National Institute for Health and Clinical Excellence

ADHD Quality standard
Quality Standard Consultation Comments Table
21st February- 21st March 2013

ID	Comment ID	Stakeholder	Statement No	Comment on	Comments Please insert each new comment in a new row.	Response Please respond to each comment
016	1	Adult Attention Deficit Disorder – UK (AADD-UK)	General		Looking at the 4 general questions for consultation, we are concerned that the standards are only looking at the healthcare outcomes for individuals with ADHD. Nice rightly acknowledges ADHD affects many areas of an individual's life. It is surely incumbent upon them to openly state the need for all government departments to recognise that specifying health outcomes is only one part of the equation and that without integrated working, at the highest level, any improvement in improved health outcomes is, at the best, going to be very slow in coming	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
016	2	Adult Attention Deficit Disorder – UK (AADD-UK)	General		You only list 6 draft quality statements so we suggest the addition of 9 more quality statements. These suggested additional quality statements are in line with recommendations in CG72 as listed in the Full Version of CG72 in Section 12 Summary of Recommendations, pages 360-380 in addition to also contributing to the improvements outlined in the 3 national frameworks you have listed in your draft introduction. Our suggested additional quality statements will also aid the research recommendations as listed in the full version of CG72 beginning on page 380. For ease of understanding, we have listed them	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other

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					in the following rows starting with the new quality standard number 7.	evidence-based guideline recommendations continue to be implemented.
009	3	Association for Family Therapy and Systemic Practice	General		This response is submitted by AFT, the Association for Family Therapy and Systemic Practice (www.aft.org.uk). AFT is committed to supporting developments in practice, research, training and delivery of high quality therapeutic services for families and other caring groups, and is the UK's leading organisation for professionals working systemically with individuals, couples, families and other networks of care across the lifespan. AFT's membership is multi-disciplinary and includes Family and Systemic Psychotherapists (aka family therapists), clinical psychologists, psychiatrists, GPs, nurses, social workers, teachers, occupational therapists, health visitors and others committed to developing their systemic practice skills and understandings.	Thank you for your comments.
009	4	Association for Family Therapy and Systemic Practice	General		On the eve of publication of DSM5, AFT alerts the QS team to the comments of Dr Allen Frances, psychiatry professor emeritus at Duke, who chaired the DSM-4 task force. Among the 'top ten changes' within DSM-5 that especially concern Dr Frances, he includes: *' DSM 5 will likely trigger a fad of Adult Attention Deficit Disorder leading to widespread misuse of stimulant drugs for performance enhancement and recreation and contributing to the already large illegal secondary market in diverted prescription drugs.'* Frances, A (2012) DSM5 in Distress: Psychology Today	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.

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					AFT notes the statistics cited and language used in the QS introduction – that 'ADHD is thought to affect about 3-9% of school-age children and young people in the UK.... 8% of adults within England have ADHD'. AFT notes that 'having ADHD' is different from 'displaying behaviours often currently described as ADHD'. It also notes that, on the basis of statistics cited, nearly one tenth of the UK's adult population is deemed to have this 'disorder'. AFT joins those concerned at the continuing pathologising and biologising of human life.	
009	5	Association for Family Therapy and Systemic Practice	General		AFT joins many others in having serious concerns at the rates of stimulant medication prescribed to children and young people Goldacre, B (2010) The Stigma Gene: http://www.badscience.net/category/medicalisation/	Thank you for your comment.
009	6	Association for Family Therapy and Systemic Practice	General		AFT notes that, whether or not ADHD is accepted as a valid and useful diagnosis, 'Family intervention is highly appropriate for families with children who are referred for help'. Lange, G., Sheerin, D., Carr, A., Dooley, B., Barton, V., Marshall, D., Mulligan, A., Lawlor, M., Belton, M. and Doyle, M. (2005), Family factors associated with attention deficit hyperactivity disorder and emotional disorders in children. Journal of Family Therapy, 27: 76–96. doi: 10.1111/j.1467-6427.2005.00300.x Stratton, P (2010). The Evidence Base Of Systemic Family and Couples. Therapy. Association for Family Therapy, UK	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.

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009	7	Association for Family Therapy and Systemic Practice	General		AFT recognises the importance of, and ethical imperative in, inviting and engaging in continuing debates about the diagnosis and treatment of ADHD, and is thus grateful for this opportunity to consider and comment on this draft quality standard. AFT offers its comments on the QS in the context of its more general comments about ADHD diagnosis and treatment, above.	Thank you for your comment.
009	8	Association for Family Therapy and Systemic Practice	Introduction		The obvious is sometimes worth stating. There is a serious and active debate involving all relevant disciplines as to the validity and usefulness of ADHD as a diagnosis. ADHD is a term used to describe a collection of symptoms. Precipitating and maintaining factors of these symptoms may be rooted in a child or young person's life experiences (including trauma, abuse or parental mental health difficulties), important relationships and/or social and cultural contexts. Unless these possibilities are rigorously considered and addressed in assessment and intervention, and practitioners adequately trained to recognise and effectively respond to them, we are at serious risk of pathologising vulnerable children, young people and adults struggling with life's difficulties rather than a 'mental disorder'. AFT recognises the importance of effective services for families and individuals living with symptoms often diagnosed as 'ADHD', and also	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.

