INOPSU

International Network of Paediatric Surveillance Units

Annual Report 2009

Contents

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 met and communicated regularly to discuss surveillance protocols.

The European initiative was also the stimulus for the development of the Australian Unit in 1992, and later the Malaysian unit in 1994. Canada and Papua New Guinea each established a surveillance program in 1996, Latvia and New Zealand in 1997, Portugal in 2001 and Greece/Cyprus in 2003. In 1994, Wales and in 1996, the Republic of Ireland developed surveillance units using a similar methodology to the BPSU, but including surveillance for 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. The past year saw the development of a child and adolescent psychiatry surveillance unit, as well as the Scottish Paediatric Surveillance Unit. All the units contact each other for results, to share protocols and to connect researchers in different countries working on simultaneous studies.

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 and youth. 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 themselves[1].

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 Netherlands[2].

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 and the 4th gathering in London was to celebrate the BPSU 20th anniversary.

This year (2009) saw the beginning of the development of an INOPSU study database. Information on all the studies is being collated by the BPSU to form a reference of international studies undertaken, the lead investigators and details on relevant publications. Once complete this repository will be made available to the wider scientific community.

Over the past two years, INoPSU members have facilitated the surveillance of 70 different rare conditions (Appendix 1) and have now undertaken over 200 studies, of which 49 have been studied by more than one country, covering a paediatric population of over 50 million and involving over 10,000 clinicians. Details on all the activities of each surveillance unit are available form 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 - Key characteristics of INoPSU member units in 2009

Country	Child Population (aged 0-15 years) (million)	Average No. Contributing Clinicians*	Reply by Card (%)	Reply By Email (%)	Average Report Cards Returned (%)	Average Questionnaire return rate (%)
Australia	4.2	1335	18	82%	91	88
Britain	12.3	3000	93	7%	93	93
Canada	7.8 (under 19 years of age)	2500	100	0%* Under development	80	90
Cyprus/Greece	1.66	110	100	N/A	100	100
Germany	12	473 (Card:240 /Email: 233)	96	95	96	65-100 (Median: 92)
Ireland	1.32 (incl N Ire.)	228	85	15%	74	65 - 70
Latvia*						
Netherlands	3	730	1	99%	84	70
New Zealand	0.86	210	75	25	95	N/A
Portugal*	1.4	1,800	70	30	33	66
Switzerland	1.27	34	100	0	100	N/K
Wales	0.56	263	12	88	99.6%	N/K

* 2006 Data

2 Contributing to public health actions

Since it's inception in 1998, INoPSU studies have provided scientific evidence to support the following public health actions: Below are studies that have collaborated to produce joint papers, international presentations or posters.

Vaccine-Preventable Diseases

- **Pertussis Infection** (APSU, ESPED, NSCK, 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.
- **Severe Complications of Influenza** (APSU). Documented severe complications due to seasonal influenza (2007 and 2008) and pandemic H1N1 Influenza (2009) even among previously healthy children. These data supported recommendation for timely treatment and routine vaccination of children. The BPSU has also been monitoring for adverse reactions on the form of Guillain Barré and Fisher syndromes following the introduction of HIN1 vaccination.
- **Hemophilus influenza group B** (NSCK, BPSU). Study results documented a fall in HIB infections after countrywide vaccination

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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** (APSU, 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** (APSU, 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 and seatbelt related injuries** (APSU, 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. New child restraint laws enacted in Australia mandating booster seats for 4-7 year old children.
- **Chemistry set poisoning** (BPSU). Several incidents reported that supported the EU recommendations on toy packaging.

Table 2 – Studies where active collaboration has been undertaken

	APSU	BPSU	CPSP	ESPED	GCPSU	NSCK	NZPSU	SPSU	WPSU
Pertussis infection	x			x	x	x	x	x	
Neonatal herpes simplex virus	x	x	x						
Congenital cytomegalovirus infection	x	x	x						
Haemolytic uraemic syndrome	x	x	x	x		x	x	x	
Subdural haematoma	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						

*Subdural haematoma in children aged <2 years due to start in Australia in 2010

* http://www.cps.ca/English/surveillance/cpsp/Publications/Highlights/2009/October.pdf

Further information on the INoPSU is available atwww.INoPSU.com and this yearly international report is shared as part of the national reports.

3 National Units 2009 Highlights

Australia

APSU convenes a rare diseases working group consisting of researchers, clinicians and representatives from parent support groups and calls 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 an annotation in the Journal of Paediatrics and Child Health. To advance this initiative, Yvonne Zurynski travels to Europe to study initiatives for rare diseases such as Orphanet; strategic links are made with prominent charities and other organisations including the Steve Waugh Foundation, SMILE Foundation and Alliance of Genetic Support Australasia. First rare diseases workshop planned for International Rare Diseases Day February 28th 2010.

Having conducted surveillance for severe complications of seasonal influenza (2007, 2008) APSU quickly responds to the H1N1 influenza pandemic in 2009.

Paediatric Active enhanced Disease Surveillance (PAEDS). APSU in collaboration with the National Centre for Immunisation Research and Surveillance continues this active hospital-based surveillance system in four paediatric hospitals in 4 states of Australia. With support from the National Health and Medical Research Council of Australia and NSWHealth Department, PAEDS responds to the influenza H1N1 Pandemic 2009 by expanding the system to another 2 children's hospitals in NSW and conducting surveillance for all hospitalizations for influenza among children aged <15 years.

