

INQPSU



**Annual Report of the
International Network of Paediatric
Surveillance Units
2008**

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1 Introduction

Following the successful development of the British Paediatric Surveillance Unit in 1986, the same methodology was adopted and adapted in the 1990s by other countries who wished to set up active paediatric surveillance systems. In 1992, surveillance units were established in the Netherlands and Germany and, in 1994, in Switzerland (Table 1). The European paediatric surveillance units then met and communicated regularly to discuss surveillance protocols.

The European initiative was also the stimulus for the development in 1992 of an Australian unit and later the Malaysian unit (1994) to be followed by units in Canada (1996) and Papua New Guinea (1996), Latvia and New Zealand (1997), Portugal (2001) and Greece/Cyprus (2003). Wales (1994) and Republic of Ireland (1996) developed surveillance units using a similar methodology to the BPSU, but including on more common disorders (Table 1). Two non-paediatric surveillance units have affiliated to INoPSU, these being the British Ophthalmology Surveillance Unit and UK Obstetric Surveillance System. Also within the UK a specialist paediatric neurology unit has been established and in the past year a child and adolescent psychiatry surveillance unit and a Scottish Paediatric Surveillance Unit. All the units contact each other for results, sharing of protocols and to put researchers in different countries in touch with each other

Through the use of active ascertainment, surveillance units provide an efficient, effective framework for case finding for investigators who wish to study rare conditions in children. Conditions under surveillance include infections, infection-related conditions, vaccine-preventable diseases, congenital and inherited (genetic) diseases, unusual injuries or therapies and rare complications of common diseases. The units frequently encourage, facilitate or elicit studies undertaken by clinical investigators and only occasionally initiate and undertake research themselves¹.

In 1998 an International Network of Paediatric Surveillance Units (INoPSU) was formed by existing units during the 22nd International Congress of Paediatrics in Amsterdam, The Netherlands².

The first INoPSU conference was held in June 2000 in Ottawa, Canada. Following this conference a document, known as the Amsterdam-Ottawa Note, detailing the functions and structure of the network was produced. The second conference was held in April 2002 in York, UK and the 3rd in May 2004 in Lisbon, Portugal, the 4th gathering in London was to celebrate the BPSU 20th anniversary.

This year (2008) saw the 5th conference held in Munich in conjunction with the German Paediatric Society Conference. At this meeting Dr Daniel Virella, of the Portuguese PSU was nominated as the new convenor of INoPSU, Richard Lynn will continue as the liaison officer overseeing the administration of INoPSU.

Over the past two years, INoPSU members have facilitated the surveillance of 70 different rare conditions (Appendix 1) and have now undertaken over 150 studies covering a child population of over 50 million children and involving over 10,000 clinicians. Details on all the activities of each surveillance unit are available from their respective websites and also from the INoPSU website (www.inopsu.com).

The mission of INoPSU is

- to advance knowledge of rare and uncommon childhood infections and disorders
- to enable participation of paediatricians in surveillance on a national and international basis so as to achieve a series of benefits to clinical practice and health policy.

Table: 1 - INoPSU Summary– Adapted from Annual Reports 2008

| Country | Child Population (aged 0-15 years) | Average No. Contributing Clinicians* | Reply by Card (%) | Reply By Email (%) | Average Report Cards Returned (%) | Average Questionnaire return rate (%) |
|---------------|------------------------------------|--------------------------------------|-------------------|--------------------|-----------------------------------|---------------------------------------|
| Australia | 4,117,176 | ~1300 | 33% | 67% | 94% | 85% |
| Britain | 12.300,000 | 2850 | 99% | <1% | 94% | 93% |
| Canada | 5,579,835 (0-14 years incl) | 2,500 | 100% | N/A | 80% | 94% |
| Cyprus/Greece | 1,660,000 | 110 | 100 | N/A | 100 | 100 |
| Germany | 12,000,000 | 478 (Card: 244 / Email: 234) | 95% | 97% | 96% | 80-100 (Median: 90,5) |
| Ireland | 1,320,823 (incl N Ire.) | 228 | 85% | 15% | 74% | 65% - 70% |
| Latvia* | | | | | | |
| Netherlands | 3,000,000 | 782 | 1% | 99% | 86% | 70-90% |
| New Zealand | 868,000 | 215 | 14% | 86% | 91.5% | |
| Portugal* | 1,400,000 | 1,800 | 70 | 30 | 33 | 66 |
| Switzerland | 1.270,000 | 35 | 100% | N/A | 97% | N/K |
| Wales | 556,600 | 169 | 11% | 89% | 99.5% | N/K |

* 2006 Data

Since its inception in 1998, INoPSU studies have provided scientific evidence to support the following public health actions:

Vaccine-Preventable Diseases

- **Pertussis Infection** (APSU, ESPED, NSCK, NZPSU, SPSU). International study results have demonstrated the severity of this infection and the possibility of transmission from older family members. In several countries, this led to a review of the age for the first vaccine, and to a targeted approach for adult and adolescent immunization programs.
- **Neonatal-Herpes Simplex Virus** (APSU, BPSU, CPSP, ESPED, NZPSU, SPSU). Study results demonstrated significant mortality rates, with HSV-1 as the most prevalent type. The need for an HSV-1 and HSV-2 effective vaccine is evident.
- **Congenital Cytomegalovirus infection** (APSU, BPSU, CPSP). All countries documented the severity of this illness. Following a two-year study in Canada, only severely-affected CMV cases were being detected; representing a fraction of the expected numbers. Study results support the need for a new vaccine, as well as routine CMV screening.

Clinical Practice Guidelines and Health Planning Services

- **Haemolytic uraemic syndrome** (APSU, BPSU, CPSP, ESPED, NZPSU, SPSU, NSCK). This syndrome peaks in most countries during the summer, with outbreaks due to different strains of *E. Coli* in water, hamburger meat, and kindy farms. Study

results support legislative measures for safe food production, public water testing, and ongoing education on preventative measures.

- **Vitamin K Deficiency Bleeding** (ASPU, BPSU, CPSP, ESPED, NSCK, NZPSU, SPSU). Study results demonstrated that most cases are of late onset and related to liver disease; with many patients receiving none or incomplete prophylaxis. Results reaffirmed the recommendations for the continued use of vitamin K prophylaxis in order to prevent hemorrhagic diseases of the newborn.
- **Vitamin D Deficiency Rickets** (ASPU, CPSP, WPSU). Although not as rare as first anticipated, the majority of cases were found in darker skinned and exclusively breastfed children. Study results reinforce the clinical practice guideline that Vitamin D supplementation should be given to all exclusively breastfed children, in order to prevent nutritional rickets.
- **Early-Onset Eating Disorders** (ASPU, BPSU, CPSP, NSCK). Food avoidance was signaled to be the most predominant clinical feature in early-onset eating disorders; with patients presenting with significant weight loss and the need to be hospitalized. Study results demonstrate the need to establish pre-adolescent diagnostic criteria, and early detection through the use of growth charts.

Injury Prevention

- **Lap-belt syndrome** (ASPU, CPSP). Both countries confirmed the lack of uniform legislative measures and signaled high morbidity rates. In Canada, 25% of reported children were left paraplegic, following a motor vehicle crash. Data gained from these studies have supported advocacy for age and size appropriate use of restraints in motor vehicles.
- **Chemistry set poisoning** (BPSU). Several incidents reported that supported the EU recommendations on toy packaging.
- **Accidental lamp oil poisoning** (ESPED). Ingestion of very small amount of lamp oil can seriously harm a child's health.

Table 2 - Studies that have led to collaboration

| | ASPU | BPSU | CPSP | ESPED | GCPSU | NSCK | NZPSU | SPSU | WPSU |
|--------------------------------------|------|------|------|-------|-------|------|-------|------|------|
| Pertussis infection | x | | | x | x | x | x | x | |
| Neonatal herpes simplex virus | x | x | x | x | | | x | x | |
| Congenital cytomegalovirus infection | x | x | x | | | | | | |
| Haemolytic uraemic syndrome | x | x | x | x | | x | x | x | |
| Vitamin K deficiency bleeding | x | x | x | x | | x | x | x | |
| Vitamin D deficiency rickets | x | | x | | | | | | x |
| Early-onset eating disorders | x | x | x | | | x | | | |
| Seatbelt syndrome | x | | x | | | | | | |
| Chemistry set poisoning | | x | | | | | | | |
| Accidental lamp oil poisoning | | | | x | | | | | |

Further information on the INoPSU is available from its (www.inopsu.com) and this yearly international report is shared as part of the national reports.

