CAPSS
CHILD & ADOLESCENT
PSYCHIATRY SURVEILLANCE SYSTEM

The Child and Adolescent Psychiatry Surveillance System (CAPSS)

The Ten Year Report: 2019

Prepared by Ceri Price, Andrew McWilliams & Adele Warrilow

Editor: Eleanor Smith with contributions from CAPSS Executive Members

Date : January 2020 CCQI 330
Publication number : CCQI 330

Foreword

The importance of psychiatric disorders in children and young people cannot be over emphasised. It is not just the patient who suffers, the impact on families and carers is huge.

I am therefore very pleased to be able to congratulate all who have ensured the continued success of the Child and Adolescent Psychiatry Surveillance System (CAPSS), which has celebrated its 10th birthday this year. Having started out as a pilot set up to support the study of eating disorders in young children CAPSS is now an established surveillance unit. Over the last decade it has supported researchers to study a range of disorders. It is great to see continued collaboration with the British Paediatric Surveillance Unit and to hear that a number of studies are being run jointly through the two surveillance systems.

CAPSS studies continue to influence national policy and provision of services, through high impact publications and wide dissemination of learning. This helps to improve the daily lives and safety of children and adolescents. Despite significant pressures on services, front line Child and Adolescent Psychiatrists from across the UK and the Republic of Ireland continue to dedicate time to support researchers' efforts. This contribution is critical to the future success of CAPSS - so please keep responding to the CAPSS emails!

Whatever the future challenges of research governance, infrastructure funding and clinical service provision I am sure the work of CAPSS will continue to flourish under the care of the CAPSS executive.

Professor Wendy Burn

President of the Royal College of Psychiatrists

Contents

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 these studies 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.

3. How does CAPSS work?

a. Application Process

The CAPSS Executive Committee reviews all applications submitted by investigators who want to use the CAPSS reporting system. This is a two-stage process (Figure 1).

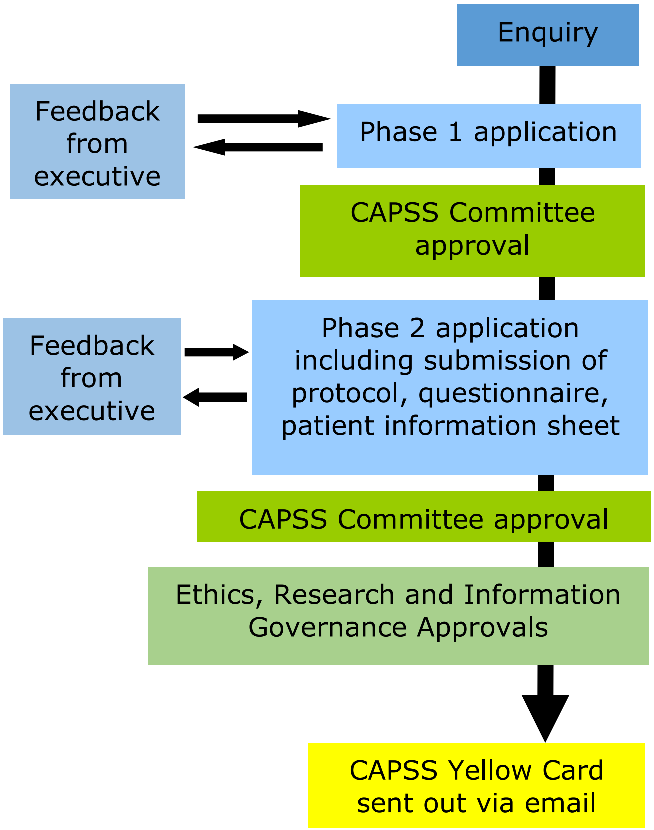


Figure 1. Application stages to using CAPSS

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.

