

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 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 e-card to over 4,000 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 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 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:

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Public Information Leaflet

Surveillance of the outcome of resuscitation for term babies with no heart rate at 10 minutes

This leaflet provides information about a new study of term babies (born after 37 weeks of pregnancy) who need prolonged resuscitation after birth. 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.

Why is this important?

Very rarely, babies can encounter problems during labour and delivery and their hearts stop beating. These babies have a reduced supply of blood and oxygen to their brain and require help in getting their heart to start again. This process is known as resuscitation and is required immediately after birth. If the lack of blood and oxygen is severe, it can cause injury to the brain that can be fatal, or may leave survivors with long-term disabilities.

International resuscitation guidance advises doctors and nurses to consider stopping resuscitation efforts if the heart beat does not return by 10 minutes of age. This advice is based on studies that report that if the heart beat does not return by 10 minutes, babies may have a serious disability or may not survive.

The outcome for survivors has improved in recent years following the introduction of cooling treatment for babies who suffer a brain injury during birth. It may be that this guidance is no longer appropriate.

What are the aims of this study?

This study aims to find out how many term babies born in the United Kingdom and Republic of Ireland receive prolonged resuscitation after birth and have no heart rate detected at 10 minutes of age. We will describe how many of these babies survive and their long-term development.

How will the information be collected?

Information about resuscitation, intensive care and long-term outcomes will be collected using questionnaires, which will be completed by the doctor responsible for the care of the baby. The research team will not contact parents or families directly. The information collected will be anonymised and safely stored to protect patient confidentiality.

What are the possible risks and benefits?

It is important that doctors and nurses make decisions based on the best and most recent research. This study will help us to understand how long to continue resuscitation for the sickest babies, how likely they are to survive and how many of them have serious disability when they grow up. This study will not change any of the medical care received by a baby during the research.

What if a parent does not wish their baby to be included in this study?

If you do not want your child's medical notes to be used for audit or research, you should let your GP and hospital doctors know so that this can be recorded clearly in the medical records. More information about how personal data is used can be found on the NHS Inform website - <https://www.nhsinform.scot/media/2368/how-nhs-handles-your-data-v1-nov-2018-web.pdf>

If you live in England, you 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. Visit www.nhs.uk/your-nhs-data-matters if you would like to register

How long will the study go on for?

We will study all babies who need this much resuscitation over a 2-year period. We will send a follow up questionnaire to the doctors looking after these babies at 1 year of age and again at 2 years of age to find out if they have any serious medical problems.

Where will the results be published?

Once the study is completed, you will be able to find the results on the BPSU website: www.rcpch.ac.uk/bpsu/resuscitation

Who has reviewed this study?

The study was approved by: South East Scotland Research Ethics Committee 01 (reference: 17/SS/0009); HRA Confidentiality Advisory

Group (reference: 19/CAG/0002); and Public Benefit and Privacy Panel for Health and Social Care (reference: 1819-0054).

Where can I go for support?

Sands, the stillbirth and neonatal death charity - <https://www.sands.org.uk/>

Bliss - <https://www.bliss.org.uk/>

Who to contact if you have any questions or concerns?

If you would like to discuss this project with the research team, please contact:

Dr. Gemma Sullivan, Neonatal Grid Trainee, Neonatal Unit, Simpson Centre for Reproductive Health, Royal Infirmary of Edinburgh, Little France, Edinburgh, EH16 4SA

Email: gemma.sullivan@nhslothian.scot.nhs.uk **Tel:** 0131 242 2567

If you would like to discuss this project with a medical professional who is not a member of the research team, please contact:

Dr. Edile Murdoch, Consultant Neonatologist, Neonatal Unit, Simpson Centre for Reproductive Health, Royal Infirmary of Edinburgh, Little France, Edinburgh, EH16 4SA

Email: edile.murdoch@nhslothian.scot.nhs.uk **Tel:** 0131 242 2567

Should you wish to make a complaint about any aspect of this project we would encourage you to discuss your concerns with the study sponsor:

Academic and Clinical Central Office for Research and Development (ACCORD), Research & Development Management Suite, The Queen's Medical Research Institute, 47 Little France Crescent, Edinburgh, EH16 4TJ

Email: enquiries@accord.scot **Tel:** 0131 242 3330

If you wish to make a complaint the way you or your baby has been treated you may also use the National Health Service complaints procedures. The Patient Advice and Liaison Service at your hospital will advise you about this.