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					hopes the QS Consultation will join it in supporting those practitioners and services also working to actively consider and respond to alternative explanations Timini, S and Leo, J (Eds) (2009) *Rethinking ADHD: From Brain to Culture*. Palgrave Macmillan: London Wilson, J. (2012), A social relational critique of the biomedical definition and treatment of ADHD; ethical practical and political implications. Journal of Family Therapy. doi: 10.1111/j.1467-6427.2012.00607.x	
009	9	Association for Family Therapy and Systemic Practice	Introduction		Autistic Spectrum Disorders is not mentioned in the list of common co-existing conditions, although they are commonly co-morbid with clusters of symptoms currently defined as 'ADHD'. The inclusion of 'motor control' with no further explanation is unhelpfully vague.	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
006	10	Association of School and College Leaders	General		ASCL welcomes the aspirations set out in this quality standard. It is not convinced, however, that resources are available to meet it.	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. Cost effectiveness is considered by the quality standards advisory committee during development of quality standards and a supporting document has

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						been published alongside the standard reviewing the potential cost impact and implications for commissioners and service providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
006	11	Association of School and College Leaders	General		The Association of School and College Leaders (ASCL) represents over 17,000 heads, principals, deputies, vice-principals, assistant heads, business managers and other senior staff of maintained and independent schools and colleges throughout the UK. ASCL has members in more than 90 per cent of secondary schools and colleges of all types, responsible for the education of more than four million young people. This places the association in a unique position to consider this issue from the viewpoint of the leaders of secondary schools and colleges	Thank you for your comment.
010	12	Autism Rights Group Highland	General		Throughout DSM IV is referred to, release date for DSM V is May 2013, there should be some facility for updating / reflecting this change.	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.

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010	13	Autism Rights Group Highland	Introduction		The description of ADHD does not mention that this is a neurological condition; the implication is that ADHD is only behavioural – this should be clarified / amended. Co-Existing conditions, autism should be added here as it is a co-existing condition for a significant number of people and needs to be specifically mentioned.	Thank you for your comment.
021	14	Avon and Wiltshire NHS Trust Adult ADHD clinic	General		Objective, comparable, valid measures of recovery and well-being. This would help give tangible substance to the NICE guidelines for ADHD as a while. They would also help to generate comparable data against other interventions in mental health. Our particular tool is an adaption of the Recovery Star (Sainsbury Ctr) which we have converted to a likert method. This is empirically similar to the visual Recovery star used igeneral mental health.	The quality standards advisory group reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard. The measures have been revised for the final quality standard to improve clarity.

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021	15	Avon and Wiltshire NHS Trust Adult ADHD clinic	General		We conducted a large audit of service users in 2012, which was largely based on the NICE audit support tool, In addition to this, we also conducted an audit of the Recovery and Well-Being questionnaire on the same patient group. Of the sample of 89 service users, 56 (63%) completed the Recovery and Well-being questionnaire (Adult ADHD Service, 2011) at assessment. We found that overall there was a mean drop of 'problem frequency' of 44% In patients from before and after treatment. The added advantage we have is the ability to measure take-up of social measures (involvement with the police, work and employment matters) that this tool facilitates. Our comparison of these data to recovery data in other mental health conditions underlines the very good cost-benefit return for treating ADHD in adults. Cost-benefit analysis is a wider measure than cost-effectiveness measures more commonly used in medicine, but which may miss the important considerations that need to be given to the social determinants of health (as commented originally by the Black report on the state of the NHS in 1979).	Thank you for your comment.

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008	16	British Association for Adoption and Fostering (BAAF)	General		This response is being submitted on behalf of the BAAF Health Group, which is also a special interest group of the Royal College of Paediatrics and Child Health (RCPCH). The Health Group was formed to support health professionals working with children in the care system, through training, the provision of practice guidance and lobbying to promote the health of these children. With over 500 members UK-wide, an elected Health Group Advisory Committee with representation from community paediatricians working as medical advisers for looked after children and adoption panels, specialist nurses for looked after children, psychologists and psychiatrists, the Health Group has considerable expertise and a wide sphere of influence. Our area of concern is the particularly vulnerable group comprised of looked after and adopted children and young people.	Thank you for your comment.
008	17	British Association for Adoption and Fostering (BAAF)	General		Please note that we are using 'child' to include all children and young people who are looked after.	Thank you for your comment.
008	18	British Association for Adoption and Fostering (BAAF)	General		We are disappointed by the scope of the quality standard. There appears to be more of a concern about measurement of the work than on the quality of the assessments and interventions. Further, as written it appears that all will be well if ADHD if standards 1-6 are followed, yet what about those who do not fit these boxes, e.g. those with mild or severe symptoms? Children may need to be seen for ongoing services, or at different stages of development, and particularly transition periods in growing up, not just at annual review IF they	It is not expected that all statements would apply to all groups covered by the scope.

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					are taking medication.	
008	19	British Association for Adoption and Fostering (BAAF)	General		The standard would benefit from a measurement of the quality of the assessment offered, whereas the focus seems to be simply on the assessment occurring.	We have considered all suggestions for suitable outcome measures. The QSAC prioritised measures they considered most important for measuring the quality statements. The quality measures aim to improve the structures and processes of care that are considered to be linked to outcomes, as well as specifying outcomes directly where the QSAC felt able to define these.
008	20	British Association for Adoption and Fostering (BAAF)	General		There is relatively little attention on the multidisciplinary work which, when carried out effectively, can make a significant difference to the quality of life for children and families.	The QSAC prioritised the areas of care they felt were most important for patients, based on the development sources listed. The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
008	21	British Association for Adoption and Fostering (BAAF)	General		The standard would benefit from a measurement of well-being of those with ADHD, although we acknowledge that measuring this is not an easy task; perhaps asking the children and their families what is helpful to them would be useful. It would be helpful for the standard to address the resource implications, for example that there are sufficient ADHD specialists with the required competencies to carry out the work in a timely manner.	We have considered all suggestions for suitable outcome measures. The QSAC prioritised measures they considered most important for measuring the quality statements. The quality measures aim to improve the structures and processes of care that are considered to be linked to outcomes, as well as specifying outcomes directly where the QSAC felt able to define these.
008	22	British Association for Adoption and Fostering (BAAF)	General		We very much welcome the standard's statement that all health and social carer professionals involved with those with ADHD should have appropriate competencies. It would be helpful for the standard to go a step further and address the resource implications, both of this statement, and to support commissioning of needed resources on a population basis, for	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. Cost effectiveness is considered by the QSAC during development of quality standards and a supporting document has been published alongside the standard reviewing the potential cost impact

