

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Attention deficit hyperactivity disorder

Output: Prioritised quality improvement areas for development.

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1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for attention deficit hyperactivity disorder. It provides the Committee with a basis for discussion and prioritising quality improvement areas for developing quality statements and measures, which will be drafted for public consultation.

Structure

This includes a brief overview of the topic followed by a summary of each of the suggested quality improvement areas followed with supporting information.

Where relevant, guideline recommendations selected from the key development source below are presented to aid the Committee when considering specific aspects for which statements and measures should be considered.

Development source

Unless otherwise stated, the key development source referenced in this briefing paper is as follows:

[Attention deficit hyperactivity disorder: diagnosis and management of ADHD in children, young people and adults](#). NICE clinical guideline 72 (2009).

Where relevant, guideline recommendations from the key development source are presented alongside each of the suggested areas for quality improvement within the main body of the report.

2 Overview¹

2.1 *Focus of quality standard*

This quality standard will cover the diagnosis and management of attention deficit hyperactivity disorder (ADHD) in children aged 3 years and older, young people and adults.

2.2 *Definition*

ADHD is a heterogeneous behavioural syndrome characterised by the core symptoms of hyperactivity, impulsivity and inattention. While these symptoms tend to cluster together, some people are predominantly hyperactive and impulsive, while others are principally inattentive. Two main diagnostic criteria are in current use – the

¹ Sections 2.1 to 2.4 are taken from Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults. Clinical Guideline, CG72. September 2008. Reviewed: July 2012

International Classification of Mental and Behavioural Disorders 10th revision (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV). ICD-10 uses a narrower diagnostic category, which includes people with more severe symptoms and impairment. DSM-IV has a broader, more inclusive definition, which includes a number of different ADHD subtypes. Although ICD-10 excludes any comorbidity, for the purposes of this guideline coexisting conditions are accepted as a common aspect of the diagnosis and treatment of ADHD.

Symptoms of ADHD are distributed throughout the population and vary in severity; only those with significant impairment meet criteria for a diagnosis of ADHD.

Symptoms of ADHD can overlap with symptoms of other related disorders, and ADHD cannot be considered a categorical diagnosis. Therefore care in differential diagnosis is needed. Common coexisting conditions in children with ADHD are disorders of mood, conduct, learning, motor control and communication, and anxiety disorders; in adults they include personality disorders, bipolar disorder, obsessive-compulsive disorder and substance misuse.

2.3 *Incidence and prevalence*

Based on the narrower criteria of ICD-10, hyperkinetic disorder is estimated to occur in about 1–2% of children and young people in the UK. Using the broader criteria of DSM-IV, ADHD is thought to affect about 3–9% of school-age children and young people in the UK, and about 2% of adults.

For an average general practice list size of 10,000, the average number of children and young people (3 – 15 years) requiring referral to a service for the diagnosis and management of moderate-to-severe ADHD would be 5 per year, and for adults around 3 per year.

2.4 *Management*

The provision of treatments and interventions for children, young people and their families who have ADHD is varied. The ability to recognise and diagnose the disorder and the way in which services are provided and organised for this identified group are inconsistent as services move towards providing comprehensive child and adolescent mental health services (CAMHS). The identification of affected people is unsystematic and driven largely by the extent to which parents are knowledgeable about the condition or recognise that their child might have hyperactive behaviour. Historically, services for affected children and young people have mostly been provided by CAMHS, psychiatrists with a specialism in learning disability, or paediatricians based in child development centres or in community child health departments.

The willingness of children, young people and their families to seek help has sometimes been compromised by stigma associated with mental health services.

Referral pathways can be complicated, and are subject to considerable variation in the local organisation of mental health services for children and young people. There can be difficulties with awareness and recognition of the symptoms by healthcare professionals in schools, primary and secondary care and by the other professionals who come into contact with this group. Treatments and interventions for ADHD are varied and provided in a variety of settings, usually including specialist CAMHS or paediatric clinics.

Psychological therapies include psychoeducational input, behavioural therapy, cognitive behavioural therapy (CBT) in individual and group formats, interpersonal psychotherapy (IPT), family therapy, school-based interventions, social skills training and parent management training to encourage the development of coping strategies for managing the behavioural disturbance of ADHD. Advice is sometimes given to schools and residential institutions. Remedial disciplines such as occupational therapy and speech and language therapy are sometimes involved in helping the development of individual children. Families of children and young people who have ADHD may require social support for example, child care relief, help in the home and family support workers.

In the UK, atomoxetine, dexamfetamine and methylphenidate are licensed for the management of ADHD in children and young people. The NICE technology appraisal, TA98, has concluded that these medications are effective in controlling the symptoms of ADHD relative to no treatment. Medications should only be initiated by an appropriately qualified healthcare professional with expertise in ADHD after a comprehensive assessment. Continued prescribing and monitoring of medications may be performed by GPs, under shared care arrangements.

See appendices 1, 2 and 3 for patient pathway, algorithms and key priority for implementation recommendations from NICE clinical guideline 72.

2.5 National Outcome Frameworks

The table below shows the indicators from the frameworks that the quality standard could contribute to:

NHS Outcomes Framework	Domain 4: Ensuring people have a positive experience of care.	4a Patient experience of primary care (i) GP services 4.4 Improving access to primary care services, access to (i) GP services 4.7 Improving experience of healthcare for people with mental illness: Patient experience of community mental health services
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3 Summary of suggestions

3.1 Responses

In total seven stakeholders submitted suggestions for quality improvement as part of the 2-week engagement exercise (24/10/12 – 7/11/12).

Table 1 Summary of suggested quality improvement areas

Stakeholders were asked to suggest up to 5 areas for quality improvement. These have been merged and summarised in the table below for further consideration by the Committee.

The full detail of the suggestions is provided in appendix 3 for information.

Suggested area for improvement	Stakeholder (see table 2 for abbreviations)
<u>Organisation and planning of services</u> <ul style="list-style-type: none"> • Availability of services for adults with ADHD • Use of shared care agreements between primary and secondary care • Access to multidisciplinary specialist teams for children with ADHD 	RCN, RCPCH, Lilly
<u>Identification and referral</u> <ul style="list-style-type: none"> • Screening for ADHD: identification and referral • Compilation of registers 	Lilly, RCPCH
<u>Diagnosis</u> <ul style="list-style-type: none"> • Diagnosis including full psychological assessment 	COT, RCPCH, ASCL,SCM
<u>Treatment for children and young people</u> <ul style="list-style-type: none"> • Increasing the use of psychological therapies • Support for children with ADHD in schools 	AEP, RCPCH,SCM
<u>Appropriate drug treatment</u>	SCM
<u>Treatment follow up</u> <ul style="list-style-type: none"> • Monitoring adverse effects of drug treatment • Reviewing effectiveness of treatments 	SCM
<u>Transition to adult services</u>	COT, Lilly, RCPCH,SCM

Table 2 Stakeholder details (abbreviations)

The details of stakeholder organisations who submitted suggestions are provided in the table below.

Abbreviation	Full name
RCN	Royal College of Nursing
COT	College of Occupational Therapists
RCPCH	Royal College of Paediatrics and Child Health
ASCL	Association of School and College Leaders
Lilly	Lilly UK
AEP	The Association of Educational Psychologists

4 Suggested improvement area: organisation and planning of services

4.1 *Summary of suggestions*

Stakeholders highlighted that there was a lack of service provision for adults with ADHD in spite of there being a clear population need; they also identified a need for greater consistency within commissioned services.

It was noted that there is insufficient use of shared care agreements between primary and secondary care which impacts on the capacity services have for accepting new referrals.

There was also concern raised about the access to psychological support services, it was noted that many children are looked after by paediatricians who cannot access the support of CAMHS or social care.

The following key areas for quality improvement relating to the organisation and planning of services were highlighted.

- Availability of services for adults with ADHD.
- Use of shared care agreements between primary and secondary care.
- Access to multidisciplinary specialist teams for children with ADHD.

