

CAPSS

15-year Anniversary Report



Authors:

Dr Eleanor Smith, CAPSS Executive Committee

With contributions from:

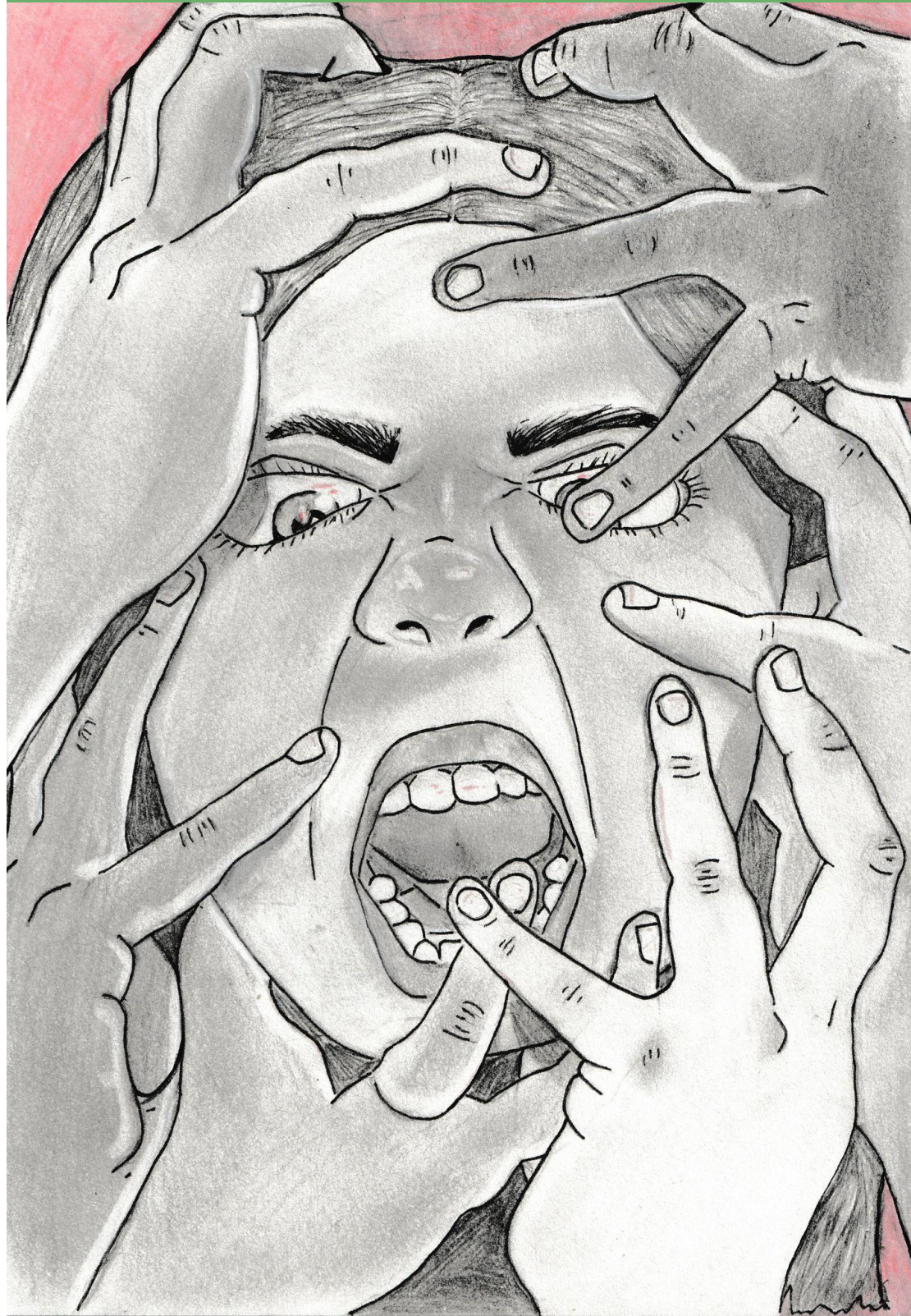
Richard Lynn and Dr Muthukrishnan Venkatesan