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					example that there are sufficient ADHD specialists with the required competencies to carry out the work in a timely manner.	and implications for commissioners and service providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
012	23	Janssen-Cilag Ltd	Introduction		Janssen notes that NICE intend to publish the final ADHD Quality Standards in July 2013. In light of the impending publication of DSM-V (expected May 2013), we anticipate that NICE will consult DSM-V in order to reflect the most current diagnostic criteria for ADHD	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
001	24	Lilly UK	General		Thank you for the opportunity to feedback on the NICE quality standard for ADHD. Please find our comments below.	Thank you for your comment.
001	25	Lilly UK	General		We would like to propose an additional quality statement which refers to primary care physicians undergoing documented training to help identify/recognise the signs and symptoms of ADHD in children, young people and adults. This is crucial for appropriate referrals and patient management to occur. Without such training the QS will be ineffective as it hinges on the identification of this patient group. We feel that it would be helpful to include training on the recognition:	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements.

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					1. of comorbidities and the overlap of symptoms, as comorbidities are commonly seen in both children and adults with ADHD (most commonly, anxiety, depression, bipolar disorder, substance abuse disorders and addiction, sleep problems and personality disorders). 2. that children, young people and adults have differing presentations of ADHD. 3. of patients at risk of substance misuse and drug diversion. The misuse of drugs and alcohol is common in individuals with ADHD.	The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
001	26	Lilly UK	General		We would like to refer back to our suggested key areas for improvement (from the engagement exercise for the ADHD QS [November 2012]). We still feel that the following is pertinent to this QS and would like to see it incorporated: Key area for quality improvement 1 – Better transition from child and adolescent mental health services (CAMHS) to adult mental health services. As per our previous comments, we feel that this is important as 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). In the latest Adult Psychiatric Morbidity Survey (2007) 8.2% of the general adult	Transition from child to adult services is in the core library of quality standards planned for development.

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					population in England were screened positive for ADHD (Bebbington et al. 2009). Despite the need effective adult services, the transition from child to adult services in the UK is poor at the moment and young adults may have difficulty in obtaining treatments after discharge from the paediatric services (Wong et al. 2009).	
022	27	RCGP	Introduction		MH- It would be useful to identify the codes that should be used in the clinical systems in primary care, secondary care and out of hours care in order to identify people with ADHD. Currently all the standards rely on local data collection where as GPES may offer an opportunity to collect the data in a standardised time. Should the needs of people with ADHD be a standard part of the Joint Service Needs Assessment?	Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. It is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full.
014	28	Royal College of Paediatrics and Child Health	General		There should be more emphasis in these standards about working with schools both when diagnosing ADHD and when monitoring the effect of treatment.	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.

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014	29	Royal College of Paediatrics and Child Health	General		The need to carefully consider co-morbid conditions should be emphasised since these may alter the treatment approaches that are most appropriate (including the choice of medication).	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
014	30	Royal College of Paediatrics and Child Health	General		There is no mention of quality of education provision for ADHD. This is disappointing given the potential for educational intervention in ADHD (as per NICE guidance). Many children with ADHD do not currently have statements, and will not have education health and care plans under the new system. These children gain few protections under the Children & Families Bill 2013, and this is an opportunity to apply evidence to ensure quality of provision, as per http://media.education.gov.uk/assets/files/pdf/b/ben%20goldacre%20paper.pdf. We would recommend that a standard be developed to express this aspiration.	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
015	31	Royal College of Psychiatrists in Wales	General		There is a need for shared care arrangements with GPs. Many GPs will not engage in	NICE quality standards are intended to demonstrate what high quality care looks like

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					prescribing for children with ADHD. Some services have designated doctors who have sessions blocked dedicate to drug prescriptions, which is poor use of clinical time. There is a need for further awareness of ADHD in children with a learning disability. They are often undiagnosed and, as a result, untreated. There is very little research in this area to support effectiveness of treatment in this group. We also need effective transition arrangements as often young people with ADHD are unwanted and not accepted by adult services unless they have co morbidity. In Wales, it is unclear where responsibilities for ADHD services fall within the Mental Health (Wales) Measure - in Part 1 (primary care) or Part 2 (secondary care)?	for a particular topic based on the best available evidence. Cost effectiveness is considered by the QSAC during development of quality standards and a supporting document has been published alongside the standard reviewing the potential cost impact and implications for commissioners and service providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
019	32	UK Adult ADHD Network	General		The UK Adult ADHD Network (www.UKAAN.org) was established in March 2009 to provide support, education, research and training for mental health professionals working with adults with Attention Deficit Hyperactivity Disorder (ADHD). UKAAN was founded by a group of experienced mental health specialists who run clinical services for adults with ADHD within the NHS. The Network was established in response to UK guidelines from the National Institute of Health and Clinical Excellence (NICE 2008) and the British Association for Psychopharmacology (Nutt et al. 2007) which for the first time gave evidence based guidance on the need to diagnose and treat ADHD in adults as well as in children; and in response to the relative lack of training and support in this area for professionals working within adult mental health services. In the last four years UKAAN has	Thank you for your comment.

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					organised 4 national and international conferences and 6 expert workshops. A number of review papers (Asherson et al. 2010, Young et al. 2011, Bolea et al. 2012, Adamou et al. 2013) have been published and a Handbook on Adult ADHD is about to be published (Asherson et al. 2013). UKAAN has organised more than 20 one-day training workshops (assessment and diagnosis, pharmacological treatment and clinical management, assessment and management, CBT, and advanced modules) for mental health professionals. UKAAN is commenting only on the draft quality statements 1, 4, 5 and 6. Statements 2 and 3 are relevant for children and adolescents only.	
002	33	British Association for Community Child Health	General	Measures	We are concerned that there are measurable areas of care that are not included in the quality standard 1. Access to treatment i.e. compliance with the 18 week RTT target. This should be reported specifically for children and young people with ADHD and should be easily available through Trust systems. 2. The proportion of children and young people, treated with medication, who receive treatment in line with the NICE guideline. The exact methodology would have to be thought through but should be possible through GP prescribing data. Key measures would include	Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. It is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full.