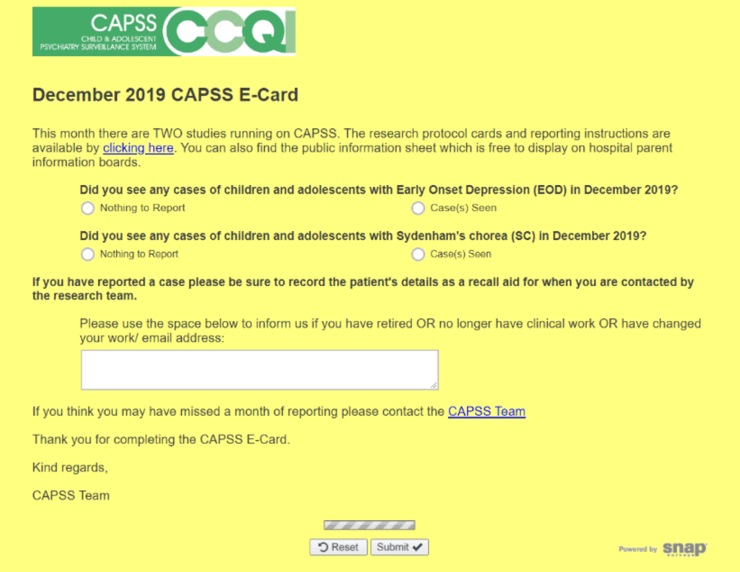
University employees need to know if their institution has Information Governance (IG) toolkit approval, which requires renewal every year. If not, it is advisable to run the study in conjunction with a local NHS trust who will have this approval, so that all information with patient identifiers can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

Further information is available via the CAPSS website (please see https://www.rcpsych.ac.uk/improving-care/ccqi/research-and-evaluation/current-research/applying-to-use-CAPSS and the health research authority (please see www.hra-decisiontools.org.uk/research/).

b. Methodology

CAPSS maintains a database of consultant child and adolescent psychiatrists working in the United Kingdom and Republic of Ireland. All members are contacted via email once per month (see Figure 2) and invited to report whether or not they have seen 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. This process is known as “active” surveillance.

This electronic notification system, introduced in 2018, replaces the former iconic yellow cards which were delivered through the post.



December 2019 CAPSS E-Card

This month there are TWO studies running on CAPSS. The research protocol cards and reporting instructions are available by clicking here. You can also find the public information sheet which is free to display on hospital parent information boards.

Did you see any cases of children and adolescents with Early Onset Depression (EOD) in December 2019?
○ Nothing to Report ○ Case(s) Seen

Did you see any cases of children and adolescents with Sydenham's chorea (SC) in December 2019?
○ Nothing to Report ○ Case(s) Seen

If you have reported a case please be sure to record the patient's details as a recall aid for when you are contacted by the research team.

Please use the space below to inform us if you have retired OR no longer have clinical work OR have changed your work/ email address:

If you think you may have missed a month of reporting please contact the CAPSS Team

Thank you for completing the CAPSS E-Card.

Kind regards,

CAPSS Team

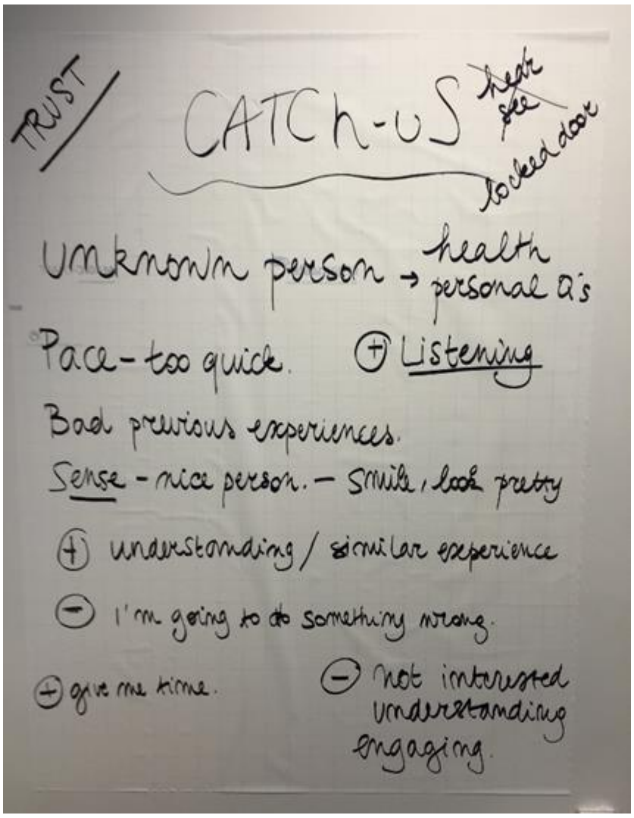
Figure 2. CAPSS email notification

Although the paper system, was preferred by some colleagues, it incurred considerable financial burden to CAPSS, due to printing and postal costs, and the administrative work of collating the inputs. As of August 2019, 642 consultants are receiving the CAPSS e-mails.

