

CATCh-uS ADHD in transition study: Understanding mental health services provided to young people with ADHD in the UK and Ireland as they move from childhood to adulthood

Submission date 17/09/2019	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered
		<input type="checkbox"/> Protocol
Registration date 03/02/2020	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan
		<input checked="" type="checkbox"/> Results
Last Edited 28/03/2023	Condition category Mental and Behavioural Disorders	<input type="checkbox"/> Individual participant data

Plain English summary of protocol

Background and study aims

Attention deficit hyperactivity disorder (ADHD) is a behavioural disorder that includes symptoms such as inattentiveness, hyperactivity and impulsiveness. ADHD was previously seen as a childhood developmental disorder, which meant that adult mental health services have not been set up to support ADHD patients who become too old for child services. This is the first in-depth study of the transition of ADHD patients from child to adult health services in the UK. It aims to investigate how many young people who have received services for ADHD as a child are in need of services as an adult, what services are available for young adults with ADHD and how people with ADHD, their parents/carers and healthcare professionals experience their transition from child to adult services.

Who can participate?

Paediatricians (doctors specialised in treating children), psychiatrists (mental health doctors) specialising in treating children and young people, young people with ADHD, parents/carers of young people with ADHD and GPs and other healthcare professionals who come into contact with young people with ADHD.

What does the study involve?

There were three parts to the study. In the first part, consultant paediatricians and child and adolescent psychiatrists provided information on the numbers of young people with ADHD who were around the age where they would need to move from child to adult services and where their care moved from and to. The mapping study aimed to create a map of services for young people with ADHD. This involved an online survey to people with ADHD and healthcare professionals, as well as Freedom of Information requests to service providers and

commissioners. The third part was to find out people's experiences of moving from child to adults services for ADHD. This involved interviews with people with ADHD, parents/carers and healthcare professionals.

What are the possible benefits and risks of participating?

This study observed and described transition. It did not change the health service provision so it did not affect the services that people would normally have received. Participants gave their time, and there was a possible risk of distress by thinking and talking about difficult experiences or worries about the future. However most participants from all backgrounds had a story that they wished to tell and thought it important to share.

Where is the study run from?

University of Exeter Medical School (UK)

When is the study starting and how long is it expected to run for?

November 2015 to August 2019

Who is funding the study?

The National Institute for Health Research (UK)

Who is the main contact?

Tamsin Ford, catchus@exeter.ac.uk

Study website

<http://medicine.exeter.ac.uk/catchus/>

Contact information

Type(s)

Public

Contact name

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Scientific

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Additional identifiers

EudraCT/CTIS number

Nil known

IRAS number

159209

ClinicalTrials.gov number

Nil known

Secondary identifying numbers

IRAS 159209

Study information

Scientific Title

Children with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services: a mixed methods project using national surveillance, qualitative and mapping studies

Acronym

CATCh-uS

Study objectives

This research focuses on young people diagnosed with ADHD in transition from children's services to adult services and aims to identify the current perceived need for transfer of young people with ADHD into adult services, to ascertain these services' utility and to map the current provision.

To address these goals, the study has the following objectives:

1. To identify how many young people with ADHD with an ongoing need for medication need a transfer to adult services and to describe this population across the UK and the Republic of Ireland (ROI)
2. To identify factors influencing service use and to identify factors leading to a transition

success/failure

3. To map the services that are currently available for young people with ADHD in transition from childhood to adulthood and summarise what they provide

Ethics approval required

Old ethics approval format

Ethics approval(s)

1. Approved 20/10/2015, NRES Committee Yorkshire & The Humber – South Yorkshire (Unit 001, Jarrow Business Centre, Rolling Mill Road, Jarrow, Tyne and Wear, NE32 3DT; +44 (0)207 104 8091; nrescommittee.yorkandhumber-southyorks@nhs.net), ref: 15/YH/0426
2. Approved 03/11/2015, HRA CAG (Skipton House, 80 London Road, London, SE1 6LH; +44 (0) 207 972 2545; HRA.CAG@nhs.net), ref: 15/CAG/0184
3. Approved, University of Exeter College of Medicine and Health ethics committee (c/o Chair Ruth Garside, European Centre for Environment and Human Health, University of Exeter Medical School, Knowledge Spa, Royal Cornwall Hospital, Truro, Cornwall, TR1 3HD), ref: 15/07/070