Cover image:

Artwork by Celeste, '*Dragon's dream*' (Competition winner, 11-years and under)

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Artwork by Scarlet, 'Control yourself' (Competition runner-up, 12-17 years)

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Foreword

Congratulations on the 15th anniversary of the establishment of CAPSS, the first child and adolescent psychiatry surveillance system worldwide. By facilitating research into rare disorders and events, CAPSS, continues to support the generation of new data on epidemiology, psychopathology and management of rare disorders and events presenting to child and adolescent psychiatrists. Shining a light on the experience and care of the children, young people and families impacted in order to influence service provision and policy play a critical role in improving the care we are able to provide. The system also supports our very busy frontline child and adolescent psychiatrists to get involved in this important work. For this the executive committee should be applauded.

Dr Lade Smith, CBE
RCPsych President

What is CAPSS?

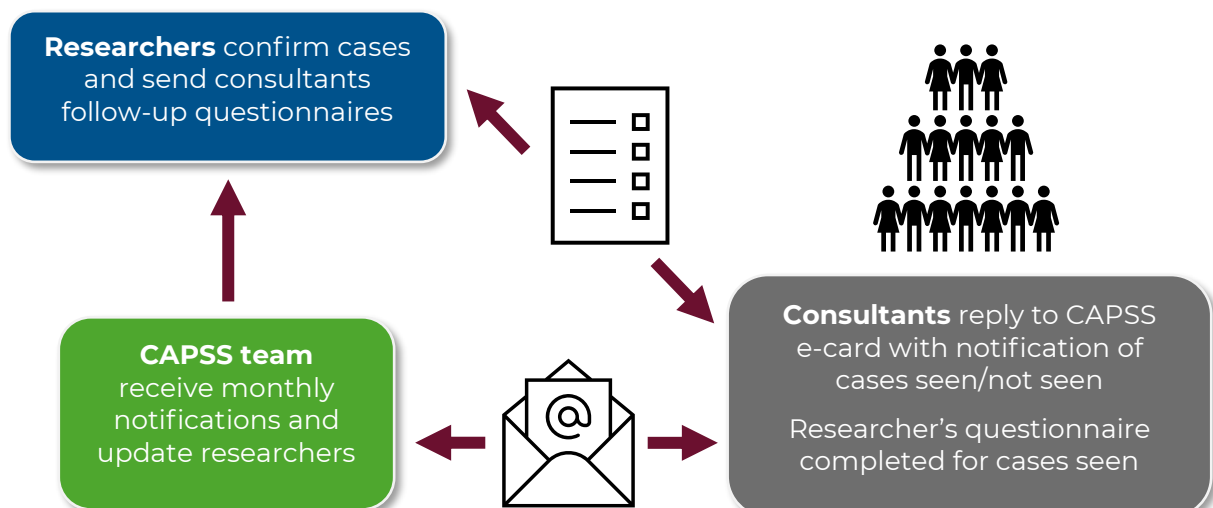
The Child and Adolescent Psychiatry Surveillance System (CAPSS) facilitates the epidemiological study of rare mental health disorders and events amongst children and adolescents. Established in 2009, and hosted by the Royal College of Psychiatrists, CAPSS allows researchers to contact consultant psychiatrists working in child and adolescent mental health services in the UK, Republic of Ireland, Jersey and the Channel Islands to undertake national surveillance.

CAPSS aims to:

- Facilitate epidemiological surveillance and research into rare child and adolescent mental health disorders and events
- Increase professional and public awareness of rare mental health disorders and events
- Make it easy for frontline child and adolescent psychiatrists to participate in epidemiological surveillance
- Inform service development and national policy, responding in a timely manner to clinical and public health concerns.

