

PUBLIC INFORMATION LEAFLET

WHAT IS THE BRITISH PAEDIATRIC SURVEILLANCE UNIT (BPSU) AND CHILD AND ADOLESCENT PSYCHIATRY SURVEILLANCE SYSTEM (CAPSS)?

The aim of the BPSU and CAPSS is to encourage the study of rare conditions in children. BPSU 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). CAPSS was launched in 2009 with the support from the Royal College of Psychiatrists Faculty of Child and Adolescent Psychiatry and, importantly, the BPSU.

WHAT DOES THE BPSU AND CAPSS 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 mental health disorder 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 and CAPSS studies can help future patients with a similar rare condition.

HOW DOES THE BPSU AND CAPSS WORK?

Each month the BPSU and CAPSS 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. The purpose is ONLY to collect information to learn more about the condition.

Incidence of Avoidant/Restrictive Food Intake Disorder in children and young people presenting to secondary care in the UK and Ireland

This leaflet provides information about a new study of Avoidant/Restrictive Food Intake Disorder (ARFID)

WHAT IS AVOIDANT/RESTRICTIVE FOOD INTAKE DISORDER (ARFID)?

Avoidant/Restrictive Food Intake Disorder (ARFID) was introduced as a new mental and behaviour disorder diagnosis in 2013. ARFID is characterised by a pattern of eating that avoids certain foods or food groups entirely and/or eating small amounts due to lack of interest in food, high sensitivity to sensory aspects of food (such as texture, colour or temperature), or feelings of fear and anxiety around food, including fear of aversive consequences such as being sick or choking. These restrictive eating patterns can result in significant health problems. It differs from eating disorders in that people with ARFID don't restrict their food intake for the specific purpose of losing weight.

To date very little is known about this disorder and its associated behaviours and outcomes in British children and adolescents.

WHAT ARE THE AIMS OF THE STUDY?

By using questionnaires sent to paediatricians through the British Paediatric Surveillance Unit (BPSU) and psychiatrists through the Child and Adolescent Psychiatric Surveillance system (CAPSS), this study aims to establish incidence rates (number of new cases) of ARFID in children and young people presenting to secondary health care, referral pathways, patterns of presentation, and clinical features (eating behaviours, medical complications and the types of medical or psychiatric presentations it is associated with).

This will allow us to compare rates, presentation and management of ARFID with other countries, as well as generating new priority research questions that could in turn inform decision making to better match patient need with sufficient funding allocations. Study results we hope will prompt further research into information on prognosis, long-term outcomes and treatment of ARFID.

HOW LONG WILL THE STUDY LAST AND WHERE IS IT HAPPENING?

This study will last for 13 months from March 2021 and will be taking place across England, Wales, Scotland, Northern Ireland and the Republic of Ireland.

WHAT DATA WILL BE COLLECTED AND USED?

Imperial College London are the sponsors and data controllers for this research study so is responsible for looking after the information and using it properly. The ARFID research team will collect information about you for the ARFID Study from your doctor. This information will include some identifiers about you and health information which is regarded as a special category of information.

The identifiers are:

- Sex
- Date of Birth
- Ethnicity

Doctors will not provide names and addresses to the study team. They will complete questionnaires using information from medical records.

The smallest amount of personally identifiable information will allow researchers to pick up if two doctors provide information on the same child and look at variations across different regions, genders and ethnicities. Your health information will allow the researchers to increase their understanding of how ARFID develops, the difficulties that children and young people with this diagnosis experience and how to improve access to appropriate treatment.

WHAT HAPPENS TO THE INFORMATION PROVIDED?

Data collected will only be looked at by authorised members of the research team. It can also be looked at by other authorised staff to ensure that the study is being carried out correctly. All information will be stored in secure cupboards in a locked office and on a password protected database and will not be shared with anyone else. The data storage will comply with the UK Data Protection Act 2018 and any amended laws in relation to data protection in the UK and Europe.

When the study finishes, personal information will be deleted or de-personalised. The data controlling organisations will securely store information for at least 10 years.

For more details about how personal information is used in the study, please see the BPSU and CAPSS websites.

- BPSU: <https://www.rcpch.ac.uk/work-we-do/bpsu/ARFID>
- CAPSS: <https://www.rcpsych.ac.uk/improving-care/ccqi/research-and-evaluation/current-research/capss/capss-studies>

If you want access to the information in your child's medical records, then you should contact your child's NHS hospital or doctor.

WHAT ARE THE POSSIBLE RISKS AND BENEFITS

The care and treatment that the child will receive will not change 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.

This study will provide an initial baseline of children and young people presenting with ARFID to secondary care in the UK and Ireland. By collecting the information about young children who develop ARFID, it is hoped to increase understanding of the condition and help improve care for individuals and families affected.

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.

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 AND SUPPORTING THIS STUDY?

Former EMS Limited (charity number 1098725, registered Oct. 9th 2017) is funding this study. Autistica and ARFID Awareness UK are supporting the study.

WHERE WILL THE RESULTS BE PUBLISHED?

Once the study is completed, you will be able to find the results on the BPSU and CAPSS websites.

WHO HAS REVIEWED THIS STUDY?

The study was approved by Black Country Research Ethics Committee (REC reference 20/WM/0256), the Health Research Authority following review by the Confidentiality Advisory Group (England and Wales) and the Public Benefit and Privacy Panel (Scotland).

WHAT ARE YOUR RIGHTS UNDER GENERAL DATA PROTECTION REGULATION?

- Please see Imperial College London's website regarding your rights under GDPR: <https://www.imperial.ac.uk/admin-services/secretariat/information-governance/data-protection/gdpr/>

WHO TO CONTACT IF YOU HAVE ANY QUESTIONS

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