

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.

HOW DOES THE BPSU WORK?

Each month the unit sends a distinctive orange card to over 3500 consultant paediatricians; 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 return it to BPSU.

WHAT DOES THE BPSU DO?

It allows doctors and researchers to find out how many children in the UK are affected by the particular disease or condition each year - this is called epidemiological surveillance. Researchers can 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.

On receiving the card, the BPSU informs the study team, who send the reporting doctor a confidential anonymised questionnaire to gather more information about the child. BPSU researchers never contact families or children and surveillance studies do not affect a child's treatment. The purpose is ONLY to collect information to learn more about the condition.

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 these conditions and the healthcare services needed to manage them.

For further information contact:

British Paediatric Surveillance Unit
Royal College of Paediatrics & Child Health
5-11 Theobalds Road, London WC1X 8SH
Tel: +44 (0) 207 0926173 / 74
E-Mail: bpsu@rcpch.ac.uk
Website: <http://www.rcpch.ac.uk/bpsu>



BRITISH PAEDIATRIC SURVEILLANCE UNIT Public Information for the Web

UK SURVEILLANCE OF TYPE 2 DIABETES IN CHILDREN & YOUNG PEOPLE UNDER 17 YEARS

What is Type 2 diabetes?

There are two main types of diabetes Type 1 and Type 2. In both types of diabetes, the child's blood sugar levels are high because there is not enough insulin, a hormone produced by an organ called the pancreas, to keep the blood sugar levels normal. In Type 2 diabetes the pancreas still makes insulin but not enough for the individual's needs as the child is 'resistant' to insulin's normal action. Too much glucose is made by the liver and cannot move into the cells of the body (mainly muscle and fat) to be used for making energy. The pancreas has to work harder to make sufficient insulin to get glucose to go into these cells, but eventually gets worn out from this extra effort.

This research study will be investigating Type 2 diabetes in children under the age of 17 years (up to seventeenth birthday). Until recently this condition was not seen in young people, being a condition seen only in adults. However there is growing evidence that the increase in childhood obesity (overweight for age and height) has resulted in cases of Type 2 diabetes being diagnosed in childhood.

Type 2 diabetes is linked with greatly increased ill health in adult life and the outcome is worse in those developing the disease at an early age. Given this, it is important to identify, treat and manage these children as well and soon as possible.

Why is this study being performed?

The last Type 2 diabetes study in the UK and Ireland was undertaken over ten years ago and there are a number of reasons why the number of newly emerging cases may have changed.

We need to collect as much information about the current type of problems associated with the disease so that we can understand the impact of current management guidelines as well as reviewing current treatment and effectiveness. We also wish to collect data on whether young people with Type 2 diabetes are good attenders at clinic and take all their medication as this is important for best care.

How is the study being performed?

Paediatricians will be asked to report through the British Paediatric Surveillance Unit (BPSU) any new cases of Type 2 diabetes seen in the past month seen in young people before their seventeenth birthday. Paediatricians will be asked to complete a short confidential questionnaire to provide information about the affected young person. We will NOT contact families and the study will not in any way affect the individual's treatment. The purpose is ONLY to collect information to learn more about the condition.

They will also provide details of the individual's medical progress, one year later.

Through analysing this information we hope to increase understanding of the causes and development of Type 2 diabetes and improve treatment.

Where is this study happening?

The study is being led by investigators based at The Bristol Biomedical Research Unit in Nutrition and Birmingham Children's Hospital in collaboration with investigators from Bristol University and Birmingham University as well as the BPSU. Surveillance will take place in all hospitals across the United Kingdom and Republic of Ireland.

How long will the study go on for?

13 months with a 12 month follow-up

How will the information be used?

BPSU researchers do not contact families or children with the condition. Children with Type 2 diabetes will continue to get the normal standard of care and treatment from their doctors.

There are no direct benefits to taking part in this study. Data collected on young people with Type 2 diabetes will help us to improve our understanding of the current problems associated with this disease. This will help target future approaches to preventing and managing the condition. All data collected will be held securely and confidentiality maintained at all times.

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 (known as dissent), so you must always your child's consultant paediatrician if you wish to dissent. If a patient (or legal guardian) dissented from their medical notes being used for research, their data would also not be used in BPSU studies.

Who to contact if patient or legal guardian does not want their records used for research (dissent)

Please contact your consultant paediatrician if you believe you may be considered for this study but wish to withhold your data. BPSU does not have permission to identify individual

Who should be contacted if you have any questions about this study?

If you have further questions or would like more information please contact Dr Abdalmonem Majbar, Bristol Royal Hospital for Children, Upper Maudlin Street, Bristol BS2 8AE, email: a.a.Majbar@bristol.ac.uk or the British Paediatric Surveillance Unit (see over page).

Who has funded the study?

The National Institute for Health Research (NIHR) which is funded by the Department of Health.

Further website information

BPSU - <http://www.rcpch.ac.uk/bpsu/t2d>

NIHR - <http://www.nihr.ac.uk/about/rare-diseases-translational-research-collaboration.htm>

Diabetes UK - <http://www.diabetes.org.uk/>