How we do it:

CAPSS maintains a database of consultant psychiatrists working in child and adolescent mental health services across the UK, Republic of Ireland, Jersey and the Channel Islands. Each month consultant psychiatrists are sent an electronic reporting card which asks them to indicate whether they have seen 'a case' in the last month. At the end of each month CAPSS lets the research team know how many cases have been reported and shares contact details of the consultant psychiatrists who have reported seeing a relevant 'case'. The research teams then contact the consultant psychiatrists directly and ask them to provide further information. All CAPSS studies, with relevant approvals, use information from patients records without directly contacting patients.



CAPSS study findings, outputs and impacts

Below are snapshots of the studies CAPSS have facilitated. Further details are available via the respective publications.

Early onset eating disorder (EOED)

The first UK study to investigate eating disorders in children under the age of thirteen. This study was the precursor to CAPSS, effectively acting as a proof of concept. The study adapted the surveillance protocols used by the Australian and Canadian Paediatric Surveillance Units.

Key Findings: 208 individuals identified who met criteria for EOED, almost twice the number anticipated, an estimated incidence of 3.01 per 100,000. Higher rates of males than are commonly reported were identified and findings suggest that the majority of children with EOED are not being recognized until medical complications become severe.

Study Outputs & Impacts: Three published papers, numerous national and international conference presentations, workshops and webinars. The study led to the development of the Junior Marispan 2010 guidelines for the management of Anorexia Nervosa. It has also contributed to decision making in relation to service provision, both in early intervention and in relation to child psychiatric inpatient beds. This study led to the official development of CAPSS.

Lynn, R.M., Viner, R.M. and Nicholls, D.E. (2012), Ascertainment of early onset eating disorders: a pilot for developing a national child psychiatric surveillance system. *Child Adolesc Ment Health*, 17: 109-112. <https://doi.org/10.1111/j.1475-3588.2011.00613.x>

Avoidant/restrictive food intake disorder (ARFID)

This joint BPSU/CAPSS study aimed to collect data on ARFID, a psychiatric disorder introduced as a new diagnosis in 2013. ARFID is characterised by food avoidance or restriction due to sensory characteristics of foods, lack of interest in eating or feelings of fear of aversive consequences of eating.

Key Findings: 319 cases of ARFID were reported aged 5-17 years of which 174 were male; giving an incidence of 2.79 per 100,000. Those reported by paediatricians were more often male, had more chronic symptoms and were more likely to be associated with Autism Spectrum Disorder. Where follow-up data was available, 23% showed no change, 3% worsened. Four different subtypes were identified using latent class analysis.

Study Outputs & Impacts: Three published papers, numerous national and international conference presentations, workshops and webinars.

Sanchez-Cerezo, J., Neale, J., Julius, N., Lynn, R. M., Hudson, L., & Nicholls, D. (2024). Incidence of avoidant/restrictive food intake disorder in children and adolescents across the UK and Ireland: a BPSU and CAPSS surveillance study. *BMJ open*, 14(11), e088129. <https://doi.org/10.1136/bmjopen-2024-088129>

Narrow Phenotype Paediatric Bipolar I (NPBD)

Data on the epidemiology of the NPBD, associated features (including comorbidities) and outcome in the British Isles are very limited. The primary aim of the study was to estimate the incidence of first-time diagnosis of NPBD in children and adolescents under 16 years old. Outcomes at one year follow-up were also reviewed.

Key Findings: 151 reports were received. Of these, 33 cases met the analytic case definition of NPBD. Of the 33 confirmed cases, one-year follow up data was collected for 30 cases. The figures are consistent with an estimated annual incidence of 0.59 per 100,000.

Study Outputs & Impacts: Three published papers, several national and international conference presentations, workshops and webinars. This study led to the development of the Adolescent Bipolar Service (now the National Specialist Adolescent Mood Disorders Service (NSAMS)), which is a second opinion service for young people with suspected mood disorder.

