

This Issue

- 1 Welcome
- 2 About CAPSS
- 3 Current Studies
- 4 Previous Study and Potential study
- 5 Response rates



WELCOME

We hope you are safe and well during this extraordinary time.

In order to provide support during COVID-19, the CCQI has put together some webinars, you can find recordings at: <https://www.rcpsych.ac.uk/improving-care/ccqi/resources/ccqi-webinars>. Of particular interest are the webinars by the Child and Adolescent Community Team and the Child and Adolescent Inpatient Services Team.

CAPSS recently published our 10-year report. You can find a copy on our new and improved website, please do take a look.



Picture by Daisy Goodyear, Competition Winner

CAPSS Ten Year Report

Available online:

<https://www.rcpsych.ac.uk/improving-care/ccqi/research-and-evaluation/current-research/capss>

About CAPSS

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.

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

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 fill in a survey 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, "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 534 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.



Figure 1

Current Study

Sydenham's Chorea

Sydenham's Chorea launched on CAPSS in May 2019. We have not currently had any cases reported as 'seen' through CAPSS.

What is Sydenham's Chorea?

Chorea is the term for abnormal movements described as rapid, irregular, aimless and involuntary. The most common cause of childhood chorea is Sydenham's chorea (SC), which may occur up to six months following a streptococcal infection.

Symptoms may last for two years or more, sometimes evolving into a chronic condition. SC is often accompanied by emotional and behavioural symptoms, such as anxiety, tics, obsessions and compulsions, and hyperactivity, which can persist and may be severe and disabling. Children may therefore present to clinicians in paediatrics or child mental health services.

The Surveillance Study

Little is known about how frequently SC now occurs in the UK and the Republic of Ireland (ROI) or how often children with SC present to CAMHS. Through the British Paediatric Surveillance Unit and CAPSS, we have been asking paediatricians and child psychiatrists to report cases of suspected or confirmed Sydenham's chorea seen in their service.

We have been working with the family charity the Sydenham's Chorea Association to design this research. The aim of this study is to examine the current pattern and presentation of the disorder, raise awareness and inform the planning of services.

What are we looking for?

Please report children and young people aged 0-16 years who have or have had a suspected or confirmed diagnosis of Sydenham's chorea (e.g., by a paediatrician) and present to you for the first time within the current episode of care (regardless of whether this is their first contact with CAMHS or not) with one or more psychiatric symptoms. Please report any case even if you believe the case may have been reported from elsewhere. Reporting is running until December 2020.

How to report?

Consultant child and adolescent psychiatrists are asked to report cases through the monthly CAPSS e-card. If other team members think they may have seen an eligible child, we encourage you to make the team consultant aware and facilitate reporting of the case.

Further Information

Please contact Dr Tamsin Newlove-Delgado at the University of Exeter Medical School (t.newlove-delgado@exeter.ac.uk) for more information about this study.

Further information (including on ethical approvals) is also available on the CAPSS website:

<https://www.rcpsych.ac.uk/improvingcare/ccqi/research-and-evaluation/currentresearch/capss/capss-studies>
<http://www.sydenhamschorea.org.uk/>

CAPSS Ten Year Report

Available online:

<https://www.rcpsych.ac.uk/improving-care/ccqi/research->

Previous Study

Early Onset Depression (EOD) Surveillance Study

The **Early Onset Depression** (EOD) study recently finished after starting to collect data from January 2019. It achieved an average response rate of 60% on the CAPSS database, thank you to all who responded. To date 156 cases of EOD have been notified. Every clinician who has notified that they have seen a case receives 1 questionnaire per case from the researchers. Of the 156 cases, 47 questionnaires returned. Out of the 47 returned questionnaires 23 cases were found to be eligible for inclusion in the study.

The EOD study is now in the second year of data gathering and are approaching clinicians of eligible cases to complete a follow-up questionnaire one year after their initial notification. They are also attempting to contact clinicians who notified a case last year but did not return a completed questionnaire to gain information as to whether they still believe the case to be EOD or if their diagnoses has changed.

Upcoming Studies

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. This study will look at the incidence in children and young people (aged 5-17 years) presenting to secondary care in the UK and Ireland.

We are hoping to start this study in Autumn 2020.

Far Away from Home

This research focuses on young people, aged 13-17 years, who require admission to hospital for psychiatric care.

Unfortunately, there are few units that serve children with poor mental health, so places are limited and some young people are admitted to units located far away from their home or to adult wards. At present, little is known about how many young people are admitted far away from home or to adult wards or the factors that contribute to such admissions.

This research aims to find out how many young people in England are admitted to adolescent units further than 50 miles from their home, to a different NHS region, or to adult wards. It will also explore the views and experiences of doctors who are involved in referring young people for inpatient care.

We are hoping to start this study in Autumn 2020.

Response rates

The responses of 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 Sydenham's Chorea, 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.

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 fill in the survey, we do not know if you did not see a case or did not receive the card.

Change of details

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.

Certificates

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 in December annually. Please email us if you would like a certificate before then.

New studies

If there is a study you think would benefit from using active surveillance methodology, please [get in contact](#) with the team for more information about the application process.

Contact the Team

Stephanie Learmonth, Programme Manager

Stephanie.Learmonth@rcpsych.ac.uk
0203 701 2688

Daphne Papaioannou

Daphne.Papaioannou@rcpsych.ac.uk
0207 780 5753

Holly Lowther

Holly.Lowther@rcpsych.ac.uk
0203 701 2696

Twitter

Follow us: [@rcpsych](#) and [@rcpsychCCQI](#) and use [#capss](#) for up-to-date information

CAPSS@rcpsych.ac.uk

**Royal College of Psychiatrists (CCQI)
Child and Adolescent Psychiatry
Surveillance System**

21 Prescott Street
London
E1 8BB