Results of the second systematic evaluation of the APSU published.

Britain

In 2009 the BPSU was delighted when it was successful in obtaining a further three years funding from the Policy Research Programme of the Department of Health. The grant covers a three year period to March 2012

In March 2009 the BPSU held a successful one day conference. All presentations were of high quality and positively evaluated by the delegates. Sheila Shribman, in the key note address, introduced us to the key elements of the Children's Plan "Healthy lives, brighter futures". Other presentations were on MRSA, HIV, herpes, emerging infections, varicella, neonatal hyperbilirubinaemia, vitamin K prophylaxis, feto-maternal alloimmune thrombocytopenia, and early onset eating disorders

The units Chair Prof Alan Colver stepped down after three and a half years in the role. A new chair, Prof Alan Emond was appointed in July and the BPSU Executive are looking forward to continuing to work with him

Canada

In 2009, the CPSP worked in close collaboration with Health Canada and the Public Health Agency of Canada during the influenza A H1N1 pandemic to provide education to participants and to collect timely epidemiological data through:

- CPSP Highlight: Respiratory distress and the flu: What should a physician know? – Paediatr Child Health 2009; 14(9): 571-2
- CPSP one-time survey: Paediatric antiviral drug use and potential ARs. http://www.cps.ca/English/surveillance/cpsp/studies/Antivirals.pdf
- CPSP – ADR Tip of the Month: Important possible side effects associated with TamifluTM

CPSP also participated in the 20th European Society of Paediatric and Neonatal Intensive Care (ESPNIC) Medical and Nursing Annual Congress and in the 50thy European Society of Paediatric Research (ESPR) Annual Meeting with the following respective poster presentations: "The International paediatric surveillance network: research in action" and "Active neonatal disease research through surveillance: The Canadian experience.

Greece

No highlights submitted this year

Germany

Two important papers were published this year, these being

- Nowak-Göttl U. Role of endogenous testosterone concentration in pediatric stroke. Ann Neurol 2009; 66:754-758
- Lainka E, Neudorf U, Lohse P, Timmann C, Stojanov S, Huss K, von Kries R, Niehues T. Incidence of TNFRSF1A mutations in German children: epidemiological, clinical and genetic risks. Rheumatology 2009;48 (8):987-991

Ireland
No highlights submitted this year

Netherlands

Again our highlight was alcohol intoxication. The children were 11-17 years old. Number of notifications of boys and girls were the same. There is a rise of 13% compared to 2008, compared to 2007 this is a rise of 48% and to 2007 a rise of 68%. Of course this is the tip of the iceberg. The blood alcohol level is comparable to 10-15 units of alcohol. The children are in coma for a mean of 3 hours. The therapy consisted of IV fluids in 80% of the cases.

The alcohol drunk was mostly strong (gin, whiskey) in 36%, beer in 12% or mix 11%. The rest was a mix of several alcoholic beverages. They went into coma in the house of friends (30%), in the street (27%), in a bar (18%) or at home (8%) They received the alcohol from friends (42%) or at home (28%) or bought it in a bar (18%) or in the supermarket (12%).

	2007	**2008**	**2009**
Admissions by paediatricians	297	337	500
Mean age on admission	15,3	15,0	15,7
Level of school			Lower 40% Medium 20% Higher 15% Unknown 25%
‰ blood alcohol	1,8	1,8	1,8

New Zealand

- NZPSU were successful in negotiating another three year contract with the Ministry of Health
- An important paper was published in 2009:
  Dickson N, Kara T, Tuohy P *Rapid national survey of renal stones in New Zealand Infants*
  Journal of Paediatrics and Child Health 45(2009) 633-635
- 5 years of surveillance was completed in 2009 of Inborn Errors of Metabolism

Portugal
No highlights submitted this year

Switzerland

Extended spectrum beta-lactamase producing gram negative bacteria in infants in Switzerland:

The study on ESBL-producing gram negative bacteria in children was initiated in July 2008.
According to preliminary result as, there has been a significant increase in reported cases in 2009 compared to 2008, i.e. 69 cases compared to 33 cases for the second half-year periods 2009/2008. The majority of cases were identified either on the day of admission or within one or two days after admission to the hospital and didn't have classical risk factors for ESBL-GNB. This leads to the suspicion that infections in Switzerland mainly occur within the community rather than in the hospital setting. However, the subsequent years of surveillance will generate further data on ESBL-GNB in paediatric clinics in Switzerland and may or may not substantiate these findings.

Wales

Conditions currently being surveyed by the WPSU are deaths in children with epilepsy, neonatal hypoxic-ischaemic encephalopathy, benign childhood epilepsy with centro-temporal spikes and the child death review pilot study. A new study from August 2010 is neonatal invasive fungal infections. Recently completed studies in 2009 are gallstones, craniosynostosis, long term ventilation and nosebleeds in infancy, and which we will be highlighting in the next biannual report of the WPSU.

The WPSU response rates have remained excellent: we are currently working on improving the completion rate for study questionnaires by responding promptly to notifications with an unique notification number. We encourage those notifying cases to retain the number with the case details for them to respond to the researchers (who we hope will in turn promptly contact WPS members who notify cases using the unique case reference) with a short turnaround time. We hope that this will minimise the delay between notification and questionnaire completion.