It is crucial that the CAPSS response rate be kept as high as possible to ensure the reliability of the findings 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 emails or move jobs it is important that they inform the CAPSS administrator (CAPSS@rcpsych.ac.uk) to ensure that their contact details are updated.

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 minimal patient identifiable data to allow the identification of any child reported by more than one consultant. In addition to identifying duplicate reporting of the same case/event this data set 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).



TRUST

CATCh-uS

~~hear~~
~~see~~
locked door

Unknown person → health
personal Q's

Pace - too quick. ⊕ Listening

Bad previous experiences.

Sense - nice person. - Smile, look pretty

⊕ understanding / similar experience

⊖ I'm going to do something wrong.

⊕ give me time.

⊖ not interested
understanding
engaging.

Figure 3. Input from secondary school children for 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. Moving forward CAPSS is exploring the possibility of involving non-consultant grades 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 recognized 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 (<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 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 0.59/100,000 (95% CI 0.41 – 0.84). This is the first data set from the UK that examines the incidence of NPBD and subsequent short-term outcomes. This study led to the development of the Adolescent Bipolar Service (now the Specialist Adolescent Mood Disorders Service (SAMS)), 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.

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 aimed 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-5 anorexia nervosa were 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 has been 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, Sharon Blake, Tamsin Newlove Delgado, Cornelius Ani, Moli Paul, Tracey Elliott, Catherine Shotton, Susan Young, Phil Asherson, Kapil Sayal, Chris Hollis and Stuart Logan.

Funding: NIHR Health Service and Delivery Research Programme

The NIHR-funded CATCh-uS project led by the University of Exeter explored what happens to young people needing ongoing management of ADHD when they are too old for children's services. The aim of CATCh-uS was to provide information and insights on how to improve health services for young people with ADHD and, ultimately, to optimise their health and wellbeing.

The project included a surveillance study to examine how many young people with ADHD require ongoing treatment in adult services (as defined by a clinician); a qualitative study with young people, parents and clinicians to explore their experiences of transition; and a mapping study to identify the services available across the country for adults with ADHD.

Up to 40% of young people with ADHD continue to have symptoms into adulthood that affect their functioning, and these young people are more at risk of poorer outcomes such as difficulties with education, employment and relationships, contact with criminal justice systems, and worse physical and mental health. Since 2008, NICE guidance has recommended that young people with ADHD who need continuing treatment after leaving child services should make a smooth transition into adult services, but previous research suggested that many young people with ongoing ADHD health care needs did not make this transition and that some missed out on the treatment they needed. National registry studies suggest that continued ADHD medication into early adulthood is associated with substantially reduced levels of suicidal behaviour (Chen et al, 2014), depression (Chang et al, 2016) , substance misuse (Chang et al., 2014) road traffic accidents (Chang et al, 2017), convictions and violent reoffending (Lichtenstein et al, 2013). Transitional care for the graduates of children's services with ADHD and ongoing clinical need is therefore extremely important. And of course, medication is not the only kind of specialist care that these young people need or want.

Surveillance study of Gender Identity Disorder in Childhood and Adolescents

Investigators: Sophie Khadr, Polly Carmichael, Vicky Holt, Edna Roche and 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.

b. Ongoing 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 Bahgaat Mohamed, Benardaka Dubicka, Priya Hodgins, Daphne Korczak, Richard Lynn, Eleanor Smith and Paul Wilkinson.