2 INoPSU Conference 2008

Following on from the successful 4th INoPSU meeting held in London during 2006, a fifth meeting was organised in Munich to coincide with the German Paediatric Society (GPS) annual scientific conference. Fifteen representatives from eight units attended the meeting only representatives from New Zealand, Wales, Ireland and Latvia were unable to attend.

The meeting allowed representatives from each of the national units to meet and exchange views on rare disease surveillance and issues that affect each of the units, particularly funding and the increasing need for confidentiality and consent. The morning session attended by over 50 conference delegates of the GPS scientific meeting, allowed INoPSU the chance to showcase its work. Presentations on prevention of paraffin aspiration in children (Ger); rapid response to flu complications (Aus); mad cow disease (UK), seatbelt injuries; fetal alcohol (Aus); cerebral palsy (Por) and the impact of INoPSU on disease surveillance (Can) were given. The presentations can be downloaded from <http://www.inopsu.com/publications/index.html>.

The afternoon saw the INOPSU business meeting, held in a local restaurant (inset). Here reports were received from the unit representatives. It was with concern we received news that several units are struggling; it was noted that the Trinidad unit has not been developed; and that the Papua New Guinea units has ceased surveillance. It was however, reported that the Argentine, Scotland and Italy are interested in developing similar such units and INOPSU will be lending support if needed. A new work programme was agreed; one aim being to increase the profile of INoPSU work at international conferences another to improve communication and the sharing of research protocols.

Finally, Daniel Virella of the Portuguese Paediatric Surveillance Unit will be INoPSU convenor for the next 2 years, replacing Rob Pereira from the Netherlands.

For further information on INOPSU please contact the BPSU office (bpsu@rcpch.ac.uk or visit www.inopsu.com)

Figure 1 INoPSU Delegates



3 National Units 2008 Highlights

Australia

The APSU undertook its second systematic evaluation of the APSU surveillance system completed according to the U.S. Centers for Disease Control (CDC) and Prevention criteria for surveillance programs, with detailed comments received from over 860 paediatricians. Two papers submitted for publication.

In 2008 APSU celebrated 15 years of surveillance by launching the "APSU: Celebrating 15 years of Surveillance 1993-2007" book and by holding special sessions at the Royal Australasian College of Physicians Annual Congress. More information please go to: <http://www.apsu.org.au/index.cfm?objectid=276B3B64-A05B-98BC-FE6A3F2F45201C35>

APSU called for a national response to the significant impacts of rare childhood diseases in Australia by publishing a paper in Archives of Disease in Childhood, a letter in the Medical Journal of Australia and securing a Creswick Fellowship to enable travel to Europe in 2009 to study initiatives for rare diseases.

APSU presented two papers at the bi-annual INoPSU meeting in Munich.

The Paediatric Active enhanced Disease Surveillance (PAEDS) of the APSU in collaboration with the National Centre for Immunisation Research and Surveillance conducted a pilot study in four paediatric hospitals in 4 states of Australia to determine feasibility of conducting active hospital-based surveillance similar to the IMPAct system in Canada.

APSU conducts surveillance for severe complications of influenza during the 2007 and 2008 influenza season and plans to repeat this surveillance in subsequent years.

Britain

In 2008 the BPSU secured an £700,000 extension of its grant from the Department of Health for a further 3 years until spring 2012. In conjunction with the DH policy unit the BPSU has drawn up a work program which will reflect the needs of those who wish to use the BPSU and the research priorities within the DH.

The BPSU also embarked on an internal evaluation of BPSU processes, outputs and the degree to which the BPSU meets its aims and objectives. This was conducted using U.S. CDC guidelines on assessing surveillance systems. Part of this evaluation incorporate surveys of the opinions of investigators and clinicians. Feedback was positive and the system is found to be both useful and valued by paediatricians with 84% paediatricians considering the surveillance of rare paediatric disease to be important and 43% stating that they had changed their clinical practice following the outcome of BPSU studies.

Two new UK surveillance units have recently been developed with the help of the BPSU. This system will use the same methodology as the BPSU, and after initially running from the BPSU offices, has now been transferred to the Royal College of Psychiatry to be run as a new autonomous surveillance unit. Further details are available at www.rcpsych.ac.uk. The second new unit is the Scottish Paediatric Surveillance System. Based in Edinburgh the unit will commence surveillance in September 2009 study to be surveyed for include inflammatory bowel disease and fetal alcohol syndrome.

Canada

In 2008, the CPSP successfully conducted enhanced surveillance on the emerging issue of melamine contamination of powdered milk products, in collaboration with the NZPSU. Emergency response exemplifies the excellent added value of investing in a national network of active surveillance well connected with front-line paediatricians and public health officials.

Studies were completed on congenital CMV infections, head injury secondary to suspected child maltreatment (abuse or neglect), medium-chain acyl-coenzyme A dehydrogenase deficiency, non-type 1 diabetes mellitus and transfusion-related acute lung injury.

One-time survey questions were done on paediatric pre-travel care and travel-related illnesses in paediatrics. This led to the development and distribution of a communication poster that was widely distributed.

Cyprus/Greece

Our Unit has been one of the newest of INoPSU, established by Professor C Hadjichristodoulou and Professor M.Theodoridou in 2002. It consists of clinicians from both Greece and Cyprus running studies respectively. The Unit has been currently running two studies only in Greece.

Two independent studies regarding a network of clinicians reporting Congenital Toxoplasmosis and Haemolytic- Uraemic Syndrome cases were still running throughout 2008. Epidemiological data are expected before the end of 2009. This could be the stimulus for the implementation of new studies, as participation of clinicians was satisfying during the study period. However we are thinking of creating a new reporting system based preferably on e-mailing.

Germany

We were pleased to host the 5th INOPSU conference in Munich in October as part of the German Paediatric Society Scientific Conference; over 15 unit representatives attended. The open session within the society meeting was attended by over 50 conference delegates who heard presentations on recent INoPSU activities.

Ireland

The work of the unit has demonstrated the impact surveillance can have on health service policy. Initial results from Kawasaki Disease (KD) study indicate that many children were not referred for cardiology assessment in a timely manner. The importance of cardiology assessment in cases of KD is due to be highlighted to Irish paediatricians, based on the findings of the study. Data from the complicated pneumonia study is being used to provide baseline surveillance data for the introduction of conjugate pneumococcal vaccine into the routine childhood immunisation schedule in Ireland.

Results from a two year pilot study of neonatal screening for congenital toxoplasmosis has led to a recommendation for toxoplasmosis to be included in the national neonatal screening programme in Ireland. Whilst results of the severe bronchiolitis study have provided new insight into the epidemiology of RSV infection in Ireland, and contributed to the ongoing assessment of paediatric ICU requirements in Ireland.

Latvia

No report submitted

Netherlands

The Netherlands unit reported on concerns about the impact of drinking in the young. A survey monitored the impact of admissions due to alcohol intoxication. 337 children were admitted (13% more than in 2007), mean age was 15 y, 48% boys, the youngest was 10y, mean blood alcohol level was 1.9 promille (this is about 10 glasses of alcohol). It is certainly on the political agenda now. Many articles in the papers were published and it appeared on television. Five polyclinics on alcohol problems were started in the country.

New Zealand

The highlight for the NZ unit in 2008 was one off study undertaken to explore the possibility of melamine associated renal stones in New Zealand Infants.

The importance of this study was in the method, which showed we could undertake rapid surveillance across New Zealand to potentially identify any new problems early.

Portugal

Over the next couple of years, new INoPSU convenor Daniel Virella from the Portuguese PSU wishes to strengthen and raise the profile of the network, including activities and output. He also encouraged closer association between national units undertaking simultaneous studies. One of the goals is for each unit to advocate for a national plan on rare diseases at the government level and to encourage further epidemiological research and to advance knowledge in this field.

Switzerland

In the past year the Swiss Paediatric Surveillance Unit has completed a seven-year study on neural tube defects (NTDs) and identified 140 cases. Of these 68 cases (48%) were born alive and included 58 meningoceles, nine encephaloceles and one anencephaly. A Poretta et al. published an article in the Swiss Medical Weekly entitled "Neural tube defects in Switzerland from 2001 to 2007; are periconceptual folic acid recommendations being followed? "NTDs remain a frequent problem in Switzerland, although correct periconceptual folic acid supplementation is known to be effective in reducing the prevalence of NTDs. Consequently, only a public health policy that included folic acid fortification of food is likely to result in significant prevention of NTDs.

