

CAPSS
CHILD & ADOLESCENT
PSYCHIATRY SURVEILLANCE SYSTEM



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The Child and Adolescent Psychiatry Surveillance System (CAPSS)

The Seven Year Report: 2016

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Editor: Eleanor Smith with contributions from CAPSS Executive Members

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Foreword

Congratulations to all who have been involved in this important work. The progress made over the last seven years, particularly in the time since the last report, has been most impressive. I am particularly cheered to see such strong engagement among trainees in the Executive Committee, whilst the unrepentant academic in me also is delighted to see all those studies so far completed finding good homes in high impact journals as well as being disseminated widely to practitioners and families alike. It is great to see the continuing collaboration with the British Paediatric Surveillance Unit across so many studies; the CAPSS has much to learn from their experience and welcomes their ongoing support. And this is not the end - I can see numerous studies ready to start thanks to NIHR funding. Likewise, good to see the collaboration between CAPSS and the Health Research Authority to ensure that this important research continues with due regard to the current ethical approval system. There is also growing interest from other faculties within the college about what this methodology offers. Most importantly, the CAPSS is influencing policy and practice for services that work with children and adolescents who have rare disorders or end up in rare predicaments 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 well done, and now keep calm and carry on.

A handwritten signature in black ink, reading "Simon Wessely". The signature is written in a cursive style with a long, sweeping underline that extends to the right.

Professor Simon Wessely

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 to date 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].

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 these disorders and events as well as their impact on 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

With support from the Royal College of Psychiatrists (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 £12,500 for one year’s surveillance.

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).

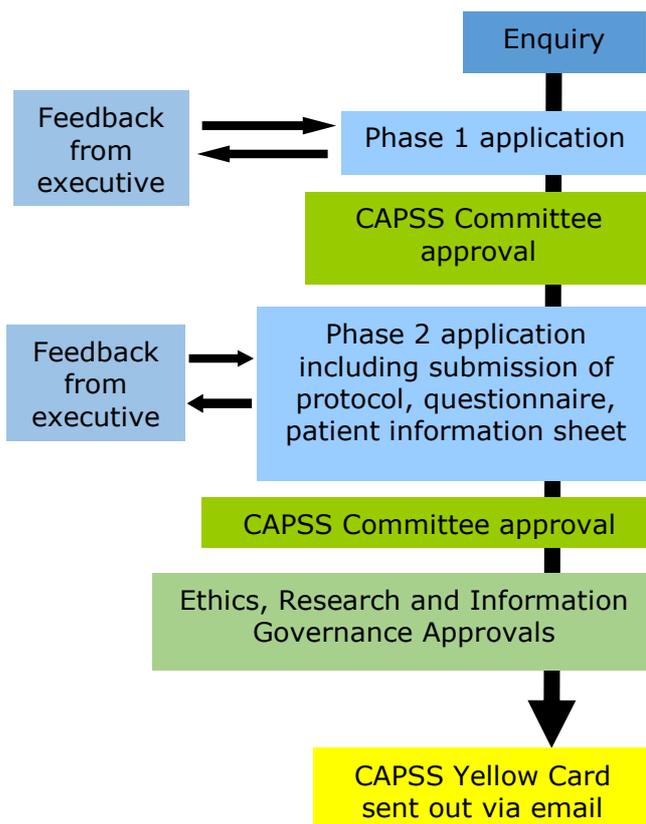


Figure 1. Application stages to using CAPSS

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 and adolescent 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 precise 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.

