The Child and Adolescent Psychiatry Surveillance System (CAPSS)
The First Five Years

Editor: Dr Eleanor Smith with contributions from CAPSS Executive Members

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Foreword

This really is a five year birthday celebration. Congratulations to all who have been involved in this important work over time. The progress made in five short years has been a truly impressive example of the best of collaborations across mental health funding bodies.

From the early days of the first pilot system in 2005, today we have a well established ethically robust process, with excellent rates of reporting from clinicians. The aims of CAPSS are being achieved with high impact publications and wide dissemination of learning. Most importantly the CAPSS is helping to improve the daily lives and safety of children and adolescents across the United Kingdom and Ireland.

Whatever the future challenges of research governance and infrastructure funding I am sure the work of CAPSS will continue to flourish under the care of the CAPSS executive. So keep returning completed cards.

Susan Bailey

Professor Dame Sue Bailey

President of the Royal College of Psychiatrists
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1. Introduction

The Child and Adolescent Psychiatry Surveillance System (CAPSS), established in 2009, supports the epidemiological study of rare mental health disorders or events amongst children and adolescents across the United Kingdom and Ireland through a process of active surveillance.

This report describes the CAPSS process, summarises the achievements of the unit’s first five years and outlines plans for future developments.

2. In the Beginning...

The British Paediatric Surveillance Unit (BPSU) has used active surveillance to examine rare disorders that present to consultant paediatricians since the 1980s. Many of their findings have dramatically changed practice and policy around several conditions [1].

In 2005 a parallel pilot system (CAPSS) was developed by Dr Dasha Nicholls and Richard Lynn to include child and adolescent psychiatrists to maximise the identification of cases for a BPSU study of early onset eating disorders. The pilot system was found to be feasible and acceptable to child and adolescent psychiatrists, with 99% of responding psychiatrists supporting the need for surveillance and 95% stating that they would continue to contribute [2].

With support from the Royal College of Psychiatrists

**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
(RCPsych), the BPSU and the Mental Health Research Network (who provided £5000 for the nascent CAPSS as a clinical research group), CAPSS was officially launched in spring 2009.

In addition to seed funding from the RCPsych’s Faculty of Child and Adolescent Psychiatry (£23,000), and core funding secured from The Children’s Research Fund (£30,000) and the Health Quality Improvement Partnership (£20,000), investigators who use the system contribute a set fee to cover the running of their study on CAPSS. This is currently £10,000 for one year’s surveillance, and £15,000 for studies that run into a second 12-month period.

3. How Does CAPSS Work?

a. Application process

The CAPSS Executive Committee reviews all applications submitted by investigators who want to use the “yellow card” reporting system. This is a two-stage process (figure 1). The phase 1 application determines whether the study would be feasible, centring around the development of a clear surveillance case definition that can be used for screening to ensure that child psychiatrists will be able recognise and report cases or events as accurately as possible. The more detailed phase 2 application includes
further refinement of the surveillance case definition, as well as the more restrictive analytic case definition that the researchers use to identify cases that meet the study criteria. This analytic case definition informs the development of the study questionnaires and protocol. Each study going through the CAPSS application process is allocated to a member of the executive who will be available to provide advice to investigators on the CAPSS application process.

Following discussion with the Health Research Authority the executive have been advised that studies to be run on CAPSS require approval from the Consent Approval Group, as they access clinical data without consent, but they do not require NHS ethics or approval from Research and Development (R&D) departments. Those leading projects are advised to discuss proposals with their local university ethics committee at an early stage.

Further information is available via the CAPSS website (please see http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/research/capss.aspx) and the health research authority (please see www.hra-decisiontools.org.uk/research/).

b. Methodology

CAPSS maintains a database of all Consultant Child and Adolescent Psychiatrists in the United Kingdom and the Republic of Ireland. Using contact details from this database CAPSS administrative staff send out a CAPSS yellow card to each consultant every month (see figure 2). The consultant is asked to

![Child & Adolescent Psychiatric Surveillance System Report Card](image-url)

**Figure 2.** Yellow Card sent to consultants
report whether or not they have assessed a child with the rare disorder(s) or clinical event(s) under study over the last month. The CAPSS administrator notifies the appropriate investigator of any positive reports, after which the investigator sends a questionnaire to the reporting psychiatrist to gather further information. It is important that the yellow card is returned to report that a psychiatrist has not seen a case/event. This process is known as “active” surveillance.

