

# INOPSU

## Multi-national collaboration to assist paediatric infectious disease surveillance The International Network of Paediatric Surveillance Units

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### Background

- The International Network of Paediatric Surveillance Units (INoPSU) is a network to facilitate communication and international collaboration among national paediatric surveillance units (PSU's) across the world
- The Network established in 1998 involves 10,000 senior paediatricians covering a child population of 50 million
- INoPSU undertakes national active surveillance of rare childhood conditions, including infections, genetic disorders, mental health issues, and rare injuries. Case identification and reporting is made by paediatricians
- INoPSU enables communication among PSU's and researchers, and facilitates international studies using similar surveillance methodology which enables international comparisons of incidence, clinical practice and outcomes

### Goals & Objectives

- Advance knowledge on uncommon diseases or conditions with high disability, morbidity and mortality
- Facilitate sharing of information and collaboration among researchers
- Encourage the sharing of protocols thus enabling simultaneous, sequential data collection and comparison between countries
- Respond promptly to international emergencies relating to rare childhood conditions or emerging diseases

### Mechanisms

Constituents of the network communicate through an administrative hub based within the British Unit (BPSU).

Communication is through:

- Virtual network
- Website – [www.inopsu.com](http://www.inopsu.com)
- E-newsletters
- Regular communications between PSUs
- Progress reports
- Peer reviewed papers
- Presentations
- Bi-annual conferences

### Examples of Multi-National Surveillance

Condition	Countries Undertaking Surveillance
<b>Infections</b>	
Hepatitis C virus	Aus, UK, Can
HIV/AIDS	Aus, UK, NZ, NL
Herpes simplex virus	Aus, UK, Can Switz
Group B streptococcus	Port, Can, UK, NL, Ger
<b>Infection-related conditions</b>	
Haemolytic uraemic syndrome	Greece, NZ, Switz, Port, Can, UK, Aus, Latvia, Ger
Progressive intellectual and neurological deterioration	UK, Can
<b>Vaccine-preventable diseases</b>	
Acute flaccid paralysis	Aus, Can, NL, NZ, Switz, UK
Congenital rubella	Aus, UK, NL, NZ, Switz, Can
Invasive Haemophilus Influenzae	Ger, Aus, UK, NL
Pertussis	Switz, Ger, NL, Aus

### International Coverage

INoPSU currently has 12 member countries  
*Australia, Britain, Canada, Germany, Greece, Latvia, Netherlands, New Zealand, Portugal, Ireland, Switzerland, Wales*



### Results

Since 1998 the network has facilitated surveillance of over 200 rare paediatric conditions, including over 70 rare infections.

The data collected has enabled researchers to:

- Evaluate infectious diseases policies and inform development of new ones
- Inform the need for development of new vaccines
- Characterize epidemiology of emerging/re-emerging diseases & conditions
- Elucidate geographical differences
- respond rapidly during outbreaks/epidemics

### Impact

- Surveillance of acute flaccid paralysis in Australia was central to the process of WHO certification of the Western Pacific region as polio-free
- Surveys of congenital rubella, subacute sclerosing panencephalitis, meningoenephalitis, Haemophilus influenzae type B, pertussis and acute flaccid paralysis have been crucial to monitoring the success of immunisation programmes in different countries
- Childhood HIV surveillance led to changes in antenatal screening policy in Australia and UK
- The association between haemolytic uraemic syndrome and different subtypes of Shiga toxin-producing E.coli responsible has been studied in Australia, UK, Canada, Greece, Germany, Latvia, New Zealand, Portugal and Switzerland
- Through surveillance of progressive neurological and intellectual deterioration variant Creutzfeld-Jakob Disease has been monitored in the UK and Canada
- Neonatal herpes simplex virus: Significant mortality rates; HSV-1 most prevalent. Findings suggest the need for an HSV-1/HSV-2 effective vaccine

### Conclusion

- INoPSU has informed new public health policy and clinical practice
- It provides a blueprint for development of new networks e.g. ophthalmology
- Paediatric Surveillance Units have responded to emerging infectious disease threats
- INoPSU has the potential to prospectively identify children with rare diseases to support future research and establishment of cohorts and registries

### Selected Joint Papers

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; 4(8):499-500

Grenier D et al. Beyond Counting Numbers – Public Health Impact of Studies Conducted through National Paediatric Surveillance Units. Arch Dis Child Jun 2007; 92:527-533