for which case numbers are low.

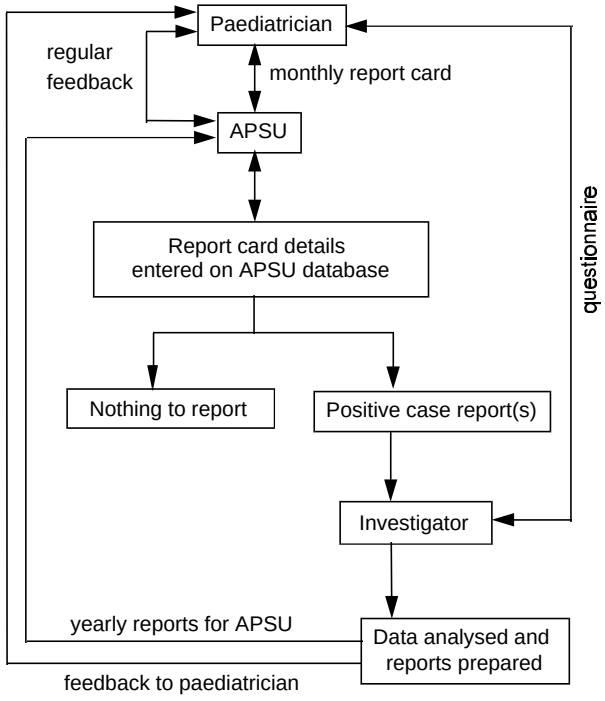
Estimated annual incidence has been calculated from valid (confirmed and probable) cases notified to the end of 1997. For incidence calculated per 100,000 births, only cases born in Australia have been included.

Results

Overview

The development and infrastructure funding for APSU has been derived primarily from competitive research grants totalling about $340,000 for 1993-1998 inclusive. Additional funding for communicable diseases studies has been received from the Commonwealth Department of Health and Aged Care or its precursors ($32,000). The NSW Department of Health ($10,000), the National Centre for HIV Epidemiology and Clinical Research ($10,000) and industry ($25,000) have also provided funding. The total APSU budget for 1997 was approximately $100,000 including salaries of three part-time administrators/ researchers ($73,000), postage ($11,000), printing ($7,000) and costs of the annual scientific meeting. Funding for the time spent by the Director and Assistant Director in APSU activities is not included in the budget because their salaries are provided by the University of Sydney and the New Children's Hospital. Establishing a new condition to be monitored through the APSU incurs no additional real cost because the time of reviewers and

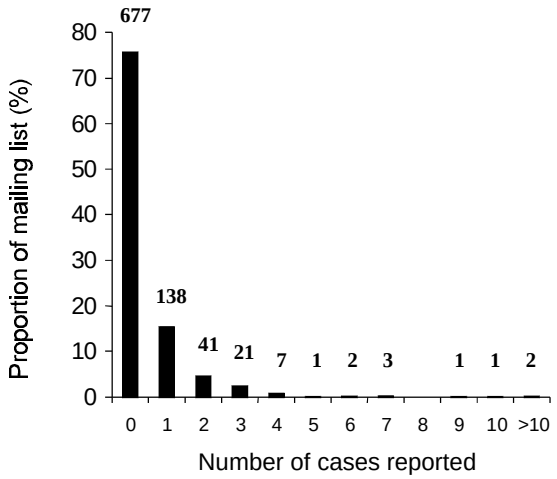
Figure 2. How the APSU works



APSU directors is unpaid. Investigators are asked to ensure that adequate funding is available to undertake their planned research. The amount of money required for mailing and research time varies for each investigator depending on the frequency of notifications for the condition they are monitoring.

A detailed evaluation of the APSU found it to be useful, simple flexible and acceptable to its users.[3] Most clinicians on the mailing list reported that completing monthly report cards was not a burden. For most clinicians it takes one to two minutes each month to simply tick 'nothing to report' or to write the number of cases of each condition seen in the previous month. In 1997 the majority (76%) of clinicians did not report a case and less than 2 per cent reported four or more cases (Figure 3). Most clinicians who had notified cases said that the length of questionnaires requesting further information was acceptable and that requested information was appropriate and available. The majority of the mailing list (62%) who responded to a recent survey said information provided by the APSU was educationally useful.

Figure 3. Respondent workload, 1997.



Since its inception there has been a progressive increase to 94% in the proportion of cards returned to the APSU each month (Figure 4), with all states and territories and specialty groups (general paediatricians, paediatric subspecialists, other community child health clinicians, other specialists, paediatric surgeons) having a response rate of 86% or more in 1997. In February 1997, APSU became the first paediatric surveillance unit to introduce e-mail reporting with 101 (11%) clinicians electing to report by this method by the end of the year. Response rate for e-mail reporting in 1997 was 99%.

