

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

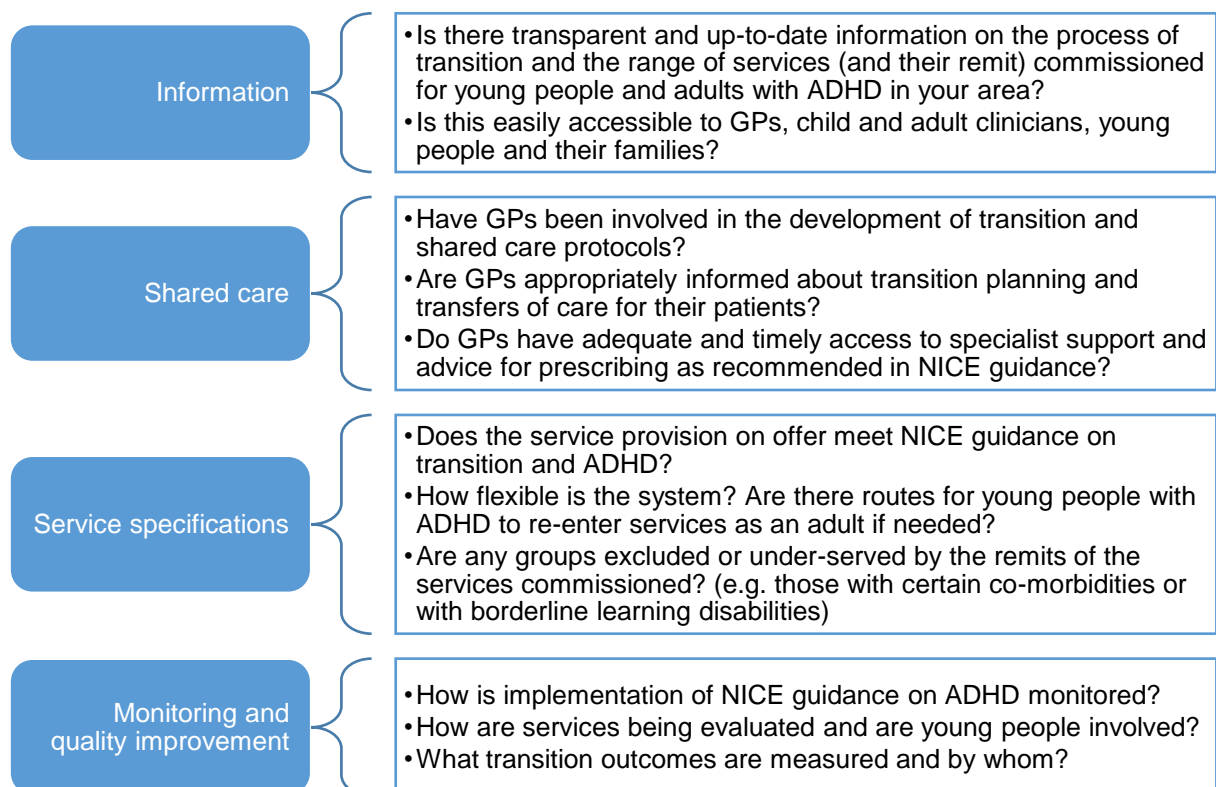
The NIHR-funded CATCh-uS project explored what happens to young people needing ongoing management of their ADHD when they are too old for children’s services. The aim was to provide information and insights for services to use to improve healthcare for young people with ADHD and, ultimately, to optimise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



Headline findings

The majority of young people with clinically-defined ongoing need do not make a transition to adult mental health services

- **At least 202-511 per 100,000 people aged 17-19 per year** required ongoing medication, which NICE recommendations suggest should be monitored by a specialist. This is likely to be an underestimate and excludes psychosocial interventions
- 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**
- Although **75%** of cases needing transfer were **referred** to adult services, of those fewer than **two-thirds were accepted**, and **only 22% eventually attended a first appointment**

Implementation of NICE guidance on transition was highly variable

- Only **6%** of cases we examined experienced '**optimal**' transition (defined as evidence of planning, information transfer, joint working and continuity of care)
- Barriers to 'optimal' transition included **poor communication** between services, **lack of documentation** of ongoing needs, and **lack of information** for clinicians and patients on what is 'on offer' locally, as well as a lack of adult services

Many young people experience difficulties gaining access to long-term adult ADHD care

- Many felt that adult ADHD services were less able to respond to their and their families' needs than children's services
- For different reasons, some young people left or lost contact with services whilst they still needed help, and experienced **barriers to returning to services**

Challenges for primary care

- GPs were often involved in transition '**by default**', instead of being included in a planned process, and **lacked information** on services to support their patients
- There were concerns over shared care prescribing arrangements for over-18s, and some GPs felt they were **not adequately involved or consulted** on protocols
- Some GPs perceived ADHD prescribing to be particularly high **risk**, and often felt unsupported to manage this risk
- There were also concerns about prescribing when **documentation** of diagnoses and recording of recent assessments by specialists was missing, unclear or incomplete

Availability of services for adults with ADHD

- Provision was **variable**; not all Trusts provided dedicated ADHD services for adults
- **Fewer than 30%** of identified dedicated services provided the **full range of NICE recommended treatments**
- More detail available on the [interactive map of services](#) created by the team and maintained by the UK Adult ADHD network.

More information

CATCh-uS project: <http://medicine.exeter.ac.uk/catchus/>

CATCh-uS interactive map of services: <https://www.ukaan.org/adult-adhd-service-map>

NICE Guidance on ADHD: <https://www.nice.org.uk/guidance/NG87>

NICE Guidance on Transition: <https://www.nice.org.uk/guidance/ng43>

Latest publication from surveillance study: [Eke et al. 2019, British Journal of Psychiatry](#)

Further questions or reference requests? Contact: t.newlove-delgado@exeter.ac.uk

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