INOPSU
INTERNATIONAL NETWORK OF PAEDIATRIC SURVEILLANCE UNITS

15 Years of International Research into Rare Childhood Diseases

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INoPSU Mission

INoPSU supports international cooperation among national Paediatric Surveillance Units to advance epidemiological and clinical knowledge in the area of rare childhood conditions.

Aims

- To facilitate communication and cooperation between existing national paediatric Surveillance Units (PSUs), researchers and investigators and assist in the development of new PSUs.
- To facilitate collaboration for the study of rare childhood conditions among researchers from different nations and scientific disciplines.
- To identify opportunities for coorperative international surveillance in multiple countries by sharing information on current, past and anticipated projects, including protocols, case definitions and questionnaires.
- To identify surveillance priorities including surveillance for emerging conditions
- To vigorously encourage all PSUs to publish their results in reports, journal articles and abstracts.
- To pool results, analyses and conclusions, and facilitate their dissemination via joint international publications, presentations and/or reports to national and international health authorities
- To disseminate all publications widely to raise awareness of rare childhood conditions, to encourage early diagnosis, appropriate treatment and management.
- To contribute to the development and clarification of internationally recognised diagnostic and management criteria for rare diseases, which will help standardise their identification.
- To provide information developing international cohorts from identified cases to support potential future research.
- To support newly forming units by sharing information and advice on study and surveillance methodologies, statistical techniques, management models, and funding.
- To encourage regular formal evaluation of PSUs participating in INoPSU and to share evaluation methodology.
- To provide a forum for discussion of issues relating to surveillance including data validation and protection, ethics and confidentiality and to develop relevant guidance for use by PSUs.
- To respond promptly to international emergencies relating to rare childhood conditions where national and international studies can make a contribution to science or public health.
- To raise awareness of the benefits of surveillance to the whole community including the general public, patient groups, health care professionals and decision makers.

From the INoPSU Co-Chairs

Congratulations to all Paediatric Surveillance Units (PSUs) across the globe who have contributed to the success of INoPSU over the last 15 years. Established in 1998, INoPSU now includes 12 PSUs among its membership. Incredibly, many of the PSUs have been collecting data on rare childhood conditions for 20 years or more.

INoPSU provides a highly successful and easily accessible platform for international collaboration. No other network enables international comparisons of demographics, diagnosis, treatments and outcomes for rare childhood conditions. Over 300 rare conditions have been studied including rare infectious and vaccine preventable diseases, rare genetic disorders, mental health disorders, child injuries and immunological conditions. Important innovations in surveillance methodology include: rapid response to the H1N1-09 influenza pandemic and conducting once-off surveys to provide pilot data to inform future research. INoPSU data have been widely disseminated in journal publications and through the media to inform policy and clinical practice, and to underpin further research.

Based on methodology developed by the British Paediatric Surveillance Unit in 1985, PSU's involve paediatricians and other child health clinicians (~10,000 participants) who voluntarily contribute data on rare conditions every month. We simply couldn't do this important work without the tireless dedication and commitment of all participants who report cases and we are very grateful for their important contribution.

INoPSU plays an important role in rare disease education. PSUs disseminate study protocols and diagnostic criteria, and educational resources for families; by working collaboratively with parent groups and foundations, we have brought research closer to the children.

Although there have been many successes for INoPSU and its members, some important challenges remain. None of the PSUs have ongoing funding and keeping units is an enormous effort.

We acknowledge the outstanding contribution of all involved in INoPSU since its inception, especially the past INoPSU Chairs/Convenors including: Angus Nicoll, Elizabeth Elliott, Reudiger Von Kries, and Daniel Virella for providing leadership, guidance and vision for the network. We acknowledge the hard work of Richard Lynne (BPSU) who has provided secretariat support to INoPSU for many years.

The opportunity to meet every 2 years or so has been invaluable to support network development, to share research results and to plan new studies and publications. Most of all we value the friendships with international colleagues. As an international network we are always keen to expand, and we are always ready to support the development of new national paediatric surveillance units in other countries.

As Co-Chairs of INoPSU we are very proud of this unique collaboration and its many achievements! We look forward to a bright future for INoPSU.