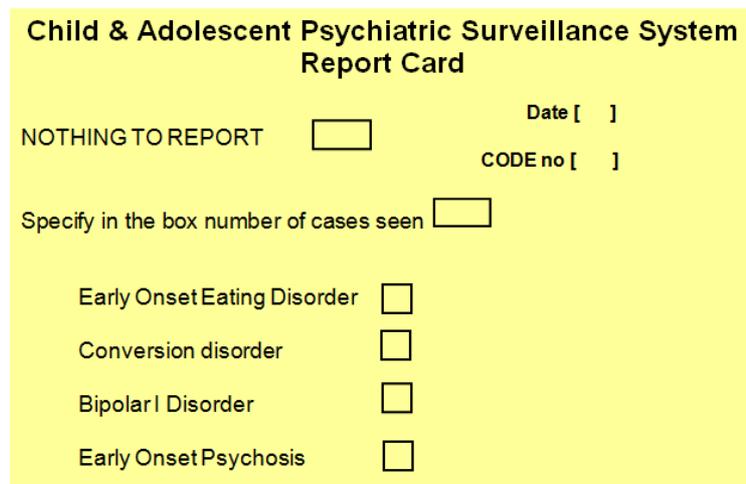
A positive ethical opinion is required. Depending upon the nature of the study undertaken this may be NHS or University ethics. Following discussion with the Health Research Authority (HRA) the Executive have been advised that studies to be run on CAPSS require approval from the Confidentiality Advisory Group, as CAPSS studies access identifiable clinical data without consent, and the new proportional HRA approval for multisite studies. Researchers need to seek approval from the sponsor for the study, which would usually be through the NHS trust Research and Development Department (R&D) or university at which the principal investigator works. There is no requirement for reporting consultants to seek additional local R&D approval before reporting cases.

University employees need to know if their institution has Information Governance (IG) toolkit approval, which requires renewal every year. If not, it is advisable to run the study in conjunction with a local NHS trust who will have this approval, so that all information with patient identifiers can be handled through the trust. The Scottish equivalent of CAG, the Public Benefits and Privacy Panel (PBPP) have approved BPSU methodology, so data can be collected in Scotland without consent. CAPSS is in the process of gaining similar approval. As the process of approval may change, all proposals should be discussed with local R&D departments and CAPSS for the most up to date information on ethics approval.

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). As of June 2016, 651 consultants are receiving the card; either via post or via e-mail. The consultant is asked to 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.



The image shows a yellow report card titled "Child & Adolescent Psychiatric Surveillance System Report Card". It contains the following fields and options:

- NOTHING TO REPORT
- Date []
- CODE no []
- Specify in the box number of cases seen
- Early Onset Eating Disorder
- Conversion disorder
- Bipolar I Disorder
- Early Onset Psychosis

Figure 2. Yellow Card sent to consultants

It is crucial that the CAPSS 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).

We plan to transfer to an electronic "card" delivered by email, so watch this space. Get in touch if you would like to be part of the pilot or if your email address changes.

The positive report is based on a broad (surveillance) definition of the disorder/ event under study. The initial questionnaire, 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 if 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.

All researchers are encouraged to seek public and patient involvement (PPI) to inform research questions, methodology, analysis and dissemination strategy (see Figure 3).

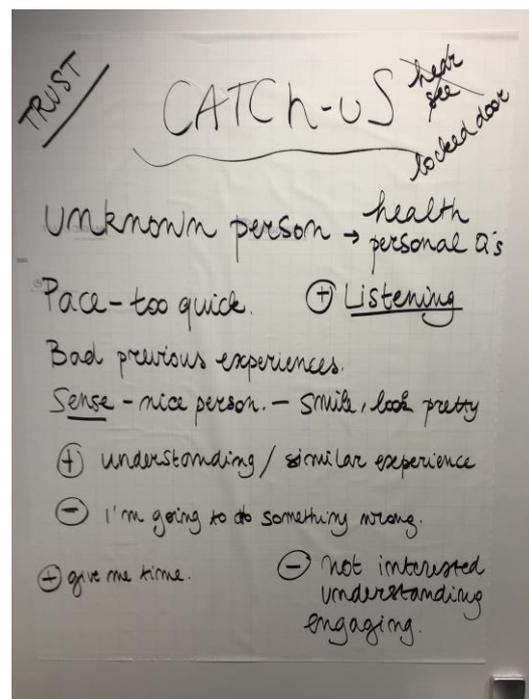


Figure 3. Input from secondary school children to the CATCH uS study

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, 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 child and adolescent psychiatrists (and in some cases consultant paediatricians), which provides a more accurate picture of the service

level incidence of rare disorders or events. CAPSS is also keen to get non-consultant grades more involved in data collection.

