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CHILD AND ADOLESCENT
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ADHD and the issues of service transition

CAPSS 15 year anniversary symposium

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University of Exeter (on behalf of the CATCh-uS team)



University
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Child to adult service transition is important to manage well



- Young adulthood is a time of new experiences and development, but also of risk:
 - Onset of new mental health conditions
 - Risk taking behaviours and experimentation
 - Increasing expectations to become involved in decision making and self management
 - Multiple simultaneous transitions

Transition



“A **purposeful, planned process** that addresses the **medical, psychosocial and educational / vocational needs** of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems”

National Service Framework (NSF) for Children, Young People and Maternity Services

NICE Guidance



Transition NG43 2016

- **Involvement**
- **Developmentally appropriate & strengths-based** support
- Responsibility of **both** child and adult services
- **Planning** early
- Support **before, during and after** transition
- ‘Elements of transition’: planning meeting, handover period, transition worker

ADHD NG87 updated 2019

- **Regular contact** & structured support (specialist?)
- **Medication** if required
- **Shared care protocols** with primary care “if required”
- **Reassessment** and **information transfer** stressed in relation to transition

Why study transition in ADHD?



Features of ADHD can make the transition between services harder to manage



Historically seen as a condition of childhood – with services configured accordingly



Lack of a national estimate of those needing to transition to adult services



Young people with ADHD less likely to make the transition, with high rates of medication cessation from 16 to 18



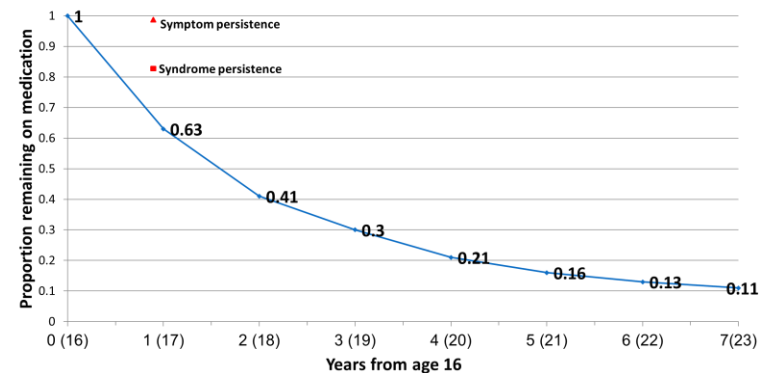
BJPsych The British Journal of Psychiatry (2010)
197, 305-312. doi: 10.1192/bjp.bp.109.075135

Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study

Swaran P. Singh, Moli Paul, Tamsin Ford, Tami Kramer, Tim Weaver, Susan McLaren, Kimberly Hovish, Zobia Islam, Ruth Belling and Sarah White

Singh SP, Paul M, Ford T, et al. Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study. British Journal of Psychiatry. 2010;197(4):305-312. doi:10.1192/bjp.bp.109.075135

Kaplan Meier plot of probability of remaining on medication over time from age of 16



Newlove-Delgado T, Ford TJ, Hamilton W, Stein K, Ukoumunne OC. Prescribing of medication for attention deficit hyperactivity disorder among young people in the Clinical Practice Research Datalink 2005-2013: analysis of time to cessation. Eur Child Adolesc Psychiatry. 2018 Jan;27(1):29-35. doi: 10.1007/s00787-017-1011-1.

Children and young people with ADHD in transition from child to adult services (CATCh-uS)



Disclosure



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- Health Services and Delivery Research Programme (HS&DR) (Ref: HS&DR - 14/21/52)
- This talk presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

The CATCh-uS team



Principal Investigator:

Tamsin Ford

Project manager:

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Researchers:

Helen Eke & Anna Price

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Anna Stimson

Cornelius Ani - Imperial College
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Chris Hollis - University of Nottingham
Bryony Beresford - University of York

Susan Young - Imperial College
Tamsin Newlove-Delgado - Exeter
Stuart Logan - Exeter
Tracy Elliot - Cerebra
Catherine Shotton - Parent



Research questions

How many young people need ongoing support for their ADHD once too old for children's services?