Yvonne Zurynski
(Australia)

Danielle Grenier
(Canada)

Co-Chairs of INoPSU

Development of INoPSU

The British Paediatric Surveillance Unit (BPSU) established in 1986, developed an efficient and effective surveillance method to capture prospective, detailed epidemiological and clinical data on rare childhood diseases. The surveillance method relies on all paediatricians reporting cases via a central national platform – the paediatric surveillance unit (PSU). This methodology was later adopted and adapted to set up PSUs in the following countries: Netherlands and Germany (1992), Australia (1993), Switzerland, Malaysia and Wales (1994), Canada, Republic of Ireland and Papua New Guinea (1996), New Zealand and Latvia (1997), Portugal (2001), Greece/Cyprus (2003), Scotland (2008). Belgium joined INoPSU in 2011 after conducting surveillance for several years.

On INoPSU's 15th Anniversary, the following PSUs are actively conducting surveillance: England, Wales, Ireland, Scotland, Netherlands, Germany, Australia, Canada, New Zealand, Portugal and Belgium. PSUs provide a national framework accessible to many teams of researchers and clinicians for active case finding. The PSUs facilitate studies undertaken by external clinical research teams and occasionally initiate and undertake surveillance studies themselves, or develop studies in response to calls from government agencies. Conditions under surveillance include infections and vaccine preventable diseases and conditions, congenital and inherited (genetic) diseases, unusual injuries, rare adverse outcome of therapies and rare complications of more common conditions.

In the early years, the European PSUs met and communicated regularly to discuss surveillance methodology and protocols. In 1998 an International Network of Paediatric Surveillance Units (INoPSU) was formed by 10 PSUs during the 22nd International Congress of Paediatrics in Amsterdam, The Netherlands.

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. With secretariat support from Richard Lynne in the BPSU and a website (www.inopsu.com) administered by the APSU, INoPSU formed a virtual network with frequent e-mail communication and conferences held every two years or so. The INoPSU website was redeveloped by the BPSU in 2005 and again by the APSU in 2013. The website is the hub of the virtual network and houses a database of studies (>280 conditions studied), key publications and resources supporting the development of new units.

The network is a powerful collaboration with reporting by >10,000 paediatricians on a population of approximately 40 million children. Simultaneous data collection using shared methodology has enabled international comparisons in epidemiology, diagnosis, treatment and outcomes for rare childhood conditions.

In more recent years, INoPSU has collaborated beyond PSUs, including with rare disease patient organisations, Orphanet (a repository of information and resources about rare diseases) and with other surveillance systems using similar methodology: eg. the British Ophthalmology Surveillance Unit, the UK Obstetric Surveillance System, the Australian Maternal and Obstetric Surveillance System.

INoPSU has been instrumental in informing clinical practice and public health policy on rare diseases for the last 15 years and aims to continue this important work into the future.

Current active membership

Member Units	Child population <15 years	No. Clinicians reporting	Response rate
Australian Paediatric Surveillance Unit (APSU)*	3997232	1400	92
Belgium Paediatric Surveillance Unit	1647953	890	65
British Paediatric Surveillance Unit (BPSU)*	9386000	3000	93
Canadian Paediatric Surveillance Program (CPSP)*	5345585	2,800	77
German Paediatric Surveillance Unit (ESPED)*	9756043	460	93
Irish Paediatric Surveillance Unit (IPSU)	979590	230	75
Netherlands Paediatric Surveillance Unit (NSCK)*	2882674	850	80
New Zealand Paediatric Surveillance Unit (NZPSU)*	875637	190	92
Portugal Paediatric Surveillance Unit (PPSU)	1738054	1800	35
Swiss Paediatric Surveillance Unit (SPSU)*	1207990	35	100
Welsh Paediatric Surveillance Unit (WPSU)	520000	232	99