Study design

Observational

Primary study design

Observational

Secondary study design

Surveillance study, cross-sectional study and qualitative analysis

Study setting(s)

Other

Study type(s)

Other

Participant information sheet

Separate information sheets for each study are available via NIHR and catchus@exeter.ac.uk

Health condition(s) or problem(s) studied

Attention deficit hyperactivity disorder

Interventions

Level of need: Surveillance Study and electronic case note survey

To assess ongoing service needs, we collected surveillance data via the Child and Adolescent Psychiatry Surveillance System (CAPSS) and the British Paediatric Surveillance Unit (BPSU). Over a period of 12 months, consultant paediatricians and child psychiatrists reported ADHD patients who were prescribed ADHD medication, were within 6 months of the upper age boundary of their service and who would require ongoing services for their medication management. Young people with ADHD and comorbid diagnoses, including learning/developmental disabilities, were reported only if it was their ADHD that required ongoing drug treatment. Young people were excluded from the study if they had a diagnosis of ADHD but did not require medication or were unwilling to take it, they required transition to an adult service only for a psychiatric comorbid condition, or they had already been notified to the study.

Those who reported a case were sent a baseline notification survey to collect details of patient

treatment and planned transition. After 9 months, a follow-up questionnaire was sent to the reporting clinician to confirm the outcome and details of the transition. To triangulate the data, we also undertook a Clinical Notes Review at one Health Trust which enabled us to compare the total number of cases reported as eligible for transition and the details of transition.

Mapping Study

The mapping study was designed to identify and locate adult health services for patients with ADHD. By making the map available publicly it was also designed to optimise service provision. An online survey distributed via organisational email lists and social media collected data from patients and health professionals. Freedom of information (FOI) requests (based on the same questions as the online survey) were also sent to commissioners and service providers. Responses were displayed and analysed by informant group and location using mapping software. Services were categorised into four groups: dedicated ADHD NHS services, generic NHS services where respondents had experienced care for ADHD, NHS Child Services or Non-NHS services where respondents had received care for ADHD, and ADHD services identified but no respondent reported experience of ADHD care from them.

Utility of services

Semi-structured interviews were conducted with seven stakeholder groups to gather a better understanding of the transition process for ADHD patients. These groups were patients pre-transition, patients post-transition, patients who did not transition but returned to adult services, parents of children with ADHD (some of whom were pre-transition, some post transition and some who did not transition), paediatricians and child psychiatrists, health professionals working in adult mental health services, and GPs. The first four groups were recruited via clinical research nurses, the other groups were recruited from the surveillance and mapping studies, with some GPs also recruited via Twitter or through a snowball method. Data from each stakeholder group were analysed separately using a Framework Analysis approach and then compared to look for consensus and differences in views and experiences of transition.

Intervention Type

Other

Primary outcome measure

Surveillance study:

1. Need for transition quantified as the rate per 100,000 17- to 19-year-olds

Secondary outcome measures

Surveillance study:

1. Successful transition quantified as the rate of attendance at at least one appointment by 9-month follow up per 100,1000 17- to 19-year-olds
2. Quality of transition assessed using a questionnaire baseline and 9 months later

Mapping:

3. Reports of services for adults with ADHD (known about and experience of) assessed via bespoke online questionnaire at a single timepoint per participant

Qualitative survey:

4. Optimal transition assessed using semi-structured interviews at a single timepoint per participant using a topic guide to ensure all salient areas were covered

Overall study start date

01/11/2015

Completion date

31/08/2019

Eligibility

Key inclusion criteria

For the surveillance study:

1. Consultant child and adolescent psychiatrists and paediatricians registered with the BPSU and CAPSS

For the mapping study:

2. Practitioners (child and adult services) working with young people with ADHD
3. Mental health service commissioners
4. Patients with ADHD
5. Carers of young people with ADHD