The Chair of CAPSS Executive Committee sits on the equivalent committee of BPSU. The two units work closely together in relation to methodology and individual study proposals. Informal collaborations between members of the CAPSS Executive Committee and researchers with relevant interest groups and networks in Child and Adolescent Mental Health Services (CAMHS) have improved ascertainment through encouraging participation.

4. CAPSS Outputs

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, aiming to identify new cases of childhood onset eating disorders (ED) (<13 years) presenting to paediatrics and CAMHS.

208 individuals were identified, almost twice the number anticipated, an estimated incidence of 3.01/ 100 000. Studies in Australia, Canada and Great Britain (GB) of childhood-onset ED have now been completed. All identified higher rates of males than are commonly reported, and suggest that the majority of children with ED are not being recognised until medical complications become severe.

The impact of these studies has been significant. They added impetus to making the diagnostic criteria for ED in DSM-5 more developmentally sensitive. They stimulated further research, including the COSTED trial looking at the relationship between incidence, service configuration, and associated health costs for young people with ED across GB. They have influenced the training agenda for paediatricians and child mental health

providers, and stimulated clinical guidelines for early medical management (Junior MARSIPAN 2010). Importantly, this work has also fostered closer collaboration between paediatricians and psychiatrists in the care of this vulnerable patient group.

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.

Surveillance study of Narrow Phenotype Paediatric Bipolar I Disorder in the British Isles: Incidence and 1 year follow up

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 and North East Branch of the Mental Health Foundation

Paediatric Bipolar Disorder (onset before age 16 years) is a disorder that has seen a dramatic increase in rates of diagnosis particularly in the 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 the 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 examined the incidence and clinical presentation of gender dysphoria in UK and Irish children and adolescents aged 4 to 15 years inclusive. New cases were reported by clinicians over a 19-month period (November 2011 – June 2013) and validated against DSM-IV criteria. There were 230 confirmed cases during the reporting period excluding duplicates (98 males), with a median age at diagnosis of 14.68 (interquartile range 12.1 – 15.31) years. Approximately two thirds of cases aged less than 12 years were male (36 of 57 cases), with females comprising almost two thirds of cases aged 12-15 years (111 of 173 cases). At least one co-morbid mental health condition was present in 52% of 12-15 year olds and 26% of under 12s. There was a history of self-harm in 47% of 12-15 year olds.

Ongoing work is looking at outcomes at one and two years following presentation, with a view to informing service provision and clinical management in this area.

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

Investigators: Sarah Byford, Ivan Eisler, Dasha Nicholls, Simon Gowers, Susan Ringwood, Fiona McNicholas, Geraldine Macdonald, Tamsin Ford, Robin Glaze, Mima Simic, Barbara Barrett, Jo Fletcher

Funding: NIHR Health Service and Delivery Research Programme

This study aims to evaluate the cost and cost-effectiveness of existing community-based models of service provision for child and adolescent anorexia nervosa and to model the impact of potential changes to the provision of specialist NHS services using decision analytic modelling techniques. New cases of young people aged 8-17 years and 11 months with DSM-V anorexia nervosa will be included and data used to estimate incidence, classify the model of care provided for each case and map models of care across the British Isles. Follow-up data will be used to estimate the relative cost of all cases, determine the cost and cost-effectiveness of different models of community-based care provision and explore the impact on cost and cost-effectiveness of potential changes to the provision of specialist community-based services in the British Isles.