**Indicates inaugural units who formed INoPSU in 1998*

Munich 2008

INoPSU milestones

Year	Milestones
1998	➢ At the 22nd International Congress of Paediatrics 10 PSUs agreed on a document that outlines the formation of INoPSU – *The Amsterdam Note* ➢ Angus Nicoll (United Kingdom) elected as first Convenor of INoPSU
2000	➢ First INoPSU Conference - Ottawa, Canada ➢ The Amsterdam Note is ratified and the terms of reference accepted and renamed *Amsterdam-Ottawa Note* ➢ Elizabeth Elliott (Australia) elected as the second Convenor of INoPSU ➢ INoPSU website launched ➢ British Ophthalmology Surveillance Unit joins INoPSU as an affiliate m ➢ Richard Lynne agrees to manage INoPSU secretariat
2001	➢ Portuguese Surveillance Unit launched ➢ Victor Marssault (Canada) successfully applies for affiliate membership of the International Paediatric Association (IPA) for INoPSU ➢ INoPSU published its first paper: An International network of paediatric surveillance units: A new era in monitoring uncommon diseases of childhood. *Paediatr Child Health 2001*; 6(5)250-9
2002	➢ Second INoPSU Conference – York, England ➢ First INoPSU Progress Report 1999-2002 published
2003	➢ Greece/Cyprus Unit launched and joins INoPSU ➢ Email reporting begins in some units
2004	➢ Third INoPSU Conference - Lisbon, Portugal ➢ Ruediger von Kries (Germany) elected Convenor of INoPSU ➢ New INoPSU website launched ➢ INoPSU workshop held at the International Congress of Paediatrics Cancun, Mexico
2005	➢ INoPSU paper published: How to acknowledge the work of our contributors.
2006	➢ Fourth INoPSU Conference - London, England ➢ Policy and practice impacts of INoPSU studies presented ➢ Web-based reporting available in some units
2007	➢ Landmark INoPSU paper published: Beyond counting cases: Public health impact of national paediatric surveillance units. *Arch Dis Child* 2007; 92(6): 126-30 ➢ Paediatric Active Disease Surveillance (PAEDS) launched in Australia ➢ Malaysian and Papua New Guinea units fold

Year	Milestones
2008	➢ Fifth INoPSU Conference - Munich, Germany ➢ Daniel Virella (Portugal) elected as INoPSU convenor ➢ INoPSU E-newsletter launched ➢ APSU celebrates 15 years of surveillance ➢ Scottish Paediatric Surveillance Unit launched
2009	➢ Child and Adolescent Psychiatry Surveillance Unit launched in the UK ➢ Updated paper on public health impacts published: *Paediatr Child Health*. 2009 14(8): 499–500. ➢ Surveillance in response to the H1N1-09 pandemic (APSU, SPSU) ➢ CPSP celebrates 15 years of Surveillance
2010	➢ Sixth INoPSU conference - Dublin, Ireland ➢ Yvonne Zurynski (Australia) and Danielle Grenier (Canada) elected as Co-Chairs of INoPSU ➢ Latvian Unit and Cyprus-Greece Unit folds ➢ Some INoPSU units start working more closely with rare disease parent organisations
2011	➢ Seventh INoPSU conference - Montreux, Switzerland ➢ Belgium Paediatric Surveillance Unit joins INoPSU ➢ BPSU celebrates 25 years of surveillance
2012	➢ Transfer of INoPSU management from BPSU to APSU ➢ BPSU under threat of closure ➢ 20 Years of surveillance for Netherlands and Germany
2013	➢ Eighth INoPSU conference – Melbourne, Australia ➢ APSU celebrates 20 years of surveillance ➢ New website launched ➢ INoPSU celebrates 15 years: 15 Year Report launched at the ICP in Melbourne, Australia

