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## WELCOME

CAPSS provides the most accurate and cost effective way to study rare psychiatric disorders or events. Even very large surveys have too few cases to draw clear conclusions from with reference to rare disorders, and while centres of clinical excellence may have a sufficient number of cases, any findings can be very misleading due to factors associated with referral to such centres.

Surveillance epidemiology has the advantage of prospective contemporaneous national data collection from consultant psychiatrists (and in some cases consultant paediatricians), which provides a more accurate picture of the service level incidence of rare disorders or events.

We also want to welcome Stephanie Learmonth to the CAPSS team. Stephanie has taken over from Alan Quirk as Programme Manager and will be working closely with the Executive Committee to ensure that CAPSS continues to be an effective surveillance system for rare psychiatric conditions in children and adolescents.

### **CAPSS aims:**

- Facilitate epidemiological surveillance and research into rare child and adolescent mental health disorders and events
- Increase awareness among the medical profession and public about the less common mental health disorders that affect children and adolescents
- Allow psychiatrists to participate in surveillance of such conditions
- Inform clinical strategy and public health policy
- Respond in a timely manner to clinical and public health concerns

# About CAPSS

CAPSS was launched in Spring 2009 with the support from the College, the Faculty of Child and Adolescent Psychiatry and importantly the British Paediatric Surveillance Unit who have had over 20 years experience in rare disease surveillance.

This section provides information about how CAPSS is structured, how the system works; its commitments to confidentiality and contacts to key people.

**Methodology:** CAPSS uses the active surveillance methodology developed so successfully by the BPSU.

A report card containing a list of conditions being surveyed, is sent every month to all respondents on a mailing list. The mailing also includes reporting instructions and, where appropriate, protocols for new studies.

The reporting clinicians are asked to check boxes against any of the reportable conditions they have seen in the preceding month, or to check a "nothing to report" box if none have been seen, and return the card to the CAPSS office.

"Positive" returns are identified by the unit's administrator and then notified to the appropriate investigator, who then contacts the reporting clinician directly to request completion of a brief data collection form.

Currently totalling 1000 respondents, the list aims to include all hospital, university and community paediatric consultant psychiatrists who are members of the RCPsych.

The aim is to involve every senior doctor who is likely to have clinical responsibility for children with rare conditions.

For many studies ascertainment and quality of individual case data are improved by use of other data sources such as consultant paediatricians via the RCPCH and Hospital Episode Statistics.

The ten-year report on CAPSS and the work it has done will be coming out soon!

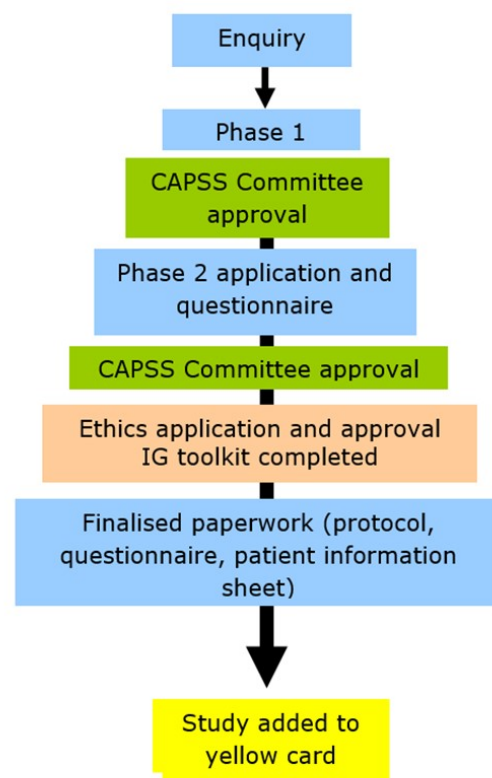


Figure 1

## Contact the Team

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Follow us: @rcpsych and @ccqi\_ and use #capss for up-to-date information

# Current Studies

## Early Onset Depression

This study was launched in January 2019. Early Onset Depression can occur in children as young as three years old and is associated with depression in the young person's parents.

