

CHILDREN AND ADOLESCENTS WITH ADHD IN TRANSITION BETWEEN CHILDREN'S SERVICES AND ADULT SERVICES (CATCH-uS)

(Short Study Name: ADHD Transition Between Children's & Adult Services)

Abstract

This project focuses on what happens to young people with Attention Deficit Hyperactivity Disorder (ADHD) when they are too old to stay with children's services. We know little about how many areas have specialist services for adults with ADHD and how many young people need to move to them when they are too old for children's services. Until the late 20th century, ADHD was a controversial diagnosis. Once generally accepted, it is seen as a developmental disorder of children, and so mental health services for adults are not set up to manage young adults who have ADHD and continue to want support to cope with their lives.

There are National Institute for Health and Care Excellence (NICE) guidelines about the management for ADHD in adulthood, and this often involves taking medication that General Practitioners feel inexperienced to prescribe without support from specialists, as happens with children. Existing work suggests that young people with developmental disorders like ADHD are particularly likely not to transfer to adult mental health services, there has yet to be an in depth study of this issue in the UK. This will be the first national study to examine how many young people are in need of services for ADHD as adults. We will also explore how current service users and service providers experience this transition.

This project consists of 3 streams: 1) a 13 month surveillance study of young people with ADHD; 2) a qualitative study to explore the views and experiences of service users; 3) a mapping study that will combine information about the location of services from the surveillance and interviews with email/postal surveys of service commissioners, providers and key service user groups.

Principal Investigator

Professor Tamsin Ford, Professor of Child and Adolescent Psychiatry
University of Exeter Medical School, South Cloisters, St Luke's Campus, Exeter EX1 2LU
Tel: 0139 272 2973 **Email:** t.j.ford@exeter.ac.uk

Co-investigators

Astrid Janssens, Cornelius Ani, Philip Asherson, Kapil Sayal, Moli Paul, Chris Hollis, Bryony Beresford, Susan Young, Tamsin Newlove-Delgado, Stuart Logan, Tracy Elliot (Cerebra, Charity), Catherine Shotton (Parent of a child with ADHD)

Website

www.rcpch.ac.uk/bpsu/adhd

Background

Transition aims to support a young person into a new life stage and extends beyond the simple transfer of clinical responsibility and clinic appointments.¹ It is a multidimensional process that continues into adult care marked by joint responsibilities and multidisciplinary working.² Optimum transition is characterised by planning, information transfer across teams, joint working between teams and continuity of care following the transfer of service provision.³ Poor transition may result in young people with on-going needs disengaging from services,^{4,5} and worsen their longer-term outcomes.⁶

Once considered to be a condition restricted to childhood, there is clear evidence that ADHD persists into adulthood for many young people.⁷ Recent NICE treatment guidelines have recognised the importance of ADHD in adults, which formalises its status as a long-term condition.⁸ While ADHD is relatively common within children's services, mental health services were never configured to work with adults with ADHD. Many adult mental health practitioners lack experience and training in its management and still have negative and sceptical attitudes towards adult ADHD as a condition that warrants intervention.⁹⁻¹² Community paediatricians and child psychiatrists describe massive attrition in attendance at school leaving age, so that relatively few are referred onto adult services, where these exist. Previous studies revealed patchy transitional care provision¹³ and identified barriers to good transition such as a lack of clarity on service availability and the operation of different eligibility criteria between child and adult mental health services, with variable service provision for young people with ADHD.¹⁴ In many areas, this is compounded by a lack of services for onward referral.^{5, 15, 16}

Coverage	United Kingdom and the Republic of Ireland
Duration	November 2015 to November 2016 (13 months of surveillance), with a 9 month follow-up.
Research Questions	<ul style="list-style-type: none"> ▪ To estimate the range and mean age for transition to adult services and variation within this across the UK and Republic of Ireland for CAMHS. ▪ To estimate the incidence rate of young people with ADHD who require ongoing medication for ADHD after they pass the age-boundary for the service that they attend and variation within this across the UK and Republic of Ireland ▪ To describe what services are offered to young people going through this age-boundary ▪ To estimate the proportion of young people with ADHD judged in need of transition who successfully transfer to a specialist adult health service, defined as an accepted referral to adult services within the time frame of the current study
Case definition	<ul style="list-style-type: none"> ▪ Young person with a clinical diagnosis of ADHD who is reviewed for the first time when within 6 months of reaching the services' age boundary, whatever this may be. Young people should only be reported once and those that have already been seen and reported in this time-scale should not be reported a second time. ▪ The young person is considered to require continued drug treatment for their symptoms of ADHD after crossing the service age boundary. ▪ The young person should not have been reported previously to the BPSU in relation to the current study. ▪ Young people with ADHD and comorbid diagnoses, including learning / developmental disabilities, should be reported only if it is their ADHD for which on-going drug treatment in adult services is required. <p>Exclusion criteria:</p> <ul style="list-style-type: none"> ▪ Young people with a past / current history of ADHD but who do not require medication for their ADHD. ▪ Young people with past / current ADHD who are not currently taking medication for their ADHD. ▪ Young people with past / current ADHD who require transition to adult mental health services in relation to comorbid difficulties, but not require, or take current drug treatment for their ADHD ▪ Young people who have been reported previously to the BPSU in relation to the current study. ▪ Young people who transition from paediatric services to <u>CAMHS</u>.
Reporting instructions	Please report any young person with ADHD taking medication for ADHD seen by you for the first time in the 6 months preceding the young person reaching your service's age boundary. Please report any case even if you believe the case may have been reported from elsewhere.
Methods	<p>Stream 1: A 13 month surveillance study using BPSU and Child and Adolescent Psychiatry Surveillance System (CAPSS) of young people with ADHD on medication who are within 6 months of the age-boundary for discharge from their children's service. A 9 month-follows-up to will then take place to find out further about the process of transfer and their care pathway.</p> <p>For more detailed explanation of the methodology for Stream 2-3, please contact the research team.</p>
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Ethics approval	This study has been approved by NRES South Yorkshire Research Ethics Committee – Yorkshire & The Humber - (REC reference: 15/YH/0426) and has been granted Section 251 HRA-CAG permission (CAG Reference: 15/CAG/0184).
Support group	UK ADHD Network (UKAAN) and Adult Attention Deficit Disorder UK (AADD-UK)

For further information about the study, please contact:

Professor Tamsin Ford, University of Exeter Medical School, South Cloisters, St Luke's Campus, Exeter EX1 2LU
Email: t.j.ford@exeter.ac.uk **Tel:** 0139 272 2973

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