Service for the diagnosis and management of attention deficit hyperactivity disorder in children and young people ................................................................. 4

Services for children and young people up to the age of 19 years ............ 4
Commissioning a service for the diagnosis and management of attention deficit hyperactivity disorder in children and young people ..................... 6

Benefits ........................................................................................................ 7
Key clinical issues ........................................................................................ 7
National drivers ............................................................................................ 8
References.................................................................................................... 9

Specifying a service for the diagnosis and management of attention deficit hyperactivity disorder in children and young people ...................... 11

Service components ................................................................................... 11
  Identification and appropriate referral for assessment and diagnosis of children and young people with ADHD ................................................... 11
  Management of children and young people with ADHD ......................... 12
Service models ........................................................................................... 14
Service specification ................................................................................... 15
References .................................................................................................. 17

Determining local service levels for a service for the diagnosis and management of children and young people with ADHD ................................. 18

Benchmarks for a standard population ....................................................... 18
Services for young people aged 3 to 17 years ........................................... 18
Further information ..................................................................................... 19

Assumptions used in estimating a population benchmark ....................... 20

Epidemiological data .................................................................................. 20
Current practice .......................................................................................... 20
For the purpose of this benchmark, and based on the opinion of the topic-specific advisory group, we have assumed that all these patients have either moderate or severe ADHD ..................................................... 21
Published research ..................................................................................... 21
Expert clinical opinion ............................................................................... 21
Conclusions ................................................................................................ 21
Services for young people aged 3 to 17 years ........................................... 22
References .................................................................................................. 23

The commissioning and benchmarking tool ................................................ 24
Identify indicative local service requirements ............................................. 24
Review current commissioned activity ....................................................... 24
Identify future change in capacity required ................................................ 24
Model future commissioning intentions and associated costs ................... 25
Ensuring corporate and quality assurance.....................................................26
  Local quality assurance..............................................................................26
  Further information.....................................................................................28
Topic-specific Advisory Group: service for ADHD in children and young people
.......................................................................................................................30
Service for the diagnosis and management of attention deficit hyperactivity disorder in children and young people

This commissioning guide provides support for the local implementation of NICE guidance through commissioning, and is a resource to help health professionals in England to commission an effective service for the diagnosis and management of attention deficit hyperactivity disorder (ADHD) in children and young people.

This commissioning guide should be read together with the following NICE guidance:

- NICE clinical guideline CG72, Attention deficit hyperactivity disorder: diagnosis and management of ADHD in children, young people and adults
- NICE technology appraisal TA102, Parent-training/education programmes in the management of children with conduct disorders
- NICE technology appraisal TA98, Methylphenidate, atomoxetine and dexamfetamine for attention deficit hyperactivity disorder in children and adolescents.

The guidance covers clinical and cost effectiveness in detail and underpins the content of this guide. Implementation of the guidance noted above is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement this guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in the guidance should be interpreted in a way which would be inconsistent with compliance with those duties.

Services for children and young people up to the age of 19 years

The NICE clinical guideline CG72 on ADHD refers to ‘children’ as aged 11 years and younger and does not cover the management of ADHD in children younger than 3 years. ‘Young people’ are defined as those aged between 12 and 18 years. It also notes that these categories are flexible and clinicians should use their judgement about a child or young person’s developmental, as opposed to their chronological, age.

This commissioning guide covers the management of ADHD in children as defined by NICE clinical guideline CG72 on ADHD, that is, aged between 3
and 11 years. It covers only those young people aged between 12 and 15 years because the NICE commissioning guide on a service for the diagnosis and management of ADHD in adults includes services for the transition of young people aged 16–17 years into adult services.

Commissioners will need to consider how best to ensure that services are provided across all age groups because service configuration and the timing of transition to adult services may vary locally. To ensure that the needs of young people up to the age of 19 years and those in transition to adult services are met, commissioners are advised to use this commissioning guide in conjunction with the commissioning guide on a service for the diagnosis and management of ADHD in adults. The assumptions section within this guide provides a rate for the estimated service requirements of children and young people aged 3–15 years. It also provides a rate for the estimated service requirements of young people up to and including the age of 17 years, which can be used within the commissioning and benchmarking tool to determine local service.

Commissioning this service is likely to require healthcare and joint commissioners to work closely with health and social services, education, children’s trusts, adult ADHD services, and the third sector to provide a multidisciplinary response to children and young people with ADHD.

The guide:

- makes the case for commissioning a service for ADHD in children and young people a service for ADHD in children and young people
- specifies service requirements
- helps you determine local service levels
- helps you ensure corporate and quality assurance.

The full text of this commissioning guide can be downloaded or accessed from the navigation menu on the right hand side of the screen. Download the openly available commissioning and benchmarking tool, there is no need to register.

We are keen to improve the commissioning guides in order to better meet the needs of commissioners. Please send us your ideas for future topic-specific guides or other comments.

Read the NICE disclaimer for information on the use and accuracy of content on the NICE website.