CAPSS response rate is now nearly 80% (figure 3) and it is crucial that the response rate be kept as high as possible to ensure the reliability of the findings that come out of CAPSS studies. The CAPSS administrator works very hard to keep the database up to date, if consultant child and adolescent psychiatrists are not receiving a card or move jobs they need to inform the CAPSS administrator (CAPSS@rcpsych.ac.uk).

![Figure 3. Yellow Card response rate](image)

The positive report is based on a broad (surveillance) definition of the disorder/event under study. The initial questionnaire, which is sent out following the positive report, asks for further information to establish whether the case/event fulfils the narrower analytic case definition. This process aims to identify all potential cases/events for further examination by the investigator. The questionnaire collects a minimal patient identifiable data set to allow the identification of any child that is reported by more than one consultant (possibly because they are seen in more than one service). In addition to identifying duplicate reporting of the same case/event this may provide some information about regional
variation. With this exception, only data that specifically answer the study’s research aims are collected.

c. Advantages of 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. 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.

4. The First Five Years

a. Completed studies

**Childhood Eating Disorders: British National Surveillance Study**

Investigators: Dasha Nicholls, Richard Lynn and Russell Viner

Funding: Hyam Wingate Foundation

CAPSS was developed in order to run this study, which also ran through the BPSU, and aimed to identify new cases of childhood onset eating disorders (<13 years) presenting to secondary care paediatrics and CAMHS. 208 individuals were identified, almost twice the number anticipated, giving an estimated incidence of 3.01/100 000. Key findings included a long time from onset of symptoms to presentation (>8 months), and the high number (50%) admitted to hospital. At 1 year, most were still in treatment and seven still in hospital. The study, published in the British Journal of Psychiatry, was also undertaken in Australia and Canada, and together they influenced changes to diagnostic criteria for eating disorders (EDs) to better capture presentations in younger children. Since the study, recognition of childhood eating
disorders has improved, focus has shifted to early intervention, and
guidelines to improve the medical care of young people with anorexia
nervosa have been developed.

Whether incidence has increased in the 10 years since the study has not
yet been established definitively, but a further study is planned.

**Non-Transient Childhood Conversion Disorder**

Investigators: Cornelius Ani, Richard Reading, Richard Lynn, Simone
Forlee, Elena Garralda

Funding: BUPA Foundation

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. Starting in 2008, 204 cases were identified
giving a 12-month incidence of 1.30/100,000 (95% CI 1.11-1.52). The
most common symptoms were motor weakness and abnormal
movements, with multiple symptoms at presentation being the norm.
Antecedent stressors were reported for 80.8%, most commonly bullying in
school. Most children required in-patient admission with frequent medical
investigations. 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. This is the largest study of incident cases of
childhood conversion disorder ever published in the medical literature.

**Paediatric Bipolar I Disorder**

Investigators: Adi Sharma, Joanne Neely, Nigel Camilleri, Tony James,
Heinz Grunz, Ann Le Couteur

Funding: Research and Clinical Effectiveness Department, Northumberland
Tyne and Wear NHS Trust
Paediatric Bipolar Disorder (onset before age 16 years) is a disorder that has seen a dramatic increase in rates of diagnosis particularly in USA. Data on the epidemiology of the Narrow Phenotype Bipolar I Disorder (NPBD), its associated features (including comorbidities) and outcome in the British Isles is 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. Secondary aims included determination of symptom and diagnostic profile at presentation, frequency of co-morbid conditions, associated genetic and psychosocial factors, short term and intermediate management strategies and clinical outcomes at one year follow up.

