Minutes of the meeting of the Precedent Set Sub Committees of the Confidentiality Advisory Group

Reported October 2015

Reviewers:

Name	Capacity	Items
Dr Mark Taylor	Chair	1a
Dr Murat Soncul		1a
Professor Barry Evans		1a

1. NEW PRECEDENT SET REVIEW APPLICATIONS – RESEARCH

a) CATCHuS: Children with ADHD in transition to adult services -15/CAG/0184

This application from University of Exeter Medical School set out the purpose of utilising the BPSU surveillance methodology and Child and Adolescent Psychiatry Surveillance Service (CAPSS) to focus on young people with Attention Deficit Hyperactivity Disorder (ADHD) when they are too old to stay with children's services. Existing work suggests that Young People with 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.

This project has two main streams of research. A six months surveillance study of Young People with ADHD on medication that are within six months of the age boundary for discharge from their children's service with a nine month follow-up to find out where these Young People were transferred to. The surveillance element of the study will run in parallel through the Child and Adolescent Psychiatry Surveillance Service (CAPSS) and the British Paediatric Surveillance Unit (BPSU). Each month these units will mail a tick box response card to all consultant paediatricians and child psychiatrists in the UK and ROI. Consultants will report whether, within the last month, they have seen a young person who needs ongoing medication for ADHD and is within six months of the age boundary for their service. Reporting clinicians will be sent a baseline questionnaire to confirm the eligibility of the case, collect details about current treatment and comorbidity and collect minimal identifier details to allow linkage to follow up reports. Additionally, researchers will ask for contact details of the adult service to whom they referred, ask them to evaluate the different aspects of an optimal transition and whether they are willing to be interviewed. After nine months, a follow-up questionnaire will be sent to each reporting clinician for each reported case to establish if the young person was successfully referred to adult services.

The other elements of the study do not require s251 support as they do not involve the use of clinical data without consent. Five Trusts will act as recruitment centres. Practitioners from these recruitment sites will scan their patient database for eligible young people. The research nurses enrolling participants will only be informed about and approach individuals who have indicated via a discussion with their clinician that they would be happy to have a conversation with a research nurse about the study. The research team will then conduct interviews with Young People and health care professionals to explore their views and experiences of the transition between children's and adult services. Finally the study will map services available for young adults with ADHD.

A recommendation for class 5 and 6 support was requested to cover access for auditing, monitoring and analysing patient care and treatment and to allow access to an authorised user for one or more of the above purposes.

Confidential patient information requested

Access was requested to NHS number, Hospital number, first four digits of the postcode, gender, age in years, ethnicity.

Confidentiality Advisory Group advice

Public interest

Members agreed that this study was in the public interest with benefits to areas where there could be service improvement.

Practicable alternatives

Members considered whether a practicable alternative to the disclosure of patient identifiable data without consent existed, taking into account the cost and technology available in line with Section 251 (4) of the NHS Act 2006.

- Feasibility of consent

It was noted that this study was aiming at high ascertainment levels and uses a methodology where doctors complete a monthly questionnaire on patients with a variety of different conditions they have seen in the previous month, and complete the questionnaire when the patients are not present. Members agreed that to complete the questionnaire postcard at each consultation when the patient is present would not be practical, and would result in poor levels of reporting. Clinicians will seek consent from those invited to interview.

Additional points

Members noted that the application did not provide a project web site address and that the consent forms for the interview study did not mention or explain the surveillance study. It was noted that the Royal College Paediatrics and Child Health (RCPCH) had very informative web pages about BPSU, including lists with links to current and past studies on the reporting card, a note on confidentiality and security, and a leaflet designed for researchers to give to patients and the public. However this had not been mentioned in the application as a potential area for patient/public notification. Similarly there did not seem to be any patient notification on the BPSU website. Members agreed that more could be done by the applicant to notify patients and the public about the study.

Confidentiality Advisory Group advice conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met and that there was a public interest in projects of this nature being conducted, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.