

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 contacts almost 3500 consultant paediatricians and specialists with a list of 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.

For further information contact:

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BRITISH PAEDIATRIC SURVEILLANCE UNIT Public Information Leaflet

Severe complications of Enterovirus and human Parechovirus infections in children

Clinical study on management and outcome of children in UK and Ireland with severe Enterovirus and human Parechovirus infections

This leaflet provides information about a new study on severe enterovirus and human parechovirus infections in children. It aims to provide 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 are enterovirus and human parechovirus?

Enterovirus and human parechovirus are two related viruses that commonly cause self-limiting infections in children, mainly flu-like illnesses, and diarrhoea and vomiting. Rarely, however, both these viruses can cause severe illness and complications that may cause permanent damage or death.

Why do some children develop severe Enterovirus and human Parechovirus infection?

Enterovirus and human parechovirus are common causes of mild infections in children and adults. They spread very easily from person to person through saliva droplets when sneezing or coughing. The viruses usually stay in the nose and the back of the throat (causing cold symptoms) or in the digestive system (causing vomiting and diarrhea), 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.

What are the aims of this study?

We would like to collect important information about how often such severe infections occur in children, the course of the illness, who looks after the children when they are ill, what treatment they receive and how they recover from their infection. We hope that our results will lead to national guidelines that will improve the way doctors look after such children in the future. We will also try to find out if different strains of the viruses might be causing different illnesses. This could help us identify children who might be more likely to have long-term problems after recovering from their illness.

How will the information be collected?

Paediatric consultants across the UK and Ireland will be asked to report cases to the BPSU every month and then complete a detailed clinical questionnaire about the child's illness. The information provided will not contain any names, so it will not be possible to identify the child from the details provided by the paediatrician.

What are the possible risks and benefits?

There are no risks or direct benefits for your child. The care your child receives will remain the same. No additional tests or treatments will be performed. Your child's doctor will usually complete the questionnaire after your child has been discharged from hospital. We are hoping the information we collect will improve the way doctors look after children with similar illnesses in the future.

Where is this study happening?

The NHS uses medical records for 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 research so you must always let your child's consultant paediatrician or psychiatrist know if you do not wish their medical notes to be used for research. If this is the case, your child's data will not be used in BPSU studies.

Where is this study happening?

The study is taking place in all hospitals across the United Kingdom and Republic of Ireland.

How long will the study go on for?

We will collect information for all children with severe enterovirus or human parechovirus infection over a 13 months period beginning February 2019. 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.

Who is funding this study?

The costs of this study are covered by Public Health England and St. George's University of London.

Where can I go for support?

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

Who can I contact if I have any questions?

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