

## 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 particular 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 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:

British Paediatric Surveillance Unit, Royal College of Paediatrics and Child Health, 5-11 Theobalds Road, London, WC1X 8SH,  
T: +44 (0) 207 092 6173/4  
Email: [bpsu@rcpch.ac.uk](mailto:bpsu@rcpch.ac.uk) Website: [www.rcpch.ac.uk/bpsu/](http://www.rcpch.ac.uk/bpsu/)



## Public Information Leaflet

### A Surveillance Study of Congenital and Hospitalised Neonatal Varicella

This leaflet provides information about a new study of chickenpox in babies.

Chickenpox (varicella) is a common childhood infection which most individuals in European countries, such as the United Kingdom will have contracted by the time they are teenagers. Although it is often mild, severe chickenpox is more likely in young babies, pregnant women and those with poorly functioning immune-systems.

Chickenpox can be particularly devastating if contracted during pregnancy as the infection can be passed to the developing baby increasing the likelihood of stillbirth and premature birth. Chickenpox acquired in this way is known as fetal varicella syndrome (FVS). It can cause problems with the way that the affected infant learns and develops, and many affected babies have lifelong health problems such as learning disabilities and visual impairment. Babies that contract chickenpox in the first month of life (neonatal varicella) are also vulnerable to severe consequences such as breathing difficulties and brain infection as their immune systems are still developing. Due to the severity of the condition in young babies, most babies that catch the virus in the first month of life will be admitted to hospital rather than receiving care from their General Practitioner.

A safe and effective chickenpox vaccine has been developed but it has not been implemented as part of the UK or Portugal routine immunisation programmes. Important information is lacking regarding the burden of severe chickenpox especially fetal varicella infection (FVS) and infection in

the first month of life (hospitalized neonatal varicella), as this data is not routinely collected. This information is crucial to guide decisions about the benefits and cost effectiveness of introducing the chickenpox vaccine. The Joint Committee on Vaccination and Immunisation (JCVI) in the United Kingdom and its counterpart in Portugal are currently reviewing decisions about whether to introduce chickenpox immunisation into the schedules in their respective countries. The findings from this study will therefore have direct policy relevance and help inform this decision-making process.

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

This study aims to collect data on the number and severity of fetal varicella syndrome and babies hospitalized with neonatal varicella infections over a 13-month surveillance period. This crucial information will help inform public health interventions in both countries and guide decisions regarding introducing a routine chickenpox vaccine.

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

This study will last for 13 months and will be taking place across the United Kingdom and Portugal.

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

The UK Health Security Agency (formerly Public Health England) is the sponsor and data controller for this research study so is responsible for looking after the information and using it properly.

We will collect information about children with a new diagnosis of neonatal varicella (chickenpox in babies from 0-28 days old) and fetal varicella syndrome (chickenpox contracted in the womb) 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. The Doctors 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 entirely as this would make the research invalid as we need to make sure we are not collecting the information on the same person more than once. When the study finishes, personal information will be deleted or de-personalised. The data will be securely stored for at least 20 years.

For more details about how personal information is used in the study, please see the BPSU website.

If you want access to the information in your child's medical records, then you should contact your child's NHS hospital or doctor.

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

Hospitals will record if patients do not want their medical records to be used for audits or research. You must tell your doctor or hospital if you do not want your records to be used. More information can be found at: <https://www.hra.nhs.uk/information-about-patients/>

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/) or by calling 0300 303 5678. Families can also opt-out of having their medical information used for research by informing their attending clinician. Opt-out information is also available on the BPSU website.

For individuals living in Scotland and Northern Ireland, please inform the doctor treating your child for FVS/neonatal varicella if you do not want them to be included in this study.

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

The European Society for Paediatric Infectious Diseases is funding this study.

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

Once the study is completed, you will be able to find the results on the BPSU website.

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

The study was approved by the Research Ethics Committee (Ref 22/SW/0040, the Health Research Authority Confidentiality Advisory Group (England and Wales), the Public Benefit and Privacy Panel (Scotland) and the Privacy Advisory Committee (Northern Ireland).

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

Dr Gayatri Amirthalingham, Consultant Epidemiologist  
[phe.neopox@nhs.net](mailto:phe.neopox@nhs.net)