Surveillance study

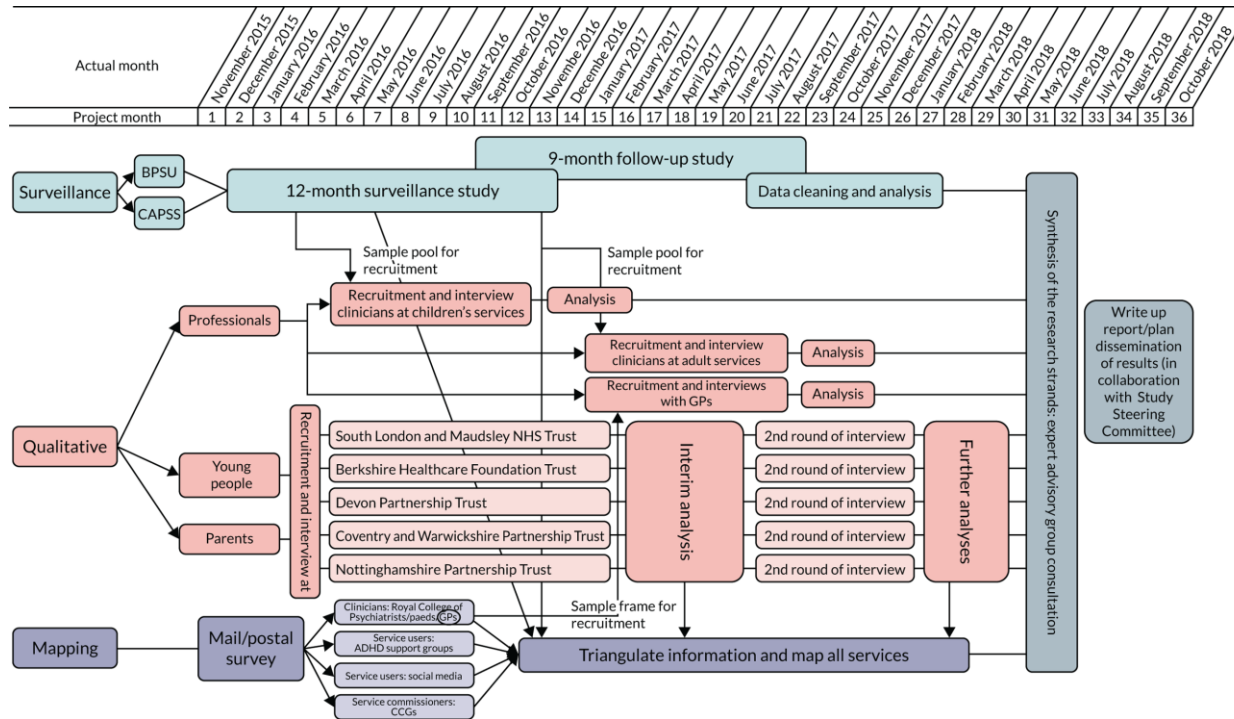
How do YP, their families and the professionals working with them experience the transition?

Qualitative study

How many and which areas have services for young adults with ADHD (what do they offer)?

Mapping study

Complex mixed methods design





Surveillance study

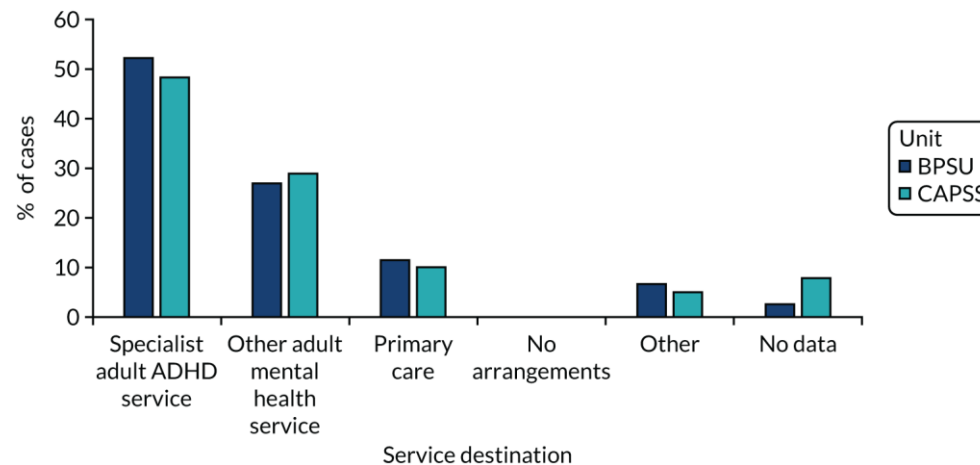
- Clinical diagnosis of ADHD
- Receiving medication treatment
- Requiring continuation of drug treatment
- Within 6 months of service age boundary
- First time reported to the study

