

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- 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 a 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 to study what might have caused it, how to diagnose and treat it. Future patients with rare conditions will benefit from it.

How does the BPSU work?

Each month the BPSU sends an orange card to almost 3500 consultant paediatricians and specialists; the card 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 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 90 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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BRITISH PAEDIATRIC SURVEILLANCE UNIT

Public Information Leaflet

CATCh-uS:

Children and adolescents in transition from children's services to adult services

This leaflet provides information about a new study of young people with attention deficit hyperactivity disorder (ADHD) in transition from children's services to adult services. It aims to provide information about the condition, why this study is important and what we hope to show by doing it. It also provides the contact details of the researchers undertaking the study and a link to the website where the results will be published.

Young person with attention deficit hyperactivity disorder (ADHD) within reach of the services' age boundary requiring continued drug treatment for their ADHD

Attention deficit hyperactivity disorder (ADHD) is a common condition that affects children and adolescents and can continue into adulthood for some. Children with ADHD generally have problems paying attention or concentrating. They cannot seem to follow directions and are easily bored or frustrated with tasks. They also tend to move constantly and are impulsive. These behaviours are generally common in children; they occur more often than usual and are more severe in a child with ADHD. The behaviours that are common with ADHD interfere with a child's ability to function at school and at home.

Once considered to be a condition restricted to childhood, there is clear evidence that ADHD persists into adulthood for many young people. Recent National Institute for Health and Care Excellence (NICE) treatment guidelines have recognised the importance of ADHD in adults, which formalises its status as a long-term condition. Adults with ADHD may have difficulty with time management, organisational skills, goal setting, and employment. They may also have problems with relationships, self-esteem, and addictions.

What are the aims of this study?

An increasingly large group of young adults who have been diagnosed and managed within children's services are growing out of these services' remit. This study aims to study how many young people with ADHD are in need of services for ADHD as adults.

How will the information be collected?

The doctor who is caring for a specific child or young person will send researchers at BPSU some anonymous information about the case. Through this information we hope to increase understanding of this problem and start to look at how services could be improved.

How will the information be used?

The study will not have any negative effect on the care and treatment these young people are currently receiving as a result of the information being collected in this study. Information will not identify any individual and confidentiality will be maintained at all times.

It is hoped that collecting information on young people with ADHD with ongoing medical needs, will help to improve understanding of the problem and the care for individuals and families affected.

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 notes to be used for audit or research so you must always let your child's consultant paediatrician know if you do not wish their medical notes to be used for research. If so their data would also not be used in BPSU studies.

Where is this study happening?

The study will be taking place across the United Kingdom, the Republic of Ireland and the Channel Islands.

How long will the study go on for?

The study surveillance will last for 13 months.

Who is funding this study?

This project is funded by the National Institute of Health Research (NIHR) Health Services and Delivery Research (HS&DR) Programme, special call for evaluative research for long-term conditions in children and young people.

Who to contact if you have any questions

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Further information

BPSU: <http://www.rcpch.ac.uk/bpsu/adhd>
UK ADHD Network (UKAAN): <http://www.ukaan.org/>
Adult Attention Deficit Disorder UK (AADD-UK): <http://aadduk.org/>