Sharma, A., Neely, J., Camilleri, N., James, A., Grunze, H., & Le Couteur, A. (2016). Incidence, characteristics and course of narrow phenotype paediatric bipolar I disorder in the British Isles. *Acta psychiatrica Scandinavica*, 134(6), 522–532. <https://doi.org/10.1111/acps.12657>

Early onset depression (EOD)

This is the first study in the British Isles to use surveillance epidemiology to look at children under the age of 13 years old presenting with first episode of depression. Data were collected to establish incidence, characterise symptom profiles and describe interventions being used by treating clinicians. A one and two-year follow-up was undertaken to provide information about what happens to this group over time.

Key Findings: 154 reports were received of which 29 met the analytical case definition for EOD, yielding an incidence of 0.28 per 100,000. At 2 years follow up 7 cases converted to Bipolar Disorder and 17 children had a further episode of depression. Reported cases had severe illness, characterized by high rates of suicidality and psychotic features, with many children requiring inpatient care.

Study Outputs & Impacts: One submitted publication, several national conference presentations. The impact of the study in terms of national policy and management review has yet to be determined.

Childhood-Onset Non-Affective Psychoses in under 14-year-olds

The study aimed to estimate the incidence and to describe clinical features, presentation, comorbidities, family psychiatric history, management and one-year outcomes of non-affective psychosis in under 14-year-olds in the United Kingdom and Ireland.

Key Findings: 122 potential cases were reported during the 13-month surveillance period, 15 cases met a provisional diagnosis. One-year outcome data was obtained for 12 individuals, 8 of which met the criteria for schizophrenia or related diagnosis, equating to an estimated incidence of 0.21 per 100,000. Delusions were the most common presenting symptom followed by hallucinations. Illness outcomes at 1 year were generally poor. Childhood-onset schizophrenia appears to be a rare but serious disorder.

Study Outputs & Impacts: There was one publication and several regional and national presentations.

Tiffin, P. A., & Kitchen, C. E. W. (2015). Incidence and 12-month outcome of childhood non-affective psychoses: British national surveillance study. *British Journal of Psychiatry*, 206(6), 517–518. <https://doi.org/10.1192/bjp.bp.114.158493>

Gender Dysphoria

This joint BPSU and CAPSS study examined the incidence and clinical presentation of gender dysphoria in UK and Irish children and adolescents aged 4 to 15 years.

Key Findings: There were 230 confirmed cases during the reporting period, with a median age at diagnosis of 14.7 years old. Approximately two thirds of cases were aged less than 12 years old were male (36 of 57 cases), with females comprising almost two thirds of cases aged 12-15 years old (111 of 173 cases). At least one co-occurring mental health condition was present in 52% of 12–15-year-olds and 26% of under 12-year-olds. There was a history of self-harm in 47% of 12–15-year-olds.

Study Impacts: One paper was published and a couple of conference presentations given.

Khadr S, Masic U, Clarke V, Lynn RM, Holt V, Carmichael P. Key socio-demographic characteristics of children and adolescents with gender dysphoria: A British Isles surveillance study. *Clinical Child Psychology and Psychiatry*. 2022;27(4):1106-1123. [doi:10.1177/13591045221108840](https://doi.org/10.1177/13591045221108840)

Sydenham's Chorea (SC)

A patient group led initiative to undertake surveillance with paediatricians via the BPSU and with child and adolescent psychiatrists through the CAPSS. The study aimed to examine the current pattern of SC, raise awareness of its course and complications and inform service planning.

Key Findings: Over 24 months there were 72 reports, all by paediatricians, 43 met the eligibility of suspected or confirmed SC. This translates to an estimated paediatric service-related incidence rate of new cases of 0.16 per 100 000 children aged 0–16 years old in the UK. Over 75% of cases presented with emotional and/or behavioural symptoms. Almost all cases were prescribed courses of antibiotics of varying duration, and around a quarter of cases (22%) received immunomodulatory treatment.

Study Outputs & Impacts: One paper has been published. It was felt that there is a further need for development of consensus around identification, diagnosis and management across child health settings.