A few years ago we changed our reporting system from a card-based system to an email-based system. This has been remarkably successful. However, this has meant that there is a reasonable amount of manual checking to be done. We have agreed to trial a web-based reporting system. This is through the new WPS website (www.welshpaediatrics.org.uk) in August 2010, and we hope that all WPS members will try this out, as it promises to make things more efficient. Anyone choosing to remain on their existing reporting system however, can do so, but we hope that early feedback will indicate that members find it just as easy as email reporting.

4 Studies undertaken by PSU's in 2009

Study	Unit
Acute encephalitis/encephalomyelitis	PPSU
Acute flaccid paralysis	APSU,CPSP, NZPSU, SPSU
Acute post streptococcal glomerulonephritis	NZPSU
Acute rheumatic fever	APSU,SPSU
Adolescent pregnancy	LPSU
Adrenal insufficiency	IPSU
Adverse drug reactions – serious and life threatening	CPSP, NZPSU
Alcohol intoxication	NSCK
Anaphylaxis (immunization)	BPSU, ESPED, SPSU
Asthma - "Difficult to treat"	NSCK
Bulimic eating disorders	CPSP
Cerebral palsy among five-year-olds	PPSU
Chronic fatigue syndrome	NSCK
Children without legal status	NSCK
Complementary and alternative medicine - serious adverse events	CPSP
Complications of measles	ESPED
Congenital adrenal hyperplasia	BPSU
CNS inflammatory demyelinating disease	BPSU
Congenital cytomegalovirus infection	APSU, PPSU
Congenital myotonic dystrophy	CPSP
Congenital renal or urological defects	NSCK
Congenital rubella syndrome	APSU, BPSU, NZPSU, SPSU
Congenital toxoplasmosis	CGPSU, PPSU, SPSU
Conversion disorder	BPSU
Craniosynostosis	WPSU
Cystic fibrosis	NSCK
Diabetes mellitus	LPSU, PPSU, ESPED
EBV-associated lymphoproliferative diseases in non-immuno-compromised children	ESPED
Epilepsy (deaths)	WPSU
Epistaxis in infancy	WPSU
Extended-spectrum ß-lactamaseproducing 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
Group B streptococcal/Escherichia coli infections (invasive neonatal)	ESPED
Guillain Barré/Fisher Syndrome	BPSU
Hemoglobinopathy	NSCK
Hemolytic uremic syndrome	CGPSU, NZPSU, PPSU, SPSU
Hepatitis C virus infection	APSU
HIV/AIDS (perinatal HIV exposure)	APSU,BPSU, NZPSU
Hyperbilirubinemia	NSCK.SPSU
Hypernatraemia – severe neonatal	BPSU, NSCK
Idiopathic intracranial hypertension (pseudotumor cerebri)	BPSU
IgG-subclass and/ or antipolysaccharide antibody deficiency	NSCK
Inborn errors of metabolism	NZPSU
Infection with new flu A/H1N1	ESPED
Influenza (pandemic A/H1N1 2009)	APSU
Interrupted pregnancy in adolescents	LPSU
Intussusception	APSU,BPSU

Iron-deficiency anemia - severe	CPSP
Juvenile dermatomyositis	ESPED
Juvenile idiopathic arthritis	CPSP
Juvenile myoclonic epilepsy	WPSU
Kawasaki disease	NSCK.PPSU
Kernicterus	CPSP
Langerhans cell histiocytosis	CPSP
Leukemia - Transient leukemia in Down Syndrome	LPSU, NSCK
Life-threatening event and unexplained death in neonates on the first day of life	ESPED
Long-term ventilation	WPSU
Lymphoma: Hodgkin's, non-Hodgkin's	LPSU
Medium-chain acyl-CoA dehydrogenase deficiency	BPSU
Methicillin-resistant *Staphylococcus aureus* (MRSA)	CPSP
Multiple sclerosis/ADEM	NSCK,ESPED,BPSU
Neonatal bacterial or fungal infection in the first week of life (proven)	NZPSU
Neonatal herpes simplex virus infection	APSU
Neonatal hypoxic-ischaemic encephalopathy	WPSU
Neuromuscular disorders	APSU
Neurological defects because of Rotavirus infections	ESPED
Osteitis, non-bacterial / Bacterial Osteomyelitis	ESPED
Pertussis	SPSU
Pneumococcal sepsis/Meningitis	ESPED
Progressive intellectual and neurological deterioration (PIND)	BPSU
Rett Syndrome	APSU
Severe combined immunodeficiency	CPSP
Shaken baby syndrome	ESPED
Sinus venous thrombosis, neonatale	ESPED
Sudden unexpected early postnatal collapse	BPSU
Sytemic lupus erythematosis	APSU
Toxic shock syndrome	BPSU
Travel-related illnesses in paediatric travellers who visit friends and relatives abroad	CPSP
Varicella (neonatal, congenital, and severe complications)	APSU, IPSU, PPSU
Vitamin D deficiency rickets	WPSU
Vitamin K deficiency bleeding	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

5 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*. 2009; **14** (**8)**: 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; **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 (**5): 250-9

4. Pereira-da-Silva L, von Kries R, Rose D, Elliott E. Acknowledging contribution to surveillance studies. *Arch Dis Child*. 2005; **90(7**):768.