4.2 *Selected recommendations from development source*

Recommendations from the development source relating to all three suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

Organisation and planning of services

NICE CG 72 - Recommendation 1.1.1.1

Mental health trusts, and children's trusts that provide mental health/child development services, should form multidisciplinary specialist ADHD teams and/or clinics for children and young people and separate teams and/or clinics for adults. These teams and clinics should have expertise in the diagnosis and management of ADHD, and should:

- provide diagnostic, treatment and consultation services for people with ADHD who have complex needs, or where general psychiatric services are in doubt about the diagnosis and/or management of ADHD

- put in place systems of communication and protocols for information sharing among paediatric, child and adolescent, forensic, and adult mental health services for people with ADHD, including arrangements for transition between child and adult services
- produce local protocols for shared care arrangements with primary care providers, and ensure that clear lines of communication between primary and secondary care are maintained
- ensure age-appropriate psychological services are available for children, young people and adults with ADHD, and for parents or carers.

The size and time commitment of these teams should depend on local circumstances (for example, the size of the trust, the population covered and the estimated referral rate for people with ADHD).

4.3 Current UK practice

Availability of services for adults with ADHD

Stakeholders highlighted a study which reviewed the difficulties of young people with ADHD and their families who are transitioning between services². This study concluded that although many adult mental health services have started to take more interest in the assessment and treatment of adults with ADHD, current service provision for adults is poor.

Stakeholders highlighted findings from the 2007 adult psychiatric morbidity study which reported that 8.2% of the surveyed population have ADHD characteristics³. This study reports that there is an under diagnosis of ADHD in adults. This is due to the presence of comorbid psychiatric conditions and a lack of doctors trained to diagnose ADHD in adults. As a consequence adults with ADHD do not access services for treatment of their ADHD but may access services for other mental health reasons.

Use of shared care agreements between primary and secondary care

Stakeholders highlighted that there was a lack of information on the number of shared care agreements in the UK but understood the numbers to be low. No published evidence was provided to support this, so the suggestion is based on knowledge and experience of the stakeholders alone.

Access to multidisciplinary specialist teams

A focussed literature search identified two additional reports of UK current practice for this suggested area for quality improvement.

² Young et al. (2011) Avoiding the 'twilight zone': Recommendations for the transition of services from adolescence to adulthood for young people with ADHD. *BMC Psychiatry* 11:174.

³ Bebbington et al. (2009) Adult Psychiatric Morbidity in England, 2007. The NHS Information Centre for Health and Social Care.

A 2009 survey on service provision by paediatricians in the UK identified that there is a wide variation in the services offered to children with ADHD and there is a need for greater collaboration between paediatricians and other specialist professionals⁴.

The 2008 national CAMHS review report⁵ found that there are unacceptable variations in service provision for children. The report also found that children were often parcelled up into individual services so their needs were not met in holistic ways and sometimes not met at all.

⁴ Banerjee S et al (2009). ADHD service provision by paediatricians: UK survey. *Clinical Governance: An International Journal* 14 (3): 236 - 241

⁵ Department of Health (2010). *Keeping children and young people in mind: the Government's full response to the independent review of CAMHS.*

5 Suggested improvement area: identification and referral

5.1 Summary of suggestions

Stakeholders reported that there was an under diagnosis of ADHD nationally. This has led to true rates of the condition not being known. If people with ADHD are not identified, they are not able to access the range of support and treatment options which can help to address outcomes, such as associated functional impairments and quality of life, and management of co-morbidities. Stakeholders identified that there are variations in the referrals routes for patients into secondary care which leads to service inequity across the country. Stakeholders did not specify whether referral onwards was required for confirmation of diagnosis or for further assessment. Discussion is required by the committee in order to define this further.

The following specific areas for quality improvement and potential development by the QSAC were highlighted:

- Screening for ADHD: identification and referral
- Compilation of registers

5.2 Selected recommendations from development source

NICE clinical guidance 72 recommends that screening for ADHD in children is **not** carried out.

Identification and referral in children and young people with ADHD

NICE CG 72 - Recommendation 1.2.1.1

Universal screening for ADHD should not be undertaken in nursery, primary and secondary schools.

Recommendations from the development source relating to the suggested improvement areas of screening for ADHD: identification and referral have been provisionally selected and are presented below to inform QSAC discussion.

Identification and referral in children and young people with ADHD

NICE CG 72 - Recommendation 1.2.1.3

Referral from the community to secondary care may involve health, education and social care professionals (for example, GPs, paediatricians, educational psychologists, SENCOs, social workers) and care pathways can vary locally. The person making the referral to secondary care should inform the child or young person's GP.

NICE CG 72 - Recommendation 1.2.2.1

Adults presenting with symptoms of ADHD in primary care or general adult psychiatric services, who do not have a childhood diagnosis of ADHD, should be referred for assessment by a mental health specialist trained in the diagnosis and treatment of ADHD, where there is evidence of typical manifestations of ADHD (hyperactivity/impulsivity and/or inattention) that:

- began during childhood and have persisted throughout life
- are not explained by other psychiatric diagnoses (although there may be other coexisting psychiatric conditions)
- have resulted in or are associated with moderate or severe psychological, social and/or educational or occupational impairment.

NICE CG 72 - Recommendation 1.2.2.2

Adults who have previously been treated for ADHD as children or young people and present with symptoms suggestive of continuing ADHD should be referred to general adult psychiatric services for assessment. The symptoms should be associated with at least moderate or severe psychological and/or social or educational or occupational impairment.

Compilation of registers

The compilation of registers is not directly covered in NICE clinical guideline 72 and no recommendations are presented relating to the suggested quality improvement area.

5.3 Current UK practice

A study of the prevalence of ADHD in 4 general adult outpatient psychiatry clinics in the North West of England found ADHD was present in 22% of patients, 27 out of 124 patients⁶. It was of almost equal prevalence between genders, with 12 males and 15 females being identified. This study concluded that current childhood diagnostic criteria may not be suitable for use in adults with ADHD as they might underestimate the true prevalence of the disorder.

A focussed literature search identified a report by NHS Quality Improvement Scotland which sought views from its ADHD Project User and Parent/Carer

⁶ Rao P et al. (2011) Prevalence of ADHD in four general adult outpatient clinics in North East England. *Progress in Neurology and Psychiatry* 15(5): 7-11.

Subgroup. It reported that clearly defined pathways were needed so that parents and carers knew how to get an ADHD assessment⁷.

⁷ Attention Deficit and Hyperkinetic Disorders Services Over Scotland: Report of the ADHD Project User and Parent/Carer Subgroup (April 2008) NHS Quality Improvement Scotland

6 Suggested improvement area: diagnosis

6.1 Summary of suggestions

The suggested area for quality improvement identified by stakeholders is the 'quality of diagnosis'.

Stakeholders identified that diagnosis for ADHD does not always include a full assessment of the patient's impairments in all settings, nor does it include all relevant professionals. Assessments are also often found not to take into account a patient's co-morbidities.

The role of the multidisciplinary team during diagnosis is covered in section 4: organisation and planning of services.

Stakeholders report that there are inconsistencies in diagnosis and subsequent management for children with ADHD. Stakeholders highlighted that the diagnosis of children can often be delayed and that there are instances of over diagnosis in some areas.

6.2 Selected recommendations from development source

Recommendations from the development source relating to this suggested improvement area have been provisionally selected and are presented below to inform QSAC discussion.

Diagnosis of ADHD

NICE CG 72 - Recommendation 1.3.1.1

A diagnosis of ADHD should only be made by a specialist psychiatrist, paediatrician or other appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD, on the basis of:

- a full clinical and psychosocial assessment of the person; this should include discussion about behaviour and symptoms in the different domains and settings of the person's everyday life, and
- a full developmental and psychiatric history, and
- observer reports and assessment of the person's mental state.

NICE CG 72 - Recommendation 1.3.1.2

A diagnosis of ADHD should not be made solely on the basis of rating scale or observational data. However rating scales such as the Conners' rating scales and the Strengths and Difficulties questionnaire are valuable adjuncts,

and observations (for example, at school) are useful when there is doubt about symptoms.

