

Background and methods

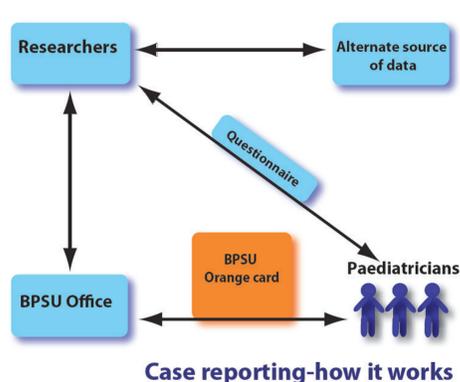
The British Paediatric Surveillance Unit (BPSU) was founded in 1986 to facilitate research into rare childhood diseases and disorders. Although such conditions are individually uncommon, together they affect thousands of children.

The BPSU is supported by the Royal College of Paediatrics and Child Health, Public Health England (PHE), UCL - Institute of Child Health (ICH) and GOSH Children's Charity (GCC).

The BPSU uses an active surveillance methodology. Through the dissemination of a monthly electronic reporting card over 3,400 consultant paediatricians in the UK and Ireland are asked to notify the BPSU of any incidences of specific conditions under surveillance. On a monthly basis there is a response rate of over 90%. Once a positive notification has been received the research team is informed and a clinical proforma is sent to the reporting clinician to complete.

In order to maximise case ascertainment, the BPSU encourages its research teams to use multiple data sources including laboratory reporting, the Office for National Statistics and other surveillance systems.

The methodology has been so successful that it has been transcribed to other countries leading to the foundation of the International Network of Paediatric Surveillance Units.



British Paediatric Surveillance Unit Report Card

NOTHING TO REPORT April 2016 [1604]
CODE No []

Specify in the box the number of cases seen

<input type="checkbox"/>	HIV Infection & Perinatal HIV Exposure
<input type="checkbox"/>	Progressive Intellectual & Neurological Deterioration
<input type="checkbox"/>	Congenital Rubella
<input type="checkbox"/>	Nutritional Rickets
<input type="checkbox"/>	Type 2 Diabetes < 17 years of age
<input type="checkbox"/>	Acute Rheumatic Fever
<input type="checkbox"/>	Behçet's Syndrome
<input type="checkbox"/>	Visual Impairment & Blindness (excl ROI)
<input type="checkbox"/>	ADHD Transition Between Children's & Adult Services
<input type="checkbox"/>	Female Genital Mutilation < 16 years of age
<input type="checkbox"/>	Pierre Robin Sequence
<input type="checkbox"/>	Congenital Zika Syndrome

Results

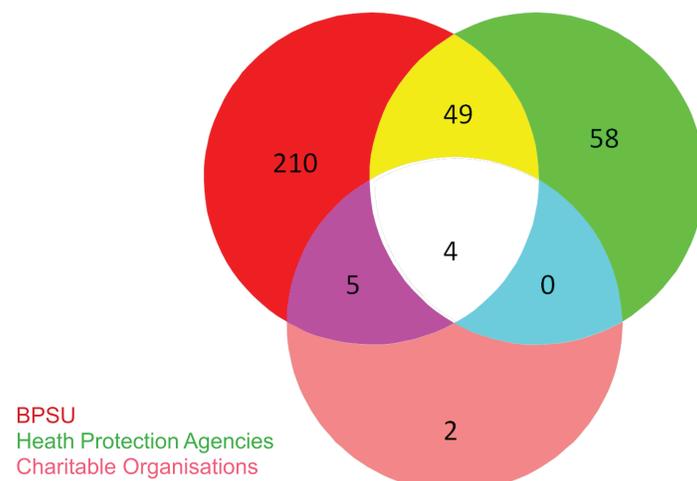
The BPSU has facilitated the study of over 100 rare paediatric disorders and infections to answer questions that are relevant to health policy in the UK. In particular informing and evaluating:

- vaccination policies (MMR; adverse reactions to H1N1, Haemophilus influenzae type B efficacy, rota virus);
- newborn screening programmes (congenital anomalies - congenital hypothyroidism, congenital cataract), inborn errors of metabolism (medium chain acyl CoA dehydrogenase deficiency) and infections (neonatal herpes, HIV infection);
- clinical practice (biliary atresia, type 2 diabetes and eating disorders);
- emerging public health emergencies (progressive intellectual and neurological deterioration, haemolytic uraemic syndrome and congenital Zika syndrome).
- Over 10 studies used multiple sources, such as national health laboratory systems (e.g. MRSA; HIV; Group B strep; HUS; acute infectious hepatitis). See box opposite for an example of multiple source ascertainment.

Acknowledgments

The BPSU wishes to thank the RCPCH, PHE, ICH and GCC for supporting the work of the BPSU and all clinicians for returning the electronic cards, reporting cases and completing the questionnaires.

Multiple cases ascertainment: bacterial meningitis < 90 days, 2010 - 2011



Examples of public health impact

Government bodies and other agencies use the evidence gathered by the BPSU to inform their response to public health interventions.

Clinical and public health policy impacts:

- Supported public health prevention strategies e.g. informing or supporting vaccination programmes such as rubella, varicella Haemophilus influenzae B; monitoring newly emerging disease e.g. variant CJD, E.coli O157, tuberculosis and congenital Zika syndrome.
- Provided data on accidents and injuries e.g. drowning and near drowning; accidental poisoning; shaking baby syndrome, abdominal injuries; Munchausen's syndrome by proxy.
- Drug safety and monitoring e.g. exchange blood transfusion issues, anaphylaxis following immunisation, Reye syndrome and aspirin warning; fatal ADR's, Guillain Barré/Fisher syndrome following H1N1 vaccination.
- Data on MCADD, Group B streptococcal disease, congenital adrenal hyperplasia and congenital hypothyroidism informed national screening policy

Supported national action on rare disease

- The BPSU, with other national rare disease organisations, has been a strong advocate for the continuing need to expand and develop research into the field. The BPSU contributed to the development of the UK Rare Disease Strategy that was published by the Department of Health in 2013. Through the BPSU's work with PHE, evidence on newly emerging and re-emerging disease has been collected.

Vaccine Policy

- HiB vaccine failures were monitored following the introduction of the vaccine in 1992. After the initial success of the vaccine cases started presenting again and a pre-school booster was introduced

Conclusions

BPSU studies have informed on a range of public health policies to control or mitigate the effects of infectious diseases, have contributed evidence to input into guideline development to aid the management of rare conditions and have raised awareness of paediatric rare disease among clinicians and the public alike.

It provides a simple system for active surveillance of rare childhood conditions and is recognised as an important resource in the UK and internationally.

