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 and its parent bodies are 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. On receiving the card, the BPSU informs the investigation team, who send the reporting doctor a short confidential questionnaire for more information about the affected child. BPSU researchers never contact families or children and surveillance studies don't ever affect a child's treatment. The purpose is ONLY to collect information to learn more about the condition.

How does the BPSU work?

Each month the unit sends a distinctive orange card to over 4000 consultant paediatricians; the card lists the rare conditions currently being studied. If a doctor has seen a child affected by one of these conditions they tick a box on the card and return it to BPSU.

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 Button battery ingestion, inhalation or insertion

This leaflet provides information about a new study of button battery ingestion, inhalation or insertion. It aims to provide information about the condition, why this study is important and what we hope to show by doing it. It includes the contact details of one of the researchers carrying out the study and a link to the website where the results will be published.

What is a button battery?

small electronic devices are powered by button batteries. These devices can range from musical cards to remote controls. Button batteries can range in size but are usually round, silver in colour and smaller than a 10p coin and currently there is no legislation for devices or packaging that contain them to be child proof.

Why is this matter important?

Children who have accidentally swallowed or inhaled a button battery, which has subsequently become stuck in the food or wind pipe, have had serious injury or even died due to internal burning by a chemical reaction.

Why is this study important?

In the United Kingdom and Ireland we do not know how many children accidental swallow or choke on button batteries. In the USA and Australia there have been similar studies to find this number out.

Without this information of how many children are affected, it is difficult to know how to not only support prevention strategies but also raise awareness of the risks of accidentally ingestion or choking. The study would also look towards helping to guide doctors and nurses how to better treat these children.

Where is this study happening?

This study is being led by a small team of medical staff based in Leeds, Bristol, Bradford and Dublin and it will be taking place in all hospitals across the England, Wales, Northern Ireland and the Republic of Ireland.

How long will the study go on for?

The study will run for 13-months.

What if a parent does not wish their baby to be included in this study?

If you do not want your child's medical notes to be used for audit or research, you should let your GP and hospital doctors know so that this can be recorded clearly in the medical records. More information about how personal data is used can be found on the NHS Inform website - https://www.nhsinform.scot/media/2368/how-nhs-handles-your-data-v1-nov_2018-web.pdf

If you live in England, you 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. Visit www.nhs.uk/your-nhs-data-matters if you would like to register

How will the information be collected?

Medical doctors looking after children who have had a battery removed or had an attempted removal will fill in an electronic questionnaire and send this anonymous information to the study investigators.

Through looking at this information we hope to improve treatment of these children and look towards a robust awareness campaign.

What are the possible risks and benefits?

Information that is collected will not identify anyone and confidentiality will be maintained at all times.

Through collecting this information, we hope to improve treatment and raise awareness.

Who has reviewed this study?

The study was approved by: Yorkshire & The Humber - Bradford Leeds Research Ethics Committee (reference: 18/YH/0449); HRA Confidentiality Advisory Group (reference: 19/CAG/0019).

Who to contact if you have any questions or concerns?

If you would like to discuss this project with the research team, please contact:

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