London 2006

National surveillance: how we do it

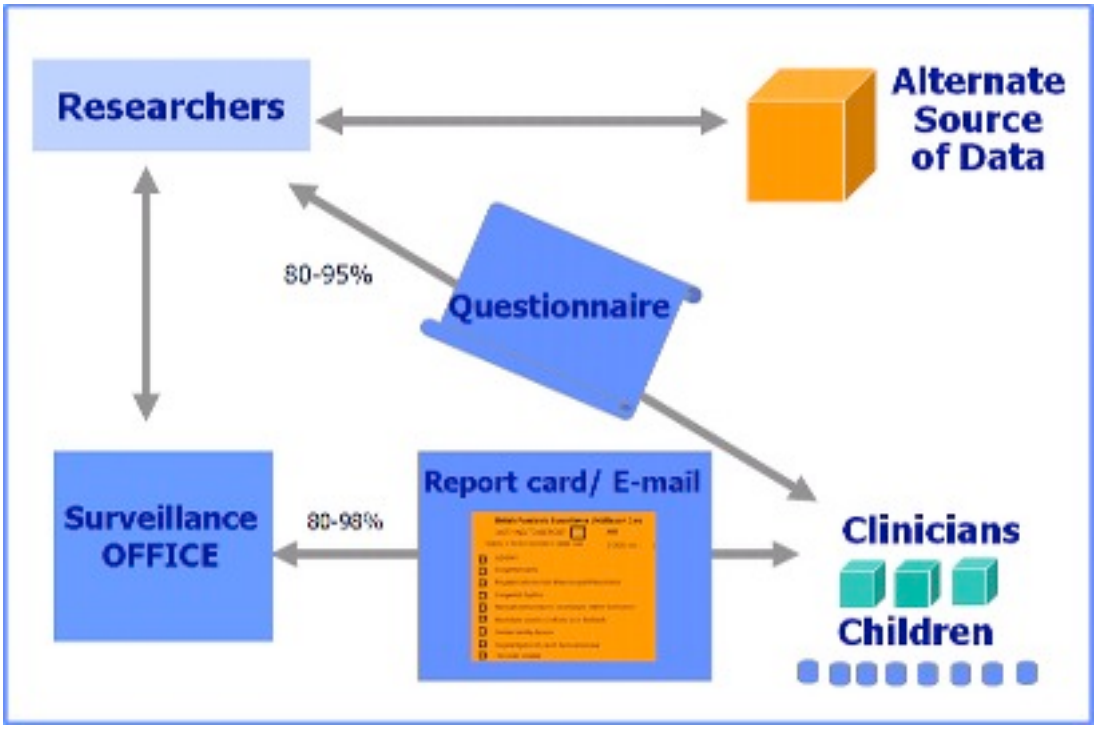
Rare diseases have significant health, psychosocial and economic impacts on children, families, health professionals and health services. By definition each rare disease occurs infrequently, however there are thousands of different rare diseases and when taken as a group they affect a significant proportion of the population. Most begin in childhood, are difficult to diagnose, complex, chronic and associated with disability.

Researching rare diseases is difficult, as adequate numbers of cases for meaningful interpretation are almost impossible to ascertain in a single centre. National and international collaboration is often essential.

National PSUs provide an active surveillance system involving many paediatricians who report newly diagnosed cases according to standardised case definitions via a centralised surveillance system. ~10,000 clinicians have signed on to PSU surveillance databases and they respond every month to monthly report cards listing up to 16 different rare diseases. Cards must be returned whether or not a case is seen which provides a measure of participation. All case reports are followed up with a questionnaire to collect details about medical history, clinical presentation, investigations, treatment and short-term outcomes. The response rates to the report cards are ~80-95%. Workload for paediatricians is relatively low as the majority of clinicians have nothing to report, or one or two cases per year. Benefits for participating clinicians include education and awareness about rare diseases, and involvement in research.

PSUs are very efficient as paediatricians report voluntarily and a number of diseases can be studied simultaneously. Alternative sources of data are used where they exist. Researchers value PSUs for easy access to detailed and timely data on rare diseases. These unique data are shared through the INoPSU to support international collaborations.

PSU Surveillance Methodology



INoPSU key facts

- ~280 rare diseases/conditions studied
- 11 international units are current members
- Formal evaluations of at least 3 units according to Centres for Disease Control and Prevention (CDC) criteria
- >10,000 paediatricians report cases to all PSUs
- Population covered: ~40 million children
- INoPSU provides education for clinicians, families and the public
- BPSU has been conducting surveillance for 27 years
- Netherlands, Germany and Australia: > 20 years of surveillance
- Eight INoPSU conferences held around the world

The Portuguese Paediatric Surveillance Unit (PPSU) was created in 2001, using the British Paediatric Surveillance Unit model. It was due to the vitality, example and encouragement of our fellow partners in INoPSU that the PPSU grew and developed nationally and as an active member of this international partnership. For 15 years researchers from four continents and 17 nations have been able to share discuss their experiences, achievements and frustrations, and to find innovative solutions together. INoPSU and each of its members were, are and will be an important source of inspiration and incentive to the PPSU and to our research teams. Paediatric surveillance and international collaboration are here to stay. Happy anniversary INoPSU! Thank you APSU! ***Dr Daniel Virella, President, Executive Committee, Portuguese Paediatric Surveillance Unit, Past Convenor of the INoPSU.***