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					• the proportion of the population who are treated with medication (should be 1 to 2% of the school-age population) This measure would help to identify those commissioners who are failing to provide good access to psychological support when used in conjunction with measure 3 and 4 above, and also those where ADHD is under or over-identified. • The proportion of children who receive repeat prescriptions in primary care as part of a shared care protocol (Para 1.8.1.4) • The proportion of children of pre-school age who are receiving medication for ADHD (this should be rare but may indicate those areas who are not commissioning behaviour based treatments for pre-school children) • The proportion of all children on treatment who are treated with methylphenidate • the proportion of young people over the age of 11 i.e. secondary school pupils, who are treated with long acting medication (Para 1.5.1.1) • The average dose per patient (can be calculated easily using GP prescribing data) • the total spend on ADHD	

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					medication in each healthy economy per population 3. Patient reported outcome measures and patient feedback should be required as a matter of routine at least once a year. There are several validated tools that could be used including the short Conner's questionnaire; HONOSCA questionnaires and the Strength and Difficulties Questionnaire. The new outcome measure for children will include regular patient feedback in all settings, so ADHD patients could be identified separately. 4. The proportion of children and young people with ADHD of school-age who attain five GCSEs at grade C or above compared with the overall school-age population (Selecting a particular group of children and young people is already possible for Looked after Children and should therefore be equally possible for children with ADHD). 5. The proportion of children and young people with ADHD of school-age who have been excluded compared with overall exclusions. (This should be possible by collating information on school SEN registers and exclusions) 6. The proportion of children and young people with ADHD aged 16 and over who are NEET compared with the overall numbers who are NEET The number of children and young people who have died in whom ADHD is mentioned on the	

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					death certificate	
014	34	Royal College of Paediatrics and Child Health	Introduction	Page 2, line 2	As personality disorder is in plural, bipolar disorder, obsessive-compulsive disorder and substance misuse should also be all in plurals.	Thank you for your comment.
014	35	Royal College of Paediatrics and Child Health	Introduction	Page 2, line 5	ADHD is not diagnosed until the child is 5 years of age or older.	Thank you for your comment.
014	36	Royal College of Paediatrics and Child Health	Introduction	Page 5, last line	Parents or carers of ADHD are offered the input by CAMHS to a parent training / individual one to one counselling (this has been repeated frequently subsequently).	Thank you for your comment.
009	37	Association for Family Therapy and Systemic Practice	General	Question 1	Yes. In those quality statements which currently state an outcome as 'rates of new diagnosis of ADHD' (QS1: also mentioned as a numerator in QS2) data also needs to be collected on 'rates of new assessment of NOT having ADHD' ; also data on referral of those not diagnosed to alternative appropriate treatments and supports to help people better manage difficulties in their behaviours, lives and relationships. Without such data it may be difficult to assess possibilities of 'over-diagnosis', and whether sufficient attention is being given to other possible explanations and treatments. If 'diagnosis' alone is an outcome, we also wonder if there is a risk that diagnostic performance will be linked to 'amount of diagnosis' rather than to rigorous, curious and accurate assessment of presenting behaviours and possible solutions.	Thank you for your suggestions. Outcome measures are stated where the quality standards advisory group felt these were appropriate, measureable and specifically attributable to the action stated in the statement.
002	38	British Association for Community Child Health	General	Question 1	We would like to suggest the healthcare outcomes below for each of the quality statements 1. The proportion of children diagnosed	Thank you for your suggestions. Outcome measures are stated where the quality standards advisory group felt these were appropriate, measureable and specifically

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					with ADHD who are under the care of a paediatrician or child and adolescent psychiatrist trained in the management of ADHD. This should be available through the Children's minimum datasets for paediatrics and CAMHS. All children receiving ADHD medication in primary care should be under secondary care supervision. (We are not sufficiently familiar with primary care systems to be able to comment on whether this can be measured nationally) 2. It should be possible through commissioning information to establish whether each CCG has a transition pathway in place. 3. The availability of parent training should be measurable by each CCG reporting how many places it commissions on such programmes, how many of these places are taken up and comparing this with the total number of new diagnoses of ADHD in their area during the year. 4. As in measure 3. 5. As mentioned above, we have concerns about how this can be measured in practice It should be possible through the Children's minimum dataset in both paediatrics and CAMHS, to measure how often children and young people with ADHD are reviewed. Note that children and young people with difficulties may be reviewed more often than six monthly in order to adjust their treatment. Commissioners should also be required to state in their service specifications for ADHD services the follow-up	attributable to the action stated in the statement.

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					ratio they expect for children and young people with ADHD based on NICE guidance.	
014	39	Royal College of Paediatrics and Child Health	General	Question 1	1. The proportion of children diagnosed with ADHD who are under the care of a paediatrician or child and adolescent psychiatrist trained in the management of ADHD. This should be available through the Children's minimum datasets for paediatrics and CAMHS. All children receiving ADHD medication in primary care should be under secondary care supervision. (We are not sufficiently familiar with primary care systems to be able to comment on whether this can be measured nationally). 2. It should be possible through commissioning information to establish whether each CCG has a transition pathway in place. 3. The availability of parent training should be measurable by each CCG reporting how many places it commissions on such programmes, how many of these places are taken up and comparing this with the total number of new diagnoses of ADHD in their area during the year. 4. As in measure 3. 5. As mentioned above, we have concerns about how this can be measured in practice 6. It should be possible through the Children's minimum dataset in both paediatrics and CAMHS, to measure how often children and young people with ADHD are reviewed. Note that children and young people with difficulties may be	Thank you for your suggestions. Outcome measures are stated where the quality standards advisory group felt these were appropriate, measureable and specifically attributable to the action stated in the statement.

