

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, Public Health England and Great Ormond Street Institute of Child Health (University College London).

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 e-card to over 4,000 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 120 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.

For further information contact:

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Public Information Leaflet

Surveillance of Clinical characteristics of children with pneumococcal meningitis

This leaflet provides information about a new study on clinical characteristics of children with pneumococcal meningitis. It aims to provide information about the disease and why this study is important. 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 pneumococcal meningitis?

Pneumococcal meningitis is inflammation of the lining of the brain caused by the pneumococcal bacteria (*streptococcus pneumoniae*). There are almost 100 different pneumococcal strains (serotypes) that cause serious infections in humans. Pneumococcal meningitis is a serious illness and can be fatal. In industrialised countries such as the UK, up to a third of survivors of pneumococcal meningitis develop long-term complications, such as epilepsy, hearing loss and brain damage.

Why do some children develop pneumococcal meningitis?

The pneumococcal bacteria usually live in the nose and back of the throat and can spread from person to person through coughing and sneezing. It is the most common bacterial cause of ear and chest infections but in some cases the infection may spread to the blood stream, to internal organs and even to the brain. The reason why this occurs in some people and not in others is not known.

Pneumococcal vaccines are effective in preventing pneumococcal meningitis caused by strains covered by the vaccine. However, most cases are now due to newly emerging strains, which are not covered by existing vaccines (non-vaccine strains). Information will be collected in

order to have a better understanding of the risk, course of illness, clinical presentation (e.g. signs and symptoms), management, complications and outcomes of children with pneumococcal meningitis caused by these new emerging bacterial strains.

Data collected will help improve our understanding of the current problems associated with this condition. This will help shape future approaches to preventing and managing the condition.

How long will the study last and where is it happening?

Information about all children with pneumococcal meningitis infection will be collected over a 25-month period. The reporting doctors will also be asked to complete another short questionnaire 12-months later to find out if any children suffered from long-term complications. Clinical data will be collected through the UK, Northern Ireland and the Republic of Ireland.

How will the information be collected and used?

Public Health England (PHE) is the sponsor and data controller for this study and is responsible for looking after the information and using it properly.

We will collect information about children with a new diagnosis of pneumococcal meningitis from the doctors who are looking after them. Doctors will complete questionnaires using medical records. Doctors will not provide names and addresses to the study team but they will provide details like sex, ethnic group and date of birth. The least amount of personal information will be collected so that the duplicate cases can be identified and removed before analysis. PHE will securely store all the information collected as part of this study for 20 years.

As we do not collect names and addresses for individual children with pneumococcal meningitis, it will not be possible for us to remove, change, withdraw or provide access to personal information for individual children in the study. If you want to find out more about how the information is used and stored or if you would like more information about study withdrawal, please contact Dr Godwin Oligbu on email: godwin.oligbu@nhs.net

BPSU researchers do not contact families or children with the infection. Children with pneumococcal meningitis will continue to get the normal standard of care and treatment from their doctors.

What if I do not want my child to be involved?

Hospitals will record if parents do not want their child's notes to be used for audit or research so you must tell your doctor if you do not want your child's notes used. If you do this, then your child's notes will not be used in any BPSU study.

In addition, individuals living in England can register a national data opt out. Registering an opt out means that none of your child's NHS information relating to care provided in England would be used for research or planning www.nhs.uk/your-nhs-data-matters/

Who is funding and supporting this study?

This study is funded by the Sir Peter Tizard Bursary (www.rcpch.ac.uk/bpsu/bursary) through the BPSU and the Royal College of Paediatrics and Child Health and by a grant from Action Medical Research (www.action.org.uk).

Where will the results be published?

Once the study is completed, you will be able to find the results on the BPSU website: www.rcpch.ac.uk/bpsu/pneumococcal-meningitis

Who has reviewed this study?

The study was approved by: The London-Dulwich Research Ethics Committee (reference: 19/LO/0978); HRA Confidentiality Advisory Group (reference: 19/CAG/0073); and Public Benefit and Privacy Panel for Health and Social Care (reference: 1819-0357).

Where can I go for support?

If you have any questions about meningitis, you can contact Meningitis Research Foundation (www.meningitis.org) or Meningitis Now (www.meningitisnow.org)

Who to contact if you have any questions

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