

What is the Child and Adolescent Psychiatry Surveillance System (CAPSS)?

CAPSS, the Child and Adolescent Psychiatry Surveillance System, was officially launched in April 2009 and is based within the College Centre for Quality Improvement (CCQI). CAPSS supports the epidemiological study of rare mental health disorders or events amongst children and adolescents across the United Kingdom (UK) and Ireland through a process of active surveillance.

What does the CAPSS do?

The CAPSS allows psychiatrists and researchers to find out how many children in the UK and Republic of Ireland (ROI) are affected by the particular disease or condition each year – this is called epidemiological surveillance. Doctors can also gather information about all the cases of a particular rare condition so that they can begin to understand what might have caused it and how to diagnose and treat the problem.

How does the CAPSS work?

CAPSS maintains a database of all Consultant Child and Adolescent Psychiatrists in the UK and the ROI. Using contact details from this database CAPSS administrative staff send out a CAPSS e-card to each consultant every month. The card lists the conditions currently being studied. If a consultant has seen a child affected by one of these rare disorder(s) or clinical event(s) under study over the last month, they tick a box on the card and return it to the CAPSS. 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 e-card is returned to report that a psychiatrist has not seen a case/event. This process is known as “active” surveillance. CAPSS researchers never contact families or young people and surveillance studies do not affect current treatment. The purpose is ONLY to collect information to learn more about the condition and improve treatment in the future.



Public Information Leaflet

Admissions Far Away from Home

Surveillance study of current practices for accessing inpatient care for young people

This leaflet provides information about a new study of access to inpatient care for adolescents with mental health difficulties, in England. It explains why this study is important and what we hope to show by doing it. It also provides contact details of the researchers undertaking the study and a link to the website where the results will be published.

What is the issue?

This research focuses on young people, aged 13-17 years, who require admission to hospital for psychiatric care. Some young people cannot access such care close to where they live. Many types of serious mental health conditions start during the teenage years. In the long term, young people with severe mental health problems are at risk of having poor mental and physical health as well as difficulties with holding down a job, social involvement and activities, and making and maintaining friendships and relationships. These poor outcomes may be more likely if their early experience of support from services is poor and disjointed. We want to understand and improve the experience of care for young people with such severe mental health problems that they need to be admitted to hospital.

What are the aims of this study?

This project aims to establish the extent of admissions to adolescent units at distance from home or to adult wards, in England.

How will the information be collected?

We will collect information about young people from the doctor looking after them. Doctors will not provide names and addresses to the study team, but they will provide details like NHS number, post code, gender, ethnic group and date of birth. They will complete questionnaires using information from medical records.

The smallest amount of personally identifiable information will be passed to CAPSS and the study team in order to eliminate duplicate cases and to establish distance between the young person's home and admission unit. Through the doctor who is caring for a specific child or young person providing information, such as the type of problem or how long they were in hospital, we hope to increase understanding about these types of admissions and start to look at how services could be improved.

The University of Nottingham is responsible for looking after the information and using it properly. We will keep all information about you safe and secure. We cannot withdraw or remove personal information from the study as this would make the research invalid. When the study finishes, personal information will be deleted or de-personalised. The University of Nottingham will securely store information for 7 years.

What are the possible risks and benefits?

The study will not have any negative effect on the care and treatment these young people are currently receiving as a result of the information being collected in this study. Information will not identify any individual and confidentiality will be maintained at all times. However, if you (as a young person or their parent/carer) wish to opt out or object or dissent to the use of your information for this purpose, please let your Consultant know. Further information or to register any objections to the use of your data can be found on the National Data Opt-Out website (<https://digital.nhs.uk/services/national-data-opt-out>).

The study will provide an understanding, at a national level, of how many young people experience these different types of inpatient care, and how this could be improved. The study will help us to assess the impacts of admission far away from home and make recommendations on how best to improve access to local inpatient services.

Where is this study happening?

The study will be taking place across England.

How long will the study go on for?

The initial study will last for one year. We will then collect follow-up data from the doctor about what happens to the cases they report, for a further 6 months.

Who is funding this study?

This study is funded by the National Institute for Health Research Applied Research Collaboration East Midlands (NIHR ARC-EM).

Who to contact if you have any questions:

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For further information

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Child and Adolescent Psychiatry Surveillance System

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