Wales

The WPSU performs monthly surveillance on a child population of just under 600 000. Respondents are chiefly paediatric consultants, with an *ad hoc* allocation of other medical specialists as dictated by the nature of the study being undertaken. About 200 paediatricians report to the WPSU, with an average return of report cards being 99%. Wales is also consistently the best-reporting region in the UK for the BPSU, which reflects the ongoing commitment of paediatricians in Wales to this initiative. The WPSU is currently facilitating six studies: gallstones in children, craniosynostosis, long-term ventilation, nosebleeds in infancy, vitamin D deficiency and neonatal hypoxic-ischaemic encephalopathy.

Over the last year the WPSU has successfully ported the reporting system from a card-based to a chiefly electronic means of reporting cases, with virtually no change in the response rate. The time for reports to come through to the WPSU office is also very short, with more than two-thirds being within two days of the "electronic cards" going out. The report rate is in contradistinction to the report completion rate, which is very poor, ranging from 40 to 80%. This aspect of the WPSU function will be the focus of our efforts for the next year.

4 Studies undertaken by PSU's in 2008

| Study | National Paediatric Study Surveillance Units |
|--|--|
| Acute encephalitis/encephalomyelitis | PPSU |
| Acute flaccid paralysis | CPSP, NZPSU, SPSU |
| Acute post streptococcal glomerulonephritis | NZPSU |
| Acute rheumatic fever | SPSU |
| Adolescent pregnancy | LPSU |
| Adrenal insufficiency | IPSU |
| Adverse drug reactions – serious and life threatening | CPSP, NZPSU |
| Alcohol intoxication | NSCK |
| Anaphylaxis (immunization) | BPSU, ESPED, SPSU |
| Bleeding complications after tonsillectomy/adenoidectomy | ESPED |
| Bulimic eating disorders | CPSP |
| Cerebral palsy among five-year-olds | PPSU |
| Chronic fatigue syndrome | NSCK |
| Complicated Pneumonia | IPSU |
| Congenital adrenal hyperplasia | BPSU, IPSU |
| Congenital cytomegalovirus infection | CPSP, PPSU |
| Congenital myotonic dystrophy | CPSP |
| Congenital renal or urological defects | NSCK |
| Congenital rubella syndrome | APSU, BPSU, NZPSU, SPSU |
| Congenital toxoplasmosis | CGPSU, PPSU |
| Conversion disorder | BPSU |
| Craniosynostosis | WPSU |
| Cystic fibrosis | NSCK |
| Diabetes mellitus | CPSP, LPSU, PPSU |
| Down syndrome and Leukaemia | NSCK |
| Epistaxis in infancy | WPSU |
| Extended-spectrum β -lactamase-producing enteric Gram-negative bacilli | SPSU |
| Fetal alcohol syndrome | NSCK |
| Feto-maternal alloimmune thrombocytopenia | BPSU |
| Gallstones | WPSU |
| Genital herpes under 11 years | BPSU |
| Group B streptococcal sepsis | APSU, PPSU |
| Head injuries secondary to suspected child maltreatment (abuse or neglect) | CPSP |
| Hemoglobinopathy | NSCK |
| Haemolytic uremic syndrome | CGPSU, NZPSU, PPSU, SPSU |
| Hepatitis C virus infection | APSU |
| HIV/AIDS (perinatal HIV exposure) | BPSU, NZPSU |
| Hyperbilirubinaemia | NSCK, SPSU |
| Idiopathic intracranial hypertension (pseudotumor cerebri) | BPSU, ESPED |
| Inborn errors of metabolism | NZPSU |
| Influenza | APSU, ESPED |
| Interrupted pregnancy in adolescents | LPSU |
| Intussusception | BPSU |
| Juvenile idiopathic arthritis | CPSP |
| Juvenile myoclonic epilepsy | WPSU |
| Kawasaki disease | NSCK, PPSU, CPSP, IPSU |
| Kernicterus | CPSP |
| Leukaemia | LPSU, NSCK |
| Langerhans Cell histiocytosis | CPSP |
| Long-term ventilation | WPSU |
| Lymphoma: Hodgkin's, non-Hodgkin's | LPSU |
| Medium-chain acyl-CoA dehydrogenase deficiency | BPSU, CPSP |

| | |
|--|-------------------|
| Methicillin-resistant <i>Staphylococcus aureus</i> (MRSA) | CPSP |
| Multiple sclerosis/ADEM | NSCK |
| Neonatal herpes simplex virus infection | SPSU |
| Osteitis, non-bacterial | ESPED |
| Paracetamol overdose | IPSU |
| Pertussis | SPSU |
| Progressive intellectual and neurological deterioration (PIND) | BPSU |
| Severe asthma | ESPED, NSCK |
| Serious adverse events associated with complementary and alternative medicine | CPSP |
| Severe combined immunodeficiency | CPSP |
| Sudden unexpected early postnatal collapse | BPSU |
| Toxic shock syndrome | BPSU |
| Transfusion-related acute lung injury | CPSP |
| Travel-related illnesses in paediatric travellers who visit friends and relatives abroad | CPSP |
| Varicella (neonatal, congenital, and complications) | IPSU, PPSU |
| Vitamin D deficiency rickets | WPSU |
| Vitamin K deficiency bleeding/HDNB | BPSU, NZPSU, SPSU |
| Walker injuries | PPSU |

Legend:

| | |
|-------|--|
| APSU | Australian Paediatric Surveillance Unit |
| BPSU | British Paediatric Surveillance Unit |
| CGPSU | Cyprus/Greece Paediatric Surveillance Unit |
| CPSP | Canadian Paediatric Surveillance Program |
| ESPED | German Paediatric Surveillance Unit |
| IPSU | Irish Paediatric Surveillance Unit |
| LPSU | Latvian Paediatric Surveillance Unit |
| NSCK | Netherlands Paediatric Surveillance Unit |
| NZPSU | New Zealand Paediatric Surveillance Unit |
| PPSU | Portuguese Paediatric Surveillance Unit |
| SPSU | Swiss Paediatric Surveillance Unit |
| WPSU | Welsh Paediatric Surveillance Unit |

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Affiliated Units

UK Obstetrics Surveillance System
British Ophthalmology Surveillance Unit
British Paediatric Neurology Surveillance Unit

Developing and supporting new units

INoPSU have had several enquiries over the years from paediatricians in countries who wish to develop similar such surveillance systems. In many cases INoPSU members have given advice on developing a surveillance unit. The BPSU have produced a short document that outlines what is required (**Appendix 3**). Recent enquiries have come from clinicians in the Argentine, Scotland and Italy as well as clinicians from other specialists in the UK (child psychiatry) and Australia (ophthalmology). Such enquiries have led to the recent establishment of the Child and Adolescent Psychiatry Surveillance Systems (UK) and the Scottish Paediatric Surveillance Unit

6 INoPSU Publications

1. Grenier D, Lynn R, Zurynski Y on behalf of all national paediatric surveillance unit investigators. Public health impacts of the International Network of Paediatric Surveillance Units. *Paediatr Child Health* Vol **14** No **8** October 2009 pg 499-500
2. Grenier D, Elliott EJ, Zurynski Y, Pereira R Rodrigues, Reece M, Lynn R, Kries von R Beyond Counting Cases: Public Health Impact of National Paediatric Surveillance Units. *Arch Dis Child*. 2007 Vol.**92** (**6**) 527-55.
3. Elliott E, Nicoll A, Lynn R, Marchessault V, Hirasing R (INoPSU Secretariat), on behalf of INoPSU members An international network of paediatric surveillance units: A new era in monitoring uncommon diseases of childhood. . *Paediatrics and Child Health*; 2001 **6**: No 5 pg 250-9
4. Pereira-da-Silva L, von Kries R, Rose D, Elliott E. Acknowledging contribution to surveillance studies. *Arch Dis Child*. 2005 Jul;**90**(7):768.
5. Cornelissen M, McNinch A, Tripp J, Shrubiger G, Loughnan P, von Kries R. Prospective studies on vitamin K deficiency bleeding in various countries. *Eur J Pediatr* 1997;156:126-30.
6. Cornelissen M, Von Kries R, Loughnan P, Schubiger G. Prevention of vitamin K deficiency bleeding: efficacy of different multiple oral dose schedules of vitamin K. *Eur J Pediatr* 1997;**156**:126-30.
7. Conyn-van-Spendonck MAE, Heath P, Slack M, con Kries R. Paediatric surveillance as a tool for the evaluation of National Immunisation Programmes, particularly of immunisation against invasive infection by *Haemophilus influenzae* type b. *Paediatric Research* 1995: **38**: 423-33
8. INOPSU Report 1998-2002. Royal College of Paediatrics and Child Health - London 2003.