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					reviewed more often than six monthly in order to adjust their treatment. Commissioners should also be required to state in their service specifications for ADHD services the follow-up ratio they expect for children and young people with ADHD based on NICE guidance.	
016	40	Adult Attention Deficit Disorder – UK (AADD-UK)	General	Question 2	What important areas of care, if any, are not covered by the quality standard? The biggest gap in this standard is the lack of commitment to the need for psychological support for adults who were never diagnosed in childhood. Our experiences and discussions with adult support groups shows that while many adults can and do benefit from medication, medication alone does not address for a significant number of adults the dysfunctional ways that we have developed to help us cope with our undiagnosed condition. We need proper commitment from NICE with quality statements that state that Adult ADHD treatment must include appropriate psychological support for those who request it.	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
009	41	Association for Family Therapy and Systemic Practice	General	Question 2	Throughout the draft quality statements there is a lack of detail and discussion regarding psychological approaches to the treatment of children and young people with a diagnosis of severe ADHD and their families. These families often benefit the least from parent training, as it is too general, and most from tailored therapeutic interventions such as Systemic Family Therapy	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements.

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						The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
009	42	Association for Family Therapy and Systemic Practice	General	Question 2	The QS needs to include mention of transition services and processes for young adults leaving CAMHS and entering adult services. Some CAMHS services go up to age 16. How will the QS support effective and appropriate provision for 16-18 year olds in those areas ?	Transition from child to adult services is in the core library of quality standards planned for development.
009	43	Association for Family Therapy and Systemic Practice	General	Question 2	There needs to be greater consideration of the frequency and nature of reviews, and what is being reviewed. It is AFT's view that these need to include a relational frame to continuing assessment - considering the holistic functioning of the child, young person or adult within their wider network - rather than medication only.	It is expected that reviews will mean something different for different quality statements, different patients and different services. Where the QSAC felt able to define this for the broad scope of the quality standard, definitions are provided.
009	44	Association for Family Therapy and Systemic Practice	General	Question 2	Effective psychological interventions for individual families and groups of families need to engage and attend to the needs of all family members, including siblings. Parenting groups are often too general to address the needs of families with children with serious behavioural difficulties. They can also push siblings and other important people out of the frame. A systemic frame to assessment and interventions helps ensure the needs of all affected family members are considered.	The QSAC identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
017	45	British Psychological Society	General	Question 2	Many of the issues raised above regarding adult offenders also apply within the young justice system. ADHD in young offenders is all too often being missed, misdiagnosed or inadequately treated despite appropriate treatment and	The QSAC considered equality issues throughout development of the quality standard. A section on 'Diversity, equality and language' can be found in the final quality standard. The quality standard also contains

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					support being likely to reduce symptoms, improve behavioural and emotional control, and improve pro-social skills significantly impacting positive not only on the individual but the community via influencing the criminal trajectory (Harpin & Young). UK prison studies have indicated a rate of ADHD of 43% in 14-year-old youths (Rusmussen et al., 2001). Young people within the youth justice system are less likely to be engaged with standard health services and therefore it is vitally important that their needs are recognised with the youth justice systems where historically this has not always been the case (Harrington et al., 2005). We suggest that this (in addition to the adult offending population) is a population that needs to be given specific consideration and is not comprehensively covered by current the quality standards 2-6 covering children and young people. Harpin, V., & Young, S. (2012) The Challenge of ADHD and Youth Offending. *Focus Issue. The Management of ADHD in Children, Young People and Adults*, Cutting Edge Psychiatry in Practice (cepip.org) 138. Rasmussen, K., Almvik, MR., Levander, S,. (2001) Attention Deficit Hyperactivity Disorder, Reading Disability, and Personality Disorders in a Prison Population. Journal of the American Academy of Psychiatry and the Law. **29**: 186–193 Harrington, R., Bailey, S., Chitsabesan, P., Kroll, L., Macdonald, W., Sneider, S., Kenning, C., Taylor, G., Byford, S., and Barrett, B. (2005) "Mental health needs and effectiveness of provision for young offenders in custody and in the community." *Youth Justice Board for*	an equality and diversity considerations section for specific statements.

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					England and Wales	
005	46	Hyperactive Children's Support Group	General	Question 2	The published guidelines include a section on dietary interventions (Section 9) with four recommendations (9.4.1.1 – 9.4.1.4.) Recommendation 9.4.1.1 states that "healthcare professionals should stress the value of a good and balanced diet, nutrition and exercise." Recommendation 9.4.1.3. states that "clinical assessment for ADHD should include enquiry about foods or drinks that have been noted to influence an individual child's behaviour", and if there is a clear link to keep a food diary; if the diary supports a relationship between specific foods and behaviour then referral to a dietician should be offered. There is no mention of this in the draft quality standards, and no measure of the success or otherwise of this outcome, which should be included in the document.	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
001	47	Lilly UK	General	Question 2	The following areas of care are not covered by the quality standard: Prisons/forensic settings/criminal justice system. We feel that it would be extremely beneficial to include these areas of care within the quality standard for the reasons outlined in section 5.18.1.4 of CG72, "*It is important that individuals with ADHD are identified and receive treatment in these settings as this may have a positive impact on their quality of life, increase the effectiveness of other forensic rehabilitation activities and treatments provided to them, contribute to a reduction in antisocial behaviour and offending and increase public safety. Treatment of ADHD symptoms may improve treatment engagement and readiness more generally and provide service*	The QSAC considered equality issues throughout development of the quality standard. A section on 'Diversity, equality and language' can be found in the final quality standard. The quality standard also contains an equality and diversity considerations section for specific statements.