NICE CG 72 - Recommendation 1.3.1.3 (KPI)

For a diagnosis of ADHD, symptoms of hyperactivity/impulsivity and/or inattention should:

- meet the diagnostic criteria in DSM-IV or ICD-10 (hyperkinetic disorder),⁵ and
- be associated with at least moderate psychological, social and/or educational or occupational impairment based on interview and/or direct observation in multiple settings, and
- be pervasive, occurring in two or more important settings including social, familial, educational and/or occupational settings.

As part of the diagnostic process, include an assessment of the person's needs, coexisting conditions, social, familial and educational or occupational circumstances and physical health. For children and young people, there should also be an assessment of their parents' or carers' mental health.

6.3 Current UK practice

Stakeholders drew attention to NICE clinical guideline 72: The diagnosis and management of ADHD in children, young people and adults and the Department of Health National service framework for children, young people and maternity services. No published studies on current practice were highlighted for this suggested area for quality improvement.

7 Suggested improvement area: treatment for children and young people

7.1 Summary of suggestions

Stakeholders noted high levels and potentially inappropriate prescribing of drugs to treat ADHD within the UK, with practitioners often preferring to prescribe drugs than recommended use of psychological treatments.

Stakeholders highlighted there is a need to promote use of non pharmacological treatments.

In addition, stakeholders suggested that educational policy can potentially discourage a therapeutic approach for supporting children noting that some children with ADHD are being excluded from school.

The following specific areas for quality improvement and potential development by the QSAC were highlighted:

- Increasing the use of psychological therapies.
- Support for children with ADHD in schools.

7.2 Selected recommendations from development source

Recommendations from the development source relating to these suggested improvement areas have been provisionally selected and are presented below to inform QSAC discussion.

Treatment for pre-school children

NICE CG 72 - Recommendation 1.5.1.1

Drug treatment is not recommended for pre-school children with ADHD.

NICE CG 72 - Recommendation 1.5.1.3 (KPI)

Healthcare professionals should offer parents or carers of preschool children with ADHD a referral to a parent-training/education programme as the first-line treatment if the parents or carers have not already attended such a programme or the programme has had a limited effect.

Treatment for school-aged children and young people with ADHD and moderate impairment

NICE CG 72 - Recommendation 1.5.2.1

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 nondrug interventions, or whose symptoms have not responded sufficiently to parent-training/education programmes or group psychological treatment.

NICE CG 72 - Recommendation 1.5.2.4 (KPI)

If the child or young person with ADHD has moderate levels of impairment, the parents or carers should be offered referral to a group parent-training/education programme, either on its own or together with a group treatment programme (cognitive behaviour therapy [CBT] and/or social skills training) for the child or young person.

Pre-drug treatment assessment

NICE CG 72 - Recommendation 1.5.4.2 (KPI)

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.

Treatment for school-aged children and young people with ADHD and moderate impairment

NICE CG 72 - Recommendation 1.5.2.3 (KPI)

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.

7.3 *Current UK practice*

Increasing the use of psychological therapies

No published reports were highlighted by respondents on increasing the use of psychological therapies and appropriateness of prescribing; this suggested area for quality improvement is based on stakeholders' knowledge and experience.

Support for children with ADHD in schools

Stakeholders made reference to the 2012 Office of the Children's Commissioner School Exclusions Inquiry which found that pupils with special educational needs were 8 times more likely to be permanently excluded from school than their peers⁸.

⁸ They never give up on you. Office of the Children's Commissioner: School Exclusion Enquiry 2012.

8 Suggested improvement area: appropriate drug treatment

8.1 Summary of suggestions

The suggested area for quality improvement is appropriate prescribing of drugs to treat ADHD in children and young people with severe ADHD and adults with ADHD.

It was also noted that drug doses should be titrated on an individual basis in order to maximise the patient's treatment response.

8.2 Selected recommendations from development source

Recommendations from the development source relating to this suggested improvement area have been provisionally selected and are presented below to inform QSAC discussion.

Treatment for school-age children and young people with severe ADHD (hyperkinetic disorder) and severe impairment.

NICE CG 72 – Recommendation 1.5.3.1(KPI)

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.

Treatment of adults with ADHD

NICE CG 72 – Recommendation 1.7.1.1

For adults with ADHD, drug treatment should be the first-line treatment unless the person would prefer a psychological approach.

How to use drugs for the treatment of ADHD

NICE CG 72 – Recommendation 1.8.1.3

During the titration phase, doses should be gradually increased until there is no further clinical improvement in ADHD (that is symptom reduction, behaviour change, improvements in education and/or relationships) and side effects are tolerable.

Initiation and titration of methylphenidate, atomoxetine and dexamfetamine in children and young people

NICE CG 72 - Recommendation 1.8.2.1

During the titration phase, symptoms and side effects should be recorded at each dose change on standard scales (for example, Conners' 10-item scale) by parents and teachers and progress reviewed regularly (for example, by weekly telephone contact and at each dose change) with a specialist clinician.

Initiation and titration of methylphenidate, atomoxetine and dexamfetamine in adults

NICE CG 72 - Recommendation 1.8.3.2

During the titration phase, symptoms and side effects should be recorded at each dose change by the prescriber after discussion with the person with ADHD and, whenever possible, a carer (for example, a spouse, parent or close friend). Progress should be reviewed (for example, by weekly telephone contact and at each dose change) with a specialist clinician.

8.3 *Current UK practice*

No published reports relating to current practice were highlighted by stakeholders for this quality improvement area; this area is based on stakeholder's knowledge and experience.

9 Suggested improvement area: treatment follow up

9.1 Summary of suggestions

Stakeholders identified that there was a need for practitioners who give drug treatments to people with ADHD to monitor for side effects. They highlighted that a failure to monitor for side effects can lead to serious adverse outcomes for patients.

Stakeholders identified there was a need for practitioners who are providing drug treatment or psychological therapies to review the treatment for effectiveness and adjust patients treatment plans accordingly. Treatment should be reviewed following initiation and annually for long term interventions.

- Monitoring side effects of drug treatment
- Reviewing effectiveness of treatment, drug and psychological

9.2 Selected recommendations from development source

How to use drugs for the treatment of ADHD

NICE CG 72 - Recommendation 1.8.1.5

Side effects resulting from drug treatment for ADHD should be routinely monitored and documented in the person's notes.

Monitoring side effects and the potential for misuse in children, young people and adults

NICE CG 72 – Recommendation 1.8.4.1

Healthcare professional should consider using standard symptom and side effect rating scales throughout the course of treatment as an adjunct to clinical assessment for people with ADHD.

NICE CG 72 - Recommendation 1.8.4.2

In people taking methylphenidate, atomoxetine, or dexamfetamine:

- height should be measured every 6 months in children and young people
- weight should be measured 3 and 6 months after drug treatment has started and every 6 months thereafter in children, young people and adults

- height and weight in children and young people should be plotted on a growth chart and reviewed by the healthcare professional responsible for treatment.

NICE CG 72 - Recommendation 1.8.4.6

In people with ADHD, heart rate and blood pressure should be monitored and recorded on a centile chart before and after each dose change and routinely every 3 months.

Duration, discontinuation and continuity of treatment in children and young people

NICE CG 72 – Recommendation 1.8.6.1

Following an adequate treatment response, drug treatment for ADHD should be continued for as long as it remains clinically effective. This should be reviewed at least annually. The review should include a comprehensive assessment of clinical need, benefits and side effects, taking into account the views of the child or young person, as well as those of parents, carers and teachers, and how these views may differ. The effect of missed doses, planned dose reductions and brief periods of no treatment should be taken into account and the preferred pattern of use should also be reviewed. Coexisting conditions should be reviewed, and the child or young person treated or referred if necessary. The need for psychological and social support for the child or young person and for the parents or other carers should be assessed.

Duration, discontinuation and continuity of treatment in adults

NICE CG 72 – Recommendation 1.8.7.1

Following an adequate response, drug treatment for ADHD should be continued for as long as it is clinically effective. This should be reviewed annually. The review should include a comprehensive assessment of clinical need, benefits and side effects, taking into account the views of the person and those of a spouse, partner, parent, close friends or carers wherever possible, and how these accounts may differ. The effect of missed doses, planned dose reductions and brief periods of no treatment should be taken into account and the preferred pattern of use should also be reviewed. Coexisting conditions should be reviewed, and the person treated or referred if necessary. The need for psychological, social and occupational support for the person and their carers should be assessed.