7 INOPSU History Timeline

| Year | Activity | Year | Activity |
|--------|---|------|---|
| 1984 | British Paediatric Surveillance Unit (BPSU) Committee set up | | Joint national study on Vitamin K deficiency bleeding published - Eur J Pediatr 1997;156:126-30. |
| 1985 | BPSU pilot surveillance commenced | | |
| Jun-86 | BPSU Launched | | |
| 1988 | Professor Guus de Jonge in Netherlands discuss BPSU with JD Baum | 1998 | At the 22nd International congress of Paediatrics in Amsterdam 10 units agree a document (Amsterdam Note) that outlines the formation of INOPSU |
| 1988 | Professor Eberherdt Schmidt in Germany discusses BPSU with JD Baum | | The Amsterdam Note is ratified at the first INOPSU conference, held in Ottawa Canada. Document outlining INOPSU terms of reference renamed Amsterdam-Ottawa note. |
| 1990 | Dutch Paediatric Association approved a Dutch surveillance unit | | British Ophthalmology Surveillance Unit accepted into INOPSU as an affiliate member |
| 1992 | Dutch and Germany Units launched | 2000 | INOPSU web site launched |
| 1992 | Dr Elizabeth Elliott spoke to Dr Susan Hall re: BPSU activities | | Prof.Hadjichristodoulou talks with the BPSU with the aim of developing a Greece/Cyprus unit |
| 1992 | Dr Elizabeth Elliott launches Australian Unit with support of Australian College of Physicians | | Portuguese Paediatric Surveillance Unit launched |
| 1992 | Professor Joe Sibert at the Welsh Paediatric Society meeting suggested the establishment of a Welsh unit separate from the BPSU | | At the International Paediatric Association (IPA) meeting INOPSU accepted as an affiliate |
| 1992 | Welsh Paediatric Surveillance System (WPSS) was set up in 1994 as a joint venture between the University of Wales Departments of Child Health (Professor Jo Sibert) and Public Health Medicine (Professor Stephen Palmer) | 2001 | INOPSU publish first paper - Rare disease surveillance: an International perspective |
| | Malaysian Paediatric Surveillance Unit launched with assistance from Australia | 2002 | 2nd INOPSU conference held in York, UK |
| | 1st and 2nd EU grant applications submitted - rejected | 2003 | Greece/Cyprus Unit launched |
| 1994 | Germans, Dutch and British Units met with the newly formed Swiss Unit in Leiden for the first European Paediatric Surveillance Unit meeting | | 3rd INOPSU conference held in Lisbon, Portugal |
| | Dr Victor Marchessault, who was a member of the British Paediatric Association took the idea of a paediatric surveillance back to Canada | | INOPSU website redeveloped |
| 1995 | | | INOPSU present workshop at IPA meeting in Cancun, Mexico |
| | First joint EPSU study published. - Pediatr Res 1995;38:423-33 | 2004 | INOPSU paper - How to acknowledge the work of our contributors": a paper appeared in July 2005: Arch Dis Child: 90:768 |
| 1995 | European units present at ESPID conference in Denmark | 2006 | 4th INOPSU conference held in London, UK |
| 1996 | Launch of the Canadian Paediatric Surveillance Programme | | INOPSU paper published in Archives of Disease in Childhood |
| | Papua New Guinea Surveillance Unit launched with assistance from Australia | 2007 | FP7 Grant application for funding rejected |
| 1996 | Professor Elizabeth Elliott wrote to the BPSU proposing the development of an International surveillance unit network | | Malaysian and Papua New Guinea Units fold |
| 1996 | Launch of the New Zealand, Irish and Latvian Unit | 2008 | 5th INOPSU conference held in Munich, Germany |
| 1997 | | 2008 | E-newsletter launched |
| | | 2009 | Malaysian unit re-launched |
| | | 2009 | Child and Adolescent Psychiatry unit launched in the UK |
| | | 2009 | Scottish Paediatric Surveillance Unit launched in September |

Appendix 1 Publications and Presentations 2008

Australia

Publications

1. Roberts JA, Grant KA, Ibrahim A, Thorley BR. Annual report of the Australian National Poliovirus Reference Laboratory 2007. *Commun Dis Intell.* 2008 Sep;32(3):308-15.
2. Elliott EJ, Payne J, Morris A, Haan E, Bower C. Fetal alcohol syndrome a prospective national surveillance study. *Archives of Disease in Childhood* 2008; 93:732-737.
3. Elliott EJ, Bower C. Alcohol and pregnancy: the pivotal role of the obstetrician. *Australian and New Zealand Journal of Obstetrics and Gynaecology.* 2008; 48:236-239.
4. Fremantle E, Zurynski Y, Mahajan D, D'Antoine H, Elliott EJ. Indigenous child health: urgent need for improved data to underpin better health outcomes. *Medical Journal of Australia* 2008; 188: 588-591.
5. Giles ML, McDonald AM, Elliott EJ, Ziegler JB, Hellard ME, Lewin SR, Kaldor JM. Variable uptake of recommended interventions to reduce mother to child transmissions of HIV in Australia, 1982-2005. *Medical Journal of Australia* 2008; 189(3) 151-154.
6. Gleeson HK, Wiley V, Wilcken B, Cowell CT, Thomsett M, Byrne G, Elliott E, Ambler GR. Two year pilot study of newborn screening for congenital adrenal hyperplasia in New South Wales compared with nationwide case surveillance in Australia. *Journal of Paediatrics and Child Health* 2008 (44): 554-559.
7. He S, Zurynski Y, Elliott E. Evaluation of a national resource to identify and study rare diseases: the Australian Paediatric Surveillance Unit. *Journal of Paediatrics and Child Health.* 2009 (In press).
8. He S, Zurynski Y, Elliott E. Paediatricians views of the acceptability, value and limitations of a national rare diseases surveillance program. *Archives of Disease in Childhood* 2008 (Submitted).
9. Jaffe A, Zurynski Y, Beville L, Elliott E. Call for a national plan for rare diseases. *Journal of Paediatrics and Child Health.* 2008 (In press).
10. Lester-Smith D, Zurynski Y, Booy R, Festa M, Kesson AM, Elliott E. The burden of childhood influenza in a tertiary paediatric setting. *Communicable Diseases Intelligence* 2008 (Submitted).
11. Madden S, Morris A, Zurynski Y, Kohn M, Elliott E. The burden of eating disorders in children aged 5-13 years in Australia. *Medical Journal of Australia* 2008 (In press).
12. McDonald A, Zurynski Y, Wand HC, Giles M, Elliott E, Ziegler J, Kaldor J. Perinatal exposure to HIV among children born in Australia. *Medical Journal of Australia* 2008 (In press).
13. Michael M, Elliott E, Ridley G, Hodson E, Craig J. Interventions for haemolytic uraemic syndrome and thrombotic thrombocytopenia purpura. *Cochrane Renal Group.* 2008 (In press).
14. Peadon E, Bower C, Elliott EJ. Teenage smoking in pregnancy and birthweight: a population study, 2001-2004. *Medical Journal of Australia* 2008; 189(4):237-238 (Letter).
15. Peadon E, Fremantle E, Bower C, Elliott EJ. International survey of diagnostic services for children with fetal alcohol spectrum disorders. *BMC Pediatrics*, 2008; 8:12.
16. Wood N, Quinn HE, McIntyre P, Elliott EJ. Pertussis in infants: preventing deaths and hospitalisations in the very young. *Journal of Paediatrics and Child Health* 2008; 44:161-165.
17. Wood N, McIntyre P. Pertussis: review of epidemiology, diagnosis, management and prevention. *Paediatric Respiratory Reviews.* 9(3):201-11;quiz211-2, 2008 September.
18. Yee A, De Ravin SS, Elliott EJ, Ziegler J. Severe combined immunodeficiency: a national surveillance study. *Pediatric Allergy and Immunology* 2008; 19:4 298-302.
19. Young DJ, Bebbington A, Anderson A, Ravine D, Ellaway C, Kulkarni A, de Kerk N, Kaufmann WE, Leonard H. The diagnosis of autism in a female: could it be Rett syndrome? *European Journal of Pediatrics.* 167 (6): 661-9, 2008 June.
20. Zurynski Y, Elliott E. Australian Paediatric Surveillance Unit Annual Report, 2006. *Communicable Diseases Intelligence* 2008; 32(1).
21. Zurynski Y, Bilston L, Elliott EJ. Booster seat use by children aged 4-11 years: evidence of the need to revise current Australasian standards to accommodate overweight children. *Medical Journal of Australia* 2008; 189: (3). (Letter).
22. Zurynski Y, Lester-Smith D, Festa MS, Kesson AM, Booy R, Elliott EJ. Enhanced surveillance for serious complications of influenza in children: role of the Australian Paediatric Surveillance Unit. *Communicable Diseases Intelligence* 2008; 32(1): 71-76.
23. Zurynski Y, Reeve K, Leonard H, Elliott E. Rare diseases: how should we respond? *Archives of Disease in Childhood* 2008; 93(12):1071-1074.
24. Zurynski Y, Mahajan D, Elliott E. Australian Paediatric Surveillance Unit: Annual Report 2007. *Communicable Diseases Intelligence* 2008 (In press).