- Topic-specific Advisory Group: service for ADHD in children and young people
Commissioning a service for the diagnosis and management of attention deficit hyperactivity disorder in children and young people

Attention deficit hyperactivity disorder (ADHD) is a heterogeneous behavioural syndrome characterised by the core symptoms of hyperactivity, impulsivity and inattention. Symptoms of ADHD are distributed throughout the population and vary in severity; only those with significant impairment meet criteria for a diagnosis of ADHD. Common coexisting conditions in children with ADHD are disorders of mood, conduct, learning, motor control and communication, and anxiety disorders. A survey that included impairment in the diagnosis concluded that ADHD affects around 4% of school-age boys and 1% of girls in the UK [1]. However, estimates of prevalence vary depending on the diagnostic criteria used. There is also a correlation between the prevalence of mental health problems in children and young people and deprivation[2]. Services are mostly provided by child and adolescent mental health services (CAMHS), paediatric services based in child development centres, or in community child health departments and learning disability services.

Although in England and Wales only a minority of children will seek or receive medical treatment, it is estimated that children with ADHD place a significant cost on health, social and education services, reaching £23 million for initial specialist assessment, and £14 million annually for follow-up care, excluding medication. Children with ADHD are also much more likely to have learning difficulties and incur higher educational costs than children without ADHD[3].

ADHD is a chronic condition that places a significant emotional and financial burden on carers and families, who need a great deal of support to help manage their child’s problems[1]. ADHD is associated with poor school achievement and a higher rate of disruptive disorders. Severe levels of hyperactivity and impulsivity also make children more likely to develop an antisocial adjustment and more likely to show personality dysfunction or substance misuse in later adolescence and adult life[1].

Evidence suggests that ADHD is underdiagnosed and undertreated in the UK[3] and that referral pathways can be complicated. Diagnosis and the provision of treatment for children is varied, as is the way services are organised. Children and their families often experience variable waiting times and there may be significant delays between seeking help and diagnosis. In addition, the willingness of children and their families to seek help has sometimes been compromised by the stigma associated with mental health services[1].

Children with ADHD have complex difficulties. Some of these – for example, learning difficulties and developmental coordination problems – are traditionally covered by paediatric services and some are within the expertise of CAMHS. Another possible complication is the development of severe conduct disorder and aggressive behaviour, which is likely to significantly
increase the use of healthcare services and associated costs. In some services there is a lack of consistent assessment and treatment protocols or the ability to assess or manage coexisting conditions\(^1\). The NICE clinical guideline CG72 on ADHD notes that children and young people with ADHD would benefit from improved organisation of care and better integration of paediatric, CAMHS and adult services and has made recommendations for the effective treatments of ADHD with comorbid conduct disorders.

**Benefits**

The potential benefits of robustly commissioning an effective service for the diagnosis and management of ADHD in children and young people include:

- **improving the recognition, accurate diagnosis and treatment of ADHD in children and young people** and limiting the impact of late initiation of treatment, and of undiagnosed and untreated ADHD
- **reducing inappropriate referrals** through improving the information provided at referral\(^4\)
- **reducing the distress from the symptoms of ADHD** in children and young people and their parents and/or carers
- **providing better integrated care and effective treatment that will improve the quality of life** of children and young people with ADHD, their families and carers
- **reduce the financial implications and psychological burden of ADHD to society**\(^1\)
- **reducing inequalities** by improving access to services for children and young people with ADHD and, in particular, to non-pharmacological treatments
- **increasing patient choice**, and improving partnership working, patient experience and engagement
- **better value for money**, through helping commissioners to manage their commissioning budgets more effectively – this may include opportunities for clinicians to undertake local service redesign to meet local requirements in more appropriate and novel ways.

**Key clinical issues**

Key clinical issues in providing an effective service for the diagnosis and management of ADHD in children and young people are:

- **ensuring that appropriate referral pathways are in place** to ensure parity of access to assessment and treatment options including ongoing support
- **ensuring access to parent-training/education programmes and psychology services**
• **ensuring the service is integrated** with other health, education and social services for children and young people with ADHD

• **ensuring there is training for teachers**

• **providing effective and efficient clinical care** in line with [NICE clinical guideline CG72 on ADHD](#), ensuring that comorbidity is managed appropriately and that the complex needs of children and young people with ADHD and their parents or carers are met

• **providing the best possible measurable outcomes** for individual children and young people, their parents and carers, and local communities

• **ensuring that there is responsive engagement with the third sector, and health, education and social services**

• **providing a quality assured service.**

**National drivers**

National priorities and initiatives relevant to commissioning a service for the diagnosis and management of ADHD in children and young people include:

• **World class commissioning.**

• **The NHS in England: the operating framework for 2009/10.** See the vital signs tier 2 national priority target for local delivery, which outlines the effectiveness of CAMHS, and the percentage of primary care trusts (PCTs) and local authorities that are providing a comprehensive CAMHS and ensuring that vulnerable children have access to services.

• **High quality care for all: NHS next stage review final report** identifies the need for locally-led, patient-centred and clinically driven change. Services for children is one of the four key areas identified for change.

• **National service framework for children, young people and maternity services on child and adolescent mental health** identifies the requirements of a comprehensive CAMHS and sets out a plan for improving the mental health of children, including timely access and integrated, high-quality, multidisciplinary services.