5. Tripp J, Cornelissen M,Loughnan P, McNinch A, Schubiger G, von Kries R Suggested protocol for the reporting of prospective studies of vitamin K deficiency bleeding (previously called hemorrhagic disease of the newborn) in Vitamin K in Infancy Hathaway & Sutor (eds) Pub Schattauer 1995

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;1**56(2)**: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.

6 Developing a national paediatric surveillance unit

General Principles

Engagement and support of the majority of paediatricians in a particular area It is absolutely essential for the establishment of the paediatric surveillance unit (PSU) . Surveillance research draws its strength from the commitment of the participating paediatric community. Every report counts. Support of paediatricians and paediatric sub-specialitsts is crucial. They are the ones who return the monthly card and complete the detailed questionnaires that enable researchers to gather the necessary information on rare diseases and conditions.

Support and collaboration from the College or national specialty society during the establishing of a new PSU is also highly recommended as their involvement engenders credibility amongst the community of paediatricians and researchers.. Not only for supporting the infrastructure, but also for credibility amongst the community of paediatricians and researchers. . Furthermore strong links with a national specialty society and public health agency are necessary for infrastructure support, funding, dissemination of information about the PSU, and advocating for policy that may be supported by study results.

To raise awareness and gain interest from paediatricians we recommend that the idea of a PSU is widely presented at conferences and meetings and the support from the national society or college is visible on these occasions. The usefulness of PSUs should be demonstrated by presenting information about the already successful PSUs around the world and the impacts they have had on policy and practice.

The activities of PSUs need to be monitored and principles of good governance need to be applied. Most of the PSU's have an Executive Committee, Steering Committee, Board or Advisory Committee. Whatever name is chosen, the committee will have a clear terms of reference and will consist of clinicians, epidemiologists and representatives of constituent institutions. Committees usually meet face-to-face on a regular (yearly/bi-yearly basis) to discuss new study proposals and administrative issues. Correspondence by email takes places during the year or some units prefer to use regular teleconferences.

Criteria and process for the evaluation of proposals suggesting conditions for surveillance should be set and made available to potential researchers and other participants. Usually conditions that are high in disability, morbidity, mortality and economic cost to society, despite their low frequency are studied by PSUs. Workload for participating paediatricians/sub-specialists must be taken into account when evaluating study proposals. Smaller units have by necessity included studies with conditions of higher incidence in order to collect enough data for meaningful analysis. A process for evaluating proposals must be established and usually consists of a review by the Steering Committee or a sub-committee with appropriate expertise.

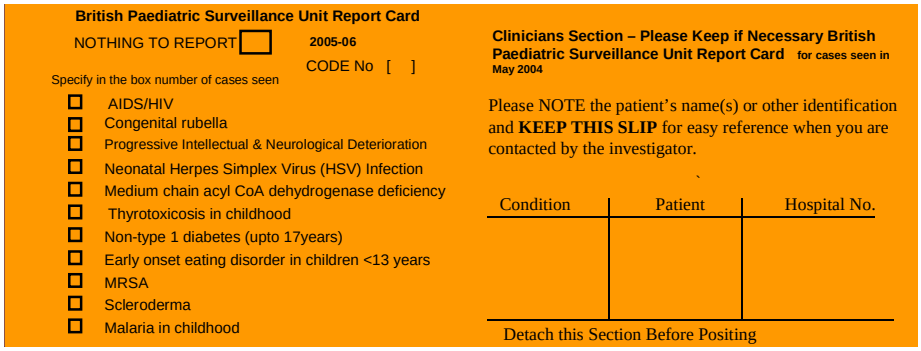
Funding is required to support central coordination of the PSU. In some instances, costs are absorbed by the institutions where the PSU is sited and in other instances, funding is provided by the national public health agency. Not all the PSU's have or require full-time staff, however, a PSU cannot run efficiently without at least some dedicated support staff time. This is of utmost importance to keep paediatricians actively engaged - paediatricians who volunteer to participate soon lose interest if activities are run erratically or inefficiently. Costs of printing, postage, software and hardware and their maintenance, and costs for PSU accommodation must also be covered.

To run a PSU efficiently you will need to:

- Have engaged with paediatricians, have their Interest, good will and willingness to report and to provide information on the conditions under surveillance
- Have established governance structures and procedures, including regular review of these
- Maintain a current and accurate database of all paediatricians in active clinical practice in the jurisdiction who have elected to participate
- Coordinate the timely and efficient distribution of monthly surveillance cards or emails to paediatricians
- Have protocols and case definitions for a number of conditions before surveillance starts.
- Monitor response rates to the report cards. Most paediatricians will have nothing to report most of the time, however, a 'nil' response is extremely important and indicates that clinicians are actively engaged in identifying cases.
- Send appropriate questionnaires to participants and notify research teams when cases are identified and follow-up on any questionnaire not completed
- Promptly respond to general inquiries from participating paediatricians
- Provide support to researchers wanting to develop protocols for new conditions

- Disseminate information on the surveillance unit and study results via peer-review publications, presentations, annual reports and websites. Timely and wide dissemination of study results and recommendations is essential to demonstrate the value of a PSU.