Reports

1. Mahajan D, Zurynski Y, Peadon E, Elliott E (Eds.) Australian Paediatric Surveillance Unit Biannual Research Report 2005-2006. 8,2008, ISSN: 1443-3524.
2. Srikanthan S, Zurynski Y, Elliott E. Australian Paediatric Surveillance Unit: Celebrating 15 years of surveillance. Australian Paediatric Surveillance Unit, Sydney 2008; ISBN: 978-0-646-49063-2.

Abstracts

1. He S, Zurynski Y, Elliott E. Second evaluation of The Australian Paediatric Surveillance Unit: An excellent report card. *Journal of Paediatrics and Child Health* 2008; 44(9): A16.

- Lester-Smith D, Zurynski Y, Festa M, Kesson A, Booy R, Elliott E. Significant burden of childhood influenza in a tertiary paediatric setting. *Journal of Paediatrics and Child Health* 2008; 44(9): A12.
- Lloyd-Johnson C, Danchin, M, Zurynski Y, Elliott E, Richmond P, Krause V, Beggs S, Nissen M, Gold M, Bines, J. Preliminary national data on acute Intussusception in Children aged ≤ 24 months from the Australian Paediatric Surveillance Unit (APSU). *Journal of Paediatrics and Child Health* 2008; 44(9): A7.
- Mahajan D, Fremantle E, Zurynski Y, D' Antoine H, Elliott EJ. Indigenous child health: urgent need for improved data to underpin better health outcomes. *Journal of Paediatrics and Child Health* 2008; 44(9): A23.
- Munns C, Zacharin M, Rodda C, Davis E, Harris M, Batch J, Pascoe M, Fairchild J, Lafferty A, Whybourne A, Ward L, Morley R, Garnett S, Burgner D, Geddes J, Cherian S, Mahajan D, Zurynski Y, McKay N, Cowell C. Vitamin D Deficiency Rickets In Australian Children: An APSU Study. *Journal of Paediatrics and Child Health* 2008; 44(9): A7.
- Peadon E, Burgner D, Buttery J, Elliott E, Gold M, Nissen M, Zurynski Y, Booy R. Congenital, neonatal and severe varicella in Australia following the introduction of national immunisation. *Journal of Paediatrics and Child Health* 2008; 44(9):A19.
- Peadon E, Payne J, Henley N, O'Leary C, D'Antoine H, Bartu A, Bower C, Elliott E. Alcohol and pregnancy: what influences Australian women's knowledge, attitudes and practice? *Journal of Paediatrics and Child Health* 2008; 44(9): A6.
- Pym M, Adams J, Booy R, Buttery J, Elia S, Elliott E, Gold M, Heath C, Marshall H, McIntyre P, Phillips A, Rhind L, Richmond P, Royle J, Wall K, Wood N and Zurynski Y. The development and trial of paediatric active enhanced disease surveillance (PAEDS): A new surveillance mechanism for Australia. *Journal of Paediatrics and Child Health* 2008; 44(9): A16.
- Rawlinson W, McMullan B, Howard J, Robertson P, Palasanthiran P. Congenital CMV infection: APSU data and follow-up of a cohort of affected infants. *Journal of Paediatrics and Child Health*. 2008; 44(9): A15.
- Villano DJ, Kornberg AJ, Lamont P, North KN, Rowe P, Sinclair K, Ryan MM. APSU study of neuromuscular disorders in childhood. *Journal of Paediatrics and Child Health*. 2008; 44(9):A18.
- Zurynski Y, Lester-Smith D, Festa M, Kesson A, Booy R, Elliott E. Rapid enhanced surveillance for serious complications of influenza in children using the Australian Paediatric Surveillance Unit. *Journal of Paediatrics and Child Health* 2008; 44(9): A11.
- Zurynski Y, McCaskill M, Bilston L, Leditschke F, Dilley A, Elliott E. Child injuries and deaths associated with inappropriate use of child restraints and seatbelts. *Journal of Paediatrics and Child Health*. 2008; 44(9): A6.

Presentations

- Elliott E. FASD in Australia: current status and challenges. National Fetal Alcohol Spectrum Disorder (FASD) workshop. 19-20 August 2008. Stamford Grand Glenelg, Adelaide.
- Elliott E. Women's attitudes, knowledge and practice regarding FASD and alcohol use in pregnancy. National Fetal Alcohol Spectrum Disorder (FASD) workshop. 19-20 August 2008, Stamford Grand Glenelg. Adelaide.
- Elliott E. Interventions for FASD and international survey. National Fetal Alcohol Spectrum Disorder (FASD) workshop. 19-20 August 2008, Stamford Grand Glenelg. Adelaide.
- Elliott E. Drinking for two: alcohol, pregnancy and the unborn child. Healthy Start to Life Research Initiative National Conference – "Alcohol in pregnancy: is any too much"? 13-14 November 2008 Monash University, Melbourne.
- Fremantle E, Zurynski Y, Mahajan D, D'Antoine H, Elliott E. Health data on Indigenous children: what do we need to improve health outcomes? Coalition for Research to Improve Aboriginal Health (CRIA) Conference, May 2008, Sydney.
- Munns C, Zacharin M, Rodda C, Davis E, Harris M, Batch J, Pascoe M, Fairchild J, Lafferty A, Whybourne A, Ward L, Morley R, Garnett S, Burgner D, Geddes J, Cherian S, Mahajan D, Zurynski Y, McKay N, Cowell C. Vitamin D Deficiency Rickets In Australian Children: An APSU Study. ANZBMS 2008 ASM. 2008 August 30, Melbourne.
- Zurynski Y, Lester-Smith D, Festa MS, Kesson AM, Booy R, Elliott EJ. Rapid response surveillance for severe complications of influenza in children. INoPSU Bi-Annual Scientific Meeting, Munich. September 12, 2008.
- Zurynski Y, Elliott E. From surveillance to policy development: Seatbelt injuries and fetal alcohol syndrome in Australia. INoPSU Bi-Annual Scientific Meeting, Munich. September 12, 2008.
- Zurynski Y. The burden of rare childhood diseases: How is Australia responding? Children's Health Conference 17-18 November 2008. Manly Pacific Sydney, Manly.

Invited Presentations for the APSU session RACP Congress 11-15, 2008, Adelaide

- E Elliott. Paediatricians and the APSU: 15 years of collaboration – Plenary Session.
- E Elliott on behalf of the Alcohol in Pregnancy Research Group. Fetal alcohol syndrome (FAS): from surveillance to policy.
- Grenier D, Elliot EJ, Zurynski Y, Pereira RR, Preece M, Lynn R, von Kries R, Zimmerman H, Dickson NP, Virella D and all participants and investigators of the International Network of Paediatric Surveillance Units. Impacts of the International Network of Paediatric Surveillance Units.
- Jones CA. Surveillance for perinatal viral infections of medical importance in Australian children: Hepatitis C Virus, Herpes Simplex Virus and Rubella.
- Kaldor J, McDonald A, Zurynski Y, Studdert J, Elliott E, Ziegler J. Perinatal exposure to HIV in Australia, 1982-2006.
- Morris A, Madden S, Zurynski Y, Kohn M and contributors to the Australian Paediatric Surveillance Unit. Early-onset eating disorders in Australian children.
- Rawlinson WD, Hall B on behalf of the APSU Congenital Cytomegalovirus Project. APSU: Congenital cytomegalovirus reporting.
- Ryan M. Polio free: Surveillance for acute flaccid paralysis.
- Zurynski Y, Chang H, Frith K, McKay N, McCaskill M, Bilston L, Leditschke F, Dilley A, Elliott E and all clinicians who report to the Australian Paediatric Surveillance Unit. Seatbelts and child restraints: injuries, deaths and the law.