Dublin 2010

Impacts of INoPSU studies

Approximately 280 rare conditions have been studied, providing scientific evidence to support public health actions including: informing vaccination and infectious diseases policy; supporting the development of clinical guidelines and health policy; and supporting new research endeavours. We highlight the impacts of some studies below, however, for a complete detailed list of conditions including unit contacts please visit www.inopsu.com

Informing vaccination and infectious diseases policy

- **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*). Documented serious birth defects associated with cCMV often resulting in deafness and blindness. Many women who carry CMV are asymptomatic. Study results support the need for a new vaccine, as well as routine CMV screening in pregnancy and among.
- **Severe Complications of Influenza** (*APSU, SPSU*). APSU documented severe complications including encephalitis, pneumonia and rhabdomyolysis due to seasonal influenza (2007-2012) and pandemic H1N1-09 Influenza even among previously healthy children. SPSU reported many admissions to paediatric intensive care units with serious complications during the H1N1-09 pandemic. These data supported recommendations for timely treatment and routine influenza vaccination of children.
- **Adverse reactions to Influenza vaccination** (*BPSU*). Monitoring for potential adverse reactions including Guillain Barré and Fisher syndromes following the introduction of the H1N1-09 containing influenza vaccine, showed a lack of association between vaccination and these severe adverse events in the UK.
- **Acute Flaccid Paralysis** (*APSU, BePSU, CPSP, NZPSU, SPSU*): PSU's contribute to the World Health Organisation (WHO) efforts to eradicate poliomyelitis by conducting surveillance for acute flaccid paralysis, a common presentation of polio virus infection. INoPSU is currently reviewing the surveillance methods used internationally which will inform the feasibility of applying WHO surveillance targets in developed countries.

Informing clinical practice, health policy and further research

- **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 supported 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. In Australia, many children were from refugee families, while in Canada many children were reported from regions in high latitudes. Study results reinforce the need for screening for Vitamin D levels and supplementation in high risk groups including dark skinned children living at high latitudes, refugee children and some exclusively breastfed children, in order to prevent nutritional rickets.

- **Early-Onset Eating Disorders** (APSU, BPSU, CPSP, NSCK). Food avoidance was the most common clinical presentation among children aged 5 to 13 years; about 20% were boys. Significant weight loss, or failure to gain weight during a period of growth were hallmark findings. Diagnosis was often delayed with approximately one third presenting only after medical complications such as bradycardia, hypothermia and hypotension were apparent. Many were hospitalized. The most common co-morbidities were depression and anxiety. Results demonstrated the need for clinical criteria that can be used in the diagnosis of eating disorders in young children and called a review of current DSM-IV criteria.

- **Lap-belt syndrome and seatbelt related injuries** (APSU, CPSP). Both countries confirmed the lack of uniform legislative measures and signaled high morbidity rates. In the Canadian study of lap-belt injuries, 25% of reported children were left paraplegic, following a motor vehicle crash. The Australian study showed that many young children were using the wrong restraint of their age sustaining serious abdominal, spinal and head injuries. Data gained from these studies have supported advocacy for age and size appropriate use of restraints in motor vehicles. New child restraint laws were enacted in Australia mandating booster seats for 4-7 year old children.

Montreux 2011

Establishing a National PSU

There are a number of issues to consider when establishing a National Paediatric Surveillance Unit in your country. We offer the following guidance but nothing replaces discussions with the INoPSU leaders or with a paediatric surveillance unit which is already operating in a country in your region: Yvonne Zurynski: yvonne.zurynski@health.nsw.gov.au; Danielle Grenier danielleg@cps.ca; or Richard Lynne Richard.Lynn@rcpch.ac.uk

General principles:

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

To raise awareness and gain interest from paediatricians we recommend that the idea of a PSU is widely presented at conferences and meetings where the support from the national society or college is visible. Demonstrating the successful policy and clinical practice impacts of established PSUs provides a powerful tool to gain interest.