Children and adolescents with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (CATCh uS)

Investigators: Tamsin Ford, Astrid Janssens, Helen Eke, Anna Price, Anna Stimson

Funding: NIHR Health Service and Delivery Research Programme

This is a joint CAPSS/ BPSU study. Existing work suggests that young people with developmental disorders like ADHD are particularly likely not to transfer to adult mental health services, but there has yet to be an in-

depth study of this issue in the UK. The main project consists of a surveillance study of young people with ADHD on medication who are approaching discharge from children's services with a nine month-follow-up to find out where they are transferred to. Additionally, interviews with key stakeholders are being conducted to explore views and experiences of the transfer (a change of provider) and transition (the quality and experience of this process). Furthermore, a mapping study will combine information about the location of services for young adults with ADHD from the surveillance and interviews with email/ postal surveys of service commissioners, service providers and key service user groups for young adults with ADHD. Carrying out this work will provide recommendations to the transition process for young people with ADHD and thus improve their health and wellbeing.

c. Forthcoming studies

Childhood Disintegrative Disorder Surveillance Study

Investigators: Michael Absoud, Jessica Turnbull, Marinos Kyriakopoulos, Tammy Hedderly, Ming Lim, Dianne Newbury and Gillian Baird

Funding: The Shirley Foundation

This joint BPSU and CAPSS study will investigate Childhood Disintegrative Disorder, a rare condition where a previously normal child very rapidly loses intellectual and developmental skills, in UK and Irish children and adolescents. It aims to establish the incidence, demographic and clinical characteristics of the condition, provide information on current investigative and management approaches, and contribute towards planning of future studies on aetiology, raise awareness of the condition amongst clinicians, and assist in planning of services at a regional and national level.

Early Onset Depression Surveillance Study

Investigators: Adi Sharma, Hani Ayyash, Mohamed Bahgat Mohamed, Benardaka Dubicka, Priya Hodgins, Daphne Korczak, Richard Lynn and Paul Wilkinson.

Funding: Northumberland Tyne and Wear NHS Foundation Trust

This will be the first study in the British Isles looking into the surveillance epidemiology of early onset depression in children between the ages of 3 years and less than 13 years. The study aims to review how these children are being managed, the complexity of presentations, and consideration can then be given on how specific treatment guidelines could be developed.

d. Teaching and Training

CAPSS Workshop: "Surveillance Epidemiology in Mental Health"

In May 2013, Professor Tamsin Ford, Chair of the CAPSS Executive, and 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 public health trainees, was very well received.

Child and Adolescent Psychiatry Faculty Conference

The CAPSS team hosted research workshops in 2011, 2012 and 2016, 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 - 2015) and will do so at the 2016 joint Child and Adolescent and General Adult Psychiatry faculty conference to raise the profile of CAPSS, inform psychiatrists of the training opportunities that it offers and encourage them to run studies using the system.

Trainee Involvement

The CAPSS Executive Committee encourages trainee participation in its work. Currently, four trainees from across the UK are members of the committee, gaining experience in critical appraisal of research proposals as well as a broad overview of the opportunities and challenges associated with clinical research in CAMHS.

e. Publications from CAPSS Studies

- Sharma AN, Neely J, Le Couteur AS, Grunze H, Nicholls D, James A, Graham P, Lynn R, Scott J, Ferrier IN. (2009). Study of pediatric bipolar disorder in UK and ROI: development of a case definition and pilot data from North East England. *Bipolar Disorders* 11(1) 79.
- Sharma A, Le Couteur AS, Nicholls D, Graham P, Lynn R, Ferrier IN. (2009). Paediatric bipolar disorder: A way forward. *British Journal of Psychiatry* 192(2) 150-1.
- Nicholls D, Lynn R, Viner R (2011). Childhood eating disorders: British national surveillance study. *British Journal of Psychiatry* 198. 295-301
- Lynn RM, Viner RM, Nicholls DE (2012). Ascertainment of early onset eating disorders; A pilot for developing a National Psychiatric Surveillance System. *Child and Adolescent Mental Health* 17, 109-112.
- Hudson LD, Nicholls DE, Lynn RM, Viner RM. (2012). Medical instability and growth of children and adolescents with early onset eating disorders. *Archives of disease in childhood*; 97, 779-784.
- 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, 413-8.
- 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.

