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Mental Health, Education and Training Services

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Investigating adult ADHD services in England

An audit of ADHD service provision for adults in England

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Foreword

The scientific evidence showing the lifetime impact of unidentified, undiagnosed and untreated ADHD is unequivocal. Equally, the social and economic impact of treating ADHD and the real cost savings that can be achieved if appropriately managed and treated, have also been proven.

In light of this, it is now more pressing than ever that we need an effective and broad reaching public health campaign that specifically focuses on ADHD – to draw awareness to the condition and provide clear self-care strategies for those who have ADHD.

Alongside this, we also need effective healthcare system mechanisms so that the evidence on the broader implications for physical and mental health risks associated with ADHD is disseminated to all those involved with designing and delivering services to diagnose, treat and manage people with ADHD. This includes primary care physicians, nurses and commissioning bodies and will help to ensure the implementation of the National Institute for Health and Care Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN) guidelines for ADHD with consistency and inform planning for ADHD services across the UK.

This timely report, supported by the ADHD Foundation, proposes six key recommendations which are aimed at helping improve the quality and provision of ADHD services in England.

However, while NHS England and the Department of Health and Social Care are looking seriously at the inconsistencies and challenges to improving health care for the 1.7 million people[1,2,3] who have ADHD in England, we also need to see similar initiatives developed in Wales, Scotland and Northern Ireland.

Dr Tony Lloyd,
CEO, ADHD Foundation

Key findings

Takeda conducted a Freedom of Information (FoI) request of every Clinical Commissioning Group (CCG) in England. 174 responses were received out of 195. These responses were used to inform the analysis and findings included in this report.

6.9%

(12 out of 174 CCGs which responded) were able to provide an approximation of the number of adults with a formal diagnosis of ADHD

Less than one third

of responding CCGs (30.5% or 53 out of 174) were able to provide a precise number or approximation of the number of adults they commissioned services for in 2017-18

35.6%

of CCGs were able to provide a figure for the total amount of budget spent annually on commissioned ADHD services for those over 18. Of these CCGs:

Less than £50,000 | £50,000 – £99,999 | Over £100,000

9.8%

(17 out of 174 CCGs which responded) stated that there was some form of cap on the number of adults they commissioned services for in 2017-18

Only 11 CCGs

were able to provide a figure for the total amount of budget spent annually on commissioned ADHD services for those under 18

38.5%

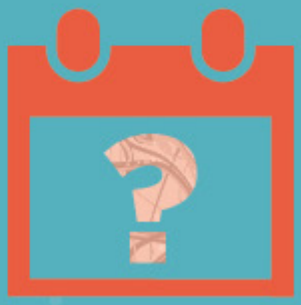
(67 out of 174 CCGs which responded) explained that they commission their ADHD services as part of a block contract

14.9%

(26 out of 174 CCGs which responded) made no assumptions whatsoever about the expected number of new patients over 18 that would receive a diagnosis in a given year

13.8%

(24 out of 174 CCGs which responded) set no expectations about the number of patients over 18 who would be reviewed per annum



Only 20.1%

(35 out of 174 CCGs which responded) were able to provide information on waiting times from referral to diagnosis

104 weeks

Of those CCGs which did provide information, the longest average waiting time recorded was 104 weeks, with the shortest being 4-6 weeks

Only 30.5%

(53 out of 174 CCGs which responded) were able to provide an average waiting time or range of average waiting times from referral to assessment

201.5 weeks

Of those CCGs which did provide information, the longest average waiting time from referral to assessment was 201.5 weeks, with the shortest reported being 4 weeks

Summary of recommendations

Recommendation 1
The Parliamentary Health and Social Care Committee should conduct an urgent inquiry into the unwarranted variation in ADHD services for adults

Recommendation 2
NHS Digital should duplicate the *Mental Health of Children and Young People in England Dataset for Hyperactivity Disorders* to record information for adults

Recommendation 3
Every CCG should make clear in their commissioning plans how they will implement the NICE Guideline on ADHD

Recommendation 4
The *NHS Long Term Plan* commitment to supporting children and young people with ADHD and their families through the diagnostic process should be expanded to include adults

Recommendation 5
The four-week waiting time target, which is currently being piloted by trailblazer sites, should be extended to adults

Recommendation 6
Data should be collected about spending on ADHD so that proper population-based planning can be implemented within a locality

ADHD and its impact

Attention Deficit Hyperactivity Disorder (ADHD) is a common neurodevelopment disorder[4]. Estimates suggest that ADHD affects around 5% of school-aged children, equating to over 230,000 children and young people, with two thirds displaying symptoms into adulthood[1].