Support and collaboration from the College or national specialty society during the establishment of a new PSU is also highly recommended as their involvement engenders credibility amongst the community of paediatricians and researchers. Furthermore, strong links with a national speciality society and public health agency are necessary for infrastructure support, funding, disseminating PSU results, and advocating for policy changes that may be supported by the study results.

The activities of PSUs need to be monitored and principles of good governance need to be applied. Most of the PSUs 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. Regular email contact or teleconferences are used to keep communication open in between face to face meetings.

Criteria and processes for the evaluation of proposals suggesting conditions for surveillance should be set and made available to potential researchers and other participants. Usually PSUs monitor conditions that are rare, high in disability, morbidity, mortality and economic cost to society. Workload for participating paediatricians/sub-specialists must be taken into account when evaluating study proposals.

A PSU cannot run effectively without at least some funding is required to support central coordination to ensure that an effective and efficient service is provided for the volunteer paediatricians and for researchers. Costs include staff time, production and dissemination of surveillance protocols, information technology, communications, and accommodation. Various funding models are used in different countries. Mostly PSUs rely on support from paediatric societies/colleges, public health agencies, universities, hospitals and research grants. Sometimes support is “in-kind” rather than cash

Conditions studied by INoPSU members

Accidental Injury - Baby walkers
Accidental Injury - Serious seatbelt or lap-belt injuries
Accidental Injury - Seat belts and helmets
Acquired brain injury
Acquired demyelinating syndromes CNS
Acute Flaccid Paralysis
Acute liver failure
Acute Pancreatitis
Acute post strepocococcal glomerulonephritis (APSGN)
Acute renal failure
Acute rheumatic fever
Admitted children without legal status
Adrenal suppression
Adverse drug reactions – serious/life-threatening/fatal
Adverse effects associated with complementary and alternative medicine
Adverse neonatal outcomes of water births
Alcohol intoxication in adolescents
Ambiguous genitals/gender identity disorder
Anaphylaxis
Anaphylaxis following food ingestion
Anaphylaxis following immunisation
Apparent Life-Threatening Event (ALTE)
Arthrogryposis multiplex congenita
Aseptic meningitis following MMR-vaccination / MMR vaccine-associated Meningoencephalitis
Asthma - difficult to treat
Asthma - fatal or near fatal I
Ataxia
Autoimmune Addisons Disease
Autoimmune hepatitis
Bacterial meningitis in children under 3 months
Bacterial Osteomyelitis/Non-bacterial Osteitis
Benign Epilepsy with Centrotemporal Spikes
Biliary atresia
Bleeding complications after adenotomy/ tonsillectomy
Cerebral oedema and death following diabetic ketoacidosis
Cerebral Palsy at 5 years of age
Cerebrovascular accident in children
CHARGE association/syndrome
Chemistry set poisoning
Child death review 1
Childhood dementia
Children in house fires
Chronic fatigue syndrome
CNS Demylination
Coeliac disease
Complicated Pneumonia
Complications of measles
Congenital adrenal hyperplasia
Congenital Hypothyroidism
Congenital adrenal hyperplasia (CAH)
Congenital and idiopathic nephrotic syndrome
Congenital brachial palsy
Congenital cataracts
Congenital chylothorax
Congenital cytomegalovirus (cCMV) or CMV infection
Congenital Diaphragmatic Hernia
Congenital dislocation of hip
Congenital malformation after maternal use of anti-epileptics
Congenital malformation of urinary tract
Congenital myotonic dystrophy
Congenital rubella syndrome
Congenital syphilis
Congenital syphilis in children under 2 years of age
Congenital toxoplasmosis
Congenital urea cycle disorders
Conversion Disorder
Craniosynostosis
Creutzfeldt-Jakob disease
Critically ill child
Croypyrin-Associated Periodic Syndromes (CAPS)
Cyclical vomiting syndrome
Cystic fibrosis
Cystic periventricular leukomalacia
Diabetes - neonatal, transient and permanent
Diabetes melitus
Diabetes mellitus type II and MODY
Down's syndrome
Drowning and near drowning
Eating disorders - early onset (EOED); anorexia nervoasa/bulimia
EBV-associated lymphoproliferative diseases in non-immunocompromised children
Encephalitis and Acute Encephalomyelitis
Encephalopathy - moderate and severe
End stage renal failure
Eosinophilic Oesophagitis
Extended-spectrum -lactamase (ESBL)-producing enteric Gram-negative bacilli
Extreme obesity
Facial palsy

