

Impact of the BPSU

Educational Impact:

Dissemination of Information

Via an annual report, a quarterly newsletter, study protocol cards and a website at <http://bpsu.inopsu.com>

Public Health Impact:

Monitoring outcomes of national immunisation programmes

Surveys of congenital rubella, subacute sclerosing panencephalitis, meningoencephalitis after MMR vaccination, acute flaccid paralysis and Hib vaccine coverage.

Responding to public health emergencies

Monitoring occurrences of vCJD in the child population; assessing the impact of changing vitamin K administration in newborn, highlighting possible links between aspirin and Reye syndrome.

Informing on screening policies

BPSU studies have informed screening policy for HIV/AIDS, neonatal herpes, congenital cataract, syphilis and toxoplasmosis.

Replication:

Other UK surveillance systems

Ophthalmologists and neurologists have established similar such units.

Internationally

There are now many other national paediatric surveillance units modelled on the BPSU, including Australia, Canada, Germany, Netherlands, New Zealand, Switzerland, Latvia, Malaysia, Papua New Guinea, Portugal, Greece/Cyprus, Wales and Ireland. As a result, in 1998 INoPSU was set up to foster international links. For more information on INoPSU visit www.inopsu.com.

References

1. Impact of studies supported by the BPSU - on clinical practice, policy and service provision. Nicoll A, Lynn RM et al. *J R Soc Med* 2000; 80: 580-585
2. Surveillance for rare disorders by the BPSU. Verity C, Preece M. *Arch Dis Child* 2002; 87:269-271

Conclusion

Since its establishment the BPSU has met and exceeded the expectations of its founders, an achievement of which paediatricians can be proud. The BPSU continues to facilitate high quality research of relevance to clinical and public health practice.

Acknowledgements

The BPSU wishes to thank all clinicians for their continued support through returning cards, reporting cases and completing questionnaires. This is vital for the continued success of the BPSU.



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An introduction to the British Paediatric Surveillance Unit (BPSU)

A unit within the Research Division
of the Royal College of Paediatrics
and Child Health



**Investigating rare childhood conditions for
the future health of the nation**

Introduction

The BPSU:

- Commenced surveillance in 1986 to facilitate and enable paediatricians to participate in national epidemiological surveillance of uncommon childhood disorders.
- Is a joint venture of the Royal College of Paediatrics and Child Health, where it is located, the Health Protection Agency, the Institute of Child Health (London), the Royal College of Physicians (Ireland) and Scottish Centre for Infection and Environmental Health.
- Is supported by the Department of Health (England/Wales)
- Is run by an Executive committee consisting of paediatric consultants, epidemiologists and public health clinicians.

Main Aims of the BPSU

To encourage and facilitate:

- research into uncommon childhood infections and disorders
- paediatricians in surveillance of uncommon disorders
- an increase in awareness of uncommon disorders
- a rapid response to public health emergencies
- dissemination of information about uncommon disorders
- improvement in prevention, treatment and service planning for uncommon disorders

Results

Since its inception the BPSU has:

- undertaken over 50 studies
- sent out over 24,000 surveillance cards each year
- achieved a monthly response rate of over 90%
- achieved over 92% response to study questionnaires
- collected information on over 12,000 case reports
- facilitated the publication and presentation of over 300 papers
- held several scientific symposia
- liaised closely with parent support groups
- taken a lead in the development of the International Network of Paediatric Surveillance Units (INoPSU)

Mechanism of the BPSU

Reporting Procedure:

- Following acceptance by the BPSU Executive and approval from a multi- centre research ethics committee (MREC) the study is included on the BPSU orange card.
- The card with its menu of disorders is sent on a monthly basis to over 2400 consultant paediatricians and other specialists.
- Clinicians return the card notifying any cases seen or importantly mark the "nothing to report" box.
- The reporting clinician is contacted by the investigators and a short questionnaire is sent for completion.
- Investigators inform the BPSU whether the case report fits the agreed case definition.

British Paediatric Surveillance Unit Report Card

NOTHING TO REPORT | | Month / Year

CODE No []

Specify in box number of cases seen

HIV & AIDS

Progressive Intellectual & Neurological Deterioration

Congenital Rubella

Congenital Toxoplasmosis

Severe Hyperbilirubinaemia (>510micromol/L)

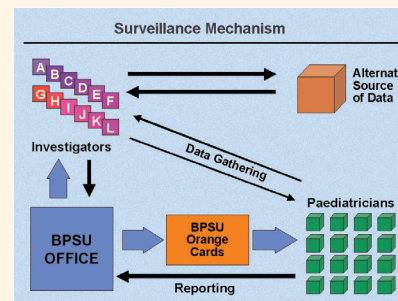
Langerhans Cell Histiocytosis

Childhood Tuberculosis

Neonatal Herpes Simplex Virus (HSV) Infection

Multiple Ascertainment:

- To help improve ascertainment the BPSU encourages the use of alternative data sources.
- Alternative data sources include laboratories, Office for National Statistics, disease registers and other similar surveillance systems.



Would You Like To Undertake a Surveillance Study?

Application Procedure:

- Contact the BPSU scientific coordinator to discuss your ideas and to receive the application guidance pack.
- Complete the 2 page Phase 1 application form according to the guidance notes.
- Discuss the application with one of our medical advisers.
- If appropriate to the BPSU methodology, a more detailed Phase 2 application will be sought.
- An annual surveillance fee is levied.
- The RCPCH has established the Sir Peter Tizard Research Bursary.

Further details are available from the BPSU website at <http://bpsu.inopsu.com/methodol.htm>

BPSU support studies that address the epidemiology of a condition and/or variations in practice and which:

- are of scientific or public health importance
- are rare – <300 cases a year
- have achievable aims
- are appropriately resourced and managed
- use additional alternative data sources
- have MREC approval and conform to Caldicott and Data Protection procedures

The BPSU cannot support studies which involve:

- common disorders
- clinical trials
- case-control studies or audit
- a complex case definition
- disorders where the majority of cases are not managed by paediatricians