

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 the University College London Great Ormond Street 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 e-card to over 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 of patients, and families are not contacted.

What has the BPSU achieved?

The BPSU has now helped to undertake surveys of over 100 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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BRITISH PAEDIATRIC SURVEILLANCE UNIT Public Information Sheet

SURVEILLANCE OF ACUTE SEVERE POISONINGS IN CHILDREN

This leaflet provides information about a new study of Acute Severe Poisonings in Children. It describes the condition being studied, 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 poisoning?

Poisoning occurs when someone is exposed to a substance that can have a bad effect on their health. Poisons are usually taken by mouth, but can also be breathed into the lungs, splashed onto the eyes or skin, or even injected into the blood.

Poisoning can be caused by many different substances. The most common are medicines, household products such as washing liquids and bleaches, and cosmetics such as nail varnish remover and perfumes.

How do children get poisoned?

Children, especially those under 5 years, are curious and frequently put things found in their home into their mouths causing accidental poisoning. Laws require the use of child-resistant packaging for some medicines and toxic chemicals, which reduces harm to children. However, these laws do not cover a large number of medications in blister packs. One or two adult tablets of certain medicines in these blister packs can lead to the death of a baby or toddler. Teenagers are also in danger of accidentally poisoning themselves if they are involved in risk taking behavior such as taking illegal drugs or alcohol. Therefore, children of all ages are at risk from accidental poisoning, which may require attendance at hospital.

Why is this study happening?

Following an accidental poisoning most children only need to be observed in hospital for a few hours before returning home. Serious harm from poisoning is rare, however very occasionally children may die or become extremely unwell and require a great deal of extra medical support.

Very little is known about these severe accidental poisonings in children. This study aims to get hold of more information so we can find ways to prevent the damage that these harmful substances can have on children.

How will the information be collected?

Medical doctors across the UK and the Republic of Ireland will fill in a questionnaire for any child less than 15 years of age who dies or is very unwell needing large amounts of monitoring and support as a result of the poisoning.

The questionnaire will ask details about the poisoning including how the poisoning occurred, what poisons were involved, what tests and treatment were needed and finally what happened after the poisoning episode. This information will be sent onto the study team in Derby who will then look at the findings. The results will be then presented in medical journals and on various websites for parents and families.

How will the information be used?

By collecting this information it is hoped that we can increase our understanding about severe poisonings among children in the UK and Republic of Ireland. This may help to improve poisoning prevention within the home and reduce problems that can follow from a child being poisoned. BPSU researchers do not contact families or children who have been poisoned.

Derby teaching hospital (DHFT) is the sponsor for this study based in the United Kingdom. We will be using information from case medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after patient information and using it properly.

Identifiable clinical information including age in months (taken from date of birth), sex and ethnicity are retained securely 5 years as a paper record and then electronically for 20 years, by DHFT.

Rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the

research to be reliable and accurate. If you withdraw from the study we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible. For more about how we use information contact Dr Elizabeth Starkey, principal investigator.

The care and treatment children receive will not change as a result of the information being collected in this study. Information collected will not identify any individual, and confidentiality will be maintained at all times.

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

Hospitals and health professionals 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. Your child's care will not be affected if they are not involved in this study.

What happens if there is a concern?

As this study will not affect clinical care there should be no problems. However, if you have any concerns about the care your child received, please contact your local hospitals Patient Advice and Liaison service (PALS).

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

The study will last for 13 months and will be taking place across the United Kingdom, the Republic of Ireland and the Channel Islands.

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/poisoning

Who has reviewed this study?

This study has been approved by Nottingham 1, East Midlands REC Research Ethics Committee 2 (REC reference: 17/EM/0464; IRAS project ID: 191072); HRA Confidentiality Advisory Group (reference: 18/CAG/0006); and the Scottish Public Benefit and Privacy Panel (1718-0299).

Who to contact if you have any questions

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