Examples of surveillance mailing cards/forms



British Paediatric Surveillance Unit Report Card

NOTHING TO REPORT ☐ 2005-06

CODE No [ ]

Specify in the box number of cases seen

- ☐ AIDS/HIV
- ☐ Congenital rubella
- ☐ Progressive Intellectual & Neurological Deterioration
- ☐ Neonatal Herpes Simplex Virus (HSV) Infection
- ☐ Medium chain acyl CoA dehydrogenase deficiency
- ☐ Thyrotoxicosis in childhood
- ☐ Non-type 1 diabetes (upto 17years)
- ☐ Early onset eating disorder in children <13 years
- ☐ MRSA
- ☐ Scleroderma
- ☐ Malaria in childhood

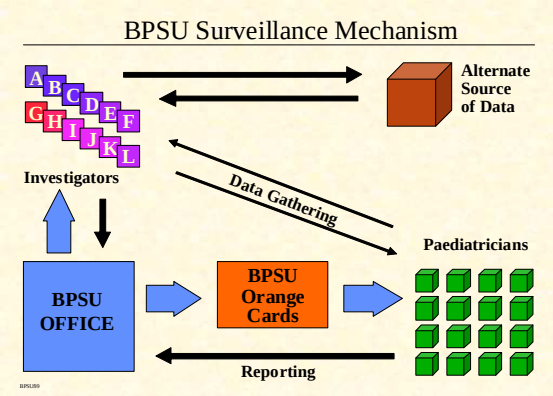
Clinicians Section – Please Keep if Necessary British Paediatric Surveillance Unit Report Card for cases seen in May 2004

Please NOTE the patient's name(s) or other identification and **KEEP THIS SLIP** for easy reference when you are contacted by the investigator.

Condition	Patient	Hospital No.

Detach this Section Before Positing

Figure 3 Summary of a PSU system



The above recommendations provide rudimentary guidance which cannot replace detailed discussion with experienced PSUs about all of the elements required to run a successful PSU. We encourage you to visit the individual websites of the national PSUs, and International Network of Paediatric Surveillance Units (www.INoPSU.com). Surveillance methodologies may differ from one PSU to another; however, active monthly surveillance using a report/email card is a common feature. Whilst some units only facilitate epidemiological studies, others initiate and undertake research in addition to surveillance. Please make contact with experienced staff within existing PSUs or with INoPSU to discuss possibilities for your country.

Conclusion

The most important element to remember is the support of national paediatricians and subspecialists. While association with the national paediatric society is crucial, participants must feel engaged in the surveillance project. Adequate and timely dissemination of study results is important to ensure participants remain interested and involved in surveillance activities. Study results should also be used to advocate for change/new policies at the government level, to advance knowledge on rare diseases, and to improve the care of children and youth with these rare diseases.

7 INoPSU History Timeline

Year	Activity
1984	British Paediatric Surveillance Unit (BPSU) Committee set up
1985	BPSU pilot surveillance commenced
1986	BPSU Launched
1988	Professor Guus de Jonge in Netherlands discuss BPSU with JD Baum Professor Eberherdt Schmidt in Germany discusses BPSU with JD Baum
1990	Dutch Paediatric Association approved a Dutch surveillance unit
1992	Dutch and Germany Units launched Dr Elizabeth Elliott spoke to Dr Susan Hall re: BPSU activities
1992	Dr Elizabeth Elliott launches Australian Unit with support of Australian College of Physicians
1992	Professor Joe Sibert at the Welsh Paediatric Society meeting suggested the establishment of a Welsh unit separate from the BPSU 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) Malaysian Paediatric Surveillance Unit launched with assistance from Australia
1994	Ist and 2nd EU grant applications submitted - rejected Germans, Dutch and British Units met with the newly formed Swiss Unit in Leiden for the first European Paediatric Surveillance Unit meeting Dr Victor Marchessault, who was a member of the British Paediatric Association took the idea of a paediatric surveillance back to Canada
1995	First joint EPSU study published. - Pediatr Res 1995;38:423-33 European units present at ESPID conference IN Denmark Launch of the Canadian Paediatric Surveillance Program Papua New Guinea Surveillance Unit launched with assistance from Australia
1996	Professor Elizabeth Elliott wrote to the BPSU proposing the development of an International surveillance unit network Launch of the New Zealand, Irish and Latvian Unit
1997	Joint national study on Vitamin K deficiency bleeding published - Eur J Pediatr 1997;156:126-30.
1998	At the 22nd International congress of Paediatrics in Amsterdam 10 units agree a document (Amsterdam Note) that outlines the formation of INOPSU The Amsterdam Note is ratified at the first INOPSU conference, held in Ottawa Canada. Document outlining INOPSU terms of reference renamed Amsterdam-Ottawa note. British Ophthalmology Surveillance Unit accepted into INOPSU as an affiliate member
2000	INOPSU web site launched Prof.Hadjichristodoulou talks with the BPSU with the aim of developing a Greece/Cyprus unit Portuguese Paediatric Surveillance Unit launched At the International Paediatric Association (IPA) meeting INOPSU accepted as an affiliate
2001	INOPSU publish firs paper - Rare disease surveillance: an International perspective
2002	2nd INOPSU conference held in York, UK
2003	Greece/Cyprus Unit launched 3rd INoPSU conference held in Lisbon, Portugal INOPSU website redeveloped INOPSU present workshop at IPA meeting in Cancun, Mexico
2004	INOPSU paper - How to acknowledge the work of our contributors": a paper appeared in July 2005: Arch Dis Child: 90:768
2006	4th INoPSU conference held in London, UK INoPSU paper published in Archives of Disease in Childhood FP7 Grant application for funding rejected
2007	Malaysian and Papua New Guinea Units fold 5th INoPSU conference held in Munich, Germany
2008	E-newsletter launched Malaysian unit re-launched Child and Adolescent Psychiatry unit launched in the UK
2009	Scottish Paediatric Surveillance Unit launched in September 6th INOPSU conference held in Ireland BPSU commences 25th year of surveillance
2010	CPSP commences 15th year of surveillance

8 Publications and Presentations 2009-2010

Australia

Publications

1. Lester-Smith D, Zurynski YA, Booy R, Festa MS, Kesson AM, Elliott EJ. The burden of childhood Influenza in a tertiary paediatric setting. *Communicable Disease Intelligence* 2009; 33(2): 209-215.