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					benefits by shortening length of stay within forensic secure services". A recent study (Lichtenstein et al, 2012), conducted over a 4 year period, has shown that crime rates can be reduced by 32-41% in patients with ADHD when treatment with medication is undertaken. **Reference**: Lichtenstein P, Halldner L, Zetterqvist J et al. Medication for attention deficit-hyperactivity disorder and criminality. N Engl J Med. 2012 Nov 22;367(21):2006-14. doi:10.1056/NEJMoa1203241.	
001	48	Lilly UK	General	Question 2	We also feel that it is important to identify patients at increased risk of substance misuse and drug diversion. Such issues appear to be more common in individuals with ADHD than in the normal population (Wilens et al. 1997; Biederman et al. 1995; Biederman et al. 1997; Molina and Pelham, 2003 and McGough et al, 2005) and presentation with ADHD may represent a good opportunity to identify and manage such problems. **References:** Wilens TE, Biederman J et al. Attention deficit hyperactivity disorder (ADHD) is associated with early onset substance use disorders. Journal of Nervous and Mental Disease, 185 (1997), pp. 475–482	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.

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					Biederman J, Wilens T et al. Psychoactive substance use disorders in adults with attention deficit hyperactivity disorder (ADHD): effects of ADHD and psychiatric comorbidity. American Journal of Psychiatry, 152 (1995), pp. 1652–1658 Biederman J , Wilens T et al. Is ADHD a risk factor for psychoactive substance use disorders? Findings from a four-year prospective follow-up study. Journal of the American Academy of Child and Adolescent Psychiatry, 36 (1997), pp. 21–29 Molina BSG and Pelham WE. Childhood predictors of adolescent substance use in a longitudinal study of children with ADHD. Journal of Abnormal Psychology, 112 (2003), pp. 497–507 McGough JJ, Smalley SL, McCracken JT et al. Psychiatric comorbidity in adult attention deficit hyperactivity disorder: findings from multiplex families. American Journal of Psychiatry, 162 (2005), pp. 1621–1627	
014	49	Royal College of Paediatrics and Child Health	General	Question 2	7. Access to treatment i.e. compliance with the 18 week RTT target. This should be reported specifically for children and young people with ADHD and should be easily available through Trust systems. 8. The proportion of children and young people, treated with medication, who receive treatment in line with the NICE guideline. The exact methodology would have to be	Thank you for your suggestions. Outcome measures are stated where the quality standards advisory group felt these were appropriate, measureable and specifically attributable to the action stated in the statement.

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					thought through but should be possible through GP prescribing data. Key measures would include: • the proportion of the population who are treated with medication (should be 1 to 2% of the school-age population). This measure would help to identify those commissioners who are failing to provide good access to psychological support when used in conjunction with measure 3 and 4 above, and also those where ADHD is under or over-identified. • The proportion of children who receive repeat prescriptions in primary care as part of a shared care protocol (Para 1.8.1.4) • The proportion of children of pre-school age who are receiving medication for ADHD (this should be rare but may indicate those areas who are not commissioning behaviour based treatments for pre-school children) • The proportion of all children on treatment who are treated with methylphenidate • The proportion of young people over the age of 11 i.e. secondary school pupils, who are treated with long acting medication (Para 1.5.1.1). • The average dose per patient	

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					(can be calculated easily using GP prescribing data). • The total spend on ADHD medication in each healthy economy per population. 9. Patient reported outcome measures and patient feedback should be required as a matter of routine at least once a year. There are several validated tools that could be used including the short Conner's questionnaire; HONOSCA questionnaires and the Strength and Difficulties Questionnaire. The new outcome measure for children will include regular patient feedback in all settings, so ADHD patients could be identified separately. 10. The proportion of children and young people with ADHD of school-age who attain five GCSEs at grade C or above compared with the overall school-age population (selecting a particular group of children and young people is already possible for Looked after Children and should therefore be equally possible for children with ADHD). 11. The proportion of children and young people with ADHD of school-age who have been excluded compared with overall exclusions. (This should be possible by collating information on school SEN registers and exclusions). 12. The proportion of children and young people with ADHD aged 16 and over who are NEET compared with the overall numbers who are NEET. 13. The number of children and young people	

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					who have died in whom ADHD is mentioned on the death certificate.	
014	50	Royal College of Paediatrics and Child Health	General	Question 2	1. Training of school staff working with children and young people with ADHD is missing. We welcome parent receiving training being a quality standard but it is not sufficient that only parents are trained. Children spend a large amount of time at school and if staff are not trained to support them this leads to poor outcomes for the child. Contact a Family regularly receive feedback from families that school staff have a poor understanding of ADHD and how to support children with ADHD. The consequences of this lead to the child falling significantly behind their peers, lacking self-confidence and developing poor self-esteem, exclusion and disengagement from school, and increased likelihood of becoming a young offender. This appears to get worse once the child starts secondary school. 2. A Key priority for implementation of the NICE guidelines on the diagnosis and management of ADHD in children, young people and adults should be: '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	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.

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					have contact with people with ADHD.' (Ref NICE guidelines - Attention deficit hyperactivity disorder - Diagnosis and management of ADHD in children. Young people and adults Sept 2008). We believe the NICE quality standard needs to reflect this priority and include a measure of how well the ADHD team is doing in supporting other agencies on management of children with ADHD - especially education - as well as parents. This would help towards meeting the objectives of Domain 1 of the public health outcomes framework 2013-16 which includes: • 1.3 pupil absence • 1.4 first time entrants to the youth justice system • 16-18 years olds not in education, employment or training • People in prison who have a mental health illness of significant mental illness • Employment for those with long term health conditions including those with a learning difficulty/disability or mental illness.	
011	51	Sussex Partnership NHS Foundation Trust	General	Question 2	An important area of care not covered here is that of liaison with other agencies, such as colleagues in education, social care or YOS. A proportion of young people with ADHD will struggle at school and it is important that school staff feel supported in managing the challenges that can arise. Some older adolescents can	The QSAC considered equality issues throughout development of the quality standard. A section on 'Diversity, equality and language' can be found in the final quality standard. The quality standard also contains an equality and diversity considerations section for specific statements.