Wooding, E. L., Morton, M. J. S., Lim, M., Mitrofan, O., Mushet, N., Sie, A., Knight, B., Ford, T., & Newlove-Delgado, T. (2023). Childhood/adolescent Sydenham's chorea in the UK and Ireland: a BPSU/CAPSS surveillance study. *Archives of disease in childhood*, 108(9), 736–741. <https://doi.org/10.1136/archdischild-2023-325399>

Non-transient Childhood Conversion disorder

Starting in 2008 and run jointly through the BPSU and CAPSS, this study aimed to document clinical incidence, features, management and 12-month outcome of non-transient childhood conversion disorder in under 16-year-olds across the United Kingdom and Ireland. It became the largest study of incident cases of childhood conversion disorder ever published in the literature.

Key Findings: 204 cases were identified giving a 12-month incidence of 1.30 per 100,000. Follow-up at 12 months was available for 147 children, when all conversion disorder symptoms were reported as improved. Most families (91%) accepted a non-medical explanation of the symptoms either fully or partially.

Study Outputs & Impacts: One paper was published and several national and international presentations. The study produced evidence which can inform the development of possible future intervention studies.

Ani, C., Reading, R., Lynn, R., Forlee, S., & Garralda, E. (2013). Incidence and 12-Month Outcome of Non-Transient Childhood Conversion Disorder in the UK and Ireland. *British Journal of Psychiatry*, 202(6), 413–418. <https://doi.org/10.1192/bjp.bp.112.116707>

Childhood Disintegrative Disorder

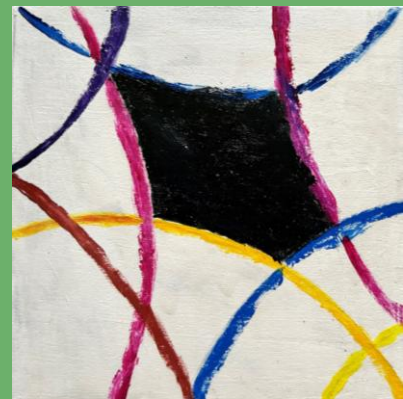
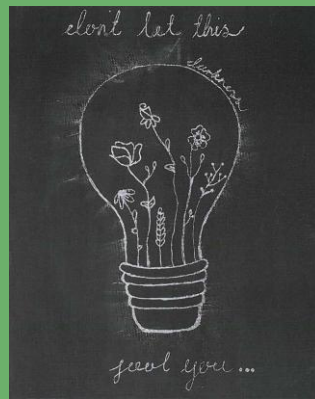
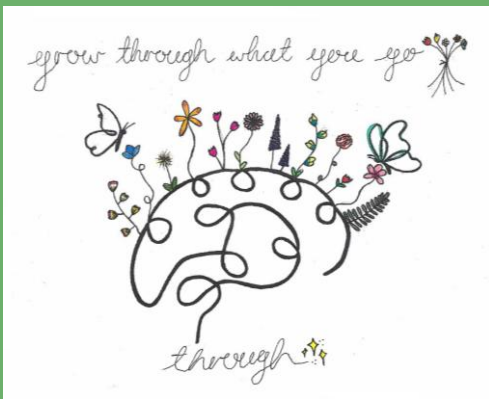
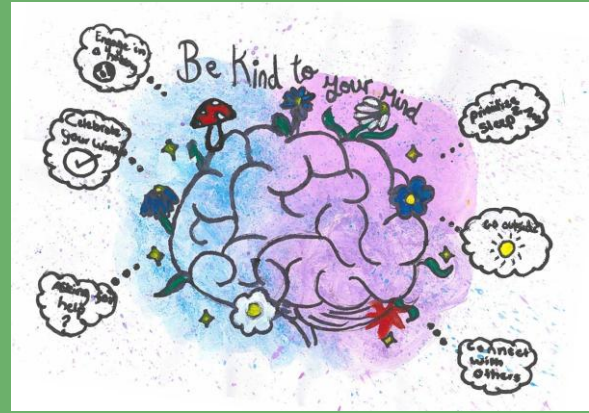
This was a joint BPSU and CAPSS study to investigate Childhood Disintegrative Disorder, a rare condition where a previously typically developing child rapidly loses intellectual and developmental skills, in UK and Irish children and adolescents. It aims were to establish the incidence, demographic and clinical characteristics of the condition, provide information on current investigative and management approaches and assist in planning of services at a regional and national level.