Recently completed studies not previously reported

2. 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):1071-1074.

3. Villano DJ, Kornberg AJ, Lamont P, North KN, Rowe P, Sinclair K, Ryan MM. APSU study of Neuromuscular Disorders of Childhood. *Journal of Paediatrics and Child Health* 2008; 44(9): A18.

Other publications:

1. Benitez-Aguirre PZ, Wood NJ, Biesheuvel C, Moreira C, Munns CF. The natural history of vitamin D deficiency in African refugees living in Sydney. *Medical Journal of Australia.* 2009; 190(8): 426-428.
2. 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; 45(9): 498 – 504.
3. Jaffe A, Zurynski Y, Beville L, Elliott E Call for a national plan for rare diseases. *Journal of Paediatrics and Child Health* 2009; 46(1-2): 2-4.
4. Madden S, Morris A, Zurynski YA, Kohn M, Elliott EJ. The burden of eating disorders in children aged 5-13 years in Australia. *Medical Journal of Australia.* 2009; 190 (8): 410-414.
5. McDonald AM, Zurynski YA, Wand HC, Giles ML, Elliott EJ, Ziegler JB, Kaldor JM. Perinatal exposure to HIV among children born in Australia, 1982-2006. *Medical Journal of Australia.* 2009; 190 (8): 416-420.
6. Michael M, Elliott EJ, Ridley GF, Hodson EM, Craig JC. Interventions for haemolytic uraemic syndrome and thrombotic thrombocytopenic purpura. *Cochrane Database of Systematic Reviews* 2009, Issue 1. Art. No.: CD003595. DOI: 10.1002/14651858.CD003595.pub2
7. Michael M, Elliott EJ, Craig JC, Ridley G, Hodson EM. Interventions for haemolytic uraemic syndrome and thrombotic thrombocytopenic purpura: a systemic review of randomised controlled trials. *American Journal of Kidney Diseases*. 2009; 53 (2): 259-72.
8. Mutch R, Peadon EM, Elliott EJ, Bower C, The need to establish a national diagnostic capacity for foetal alcohol spectrum disorders. *Journal of Paediatrics and Child Health.* 2009; 45(3): 79-81.
9. Peadon E, Rhys-Jones B, Bower C, Elliott E. Systematic review of interventions for children with Fetal Alcohol Spectrum Disorders. *BMC Pediatrics* 2009, **9:** 35.
10. Rhodes P, Prunty M, Madden S. Life threatening food refusal in two nine year old girls: rethinking the maudsley model. *Clinical Child Psychology and Psychiatry.* 2009; 14(1):63-70.
11. Stewardson AJ, Roberts JA, Beckett CL, Prime HT, Loh PS, Thorley BR, Daffy JR. Imported Case of Poliomyelitis, Melbourne, Australia, 2007. *Emerging Infectious Diseases*. www.cdc.gov/eid. Vol.15, No.1, January 2009.
12. Tofts LJ, Elliott EJ, Munns C, Pacey V, Sillence DO. The differential diagnosis of children with joint hypermobility: a review of the literature. 2009; *Pediatric Rheumatology Online Journal* 2009; 5(7):1

United Kingdom

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. Riordan A, Judd A, Boyd K, Cliff D, Doerholt K, Lyall H, Menson E, Butler K, Gibb D; 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. Foster C, Judd A, Tookey P, Tudor-Williams G, Dunn D, Shingadia D, Butler K, Sharland M, Lyall H, Gibb D. 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. Hankin CD, Lyall EGH, Peckham CS, Masters JI, Tookey PA. In utero exposure to antiretroviral therapy: UK clinic-based follow-up 2002-2005. *AIDS Care* 2009 [*In press*]
6. Salotti J A, Nanduri V, Pearce M S, Parker L, Lynn R, Windebank K P. Incidence and clinical features of Langerhans cell histiocytosis in the UK and Ireland. *Arch Dis Child* 2009; 94: 376 – 380
7. Leonard JV, Dezateux C. Newborn screening for medium chain acyl CoA dehydrogenase deficiency. *Arch Dis Child* 2009; 94(3):235-8. [Epub 2008 Oct 6]
8. Manning D. Neonatal hyperbilirubinaemia – Informing NICE guidelines. BPSU Conference March 2009, London, UK
9. Shield JPH, Lynn R, Wan KC, Haines L, TG Barrett. Management and 1 year outcome for UK children with type 2 diabetes. *Arch Dis Child* 2009; 94(3):206-9.
10. Verity C, Winstone AM, Stellitano L, Krishnakumar D, McFarland, R Will R. The clinical presentation of mitochondrial diseases in children with progressive intellectual and neurological deterioration (PIND): a national prospective population-based study. (In press)
11. Teo S S, Riordan A, Alfaham M, Clark J, Evans MR, Sharland M, Novelli V, Watson JM, Sonnenberg P, Hayward A, Moore-Gillon J, Shingadia D 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.
12. Teo S S, Riordan A, Alfaham M, Clark J, Evans MR, Watson JM, Riordan A, Sonnenberg P, Clark J, Hayward A, Sharland M, Moore-Gillon J , Novelli V, Quinn D, Shingadia D 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