Britain

Publications

1. A Judd, R Ferrand, E Jungmann, C Foster, J Masters, B Rice, H Lyall, P Tookey, K Prime. Vertically acquired HIV diagnosed in adolescence and early adulthood in the United Kingdom and Ireland: findings from national surveillance. *HIV Medicine* 2009; **10**:253-256
2. CL Townsend, BA Willey, M Cortina-Borja, CS Peckham, PA Tookey. Antiretroviral therapy and congenital abnormalities in infants born to HIV-infected women in the UK and Ireland, 1990-2007. *AIDS* 2009; **23**:519-524
3. A Riordan, A Judd, K Boyd, D Cliff, K Doerholt, H Lyall, E Menson, K Butler, D Gibb; Collaborative HIV Paediatric Study. Tenofovir use in human immunodeficiency virus-1-infected children in the United Kingdom and Ireland. *Pediatr Infect Dis J* 2009; Mar;**28**(3):204-9
4. C Foster, A Judd, P Tookey, G Tudor-Williams, D Dunn, D Shingadia, K Butler, M Sharland, H Lyall, D Gibb. Young people in the UK and Ireland with perinatally acquired HIV: the paediatric legacy for adult services. *AIDS Patient Care STDS*. 2009 March 2009, 23(3): 159-166. doi:10.1089/apc.2008.0153.
5. A De Ruiter, D Mercey, J Anderson, R Chakraborty, P Clayden, G Foster, C Gilling-Smith, D Hawkins, N Low-Beer, H Lyall, S O'Shea, Z Penn, J Short, R Smith, S Sonecha, P Tookey, C Wood, G Taylor. British HIV Association and Children's HIV Association guidelines for the management of HIV infection in pregnant women 2008. *HIV Medicine* 2008; **9**:452-502
6. The Collaboration of Observational HIV Epidemiological Research Europe (COHERE) study group. Response to combination antiretroviral therapy: variation by age. *AIDS* 2008; **22**:1463-1473
7. A Kekitiinwa, KJ Lee, AS Walker, A Maganda, K Doerholt, SB Kitaka, A Asimwe, A Judd, P Musoke, DM Gibb; Collaborative HIV Paediatric Study (CHIPS) Steering Committee; Mulago Cohort Team. Differences in factors associated with initial growth, CD4, and viral load responses to ART in HIV-infected children in Kampala, Uganda, and the United Kingdom/Ireland. *J Acquir Immune Defic Syndr* 2008; Dec 1;**49**(4):384-92
8. CL Townsend, M Cortina-Borja, CS Peckham, A de Ruiter, H Lyall, PA Tookey. Low rates of mother-to-child transmission of HIV following effective pregnancy interventions in the United Kingdom and Ireland, 2000-2006. *AIDS* 2008; **22**(8):973-81
9. C Townsend, M Cortina-Borja, C Peckham, P Tookey. Trends in management and outcome of pregnancies in HIV infected women in the United Kingdom and Ireland, 1990-2006. *BJOG* 2008; **115**:1078-1086.
10. R Chakraborty, CJ Smith, D Dunn, H Green, T Duong, K Doerholt, A Riordan, H Lyall, P Tookey, K Butler, CA Sabin, D Gibb, D Pillay. HIV-1 drug resistance in HIV-1 infected children in the UK from 1998 to 2004. *PIDJ* 2008; **27**:457-59
11. CD Hankin, EGH Lyall, CS Peckham, JI Masters, PA Tookey. In utero exposure to antiretroviral therapy: UK clinic-based follow-up 2002-2005. *AIDS Care* 2009 [In press]
12. L Samad, S Marven, H El Bashir, JC Cameron, R Lynn, B Taylor. Intussusception in children less than 12 months of age: a UK national surveillance study. *J Pediatr Surg* 2008; Nov; **43**(11):2136.
13. J A Salotti, V Nanduri, M S Pearce, L Parker, R Lynn, K P Windebank. Incidence and clinical features of Langerhans cell histiocytosis in the UK and Ireland. *Arch Dis Child* 2009; **94**: 376 – 380
14. JM Khalid, J Oerton, M Cortina-Borja, BS Andresen, et al. UK Collaborative Study of Newborn Screening for MCADD. Ethnicity of children with homozygous c.985A>G medium-chain acyl-CoA dehydrogenase deficiency: findings from screening approximately 1.1 million newborn infants. *J Med Screen* 2008;**15**:112-7
15. JV Leonard, C Dezateux. Newborn screening for medium chain acyl CoA dehydrogenase deficiency. *Arch Dis Child* 2009; **94**(3):235-8. [Epub 2008 Oct 6]
16. JP Shield, R Lynn, KC Wan, L Haines, TG Barrett. Management and 1 year outcome for UK children with type 2 diabetes. *Arch Dis Child* 2009; **94**(3):206-9.
17. C Verity, AM Winstone, L Stellitano, D Krishnakumar, R McFarland, R Will. The clinical presentation of mitochondrial diseases in children with progressive intellectual and neurological deterioration (PIND): a national prospective population-based study. (In press)
18. K Cheng, S Masters, T Stephenson, R Cooke, R Ferner, M Ashworth, A J Nunn. Identification of suspected fatal adverse drug reactions by paediatricians: a UK surveillance study. *Arch Dis Child* Jul 2008; **93**: 609 – 611.
19. S S Teo, A Riordan, M Alfaham, J Clark, MR Evans, M Sharland, V Novelli, JM Watson, P Sonnenberg, A Hayward, J Moore-Gillon, D Shingadia for the British Paediatric Surveillance Unit Childhood Tuberculosis Study Group. Tuberculosis in the United Kingdom and Republic of Ireland. *Arch Dis Child* Apr 2009; **94**: 263 - 267.
20. S S Teo, A Riordan, M Alfaham, J Clark, MR Evans, JM Watson, A Riordan, P Sonnenberg, J Clark, A Hayward, M Sharland, J Moore-Gillon, V Novelli, D Quinn, D Shingadia for the British Paediatric Surveillance Unit Childhood Tuberculosis Study Group. An evaluation of the completeness of reporting of childhood tuberculosis. *Eur Respir J* 2009; **34**: 1-4 DOI: 10.1183/09031936.00031808

Presentations

21. RL Knowles, R Lynn, H Friend, S Mitchell, C Michie, C Ihekweazu. The British Paediatric Surveillance Unit: A public health evaluation. Royal College of Paediatrics and Child Health 13th Spring Meeting, York, 2009. *Arch Dis Child* 2009; **94**(Suppl-1): Abstract G221
22. H Friend, C Ihekweazu, RL Knowles, S Mitchell, C Michie, R Lynn. Evaluating the British Paediatric Surveillance Unit: Views from users of the system. Royal College of Paediatrics and Child Health 13th Spring Meeting, York, 2009. *Arch Dis Child* 2009; **94**(Suppl-1): Abstract G246
23. JM Khalid, C Dezateux, J Oerton, C Kelnar, P Hindmarsh, RL Knowles. Prevalence and clinical features of newly diagnosed congenital adrenal hyperplasia in the UK. Royal College of Paediatrics and Child Health 13th Spring Meeting, York, 2009. *Arch Dis Child* 2009; **94**(Suppl-1): Abstract P6

24. RL Knowles, JM Khalid, J Oerton, P Hindmarsh, C Kelnar, C Dezateux. National surveillance of congenital adrenal hyperplasia in children. 36th Meeting of the British Society for Paediatric Endocrinology and Diabetes 2008. *Endocrine Abstracts* 2008;17(Nov):S1
25. RL Knowles, JM Khalid, J Oerton, P Hindmarsh, C Kelnar, C Dezateux. Prevalence and clinical features of congenital adrenal hyperplasia (CAH) in a multiethnic population without newborn screening. 6th ISNS European Regional Meeting, 27th April 2009, Prague, Czech Republic
26. D Nicholls. Early onset eating disorders – Developing a psychiatry reporting scheme. D Nicholls. BPSU Conference March 2009, London, UK
27. D Nicholls, R Lynn, R Viner, L Phinas, S Madden. Eating Disorders in Children: are the numbers really increasing? Faculty of Child and Adolescent Psychiatry Conference. September 2008, Liverpool, UK
28. M Knight. Feto-maternal alloimmune thrombocytopenia–Developing joint paediatric and obstetric reporting. BPSU Conference March 2009, London, UK]