Key Findings: 19 cases (median age 4.7 years old) were identified. All cases presented with loss of language and social skills, 50% experienced loss of bladder and bowel control, 88% experienced loss of adaptive skills, and 93% experienced loss of academic skills. The majority had significant internalising and externalising symptoms.

Study Impacts: A publication is currently in preparation.

CAPSS Art Competition

An art competition was held to help support the production of this anniversary report, inviting submissions from children and young people aged 11 years and under, and from those aged 12-17 years. We were hugely impressed with the response and we're very pleased to share with you here examples of the artwork submitted on the theme of 'My mental health and me'.



From left to right, top to bottom, artwork by: Anonymous, Hylerie, Chloe and Sophia, Rosie, Amelia and Eve, Mercy, Anonymous, Verity, Libby, Kim, Ciara and Thais, Carys.

Service delivery studies

Cost-effectiveness of models of care for young people with Eating Disorders – CostED

The first CAPSS service study funded by NIHR arose out of the success of the Early onset eating disorder study. The CostED study looked at the relationship between incidence, service configuration, and associated health care costs and outcomes for young people with anorexia nervosa. To achieve these aims, an incidence study was undertaken to identify the cohort.

Key Findings: 298 confirmed cases contributed to the cost-effectiveness analysis. Age ranged from 8 to 17 years old, 92% were girls with an overall incidence rate of 13.68 per 100,000. Young people in specialist services were found to be more severely ill than those in general CAMHS when they were first diagnosed. Despite this, care for young people in specialist services over the 1-year follow-up period cost about the same as care for those who were diagnosed in general CAMHS, and their outcomes after 1 year were also similar.

Study Outputs & Impacts: Four papers published and several presentations. Specialist services may be better value for money than general CAMHS, but such services may not save money for the NHS.

Byford S, Petkova H, Stuart R, Nicholls D, Simic M, Ford T, Macdonald G, Gowers S, Roberts S, Barrett B, Kelly J, Kelly G, Livingstone N, Joshi K, Smith H & Eisler I. (2019). Alternative community-based models of care for young people with anorexia nervosa: the CostED national surveillance study. *Health Services and Delivery Research* Volume: 7, Issue: 37, October 2019 <https://doi.org/10.3310/hsdr07370>

Children and Adolescents with ADHD in Transition between Children's and Adult Services - CATCh-uS

The NIHR-funded CATCh-uS project used a mixed methods design including qualitative work and surveillance of paediatricians and child and adolescent psychiatrists via BPSU and CAPSS. The aim was to explore what happens to young people needing ongoing management of Attention Deficit Hyperactivity Disorder (ADHD) when they are too old for children's services and to provide information and insights on how to improve care for young people with ADHD.

Key Findings: CATCh-uS estimated that the annual number of young people with an ongoing need for medication for ADHD lies between 270 and 599 per 100,000 people aged 17–19 years old. Among 315 individuals eligible for transition, 64% were accepted by adult services, but only 22% attended their first adult

services appointment. The study found that few of those who needed ongoing support for ADHD successfully transferred to adult services, and only a small proportion of those who transferred experienced optimal transitional care. Findings suggest poor adherence to the recommendations for transition from the NICE guidelines for ADHD.

Study Outputs & Impacts: The study has led to 12 publications and numerous presentations nationally and internationally, as well as resources for young people and commissioners. The study also produced a national map of adult ADHD services for use by clinicians and the public. Findings will also feed into the work of the new National ADHD Taskforce. Findings are significant for commissioners and service providers, to address the drop in attendance from child to adult services. It is imperative that mental health services develop policy and strategy to better support this group of young people in the future.