Communicable diseases

To the end of 1997 the APSU has monitored eight communicable diseases or their complications (acute flaccid paralysis, congenital and neonatal varicella, congenital rubella, haemolytic uraemic syndrome, HIV/AIDS, subacute sclerosing panencephalitis, neonatal herpes simplex virus infection and invasive *haemophilus influenzae* disease). In addition, two conditions with possible infectious aetiology (Kawasaki disease and extrahepatic biliary atresia) have been studied and children

Figure 4. Overall response rate, 1993-1997.

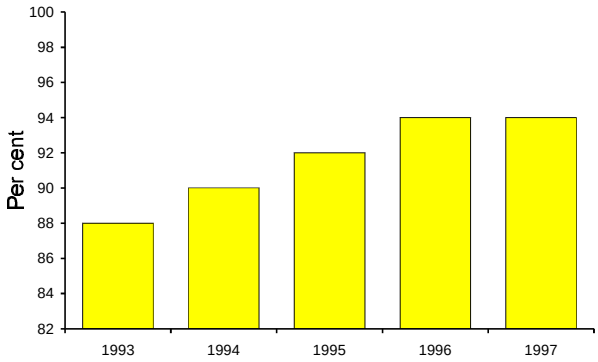


Table 1. Follow-up of notified cases, May 1993 to December 1997.

Conditions Under Surveillance	Total Reports	Confirmed or probable cases	(%)
Acute flaccid paralysis	125	80	(64)
Congenital & neonatal varicella	76	51	(67)
Congenital rubella[1,2]	80	42	(53)
Extrahepatic biliary atresia	273	110	(40)
Haemolytic uraemic syndrome	221	89	(40)
HIV/AIDS[1]	213	103	(48)
Kawasaki disease	366	149	(41)
Neonatal herpes simplex virus infection	11	5	(46)
Subacute sclerosing panencephalitis	9	4	(44)

1. Initially included old (prevalent) and new (incident) cases seen in last month
2. initial retrospective reporting to Jan 1993

notifications which were not confirmed or probable cases were either duplicate reports, an invalid reports or cases where insufficient information was provided to allow classification

notified to one study (primary immunodeficiency disorders) frequently present with infection. Table 1 shows the number of notifications to the APSU to the end of 1997 and the follow-up status of notified cases. Table 2 shows the estimated annual incidence of disease and the return rate of questionnaires sent to notifying clinicians requesting further information, to the end of 1997. Where alternative sources of cases were available the sensitivity of ascertainment of communicable disease through APSU was calculated. Sensitivity of APSU for identifying NSW cases of extrahepatic biliary atresia and haemolytic uraemic syndrome was 90 per cent and 80 per cent respectively. The APSU's sensitivity for identifying congenital rubella nationally was 92 per cent.[3]

Table 2. Estimated annual incidence of communicable diseases monitored, to the end of 1997.

Condition	Questionnaire response (%)	Incidence/ 100,000	95% Confidence Interval
Acute flaccid paralysis*	83	0.7	0.6, 0.9
Varicella Congenital[#]	95	0.8	0.2, 1.4
Neonatal		5.8	2.8, 7.8
Congenital rubella (with defects)	97	1.5	0.9, 2.4
HUS* (years)	98	1.4	1.1, 1.8
Perinatal HIV exposure	88	5.6	4.4, 7.2
Neonatal herpes simplex (HSV) infection	100	2.0	0.7, 4.9
Kawasaki disease (years)*	74	3.7	3.6, 3.8
Extrahepatic biliary atresia	92	5.4	4.0, 7.0
SSPE*	100	0.03	0.01, 0.09

* incidence is per 100,000 children aged less than 15 years; all other figures are expressed per 100,000 births

The *acute flaccid paralysis study* has provided a mechanism for Australia to participate in the global effort by the WHO to eradicate poliomyelitis and declare Australia polio-free.[4] This study, conducted by the National Centre for Disease Control in the Department of Health and Family Services, aims to identify all cases of *acute flaccid paralysis* and, through stool examination, sixty day follow-up and case review by an expert panel (the National Certification Committee), to exclude poliomyelitis as the cause. The rate of AFP identified is around the expected 1/100 000 and over half of children identified were confirmed as having Guillain-Barré syndrome. No cases of poliomyelitis have been confirmed. However, inadequate provision of information has meant that it has not been possible to exclude poliomyelitis in all cases.