• **Children and young people in mind: the final report of the national CAMHS review.**

• **Every child matters** strategy for developing effective and accessible services also identifies the use of **pooled budgets** as one of the key features of children’s trusts to combine and concentrate money effectively to shape local services, and the potential to generate economies of scale and bring efficiencies.
The joint planning and commissioning framework for children, young people and maternity services advocates effective joint planning as part of the Local Area Agreement, and commissioning as being at the heart of improving outcomes for children and young people.

- The Children Act 2004 provides the legal underpinning for the transformation of children's services as set out in particular Section 10 of the Act provides the statutory basis for Children's Trusts (the duty to cooperate).
- The Children’s Plan commitment to increasing capacity, reducing waiting times, and increasing the numbers of children and young people benefiting from specialist CAMHS, and the quality of teaching for children with special educational needs.
- Healthy lives brighter future the strategy for children’s and young people’s health produced by the Department of Health and the Department for Children, Schools and Families.
- Guidance on promoting the health and wellbeing of looked after children sets out the roles and responsibilities of PCTs and commissioners and local authorities.
- The Care closer to home initiative outlined in chapter 6 of the white paper ‘Our health, our care, our say’.
- Commissioning framework for health and well-being.
- Considering the impact of patient choice.
- A stronger local voice: a framework for creating a stronger local voice in the development of health and social care services.
- Implementation of NICE clinical and public health guidelines. These are currently core standards, and performance against these standards will be assessed by the Care Quality Commission in line with Standards for better health. See also the Care Quality Commission 2009–10 periodic review indicators for CAMHS.

Although many or all of these priorities may be relevant to the services nationally, your local service redesign may address only one or two of them.

References


Specifying a service for the diagnosis and management of attention deficit hyperactivity disorder in children and young people

Service components

The key components of a service for attention deficit hyperactivity disorder (ADHD) in children and young people are:

- identification and appropriate referral for assessment and diagnosis of children and young people with ADHD
- management of children and young people with ADHD
- developing a high-quality service for the diagnosis and management of ADHD in children and young people.

Identification and appropriate referral for assessment and diagnosis of children and young people with ADHD

The NICE clinical guideline CG72 on ADHD describes in detail the diagnostic criteria for ADHD in children and young people. The guideline notes that the diagnostic process should include an assessment of the person’s needs, coexisting conditions, social, familial and educational and physical health. For children and young people, there should also be an assessment of their parents’ or carers’ mental health.

The diagnosis of ADHD in children and young people should take place in secondary care, and should only be made by a specialist psychiatrist, paediatrician or other appropriately qualified healthcare professional. However, primary care has a role to determine the severity and impact of the problems. Healthcare professionals should consider:

- a period of watchful waiting of up to 10 weeks
- offering parents or carers a referral to a parent-training/education programme (this should not wait for a formal diagnosis of ADHD)
- children and young people with behavioural problems suggestive of ADHD can be referred by their school or primary care practitioner for parent-training/education programmes without a formal diagnosis of ADHD.

The NICE clinical guideline CG72 on ADHD identifies that referral from the community to secondary care may involve health, education and social care professionals (for example, GPs, paediatricians, educational psychologists, school special educational needs coordinators, social workers) and care pathways can vary locally. When developing care pathways commissioners
will need to consider these potential sources of referrals and ensure timely access for assessment, diagnosis and to services including non-pharmacological treatments. Currently, access to non-pharmacological treatment options may vary depending on the area[1]. Local multidisciplinary teams should have in place systems of communication and protocols for information sharing. Pathways should make it explicit that the person making the referral to secondary care should inform the child or young person’s GP.

The 1999 British Child and Mental Health Survey found that many parents discuss their concerns with professionals in education services rather than those in primary healthcare[2]. Good referral information and use of parent and teacher questionnaires can increase the proportion of children who are referred and receive a clinical diagnosis of ADHD[3]. This can be useful in making effective use of resources and supporting better access to services. The topic-specific advisory group also identified that the assessment skills and knowledge of the school special educational needs coordinators (SENCO) and educational psychologists can be a useful source of information which may support the assessment process.

Commissioners may need to consider how they achieve full participation and ownership with health, social services and education in developing pathways of care for children with ADHD. *Children and young people in mind: the final report of the national CAMHS review* identifies that joint commissioning for mental health as a whole is still underdeveloped. *Better outcomes for children’s services through joint funding: a best practice guide* notes this approach can be pivotal in enabling innovative service design, integration and close partnership working.

### Management of children and young people with ADHD

Within current service provision, psychosocial approaches – including parent-training/education programmes and training in how to manage coexisting conditions – may not be available[4]. Therefore commissioners may need to consider how to ensure services are integrated with appropriate provision of interventions and support while making the best use of a multidisciplinary team, especially for children who present with significant comorbidity.

The [NICE clinical guideline CG72 on ADHD](https://www.nice.org.uk/guidance/cg72) recommends:

- Parent-training/education programmes are the first-line treatment for parents or carers of preschool children.

