

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 GOS 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 electronic 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 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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Public Information Leaflet

Fetal Alcohol Syndrome

This leaflet provides information about a new study of Fetal Alcohol Syndrome. 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 is Fetal Alcohol Syndrome?

Fetal Alcohol Syndrome (sometimes known as FAS) is a rare condition which occurs when a developing baby is exposed to alcohol in the womb. It can result in reduced growth, challenges in learning and development and unusual facial features.

Why does Fetal Alcohol Syndrome develop?

Alcohol can cross the placenta into an unborn baby's blood stream. The exposure of an unborn baby to alcohol can then affect the development of their brain and other parts of the body, particularly the face. The exact amount of alcohol that causes Fetal Alcohol Syndrome is unknown.

In addition to the specific effects on growth, brain and facial development, babies and children affected by Fetal Alcohol Syndrome can sometimes have:

- Hearing problems
- Speech problems
- Seizures (fits)
- Liver problems
- Kidney problems
- Heart defects

What are the aims of this study?

We would like to determine the how many babies and children (up to the age of 16) are affected by Fetal Alcohol Syndrome in the UK and Ireland. We will gather information on how Fetal Alcohol Syndrome and what services they and their families require in order to support them on a day-to-day basis.

We also aim to increase awareness of Fetal Alcohol Syndrome throughout the study. Doctors will receive information and education about the specific facial features of Fetal Alcohol Syndrome when completing the study questionnaire.

Better awareness and education amongst doctors, we hope, will lead to earlier diagnosis, allowing positive interventions and support for affected families earlier.

How will the information be collected?

The doctors caring for babies and children with Fetal Alcohol Syndrome will complete a questionnaire and send the information to the research team in Leeds.

The information on the questionnaire can then be analysed and will increase our understanding about the numbers of babies and children affected by the condition, and potentially allow better planning and delivery of services for affected families.

How will the information be used?

British Paediatric Surveillance Unit (BPSU) researchers do not contact families or children with the condition. Children with FAS will continue to get the normal standard of care and treatment from their doctors.

We hope that this study will have benefits for future children with the condition by providing us with more information on how many children are affected by this condition.

Data collected on young people with FAS will help us to improve our understanding of the current problems associated with this condition. This will help shape future approaches to preventing and managing the condition. Improved knowledge will allow better planning and delivery of specialised services. All data collected will be held securely and confidentiality maintained at all times.

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 consultant paediatrician know if you do not wish your child's medical notes to be used for research. If so, the data will not be used in BPSU studies.

Where is this study happening?

This study is being led by doctors and nurses at the Leeds General Infirmary and will be taking place in all hospitals across England, Scotland, Wales, Northern Ireland and the Republic of Ireland.

How long will the study go on for?

The study will continue for 13 months starting in October 2018.

Who is funding this study?

This study is being funded by the Sir Halley Stewart Trust with matched funding from Public Health England.

Who has reviewed this study?

This study has been approved by London - Camden & Kings Cross Research Ethics Committee (REC reference: 17/LO/1020; IRAS project ID: 212510); HRA Confidentiality Advisory Group (reference: 17/CAG/0161); and the Scottish Public Benefit and Privacy Panel (1718-0262).

Who to contact if you have any questions

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Useful links

- FAS Aware UK (<https://www.fasaware.co.uk/>)