Monitoring cases of *haemolytic uraemic syndrome (HUS)* with simultaneous examination of stool and serum from cases has given clinicians throughout Australia access to specialised centralised laboratory techniques and has identified the heterogeneous range of organisms responsible for HUS. Information from this study has contributed to efforts to prevent and control HUS including changes to the code for the manufacture of fermented meat products; requirement for notification of HUS cases to state health departments; and public education about food storage and preparation.[5]

The APSU provides a source of reporting of cases of perinatal exposure to HIV and cases of diagnosed HIV infection in children.[6] This supplements mandatory reporting of cases of diagnosed HIV infection and AIDS to state and territory health authorities. In 28 (46%) cases of perinatal exposure reported in Australia between 1994 and 1997, the APSU was the only source of case notification. Preventive interventions to reduce the risk of mother to child transmission, such as uptake of zidovudine during pregnancy and avoidance of breast-feeding, are being monitored among women diagnosed with HIV infection prior to delivery.

Although clinicians are asked to report any new case of HIV or AIDS in a child under 16 years of age, all notifications since 1995 have been cases of perinatal exposure. No new diagnoses due to blood transfusion in children born in Australia have been reported since 1990. All such products were given prior to 1985.[7]

A study of *congenital and neonatal varicella* has allowed assessment of the burden and clinical spectrum of congenital and neonatal varicella infection prior to the availability in Australia of varicella vaccination, which is currently being trialed in infancy. Data from this study has identified that congenital varicella is more common than previously recognised in Australia.[8] This may reflect increased recognition of a condition following a request for notification. Presentation may be with disseminated herpes zoster early in life and the range of defects includes skin scarring, central nervous system, cardiac and ocular deformity.

In the study of *congenital rubella*, comparison with population data confirmed that children born in Australia in 1995 and 1996 to mothers born outside Australia were at an increased risk of being affected. The need to pay particular attention to the vaccination status of this subgroup of women and to adequately investigate women with symptoms consistent with infection in pregnancy are seen as important preventive strategies.

Subacute sclerosing panencephalitis, though rare, continues to occur and the APSU is providing a mechanism to monitor this most devastating complication of measles. There may be an underascertainment of cases through the APSU because clinicians are asked to report only those diagnosed under the age of 16 years and older children may present to adult physicians.

The study of *neonatal herpes simplex virus infection (neonatal HSV)* aims to determine its incidence, morbidity and mortality in Australia, its modes of presentation and the timeliness of therapeutic intervention. In 1997, five cases were identified, all with disseminated rather than local (eye, skin or mouth) disease. Three cases had involvement of the central nervous system.

It has been suggested that a subgroup of e*xtrahepatic biliary atresia* may be due to an infectious agent. The APSU study has confirmed a seasonal (winter) distribution of cases that would be consistent with an infectious aetiology. It has also provided an estimate of the national requirement for paediatric liver transplantation and confirmed that late diagnosis is a risk factor for worse prognosis.[9]

Similarly the cause of *Kawasaki disease* has not yet been determined. Information from surveillance through the APSU has contributed to a developing literature about the role of streptococcal infection and highlighted diagnostic dilemmas for clinicians which may contribute to suboptimal management of this condition.[10] This study has also identified limitations of international disease classification systems and the effect of these on outcomes.

Invasive *H. influenzae* disease was monitored from January 1998. This study aims to provide an additional source of notification of cases of invasive *H. influenzae* disease in children and to determine the proportion of

cases of invasive *H. influenzae* disease which are due to vaccine failure. Information obtained through the APSU has provided details about both clinical and laboratory risk factors which are not available from laboratory or mandatory reporting schemes. Whether *H. influenzae* isolates from cases that are due to vaccine failure differ from those that are not due to vaccine failure is yet to be determined.

Discussion

After five years active surveillance the APSU is functioning well. High return rates of monthly report cards and questionnaires and feedback received from users during a recent evaluation confirm that the scheme is acceptable to its users. It is a simple and relatively cheap system to run. It is difficult to determine the cost-benefits of this system. However, direct costs are low, especially considering APSU facilitates simultaneous monitoring of several conditions. The APSU is not a disease register, but an anonymous case-finding system. It is neither sufficiently timely, nor has the resources or the expertise to function as a public health unit in following up disease contacts or tracing infective sources.