NICE CG 72 – Recommendation 1.8.7.2

An individual treatment approach is important for adults, and healthcare professional should regularly review (at least annually) the need to adapt patterns of use, including the effect of drug treatment on coexisting conditions and mood changes.

Poor response to treatment

NICE CG 72 - Recommendation 1.5.6.1

If there has been a poor response following parent-training/education programmes and/or psychological treatment and treatment with methylphenidate and atomoxetine in a child or young person with ADHD, there should be a further review of:

- The diagnosis
- Any coexisting conditions
- Response to drug treatment, occurrence of side effects and treatment adherence
- Uptake and use of psychological interventions for the child or young person and their parents or carers
- Effects of stigma on treatment acceptability
- Concerns related to school and/or family
- Motivation of the child or young person and the parents or carers
- The child or young person's diet.

9.3 Current UK practice

Monitoring side effects of drug treatment

No published reports were highlighted by stakeholders for this quality improvement area; this area is based on stakeholder's knowledge and experience.

A focussed literature review identified one UK study which reviewed current practice for monitoring for drug side effects in 38 patients within its CAMHS service. It found that although the service was almost fully compliant with monitoring the height and weight of patients at medication initiation it did not monitor the blood pressure and heart rate before and after dose changes⁹.

⁹ Soppit R et al. (2010) Drug Treatment for Attention Deficit Hyperactivity Disorder (ADHD). Journal of Clinical Audits 2 (2):62-66.

Reviewing effectiveness of treatment, drug and psychological

No published reports were highlighted by stakeholders for this quality improvement area; this area is based on stakeholder's knowledge and experience.

10 Suggested improvement area: transition to adult services

10.1 Summary of suggestions

Stakeholders reported low levels of provision for assessment and support of vocational and social issues during transition planning for school leavers.

Stakeholders also highlight that the provision of transition services for young people is not well established and the provision of treatment outside of the paediatric setting can be variable.

No further specific areas for quality improvement and potential development by the QSAC were highlighted.

10.2 Selected recommendations from development source

Recommendations from the development source relating to the suggested improvement area have been provisionally selected and are presented below to inform QSAC discussion.

Transition to adult services

NICE CG 72 - Recommendation 1.6.1.1

A young person with ADHD receiving treatment and care from CAMHS or paediatric services should be reassessed at school leaving age to establish the need for continuing treatment into adulthood. If treatment is necessary, arrangements should be made for a smooth transition to adult services with details of the anticipated treatment and services that the young person will require. Precise timing of arrangements may vary locally but should usually be completed by the time the young person is 18 years.

NICE CG 72 - Recommendation 1.6.1.2

During the transition to adult services, a formal meeting involving CAMHS and/or paediatrics and adult psychiatric services should be considered, and full information provided to the young person about adult services. For young people aged 16 years and older, the care programme approach (CPA) should be used as an aid to transfer between services. The young person, and when appropriate the parent or carer, should be involved in the planning.

NICE CG 72 - Recommendation 1.6.1.3

After transition to adult services, adult healthcare professionals should carry out a comprehensive assessment of the person with ADHD that includes

personal, educational, occupational and social functioning, and assessment of any coexisting conditions, especially drug misuse, personality disorders, emotional problems and learning difficulties.

10.3 Current UK practice

Stakeholders drew attention to NICE clinical guideline 72: The diagnosis and management of ADHD in children, young people and adults and the Department of Health National service framework for children, young people and maternity services as supporting evidence.

The guidance for commissioners of mental health services for young people making the transition from child and adolescent to adult services report, produced by the Joint Commission Panel for Mental Health¹⁰ summarises the current difficulties surrounding transition. It states that there is considerable variation across the country in the upper age limit for CAMHS and continuity of care is affected by the different care planning systems in use within CAMHS and adult mental health services (AMHS). The guidance also highlights a number of good practice examples of transition clinics across the country and summarises what a model transition services should look like.

The 2010 Transition from CAMHS to adult mental health services (TRACK) study¹¹ found that nearly a third of teenagers are lost from care during transition. They found that young people with neurodevelopmental disorders such as ADHD were most likely to fall through the care gap between CAMHS and AMHS. The limited number of adult services for ADHD was also identified as a barrier to effective transition which leads to a reduced continuity of care between the two services.

A 2011 study into the transition of young people into adult services found there was a lack of services available for adults and limited guidance on how best to achieve transition for young people into adult services¹².

¹⁰ Joint Commissioning Panel for Mental Health (2012). Guidance for commissioners of mental health services for young people making the transition from child and adolescent to adult services. Volume two: Practical mental health commissioning. www.jcpmh.info

¹¹ Transition from CAMHS to Adult Mental Health Services (TRACK): A Study of Service Organisation, Policies, Process and User and Carer Perspectives (January 2010). Report for the National Institute for Health Research Service Delivery and Organisation programme.

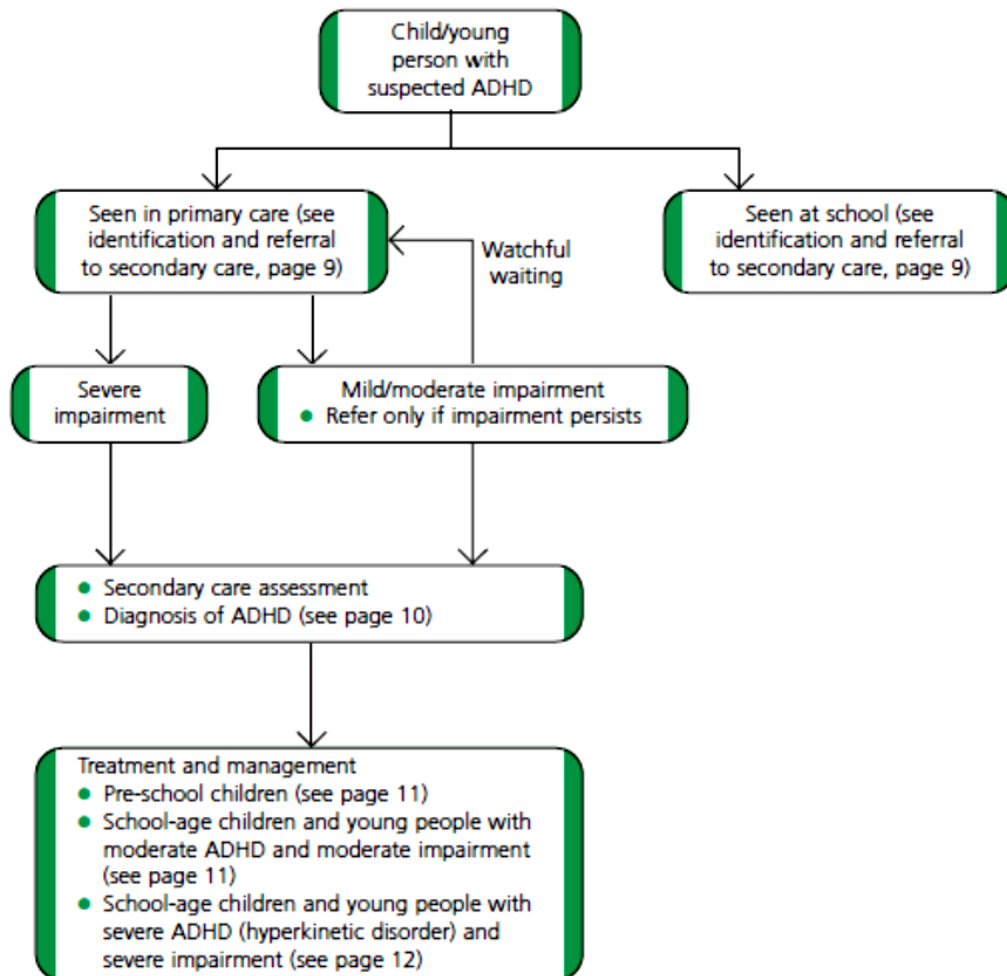
¹² Young et al. Avoiding the 'twilight zone': Recommendations for the transition of services from adolescence to adulthood for young people with ADHD. *BMC Psychiatry* 2011 11:174.

