

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

Chronic Recurrent Multifocal Osteomyelitis/Chronic Nonbacterial Osteomyelitis

This leaflet provides information about a new study of Chronic Recurrent Multifocal Osteomyelitis/Chronic Nonbacterial Osteomyelitis (CRMO/CNO). It aims to provide information about the condition, why this study is important and what we hope to learn from it. It also provides contact details of the researchers undertaking the study and a link to the website where the results will be published.

What is CRMO/CNO?

CRMO, also known as CNO (chronic nonbacterial osteomyelitis), is a rare disease where a patient's immune system attacks their bones by mistake, causing bone pain and swelling. It occurs primarily in children and teenagers. In mild cases, patients need only anti-inflammatory medication (e.g. ibuprofen) to control their symptoms. However, it can be more serious in others, causing fractures in the spine that can be very painful and have long-term consequences.

What causes CRMO/CNO?

We do not know what causes CRMO/CNO. It is likely to be caused by a combination of genetic and environmental factors.

What are the aims of this study?

From this study, we want to know how common CRMO/CNO is, and who is involved in the care of CRMO/CNO patients. This will help to guide planning in healthcare services. There is often a delay in diagnosis as some doctors are not aware of this rare condition. Therefore, we aim to promote awareness of CRMO/CNO among medical doctors, including general paediatricians and orthopaedic surgeons. This will shorten the diagnostic interval, enabling patients to receive earlier treatment with fewer complications.

Moreover, by looking at the existing treatments patients receive and their outcome, the study will allow us to understand the different treatments being used across the country, the short-term outlook, and complications. Patients and carers can then be better informed of the disease progression and its treatment options.

How will the information be collected and used?

Cambridge University Hospitals 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 a new diagnosis of CRMO/CNO 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. Cambridge University Hospitals 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' www.rcpch.ac.uk/bpsu/crmo.

If you want access to the information in your child's medical records, 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 and we will respect this. You must tell your doctor or hospital if you do not want your child's record to be used. You may still choose to opt out once the study has started, and 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/.

Where is this study happening?

We are collecting information from paediatric doctors across the UK and the Republic of Ireland. The study team is based in Cambridge and all the results will be analysed in Cambridge.

How long will the study last?

We will identify any new cases of CRMO/CNO over a 13-month period. Then the follow up study will last 12 months. The study will therefore last 25 months in total.

Who is funding this study?

This study is being funded by the BPSU Sir Peter Tizard Research Bursary and Addenbrooke's Charitable Trust.

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/crmo) and Cambridge University Hospitals website.

Who has reviewed this study?

This study has been approved by London - Central Research Ethics Committee (reference: 20/LO/0195); HRA Confidentiality Advisory Group (reference: 20/CAG/0029); and Public Benefit and Privacy Panel for Health and Social Care (reference: 1920-0202).

Whom to contact if you have any questions?

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