

## 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 surveillance. Doctors can also collect information about children with a particularly rare condition. This will help them to understand what might have caused the condition and how to manage it better. BPSU studies can help future patients with a similar rare condition.

## How does the BPSU work?

Each month the BPSU sends an online e-card (electronic note) to over 4,000 consultant paediatricians and specialist doctors. The card lists any rare conditions currently being studied. If any doctor has seen a child with one of these conditions, they tick a box on the card and send it back. The BPSU tells the research team who send the doctor a short confidential questionnaire asking for more information from the medical record. 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 studies of over 120 rare conditions that affect children. These have helped to improve understanding of the rare conditions, such as why they occur and how to improve prevention, treatment and care.

## For further information about the BPSU contact:

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## British Paediatric Surveillance Unit Public Information Leaflet

# Neonatal Stroke

This leaflet provides information about a new study of neonatal stroke in babies. 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 researchers undertaking the study and a link to the website where the results will be published.

## What is neonatal stroke?

Stroke is a condition that is often associated with older people. However, anyone including babies can have stroke. Neonatal stroke occurs when the blood supply to part of the brain is disrupted in babies. As different parts of the brain have different function, babies with neonatal stroke have different outcomes. Some recover fully after a stroke, while others may have problems walking, moving their arms or expressing themselves. Some may develop fits throughout childhood.

## Why is this study important?

Stroke in babies is rare and different from those of older children and adults. Presently, we have insufficient information about the number of babies with neonatal stroke. Most clinicians will see only a few cases in their career. Therefore, we know little about which babies are most at risk and what problems they will likely face. There is also no agreed guidance on how we should investigate and treat babies with stroke. Hence, this study is needed to answer these questions to improve the care of babies with neonatal stroke.

## **What are the aims of this study?**

Firstly, we aim to find out about the number of babies who develop neonatal stroke in the United Kingdom and Republic of Ireland. We will also determine the outcome of babies with neonatal stroke, including their development at 2 years old. This will improve our understanding of neonatal stroke allowing better allocation of resources to support babies with this condition.

Secondly, we aim to describe which babies are more likely to develop neonatal stroke and what symptoms they display. A better understanding of the factors associated with neonatal stroke will help design future research looking at prevention and new treatment.

Thirdly, we aim to describe how neonatal stroke is investigated and managed. This will help develop an agreed pathway in managing neonatal stroke, ensuring every baby with this condition will receive the same best care across the regions.

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

This study will last for about 3 years (13-months surveillance with 2-years follow up) from April 2022. The study will be taking place across the United Kingdom and Republic of Ireland. The study is led by researchers based at the University of Nottingham.

## **How will the information be collected and used?**

The University of Nottingham is the sponsor for this study and is responsible for looking after the information and using it properly.

We will collect information about babies with a new diagnosis of neonatal stroke from the doctors who are looking after them. Doctors will not provide names and addresses to the study team, but they will provide details like sex, ethnic group and date of birth. They will complete questionnaires using information from medical records.

The smallest amount of personally identifiable information will be used. We cannot withdraw or remove personal information from the study as this would make the research invalid. When the study finishes, personal information will be deleted or de-personalised.

All study data is collected, analysed and held securely for at least 20 years within the University of Dundee – Health informatics Centre safe haven (<https://www.dundee.ac.uk/hic/hicsafehaven/>). It is ISO 270001 certified with the highest level of data security possible.

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For more details about how personal information is used in the study, please see the BPSU website [www.rcpch.ac.uk/work-we-do/bpsu/neonatal-stroke](http://www.rcpch.ac.uk/work-we-do/bpsu/neonatal-stroke). If you want access to the information in your child's medical records, then you should contact your child's hospital or doctor. There is no anticipated risk by joining the study and your baby's care will not be impacted.

## **What if I do not want to be involved?**

Hospitals will record if patients do not want their medical records to be used for audit or research. You must tell your doctor or hospital if you do not want your records to be used. If you choose to opt out, a small amount of your personal information (such as hospital number) will be held for the duration of the study, to make sure no further information is collected about you.

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/](http://www.nhs.uk/your-nhs-data-matters/).

## **Who is funding and supporting this study?**

This study is being funded by the British Paediatric Surveillance Unit (BPSU) Sir Peter Tizard Bursary. Bliss, the national charity for babies born preterm or sick, is supporting the study.

## **Where will the results be published?**

Once the study is completed, you will be able to find the results on the website: [www.rcpch.ac.uk/work-we-do/bpsu/neonatal-stroke](http://www.rcpch.ac.uk/work-we-do/bpsu/neonatal-stroke).

## **Who has reviewed this study?**

The study was provided a favourable opinion by Nottingham 1 REC (Reference 21/EM/0110), supported by the Health Research Authority on advice from the Confidentiality Advisory Group (England and Wales) and the Public Benefit and Privacy Panel (Scotland).

## **Who to contact if you have any questions?**

Please contact the investigator

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