Up to 1.5 million adults in the UK are thought to have ADHD[2,3], but the combination of poor understanding of the condition, stigma, and delays in diagnosis means that just 120,000 adults are formally diagnosed with the disorder[5]. The long-term effects of untreated ADHD are well documented, with increased rates of other health problems, poor social functioning, and antisocial behaviour[6].

Many people with ADHD are also known to have **co-morbid conditions**. Adults with ADHD are significantly more likely than the general population to experience other psychiatric disorders. In particular, mood and anxiety disorders, other neurodevelopmental disorders and substance use disorders are potential comorbidities[7]. These conditions can be exacerbated if the underlying ADHD is not identified and treated. There is also a **higher mortality rate** among those with ADHD[8]. The risk of death is even more pronounced if the diagnosis is delayed until adulthood[8].

ADHD can also have a huge impact on social and interpersonal relationships. People with ADHD are:

- four times more likely to avoid social events[9]
- three times more likely to lose friends[9]
- five times more likely to get into arguments or fights[9]

ADHD has **an associated burden on carers**. Parents may experience depression, anxiety and stress, and may feel stigmatised by social groups. ADHD has been associated with high levels of family conflict and poor family cohesion[10].

The impact of ADHD is not just restricted to individuals, with the **effects of the condition felt across wider society**. While it is known that ADHD can cause difficulties during school-days, there is growing evidence of the specific challenges in workload and time-management in the workplace[11,12]. Those with ADHD are twice as likely not to take up full-time employment[13]. It is also estimated that 24% of **the prison population** has ADHD[14] creating an additional strain on the criminal justice system. Undiagnosed ADHD costs the UK billions every year[15].

Failing to quickly and efficiently diagnose ADHD can have a profound impact on an individual's quality of life. By not prioritising the needs of people with ADHD we are committing them to a life where they may not be able to fulfil their potential in the workplace, in relationships and in society. Early identification, diagnosis and effective management of ADHD are critical in removing some of the challenges faced by people with ADHD.

Case study
Jannine's story

At 18, I was homeless. I slept rough in Luton. I remember my feet being so cold and wet that I walked into BHS, took mine off, put a new pair on and left without paying. No, it wasn't an isolated incident. I stole food too. And it's a slippery slope! I had nothing and no one. By 19, I was married. I mistook need for love. My daughter came along soon after and I was divorced by 21.

My (abusive) father offered to help my ex-husband get custody of my daughter. Far from this making me crumble as people had expected, love prevailed. All the love, kindness and good examples shown to me by strangers came back to me, and I began down the road of turning me around. Nothing was going to separate me from the only person who had ever given me unconditional love. My baby girl was my driving force from that day to this.

When I went to see my GP to ask for a referral for an ASD/ADHD assessment, he made one. He listened to me and said he didn't think I had it, but I probably had more knowledge on the subject than him (I was a teaching assistant in a special school).

I didn't know peace until after my ADHD diagnosis. I didn't know me. I didn't get to thrive. I was just surviving in a mess and a muddle. As I say, I had amazing successes and shameful falls from grace. The middle ground eluded me, and I had no roots. I have very stable roots now!

Why did I have to wait so long? Why did I have to go through all of that? ADHD is apparent in my school reports and probably in my social worker reports. It should have been addressed a long time ago.

Sadly, too many are still going through this sort of thing. We worry about diagnosing and medicating. Parents worry about being judged or having their children judged. Adults worry about prejudice. ADHD is challenging enough to contend with without prejudice and judgement. Enough of that. It has to stop!