Eke, H., Ford, T., Newlove-Delgado, T., Price, A., Young, S., Ani, C., ... Janssens, A. (2020). Transition between child and adult services for young people with attention-deficit hyperactivity disorder (ADHD): findings from a British national surveillance study. *The British Journal of Psychiatry*, 217(5), 616–622. <https://doi.org/10.1192/bjp.2019.131>

Far Away from Home

This research aims to understand and improve the experience of care for young people who require inpatient mental health care and, specifically to find out the numbers of 13–17 year-olds admitted to general adolescent units at distance from home or to adult psychiatric beds. The study also aimed to describe the clinical characteristics and outcomes of the young people affected.

Key Findings: Young people for whom admissions are requested on an emergency basis frequently wait a week or more for a CAMHS bed, with most waiting in an acute hospital setting. Clinical risk is a main driver for these admissions, with suicide risk present in 80% and risk management requested in almost every case. The average length of at-distance admissions is 15 days longer than the overall average length of inpatient CAMHS admissions, with a delay to discharge in one-third of cases. At 6-month follow up, 20% were still in hospital, with the majority of these still admitted at-distance.

Study Outcomes & Impacts: Five publications so far from the “Far Away from Home” programme (with further papers in submission) and the findings have been presented nationally and internationally, including in an animation video and an NIHR webinar. The findings have been shared and discussed with national commissioning leads and the learning from the study is being adopted into national service specifications and provider contracts for inpatient care.

Holland J, Roe J, Guo B CAPSS Scientific Committee, et al
‘Far Away from Home’: adolescent inpatient admissions far from home, out of area or to adult wards: a national surveillance study, *BMJ Ment Health* 2023;26:e300843.

Research collaborations

National

CAPSS is not alone in using prospective surveillance to monitor rare conditions. In the UK there are several such units using the methodology devised by the British Paediatric Surveillance Unit – BPSU.

- BPSU helped CAPSS through supporting development, advising on documentation and from the outset, being represented on the CAPSS Executive.
- CAPSS is also represented on the BPSU scientific committee.
- To maximize case ascertainment there has been joint surveillance of five studies, early onset eating disorders, avoidant/ restrictive food intake disorder, Sydenham’s Chorea, conversion disorder and gender dysphoria,
- CAPSS collaborated with British Association of Community Child Health to identify the types of mental health conditions their members manage.

Hani F Ayyash, Michael Oladipo Ogundele, Richard M Lynn, Tanja-Sabine Schumm, Cornelius Ani - Involvement of community paediatricians in the care of children and young people with mental health difficulties in the UK: implications for case ascertainment by child and adolescent psychiatric, and paediatric surveillance systems: *BMJ Paediatrics Open* 2021;5:e000713.

International

CAPSS is unique in that internationally, it is the only such unit aimed at child and adolescent psychiatrists. However, there are several units across the globe, who through their own paediatric units facilitate surveillance of mental health conditions. The International Network of Paediatric Surveillance Units – INOPSU – www.inopsu.com of which CAPSS is an affiliate, links all the individual units. INOPSU offers the opportunity for collaboration, protocol sharing and data comparison.

The committee are interested in exploring opportunities to establish a network of child and adolescent psychiatric surveillance units. This will help develop better frameworks for the identification and management of rare disorders and events seen within CAMHS.

Venkatesan, M., Smith, E., Kyriakopoulos, M., & Sharma, A. N. (2024). The Royal College of Psychiatrists Child and Adolescent Psychiatry Surveillance System for rare events and disorders: highlighting the need for an international network for surveillance. *BJPsych International*, 1-4. <https://doi.org/10.1192/bji.2024.36>.

Communication, dissemination and public engagement

Communication, dissemination and public engagement has always been a main objective of CAPSS and the studies it has facilitated. CAPSS has achieved these objectives via several routes.