151 possible cases were reported during the study period between September 2009 and September 2010. Of these, 33 cases met the analytic case definition of narrow phenotype Bipolar 1 Disorder. 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 (95% CI 0.41 – 0.84). This is the first data set from the UK that examines the incidence of narrow phenotype paediatric bipolar 1 disorder and subsequent short-term outcomes. This study led to the development of the Adolescent Bipolar Service (ABS), which is a national second opinion service for young people under the age of 19 at time of referral with suspected mood disorder.

**Surveillance Study of Childhood-Onset Non-Affective Psychoses in the British Isles**

Investigators: Paul Tiffin and Charlotte Kitchen

Funding: Wolfson Research Institute and Tees, Esk and Wear Valley NHS Foundation Trust

The study aimed to estimate the one year surveillance incidence and to describe clinical features, presentation, co-morbidities, family psychiatric history, management and one-year outcomes of non-affective psychosis
in under 14 year olds in the United Kingdom and Ireland. Fifteen cases with a provisional diagnosis of non-affective psychosis were reported between September 2010 and October 2011. 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 (8/8) followed by hallucinations (7/8).

At baseline, seven of the eight identified cases had at least one probable co-morbid psychiatric disorder. At one-year all but one were taking antipsychotics and five had been admitted at least once to inpatient care. One case had made a full recovery at one-year, two had relapsing courses, two were consistently ill, two were in partial remission and one was unknown.

**b. Ongoing studies**

**Surveillance study of Gender Identity Disorder in Childhood and Adolescents**

Investigators: Sophie Khadr, Polly Carmichael, Vicky Holt, Edna Roche, Russell Viner

Funding: Tavistock and Portman Grant via the Advisory Group for National Specialised Services

This joint BPSU and CAPSS study aims to examine the incidence and clinical presentation of gender identity disorder in UK and Irish children and adolescents. New cases reported by clinicians over a 19-month period (November 2011 – June 2013) are to be validated against DSM IV criteria. This will be the first population-level data on the clinical features and presentation of childhood/adolescent gender identity disorder, informing service provision and clinical management.
c. Other activities

**CAPSS Workshop: “Surveillance Epidemiology in Mental Health”**

In May 2013 Professor Tamsin Ford, Chair of the CAPSS Executive, and Dr Richard Lynn, CAPSS Scientific Advisor, ran a full day workshop on how to run a study using CAPSS. The workshop, open to psychiatrists, paediatricians, psychologists, academics and trainees, was very well received and plans are in place to run a similar event in 2014.

**Child and Adolescent Psychiatry Faculty Conference**

The team also hosted research workshops in 2011 and 2012, and a symposium to present CAPSS studies in 2013. The CAPSS Executive has hosted social events at the annual Child and Adolescent Psychiatry Faculty Conference (2009, 2011, 2012 and 2013) to raise the profile of CAPSS, inform psychiatrists of the training opportunities that it offers and encourage them to run studies using the system.

**Response to English Department of Health**

In May 2012, the CAPSS Executive submitted a detailed response to the English Department of Health in response to their consultation on the UK plan for rare diseases, which emphasised the need for systematic methods to study the incidence and management of rare conditions throughout the UK.

**CAPSS Validation: Questionnaire to Members**

Child and adolescent mental health services (CAMHS) have a range of inclusion and exclusion criteria and not all child mental health presentations will involve psychiatrists. Service based surveillance is only meaningful if respondents surveyed are working in services where they are able to identify the patients/events studied. In winter 2013/14 an online survey undertaken by Drs Tanja-Sabine Schumm and Michael Morton explored variations in practice across CAMHS. A near 50% response rate
yielded valuable information about the denominator in CAPSS studies, which will be summarised to inform future research.