- Group-based parent-training/education programmes are usually the first-line treatment for parents or carers of children and young people of school age with ADHD and moderate impairment. This may also include group psychological treatment (cognitive behavioural therapy and/or social skills training) for the younger child. For older age groups, individual psychological treatment may be more acceptable if group behavioural or psychological approaches have not been effective, or have been refused.
• Drug treatment is not indicated as the first-line treatment for all school-age children and young people with ADHD. It should be reserved for those with severe symptoms and impairment or for those with moderate levels of impairment who have refused non-drug interventions, or whose symptoms have not responded sufficiently to parent-training/education programmes or group psychological treatment.

• In school-age children and young people with severe ADHD, drug treatment should be offered as the first-line treatment. Parents should also be offered a group-based parent-training/education programme.

• Drug treatment for children and young people with ADHD should always form part of a comprehensive treatment plan that includes psychological, behavioural and educational advice and interventions.

For the organisation and planning of services NICE clinical guideline CG72 on ADHD recommends that every locality should develop a multiagency group to oversee the implementation of the guideline, coordinate local training initiatives, and oversee the development and coordination of parent-training/education programmes.

Individual-based parent-training/education programmes are recommended by NICE clinical guideline CG72 on ADHD and NICE technology appraisal TA102 on parent-training/education programmes where certain criteria are met. However, the Appraisal Committee stated that group-based programmes offer the best value for money and that commissioners should ensure that providers meet the requirements set down in the guidance.

NICE TA102 on parent-training/education programmes identifies that parent-training/education programmes can be held in a variety of settings including the hospital, clinic, community or home and conducted in groups with 6–12 participants or individually. Programmes can be run by psychologists, therapists/counsellors, social workers or community workers, but in some cases voluntary agencies or parents who have been involved in the programme themselves can be involved. Webster Stratton Incredible Years Programme and the Triple P – Positive Parenting Programme are examples that contain essential characteristics and are sufficiently effective with regard to cost.

Drug treatment should only be initiated by an appropriately qualified healthcare professional with expertise in ADHD and should be based on a comprehensive assessment and diagnosis. NICE technology appraisal TA98 on methylphenidate, atomoxetine and dexamfetamine for ADHD recommends that continued prescribing and monitoring of drug therapy may be performed by general practitioners under shared care arrangements.

Transition from children’s to adult services remains a major concern in young people with mental health problems. Commissioners will need to consider how best to ensure that services are provided for children across all age
groups as service configuration and the timing of transition to adult services may vary locally. Commissioners are advised to use this guide alongside the commissioning guide on a service for the diagnosis and management of ADHD in adults.

Developing a high-quality service for the diagnosis and management of ADHD in children and young people

NICE clinical guideline CG72 on ADHD recommends forming multidisciplinary specialist ADHD teams and/or clinics for children and young people. These specialist teams would have expertise in diagnosing and managing ADHD and the role of this team in establishing systems for communication and information sharing, and producing protocols for shared care arrangements, should be identified. The guidance also notes the importance of establishing training and education including:

- Trusts should ensure that specialist ADHD teams for children, young people and adults jointly develop age-appropriate training programmes for the diagnosis and management of ADHD for mental health, paediatric, social care, education, forensic and primary care providers and other professionals who have contact with people with ADHD.
- Teachers who have received training about ADHD and its management should provide behavioural interventions in the classroom to help children and young people with ADHD.

Currently teachers in England are not systematically trained to use these classroom management and teaching strategies. Commissioners may wish to work with local multidisciplinary specialist ADHD teams to explore opportunities for supporting training for teachers locally.

**Service models**

Commissioners may wish to consider delivering a service for ADHD in children and young people in a number of different ways, and mixed models of provision may be appropriate across a local health economy.

There is currently a range of approaches to delivering care for children and young people with ADHD, some of which are described in Best practice in ADHD: a review of the literature and care pathway. Examples of service models include: improved interagency working and assessment and the role of the specialist nurse. Questionnaires and assessment tools can also be used to support appropriate referral and in managing demand and improving the conversion rate of the number of children referred and diagnosed within the ADHD services.

The introduction of shared-care arrangements for prescribing ADHD medication and monitoring as described in NICE clinical guideline CG72 on ADHD, may help specialist centres to manage follow-up appointments and waiting times. However, children and young people with ADHD may still need
ongoing and timely access to a multidisciplinary team to optimise care. Commissioners may need to consider what contractual arrangements are in place to support this type of provision and ensure that providers have the appropriate skills and training.

An evaluation of mental health services for young children established that nurses based in the community could be a cost-effective method of providing support for young children with psychiatric illness and their families. However, few such posts are currently available, especially for nurse prescribers.

Children and young people in mind: the final report of the national CAMHS review identified that some children and young people welcomed a ‘one-stop shop’ approach, where they could get help on a wide range of issues, including mental health, as this approach was perceived as being less stigmatising.

The topic-specific advisory group noted that in many areas parent-training and education programmes are not currently in place, and commissioners may wish to consider the third sector as a provider of evidence-based programmes. Families and/or carers of children and young people with ADHD often need long-term support; social care and/or the third sector may be able to provide this, which may release capacity within specialist services.

Therefore commissioners may consider working with third sector providers in the design and delivery of service models that include the NHS working with non-NHS providers and/or the third sector to offer innovative models of service provision. Better outcomes for children’s services through joint funding: a best practice guide identifies the opportunities that joint commissioning provides to enable integrated and innovative service design alongside close partnership working.