Hosting and contributing to conferences and events: CAPSS has been a mainstay of the Child and Adolescent Faculty conference for several years. Here workshops on how to run studies to presentations of study findings have been undertaken, culminating in the 15th anniversary symposia held at the Royal College of Psychiatry in spring 2025.

Expanding opportunities for mental health education and training: Over the last 3 years in addition to research outputs CAPSS has also delivered training for frontline healthcare professionals on a range of topics, either through webinars or masterclasses. The CAPSS' webinars are easily accessible and provide an hours' worth of training on a clinically relevant topic. The more intensive full day CAPSS masterclasses provide the opportunity to meet with subject experts to explore specific areas of clinical practice. From the outset CAPSS has invited trainees to sit on and contribute to the work of the executive committee.

Public health advocacy: CAPSS facilitated studies have made a considerable impact in influencing health service policy and in guideline management. This has been recognized by NIHR who have now funded several studies. Going forward CAPSS will continue to encourage studies that can influence health policy as well as continuing to investigate epidemiology.

Website and other media: The CAPSS website highlights studies and their findings and provides guidance on how to undertake surveillance and navigate the associated ethics and governance requirements. Recently a newsletter has been launched with all the current news on CAPSS and rare mental health activities.

Active patient and public involvement and engagement (PPIE): CAPSS requires all studies to demonstrate PPIE when submitting applications. Studies are also required to disseminate findings into the public domain.



CAPSS masterclass, October 2024

A message from Dr Aditya Sharma CAPSS Chair



It fills me with great pleasure and warmth writing this piece celebrating 15 years of the Royal College of Psychiatrists Child and Adolescent Psychiatry surveillance system. Having been a trainee member when it was first founded it fills me with great pride to see all that the system has been able to achieve. Looking ahead we hope that CAPSS can combine with other child and adolescent psychiatry surveillance systems across the world to provide richer data sets regarding rare events and disorders. A recent publication in the British Journal of Psychiatry International sets the scene very well for the same.

As you would have seen in this report CAPSS has had a huge impact for service development across the country. Furthermore, it has provided clinically relevant data on epidemiology, presentation, management and outcomes for Child and Adolescent psychiatry consultants at the front line. These data have also been very informative for policy makers.

I would like to take this opportunity to thank the previous chairs for CAPSS including Professor Dasha Nichols, Professor Elena Garalda and Professor Tamsin Ford. Thank **you** for your guidance in steering CAPSS. I would also like to thank all former and current members of the Executive Committee of CAPSS and in particular the trainee members. The input from members of CCQI has been invaluable providing excellent operational support. Most importantly, I would like to thank all the consultants in Child & Adolescent Psychiatry who have provided data using the monthly reporting cards and subsequently filled up questionnaires. I understand that the healthcare system is very stretched and as a result so are you, but your input is invaluable in advocating for better care for young people and their families.

Here's looking forward to the next 15 years.

A handwritten signature in black ink, appearing to read 'Aditya Sharma', with a horizontal line underneath.

Dr Aditya Sharma
CAPSS Chair

Acknowledgments

All CAPSS executive members present and past

All at the CCQ!

Colleagues from the BPSU past and present

RCPsych Faculty of Child and Adolescent Psychiatry, Mental Health Research Network, the Children's Research Fund and the Health Quality Improvement Partnership who have all provided CAPSS with funding

Huge thanks to all the children and young people who sent in amazing submissions to our 'My mental health and me' artwork competition, which are included in this report

And of course, all Consultants Psychiatrists working in child and adolescent mental health services who have completed CAPSS reporting cards without whom we would not be able to undertake surveillance.



CAPSS Executive Committee, November 2024



CAPSS Executive Committee, November 2015



CAPSS Executive Committee, October 2009



Artwork by Shazara, 'Neuro-girl' (Competition runner-up, 11-years and under)



Artwork by Isabelle, *untitled*
(Competition winner, 12-17 years)