Surveillance period (12 months) 2015-2016

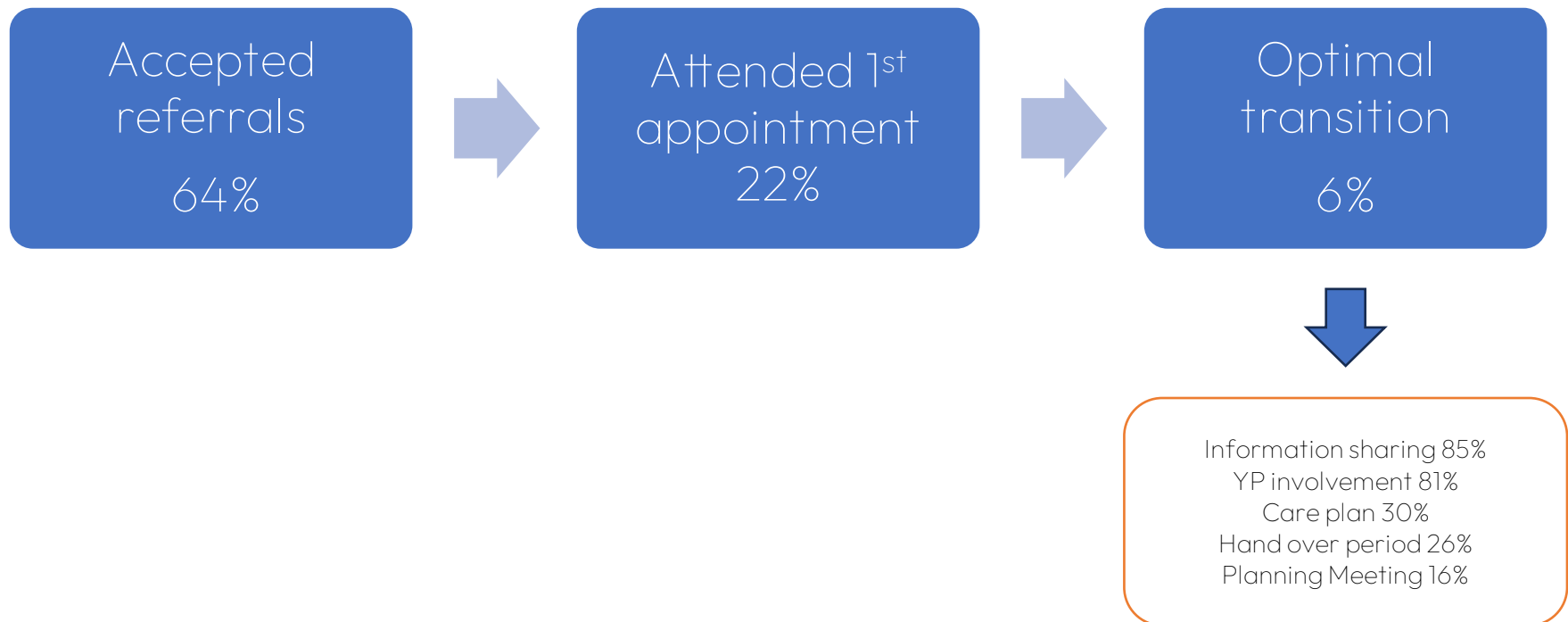
Follow-ups (9 months) 2016-2017



Destinations of young people on leaving child services



Outcomes of those referred to adult mental health services



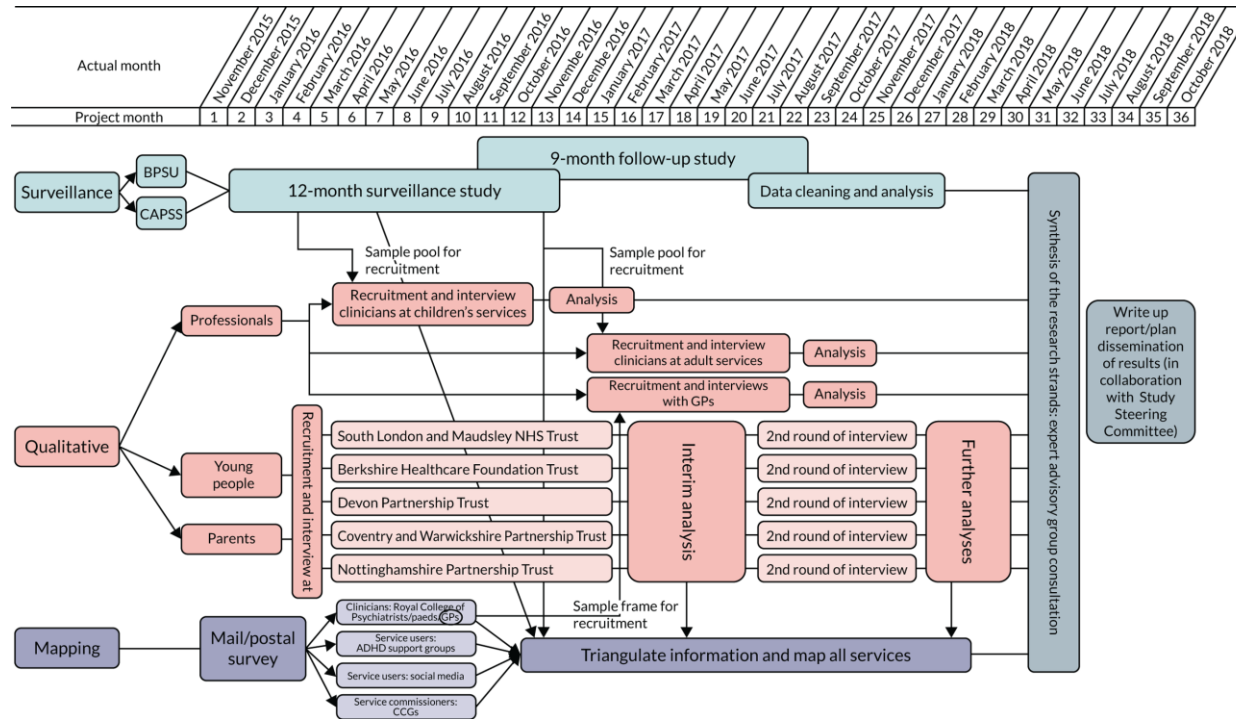
For those aged 17–19, incident rate (range adjusted for non-response) of transition need was 202–511 per 100 000 people aged 17–19 per year, with successful transition of 38–96 per 100 000 people aged 17–19 per year.

In an example CCG with a population of 318,000 and 10,800 17–19 year olds, this would translate to 20–60 young people per year