Canada

Publications

1. The Canadian Paediatric Surveillance Program: A framework for the timely data collection on head injury secondary to child maltreatment. Bennett S, Grenier D, Medaglia A. *Am J Prev Med* 2008;34(4S):S140-2
2. Prevention of kernicterus – New guidelines and the critical role of family physicians. Shaw E, Grenier D. *FP Watch, Can Fam Physician* 2008 April:54
3. The spectrum of seat belt syndrome among Canadian children: Results of a two-year population surveillance. Santschi M, Lemoine C, Cyr C. *Paediatr Child Health* 2008;13(4):279-83

Abstracts and poster presentations

1. Ensuring our polio-free status: active acute flaccid paralysis surveillance (AFP) in Canada. Garner MJ, Macey JF, Desai S, Grenier D. Canadian Immunization Conference, Toronto, Ontario, in December. (Poster)
2. The power of adverse drug reaction reporting. Zimmerman M, Rieder M. Canadian Paediatric Society Annual Conference, Victoria, British Columbia, in June. (Oral)
3. The extent and nature of head injury secondary to child maltreatment in Canada: A 3-year surveillance study. Bennett S, Fortin G, Ward M. Seventh North American Conference on Shaken Baby Syndrome/Abusive Head Trauma, Vancouver, British Columbia, in October. (Oral)
4. Congenital cytomegalovirus infection in Canada: Cases reported by paediatricians to the Canadian Paediatric Surveillance Program, Vaudry W, Lee BE, Rosychuk R, Pelletier L. Canadian Paediatric Society Annual Conference, Victoria, British Columbia, in June. (Oral)
5. Medical morbidity and mortality in a population based sample of congenital myotonic dystrophy. Ho A, Campbell C. Muscle Study Group Meeting, Buffalo, New York, in September. (Poster)
6. Restrictive eating disorders in children: Global findings from the International Network of Paediatric Surveillance Units. Pinhas L. International Conference on Eating Disorders, Seattle, Washington, in May. (Oral)
7. Impacts of the International Network of Paediatric Surveillance Units. Grenier D. Annual Conference of the German Pediatric Society and the 5th INoPSU Meeting, Munich, in September. (Oral)
8. Impacts of the International Network of Paediatric Surveillance Units. Grenier D. The Royal Australasian Paediatric Congress, Adelaide, in May. (Oral)
9. Canadian national surveillance for juvenile idiopathic arthritis. Tucker L, Dancey P, Oen K, Huber A, Lagacé C, Espinosa V, and the Canadian Alliance for Pediatric Rheumatology Investigators (CAPRI). American College of Rheumatology Annual Scientific Meeting, San Francisco, California, in October. (Oral)
10. The incidence of kernicterus in Canada 2007–2009. Sgro M, Campbell D, Shah V. Canadian Paediatric Society Annual Conference, Victoria, British Columbia, in June. (Oral)
11. Severe neonatal hyperbilirubinaemia and neurological findings in Canada. Sgro M, Campbell D, Barozzino T, Fallah S, Shah V. Canadian Paediatric Society Annual Conference, Victoria, British Columbia, in June. (Oral)
12. The incidence of kernicterus in Canada 2007–2009. Sgro M, Campbell D, Shah V. Pediatric Academic Societies (PAS) Annual Meeting, Honolulu, Hawaii, in May. (Poster)
13. Severe neonatal hyperbilirubinaemia and neurological findings in Canada. Sgro M, Campbell D, Barozzino T, Fallah S, Shah V. Pediatric Academic Societies (PAS) Annual Meeting, Honolulu, Hawaii, in May. (Poster)
14. The incidence of kernicterus in Canada. Sgro M. 7th Annual Neonatal & Maternal-Fetal Medicine Research Day. Mount Sinai Hospital, Toronto, Ontario, in April. (Invited lecture)
15. Multiple magnet ingestions in Canadian children: A survey of Canadian health care providers. D'Mello JR, Warda L, Briggs G. Canadian Paediatric Society Annual Conference, Victoria, British Columbia, in June. (Poster)
16. Incidence of medium chain acyl-coenzyme A dehydrogenase deficiency in Canada using the Canadian Paediatric Surveillance Program (September 2005 – September 2008). Prasad C, Speechley KN, Dyack S, Rupar CA, Chakraborty P, Kronick JB. Canadian College of Medical Geneticists Annual Scientific Meeting, in St. John's, Newfoundland, in September. (Poster)
17. Sentinel network collaboration for pan-Canadian surveillance of NT1DM. Hamilton J, Dean H, Amed S, Lambert-Lanning A, Laubscher T, Dannenbaum D. Family Medicine Forum, Toronto, Ontario, in November. (Oral)
18. National surveillance for non-type 1 diabetes (NT1DM) in Canadian children. Amed S, Dean H, Hamilton J, NT1DM Study Team. CDA/CSEM Professional Conference and Annual Meetings, Montreal, in October. (Oral)
19. Rheumatic fever in Canada: Results from a national surveillance program. Dancey P, Templeton C, Human DG, Rahman P, Cooper A. American College of Rheumatology, Pediatric Rheumatology Symposium, Keystone, Colorado, in March. (Poster)

20. Injury prevention surveillance: A research asset for advocacy. Grenier D, Davis MA, Ugnat A-M, Laffin Thibodeau M. Family Medicine Forum, Toronto, Ontario, in November. (Poster)
21. Indigenous health research through surveillance. Grenier D, Ugnat A-M, Painchaud L. Canadian Paediatric Society Annual Conference, Victoria, British Columbia, in June. (Poster)

Germany

Publications

1. Milde-Busch A, Kalies H, Rückinger S, Siedler A, Rosenbauer J, von Kries R. Surveillance for Rare Infectious Diseases: is one passive data source enough for Haemophilus influenzae? Eur J Public Health 2008; 1-5(DOI: 10.1093/eurpub/ckn23)
2. Handwerker G. Narkolepsie. Monatsschr Kinderheilkd 2007; 155: 624-629
3. Grote V, von Kries R, Rosenfeld E, Belohradsky B H, Liese J. Immunocompetent children account for the majority of complications in childhood herpes zoster. J Infect Dis 2007; Nov 15;196(10):1455-1458
4. Grote V, von Kries R, Springer W, Hammersen G, Kreth H W, Liese J. Varicella-related death on children and adolescents – Germany 2003-2004. Acta Paediatr 2008; 97:187-192
5. Liese JG, Grote V, Rosenfeld E, Fischer R, Belohradsky B H, von Kries R and the ESPED Varicella Study Group. The Burden of Varicella Complications Before the Introduction of Routine Varicella Vaccination in Germany. Pediatr Infect Dis J 2008; 27:119-124

Ireland

Publications

1. Fitzpatrick E, Bourke B, Drumm B, Rowland M. The incidence of cyclic vomiting syndrome in children: population-based study. Am J Gastroenterol. 2008 Apr;103(4):991-5.Epub 2007 Dec 5.
2. Ferguson W, Mayne PD, Lennon B, Butler K, Cafferkey M. Susceptibility of pregnant women to toxoplasma infection--potential benefits for newborn screening. Ir Med J. 2008 Jul-Aug;101(7):220-1.

Netherlands

Publications

1. Driessen GJ, Pereira RR, Brabin BJ, Hartwig NG. Imported malaria in children: a national surveillance in the Netherlands and a review of European studies. Eur J Public Health 2008;18(2)184-8.
2. Ijland MM, Pereira RR, Cornelissen EA. Incidence of late vitamin K deficiency bleeding in newborns in the Netherlands in 2005: evaluation of the current guideline. Eur J Pediatr 2008;167(2):165-9.
3. Weijerman WE; Furth MA van, Vonk Noordegraaf T; Wouwe JP van , Broers CJ, Gemke RBBJ, Prevalence, neonatal characteristics and first year mortality of Down syndrome: a national study. J Pediatrics. 2008, 15-9.
4. Wouwe JP van, Jacobusse G, Buuren S van. Seasonal variation in the diagnosis of type 1 diabetes. (letter) Diab Res Clin Res 2008;79:e13.

