

What is the British Paediatric Surveillance Unit (BPSU)?

The aim of the BPSU is to encourage the study of rare conditions in children. It was founded in 1986 by the Royal College of Paediatrics and Child Health, the Health Protection Agency and the University Of London- Institute Of Child Health.

What does the BPSU do?

It allows doctors and researchers to find out how many children in the UK and the Republic of Ireland are affected by the particular disease or condition each year - this is called epidemiological surveillance. Doctors can also gather information about all the cases of a particular rare condition so they can begin to understand what might have caused it and how to diagnose and treat. BPSU studies can benefit future patients with rare conditions.

How does the BPSU work?

Each month the BPSU sends an orange card to almost 3500 consultant paediatricians and specialists; the card lists the rare conditions currently being studied. If any doctor has seen a child affected by one of these conditions they tick a box on the card and send it back. The BPSU informs the research team who send the doctor a short confidential questionnaire asking for more information. Researchers are not told the names and addresses of patients, and families are not contacted.

What has the BPSU achieved?

The BPSU has now helped to undertake surveys of over 90 rare conditions which may affect children. These have helped to increase understanding of why the conditions occur and can help to provide better diagnoses and treatments.

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Surveillance of invasive Listeria infections in infants under 90 days of age

This leaflet provides information about a new study of Listeria infection in young infants. It aims to deliver information about the condition, why this study is important and what we hope to show by doing it. It also provides contact details of the researchers undertaking the study and a link to the website where the results will be published.

What is Listeria Infection?

Listeria infections, or Listeriosis, is a disease caused by Listeria, a bacterium (germ) that affects babies in the first months of life, pregnant women, people with weakened immune systems and the elderly. In pregnant women it can cause miscarriage, premature birth, death or severe disease in newborn babies, often leaving the baby with long-term disabilities. Listeria infections appear to be becoming more common.

Why does Listeria infection develop?

Pregnant women can become infected by eating infected food, such as fresh cheese and unpasteurised milk, and may then pass on the infection to their unborn babies. This can cause miscarriage, premature birth, death or severe disease in newborn babies, often leaving the baby with long-term disabilities.

What are the aims of this study?

The main study aims are to:

1. Understand how common listeria infection is in babies less than 3 months of age and describe the short and long-term health problems caused by the infection, including how many babies die or have severe disabilities.
2. Better define the age at which babies become ill and how the disease is currently treated. This will provide information to update the national antibiotic guidelines for doctors treating these babies.
3. Identify which population groups are most at risk of the disease, to best target prevention campaigns.

How will the information be collected?

All paediatric doctors will be asked every month how many cases of listeria infections in infants under 90 days of age they have seen. The research team will then send the reporting doctor a short confidential questionnaire for more information about the affected child and The researchers will then follow these cases up one year later with a short questionnaire to understand how the baby is and whether any consequences from the infection are present.

Currently microbiology laboratories also collect information about listeria infections. We plan to compare the data collected through our survey with this data to ensure that all cases are included.

How will the information be used?

BPSU researchers do not contact the children or families with the condition. Cases that are reported are sent to the research team without any names or addresses. All information that is collected will be confidential and stored securely.

We hope that the information will help inform national antibiotic guidelines, for example through designing better healthcare services to make sure all patients have access to the best care.

How to opt out of the research?

The NHS uses medical records for audit or research to improve future health and care. Hospitals and health professionals record when you do not want your child's notes to be used for audit or research so you must always let your child's consultant paediatrician know if you do not wish their medical notes to be used for research. If so, their data will not be used in BPSU studies.

Where is this study happening?

We are collecting information from doctors in the UK and Ireland. The study team are based at St George's University of London and all the results will be analysed here.

How long will the study go on for?

We will ask doctors to report any new cases of invasive listeria over a 25 month period. We will then send them a questionnaire one year after they made the diagnosis. The study will therefore last 3 years in total.

Who is funding this study?

This study is being funded by St George's, University of London

Further information?

BPSU: <http://www.rcpch.ac.uk/bpsu/listeria>

BLISS: <http://www.bliss.org.uk>

Who to contact if you have any questions

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