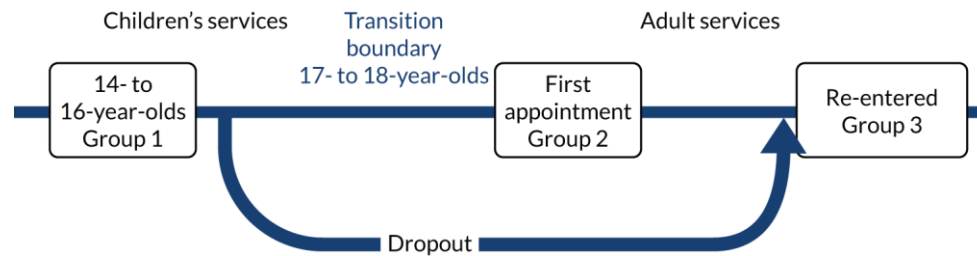
	Incidence rate
Observed incidence:	
Incidence: eligible for transition (all eligible individuals identified in 12 months) per 100 000 per year	$(315/116\ 651) \times 100\ 000 = 270.0$
Incidence: successful transition (referral made, accepted and first appointment attended) per 100 000 per year	$(55/116\ 651) \times 100\ 000 = 47.1$
Incidence: eligible for transition aged 17–19 (all eligible individuals aged 17–19 identified in 12 months) per 100 000 per year	$(269/116\ 651) \times 100\ 000 = 230.6$
Incidence: successful transition aged 17–19 (referral made, accepted and first appointment attended) per 100 000 per year	$(51/116\ 651) \times 100\ 000 = 43.7$
Correction for non-returned notification cards (no age known):	
Returned	73.7%
No response	26.3%
Assumption 1: observed incidence applies to half (13.2) of non-returned (26.3%) cards because clinicians are more likely to respond with cases to report	$(13.2 + 26.3)/73.7 = \text{coefficient } 0.54$
Assumption 2: observed incidence applies to all non-returned cards; assumes no difference in incidence between cases that were reported and not reported	$100/73.7 = 1.36$
Correction for non-returned baseline questionnaires (no age known):	
Returned	$377/614 = 61.4\%$
	$100/61.4 = \text{coefficient } 1.63$
Combined coefficients for individuals aged 17–19 only:	
Adjusted incidence rate 1 = incidence rate × correction for unreturned notification cards (assumption 1) × correction for unreturned baseline questionnaires	Eligible for transition: $230.6 \times 0.54 \times 1.63 = \mathbf{202.9}$
	Successful transition: $43.7 \times 0.54 \times 1.63 = \mathbf{38.5}$
Adjusted incidence rate 2 = incidence rate × correction for unreturned notification cards (assumption 2) × correction for unreturned baseline questionnaires	Eligible for transition: $230.6 \times 1.36 \times 1.63 = \mathbf{511.2}$
	Successful transition: $43.7 \times 1.36 \times 1.63 = \mathbf{96.9}$



Qualitative study



Recruitment of young people: 3 key groups



Pre-transition (14-16): ADHD = Medication = To fit in at school

I have not
thought about
ADHD when
growing up.

ADHD will calm
down over the
years

I have never met
an adult with
ADHD – I don't
know what the
future holds



Post-transition: it's a big jump

Change of level of support is dangerous: you might get off the rails

You need to know what you need and dare to ask for help. That's hard and I didn't know that was going to happen.

It wasn't too bad...

I didn't know what to expect – that was annoying and scary



Leaving and re-entering services: Drifting and disengaging Not always an active choice

It's just that I didn't feel that they were pressuring me enough to say with them. After I said I don't want to be with them they were like, 'Alright, fine. We can't really force you.'

The clinician didn't ask me why I stopped. If I knew what I know today then I would never have stopped...

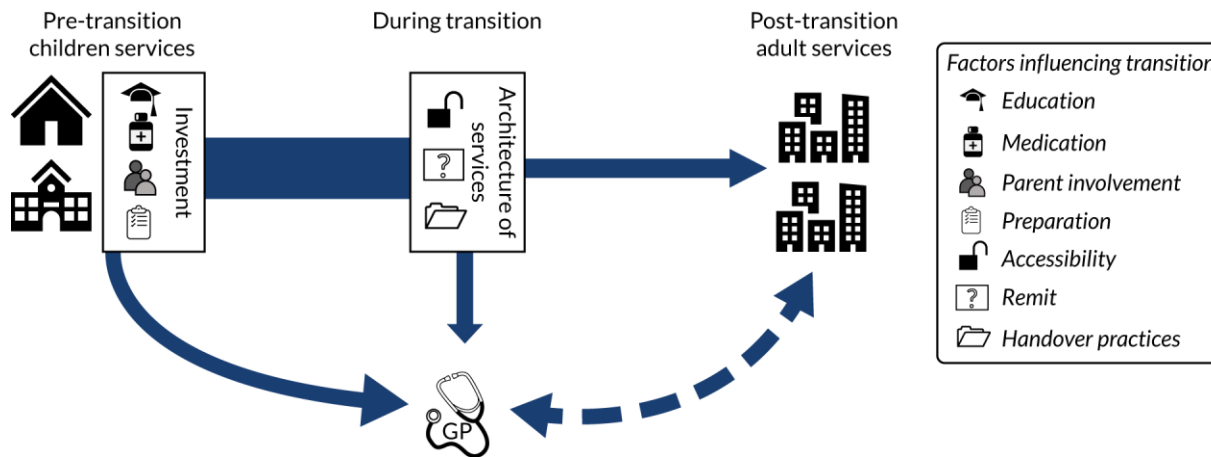
How to re-enter?