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					come to the attention of YOS and may have undiagnosed ADHD and again it is important that YOS staff are aware of possible signs of ADHD and know when to refer on to other services. (Consultant Nurse, CAMHs)	
001	52	Lilly UK	General	Question 3	We believe that QS 1 – '*Adults who present with symptoms of ADHD, who do not have a childhood diagnosis of ADHD, are referred for assessment to an ADHD specialist'* is the most important QS. The latest Adult Psychiatric Morbidity Survey (2007) identified that 8.2% of the general adult population in England were screened positive for ADHD (Bebbington et al. 2009). Furthermore, a number of studies have demonstrated that the screening of adult psychiatric outpatients will identify ADHD in approximately 20% of attendees (Montes et al. 2007; Rao and Place 2011; Syed et al. 2010) CG72, section 2.7.2 lists the following issues faced by adults with ADHD: educational and occupational disadvantages, substance misuse, association with crime and differential and mistaken diagnoses. Untreated/poorly managed ADHD may pose significant burden to both the individual and society. **References**: 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.	Thank you for your comment.

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					Almeida Montes LG, Hernández García AO, Ricardo-Garcell J. ADHD prevalence in adult outpatients with nonpsychotic psychiatric illnesses. J Atten Disord. 2007;11(2):150-6. Rao P and Place M. Prevalence of ADHD in four general adult outpatient clinics in North East England. Progress in Neurobiology and Psychiatry. 2011; 15(5):7-10 Syed H, Masaud TM, Nkire N et al. Estimating the prevalence of adult ADHD in the psychiatric clinic: a cross-sectional study using the adult ADHD self-report scale (ASRS). Ir J Psych Med 2010; 27(4): 195-197	
014	53	Royal College of Paediatrics and Child Health	General	Question 3	Quality statements 1 and 2, the suggested quality standard described above on transition between child and adult services	Thank you for your comment.
014	54	Royal College of Paediatrics and Child Health	General	Question 3	We would suggest that quality statement 3 is the most important, but should be amended to say: '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 parents, mental health, paediatric, social care, education, forensic and primary care providers and other professionals who have contact with people with ADHD.'	Thank you for your comment. The final quality statement is, Parents or carers of children and young people with suspected or confirmed ADHD are offered a referral to a parent-training and education programme.
011	55	Sussex Partnership NHS Foundation Trust	General	Question 3	Arguably the most important of the standards is standard 3 as if parents are supported to manage difficulties, the situation is much more positive both for the young person and their carers (Consultant Nurse, CAMHs)	Thank you for your comment.
016	56	Adult Attention Deficit Disorder – UK (AADD-	General	Question 4	We feel that localities need to be measured as to whether or not they have included ADHD (for	Thank you for your suggestions. Outcome measures are stated where the QSAC felt

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		UK)			children, young people, as well as adults) as a topic in their Joint Strategic Needs Assessment	these were appropriate, measureable and specifically attributable to the action stated in the statement.
017	57	British Psychological Society	General	Question 4	The Society welcomes these quality standards which are for the most part comprehensive and very clear. We recognise an urgent need for such standards to ensure the current NICE guidelines are appropriately implementation to give all children, young people and adults diagnosed with ADHD the best possible outcomes. In relation to question 3 regarding which is the most important quality standard, The Society suggests that all standards suggested are vitally important and as regards question 4, we do not feel that any of the quality measures are wholly inappropriate. See comments below for a number of small amendments that we feel would improve the usefulness and comprehensiveness of the standards as they are at present. As stated above, overall The Society believes this is an excellent document that will highly welcomed by our members.	Thank you for your comment.
001	58	Lilly UK	General	Question 4	The quality measure in QS 5 is inappropriate. It states, 'Evidence of local arrangements to ensure that people with ADHD who are starting drug treatment have their initial drug dose adjusted over a period of 4 to 6 weeks by an ADHD specialist'. This dose titration schedule is outside of the atomoxetine product licence. Please see our previous comments relating to QS 5.	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard. The measures have been revised for the final quality standard to improve clarity.
014	59	Royal College of Paediatrics and Child Health	General	Question 4	See Q2 and below	Thank you for your comment.

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022	60	RCGP	General	Section 2	MH- there is no minimum standard for waiting time from referral to being seen and exceptional funding from the PCT/CCG is often required to see an out of area specialist. The Specialist should be local to the person	Thank you for your comment.
009	61	Association for Family Therapy and Systemic Practice	General	Section 2, intro, para 3	Should this read: '... to help them ask questions about the care they receive'?	Thank you for your comment.
009	62	Association for Family Therapy and Systemic Practice	General	Section 2, intro, para 4	This states that: 'All health and social care professionals involved in assessing, caring for and treating children, young people and adults with ADHD should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard'. AFT requests that professionals also have the training and competencies to consider alternative explanations of symptoms. It would be useful if 'sufficient and appropriate training' were defined. Given the importance of identification of and effective response to relational and contextual factors that may be influencing people's behaviour, AFT recommends inclusion of systemic competencies and training *Systemic Psychological Therapies Competences Framework* Details of systemic training levels is available via the AFT website http://www.aft.org.uk/training/view/training-overview.html	It is expected that 'sufficient and appropriate training' will mean something different for different quality statements, different patients and different services. Where the QSAC felt able to define this for the broad scope of the quality standard, definitions are provided.
012	63	Janssen-Cilag Ltd	General	Section 7.2: Future quality	While transition of patients from children's to adult services is identified here as an area for future development, Janssen believes this Quality Standard should be brought forward into	Transition from child to adult services is in the core library of quality standards planned for development.