d. Publications from CAPSS studies and activities


**Academic and Invited Presentations**

- Toronto Sick Kids Grand Rounds Eating Disorders in Children – do they differ from adolescents? A three country comparison via teleconference December 2007
• Child & Adolescent Psychiatry Annual Meeting Childhood eating disorders: are the numbers really increasing? Nicholls D Liverpool Sept 2008
• BPSU conference Early onset eating disorders – Developing a child psychiatry reporting scheme Nicholls D London March 2009
• World Congress of the International Association for Child and Adolescent Psychiatry and Allied Professions Epidemiology and clinical features of childhood conversion disorder in United Kingdom and Ireland Ani C, Reading R, Lynn R, James V, Forlee S, Garralda E Beijing June 2010
• AED International Conference on Eating Disorders Eating Disorders in boys. Madden S, Nicholls D, Phinhas L. Salzburg June 2010
• Royal College of Psychiatrists Faculty of Child and Adolescent Psychiatry Annual Meeting Findings from the joint CAPSS / BPSU conversion disorder study Ani C, Reading R, Lynn R, James V, Forlee S, Garralda E Oxford September 2010
• Child & Adolescent Psychiatry Annual Meeting Surveillance of rare child psychiatric conditions in the UK and Ireland Lynn R, Nicholls D, Ford T Cambridge Oct 2011
• CAMHS Research Network Early onset psychosis study York January 2012
• National Institute of Health Paediatric Bipolar Disorders Conference Early onset bipolar disorder- follow up phase Harvard University March 2012
• Scottish Child and Adolescent Psychopharmacology Special Interest Group Early onset bipolar disorder March 2012
• German Bipolar Conference Early onset bipolar disorder Innsbruck Austria May 2012
• World Congress of the International Association for Child and Adolescent Psychiatry and Allied Professions Incidence and 12 month outcome of childhood Conversion Disorder in the United Kingdom and Republic of Ireland: A clinical surveillance population study Ani C, Reading R, Lynn R, Forlee S, Garralda E Paris July 2012
• Royal College of Psychiatrists Faculty of Child and Adolescent Psychiatry Annual Meeting Incidence and 12 month outcome of childhood Conversion Disorder in the United Kingdom and Republic of Ireland: A clinical surveillance population study Ani C, Reading R, Lynn R, Forlee S, Garralda E Manchester September 2012
• Northumberland Tyne and Wear NHS Foundation Trust meets Primary Care Trust Event Early onset bipolar disorder October 2012
• International Association of Adolescent Health BPSU-CAPSS Surveillance Study of GID in Children and Adolescents Khadr S Istanbul June 2013
• Royal College of Paediatrics and Child Health Spring Meeting BPSU-CAPSS Surveillance Study of GID in Children and Adolescents Khadr S Glasgow June 2013
• 9th Joint Meeting of Paediatric Endocrinology Study of Gender Identity Disorder in Children and Adolescents Khadr S Milan September 2013
• Royal College of Psychiatrists Faculty of Child and Adolescent Psychiatry Annual Conference BPSU-CAPSS Surveillance Study of GID in Children and Adolescents Khadr S Edinburgh September 2013
• British Society of Paediatric Endocrinology & Diabetes BPSU-CAPSS Surveillance Study of Gender Dysphoria in Children and Adolescents Khadr S Brighton November 2013
5. The Future

In addition to studies currently under review by the CAPSS executive, there are number of exciting plans for the next five years.

Given the increased interest in CAPSS and enquiries from researchers and clinicians about potential studies, the next challenge will be to ensure the system is sustainable. Securing infrastructure funding would reduce the costs of running a study on CAPSS, making it easier for researchers to use the system. Switching to email reporting (for both initial case reporting and subsequent questionnaires) may help reduce costs in the longer term. However, a high response rate is key to the generation of useful data and so it will be important to monitor the impact of any changes made to CAPSS methodology.

The CAPSS Executive sees itself as having a key role in supporting interested trainees and new consultants gain experience and understanding of research. The Executive are exploring mechanisms that could be used to link interested trainees with interested supervisors, such as a repeat of the workshop we ran for researchers, and trainees or consultants at the Royal College of Psychiatrists. The Executive is also keen to increase the trainee representation on the committee as this provides a useful insight into research process as well an opportunity to hone critical appraisal skills.

There are challenges in navigating the ever-changing research government environment. It is expected that CAPSS studies will require formal ethical approval via university departments, but the separation from NHS Ethical approval and local R&D approval will remove logistical barriers and speed the process of obtaining approval, while ensuring research governance is maintained.
Message from Professor Tamsin Ford, Chair of CAPSS Executive Committee

The first five years have been extremely productive and useful, not to mention fun. I would like to thank all those who have contributed, including funders, investigators and current and former CAPSS staff and executive committee members.