For the qualitative study:

6. Healthcare professionals working in secondary healthcare for children or adult mental health services, i.e. those working in child mental health, adult mental health, paediatrics or primary care who had experience of working with young people who had ADHD and required ongoing services into adulthood and therefore transition
7. General practitioners (GPs)
7. Parents of children with ADHD
8. Young people with ADHD pre-transition, i.e. aged 14 to 16 years and attending CAMHS
9. Young people with ADHD post-transition, i.e. aged 18 or over and transitioned straight from children's services without a break in service
10. Young people with ADHD who dropped out of CAMHS and re-engaged with adult mental health services, i.e. aged 18 years or over and had re-entered services with a gap in service contact for at least 1 year

Participant type(s)

Mixed

Age group

Mixed

Lower age limit

18 Years

Sex

Both

Target number of participants

No targets as not appropriate to the methods

Key exclusion criteria

For the surveillance study:

1. Patients not willing or able to take medication for ADHD

For the qualitative study:

2. Potential participants who the managing clinician thought it inappropriate for the research nurse to make contact with because of clinical severity, safeguarding or risk to others

Date of first enrolment

01/12/2015

Date of final enrolment

31/05/2019

Locations

Countries of recruitment

England

Ireland

United Kingdom

Study participating centre

University of Exeter Medical School

St Luke's Campus

Heavitree Road

Exeter

United Kingdom

EX1 2LU

Study participating centre

Devon Partnership Trust

Wonford House Hospital

Exeter

United Kingdom

EX2 5AF

Study participating centre

Kings College London, Institute of Psychiatry, Psychology and Neuroscience

De Crespigny Park

London

United Kingdom

SE5 8AF

Study participating centre

Coventry & Warwickshire Partnership NHS Trust
Wayside House Wilsons Lane
Coventry
United Kingdom
CV6 6NY

Study participating centre
Berkshire Healthcare Foundation NHS Trust
Fitzwilliam House, Skimped Hill Lane
Bracknell
United Kingdom
RG12 1JX

Study participating centre
Nottinghamshire Healthcare NHS Trust;
Duncan Macmillan House Porchester Road
Nottingham
United Kingdom
NG3 6AA

Sponsor information

Organisation
University of Exeter Research Ethics and Governance

Sponsor details
Research Ethics and Governance Office
University of Exeter
Lafrowda House
St Germans Road
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01392 726621
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Sponsor type
University/education

Website
<https://www.exeter.ac.uk/cgr/researchethics/>

Funder(s)

Funder type

Government

Funder Name

National Institute for Health Research

Alternative Name(s)

National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type

Government organisation

Funding Body Subtype

National government

Location

United Kingdom

Results and Publications

Publication and dissemination plan

Throughout this programme of research, we have disseminated our findings via regional, national and international conferences and social media. One of our most impactful outputs is the map of mental health services for adults with ADHD. There were high levels of interest in the map, with over 30,000 views on our website in 12 months and 44,000 impressions on Twitter in 2018. The map was also used by the Exploring Diagnosis research project to send information leaflets to relevant services. UKAAN have agreed to host and keep the map updated and so, as a legacy of the research, it will be available on their website: <https://www.ukaan.org/adult-adhd-service-map>

As of September 2019, several articles are already published. The NIHR report will be published in 2020 and further papers are in preparation.

Intention to publish date

31/12/2020

Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study will be available upon request from Tamsin Ford at the following email address: catchus@exeter.ac.uk. The qualitative data contain potentially identifiable data despite redactions, and likewise the surveillance data, given the size of the dataset, may also identify individuals. We are happy to share on a named individual basis. The map is now hosted by UK-AAN who will be keeping it updated: <https://www.ukaan.org/adult-adhd-service-map-overview>.

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Other publications	comparison of surveillance and case note review methods	20/08/2019	18/09/2019	Yes	No
Results article	mapping study results	01/12/2019	18/09/2019	Yes	No
Results article	surveillance study results	01/11/2020	18/09/2019	Yes	No
Results article		01/11/2020	28/03/2023	Yes	No
HRA research summary			28/06/2023	No	No