Fetal alcohol syndrome
Fetomaternal alloimmune thrombocytopenia
FIRES - Febrile infection-related epilepsy syndrome
Food protein induced enterocolitis syndrome (FPIES)
Foregut and hindgut malformations
Fragile-X syndrome
Fungal Infections / neonatal
Galactosaemia
Gall stones in children
Genetic-based severe early hearing impairment
Genital herpes
GLUT 1 - Glutaric aciduria 1
Gonorrhoea, syphilis, chlamydia, trichimas infeciion
Group A streptococcal-infection exclusive glumerulonefritis
Group B streptococcal infection/invasive disease/ infection in the newborn
Gullain Barre/Fisher Syndrome
Haemoglobinopathy
Haemolytic uraemic syndrome
Haemophagocytic lymphohistiocytosis (HLH)
Haemorrhagic shock encephalopathy syndrome
Head injury secondary to suspected child maltreatment (abuse or neglect)
Hemoglobinopathy I
Hemoglobinopathy II
Henoch-Schönlein Purpura
Hepatitis C virus (HCV) infection
Hereditary periodic fever syndrome (FMF, HIDS, MA, TRAPS, CINCA, MWS, FCAS)
Higher order births (Multiple Births)
Hirschsprung’s disease
HIV infection, AIDS and perinatal exposure to HIV
Hyperbilirubinaemia /kernicterus or need for exchange transfusion
Hyperinsulinaemic hypoglycaemia
Hypernatraemia
Hypocalcaemic seizures secondary to vitamin D deficicency
Hypophosphatasia
Hypoxic-ischaemic encephalopathy
Idiopathic intracranial hypertension
Idiopathic juvenile osteoporosis
Idiopathic nephrotic syndrome
Idiopathic thrombocytopenia/ thrombocytopaenic purpura
IgG-subklasse and/or antipolysacharide antistofdeficiëntie
Immune Thrombocytopenia Purpura
Imported tropical diseases (malaria,schistosomiasis, leishmaniasis)
Inborn errors of metabolism
Infantile Salt Wasting Secondary to Urosepsis
Inflammatory bowel disease - chronic
Influenza- severe or associated intensive care and deaths cases among children and adolescents
Ingestion of lamp oil (intoxications)
Inherited hypocalemic salt-losing tubulopathies / Bartter-like syndromes
Insufficient' breastfeeding
Intersexuality and severe genital malformations
Interstitial lung disease - chronic
Intravenous fluid-related symptomatic acute hyponatremia
Intussusception
Intussusception in children < 12 months of age
Invasive fungal infections in VLBW children
Invasive Haemophilus influenzae infection
Invasive neonatal group B streptococcal infection
Invasive Staphylococcus aureus infection
Iron-deficiency anemia in infants and young children
Irregular blood group antagonism non-D non-ABO
Juvenile dermatomyositis
Juvenile idiopathic arthritis
Juvenile myoclonic epilepsy
Juvenile onset recurrent respiratory papillomatosis
Kawasaki disease
Langerhans cell histiocytosis (LCH)
Leigh syndrome / Leigh-like syndrome
Life threatening and lethal poisoning
Life-threatening events and unexplained deaths in neonates on the first day of life
Long term parenteral nutrition
Long term ventilation
Lowe syndrome
Major depressive disorder – early onset
Malaria in childhood
Malignant disease - newly diagnosed
Marfan's syndrome
Measles, mumps, rubella-meningococcal meningitis
Medium Chain Acyl CoA Dehydrogenase Deficiency (MCADD)
Meningitis/neontal meningitis
Methicillin-resistant Staphylococcus aureus in hospitalized children
Missed CAH
Missed congenital hypothyreoidism
Missed cystic fibrosis
Missed metabolic disease
Missed sickellcel in neonatal heelprick
Multiple sclerosis
Munchausen by proxy syndrome
Munchausen Syndrome by Proxy/Non-accidental Poisoning