Those who develop EOD are four times more likely to be at risk of attempting suicide than those who develop depression in later life. Little is known about how common the disorder is in young people under the age of thirteen years.

The research team wish to gain increased and more accurate knowledge about the number of cases of EOD in order to development management approaches for children with this treatable illness.

The study will be ongoing with CAPSS for 13 months and you should have already received the electronic reporting cards for the months of January to August.

## Response rates

The responses from CAMHS consultants as to whether you have seen any cases being studied is integral to the success of the surveillance system. We encourage consultants who receive the electronic reporting cards to respond each month even if you have not seen a case.

If you have yet to fill out your electronic reporting cards for either of these studies since they were launched earlier this year, please [get in contact](#) with your response rates so we can make the best of this system.

Having up-to-date contact details for consultants who take part in the active surveillance is also essential to ensuring that we have a high response rate and, therefore, capture as many cases as possible.

If you have had a change of email address, are retiring, are soon to move hospital, or no longer wish to be part of the surveillance system, please [contact the team](#) who will change or remove your email address from our database.

## Sydenham's chorea

The **Sydenham's chorea** study launched in May 2019. Chorea is the term for abnormal movements described as rapid, irregular, and involuntary.

Sydenham's chorea is often accompanied by psychiatric symptoms such as obsessions and compulsions. Psychiatric disorders triggered by Sydenham's chorea may be long-lasting and disabling.

Although Sydenham's chorea can resolve within six months, it can follow a relapsing course for up to two years. Little is known about how frequently Sydenham's chorea occurs in the UK and Republic of Ireland.

Given the impact on the lives of patients and families, the research team wish to examine the current pattern and presentation of the disorder to raise awareness and inform the planning of services. Like the EOD study, the Sydenham's chorea team are running this study on CAPSS for 13 months. You should have received electronic reporting cards for the months of May to August.

We appreciate the time you take to fill out the electronic reporting cards each month and offer certificates of participation.

The certificates can be used in your annual appraisal to show that you have taken part in active surveillance. These certificates will be sent out annually, starting in December 2019.

**REMEMBER** that a "No I have not seen a case" response is as important as a positive report, so that we can establish a response rate. If you do not send it back, we do not know if you did not see a case or did not receive the card.

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## Previous Study

### Childhood Disintegrative Disorder Surveillance Study

Childhood Disintegrative Disorder (CDD) is a rare childhood condition in which a previously normal child very rapidly loses intellectual and developmental skills. The loss of skills occurs after the age of 2 years, and results in impairments similar to features of severe Autism Spectrum Disorder (ASD).

CDD is currently categorised as a distinct condition in the International Classification of Diseases, Tenth Revision (F84.3), however has been incorporated into the wider ASD category within the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V).

The cause of this devastating condition is not currently known, and approaches to investigate and manage children vary between clinicians. This can lead to confused messages to the family, adding to the distress already encountered from grieving the loss of a previously healthy child.

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## Upcoming Study

### Incidence of Avoidant/Restrictive Food Intake Disorder

Avoidant/Restrictive Food Intake Disorder (ARFID) is an eating or feeding disturbance that is characterised by a persistent failure to meet appropriate nutritional/energy levels.

ARFID is an umbrella term incorporating a number of distinct but potentially overlapping phenomena, resulting in nutritional deficits or impairment of psychosocial functioning (emotional wellbeing).

Although ARFID can occur at any age, it is presumed to be more common in younger patients. Children and adolescents with ARFID are at risk for severe acute and chronic medical complications.

New evidence regarding uncommon disorders such as ARFID provides clinicians with the necessary tools to make prompt and accurate diagnoses, and enables them to have a better understanding of when refer to secondary and tertiary specialty care.