f. Other Activities

CAPSS Validation: Questionnaire to Members

Service based surveillance is only meaningful if respondents surveyed are working in services where they are able to identify the patients/ events studied. CAMHS have a range of inclusion and exclusion criteria. In winter 2013/ 14 an on-line survey undertaken by Drs Tanja Schumm and Michael Morton explored variations in practice across CAMHS. With a response rate of approximately 50% the data yielded valuable information about the denominator in CAPSS studies.

Findings about the kind of referrals expected by CAMHS in which CAPSS respondents are based highlighted the conditions seen within these services and some notable exceptions (see table). Some conditions, usually seen in CAMHS and involving a Child and Adolescent Psychiatrist, are well captured through CAPSS Surveillance. Some conditions may not be well described by CAPSS methodology and conditions that may be seen either in CAMHS or in Child Health/ Paediatric Services may be better captured through joint surveillance with the CAPSS and the BPSU.

CAMHS in which CAPSS respondents are based receive referrals for:

- Psychosis¹
- Mood disorders¹
- Eating disorders¹
- Psychological trauma^{2,3}
- Psychological disorder associated with physical symptoms^{2,3}
- Self-harm^{2,3}
- Learning Disability²
- Autism Spectrum Disorders^{1,3}
- Attention Deficit Hyperactivity Disorder^{1,3}
- Tourette's Syndrome^{1,3}

But did not receive referrals for:

- Alcohol/ drug problems
- Disorders in infants

¹ Usually involves Child & Adolescent Psychiatrist when seen in CAMHS

² Doesn't usually involve Child & Adolescent Psychiatrist when seen in CAMHS

³ Also seen in Paediatric Services

National Survey on Mental Health Disorders in a Paediatric Clinical Setting

Drs Hani Ayyash, Michael Morton, Tanja Schumm and Richard Lynn have adapted the methodology of the CAPSS validation study to contact Community Paediatricians. The study was conducted with the kind agreement of the Chair of the British Association for Community Child Health. This UK wide survey, that is approaching completion, aims to explore the area of overlap whereby children with mental health problems may attend CAMHS in some districts but in other areas they may be seen in Community Child Health services. Initial results have indicated the important role that community paediatricians play in the lives of children with mental health disorders but also highlighted the complexity of this issue and the need for careful consideration of this in planning a surveillance study.

g. Impact of CAPSS

Informing National Policy

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. Surveillance methodology, CAPSS and the BPSU were mentioned in the Chief Medical Officers report (2013); Public Mental Health; Investing in the evidence.

Research Governance

CAPSS has excellent working relationships with both CAG and HRA. Professor Tamsin Ford has been invited to present to a collaboration and development meeting at the HRA to discuss proportionality. These links ensure that members of the CAPSS executive can provide researchers using the CAPSS system with timely and up to date advice in relationship to current research governance.

Expanding Research Capacity

CAPSS has always been keen to improve the research experience of trainees. The aim being to introduce them to the processes required to review and evaluate research protocols and to learn about the importance of disease epidemiology. The past year has seen the Executive expand the number of trainees on to the committee.

Service Development

Data from the Surveillance Study of Narrow Phenotype Paediatric Bipolar 1 Disorder informed the development of the National Adolescent Bipolar Service (ABS), a tertiary second opinion service providing assessment and management advice to local CAMHS teams. ABS is part of the Northern Centre for Mood Disorders, a joint academic clinical collaboration between Northumberland Tyne and Wear NHS Foundation Trust and Newcastle University.

