

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 is run in partnership with the Royal College of Paediatrics and Child Health, Public Health England and the UCL GOS Institute of Child Health with support from Great Ormond Street Children's Hospital.

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 it. BPSU studies can benefit future patients with rare conditions.

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 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.

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Updated 18.02.2020 V1.3



Public Information Leaflet

A prospective study of conservative care in childhood end-stage kidney disease

This leaflet provides information about a new BPSU study. The study aims to understand how many children develop end-stage kidney disease who receive conservative care for their kidney condition instead of treatments such as dialysis or kidney transplantation.

We want to understand how many children this affects; what factors are important when making decisions about treatment and how families are supported during this process.

What is End-Stage Kidney Disease (ESKD) and how does it develop?

When a person's kidneys fail, they have stopped working well enough to survive without dialysis or a kidney transplant. End-stage kidney disease (ESKD) is an incurable condition and results when kidneys are barely functioning or not functioning at all.

ESKD occurs following damage to the kidneys. This may be present from birth or develop in childhood. It may be due to a problem with the kidneys themselves or as the result of other medical problems.

What is conservative care?

This is supportive care without having dialysis or a transplant. The aim is to give the child a good quality of life by prolonging kidney function and managing symptoms or complications of kidney disease.

What are the aims of this study?

This study aims to identify children who develop ESKD where a decision not to pursue dialysis or a kidney transplant is made.

We aim to find out how many children receive conservative care for ESKD. We want to understand what conditions lead to ESKD for these children and whether they have additional health problems. We also don't know

who is involved in making decisions about their treatment, what factors are weighed up in the process, or whether families have access to specialist kidney and/or palliative care. We hope to collect this information as part of the study.

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

This study will last for a two-year period and is taking place in all hospitals that look after children across the United Kingdom and the Republic of Ireland.

How will the information be collected and used?

The UK Renal Registry 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 ESKD who receive conservative care 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. When the study finishes, personal information will be deleted or de-personalised. The UK Renal Registry will securely store 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/bpsu/ESKD>.

If you want access to the information in your child's medical records, then you should contact your child's NHS hospital or doctor. BPSU researchers do not contact the children or families with the condition. Information on reported cases are sent to the research team without any names or addresses. All information that is collected will be confidential and stored securely.

We hope that the information will help us to look after children and young people with ESKD better, for example by designing better services to make sure all patients and families have access to the best care and information.

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. If you choose to opt out, a small amount of your personal information (such as NHS number) will be held for the duration of the study, to make sure no further information is collected about you.

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/

Who is funding this study?

Kidney Research UK (<https://kidneyresearchuk.org>) is funding this study (reference Paed_RP_002_20180927).

Where will the results be published?

You will be able to find the results on the BPSU website: <https://www.rcpch.ac.uk/bpsu/ESKD>.

Who has reviewed this study?

The study was approved by: South West - Central Bristol Research Ethics Committee (reference: 19/SW/0197); HRA Confidentiality Advisory Group (reference: 19/CAG/0190); and Public Benefit and Privacy Panel for Health and Social Care (reference: 1920-0101).

Further information

UK Renal Registry: www.renalreg.org; British Association for Paediatric Nephrology: <https://renal.org/bapn>

Who to contact if you have any questions

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