Funding: Northumberland Tyne and Wear NHS Foundation Trust

This is the first study in the British Isles to use surveillance epidemiology to look at early onset depression in children under the age of 13. During the 12 month surveillance period (January 2019 to January 2020) consultant child and adolescent psychiatrists are being asked to report children under the age of 13 presenting with first episode of depression. Follow-up questionnaires will then be sent to reporting clinicians at 12 and 24 months. In addition to establishing the incidence of early onset depression, data collected will allow the research team to report on symptom profiles and interventions being used by treating clinicians, with the 2 year follow-up period providing information about what happens to this group over time.

Modern illness or a thing of the past? Surveillance study of childhood/adolescent Sydenham's chorea in the UK and the Republic of Ireland

Principal investigators: Oana Mitrofan and Tamsin Newlove-Delgado.

Funding: The Sydenham’s Chorea Association, The Royal College of Paediatrics and Child Health & British Academy of Childhood Disability Paul Polani Award and the Canadian Rare Disease Organisation.

This is the first prospective surveillance study of Sydenham’s Chorea ever performed in the UK and ROI and it is conducted through the British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatry Surveillance System (CAPSS). The study aims to examine the current pattern of Sydenham’s chorea, raise awareness of its course and complications and inform service planning. This study was inspired and developed through collaboration with the patient led family charity the Sydenham’s Chorea Association. The BPSU surveillance started in November 2018 (21 cases notified in the first six months), and the CAPSS surveillance was launched May 2019.

c. Publications from CAPSS Studies

- 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.
- 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.
- Schumm TS, Morton MJS. (2017). National Survey of child and adolescent psychiatrists' clinical activity using the Child and Adolescent Psychiatry Surveillance System (CAPSS). Archives of Disease in Childhood 102(Suppl 1). doi: 10.1136/archdischild-2017-313087.121
- Eke H, Ford T, Newlove-Delgado T, Price A, Young S, Ani C, Sayla K, Lynn RM, Paul M, Janssens A. (2019). Transition between child and adult services for young people with attention-deficit hyperactivity disorder (ADHD): findings from a British national surveillance study. British Journal of Psychiatry 1-7. doi:10.1192/bjp.2019.131
- Petkova H, Simic M, Nicholls D, et al. Incidence of anorexia nervosa in young people in the UK and Ireland: a national surveillance study. BMJ Open 2019;9:e027339. doi: 10.1136/bmjopen-2018-027339
- Byford S, Petkvoa H, Stuart R, Nicholls D, Simic M, Ford T, et al. Alternative community-based models of care for young people with anorexia nervosa: the CostED national surveillance study. Health Serv Deliv Res 2019;7(37).

d. 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. This methodology was subsequently used by Hani Ayyash in a survey of the membership of BACCH.

CAMHS in which CAPSS respondents are based receive referrals for:

- Psychosis[1]
- Mood disorders[1]
- Eating disorders[1]
- Psychological trauma[2,3]
- Psychological disorder associated with physical symptoms[2,3]
- Self-harm[2,3]
- Learning Disability[2]
- 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

e. 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. CAPSS now has a number of trainee representatives who attend executive meetings and contribute to the ongoing work undertaken by the committee to support researchers using the system.

Service Development

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.

Data from the Surveillance Study of Paediatric Bipolar Disorder informed the development of the Specialist Adolescent Mood Disorders Service (SAMS), a tertiary second opinion service providing assessment and management advice to local CAMHS teams. SAMS 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.

Data collected from clinicians through CATCh-uS has highlighted the challenges young people experience when transitioning into adult ADHD services, with results of the study being discussed within national policy meetings.

5. Letter from CAPSS Chair

Professor Tamsin Ford

In writing this I realise that I have been CAPSS Chair for 10 years and am amazed and enthused by how far we have come. The three years since our last report have been particularly productive as you can see by the Impact and Outputs sections of this report. CAPSS has successfully completed the move to electronic "cards, with a concomitant improvement in response rates and we have done a lot of work to improve and maintain our database. Three studies have completed their surveillance, and two others are in progress. Two studies funded by NIHR used surveillance methodology as the foundation for larger pieces of work (CATCh-uS; transition in ADHD; CostEd; evaluation of the cost-effectiveness of specialist versus generic eating disorder services within CAMHS), which is both novel and exciting. These studies are beginning to influence policy, commissioning and practice. For example, CATCh-uS has produced a map of ADHD services for adults, and fed results into several national policy meetings. Anecdotally, colleagues have reported that the running of these studies has focused attention within their trust on the provision for these groups, which has eased their negotiations for resources. There is huge interest in the CostEd and Gender Identity Studies, which will be publishing shortly.