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of Exeter



The ADHD transition process as perceived by key stakeholders



Mapping study (2018)

Adult ADHD Service Map

Mapping UK mental health services for adults with ADHD : National survey with comparisons reporting between three stakeholder groups This paper has now been published... please click [here](#) to read the article

The map below, created as part of the University of Exeter **CATCH-uS** project, and funded by the **NHHR**, shows services for adults with ADHD in the UK. **Group A** shows dedicated NHS adult services, other adult NHS services (**Group B**) and private, voluntary and non-adult NHS services (**Group C**). Please enlarge this map for a clearer view and to filter which group, A, B or C is displayed.

[History of this project](#)
[Contact information](#)

Services Key:

Group A. NHS Dedicated Services for Adults with ADHD

- ADHD & ASD
- ADHD
- Neurodevelopmental

Group B. NHS Adult Services for adults with ADHD (not including dedicated services)

- 0-25 service
- ASD
- Drug & Alcohol
- Generic AMH
- Health & Social Care

Please note that we are unable to answer any general questions relating to services.

Hosted by UKAAN <https://www.ukaan.org/adult-adhd-service-map>

Summary

- Few of those who needed ongoing medication for their ADHD **successfully transferred** to adult services
- Only a **small proportion** of those who transferred experienced anything that approached optimal transitional care
- Variable provision of adult ADHD services – mapping process itself provided valuable learning
- Range of experiences, including smooth transition.
- Importance of **investment, service architecture** and **information**

Impacts and outcomes

BJPsych The British Journal of Psychiatry (2020)
217, 616-622. doi: 10.1192/bjp.2019.131



Transition between child and adult services for young people with attention-deficit hyperactivity disorder (ADHD): findings from a British national surveillance study

Helen Eke, Tamsin Ford, Tamsin Newlove-Delgado, Anna Price, Susan Young, Cornelius Ani, Kapil Sayal, Richard M. Lynn, Moll Paul and Astrid Janssens



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Medical School · CATCH-uS · ADHD stories

Research and ADHD stories

We have some informative and interesting videos about the research and advice about ADHD. To view these, click on the title below and press 'play' on the video. The research team would like to thank Mike Price for all his hard work in creating these videos.

- Video: The research
- Video: Key findings from our research
- Video: What would you have liked to know about ADHD when growing up?
- Video: What things do you think are important for others with ADHD to know?
- Video: What is it like to be an adult with ADHD?
- Video: What is your experience with stigma around medication?

Advice about transition from some re-engaged Young Adult ADHD patients



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NHS to launch cross-sector ADHD taskforce to boost care for patients in England

28 March 2024

Improvement Mental health

NHS England will launch a new attention deficit hyperactivity disorder (ADHD) taskforce alongside government to improve care for people living with the condition.

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 - Generic APH
 - Health & Social Care



Please note that we are unable to answer any general questions relating to services.

ADHD Foundation @ADHDFoundation · 21 Nov
Excellent work by Exeter University and ADHD Patient Services & Organisations in making ADHD services in the U.K. @Avalanssens @Anna_M_Price @UniofExeter

Anna Price @Anna_M_Price
1000+ responses to #catchusADHD mapping survey. People across UK talking about adult #ADHD services in their area HAVE YOUR SAY: bit.ly/2m7VXD0, share & retweet...