"I didn't know peace until after my ADHD diagnosis. I didn't know me. I didn't get to thrive. I was just surviving in a mess and a muddle."

Methodology

To better understand how ADHD services are commissioned and provided, Takeda conducted a Freedom of Information (FoI) request of every clinical commissioning group (CCG) in England between 13 July and 29 September 2018. During that time, 174 responses were received out of 195. These responses were used to inform the analysis and findings included in this report. The full list of FoI questions are included in Annex 1 of this report.

Takeda has previously audited NHS trusts to understand how services for ADHD are provided. This audit found that because mental health and ADHD services are often provided by multiple trusts in a locality this makes data collection and analysis complex due to the risk of double counting patients. Therefore, CCGs were identified as the organisation most likely to hold the data we required on ADHD service provision. A pilot study of 15 CCGs was conducted to ensure that we had identified the most appropriate organisation and to test the questions we wanted to ask. Following the success of the pilot, requests were made to all remaining CCGs.

The primary focus of this audit was on adult services; however, questions were also included on services provided to children and young people to gain an understanding of CCG population planning more broadly for ADHD and expected demand for adult services in future.

It is important to note that each CCG is likely to treat FoI enquiries differently, and the quality of responses can vary accordingly. We would therefore caution against using individual CCG responses as a detailed reflection of local practice without further local investigation. However, we believe that this audit provides a good aggregate level picture of the state of service provision for ADHD in England, demonstrating that there is a range of approaches to ADHD and associated system outputs.

While it is encouraging that NHS England has made recent steps to review ADHD services in England, we hope that this report, which sets out the findings from the FoI audit and recommendations about how ADHD services could look, will serve as a useful resource to help improve ADHD services across the country.

Understanding the patient population

Up to 1.5 million adults in the UK are expected to have ADHD[2,3]. However, we do not know where these individuals are around the country and many are not diagnosed at all. The FoI request sought to determine how well CCGs understand their own patient population. The information provided found that only 6.9% of those CCGs who responded can provide an approximation of the number of adults with a formal diagnosis of ADHD, despite its national prevalence[16].

Of those that responded, the information provided varied between:

- The actual number of patients with a diagnosis
- The number of patients registered to a GP with ADHD
- The number of patients who attended an ADHD assessment

Just 6.9% of CCGs could provide an approximate number of adults with an ADHD diagnosis

It is clear that local commissioners lack an accurate understanding of the ADHD patient population that they serve. This means that they do not have an understanding of the demand which will be placed on services in terms of clinical time and financial resources.

Being able to plan appropriately for a population of patients is a key role of commissioners, so that they can allocate resources.

It is therefore worrying that our audit found that less than one third of CCGs who responded were able to provide an exact or approximate number of adults they commissioned ADHD services for in 2017-18[16].

Almost 15% of CCGs who responded to our FoI make no assumptions on the number of possible patients over 18 that would receive a diagnosis in a given year, leaving them ill-equipped for high service demand[16]. In addition, 13.8% of CCGs said that they had set no expectations about the number of patients over 18 who might be reviewed per annum[16].

14.9% could make no assumptions about the expected number of new patients over 18 that would receive a diagnosis in a given year

13.8% set no expectations about the number of patients over 18 who would be reviewed per annum

Only
30.5%
could provide a precise or approximate number of adults they commissioned services for in 2017-18

9.8% of CCGs stated that there was some form of cap on the number of adults they commissioned services for in 2017-18

The NICE ADHD guideline sets out that adults should be diagnosed by a specialist and additionally that there should be a specialist multidisciplinary team for adults with ADHD[17]. Without making planning assumptions it is difficult to ensure that the optimum amount of capacity is built in to the system so that ADHD patients can receive the support they need. Equally, assumptions help to ensure that there is no excess capacity in the system which leads to waste.

As the CQC found in their review of children and young peoples' mental health, gaps in local knowledge may contribute to gaps in support. In the CQC report, ADHD is used as an example of where some commissioners and service planners have failed to understand the particular needs of a subset of service users and have therefore failed to provide appropriate care to all children and young people with ADHD[18]. The data collected in this audit indicates that this may be the same for adults.

Challenges in the system are compounded in some areas where access to services is capped or where specialist services do not exist at all. 9.8% of CCGs responding to the request stated that they implement some form of cap on adult ADHD services, whilst nine CCGs fail to commission specific services for ADHD at all[16]. In some instances, these CCGs state that *"If adults with ADHD need to access mental health services they are able to do so within the standard timescales and would be counted within the overall numbers of people utilising mental health services, however they are not separately identified"*[19].

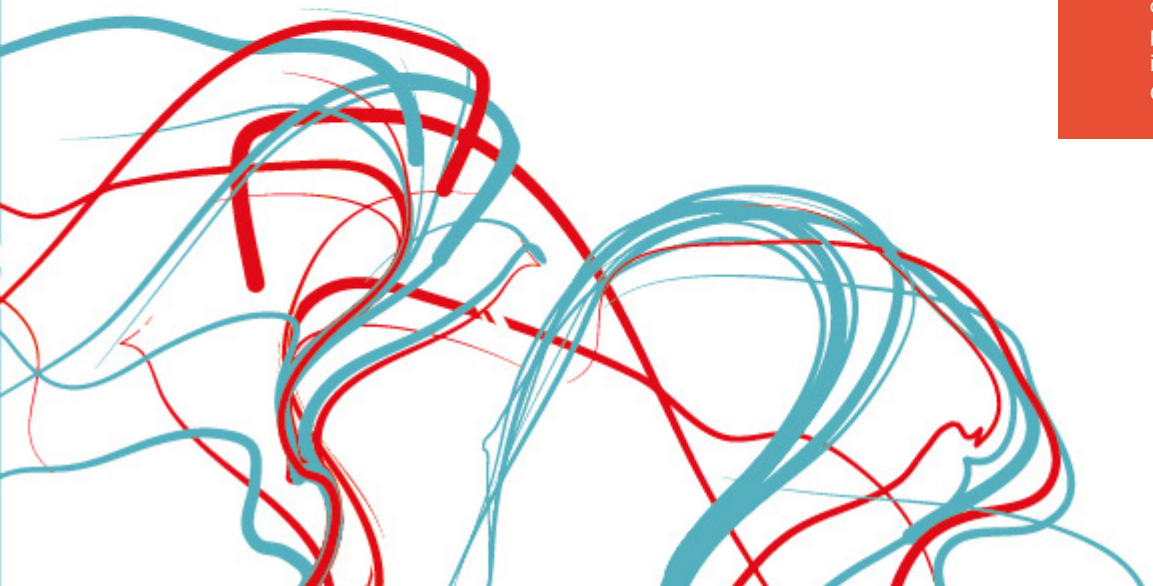
This failure to provide services builds upon a lack of forward planning by CCGs.

A lack of data – both from a local level and a national level – makes it difficult to formally assess the current state of ADHD services. Without data, it is difficult to understand the number of adults and children with the condition, or the level of support that they receive. Without understanding the population or how services operate, improvement cannot effectively be made to help CCGs cope with ever increasing demand for services. The path to proper diagnosis and management of ADHD services therefore begins with proper data collection.

Recommendation 1
The parliamentary Health and Social Care Committee should conduct an urgent inquiry into the unwarranted variation in ADHD services for adults

Recommendation 2
NHS Digital should duplicate the *Mental Health of Children and Young People in England Dataset for Hyperactivity Disorders* to record information for adults

Recommendation 3
Every CCG should make clear in their commissioning plans how they will implement the NICE Guideline on ADHD



Waiting times

As most areas do not hold information or make assessments about likely patient demands on ADHD services, it is perhaps not surprising that waiting times are hugely variable across the country.

Where you live is critical in determining how long you are likely to wait from being referred for an assessment or a diagnosis of ADHD, especially given increasing demand.

In many areas, patients experience long waits to see a specialist to be assessed and get a diagnosis. In part this may be because NICE guidelines stipulate that adults with ADHD should only be diagnosed by a specialist healthcare professional, as general practitioners (GPs) may not have the knowledge required[17]. For adults with symptoms of ADHD, NICE states that they should be referred for assessment by a mental health specialist trained in the diagnosis and treatment of the disorder[17].

Only 30.5% were able to provide an average waiting time from referral to assessment

Of those CCGs, the longest average waiting time from referral to assessment was 201.5 weeks

In response to our FoI request, less than one third of CCGs (30.5%) were able to provide an average waiting time or range of waiting times from referral to assessment for adults[16].

The range of reported waiting times from referral to assessment was significant, with the shortest reported waiting time of four weeks and the longest average waiting time of 201.5 weeks[16]. This is almost four years.

Our audit also found that, only one fifth of CCGs were able to provide information on the waiting time from referral to diagnosis for adults.

For those CCGs who were able to provide this information, waiting times ranged from four to six weeks to almost two years (104 weeks)[16].

The NHS constitution states that no patient should wait more than 18 weeks for any treatment[20]. Given that people with ADHD would need both an assessment and a diagnosis before any form of treatment is instigated, high numbers of people with ADHD are likely to be facing significant waits in excess of the 18-week standard.

Given the well documented impact these delays can have on people with ADHD, it is paramount that a waiting time standard be applied to adult ADHD services.

Only 20.1% of CCGs were able to provide information on waiting times from referral to diagnosis

Of those CCGs, the longest average waiting time recorded was 104 weeks, with the shortest being 4 weeks

Recommendation 4
The NHS Long Term Plan commitment to supporting children and young people with ADHD and their families through the diagnostic process should be expanded to include adults

Recommendation 5
The four-week waiting time target, which is currently being piloted by trailblazer sites, should be extended to adults

Spending

To provide the optimum service, commissioners need to know how much money they are spending on services. Having this information about spending on adult ADHD services would help to evaluate whether there is the right level of service provision in an area. However, in response to our FoI request only 35.6% of CCGs were able to provide a figure on the total annual spend for adults.

Of those CCGs which were able to provide information, spending figures varied with a difference of almost £675,500 between the highest and lowest spends per annuum.

The widespread use of block contracts was cited as one of the challenges which prevented accurate reporting of spending figures.

Block contracts are contracts for health services where an annual fee covers a defined range of services. This contracting method often means that it is not possible to categorise spending to an individual service such as ADHD.

More than one third of CCGs (38.5%) responding to our FoI request stated that they commission their ADHD service as part of a block contract.

Only
11 CCGs
could confirm the total spend annually on commissioned ADHD services for under 18s.

38.5% commission ADHD services as part of a block contract

Recommendation 6
Data should be collected about spending on ADHD so that proper population-based planning can be implemented within a locality

Only 35.6%
of CCGs were able to provide a figure on the total annual spend for adults

Of those CCGs:

The ADHD policy context

Historically, ADHD has not received the attention it deserves from national decision makers. It has been overlooked and under-prioritised, with Parliamentary Under Secretary of State for Health, Jackie Doyle-Price, going so far as to say that *"services for people with ADHD are a bit of a Cinderella and I would like to do my best to address that"*[21].

However, with an increased political focus on mental health, the situation is beginning to change for the better. Positive steps have been taken to begin reducing waiting times, improve data collection and streamline the patient pathway. This is to be commended, but more needs to be done by national policy makers to ensure that all people with ADHD are able to access the services and support which they need and deserve.

Most of the progress in the policy environment in ADHD is specifically focussed on children and young people. While this report is focussed on adults with ADHD it is important to understand what national decision makers are doing for children and young people as a road map for what we should be demanding for adults with ADHD.

Tackling waiting times

As identified in this audit, waiting times for people seeking a diagnosis of ADHD can be long and there are unwarranted geographical variations. The need for waiting times to be reduced for people with mental health conditions has been acknowledged by policy makers and work is beginning to tackle this.

Data quoted in a Government Green Paper show that in 2016/17 the average wait for treatment in a children's and young people's mental health service was 12 weeks[22]. However, as we found in our audit of adult services there is huge variation in the amount of time people were made to wait.

The Green Paper states that *"Waits for treatment can vary considerably in different areas, with the shortest around four weeks and the longest in one provider up to 100 weeks from referral to treatment. Latest data show that in 2016/17 the average wait for treatment in a children and young people's mental health service was 12 weeks"*[22].

Following this consultation, a trial of a four-week waiting time for access to specialist NHS children and young people's mental health is being rolled out from 2019 in local 'trailblazer' areas, with full national implementation to be decided based on the success of these by the end of 2022/23[22].

The Government has also committed to "record data on how quickly children and young people access services, how quickly they start treatment, and what outcomes are achieved"[23]. This is an important commitment, but we would urge that these data should be broken down by condition so that ADHD waiting times and outcomes can be easily analysed as a sub-group.

In addition to the commitment to trial a four-week waiting time for children and young people with ADHD, *The NHS Long Term Plan (The Plan)*, launched in January 2019, acknowledged that there needs to be more support for children and their families during the diagnostic process[24].

Encouragingly, The Plan makes a commitment to "develop packages to support children with autism or other neurodevelopmental disorders including attention deficit hyperactivity disorder (ADHD) and their families, throughout the diagnostic process"[24]. Although it is not yet clear what these packages of support will include, this is a positive step. These packages will be developed jointly by local authority children's social care, education services and expert charities. We would urge these groups to ensure that there is consistency across the country in what is included in the packages so that every child and young person receives the same level of support.

It is promising that national decision makers are beginning to focus on tackling the long waiting times experienced by children and young people. However, it is essential that this good work is extended to include adults too. As set out earlier in this report, the impact of undiagnosed ADHD in adults can be profound, both on individuals affected by the condition and on society.

Improving data collection

Our audit uncovered that data collection on ADHD is patchy, both geographically and between different datasets. This reflects findings of national bodies which have conducted their own audits of data collected on children's and young people's mental health.

A 2018 report published by the Care Quality Commission highlighted a lack of nationally collected data on children and young people's experience of using mental health services, and the absence of a national database with localised information. ADHD is given as an example of where some commissioners and service planners have failed to understand the particular needs of a subset of service users, because of a lack of data, and have therefore failed to provide appropriate care to all children and young people with ADHD. It is clear from this and our own findings that if commissioners and services do not understand the needs of people with ADHD then it is impossible for them to plan to provide the right care and support for their local population.

To help fill this gap in understanding, NHS Digital published the first ever dataset for ADHD as part of the children and young people's data set in November 2018[25]. The information published through this dataset gives nationwide insight and local intelligence. Making such data available for ADHD is extremely helpful for service planning and provision, so that commissioners and providers have a better understanding of who the patient population is and how to find them. The collection and publication of these data should be extended to adults as a matter of urgency.

Improving the patient pathway

A recurring finding in this audit and from the national policy work described above is that there can be a postcode lottery in care and support based on which services a patient interacts with. The NICE guidance on ADHD provides a comprehensive blueprint for what good care and support should look like across the whole pathway. However, this is rarely followed. Implementation of this NICE guideline should be monitored across the country so that unwarranted variations are reduced.

Case study
Billie's story

Billie was identified with speech and language disorder by age 6, displaying traits of autism, but was never given a formal assessment and diagnosis. This impacted on Billie's ability to integrate in school, finding it difficult to understand language and concentration, experiencing emotional melt downs and becoming easily overwhelmed. She was bullied and found herself isolated from her peers.

Though a very obedient, compliant child and well parented with impeccable manners, her childhood was blighted by learner anxiety and a growing lack of self-esteem and self-confidence. Billie, though academically gifted, underachieved, but was supported by the school to remain in mainstream education. Her anxiety manifested in comfort eating, developing into an eating disorder, becoming obese by age 13.

Billie left school at 16 obtaining only one GCSE. Billie was painfully shy and lacking in confidence, easily tearful about anything she thought she had got wrong or any minor mistake, working only part time up to the age of 24.

She displayed good telephone skills and was encouraged to act as a telephone receptionist. It became clear to staff that Billie displayed traits of Autism and ADHD and following a programme of training and support, she learnt to understand how her conditions impacted on her quality of life.

5 years later Billie learned to understand her condition, finally obtaining a formal diagnosis early in 2019. Following her diagnosis, Billie received coaching for her condition to teach her self-regulation skills. She is now a full-time employee and data manager. She has just purchased her own home and lives independently for the first time in her life. Her eating habits are under control and she is losing weight which has improved her physical health.

"I just cannot believe how much my life has changed. Understanding that I was not stupid or lazy, discovering that if I was different in a positive way – I think now of all the things I can do and want to do. I no longer think about what I can't do and paralyse myself with fear of failure. Knowing it, naming it – finally getting a diagnosis was like all of a sudden, the world seemed to make sense, I made sense."

Conclusion

The need for better services to properly diagnose and treat adults with ADHD is clear. Prevalence figures, service commissioning intentions and planning assumptions are all important metrics that can give an understanding of whether the system is working well for adults with ADHD. But a lack of data and information on the population, service provision, and spending are barriers to progress.

This FoI audit demonstrates that there is a worrying lack of understanding and gaps in provision for adults with ADHD. There are huge variations around the country in understanding of the ADHD population, waiting times for diagnosis and treatment, spending, and data collection. These variations are unwarranted, and action should be taken to bring waiting times down.

National level policy work is beginning to have a positive impact on ADHD, but to date this has mostly been restricted to supporting children and young people. This must change so that adults with the condition are also offered high-quality care and support.

We are keen to work with Government and the ADHD community to find solutions to these problems and to ultimately ensure that adults with ADHD have access to the high-quality services and support they deserve.

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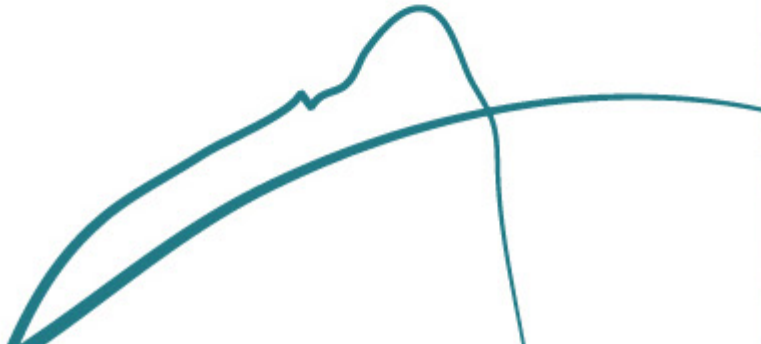

Annex 1
FoI questions

1. (i) What is the precise number of (a) children and young people (normally aged 18 and under) and (b) adults (normally over 18) you commissioned ADHD services for in the year 2017-18? (ii) Was there a maximum cap on the number of (a) children and young people and (b) adults that you commissioned services for in the year 2017-18?
2. What's your CCGs total amount of budget spent annually on commissioning ADHD services for (a) those under 18, and (b) those over 18?
3. When specifying and commissioning ADHD services, what assumptions do you make about the expected number of new patients (a) under, and (b) over 18, that will receive a diagnosis in a given year?
4. When specifying and commissioning ADHD services, what expectations do you set for the number of patients who will be reviewed per annum within the services, for (a) those under 18, and (b) those over 18?
5. How many patients (i) under 18 and (ii) over 18 in your area have a formal diagnosis of ADHD?
6. What is the average waiting time, in months, for those over 18 presenting with symptoms of ADHD (a) from referral to assessment, and (b) from referral to diagnosis?

About Takeda

Takeda has over 20 years' experience in treating ADHD and improving outcomes for ADHD patients. Takeda is committed to improving the life chances of people with ADHD: reducing stigma, challenging misconceptions and improving services and support for patients.

About the ADHD Foundation

The ADHD Foundation works in partnership with individuals, families, doctors, teachers and other agencies to improve emotional wellbeing, educational attainment, behaviour and life chances through better understanding and self-management of ADHD, ASD and related learning difficulties such as dyslexia, dyspraxia, Irlen's Syndrome, dyscalculia and Tourette's Syndrome. The ADHD Foundation also provide training for GP's, Teachers, Social Care agencies and other professionals, raising awareness to bring about positive change and inclusion in mental health, education and employment.

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Mental Health, Education and Training Services

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