Appendix 1 Pathway diagrams (CG72)

Pathway diagrams are taken from NICE CG 72: Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults. Quick reference guide.

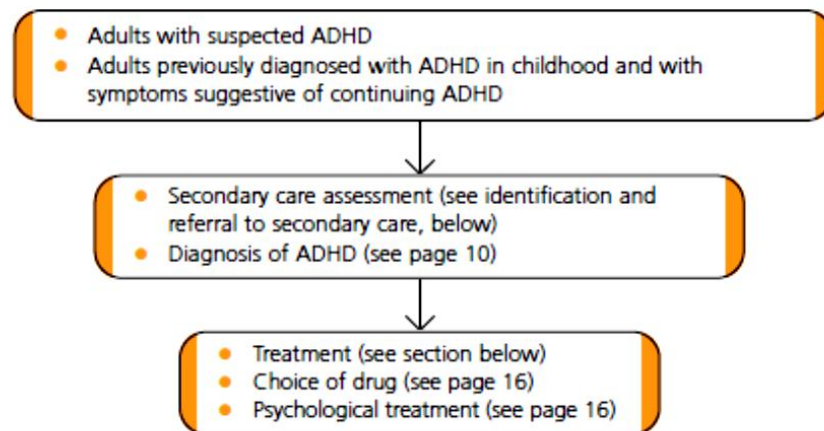
ADHD in children and young people

Care pathway



ADHD in adults

Care pathway



Appendix 2 Drug treatment (CG72)

Initial, titration and maximum doses

	Initial treatment	Titration and dose
Methylphenidate	Children aged 6 years and older and young people	Begin with low doses consistent with starting doses in the BNF. Offer modified-release preparations as a single dose in the morning. Offer immediate-release preparations in two or three divided doses.
	Adults	Begin with low doses (5 mg three times daily for immediate-release preparations or the equivalent modified-release dose). Increase dose according to response up to a maximum of 100 mg/day. Modified-release preparations may increase adherence and be preferred if there is concern about misuse or diversion. Normally offer these once daily, but no more than twice daily. Offer immediate-release preparations up to four times daily.
Atomoxetine	Children aged 6 years and older and young people	Up to 70 kg body weight: use a total starting dose of approximately 0.5 mg/kg/day. Over 70 kg body weight: use a total starting dose of 40 mg/day. Up to 70 kg body weight: increase dose after 7 days to approximately 1.2 mg/kg/day. Over 70 kg body weight: increase after 7 days up to a maintenance dose of 80 mg/day. Offer a single daily dose, or two divided doses to minimise side effects.
	Adults	Up to 70 kg body weight: use a total starting dose of approximately 0.5 mg/kg/day. Over 70 kg body weight: use a total starting dose of 40 mg/day. Up to 70 kg body weight: increase dose after 7 days to approximately 1.2 mg/kg/day. Over 70 kg body weight: increase after 7 days up to a maximum maintenance dose of 100 mg/day. The usual maintenance dose is 80 or 100 mg/day which can be offered in divided doses. Trial this dose for 6 weeks to determine effectiveness.
Dexamfetamine	Children aged 6 years and older and young people	Begin with low doses consistent with starting doses in the BNF. Offer divided doses, increasing to a maximum of 20 mg/day. Children aged 6–18 years: up to 40 mg/day may occasionally be required.
	Adults	Begin with low doses of 5 mg twice daily. Increase dose according to response up to a maximum of 60 mg/day. Offer divided doses, usually between two and four times daily.

BNF: British National Formulary

Monitoring side effects

Monitoring and intervention	Monitor according to drug treatment		
	Methylphenidate	Atomoxetine	Dexamfetamine
<p>Height</p> <ul style="list-style-type: none"> Measure every 6 months. Plot on a growth chart, which should be reviewed by the healthcare professional responsible for treatment. If growth is affected significantly consider a break in drug treatment over school holidays to allow 'catch-up' growth. 	Children and young people	Children and young people	Children and young people
<p>Weight</p> <ul style="list-style-type: none"> Measure 3 and 6 months after the start of treatment, and every 6 months thereafter. In children and young people, plot weight on a growth chart, which should be reviewed by the healthcare professional responsible for treatment. In adults, if weight loss is associated with drug treatment, consider monitoring body mass index and changing the drug if weight loss persists. Strategies to reduce weight loss, or manage decreased weight gain in children, include: <ul style="list-style-type: none"> taking medication either with or after food, rather than before meals eating additional meals or snacks early morning or late evening when stimulant effects have worn off obtaining dietary advice and eating high-calorie foods of good nutritional value. 	Children, young people and adults	Children, young people and adults	Children, young people and adults
<p>Cardiac function and blood pressure</p> <ul style="list-style-type: none"> Monitor heart rate and blood pressure and record on a centile chart before and after each dose change, and every 3 months. Sustained resting tachycardia, arrhythmia or systolic blood pressure greater than the 95th percentile (or a clinically significant increase) measured on two occasions should prompt dose reduction and referral to a paediatrician or physician. 	Children, young people and adults	Children, young people and adults	Children, young people and adults

Monitoring and intervention	Monitor according to drug treatment		
	Methylphenidate	Atomoxetine	Dexamfetamine
Reproductive system and sexual function <ul style="list-style-type: none"> Monitor for dysmenorrhoea, erectile dysfunction and ejaculatory dysfunction. 	–	Young people and adults	–
Seizures <ul style="list-style-type: none"> If exacerbated in a child with epilepsy or de novo seizures emerge, discontinue methylphenidate or atomoxetine immediately. Consider dexamfetamine instead after discussion with a regional tertiary specialist treatment centre. 	Children and young people	Children and young people	–
Tics <ul style="list-style-type: none"> Consider whether tics are stimulant-related, and whether tic-related impairment outweighs the benefits of ADHD treatment. If stimulant-related, reduce the dose or stop drug treatment or consider using atomoxetine instead. 	Children, young people and adults	–	Children, young people and adults
Psychotic symptoms (delusions, hallucinations) <ul style="list-style-type: none"> Withdraw drug treatment and carry out full psychiatric assessment. Consider atomoxetine instead. 	Children, young people and adults	–	Children, young people and adults
Anxiety symptoms including panic <ul style="list-style-type: none"> Where symptoms are precipitated by stimulants, particularly in adults with a history of coexisting anxiety, use lower doses of the stimulant and/or combined treatment with an antidepressant used to treat anxiety. Switching to atomoxetine may be effective. 	Children, young people and adults	–	Children, young people and adults
Agitation, irritability, suicidal thinking and self-harm <ul style="list-style-type: none"> Closely observe especially during the initial months of treatment or after a change in dose. Warn parents/carers about the potential for suicidal thinking and self-harm with atomoxetine, ask them to report these effects. Warn adults (aged 30 years or younger) of possible increased agitation, anxiety, suicidal thinking and self-harming behaviour, especially in the first weeks of treatment. 	–	Children, young people and adults	–
Drug misuse and diversion <ul style="list-style-type: none"> Monitor changes in potential for misuse and diversion, which may come with changes in circumstances and age. Modified-release methylphenidate or atomoxetine may be preferred. 	Children and young people	–	Children and young people

Appendix 3 Key priorities for implementation recommendations (CG72)

Key priorities for implementation recommendations which have been referred to in sections 4 - 8 of the main body of this report are highlighted in grey.

Training

- 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. [1.1.3.1]

Diagnosis of ADHD

- For a diagnosis of ADHD, symptoms of hyperactivity/impulsivity and/or inattention should:
 - meet the diagnostic criteria in DSM-IV or ICD-10 (hyperkinetic disorder)¹ and
 - be associated with at least moderate psychological, social and/or educational or occupational impairment based on interview and/or direct observation in multiple settings, and
 - be pervasive, occurring in two or more important settings including social, familial, educational and/or occupational settings.