This system is only as good as the database and your responses to it. The costs of maintaining a research database, which demands a higher level of accuracy and maintenance than can be tolerated for administration, should not be underestimated. Moreover, the CATChuS database requires the ability to opt out and to be clinically active at senior level, so we cannot merely work from the Faculty database. Thank you all for returning our emailed cards. It is so important that we hear from you and in particular please remember that responding to say "no I have not seen a case" is just as important as a positive report. We are then clear that you did receive the email and should be counted in the system so we can establish a response rate. If you do respond, we do not know if you did not see a case or did not receive the card. 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 email and think that you should be, or are aware of other clinicians who are eligible to join the database. We are particularly keen to link with senior trainees as they complete their training.

Likewise, please also complete the questionnaires for researchers about reported cases. We know that you are all extremely busy, but research is enshrined as a core activity in the NHS constitution. We are generating data that we can all work from but it is only as good as your responses. We hope that the "involvement in research" certificates that we can now produce for your annual appraisals supports this activity. And 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, processes and events every questionnaire counts.

I have no doubt that the next few years will be as productive, challenging and fun. Look out for a study of Avoidant / Restrictive Food Intake Disorder (ARFID) that has funding and is going through governance. 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 keen to expand our role in teaching and training of research methods.

I would like to thank all those who have contributed, including funders, investigators and current and former CAPSS staff and executive committee members. Particular thanks to Alan Quirk, Stephanie Learmonth, Jess Butler, Sarnetha Ravisangar and Monika Daszczuk for their hard work behind the scenes.

6. CAPSS Executive Committee

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

Hani Ayyash – Consultant Neurodevelopmental Paediatrician, Special Interest in Child Mental Health, Clinical Lead for Neurodevelopmental Pathway and Community Paediatrics, Mid and South Essex University Hospitals Group, Southend University Hospital NHS Foundation Trust, Southend on- Sea, Essex

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

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

Priya Hodgins – Consultant Child and Adolescent Psychiatry, Tees, Esk and Wear Valleys NHS Foundation Trust

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 – Specialist Registrar in Child and Adolescent Psychiatry - Great Ormond Street Hospital; Clinical Research Fellow & PhD student - Mental Health and Justice Project, King's College London & Metacognition Group, Wellcome Trust Centre for Neuroimaging, University College London

Michael Morton – Honorary Clinical Senior Lecturer in Child and Adolescent Psychiatry, University of Glasgow. Retired Consultant Child and Adolescent Psychiatrist, Royal Hospital for Sick Children, Yorkhill, Glasgow

Dasha Nicholls –Reader in Child Psychiatry, Imperial College, London and Honorary Consultant Child and Adolescent Psychiatrist; Founding Chair of CAPSS

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, Specialist Adolescent Mood Disorders 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

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

Acknowledgements:

We are extremely grateful to the ongoing support of the BPSU, particularly Hani Ayyash, Simon Lenton, Richard Lynn, Richard Reading and Jacob Avis, and also to Tanya Schumm for leading the survey of child psychiatrists about their caseload.

The artwork on the cover of this report was created by Daisy Goodyear. Daisy’s picture was selected as the winner of a competition open to children and young people across UK and Republic of Ireland.

7. References

---

[1] Nicoll A, Lynn R, Rahi J, Verity C, Haines L. Public Health Outputs from the British Paediatric Surveillance Unit and similar clinician-based surveillance mechanisms. J R Soc Med 2000; 80:580-585.

[2] 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.

If you are interested in using CAPSS, further information is available from the website https://www.rcpsych.ac.uk/improving-care/ccqi/research-and-evaluation/current-research/applying-to-use-CAPSS or by email CAPSS@rcpsych.ac.uk

CAPSS
CHILD & ADOLESCENT
PSYCHIATRY SURVEILLANCE SYSTEM

CCQI