

Case study on what best practice looks like: University Hospitals Birmingham NHS Foundation Trust

This case study has been initiated, organised and funded by Takeda UK Ltd. The case study summarises the results of a joint working project completed in 2020 between Takeda UK Ltd and the University Hospitals of Birmingham NHS Foundation Trust. Details of the joint working project can be accessed by following the link below: <https://www.takeda.com/en-gb/what-we-do/joint-working-partnerships/>

Executive Summary

- ADHD is a life-long condition which has been associated with other mental health comorbidities such as anxiety, depression, and risk of suicide
- Transitions services are important in supporting children and young people with ADHD as they become adults. But without a transitions service, there is a risk of some patients falling through the care gap and leading to poorer outcomes at such a crucial stage in life
- A robust transition pathway could address this issue by supporting patients to smoothly transfer from one service to another
- Evidence from existing services shows that demand outweighs capacity- although the Solihull team was comprised of paediatricians working with CYP and their families to provide transition support), the team was stretched thinly. As such, the service evaluation evidenced the addition of an ADHD Specialist Nurse would reduce RTT waiting time with the demand and capacity issues and help develop ADHD Care Pathways including transition
- The National Institute for Health and Care Excellence (NICE) Guideline [NG87] on ADHD provides a national standard of what the patient pathway should look like, comprising pharmacological and socio-psychological support and incorporating a bio-psychosocial model of care. With an effective, NICE-compliant, transitions service, backed by the necessary resources and funding, patients can be supported between services leading to improved patient outcomes and reduced service costs overall
- To understand how best to establish or improve an ADHD service, Takeda discussed with two Healthcare Professionals (HCPs) at the University Hospitals Birmingham NHS Foundation Trust ADHD service in Solihull to learn from their experience and demonstrate best practice for ADHD services in England

1) Introduction

The University Hospitals of Birmingham NHS Foundation Trust ADHD service in Solihull has a service which supports the transition of children and young people (CYP) with ADHD from paediatrics services into adult care. The service works with CYP and their families to prepare for transition, which includes psychological support and career advice, as well as personalised appointments with an ADHD Specialist Nurse.

As the service develops, it seeks to overcome its capacity and workforce constraints to remain compliant with NICE Guidelines.

Takeda held interviews with two healthcare professionals (HCPs) in Solihull, Dr Renu Jainer, a Consultant Community Paediatrician and Rebecca Wilkins, an ADHD Specialist Nurse, to gain a better understanding of the service and the challenges they faced. This case study presents the key points from these interviews.

2) Why should a transitions service be set up?

From our discussion with Ms Wilkins and Dr Jainer, we discovered that:

- **Without a transitions service, patients can get lost in the system.** When children are diagnosed with ADHD, their care will be provided by a child and young person service which is tailored to their needs as children, until they come to adult age. However, when they turn 18, care must be transitioned to Adult Services. It is at this point that a patient may drop out of care and get lost in between services. A transitions service addresses this

problem by helping patients to smoothly transition from one service to another and assists patients as they build a therapeutic relationship with new HCPs who will form part of their adult ADHD care

- **Implementing an effective transitions service could lead to improved quality of life in people with ADHD and savings across the wider healthcare system.** ADHD is a life-long condition which has been associated with comorbid mental health conditions such as anxiety and depressionⁱ and an increased risk of suicideⁱⁱ. The consequences of not treating ADHD adequately in childhood are well documented. Up to 75% of adults with undiagnosed or undertreated ADHD in childhood suffer with comorbid mental health conditions, a personality disorder, substance misuse or addiction problems and/or psychosocial problemsⁱⁱⁱ. However, effective treatment for ADHD, comprised of pharmacological and socio-psychological intervention, has been shown to produce reduced levels of depressive, disruptive and anxiety disorders, improved social and behavioural functions and lower levels of suicide.^{iv,v}

Good to know!
Schools and Colleges in Solihull have shown anecdotal evidence that an effective ADHD transitions service can result in fewer children being excluded



- If patients are kept in the system through a transitions service, however, a decision can be made to continue medication, or consider non-pharmacological treatment options to improve patients' Quality of Life

3) The importance of NICE Guidelines

"NICE guidelines are crucial to follow when setting up a service like this" - Rebecca Wilkins

NICE Guideline [NG87]^{vi} on ADHD provides a national standard of what the patient pathway should look like for patients who are diagnosed with ADHD who are transitioning between services. The key recommendations from the NICE guideline are as follows:


- **Before transition** - CYP should be reassessed at the school-leaving age to establish the need for continuing treatment into adulthood
- **During transition** - A meeting involving child and adolescent mental health services (CAMHS) and / or paediatrics and adult psychiatric services should take place if appropriate. Effort should also be made to involve families in the process
- **After transition** - HCPs from the adult service should carry out a comprehensive assessment of CYP diagnosed with ADHD
- **Decision making** - CYP should be involved during the transitions process to be a part of decision making and goal setting

Top Tip: As recommended in NICE Guidelines [NG43]^{vii}, a dedicated youth forum for young people to express their views on the service can help identify gaps in care and optimise the service

4) What are the challenges in setting up a service?

