



## 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 and its parent bodies are 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 rare disease or condition each year - this is called epidemiological surveillance. When a doctor sees a case of the condition they will inform the BPSU investigation team, who send the reporting doctor a short confidential questionnaire for more information about the affected child. BPSU researchers never contact families or children and surveillance studies don't ever affect a child's treatment. The purpose is ONLY to collect information to learn more about the condition.

## How does the BPSU work?

Each month the unit sends an email to over 4000 consultant paediatricians; the email lists the rare conditions currently being studied. If a doctor has seen a child affected by one of these conditions they tick a box on the email and return it to BPSU.

## What has the BPSU achieved?

The BPSU has now helped to undertake surveys of over 120 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.

## For further information 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 Surveillance of Near Fatal Asthma

This leaflet provides information about a new study of Near Fatal Asthma (NFA). It aims to provide information about the condition, why this study is important and what we hope to show by doing it. It includes the contact details of one of the researchers carrying out the study and a link to the website where the results will be published.

## What is near fatal asthma?

Asthma attacks can vary from mild to fatal. Some children and young people have an asthma attack so severe that they are close to dying from it. This is called "near fatal asthma". People who have near fatal asthma or NFA, are more likely to have more severe asthma attacks and possibly die.

## Why is this study important?

The UK historically and currently has higher rates of asthma deaths than any other country in Europe and North America, but data is lacking on how often NFA attacks occur. The results will tell us how doctors manage children when they have a near fatal asthma attack, and whether we can find better ways to treat attacks and deliver better asthma care for those who are high risk for future severe asthma attacks.

## What are the aims of this study?

We want to know how often near fatal asthma attacks happens in children and young people in the UK and Republic of Ireland.

We hope that the information will help us in three ways:

1. identify some of the risks for near fatal asthma, and with additional future research use these results to:
2. give better care to children and young people who have near fatal asthma
3. reduce future risk of severe asthma attacks and/or death.

## How long will the study go on for?

This study will last for 3 ½ years (18-months surveillance with 2-years follow up) starting in October 2022. The study will be taking place across the United Kingdom and Republic of Ireland. The study is led by researchers based at NHS Lothian and Edinburgh University.

## How will the information be collected?

This is a surveillance study that uses questionnaires to research rare conditions. You do not have to complete any of the forms or fill out a questionnaire. The doctors who are looking after your child will complete questionnaires using information from medical records. Doctors will **not** provide names and addresses to the study team but they will provide details like **ethnic group, gender, post code and date of birth**. The data will be entered onto an encrypted secure database (a safe haven). A safe haven is an approved, regulated and encrypted secure database where safeguards limit access to depersonalised data by specially trained and authorised professionals and researchers. Researchers will not see information on full post code and date of birth, but this information will be safely and securely linked to other databases in the 'safe haven' to understand factors (such as local air pollution levels or pollen counts) that might make near fatal asthma attacks more likely to happen. Individual cases will not be identified in any reports. Any information made public will be reported as a minimum of 5 cases i.e. there were five cases in Scotland and less than 5 cases in the North of England.

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 but you can opt out of further details being collected. When the study finishes, personal information will be deleted or depersonalised. The University of Edinburgh and NHS Lothian are the sponsor and data controllers for this research study, which means they are responsible for looking after the information and using it properly. They will securely store anonymous information for at least 20 years.

For more details about how personal information is used in the study, please see the BPSU website <https://www.rcpch.ac.uk/work-we-do/bpsu/near-fatal-asthma>

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?

If you think your child has had a NFA attack and do not want your child's data to be included in the study you must inform your doctor or the study team (see below). They will stop any further details about your case entering the study.

Hospitals will also 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.

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 Chief Scientists Office for Scotland. The Asthma UK and British Lung Foundation Partnership are supporting 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: <https://www.rcpch.ac.uk/work-we-do/bpsu/bpsu-study-near-fatal-asthma>

## Who has reviewed this study?

The study was given favourable ethical opinion by South East Scotland Research and Ethics Committee (Ref 22/SS/0030) the Health Research Authority Confidentiality Advisory Group (England and Wales) and the Public Benefit and Privacy Panel (Scotland). The National Office Health Protection in provides approval for Ireland.

## If you have any questions, concerns or would like to opt out?

Prof Steve Cunningham, Royal Hospital for Children and Young People, 50 Little France Crescent, Edinburgh, EH16 4TJ

Email: [loth.bpsunfa@nhsllothian.scot.nhs.uk](mailto:loth.bpsunfa@nhsllothian.scot.nhs.uk)

Website: [www.rcpch.ac.uk/bpsu/nfa](http://www.rcpch.ac.uk/bpsu/nfa)

Telephone: 0131 312 0453