

**Establishing a national surveillance system for rare Child & Adolescent
psychiatric disorders
12 month report – April 2008**

Established: May 2007

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Members:

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Remit and Aims:

To explore opportunities for the surveillance of rare psychiatric disorders and events.

The project has three stages:

1. Develop a national child and adolescent psychiatric surveillance system (CAPSS) based on the British Paediatric Surveillance Unit (BPSU) model.
2. Undertake surveillance of conditions already identified as suitable for this surveillance methodology e.g. conversion disorder, PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections), early onset psychosis, gender identity disorder.
3. Explore models for operating CAPSS as a) a partner to the BPSU b) as an independent system with potential for international research collaboration or c) a pilot for a Life Course Epidemiology System encompassing psychiatrists across the age range.

Current Status & Future Plans:

1. *CRG composition:* New members have joined the group, including representatives from the Child and Adolescent Psychiatry Faculty executive. The formation of an executive committee to oversee CAPSS (and ultimately

- supercede the CRG) is underway. User and carer involvement will be through a] the executive committee running CAPSS and b] input into individual studies. The structures developed by Young Minds will be used as a template to consider how best to utilise young people's input.
2. *Meetings*: Six meetings of the CRG and one stakeholder meeting have been held to date. A second stakeholder event aimed primarily at child and adolescent psychiatrists is being considered in tangent with the CAP Annual Residential meeting.
 3. *CAPSS development*: A business case for CAPSS has been developed in conjunction with the Royal College of Psychiatrists, precipitated by a request for access to membership data. Possible funding sources are being explored. Our objective is for CAPSS to be hosted within the RCPsych or its Research and Training Unit. Funding to develop a website and newsletter to communicate with Child and Adolescent psychiatrists (£4,500) has been secured from the CAP Faculty.
 4. *Studies to run on CAPSS*: The second study to run on the joint CAPSS/BPSU system, **Conversion Disorder** in children and adolescents, has passed the BPSU submission process and has also been successful in its bid for funding (£57,000 – BUPA). It has been provisionally adopted by the MHRN. A study of **Bipolar Disorder** in under 18s is in development. This will be the first study to run independent of the BPSU and the funding application will therefore include substantial CAPSS development costs as well as funding for user and carer involvement. A number of other conditions for study have been identified, and advice on CAMHS priority areas continue to be sought.