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 the University College London Great Ormond Street Institute Of Child Health.

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 orange card to over 3,800 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 100 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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Our study aims to establish the number of new cases and early death rates. We will record key treatments, complications and age on discharge from hospital. We hope that this study will benefit children with ichthyosis by providing us with information on exactly how rare it is, how many babies do not survive and how different doctors deal with the condition. This will help shape future approaches to managing the condition.

How will the information be collected?
The British Paediatric Surveillance Unit (BPSU) will alert doctors to this study and will collect monthly reports of newborn babies with harlequin ichthyosis or collodion membrane. The researchers in Birmingham will send a questionnaire to all doctors reporting a case, and will also collect details of the child’s progress one year later. The BPSU researchers will not contact families or children with the condition. Each case will be made anonymous and coded to ensure confidentiality. The research team will be told the baby’s date of birth and postcode purely for use in the analysis. Transfer and storage of the data will be conducted within secure systems to prevent anyone else seeing this information. Our research team will be working with the government organisation, National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) which records congenital abnormalities and rare diseases across the whole of England. The reason for working with NCARDRS is to ensure all babies born with ichthyosis are included in our study, as some may be missed using our ‘orange card reporting’ system. Only minimally identifiable information will be shared with NCARDRS.

How will the information be used?
The anonymous data will be analysed and the results will be published on the BPSU website, and shared with medical professionals, ichthyosis sufferers and NHS bodies concerned with improving services for patients.

What if you don’t want to be part of the research?
The NHS uses medical records for audit or research to improve future health and care. Hospitals and health professionals record when you do not want your child’s medical notes to be used for audit or research. If you do not want your baby’s medical information to be used for this research please tell your doctor. If this is the case, your baby’s data will not be used in this study.

Where is this study happening?
We are collecting data in the UK, Republic of Ireland. The BPSU is based in London and the research team work at Birmingham Children’s Hospital.

How long will the study go on for?
We will collect data on all babies born with the condition over 2 years. We will obtain follow-up data up to 1 year of age, and subsequent data analysis may take another year.

Who is funding this study?
The study is being funded by Great Ormond Street SPARKs fund and Birmingham Children’s Hospital Paediatric Dermatology Fund.

Who to contact if you have any questions
Please contact the principal investigator:
Dr Fozia Roked, Department of Dermatology, Birmingham Children’s Hospital, Steelhouse Lane, Birmingham B4 6NH. bwc.bchscinstudy@nhs.net. Further information on ichthyosis is available at http://www.ichthyosis.org.uk/

GDPR
Birmingham Women’s and Children’s Hospital (BWC) is the sponsor for this study based in the United Kingdom. We will be using information from your baby’s medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. BWC will keep identifiable information about you for 20 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting bwc.bchscinstudy@nhs.net. The information about your baby’s health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.