

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:

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Public Information Leaflet

Surveillance of invasive Group B streptococcal (iGBS) disease in infants up to 90 days of age in the UK and Ireland

This leaflet provides information about a new study of invasive GBS disease (iGBS) in newborns and young infants.

What is iGBS?

iGBS is a serious infection caused by a type of bacteria called Group B Streptococcus (GBS). GBS is commonly carried harmlessly by adults, including during pregnancy. However, in some newborn babies and young infants (under 90 days of age), the bacteria can enter parts of the body where it is not normally present, such as the blood or brain. This is known as invasive infection. iGBS can cause serious illnesses such as sepsis (infection of the blood) or meningitis (infection around the brain). These infections can develop in the first week of life (early-onset disease) or later, up to 3 months of age (late-onset disease). Although many babies recover, iGBS can sometimes lead to severe complications or, rarely, death. Some babies who survive meningitis may have long-term health problems, such as difficulties with learning, hearing, or movement.

What are the aims of this study?

The aim of this study is to improve understanding of iGBS in babies and how it affects them.

This study will help us to:

- find out how many babies develop iGBS each year
- understand how babies become unwell and what symptoms they have
- identify factors that may increase the risk of infection

- understand outcomes, including recovery and complications
- study the types of GBS bacteria causing infection
- understand how infections might be prevented in the future, including through antibiotics during labour or vaccines in pregnancy

We hope that this study will improve care for babies and help develop better ways to prevent these infections in the future.

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

This study will last for 13 months from September 2026 and will be taking place across the United Kingdom and Republic of Ireland.

How will the information be collected and used?

City St George's University of London (CSGUL) is the sponsor and data controller for this research study so is responsible for looking after the information and using it properly. Patient information will be processed at the UK Health Security Agency, who will act as a data processor on behalf on CSGUL in line with their privacy notice: <https://www.gov.uk/government/publications/ukhsa-privacy-notice/ukhsa-privacy-notice>

This study has approval from the Health Research Authority and is supported by Section 251 of the NHS Act 2006 (Regulation 5 of the Control of Patient Information regulations), following advice from the Confidentiality Advisory Group. This allows confidential patient information to be used without consent for this type of important public health research. This is necessary to make sure all cases are included and results are accurate.

We will collect information about children with a new diagnosis of iGBS 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. UKHSA and CSGUL will securely store information for at least 5 years. For more details about how personal information is used in the study, please see the BPSU website <https://www.bpsu.org.uk/>

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 audit 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/>

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/

If you choose to opt out, only a small amount of information (such as your child's NHS number) will be kept securely so that we can make sure no further information about your child is collected for this study

Who is funding and supporting this study?

Group B Strep Support (GBSS), a registered UK charity (Charity No. 1112065), is funding and supporting this study (<https://gbss.org.uk/>).

Where will the results be published?

Once the study is completed, you will be able to find the results on the BPSU website: <https://www.bpsu.org.uk/>

Who has reviewed this study?

The study was approved by London – Central Research Ethics Committee (26/LO/0331), the Health Research Authority Confidentiality Advisory Group (England and Wales).

Where can I go for support?

GBSS (<https://gbss.org.uk/>).

Who to contact if you have any questions or concerns?

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