Mycobacteriosis - atypical
Narcolepsy
Necrotizing fasciitis
Neonatal abstinence syndrome
Neonatal allo-immune thrombocytopenia
Neonatal B group streptococcus sepsis
Neonatal herpes simplex virus (HSV) Infection
Neonatal liver failure/perinatal hemochromatosis
Neonatal meningitis
Neonatal nectrotising enterocolitis
Neonatal oligohydramnios-sequence
Neonatal sinus venous thrombosis
Nephrotic syndrome/ steroid resistant nephrotic syndrome
Neural tube defects
Neuroborreliosis
Neuromuscular disorder
Non accidental head injury
Non CF bronchiectasis
Non Neonatal Community Acquired Invasive Staphylococcus Aureus
Non-bacterial Osteitis in childhood
Non-CAH primary adrenal insufficiency
Non-tuberculous mycobacterial infection
Nosebleeds in Infants
Obesity - morbid
Obesity-hypoventilation syndrome (Pickwickian syndrome)
Ondine's Curse
Opsuclonnis mycoclonus syndrome
Orbital cellulitis - IP
Organoacidopathia and fatty acid oxidation defects
Osteogenesis imperfecta
Paediatric myasthenia
Palliative care
Pancreatitis (acute)
Paracetomol Overdose
Peanut allergy
Periodic fever syndromes
Persistent albuminuria in the paediatric population with type 2 diabetes mellitus
Pertussis
Phantom tumor cerebri
Pierre Robin Sequence
Pleural empyema and complicated parapneumonic empyema in children and adolescents < 18 years
Pneumococcal meningitis/sepsis
Pneumonia - Complicated
Poliomyelitis
Postneonatal mortality in prematures<32wk and/or <1500 g
Prader-Willi syndrome
Pregnancy in adolescence
Primary Cillary Dyskinesia
Primary immunodeficiency diseases
Progressive Intellectual and neurological deterioration
Prolonged Infantile Cholestasis
Pyridoxine dependent seizures
Raised Blood Lead Levels
Renal failure - chronic
Respiratory syncytial virus (RSV) infections in paediatric transplant patients
Retinopathy of prematurity
Rett Syndrome
Reye's syndrome
Rota-virus gastro-enteritis, severe complications
RSV disease requiring intubation and artificial ventilation
Scleroderma
Septo-optic dysplasia
Severe bronchiolitis requiring ICU/HDU care
Severe combined immunodeficiency
Severe complications of medication
Severe Neonatal Hypernatraemia
Severe neonatal respiratory failure that requires additional critical care therapy
Shaken baby syndrome
Small intestine insufficiency
Smith-Lemli-Opitz syndrome
Splenectomy and hyposplenism
Staphylococcus scalded skin syndrome
Steroid-resistent nephrotic syndrome
Stroke / transient ischaemicattacks / cerebrovascular disease
Subacute sclerosing panencephalitis (SSPE)
Subdural haematoma and effusion in children
Sudden death in epilepsy
Sudden unexpected postnatal collapse
Surgical ligation of patent ductus arteriosus
Systemic lupus erythematosus
Systemic Neisseria-meningococcal infections
Thrombosis - deep vein
Thrombosis - neonatal
Thrombosis in childhood
Thyrotoxicosis
Tick-borne encephalitis
Toxic shock syndrome
Toxoplasma gondii - Congenital infection
Transfusion-related acute lung injury
Transient Leukaemia
Transient myeloproliferative syndrome in neonates with Down-Syndrome
Travel-related illnesses in paediatric travellers who visit friends and relatives abroad
Tuberculosis/ atypical tuberculous infection

Unexpected sudden infant death and severe apparent life-threatening events in the early postnatal period

Urea cycle disorder

Varicella - congenital-neonatal I

Varicella - severe complications

Visual impairment/Blindness - Severe

Vitamin D deficiency rickets

Vitamin K deficiency bleeding - (Haemorrhagic disease of the newborn)

X-linked anhydrotic ectodermal dysplasia

Key INoPSU publications

1. 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

2. INOPSU Report 1998-2002. Royal College of Paediatrics and Child Health - London 2003.

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

4. 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

5. 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(2):126-30.

6. 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.

7. 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

For a complete list of publications please see www.inopsu.com and websites of individual PSUs

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