New Zealand

Publications

1. Kelly P, Farrant B, Shaken Baby Syndrome in New Zealand Journal of Paediatrics and Child Health. 44, 2008; 99-107

Switzerland

Publications

1. Poretti A, Anheier T, Zimmermann R, Boltshauser E and the Swiss Paediatric Surveillance Unit (SPSU). Neural tube defects in Switzerland from 2001 to 2007: are periconceptual folic acid recommendations being followed? Swiss Med Wkly2008;138:608-13.
2. Stähelin J, Zimmermann H, Gnehm H. Tick-borne encephalitis in Swiss children 2000-2004. Paediatric Infectious Disease Journal 2008; 27: 1-3.
3. Fanconi M, Lips U. Children University Children's Hospital Zurich, Child Protection Group. Shaken baby syndrome in Switzerland – Results of the retrospective study 2002-2007. Abstract. Annual Joint Meeting of the Swiss Societies for Paediatrics, Child and Adolescent Psychiatry, Paediatric Surgery, Lugano. Juni 19-21, 2008. Swiss Medical Weekly, 2008; Suppl. 164 (3S).

Appendix 2 Work Plan 2009-2011

| | Action |
|---|--|
| 1. Future Funding | |
| Identify sources of funding for INoPSU, to help with production of reports etc. Consider another EU application | All |
| 2. Facilitation of Research and Providing a Link Service for Units | |
| Advice and support for newly formed and proposed units' Argentina, Italy | All |
| Identify disorders suitable for cross-national surveillance. | All |
| Make clinicians aware of studies being undertaken in each country. | All |
| Put researchers in touch with each other. | Secretariat |
| Annual review of Network documentation | Secretariat |
| Circulate ethical guidance for data collection | UK |
| 3. Dissemination of Results and Conclusions | |
| Produce Bi-annual report, and twice-yearly newsletter | Secretariat/CPSP |
| Produce Public Health Output paper | Australia/Canada/UK |
| Produce International HUS comparative paper | Australia/UK |
| Update generic INoPSU poster. | UK |
| Produce generic set of INoPSU slides | Australia |
| Maintain and develop website. | UK |
| Next INoPSU meeting | Ireland |
| Encourage national units to include work of INoPSU in their presentations. | All |
| 4. Liaison and Collaboration with other Organisations | |
| Maintain links with IPA, | Canada/Secretariat |
| Advise in the development of other paediatric and speciality surveillance units. European Countries, Northern, Eastern, Southern Americas Far East | Neth/Ger/Port Canada Australia UK |
| Strengthen links with parent organisations such as European Organisation for Rare Disease. | UK |
| Produce information leaflet on surveillance/INOPSU | Volunteer |
| 5. Evaluation | |
| Continually evaluate methodology of the system | All |

Appendix 3 Developing a national paediatric surveillance unit

Some General Principles

1. **It is absolutely essential that the majority of paediatricians in a particular area support the establishment of your paediatric surveillance unit (PSU).** The paediatricians are the surveillance unit. They are the ones who return the monthly card (or Email). They also complete the questionnaire and if they do not support the principle of having a surveillance unit, then it will not function properly.

Support and collaboration from the national specialty society during the establishing of a new PSU is also highly recommended. Not only for supporting the infrastructure, but also for credibility amongst the community of paediatricians and researchers and for supporting advocacy work that is needed with study results.

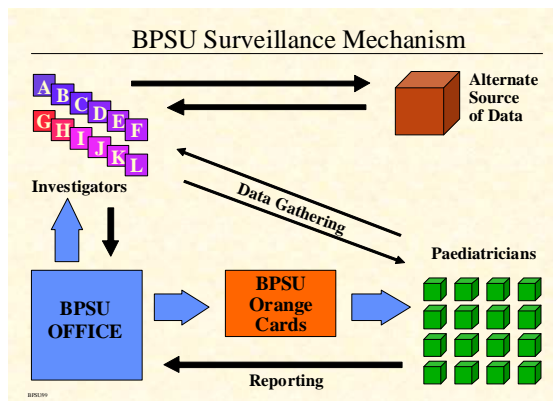
The following are therefore essential.

- There needs to be an up-to-date list of all paediatricians who are in established posts.
 - The surveillance card (Email) needs to get to each paediatrician in an efficient manner.
 - The conditions that are put on the card must be of interest to the paediatricians who are going to return the card/Email.
 - There should not be too many conditions under surveillance at any one time, which can be confusing.
 - The conditions have to be relatively rare. If paediatricians see one or two cases a year, they will be prepared to take part. If they have to report case every month, and complete a questionnaire having sent back the surveillance card, fatigue will occur with subsequent loss of interest.
 - However, some of the small units have by necessity included studies with conditions of higher incidence in order to collect enough data for meaningful analysis. You may like to discuss this further with coordinators of the Welsh or Swiss units.
 - It is essential that the paediatricians who fill in the card are informed about the results of the survey
2. **There needs to be central coordination.** In the British Isles there is a full-time scientific coordinator and research administrator. Both are based at the Royal College of Paediatrics and Child Health. The functions of a PSU office are as follows.
 - To maintain an up-to-date register of paediatricians together with a current address
 - To send the monthly surveillance card or email to paediatricians
 - To inform each surveillance group when a particular paediatrician has notified a case.
 - To monitor the response rate. Each surveillance card has a number of conditions that are under surveillance. If a paediatrician has seen a child with a condition under surveillance the paediatrician should pick the appropriate box on the card (figure 2). However if no case has been seen, then the card is still returned, which is a way of checking that the card has been received.
 - The PSU office is the centre for enquiries
 - The Scientific Coordinator is responsible for sending out publicity and reports on progress of studies. An annual report which does the same thing in a more formal way. A website can act as an effect portal for information and activities.

Figure 2 Surveillance mailing card

| British Paediatric Surveillance Unit Report Card | | Clinicians Section – Please Keep if Necessary British Paediatric Surveillance Unit Report Card for cases seen in May 2004 | |
|--|-------------|--|--------------|
| NOTHING TO REPORT <input type="checkbox"/> | 2005-06 | Please NOTE the patient's name(s) or other identification and KEEP THIS SLIP for easy reference when you are contacted by the investigator. | |
| Specify in the box number of cases seen | CODE No [] | Please NOTE the patient's name(s) or other identification and KEEP THIS SLIP for easy reference when you are contacted by the investigator. | |
| <input type="checkbox"/> AIDS/HIV | | Condition | Patient |
| <input type="checkbox"/> Congenital rubella | | | |
| <input type="checkbox"/> Progressive Intellectual & Neurological Deterioration | | | Hospital No. |
| <input type="checkbox"/> Neonatal Herpes Simplex Virus (HSV) Infection | | | |
| <input type="checkbox"/> Medium chain acyl CoA dehydrogenase deficiency | | | |
| <input type="checkbox"/> Thyrotoxicosis in childhood | | | |
| <input type="checkbox"/> Non-type 1 diabetes (upto 17years) | | | |
| <input type="checkbox"/> Early onset eating disorder in children <13 years | | | |
| <input type="checkbox"/> MRSA | | | |
| <input type="checkbox"/> Scleroderma | | | |
| <input type="checkbox"/> Malaria in childhood | | | |
| Detach this Section Before Posting | | | |

Figure 3 Summary of the system



- 3. The activity of the Surveillance Unit needs to be monitored and requests for new studies need to be considered.** Most of the PSU's have an Executive Committee. Usually the committee will consist of clinicians, epidemiologists and representatives of constituent institutions.
- 4. Funding:** Required for salaries; printing and postage costs and possible accommodation costs. The in the latter case in many instances this is absorbed by the institutions where the PSU is sited. Not all the PSU's have or require full-time staff. However it is necessary to have a central office to send out cards/emails and keep lists of paediatricians up to date. Appropriate hard and software is required to keep records of compliance rates etc. It is not reasonable to expect the unit to run efficiently without some support staff.
- 5. Conclusion:** This brief report gives some guidance, but obviously it does not give a detailed discussion about the organisation of a PSU. It will probably be helpful to have a look individual national PSU websites, which can be accessed through the International Network of Paediatric Surveillance Units website (www.inopsu.com). The surveillance methodology used by a PSU may differ from the one developed by the BPSU but active monthly surveillance using a report/email card is advisable. Whilst some units only facilitate epidemiology studies others initiate and undertake the research as well as the surveillance.

However we must emphasize that the most important point is to obtain the support of the local paediatricians. Whilst a College of Paediatric can facilitate the activity, paediatricians must feel that this project is their project. If they feel they are involved in the process and they are interested in the results of the studies, they will be much more likely to return the monthly report card and then fill in the questionnaire which follows if they report a case.