**Service specification**

Local stakeholders, including service users, should be involved in determining what is needed from a service for ADHD in children and young people in order to meet local needs. The service should be patient-centred and integrated with other elements of care for children and young people with ADHD and their parents or carers. Every child matters provides further information on the participation of children and young people in design, delivery and evaluation of services.

The service specification needs to consider:

- the required competencies of, and training for, staff responsible for providing the service, which are described in the full guideline Diagnosis and management of ADHD in children, young people and adults. NICE clinical guideline CG72 on ADHD notes that a multiagency group should coordinate local training initiatives and oversee the development and coordination of parent-training/education programmes
- the expected number of patients (this should take into account how quickly any changes in service provision are likely to take place)

- ease of access and service location; commissioners should engage with service users and other relevant individuals and organisations locally

- care and referral pathways including the identification of children and young people with ADHD in the community

- information and audit requirements, including IT support and infrastructure

- planned service improvement, including redesign, quality, equitable access, and referral-to-treatment times according to the 18 week patient pathway or equitable waiting times locally for those services currently outside 18 weeks

- service monitoring criteria.

Useful sources of information may include:

- **The standard NHS contracts for mental health and community services**

- **Transforming community services: enabling new patterns of provision** including a best practice guide for **services for children, young people and families**. This has been developed to enable the delivery of innovative, modern, responsive and evidence-based community services of a consistently high standard, and to improve the organisations providing community services to ensure they are fit for purpose.

- **Targeted mental health in schools** is a 3-year pathfinder programme launched in November 2008 aimed at supporting the development of innovative models of therapeutic and holistic mental health support in schools for children and young people at risk of, and/or experiencing, mental health problems, and their families.

- The **NHS networks: learning from practice** database offers examples of innovative commissioning across the NHS and its partners.

- The **Map of medicine** provides an information resource that visually organises the care pathway.

- The **NICE shared learning database** offers examples of how organisations have implemented NICE guidance locally.

- **Implementation advice for NICE clinical guideline CG72 on ADHD**.
References


Determining local service levels for a service for the diagnosis and management of children and young people with ADHD

**Benchmarks for a standard population**

Available data suggest that the indicative benchmark rate for referral to a service for the assessment, diagnosis and management of children and young people aged 3–15 years with moderate-to-severe attention deficit hyperactivity disorder (ADHD) is 50 per 100,000 population (all ages), **per year**.

For a **notional primary care trust** population of 250,000 the average number of children and young people needing referral for assessment, diagnosis and management of moderate-to-severe ADHD for 3–15 years would be **125 per year**.

For an **average practice** with a list size of 10,000, the average number of children and young people needing referral for assessment, diagnosis and management of moderate-to-severe ADHD for 3–15 years would be **5 per year**.

Examine the **assumptions used in estimating these figures**.

This service is likely to fall under the **programme budgeting** category 205X (other mental health disorders).

Use the service for the diagnosis and management of children and young people with ADHD **commissioning and benchmarking tool** to determine the level of service that might be needed locally and to calculate the cost of commissioning the service using the indicative benchmark and/or your own local data.

Some parents or carers of children and young people with ADHD will need referral to a group parent-training/education programme, either on its own or together with a group treatment programme (cognitive behavioural therapy [CBT] and/or social skills training) for the child or young person. The service for the diagnosis and management of children and young people with ADHD **commissioning and benchmarking tool** includes estimates of likely participation rates of parents in parent-training/education programmes and of young people in group treatment programmes (CBT or social skills training).

**Services for young people aged 3 to 17 years**

The transition of young people aged 16–17 years into adult services is included in the NICE commissioning guide on **service for the diagnosis and management of ADHD in adults**.
However, an indicative benchmark rate is also offered below for children and young people aged 3–17 years for those commissioners who wish to include young people aged 16 and 17 in the planning of services for children and young people.

Available data suggest that the indicative benchmark rate for referral to a service for the assessment, diagnosis and management of children and young people aged 3–17 years with moderate-to-severe ADHD is 60 per 100,000 population (all ages), per year.

For a notional primary care trust population of 250,000 the average number of children and young people aged 3–17 years needing referral for assessment, diagnosis and management of moderate-to-severe ADHD would be 150 per year.

For an average practice with a list size of 10,000, the average number of children and young people aged 3–17 years needing referral for assessment, diagnosis and management of moderate-to-severe ADHD would be 6 per year.

Further information

Sources of further information to help you in assessing local health needs and reducing health inequalities include:

- Annex A of the Commissioning framework for health and well-being outlines the process and data needed to undertake a joint strategic needs assessment.
- Department of Health Delivering quality and value – focus on benchmarking.
- PRIMIS+ provides support to general practices on information management, recording for, and analysis of, data quality, plus a comparative analysis service focused on key clinical topics.
Assumptions used in estimating a population benchmark

The assumptions used in estimating a population benchmark for assessment, diagnosis and management of moderate-to-severe attention deficit hyperactivity disorder (ADHD) for children and young people aged 3–15 years of 50 per 100,000 population (all ages) per year are based on the following source(s) of information:

- **epidemiological data** on the prevalence/incidence of ADHD
- **current practice** on detection rate of ADHD in primary care
- **published research** on parent-training/education programmes in the management of children with conduct disorders and ADHD
- **expert clinical opinion** of the topic-specific advisory group, based on experience in clinical practice and literature review.