Studies conducted through the APSU on communicable and related diseases have provided previously unavailable national data that have allowed estimation of the incidence of these uncommon but important conditions as well as providing demographic and comprehensive clinical information. Some studies have identified risk factors, have determined the spectrum of morbidity and mortality, have identified current management or have provided information on factors affecting short-term outcome. Others have generated hypotheses that may be tested by further research or identified potential cohorts of cases that may be used for follow-up and intervention trials. In addition, studies have allowed the evaluation of alternative methods of case-finding, estimation of sensitivity of the APSU and highlighted problems with definition and classification of disorders studied.

APSU achievements include the promotion of collaborative research between scientific disciplines and workers in different states and the provision of an interface between clinicians, public health units, health departments and other national bodies collecting data on communicable diseases. APSU is a unique system that overcomes state barriers and allows prospective collection of national data. Availability of APSU data is more timely than that from some other systems, for many of which there are inherent administrative delays. Active surveillance combined with a high response rate is maximising case ascertainment. High level of cooperation of clinicians may relate to the information provided to them by APSU.

We anticipate that APSU will make an increasing and valuable contribution to monitoring communicable diseases in childhood in Australia in the future by continuing its current activities. Potentially it may also provide a mechanism for rapid surveillance in the event of an epidemiological emergency. This could be achieved by establishing a fast track for inclusion of a new condition on the card. APSU may also repeat previous studies to enable assessment of prevention strategies (eg new vaccines) or changes in disease patterns over time. Cohorts identified in APSU studies should be used for further research using follow-up, case-control and intervention methodologies.

Acknowledgments

We thank all contributors to the APSU for their ongoing support. We also thank Rennie D'Souza (Surveillance and Management Section, National Centre for Disease Control, Dept of Health and Aged Care), Margaret Burgess (National Centre for Immunisation Research & Surveillance), Jeffrey Hanna (Tropical Public Health Unit, Cairns), David Isaacs (Department of Immunology & Infectious Diseases, New Children's Hospital), Ann McDonald (National Centre in HIV Epidemiology and Clinical Research) and Peter McIntyre (National Centre for Immunisation Research & Surveillance and Department of Immunology & Infectious Diseases, New Children's Hospital) for providing information on their studies to the APSU. The APSU gratefully acknowledges financial support received from the Financial Markets Foundation for Children, the National Centre for Disease Control of the Commonwealth Department of Health and Aged Care of Australia, the National Centre in HIV Epidemiology and Clinical Research, Commonwealth Serum Laboratories, Victoria Health and the Department of Immunology and Infectious diseases at the New Children's Hospital in Sydney.

References

1. Hall SM, Glickman M. The British Paediatric Surveillance Unit. *Archives of Disease in Childhood* 1988; 63**:**344-346.
2. Australian Paediatric Surveillance Unit. Fifth annual report 1997, Editors Elliott E, Mildenhall S, Redmond D, Williams K, Peat J, Sydney 1998:
3. Williams K, Gazarian M, Chant K, Longbottom H, Mellis C, Nolan T, Oates RK, Ruben A, Elliott E, Contributors to the APSU Evaluation of the Australian Paediatric Surveillance Unit *Archives of Disease in Childhood* 1998; In Press
4. Herceg A, Kennett M, Antony J. Acute flaccid paralysis surveillance in Australia: the first year. *Communicable Diseases Intelligence* 1996; 20**:**403-405.
5. Elliott E, Henning P, Hogg G, Knight J, O'Loughlin E, Powell H, et al. Haemolytic uraemic syndrome in Australia 1994-5. *Communicable Diseases Intelligence* 1995; 19:310-312.
6. McDonald AM, Cruickshank M, Ziegler JB, Elliott E, Kaldor JM. Perinatal exposure to HIV in Australia, 1982-1994. *Medical Journal of Australia* 1997; 166**:**77-80.
7. McDonald AM, Elliott E, Cruickshank M, MacDonald M, Ziegler J. HIV in Australian children, 1993 and 1994. *Communicable Diseases Intelligence* 1995; 19**:**238-240.
8. Forrest JM, Burgess MA. Plotting the demise of congenital rubella and varicella (editorial). *Australian & New Zealand Journal of Public Health* 1996; 20**:**4-6.
9. Elliott E, Davidson G, Dorney S, Redmond D, Smith A, Shepherd R, et al. Extrahepatic biliary atresia (EHBA) in Australia 1993-6. *Journal of Paediatrics and Child Health* 1997; 33**:**A36 Abstract.
10. Royle JA, Williams K, Elliott E, Sholler G, Nolan T, Allen R, et al. Kawasaki disease in Australia, 1993-1995. *Archives of Disease in Childhood* 1998; In Press: