

AUSTRALIAN PAEDIATRIC SURVEILLANCE UNIT

ANNUAL REPORT, 2011

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Introduction

The Australian Paediatric Surveillance Unit (APSU) continues to facilitate national active surveillance of uncommon childhood conditions. In 2011, its 18th year of operation, a range of infectious, vaccine-preventable, mental health, congenital and genetic conditions, and injuries were studied. From 1994 to the end of 2011, the APSU had run a total of 52 surveillance studies. For many childhood conditions, the APSU provides the only mechanism for national data collection.¹

In 2011, the APSU conducted national surveillance for acute flaccid paralysis (AFP), congenital cytomegalovirus (cCMV), congenital rubella, perinatal exposure to HIV and HIV infection, neonatal herpes simplex virus (HSV) infection, congenital neonatal varicella and severe complications of varicella. Surveillance for the severe complications of influenza was undertaken during the influenza season for the 4th year in a row.

Methods

Australian Paediatric Surveillance Unit

The APSU uses standardised protocols and case definitions, which are developed in collaboration with the study investigators who provide specialised expertise for each of the conditions studied. Detailed protocols and case definitions for all conditions under surveillance are available from the APSU web site (www.apsu.org.au)

In 2011, 1,375 paediatricians and other child health clinicians around Australia reported to the APSU; 84% via email or on-line. It is estimated that approximately 91% of paediatricians who have graduated as a Fellow of the Royal Australasian College of Physicians and are currently active in clinical paediatric practice within Australia are participating in the APSU. The APSU clinician database is continually updated to reflect changes in clinician details.³

Monthly report card return rates have remained at over 90% since 1994. The rate of returned report cards gives an estimate of participation.² Clinicians who report cases provide information on the child's demographics, clinical presentation, treatment and short-term outcome. The APSU is reliant on the

study investigators for the clinical review of all data received and classification of notifications according to case definition criteria.²

It is important to note that complete ascertainment of cases by the APSU is unlikely. This is particularly relevant in remote communities where children have limited access to paediatricians, hospital admissions are brief or when children are not seen by a paediatrician. The APSU encourages the use of complementary data sources where available and reporting by a range of specialists to maximise case identification.^{4,5}

Paediatric active enhanced disease surveillance

The Paediatric Active Enhanced Disease Surveillance (PAEDS) system is a joint initiative of the APSU and the National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases. This is a hospital-based surveillance system with ascertainment of cases of target conditions conducted by specialist surveillance nurses. The PAEDS system has been operating since 2007 in 4 tertiary paediatric hospitals around Australia (New South Wales, Victoria, South Australia and Western Australia), with Queensland joining the PAEDS network from July 2012. PAEDS complements surveillance for AFP where the surveillance nurses screen and investigate relevant admissions.⁶

Results

A total of 1,375 clinicians participated in the APSU surveillance during 2011. The report card return rate was 90% for 2011. The response rate was slightly lower than in previous years; this was in part due to administrative challenges faced whilst transitioning to the on-line reporting system for New South Wales clinicians as well as staff changes in the APSU. It is anticipated that the participation rate will return to previous high levels when the transition phase to on-line reporting is completed.

Acute flaccid paralysis

The World Health Organization (WHO) surveillance target of at least 1 per 100,000 children aged less than 15 years has once again been reached by combining data from the PAEDS surveillance system and the APSU. Following review by the Australian Polio Expert Panel there were 62 confirmed cases of AFP reported in 2011. The most common diagnoses

Table: Confirmed cases identified in 2011 and for the total study period, and reported rates per 100,000 of the relevant child population

Condition	Date study commenced	Questionnaire response rate (%)	Number of confirmed cases 2011	Reported rate for 2011 (per 100,000)	Number of confirmed cases for total study period	Reported rate for total study period (per 100,000 per annum)
Acute flaccid paralysis	Mar 1995	100	62*	1.4 [†]	660	1.0 [‡]
Congenital cytomegalovirus	Jan 1999	65	24	8.1 [‡]	215	6.7 [§]
Congenital rubella (with defects)	May 1993	Nil	Nil	Nil	51	0.1
Perinatal exposure to HIV	May 1993	85	35	11.7 [‡]	469	9.5 [§]
HIV Infection	May 1993	NA	6	2.0 [‡]	83	1.6 [§]
Neonatal herpes simplex virus infection	Jan 1997	79	8	2.7 [‡]	129	3.5 [§]
Congenital varicella	May 2006	Nil	Nil	Nil	2	0.1 [§]
Neonatal varicella	May 2006	Nil	Nil	Nil	18	1.3 [§]
Severe complications of varicella	May 2006	67	2	0.1 [†]	47	0.2 [‡]
Severe complications of influenza [¶]	Influenza season each year since 2008	96	36	0.8 [†]	215	1.3 [‡]

* Includes all cases of acute flaccid paralysis reported via the APSU or PAEDS. All cases have been classified by the Polio Expert Panel as 'non-polio AFP' according to World Health Organization criteria.

† Based on population of children aged less than 15 years.

‡ Based on number of births.

§ Based on population of children aged less than 16 years.

|| Two notifications were received by the APSU, clinical data had not been returned at the time of submission.

¶ Influenza surveillance was conducted each year since 2008 during the influenza season, July to September except in the pandemic year (2009) when surveillance occurred from June to October.

All reported rates based on child population estimates published by the Australian Bureau of Statistics.⁷

All of the figures were correct at the time of submission and agreed by the chief investigators for each condition. As additional information becomes available cases may be reclassified for the current year and previous years.

of non-polio AFP was Guillain-Barré syndrome (29%), followed by transverse myelitis (19%) and acute disseminated encephalomyelitis (ADEM) (8%). Other diagnoses included conversion disorder, tick bite paralysis and Bell's palsy. Faecal specimen collection rates have remained low with only 42% of cases achieving the recommended 2 samples within 14 days of onset of paralysis, and only 31% of specimens being adequate for analysis by the National Polio Reference Laboratory. This is below the target of 80% achieving the recommended 2 samples set by the WHO.

Congenital cytomegalovirus

Since January 1999, 215 confirmed cases and 75 probable cases of cCMV have been reported to the

APSU. A total of 24 confirmed cases were reported in 2011. Four infants received antiviral therapy and a further four were identified after developing hearing loss after the first year of life. This study continues to inform the debate about cytomegalovirus screening and treatment options for pregnant women and infants, as cCMV remains the most common infectious cause of congenital malformation in Australia. A detailed analysis of the cCMV data was published in the *Medical Journal of Australia* and showed that cCMV was under-diagnosed and patients were infrequently treated.⁸ During the study period neonatal hearing screening was introduced for most Australian infants and resulted in an increase in the detection of hearing loss, from 19% of cCMV cases in the period 1999–2003 to 31% in 2004–2009.⁸

Congenital rubella with defects

There were no notifications of congenital rubella in 2011; the last reported case was notified to the APSU in 2009. This is clearly a reflection of the effectiveness of the vaccination program in Australia; however, we need to remain vigilant with regards to the potential for imported cases of rubella from people migrating to Australia from countries where rubella vaccination programs may not be well established.

Perinatal exposure to HIV and HIV infection

There were a total of 35 confirmed cases of perinatal exposure to HIV reported to the APSU during 2011. Six of the 35 children perinatally exposed to HIV acquired HIV infection. One of the six was the child of an Australian-born woman whose HIV infection was diagnosed antenatally. The other 5 children were born overseas in sub-Saharan Africa (3 children) or in South East Asia (2 children). Since May 1993, there have been a total of 469 cases of perinatal exposure to HIV infection reported to the APSU and 83 cases of HIV infection. Perinatal HIV infection remains a rare occurrence among children born to women whose HIV infection was diagnosed antenatally and who made use of interventions for minimising the risk of mother-to-child transmission.

Neonatal herpes simplex virus infection

In 2011, there were 8 confirmed and 2 probable cases (awaiting confirmation from clinicians) of neonatal HSV infection: 3 from Queensland, 2 each from New South Wales and Victoria, and 1 each from the Northern Territory, South Australia and Western Australia. HSV-1 remains the dominant serotype causing disease in this population (7/10). Three infants presented with localised disease to the skin, eye or mouth, 3 infants with encephalitis, and three with disseminated disease. Of note, there were no deaths reported at the time of notification. HSV continues to cause significant disease in the newborn period, predominately due to HSV-1 in Australia. There is a trend towards reduced mortality noted over the study period. Further surveillance of this important but uncommon condition is required to determine if this trend represents a significant change. From 2012, a new study with expanded scope to include HSV disease in the newborn and infants up to 1 year of age will commence to further define temporal trends in disease presentation and outcomes.

Severe complication of varicella infection

In 2011, 2 children hospitalised with severe complications of varicella were reported to the APSU. This was a significant decrease from 2010 with a total of 9 cases reported. Severe complications noted for these patients included; ataxia and bacteraemia.

Both of the reported cases were in hospital for a total of 5 days with neither being admitted to the paediatric intensive care unit (PICU). The 2 children reported were unvaccinated and the infecting contacts were close family members (sibling and cousin).

Congenital and neonatal varicella

In 2011, there were no reported cases of congenital or neonatal varicella. A detailed analysis of surveillance data for the whole study period and a comparison with data collected by the APSU in 1994–1996 was recently published and demonstrated that the rates of congenital varicella decreased during the period 2006–2009, though this did not reach statistical significance.⁹ However, a significant reduction in the incidence of neonatal varicella was demonstrated when compared with pre-vaccination data (1995–1997), supporting the effectiveness of the varicella vaccination program in Australia.⁹

Severe complications of influenza

In 2011, 36 children with severe complications of influenza were notified to the APSU. Their median age was 4.8 years (range 0.2 months–14.8 years). As in previous years, the main complication of influenza in 2011 was pneumonia, in 17 cases (47%). Fifteen (42%) required mechanical ventilation, 7 (19%) had encephalitis associated with seizures, and 7 (19%) had laboratory proven bacterial co-infection. Two children suffered myocarditis and rhabdomyolitis and 1 child was diagnosed with Guillain-Barré syndrome. Thirty-nine per cent of children (14) had chronic underlying conditions such as asthma or other chronic lung disease, immunocompromised, chronic heart disease and a variety of genetic conditions; only one of these children was vaccinated. None of the other children who had no underlying chronic conditions were vaccinated for influenza. Sixty-seven per cent (24) of children were admitted to PICU with a median stay of 7.5 days (range 1–58 days). Three children died.

Conclusions and future directions

The APSU continues to provide national surveillance data on a number of serious rare childhood diseases. The information collected by the APSU is extremely valuable to clinicians, policy makers and the wider community. For many conditions studied, the APSU is the only source of national data.

The APSU continues to inform public health policy and improve child health in Australia. This is evident from the results of the surveillance study of neonatal and congenital varicella, in which the rates of varicella (neonatal and congenital) infections have fallen dramatically since the introduction of the varicella vaccine to the National Immunisation

Program (NIP) in Australia.⁶ These results support the continuation of this program and highlight the potential benefits of varicella vaccination in countries that do not have a vaccination policy in place.

In addition to providing ongoing national surveillance data the APSU is able to conduct seasonal surveillance and to effectively and rapidly respond to outbreaks or emerging diseases as demonstrated by the rapid response to the A(H1N1) 2009 influenza pandemic. Findings from the influenza study noted that although serious complications occurred in children who had an underlying chronic condition, very few had been vaccinated for influenza despite this being provided for under the NIP.

In children admitted to hospital with severe complications of influenza between 2008 and 2011, vaccination rates were low, with only 3% of reported cases vaccinated in 2011. This is particularly important with regards to children who have a pre-existing chronic disorder who are eligible for vaccination under the NIP.

In October 2011, the APSU commenced a new surveillance study for juvenile onset recurrent respiratory papillomatosis (JoRPP). This is a rare condition, which usually develops in childhood and is typically found in children aged less than 12 years, with the median age being 4 years. It is the most common cause of benign neoplasms of the larynx in children and is caused by human papillomavirus (HPV) infection, with HPV 6 and HPV 11 being the two most common causative genotypes.¹⁰

The APSU Biennial Research Report 2009–2010 was published in May this year and is available on the APSU web site (www.apsu.org.au).

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References

1. Zurynski Y, Elliott EJ. Australian Paediatric Surveillance Unit annual report, 2010. *Commun Dis Intell* 2011;35(3):244–249.

2. He S, Zurynski Y, Elliott E. What do paediatricians think of the Australian Paediatric Surveillance Unit? *J Paediatr Child Health* 2010;46(7–8):412–418.
3. Zurynski Y, Elliott E, Groenendyk T, Ridley G. Australian Paediatric Surveillance Unit Biennial Research Report 2009 and 2010. Westmead: Australian Paediatric Surveillance Unit; 2011.
4. Zurynski Y, Peadon E, Bower C, Elliott EJ. Impacts of national surveillance for uncommon conditions in childhood. *J Paediatr Child Health* 2007;43:724–731.
5. He S, Zurynski Y, Elliott EJ. Evaluation of a national resource to identify and study rare diseases: The Australian Paediatric Surveillance Unit. *J Paediatr Child Health* 2009;45(9):498–504.
6. Pym M, Adams J, Booy R, Buttery J, Elia S, Elliott EJ, et al. The development and trial of paediatric active enhanced disease surveillance (PAEDS): A new surveillance mechanism for Australia. Paediatrics and Child Health Division, The Royal Australasian College of Physicians, Annual Scientific Meeting, 2008. Melbourne, Victoria Australia. Abstract published in *J Paediatr Child Health* 2008;44(9):A16.
7. Australian Bureau of Statistics. Australian Demographic Statistics. December quarter 2011 Canberra: Australian Bureau of Statistics; 2012.
8. McMullan B, Palasanthiran P, Jones C, Hall B, Robertson P, Howard J, et al. Congenital cytomegalovirus—time to diagnosis, management and clinical sequelae in Australia: opportunities for earlier identification. *Med J Aust* 2011;194(12):625–629.
9. Khandaker G, Marshall H, Peadon E, Zurynski Y, Burgner D, Buttery J, et al. Congenital and neonatal varicella: impact of the national varicella vaccination programme in Australia. *Arch Dis Child* 2011;95(5):453–456.
10. Novakovic D, Cheng A, Cope D, Brotherton J. Estimating the prevalence of and treatment patterns for juvenile onset recurrent respiratory papillomatosis in Australia pre-vaccination: a pilot study. *Sexual Health* 2010;7(3):253–261.