**Epidemiological data**

Prevalence estimates of ADHD are rare in the published literature, especially in relation to the diagnostic and statistical manual of mental disorders, 4th edition (DSM-IV) and ICD-10 (International classification of diseases and related health problems, 10th revision) criteria.

The prevalence of ADHD in people aged 5–15 years is based on the 1999 British Child and Mental Health Survey and is 3.62% in males and 0.85% in females[1]. Applying these figures to the population of children and young people aged 3–15 years equates to an estimated overall prevalence of 2.27%.

**Current practice**

Data from GP practice systems are likely to underestimate the prevalence of ADHD.

IMS Disease Analyser database holds patient data from a sample of GP practice systems. Data was extracted to determine the prevalence and incidence of ADHD. This was done on the basis of Read codes that are suggestive of ADHD or notes in the records of a prescription for atomoxetine, dexamphetamine or methylphenidate.

Data from these databases suggest that the prevalence of diagnosed ADHD in the population of children and young people aged 3–15 years is around 0.7% and the incidence is around 0.05%.

These estimates are likely to be significant underestimates of both the numbers of children and young people with moderate-to-severe ADHD known
to services (those with a diagnosis of ADHD) and the numbers of children and young people with moderate-to-severe ADHD in the general population (those diagnosed with ADHD and those with ADHD but undiagnosed).

For the purpose of this benchmark, and based on the opinion of the topic-specific advisory group, we have assumed that all these patients have either moderate or severe ADHD.

**Published research**

Not all children and young people referred for specialist assessment and diagnosis will have the diagnosis of ADHD confirmed. In an ADHD clinic that screened new referrals, just under 50% of those referred for assessment had the diagnosis of ADHD confirmed[2].

**Expert clinical opinion**

The consensus opinion of the topic-specific advisory group was that the prevalence estimates from the 1999 British Child and Mental Health Survey are conservative estimates of ADHD in children and young people aged 3–15 years and should be considered to represent moderate-to-severe ADHD.

Not all children and young people who are referred for diagnosis and specialist assessment will have the diagnosis of ADHD confirmed. Based on their experience of clinical practice, the topic-specific advisory group agreed that around 50% of those referred would have the diagnosis of ADHD confirmed. The remaining 50% may have other conditions which may require intervention and/or onward referral.

**Conclusions**

Based on the epidemiological data and other information outlined above, it is concluded that 0.32% of the population of children and young people aged 3–15 years need referral to a service for the assessment, diagnosis and management of children and young people with moderate-to-severe ADHD, each year. This is based on the following assumptions:

- The population prevalence of moderate-to-severe ADHD in children and young people aged 3–15 years is 2.27%.
- The prevalence of moderate-to-severe ADHD in children and young people aged 3–15 years based on general practice data is estimated to be 0.7%.
- This means that the prevalence of diagnosed ADHD based on general practice data would need to more than treble (that is, increase by 224% or a factor of 3.24) to reach the population prevalence of moderate-to-severe ADHD.
- The incidence of diagnosed moderate-to-severe ADHD based on general practice data is 0.05%. Increasing this figure by the same amount (224% or a factor of 3.24) to the level required for
the prevalence of diagnosed ADHD to reach the population prevalence gives a result of 0.16%.

- This adjustment of the incidence rate accounts for both under-recording of known cases of ADHD and underdiagnosis of ADHD.
- This represents only 50% of the numbers referred, as not all children and young people referred will have the diagnosis of ADHD confirmed. Adjusting for this would suggest that 0.32% of the population aged 3–15 years could be referred each year. This corresponds to around 50 per 100,000 population (all ages).

Therefore the population benchmark for assessment, diagnosis and management of moderate-to-severe ADHD in children and young people aged 3–15 years is estimated to be **50** per 100,000 population (all ages) **per year**.

**Services for young people aged 3 to 17 years**

The NICE commissioning guide on a service for the diagnosis and management of ADHD in adults includes services for the transition of young people aged 16–17 years into adult services.

An indicative benchmark rate is also offered for children and young people aged 3–17 years for those commissioners who wish to include young people aged 16 and 17 in their planning of services for children and young people. The same methodology has been used as outlined above, based on the following:

- The prevalence of ADHD in the population aged 16–17 years based on the 1999 British Child and Mental Health Survey has been estimated at 2.99% in males and 0.70% in females. The assumptions section of the NICE commissioning guide on service for the diagnosis and management of ADHD in adults outlines how this has been estimated. This equates to a prevalence of ADHD in the population aged 3–17 years of 2.21%.

- Patient data from GP practice systems suggests that the prevalence of diagnosed ADHD for the population aged 3–17 years is around 0.7% and the incidence is around 0.05%.