From our discussion with Ms Wilkins and Dr Jainer, the challenges they faced when setting up the Solihull service were that:

- **Demand outweighs capacity.** The Solihull team felt that the addition of an ADHD Specialist Nurse would assist with the demand and capacity issues often seen within ADHD Care Pathways. The employment of an ADHD Specialist Nurse has proved to add value in managing the increased demand and ensuring that care pathways are NICE compliant. The hope would be to increase the head count of ADHD Specialist Nurses to further



enhance the care given in Solihull to the ADHD population of approximately 2500 CYP. With additional roles the team would be able to:

- **Increase the number of school observations** – meaning the team would not just be reliant on observations from teachers (who are unlikely to have the clinical expertise) or clinician notes
- **Ensure that patients are seen in a timely manner** – previously, CYP were reviewed at six monthly intervals. Following the addition of ADHD Specialist Nurses, patients could be reviewed at three monthly intervals or earlier if there was an identified clinical need. As a result, patients with comorbid conditions their needs would be met earlier, as they are seen in a timelier manner
- **A more streamlined transitions service** – additional ADHD Specialist Nurses would ensure that CYP are transitioned successfully and compliant with national guidelines. Ensuring effective communication and information sharing between services

5) What does a good ADHD transition service look like?

The community paediatric service which includes ADHD service provision at the University Hospitals of Birmingham NHS Foundation Trust is staffed with three whole time equivalent (WTE) Consultant Community Paediatricians and one Speciality doctor, with one Consultant Paediatrician who has opted to take the lead on ADHD as it was the need of the service.

The addition of an ADHD Specialist Nurse has meant that CYP can be transitioned to Adult Mental Health Services (AMHS) following national guidelines. The addition of a further ADHD Specialist Nurses would help adherence to the transition care pathway, meaning that CYP can be fully supported with the transfer of care.

The additional roles would ensure that each CYP has the opportunity to meet with their specialist nurse and be actively involved in the process. A successful transition, in partnership with the CYP results in continued treatment, continuity of care and potentially identifying comorbid conditions early on that may require input from AMHS. The CYP would have more regular contact with their specialist nurse, which further develops the therapeutic relationship – enhanced when the CYP is seen at school or in an environment of their choice in which they are more comfortable.

With a dedicated team of ADHD specialist nurses, CYP with a diagnosis of ADHD can be appropriately observed in a school for a diagnosis to be made and follow-up care can be provided as clinically indicated. Additional capacity would also mean patients are seen more regularly which can help build the patient-nurse relationship to help personalise each patient's care. As more patients are diagnosed and case-loads increase, it is imperative that the right workforce is in place to ensure consistent care.

With the additional workforce, communication can improve with adult ADHD services so HCPs can meet face-to-face during the transition period more regularly. Collaboration and coordination between the two services can support the effective triaging of patients, preventing patients from falling through the system and improved outcome which has been a challenge and there are plans to address this issue.

6) Making the case for a transition service

Without an effective transition service in place, there is a risk of some CYP with a diagnosis of ADHD falling through the care gap between the services provided to CYP, and the care provided to adults. Even when a patient does not experience a gap in care, the transition from adolescent to adult care can be a challenging. The transitions service supports patients through that change and can improve patient outcomes, ultimately reducing long-term healthcare costs by increasing number of young people with ADHD in further education, training and employment.

ⁱ Nutt D, et al. (2007). *Evidence based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology*. J Psychopharmacol. Jan;21(1):10-41.

ⁱⁱ Septier M, et al. (2019). *Association between suicidal spectrum behaviours and Attention-Deficit/Hyperactivity Disorder: A systematic review and meta-analysis*. Neuroscience and Biobehavioral Reviews, 103.

ⁱⁱⁱ Kooij et al. (2012). *Distinguishing comorbidity and successful management of adult ADHD*. Journal of Attention Disorders. 16:5; Suppl, 3S-19S.



^{iv} Biederman J, et al. (2019). *Quantifying the Protective Effects of Stimulants on Functional Outcomes in Attention-Deficit/Hyperactivity Disorder: A Focus on Number Needed to Treat Statistic and Sex Effects*. *Journal of Adolescent Health*, Volume 65, Issue 6, 784 – 789.

^v Shaw M, et al. (2012). A systematic review and analysis of long-term outcomes in attention deficit hyperactivity disorder: effects of treatment and non-treatment. *BMC Med* 10, 99.

^{vi} NICE, *Attention deficit hyperactivity disorder: diagnosis and management*, 2018. Available at: <https://www.nice.org.uk/guidance/ng87>. Last accessed: June 2024.

^{vii} NICE, *Transition from children's to adults' services for young people using health or social care services*, Available at: <https://www.nice.org.uk/guidance/ng43>. Last accessed: June 2024.

Date of Preparation: April 2026
Job Code: C-ANPROM/GB/NS/2263