Chris RW @C_RWright · 20 Nov 2018
Replying to @PenCLAHRC, @Anna_M_Price and 2 others
Find me a better example of genuine public service through research. Thank you so much.

Poppy Ellis Logan @poppyellislogan · 19 Nov 2018
Cannot wait to get my hands on this - will it be ok to share with patients (eg those moving to different areas of UK or thinking of doing so?)

Anna Price @Anna_M_Price
Replying to @poppyellislogan

Absolutely! info provided to #catchusADHD by 2500+ patients, their families, health workers and commissioners early in 2018... about adult #ADHD services in UK...to be shared #catchusADHD @OfficialNIHR @ADHDFoundation @ukaanorg @UniofExeter



The CATCH-uS research study: Children and adolescents with ADHD in transition between children's services and adult services

The NIHR-funded CATCH-uS project explored what happens to young people needing ongoing management of their ADHD when they are too old for children's services. The aim was to provide information and insights for services to use to improve healthcare for young people with ADHD and, ultimately, to optimise their health and wellbeing.

The project included a surveillance study to examine how many young people with ADHD require ongoing medication in adult services (as defined by a clinician); a qualitative study with young people, parents and clinicians to explore their experiences of transition; and a mapping study to identify the services available across the country for adults with ADHD.

Why is this research important?

Up to 40% of young people with ADHD continue to have symptoms into adulthood that affect their functioning. Since 2008, NICE guidance has recommended that young people with ADHD who need continuing treatment after leaving child services should make a smooth transition into adult services. However, previous reports indicated that transition was often a disruptive experience, and suggested that many with ongoing ADHD health care needs did not make the transition to adult services at all, missing out on the treatment they needed. This is important as continued ADHD medication into early adulthood is associated with substantially reduced levels of suicidal behaviour (Chen et al., 2014), depression (Chang et al., 2016), substance misuse (Chang et al., 2014) road traffic accidents (Chang et al., 2017), convictions and violent reoffending (Lichtenstein et al., 2013).

Our findings: key points to consider when planning services

- Information**
 - Is there transparent and up-to-date information on the process of transition and the range of services (and their remit) commissioned for young people and adults with ADHD in your area?
 - Is this easily accessible to GPs, child and adult clinicians, young people and their families?
- Shared care**
 - Have GPs been involved in the development of transition and shared care protocols?
 - Are GPs appropriately involved in the transfer of care for their patients?
 - Do GPs have adequate advice for prescribing medication for prescribing adults?
- Service provision**
 - Does the service provision support transition and ADHD?
 - How flexible is the system to cater for individual needs?



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Thank you!

To everyone who took part, supported and funded this project: young people, parents, professionals, collaborators, co-investigators, organisations such as UKAAN, the team at BPSU and last but not least CAPSS
Happy 15th anniversary!



References and resources



- <https://www.exeter.ac.uk/research/projects/medicine/catchus/>
- Janssens A, Eke H, Price A, Newlove-Delgado T, Blake S, Ani C, et al. The transition from children's services to adult services for young people with attention deficit hyperactivity disorder: the CATCh-uS mixed-methods study. *Health Soc Care Deliv Res* 2020;8(42). <https://doi.org/10.3310/hsdr08420>
- Commissioner briefing: <https://arc-swp.nihr.ac.uk/uploads/attachments/Projects/CATCh-uS%20summary%20for%20commissioners.pdf>
- Eke H, Ford T, Newlove-Delgado T, Price A, Young S, Ani C, et al. Transition between child and adult services for young people with attention-deficit hyperactivity disorder (ADHD): findings from a British national surveillance study. *Br J Psychiatry* 2019:1-7.
- Price A, Janssens A, Newlove-Delgado T, et al. Mapping UK mental health services for adults with attention-deficit/hyperactivity disorder: national survey with comparison of reporting between three stakeholder groups. *BJPsych Open*. 2020;6(4):e76. doi:10.1192/bjo.2020.65
- <https://www.ukaan.org/adult-adhd-service-map>