Most importantly I would like to thank all my colleagues who are returning cards, and to encourage you to continue to do so. Without your input, we cannot produce the important service level data to characterize children with rare disorders or in rare predicaments that can present huge dilemmas in terms of management. Please keep sending them in; and in particular please 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.

Maintaining the CAPSS database of Consultant Child and Adolescent Psychiatrists requires a great deal of work. You can help us ensure the database is up to date by letting the team know if you change jobs, are not receiving a yellow card and think that you should be, or are aware of other clinicians who are eligible to join the database. Among paediatricians, the receipt of the first orange card from the BPSU is seen as a rite of passage that signals becoming a consultant; it would be great to similarly embed CAPSS into the working life of child and adolescent psychiatrists.
I have no doubt that the next five years will be as productive, challenging and fun. Please do get in touch if you would like to get involved, either with ideas for studies, or to be on the committee. In five years’ time, we plan to have an established service, running several studies in parallel with a considerable role in teaching and training of research methods.
6. Members of the Executive Committee (Past and Present)

**Farhana Ali** - Executive Officer, Rare Disease UK

**Cornelius Ani** – Consultant Child and Adolescent Psychiatrist and Honorary Senior Lecturer, Imperial College London

**Hani Ayyash** - Consultant Neurodevelopmental Paediatrician, Clinical Lead for ADHD Services, Child and Adolescent Mental Health Services, Cambridgeshire and Peterborough NHS Foundation Trust, A Member of the University of Cambridge Partners

**Tamsin Ford** – Chair of CAPSS executive committee, Honorary Consultant Child and Adolescent Psychiatrist and Professor, University of Exeter Medical School

**Sophie Khadr** – NIHR Clinical Lecturer in Adolescent Health, UCL Institute of Child Health

**Marinos Kyriakopoulos** – Consultant Child and Adolescent Psychiatrist, South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, King's College London; Adjunct Assistant Professor of Psychiatry, Icahn School of Medicine at Mount Sinai, New York, USA

**Richard Lynn** – British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health, Honorary Research Fellow, University College London, Institute of Child Health, London

**Fiona McNicholas** – Consultant Child and Adolescent Psychiatrist Our Lady’s Hospital for Sick Children, Dublin, Ireland

**Nadia Micali** – NIHR Clinician Scientist, Senior Lecturer and Honorary Consultant Psychiatrist Eating Disorders and Adolescent Mental Health Research Team, Behavioural and Brain Sciences Unit, UCL Institute of Child Health

**Michael Morton** – Consultant Child Psychiatrist, Royal Hospital for Sick Children, Yorkhill, Glasgow
Dasha Nicholls – Consultant Child and Adolescent Psychiatrist and Honorary Senior Lecturer, Joint Head of Feeding and Eating Disorders at Great Ormond Street Hospital. Founding Chair of CAPSS.

Alan Quirk – Senior Programme Manager (Audits & Research), Royal College of Psychiatrists' Centre for Quality Improvement, and CAPSS Manager of Operations

Paul Ramchandani – Consultant Child and Adolescent Psychiatrist CNWL NHS Foundation Trust, Reader in Child and Adolescent Imperial College

Adi Sharma – Vice Chair, Consultant and Honorary Clinical Senior Lecturer in Child and Adolescent Psychiatry, Adolescent Bipolar Service, Northumberland Tyne and Wear NHS Foundation Trust and Newcastle University

Eleanor Smith – Trainee Representative, Senior Trainee Child and Adolescent Psychiatry, Northern Deanery

Morris Zwi – Consultant Child and Adolescent Psychiatrist, South West London and St George’s NHS Trust, London

Past Members of the CAPSS Executive: Elena Garralda, Tony James, Richard Reading and Paul Tiffin

Members of the CAPSS Executive Committee at meeting October 2009
If you are interested in using CAPSS, further information is available from the website
http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/research/capss.aspx or by email CAPSS@rcpsych.ac.uk

7. References