As part of the diagnostic process, include an assessment of the person's needs, coexisting conditions, social, familial and educational or occupational circumstances and physical health.

For children and young people there should also be an assessment of their parents' or carers' mental health. [1.3.1.3]

Treatment for preschool children

- Healthcare professionals should offer parents or carers of pre-school children with ADHD a referral to a parent-training/education programme as the first-line treatment if the parents or carers have not already attended such a programme or the programme has had a limited effect. [1.5.1.3]

Treatment for school-age children and young people with ADHD and moderate impairment

- 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. [1.5.2.3]
- If the child or young person with ADHD has moderate levels of impairment, the parents or carers should be offered 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. [1.5.2.4]

Treatment for school-age children and young people with severe ADHD (hyperkinetic disorder) and severe impairment

- 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. [1.5.3.1]

Pre-drug treatment assessment

- 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. [1.5.4.2]

Choice of drug for children and young people with ADHD

- When a decision has been made to treat children or young people with ADHD with drugs, healthcare professionals should consider:
 - methylphenidate for ADHD without significant comorbidity
 - methylphenidate for ADHD with comorbid conduct disorder
 - methylphenidate or atomoxetine when tics, Tourette's syndrome, anxiety disorder, stimulant
 - misuse or risk of stimulant diversion are present
 - atomoxetine if methylphenidate has been tried and has been ineffective at the maximum tolerated dose, or the child or young person is intolerant to low or moderate doses of methylphenidate. [1.5.5.3]

Treatment of adults with ADHD

- Drug treatment for adults with ADHD should always form part of a comprehensive treatment programme that addresses psychological, behavioural and educational or occupational needs. [1.7.1.4]
- Following a decision to start drug treatment in adults with ADHD, methylphenidate should normally be tried first. [1.7.1.5]

Appendix 4 Suggestions from stakeholder engagement exercise

See table 2 section 3 for details of abbreviations for stakeholders.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
001	RCN	Standard of assessment	<p>We find that often commissioners initially request service and do not carry out their own assessment even though patients were transferring from child to adult services and assessments validated in children are not necessarily validated in adults.</p> <p>It would be helpful for NICE to consider the quality and evidence base for assessments in its recommendations and make specific recommendations about the use of tools and scales that are specifically validated in the populations that they are to be used in.</p> <p>Also, the importance of the standard for assessments which span all health domains and are reviewed on a regular basis when prescribing is done via a shared care agreement with GPs would be helpful.</p>	There is little guidance/standard around the quality aspect of setting up adult ADHD services and few working examples to call on.	
002	COT	Key area for quality improvement 1	There is evidence that children with ADHD are restricted in the	Identification of the impact of ADHD on the child and family is an important aspect for	See Department of Health (2004). National service

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		Assessment of activity skills and participation	types of activities they participate in and their level of engagement. NICE clinical guideline 72 does not stipulate how and who is best to ascertain information regarding pervasive impact of ADHD with subsequent poorly defined criteria for referral to Occupational Therapy.	collaborative working and determining priority areas for intervention. Defining meaningful child and family centred goals is essential to support positive intervention outcomes.	<p>framework for children, young people and maternity services: Core standards . See NICE clinical guideline 72 (2009) for ADHD, and assessment recommendations to detail the full range of problems and their history, together with family, health, social, educational and demographic information.</p> <p>Evidence: Significant functional impairment in adolescence from childhood ADHD: (OR_3.4, 95% CI 1.7-6.9), reduced quality of life (OR_2.5, 95% CI 1.3-4.7) Columbia Impairment Scale and Child Health Questionnaire respectively, Bussing et al. J. Am. Acad. Child Adolesc. Psychiatry, 2010;49(6): 595–605</p>
003	COT	Intervention of co-morbid sensory/motor difficulties	Children with sensory over-responsivity and ADHD are at significantly higher risk of anxiety.	Individual programmes for diagnosis and intervention differ in their acknowledgement of the extent of co-morbidity and hence	See NICE Clinical Practice Guidelines for ADHD which report “Remedial

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			<p>Co-morbid movement difficulties create substantial functional impairments for children with ADHD.</p>	<p>investigations in these areas have different referral criteria to Occupational Therapy in particular. Subsequently therapy interventions vary considerably in the type and duration of therapy and involve variable amounts of home and school input.</p>	<p>disciplines 20 such as occupational therapy and speech and language therapy are sometimes involved in helping the development of individual children. Evidence: Sensory processing difficulties are associated with functional and behavioural limitations in ADHD. Reynolds S, Lane SJ (2009) Sensory overresponsivity and anxiety in children with ADHD. American Journal of Occupational Therapy, 63, 433–440. Mangeot et al. Developmental Medicine & Child Neurology 2001, 43: 399–406 Movement impairments also impact on functional outcomes for children with ADHD. Gustafsson et al. Dev Med Child Neurol 2009 DOI: 10.1111/j.1469-8749.2009.03407.x</p>

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
004	COT	Key area for quality improvement 3 Transition planning	Children with ADHD often under achieve academically and difficulties organising their time, meeting deadlines etc impacting on opportunities for further education and also employment prospects (Young et al., 2003). Assessment of activity performance and skills and intervention/advice for the school leaver will differ from that provided to younger people with ADHD. Occupational Therapists can be best placed to identify functional deficits impacting on further education and employment and consideration of referral to OT services/inclusion of OTs within multi-disciplinary teams should be clearly outlined.	The economic impact of ADHD is significant with many young people failing to meet expectations for further education/employment compared to other family members. Services vary considerably in their inclusion of occupational therapists within the team or broader multi-disciplinary team.	See Department of Health (2004). National service framework for children, young people and maternity services: Core standards and NICE Clinical Practice Guidelines for ADHD Comments recommending multi-agency working to include occupational therapists during transitional services would perhaps contribute towards meeting the needs of those with ADHD and working alongside future employers and occupational impact
005	RCPCH	Diagnostic practice	A sound diagnosis and formulation informs appropriate management. NICE guidance is clear on what is required.	Audit locally and experience nationally reveal inconsistencies in whether schools are consulted, the quality of assessment used to ascertain developmental level, and access to psychiatry opinion in complex cases.	
006	RCPCH	Management in schools	Schools can make a key difference for children with ADHD, as per NICE guidance.	Educational policy trends have emphasised discipline and academic results, discouraging a therapeutic approach within classrooms towards children with ADHD. There is evidence that children may be	See children's commissioner's report on exclusion: www.childrenscommissioner.gov.uk/info/schoolexclu

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				being excluded unfairly.	sions
007	RCPCH	Access to ongoing psychosocial support	Children with ADHD are at high risk of adverse psychosocial consequences, e.g. substance abuse or mental health problems.	Many children with ADHD are looked after by paediatricians with little or no back-up from social care or CAMHS. They do not know when or how to access this support.	ADDISS report: http://www.addiss.co.uk/payingenoughattention.pdf
008	RCPCH	A clearly defined and commissioned referral pathway for possible ADHD in a locality suitable for all learning abilities.	No further detail provided		
009	RCPCH	Joint CAMHS/child health service provision	No further detail provided		
010	RCPCH	Parent groups for behaviour management in every locality (as per NICE guideline) and evidence for the recommendation that families must attend before medication is used.	No further detail provided		
011	RCPCH	Guidance on tools to be used in the NHS for diagnosis.	No further detail provided		
012	RCPCH	Services for transition to adult care.	No further detail provided		
013	ASCL	Delay in diagnosis	Young people can lose valuable education time, and their condition worsens, if not diagnosed quickly.	Young people can lose valuable education time, and their condition worsens, if not diagnosed quickly.	ASCL members in schools report variable rapidity of response to referrals. In some areas 014access to suitably qualified professionals is severely