Canada

Publications: 2009

1. Grenier D, Ugnat A-M, McCourt C, Scott J, Laffin Thibodeau M, Davis MA, Dickson NP. Can active surveillance provide a rapid response to an emerging child health issue? - The melamine example. *Paediatr Child Health,* 2009 May–Jun; 14(5): 285–6.
2. S Vohra, J Brulotte, C Le, T Charrois, H Laeeque, Adverse events associated with paediatric use of complementary and alternative medicine: Results of a Canadian Paediatric Surveillance Program survey. *Paediatr Child Health*, 2009 July-august; 14(6):, 385-7.
3. B. Banwell et al..Incidence of acquired demyelination of the CNS in Canadian children. *Neurology* 2009;72;232-239
4. Campbell C. Patient registries and trial readiness in myotonic dystrophy: TREAT-NMD/Marigold International Workshop Report. Thompson R et al. Additional outcome measures for childhood and congenital DM1. *Neuromuscul Disord* 2009; 19: 860-6
5. Respiratory distress and the flu: What should a physician know? *Paediatr Child Health* 2009; 14(9): 571-2
6. Public health impacts of the International Network of Paediatric Surveillance Units. *Paediatr Child Health* 2009; 14(8): 499-500
7. Developmental regression: Always a worrying signal. *Paediatr Child Health* 2009; 14(7): 431
8. Children and spinal manipulation therapy: Ask your patients about all the therapies they seek. *Paediatr Child Health* 2009; 14(5): 285-6
9. Is melamine contamination an issue in Canada? *Paediatr Child Health* 2009; 14(4): 218
10. Canadian children who travel abroad: What are the risks? *Paediatr Child Health* 2009; 14(3): 160,176
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Publications: 2010

1. S Amed, H Dean, et al. Accepted for publication in the journal *Diabetes Care* Type 2 Diabetes, Medication-Induced Diabetes and Monogenic Diabetes in Canadian Children: A Prospective National Surveillance Study.
2. C Campbell. Accepted for publication in *Paediatrics & Child Health* Congenital myotonic dystrophy in a national registry of myotonic dystrophy.

Germany

Publications: 2009

1. Lainka E, Neudorf U, Lohse P, Timmann C, Stojanov S, Huss K, von Kries R, Niehues T. Incidence of TNFRSF1A mutations in German children: epidemiological, clinical and genetic risks. Rheumatology 2009;48 (8):987-991 (DOI: 10.1093/rheumatology/kep140)
2. Nowak-Göttl U. Role of endogenous testosterone concentration in pediatric stroke. Ann Neurol 2009; 66:754-758
3. Reuss AM, Wiese-Posselt M, Weißmann B, Siedler A, Zuschneid I, an der Heiden M, Claus H, von Kries R, Haas WH. Incidence Rate of Nontuberculous Mycobacterial Disease in Immunocompetent Children: A Prospective Nationwide Surveillance Study in Germany. Pediatr Infect Dis J 2009;28: 642-644 (DOI: 10.1097/INF.0b013e3181978e8e)
4. Rückinger S, van der Linden M, Reinert RR, von Kries R, Burckhardt F, Siedler A. Reduction in the incidence of invasive pneumococcal disease after general vaccination with 7-valent pneumococcal conjugate vaccine in Germany, Vaccine 2009; 27(31): 4136–4141
5. Rückinger S**,** von Kries R, Siedler A, van der Linden M (2009), Invasive pneumococcal disease in children: Association of serotype of Streptococcus pneumoniae with risk of severe and fatal outcome, Pediatric Infectious Disease Journal 2009; 28(2): 118-122

Publications: 2010

1. Göbel U, Heinrich B, Krauth K, Steingrüber H.-J., von Kries R. Evaluation der Prozess- und Ergebnissqualität der Erhebungseinheit für seltene pädiatrische Erkrankungen in Deutschland (ESPED) - Process and Outcome Quality of the German Paediatric Surveillance Unit. Klin Padiatr 2010;222:92-97
2. Rückinger S, van der Linden M, von Kries R. Effect of heptavalent pneumococcal conjugate vaccination on invasive pneumococcal disease in preterm born infants, BMC Infectious Diseases 2010,10:12

Greece

Publications: 2010

1. "A surveillance network for Congenital Toxoplasmosis in Greece, 2006-2009: assessment of the results" (To be submitted)