Service Redesign

CAPSS studies can inform decision making in relation to service redesign. For example, the careful description of the prevalence of early onset eating disorders has contributed to decision making in relation to service provision, both in early intervention and in relation to child psychiatric in-patient beds.

5. The future

In addition to studies currently under review by the CAPSS executive, there are number of exciting plans for the future. 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 for CAPSS would allow us to reduce the costs to researchers of running a study on CAPSS.

As part of continuous improvement informed by consultant feedback, CAPSS aims to move to **full e-reporting by the end of 2016**, a system is already successfully in use by the BPSU. Switching to e-reporting will help reduce costs in the longer term. As a high response rate is key to the generation of valid and representative data it will be important to monitor the impact of this change to the reporting process on rates of case notification. In order to enable consultants to demonstrate involvement in CAPSS reporting, the Executive **will now be providing certificates which can be used for appraisal and revalidation purposes**. These certificates will show individual response rates compared to the national average and will be available on request (capss@rcpsych.ac.uk).



Message from Professor Tamsin Ford, Chair of CAPSS Executive Committee

The two years since our last report 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. It feels like CAPSS is coming of age, as we are now running with more than one study on the card, and we move towards electronic “cards” as our sister unit, the BPSU, has already done.

Thank you for returning the cards; please continue to do so. Without your input, we cannot produce the important service level data to characterize

children in rare predicaments that can present huge dilemmas in terms of management. So please keep sending them in; and in particular please remember that a “**no I have not seen a case**” response is **just 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. Please also complete the questionnaires for researchers. We know that you are busy, but we hope that the “involvement in research” certificates that we can now produce for your annual appraisals supports this activity. **Please let us know if there are other ways in which we can support you** to make the studies that we run as high quality as possible. When studying rare conditions and events every questionnaire counts.

Maintaining the CAPSS database of Consultant Child and Adolescent Psychiatrists also requires a great deal of work. You can help us ensure the database is up to date by **letting the team know** (CAPSS@rcpsych.ac.uk) 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 few 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. We have grown from the first single study on eating disorders to an established unit running several studies in parallel. We are now working to extend the methodology to other faculties within the college and are keen to expand our role in teaching and training of research methods.

6. Current Members of the Executive Committee

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

Hani Ayyash – Consultant Neurodevelopmental Paediatrician and Honorary Senior Lecturer, Clinical lead for ADHD 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, Exeter

Blanaid Gavins – Consultant Child and Adolescent Psychiatrist, The Children's Mental Health Clinic, Dublin

Jaya Gupta – Specialty Trainee, Child and Adolescent Psychiatry, The Royal London Hospital and Great Ormond Street Hospital, London.

Priya Hodgins – Specialty Trainee, Child and Adolescent Psychiatry, Health Education North East, Newcastle

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

Richard Lynn – British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health, Honorary Senior 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

Andrew McWilliams – Academic Clinical Fellow and Specialty Trainee, Child and Adolescent Psychiatry, South London and Maudsley NHS Trust and Great Ormond Street Hospital, London

Michael Morton – Honorary Clinical Senior Lecturer, Institute of Health & Well-being, University of Glasgow, 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, London; Founding Chair of CAPSS

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

Udo Reulbach – Special Lecturer in Child and Adolescent Psychiatry, University College, Dublin

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 – Consultant Child and Adolescent Psychiatrist, Complex Neurodevelopmental Disorders Service, Northumberland Tyne and Wear NHS Foundation Trust

Adele Warrilow, Clinical Research Fellow and West of Scotland Specialty Trainee, Institute of Health & Well-being, University of Glasgow



Members of CAPSS Executive at meeting June 2016



Members of CAPSS Executive Committee at meeting March 2014



Members of the CAPSS Executive Committee at meeting October 2009

Past Members of the CAPSS Executive: Farhana Ali, Elena Garralda, Tony James, Sophie Khadr, Nadia Micali, Paul Ramchandani, Richard Reading, Paul Tiffin and Morris Zwi.

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7. References

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