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					limited.
014	ASCL	Over-diagnosis	Medicalisation of behaviour within the normal spectrum is not good for the young person or the institutions (for example schools) that serve them.	<p>This is becoming increasingly common as parents seek out their own practitioners to give them reassurance that their child is not 'naughty' or badly brought up but suffering from a condition.</p> <p>This is damaging for those who are genuinely suffering from the condition.</p>	Reports from ASL members who lead schools.
015	Lilly	Better transition from child and adolescent mental health services (CAMHS) to adult mental health services	<p>ADHD is a common behavioural mental disorder with onset in childhood before the age of 7 years (NICE 2008). Longitudinal studies have shown that symptoms of ADHD may decline in adolescence but that the majority of people with ADHD remain partially or fully symptomatic at the age of 25 and approximately 15% are fully symptomatic in early adulthood (Faraone et al. 2006).</p> <p>In the latest Adult Psychiatric Morbidity Survey (2007) 8.2% of the general adult population in England were screened positive for ADHD (Bebbington et al. 2009).</p> <p>Despite the need for effective adult services, the transition from child to adult services in the UK is not well established at the</p>	<p>The Framework for local authority and NHS commissioners of mental health and wellbeing services (March 2011) mentions that services that meet the needs of young people and provide safe and co-ordinated transitions between CAMHS and adult services are rare.</p> <p>The transition from child to adult services was clearly identified as an issue in the UK several years ago (Nutt et al. 2007) yet remains inadequate today. The NICE ADHD Commissioning Tools (NICE, 2012) indicates that: "young people often leave children's services with no readily identifiable adult service to support them, even though most young people with a sustained diagnosis will go on to have significant difficulties in adulthood". A third of teenagers are lost from care during transition and a further third experience an interruption in their care (Guidance for commissioners of mental health services for young people making the transition from</p>	<p>NICE. Attention Deficit Hyperactivity Disorder: The NICE guideline on diagnosis and management of ADHD in children, young people and adults. Full Guideline. 2008. The British Psychological Society and The Royal College of Psychiatrists. Faraone SV, Biederman J, Mick E. The Age-dependent Decline of Attention Deficit Hyperactivity Disorder: A Meta-analysis of Follow-up Studies. Psychological Medicine 2006; 36:159-65. Bebbington P, Brugha T, Coid J, Crawford M, Deverill C, D'Souza J, et al. Adult Psychiatric Morbidity in England,</p>

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			<p>moment and young adults may have difficulty in obtaining treatments after discharge from the paediatric services (Wong et al. 2009).</p>	<p>child and adolescent to adult services. Volume 2).</p>	<p>2007. 2009. London, The NHS Information Centre for Health and Social Care. ICK Wong, P Asherson, A Bilbow, S Clifford, D Coghill, R DeSoysa, C Hollis, S McCarthy, M Murray, C Planner, L Potts, K Sayal and E Taylor. Cessation of attention deficit hyperactivity disorder drugs in the young (CADDY) – a pharmacoepidemiological and qualitative study. Health Technology Assessment 2009; Vol. 13: No. 50. Practical Mental Health Commissioning A framework for local authority and NHS commissioners of mental health and wellbeing services. Volume 1 March 2011. http://www.rcpsych.ac.uk/pdf/JCP-MH%20-%20Vol%20One%20(web%20copy%2011_04_05).p</p>

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					<p>df Nutt DJ, Fone K, Asherson P, Bramble D, Hill P, Matthews K, Morris KA, Santosh P, Sonuga-Barke E, Taylor E, Weiss M, Young S; British Association for Psychopharmacology. 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. <i>J Psychopharmacol.</i> 2007;21(1):10-41. Commissioning a service for the diagnosis and management of ADHD in adults. NICE March 2012. http://www.nice.org.uk/usin/guidance/commissioning/guides/adhd/adhdcommissioning.jsp Guidance for commissioners of mental health services for young</p>

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					<p>people making the transition from child and adolescent to adult services. Volume 2. http://www.rcpsych.ac.uk/pdf/JCP-MH%20CAMHS%20transitions%20(March%202012).pdf</p>
016	Lilly	Inclusion of ADHD in adult mental health services	<p>In the latest Adult Psychiatric Morbidity Survey (2007) 8.2% of the general adult population in England were screened positive for ADHD (Bebbington et al. 2009). The NICE ADHD Commissioning tool (March 2012) comprehensively details the large number of benefits, key clinical issues and relevant national priorities that commissioning an effective service for the diagnosis and management of ADHD in adults would address. Please see link in Supporting information. However, the number of consultants offering adult services for ADHD in England and Wales is thought to be low (Edwin & McDonald, 2007; Young et al. 2011).</p>	<p>Despite evidence of an adult ADHD population with unmet needs and clear benefits outlined by NICE for commissioning adult ADHD services, there are still too few adult services available. The NICE ADHD Commissioning Tools (NICE, 2012) states that: "identification of ADHD in adults in the UK is uncommon", and "there are very few specialist or generic mental health services in the NHS for adults with ADHD, despite evidence of effectiveness". This means that there are a number of adult patients in whom the diagnosis of ADHD has been unidentified and are likely to be treated for alternative diagnoses, such as bipolar disorder, or self medicate, for example with alcohol. NICE suggest this may account for the high rates of contact reported with mental health services for adults with ADHD and in turn the associated cost implications (Commissioning a service for the diagnosis and management of ADHD in adults. NICE 2012).</p>	<p>Bebbington P, Brugha T, Coid J, Crawford M, Deverill C, D'Souza J, et al. Adult Psychiatric Morbidity in England, 2007. 2009. London, The NHS Information Centre for Health and Social Care. Edwin F & McDonald J. Services for adults with attention-deficit hyperactivity disorder: national survey. The Psychiatrist (2007) 31: 286-288. Young S, Murphy CM, Coghil D. Avoiding the 'twilight zone': recommendations for the transition of services from adolescence to adulthood for young people with</p>

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					<p>ADHD. BMC Psychiatry 2011, 11:174</p> <p>Commissioning a service for the diagnosis and management of ADHD in adults. NICE March 2012. http://www.nice.org.uk/usin/guidance/commissioning/guides/adhd/adhdcommissioning.jsp</p>
017	Lilly	Shared care agreements between primary and secondary care for existing services	Currently many ADHD patients that could be managed effectively in primary care remain under the care of specialist services due to a lack of shared care agreements. This lack of movement of patients from secondary care back into primary care limits the number of patients that can obtain referrals into secondary care.	The Joint Commissioning Panel for Mental Health Commissioning's aim is to: "improve access to, and the delivery of, mental health services with better outcomes for individuals with a mental health disorder (and their carers)". Putting in place shared care agreements that would allow patients to be managed in primary care would free up resources and allow access to secondary care for other patients that are currently unmanaged.	There is a lack of data on the number of shared care agreements in the UK although we understand this to be very low.
018	Lilly	Screening and identification of people with ADHD and subsequent patient registers	Recognition of ADHD is important to ensure appropriate treatment and because it is a risk factor for a number of comorbid psychiatric conditions, substance abuse and criminality (Rao & Place, 2011; Mannuzza et al. 2008). There are currently very little data in the UK about ADHD – be that current systems in place for care,	Putting in place processes for screening and identification of patients would begin to address the issues of undiagnosed and untreated ADHD. GP registers would provide data on the prevalence of ADHD across the country and current treatment pathways, and would encourage follow up with patients and improvement in outcomes.	Commissioning a service for the diagnosis and management of ADHD in adults. NICE March 2012. http://www.nice.org.uk/usin/guidance/commissioning/guides/adhd/adhdcommissioning.jsp Rao P & Place M. Prevalence of ADHD in 4