- Applying the same methodology outlined in this commissioning guide (increasing the diagnosed incidence by the difference between the diagnosed prevalence and population prevalence), the diagnosed incidence of ADHD in the population aged 3–17 years comes to 0.16% (increasing 0.05% by 216% or by a factor of 3.16). This represents only 50% of those referred (see above) which suggests that 0.32% of the population aged 3–17 years could be referred each year. This corresponds to a rate of **60** per 100,000 population (all ages) **per year**.
The population benchmark for a service for the diagnosis and management of ADHD in children and young people aged 3–17 years is estimated to be 60 per 100,000 population (all ages) per year.

Use the service for the diagnosis and management of ADHD in children and young people commissioning and benchmarking tool to determine the level of service that might be needed locally and to calculate the cost of commissioning the service using the indicative benchmark and/or your own local data.

**References**


The commissioning and benchmarking tool

**Download the attention deficit hyperactivity disorder (ADHD) in children and young people commissioning and benchmarking tool**

Use the service for attention deficit hyperactivity disorder (ADHD) in children and young people commissioning and benchmarking tool to determine the level of service that might be needed locally and to calculate the cost of commissioning the service, as described below.

**Identify indicative local service requirements**

The indicative benchmark based on the national average for referral to a service for the assessment, diagnosis and management of children and young people with moderate-to-severe ADHD for 3–15 years is 50 per 100,000 population (all ages), *per year*.

An indicative benchmark rate is also offered below for children and young people aged 3–17 years for those commissioners who wish to include young people aged 16 and 17 in the planning of services for children and young people.

Available data suggests that the indicative benchmark rate for referral to a service for the assessment, diagnosis and management of children and young people with moderate-to-severe ADHD for 3–17 years is 60 per 100,000 population (all ages), *per year*.

The commissioning and benchmarking tool helps you to assess local service requirements using the indicative benchmark as a starting point. With knowledge of your local population and its demographic, you can amend the benchmark to better reflect your local circumstances. For example, if your population or has a significantly lower or higher rate of ADHD than the average population, you may need to provide services for relatively fewer or more people.

**Review current commissioned activity**

You may already commission a service for ADHD in children and young people for your population. The tool provides tables that you can populate to help you calculate your current commissioned activity and associated costs.

**Identify future change in capacity required**

Using the indicative benchmark provided, or your own local benchmark, you can use the commissioning and benchmarking tool to compare the activity that you might need to commission against your current commissioned activity. This will help you to identify the future change in capacity required. Depending on your assessment, your future provision may need to be increased or decreased.
Model future commissioning intentions and associated costs

You can use the commissioning and benchmarking tool to calculate the capacity and resources needed to move towards the benchmark level, and to model the required changes over a period of 4 years.

Use the tool to calculate the level and cost of activity you intend to commission and to consider the settings in which the service for ADHD in children and young people may be provided, comparing the costs of commissioning the service across the various settings. The tool is pre-populated with data on the potential recurrent cost elements that may need to be considered in future service planning, which can be reviewed and amended to better reflect your local circumstances.

Commissioning decisions should consider both the clinical and economic viability of the service, and take into account the views of local people. Commissioning plans should also take into account the costs of monitoring the quality of the services commissioned.
Ensuring corporate and quality assurance

Commissioners should ensure that the services they commission represent value for money and offer the best possible outcomes for patients. Commissioners need to set clear specifications for monitoring and assuring quality in the service contract.

Commissioners should ensure that they consider both the clinical and economic viability of the service, and any related services, and take into account patients’ views, the view of parents or carers and those of other stakeholders when making commissioning decisions.

A service for the diagnosis and management of children and young people with attention deficit hyperactivity disorder (ADHD) needs to:

- be effective and efficient
- be responsive to the needs of children and young people and their parents or carers
- provide treatment and care based on best practice, as defined in NICE clinical guideline CG72 on ADHD
- deliver the required capacity
- be integrated with other elements of care for children and young people with ADHD
- define agreed criteria for referral, local protocols and the care pathway for children and young people with ADHD
- be patient-centred and provide equitable access, ensuring that children and young people and their parents or carers are treated with dignity and respect, are fully informed about their care and are able to make decisions about their care in partnership with healthcare professionals
- consider and respond to recommendations arising from any audit, serious untoward or patient safety incidents
- demonstrate how it meets requirements under equalities legislation
- demonstrate value for money.

Local quality assurance

Any mechanisms for quality assurance at a local level are likely to refer to the following.

- Service and performance targets, including estimated activity levels and case mix, waiting and referral-to-treatment times (ensuring that children and young people and their parents or carers do not experience unnecessary delays), complaints procedures.
• **Clinical governance arrangements**, including incident reporting.

• **Clinical quality criteria**: appropriateness of referral, consenting procedures, clinical protocols and ensuring that the child and adolescent mental health services (CAMHS) minimum data set is completed.

• **Audit arrangements**: define audit requirements, frequency of reporting, reporting route and format, and dissemination mechanisms; arrangements, and monitoring of patient outcomes.

• **Health, safety and security**: infection prevention, waste management, confidentiality procedures, legislative requirements.

• **Equipment**: testing and calibration.

• **Accreditation requirements**: for some or all elements of the service, the premises and/or staff.

• **Patient and service user experience**: using the [national patient survey](https://www.nps.nhs.uk/); taking into account perspectives and perception of service provision to help shape services; engagement to inform commissioning decisions; complaints.