Netherlands

Publications: 2009

1. Blink M, Buitenkamp TD, van Wouwe JP, van Wering ER, van der Velden VHJ, Zwaan CM. Ontwikkelingen in de diagnostiek en behandeling van leukemie bij kinderen met Down syndroom. Tijdschrift voor Kindergeneeskunde 2009; 77: 57-59.
2. Boehmer ALM, Brackel HJL, Duiverman EJ, Essen-Zandvliet EEM van, Ewijk BE van, Griendt EJ van de, Hugen CAC, Landstra AM, Versteegh FGA. Moeilijk behandelbare astma, diagnostiek en behandelopties. Tijdschrift Kindergeneesk 2009;77;255-261.
3. Breunis WB, Kuipers IM, Kuijpers TW. De ziekte van Kawasaki in Nederland. Abstract 31e Congres Kindergeneeskunde nov 2009, Tijdschr Kindergeneesk 2009; p 14.
4. Dankert-Roelse JE, Vernooij-Langen AMM. Voor- en nadelen van screening van pasgeborenen op CF. Abstract 31^{e} Congres Kindergeneeskunde nov 2009. Abstract Tijdschr Kindergeneesk 2009: p:41.
5. Ketelslegers IA, Boon M, Rodrigues Pereira R, Hintzen RQ, Catsman-Berrevoets CE. ADEM en het risico op het ontwikkelen van MS bij kinderen. Tijdschr Kindergeneesk 2009, 77(2):66-73.

6. Pelleboer RAA, Bontemps STH, Verkerk PH, Van Dommelen P, Rodrigues Pereira R Van Wouwe JP. A nationwide study on hospital admissions due to dehydration in exclusively breastfed infants in the Netherlands: Its incidence, clinical characteristics, treatment and outcome. Acta Paediatr 2010;98(5):807-11.
7. Peters M, Fijnvandraat K, Tweel XW van den, Galindo Garre F, Giordano PC, Wouwe JP van, Rodrigues Pereira R, Verkerk PH. One third of newly diagnosed children with sickle cell disease in the Netherlands evade neonatal screening. Aangeboden.
8. Rodrigues Pereira R, Draaisma JMTh. Acute disseminerende encefalomyelitis (ADEM) en multiple sclerose (MS). Tijdschr Kindergeneesk 2009;77(2):50
9. Tweel XW van der. Measuring complications of Sickle Cell disease. Proefschrift Amsterdam. Universiteit van Amsterdam. 2009: chapter 2, One third of newly diagnosed children with sickle cell disease in the Netherlands evades neonatal screening, p. 28-33

Publications: 2010

1. Hoof JJ van, Lely N van der, Rodrigues Pereira R, Dalen WE van Adolescent Alcohol Intoxication in the Dutch Hospital Departments of Pediatrics. Journal of Studies on Alcohol and Drugs. 2010;71:366-372
2. Peters M, Fijnvandraat K, Tweel XW van der, Galindo Garre F, Giordano PC, Woude JP van der, Rodrigues Pereira R, Verkerk P. Estimation of prevalence and newly diagnosed sickle cell patients in the Netherlands using a capture - recapture model. Arch Dis Child 2009. Review
3. Semmekrot BA, van Sleuwen BE, Engelberts AC, Joosten KF, Mulder JC, Liem KD, Rodrigues Pereira R, Bijlmer RP, L'Hoir MP. Surveillance study of apparent life-threatening events (ALTE) in the Netherlands. Eur J Pediatr 2010;169:22-236
4. Wieringen H van, Letteboer TGW, Balemans WAF, Ruiter S de, Rodrigues Pereira R, Lindhout D.Foetaal alcohol spectrum stoornissen in Nederland – bruikbare en betrouwbare diagnostische criteria. Ned Tijdschr Geneeskd 2010; accepted.
5. Weijerman ME, Furth AM van, Moore MD van der, Weissenbruch MM van, Rammeloo L, Broers CJM. Prevalence of congenital heart defects and persitent pulmonary hypertension of the neonate with Down syndrome. Eur J Pediatr 2010 (23 april.)

New Zealand

Publications: 2009

1. Grenier D, Ugnat A-M, McCourt C, Scott J, Laffin Thibodeau M, Davis MA, Dickson NP. Can active surveillance provide a rapid response to an emerging child health issue? - The melamine example. *Paediatr Child Health. 2009 May–Jun; 14(5): 285–286.*
2. Dickson N, Kara T, Tuohy P. Rapid national survey of renal stones in New Zealand infants. *Journal of Paediatrics and Child Health, 2009*

Switzerland

Publications: 2009

1. Berger TM, Aebi C, Duppenthaler A, Stocker M and the Swiss Paediatric Surveillance Unit. Prospective population –based study of RSV-related intermediate care and intensive care unit admissions in Switzerland over a 4-year period (2001-2005). Infection 2009;37:109-16.
2. Schifferli A, von Vigier RO, Fontana M, Spartà G et al, and The Swiss Pediatric Surveillance Unit (SPSU). Hemolytic-uremic syndrome in Switzerland: a nationwide surveillance 1997–2003: Eur J Pediatr 2009. DOI: 10.1007/s00431-009-1079-9

Publications: 2010

3. Fanconi M, Lips U. Children University Hospital Zurich, Child Protection Group. Shaken baby syndrome in Switzerland: results of a prospective follow-up study, 2002-2007. Eur J Pediatr 2010; 169: 1023-1028.

Wales

Publications: 2009

1. Welsh Paediatric Surveillance Unit Annual Report 2008, supplement to the Welsh Paediatric Journal 2009, vol 30

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Switzerland – SPSU

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Wales – WPSU

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Affiliated Units

- UK Obstetrics Surveillance System
- British Ophthamology Surveillance Unit
- British Paedaitric Neurology Surveillance Unit

Interested in developing a National Paediatric Surveillance Unit in your country?

Please contact the National PSU in your region or INoPSU on bpsu@rcpch.ac.uk

Or

Visit: www.INoPSU.com


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