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			<p>referral pathways or outcomes for patients. In addition it is thought that a number of ADHD patients remain unidentified (Commissioning a service for the diagnosis and management of ADHD in adults. NICE 2012; Rao & Place, 2011).</p>		<p>general adult outpatient clinics in North East England. Progress in Neurol & Psych 2011 15(5):7-11. Mannuzza S, Klein RG, Moulton JL 3rd. Lifetime criminality among boys with attention deficit hyperactivity disorder: a prospective follow-up study into adulthood using official arrest records. Psychiatry Res. 2008;160(3):237-46</p>
019	Lilly	Clear referral criteria for patients with suspected ADHD	The referral routes for patients with ADHD vary considerably across the country making it difficult for patients to access services.	The lack of clear routes into secondary care means that patients may find it difficult to access services and that there is great inequality across the country or 'postcode lottery' in terms of services available.	There is a lack of information available on the referral routes in the UK, although our understanding is that this varies greatly across the country.
020	AEP	To promote the increased use of psychological treatments due to professional concerns about the increased risk to children of 'false positive' diagnoses as a result of revisions to the DSM manual. This may lead as a consequence to	Over the past few years the AEP has received increased numbers of reports from our members that children with behavioural difficulties are being prescribed drugs without full discussions with other professionals to see if other strategies or approaches could be used instead of, or at least alongside, the medication.	The AEP is concerned about some of the practices around the prescription of powerful psycho-stimulant drugs, such as Ritalin, to manage children's behavioural issues which Educationalists feel fall within the normal range. Educational psychologists take forward a wide range of work around children's needs, child development and the emotional and social wellbeing of children.	More and more studies are identifying long term side effects of using these drugs, including major sleep disturbance, tremors, tardive dyskinesia, and even sudden heart failure or suicide.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		<p>inappropriate prescribing of psychotropic drugs.</p>	<p>While we recognise that NICE guidance advises that psychological treatments should occur first, we don't not feel this guidance is always being followed due to pressures of work and the shortage of time to make the multi-modal assessments advised by NICE.</p> <p>The AEP feels that there is insufficient evidence to have confidence in what the long-term neurological impact of these drugs might be on the developing brains of children and would like to see increased use of psychological treatments.</p>	<p>Figures from the Department of Health show that the number of prescriptions for these drugs has gone up from 158,000 prescriptions in 1999 to 610,000 in 2009.</p> <p>Behaviours develop over a long period of time, often with a range of complex causes; we can't "cure" the behaviours we don't like with a quick fix of medicine. They usually require careful management using the 'Team Around the Child' methodologies.</p> <p>Simply relying on medication is no solution; the AEP believes that the Quality Standard should advocate a more collaborative approach to the treatment of children with conditions such as ADHD – involving GPs, teachers, educational psychologists and healthcare professionals alongside the child's parents – that is not reliant on medication, but considers a comprehensive programme of treatment and therapies.</p> <p>It is of particular concern to the AEP that the number of children aged under six, and as young as three, who have been prescribed ADHD drugs to address challenging behaviour, including inattentiveness and hyperactivity, is rising substantially.</p>	<p>It is becoming a common practice that children are prescribed with a regimen of more than one strong medication, e.g. Ritalin, an antipsychotic drug and/or an antidepressant at the same time. There is little to no evidence about the mid to long term side-effects which these cocktails of drugs are having on the development of children's brains and on their overall psychological wellbeing.</p> <p>Moreover, clinical studies show that the beneficial effects of psycho-stimulant medication are not sustained over the long-term, necessitating stronger and stronger dosages to be prescribed over time. It is also becoming a common practice for children to be prescribed stronger dosages than recommended in the morning and at lunchtime as a "kick-start" or "top-up"</p>

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					<p>dose so that medication lasts the full school day. Some children in the West Midlands and around the country have regularly been prescribed well above the maximum dosage proposed by the manufacturers of 72mg of Methylphenidate and sometimes this has been between 100 – 144 mg which when challenged was immediately reduced, indicating the concern was correctly founded. There were 30 cases of this magnitude just in one small geographical region.</p> <p>An informal survey of educational psychology practitioners across the West Midlands has shown that there are over 100 children aged under six on psycho-stimulant medication. This is reaffirmed across the country by our members.</p>

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					<p>The youngest case was of a child aged two and a half years which was raised as a major concern by the Educational Psychologist involved. The child's primary presenting problem was anxiety which is a contra-indicator to the use of psycho-stimulants according to NICE Guidelines. This we feel is not an isolated case where these guidelines on anxiety have been ignored. Two local authorities reported 15+ such cases, three between 10 – 14 cases, and four 5-10 such cases. All the casework psychologists have major professional concerns supported by their 'Professional Codes of Practice' about such risky prescribing patterns.</p>
020	SCM	<p><u>Assessment:</u> Recognition and diagnosis of ADHD</p> <p>A comprehensive diagnostic assessment should include</p>	<p>Rates of recognition and diagnosis of ADHD very widely between different services and parts of the country.</p> <p>Diagnostic 'over shadowing' by</p>	<p>Missed diagnosis may result in failure to use appropriate evidenced-based treatment and leads to avoidable impairments</p>	<p>Diagnostic rates for ADHD in the U.K. are among the lowest in Europe</p>

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		measures of developmental level, symptom severity, functional impairment and co-morbid conditions	<p>co-morbid conditions such as ODD/CD may lead to a diagnosis of ADHD not being made.</p> <p>Practitioners find it hard to reliably distinguish between mild/moderate and severe ADHD as described in NICE Guidance.</p> <p>Treatment of ADHD is still important in the presence of co-morbidities.</p>		
021	SCM	<p><u>Recording health outcomes (i):</u> monitoring adverse effects of medication</p> <p>Practitioners delivering pharmacological and psychosocial interventions for ADHD should record health outcomes at each appointment and use the findings to adjust delivery of interventions</p>	Monitoring for adverse effects of ADHD medications is inconsistent despite NICE Guideline recommendations	Failure to routinely monitor for adverse effects may lead to serious and avoidable adverse outcomes	POMH-UK audit of monitoring ADHD medications
022	SCM	<p><u>Recording health outcomes (ii):</u> monitoring treatment response</p> <p>Practitioners delivering pharmacological and psychosocial interventions</p>	Outcome measures are infrequently used and are not benchmarked against agreed standards.	Lack of objective benchmarking of outcomes makes it difficult for clinicians to optimise treatment. In practice, standard criteria are not being used to determine whether treatment outcome is poor, moderate or good.	POMH-UK audit of monitoring ADHD medications

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		for ADHD should record health outcomes (using generic and condition specific measures) at each appointment and use the findings to adjust delivery of interventions			
023	SCM	<p><u>Practitioner competence:</u> Practitioners assessing people for ADHD and delivering pharmacological, psychological or psychosocial interventions should receive training and regular supervision that ensures they are competent in assessment and diagnosis of ADHD and in delivering interventions of appropriate content for people with ADHD and in accordance with NICE guidance</p>	Assessment and treatment of ADHD is currently delivered by a range of practitioners with very variable levels of training and competence.	Practitioner competence is crucial in delivering higher quality assessment and better treatment outcomes.	
024	SCM	<p><u>Psychosocial intervention for young people with mild to moderate ADHD:</u> Young people with mild and moderate ADHD should be offered psychosocial interventions</p>		Provision of psychosocial interventions is variable	

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025	SCM	<p><u>Medication for people with ADHD:</u></p> <p>Medication should be offered to young people (excluding pre-schoolers) with severe ADHD and adults with ADHD. Doses should be titrated upwards on an individual basis to maximise treatment response.</p>	<p>Medication (methylphenidate, atomoxetine and dexamfetamine) is the most effective intervention for ADHD.</p> <p>Doses of medication should be slowly titrated upwards using outcome monitoring to minimise adverse effects and maximise benefits.</p>	Improvement of treatment outcomes.	
026	SCM	<p><u>Review of treatment effectiveness:</u></p> <p>The effectiveness and need for on-going pharmacological and psychosocial interventions should be formally made 8 to 12 weeks after starting treatment, and re-assessed annually for long-term interventions. Treatment plans should be adjusted if there is an inadequate response or lack of response.</p>	The effectiveness of treatment requires formal review both in the early phase and for longer-term interventions (annual reviews)	Ineffective treatment should be adjusted or changed to optimise outcomes. Long-term treatment (medication) should only be continued if there is evidence of persisting benefits.	
027	SCM	<p><u>Transition to adult care at age 18:</u></p>	Many young people with ADHD fail to make a successful transition to adult services at age	Young people with ADHD who drop-out of services at age 18 in an unplanned manner are at increased risk for adverse outcomes.	TRACK study and NIHR HTA CADDY study.

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		The need for on-going care into adult life should be formally assessed at age 17 and where appropriate transition arrangements made to a service with competence in managing ADHD in adults	18.		