• **Process measure and patient outcomes**: proportion of children and young people who receive medication and/or other evidence-based treatments, for example the proportion of parents or carers who are offered a parent-training/education; impairment reduction measured by the children’s global assessment scale; symptom reduction measured through a standardised rating scale, for example Connors’ scale. Establishing outcome measures is likely to be an iterative process, especially where services are not well developed and commissioners may wish to agree trajectories for outcomes as part of the quality payments for providers. Process outcomes such as the conversion rates for the diagnosis of ADHD and/or the expected level of symptom reduction may also be a useful indicator. Commissioners may wish to consider using outcomes across service areas, for example the proportion of children and young people with ADHD in full-time education.

• **Staff competencies**: individual and team baseline requirements, which are described in the full guideline [Diagnosis and management of ADHD in children, young people and adults](https://www.nps.nhs.uk/), and monitoring and performance.

• **Information requirements**, including both patient-specific information (NHS number, referring GP, provision of high-quality information to patients/carers) and service-specific information (referral-to-treatment times, workload trends, number of complaints).
• The process for reviewing the service with stakeholders, including decisions on changes necessary to improve or to decommission the service.

• Achieving targets associated with equalities legislation.

**Further information**

**General information** on quality and corporate assurance can be obtained from the following sources:


• The [You’re welcome quality criteria self-assessment toolkit](https://www.gov.uk/government/publications/you-re-welcome-quality-criteria-self-assessment-toolkit) enables service providers and commissioners to see what to do to make health services ‘young people friendly’.

• The [National Patient Safety Agency](https://www.npsa.nhs.uk/) oversees the implementation of a system to report and learn from adverse events and near misses occurring in the NHS. The publication ‘Seven steps to patient safety’ provides an overview of patient safety and gives updates on the tools that the NPSA is developing to support patient safety across the health service.

• [NHS Alliance online resources](https://www.nhsalliance.org/). NHS Alliance is the representational organisation of primary care and primary care trusts, and provides them with an opportunity to network and exchange best practice. The alliance supports its members with an open-access helpline, in-house and joint publications and briefings, internal newsletters and a website.

• The [Department of Health commissioning framework](https://www.gov.uk/government/publications/nhs-commissioning-framework) provides guidance on the commissioning process in the context of the NHS reform agenda.

• NHS Institute for Innovation and Improvement support for commissioners includes [Commissioning for health improvement](https://www.nhiifii.org.uk/) products to accelerate the achievement of world-class commissioning; [The Productive Leader](https://www.nhiifii.org.uk/) programme to enable leadership teams to reduce waste and variation in personal work processes, and [Better care, better value indicators](https://www.gov.uk/government/publications/better-care-better-value-indicators) to help inform planning, to inform views on the scale of potential efficiency savings in different aspects of care, and to generate ideas on how to achieve these savings, and [Experience-based design](https://www.nhiifii.org.uk/), which brings staff and patients together to improve care and shape the redesign of services.

• [10 Steps to your SES: a guide to developing a single equality scheme](https://www.gov.uk/government/publications/10-steps-to-your-sees-a-guide-to-developing-a-single-equality-scheme). This guidance has been developed to assist NHS
organisations that have a duty, as public authorities, to comply with the race, disability and gender public sector duties, and in anticipation of new duties in relation to age, religion and belief, and sexual orientation.

**Specific information** on quality and corporate assurance for a service for the diagnosis and management of ADHD in and young people can be obtained from the following sources:

- The [CAMHS outcome research consortium](#) supports children and adolescent mental health services in outcome evaluation.

- [Better metrics](#) is a pragmatic project that provides clinically relevant measures of performance to support the development of measurable local targets and indicators for local quality improvement projects. See the children and maternity metric, which is currently being updated.

- [Skills for health](#) works with employers and other stakeholders to ensure that those working in the sector are equipped with the right skills to support the development and delivery of healthcare services. See details of the [children’s services competence framework](#).
Topic-specific Advisory Group: service for ADHD in children and young people

A topic-specific advisory group was established to review and advise on the content of the commissioning guide. This group met once, with additional interaction taking place via email.

**Dr David Balfour**  
Clinical Network Lead, NHS Hampshire

**Dr Val Harpin**  
Consultant Paediatrician (Neurodisability), Sheffield Children's NHS Foundation Trust

**Dr Daphne Keen**  
Consultant Neurodevelopmental Paediatrician, St George’s Healthcare NHS Trust, London

**Dr Christine Merrell**  
Education Specialist, Curriculum, Evaluation and Management Centre, Durham University

**Sheena Nixon**  
Head of Practice-Based Commissioning, Tower Hamlets PCT

**Noreen Ryan**  
Nurse Consultant, Bolton Hospitals NHS Trust

**Dr Nicola Salt**  
GP, Thurleigh Road Practice, London

**Dr Kapil Sayal**  
Clinical Senior Lecturer in Child and Adolescent Psychiatry, The University of Nottingham

**Eric Taylor**  
Emeritus Professor of Child and Adolescent Psychiatry, King's College London Institute of Psychiatry

**Dr Geoff Thorley**  
Head Clinical and Child Adolescent Psychologist, Child and Adolescent Mental Health Service, Leicester Partnership NHS Trust