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				standards	this review as it is incredibly important to ensure that services are in place to address the needs of this group of patients sooner rather than later (*please see our comments to this effect under Draft quality statement 1: Identification and referral in adults*).	
016	64	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 1		We feel that your draft quality statement 1 is not specific enough and would like to see the following added under Draft quality measure, Structure: Evidence of a local needs assessment highlighting gaps in and barriers to accessing specialist ADHD services; Evidence of local arrangements to ensure agreed referral methods are in place between primary and secondary care; Evidence of audit of waiting times in specialist ADHD services from initial referral to assessment, assessment to treatment start, and total waiting time from referral to starting treatment. Rationale: When Nice published its' guidance one of its Key priorities was listed under 5.17.1.3 where it stated "when a child is dx the parents should be offered an assessment into their mental health needs". Although Nice didn't say an assessment as to whether the parents should have an ADHD assessment, they were acknowledging the very high genetic link to ADHD. Given that is the case, why are Nice not seeing the obvious benefits of an earlier identification route for parents who have not had a childhood dx. To us this seems a missed opportunity, for Camhs and Adult ADHD clinics to work much more closely together. In our work with the parents group, we've talked to so many parents who do believe they may well have the condition, but whatever reason don't feel they can go through the hassle	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.

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					of going to adult services - that is, if there's an adult service for them to go to! We should also like to point out that since Nice correctly recognises that adults are often being treated for co-existing mental health problems within general psychiatric services while their ADHD remains unrecognised this means that there is a need for secondary mental health services to demonstrate how well they are doing in relation to general psychiatrists recognising the importance of "hidden" ADHD - MHT's need to show overall improvement. NICE needs to be much bolder in taking on poor secondary care in MHT's!	
009	65	Association for Family Therapy and Systemic Practice	Quality statement 1		Rationale: para 2. This states: Diagnosis of ADHD requires a full clinical and psychosocial assessment of multiple aspects of a person's life and should be undertaken by a healthcare professional with specialist knowledge and experience of ADHD'. AFT strongly recommends that healthcare professionals also have specialist knowledge of and experience in systemic assessments and interventions, so they are equipped to appropriately, respectfully and effectively elicit people's descriptions of their behaviours, lives and relationships, and to consider 'ADHD' and other possible explanations.	It is expected that 'sufficient and appropriate training' will mean something different for different quality statements, different patients and different services. Where the QSAC felt able to define this for the broad scope of the quality standard, definitions are provided.
009	66	Association for Family Therapy and Systemic Practice	Quality statement 1		This states that 'Service providers ensure systems are in place for adults who present with symptoms of ADHD without a childhood diagnosis of ADHD to be referred to an ADHD specialist for assessment' This begs the question of what treatments and supports are to be offered to those adults who present with 'symptoms of ADHD' but who are	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were

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					assessed as NOT having it. Without consideration of appropriate services and interventions for this client group, there is a risk that services will only be provided for those diagnosed, with little or nothing for those struggling with distressing symptoms but no diagnosis. This in turn risks pressure on practitioners to over diagnose to ensure people receive some help, however inappropriate the diagnostic label.	inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
006	67	Association of School and College Leaders	Quality statement 1		Not for ASCL to comment on.	Thank you for your comment.
021	68	Avon and Wiltshire NHS Trust Adult ADHD clinic	Quality statement 1		a) Process. The calculation of the Outcome, Rates of diagnosis of ADHD in adults, the methods in which the data are commonly collected may not capture the true result. This is because the denominator is potentially problematic on the ground. In May 2012 we conducted a review of the experiences of patients at the local ADHD support group (n=22)Diffic In response to the question 'When you wanted referral, did your GP believe that ADHD was a medical problem?' We found that 59% (13 respondents) had encountered problems persuading their GPs to believe that ADHD was a valid diagnosis in adults. Some had had to resort to legal action or moving surgeries. In essence, this means that there are many patients with ADHD who are in effect invisible because their GPs don't agree or sympathise with the notion of ADHD in adults. We have not	Thank you for your suggestions. Outcome measures are stated where the QSAC felt these were appropriate, measureable and specifically attributable to the action stated in the statement. In addition to this, each statement is followed by a rationale section which provides a brief explanation for why the statement is important with some reference to the outcomes that the action referred to in the statement has a potential causal link to.

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					enquired with GPs as to their reasons for this apparent prejudice. b) In relation to the above point, we suggest that in the heading 'Structure', the local data collection contain notes to advise researchers to focus on patients' experiences outside of the NHS, rather than the reporting data from health and social care professionals. This is the only way to begin to form true data on the actual prevalence rates of the disorder, rather than the biased underestimates due to artefact of medical ignorance/prejudice etc. We believe the duty to collect this data and use it to commissioning decisions must be explicit in NICE guidelines.	
021	69	Avon and Wiltshire NHS Trust Adult ADHD clinic	Quality statement 1		The rates of increase of referral rates should be measured Three things are causing an exponential upturn in rates of referral to Adult ADHD clinics: i) The bubble cohort of transitioning patients from the 80s and 90s who are now becoming adults ii) Parents of children diagnosed today, who see the same behaviour traits in themselves and are rightly advised to seek referral iii) Entirely new patients learning about ADHD through self-diagnosis, internet, social media etc. Therefore there is both 'catching up with adults who never new' (people coming backwards) and 'speeding up to more and more children (people coming forwards). For example, our clinic (Bristol Adult ADHD	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.

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					clinic) We have assessed approx. 1230 patients in the clinic since its inception. We have a waiting list of 212. Allow for another 300 patients in small private clinics or LD services etc. Total number of 'adults aware of or diagnosed with their ADHD' is therefore 1,742. Our clinic's catchment area is 1.6 million patients. Expected adult prevalence using even a very conservative estimate of 2% of adult population having troubling, active symptoms of ADHD, gives 32,000 patients. The number we have identified (1,742) is therefore only 5.4% of actual need. As people become more aware of ADHD, referral rates are set to increase very rapidly. Referral rate to our clinic is averaging 45 patients per month at present. In January to June 2010, we received an average of 21 referrals per month. Assuming an arithmetic or geometric rates of increase, we project to receive approx 68 to 90 referrals a month in 2015. Services must therefore plan and scale up capacity dynamically and proactively, rather than the reactive, retrospective year-to-year planning process that commissioners tend to rely on for more established conditions.	

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					The result of not predicting these rates of increase locally is clear: our clinic is pressured to keep seeing patients and sacrifice development time, time for refining processes, time for audit etc, as these are seen as outside commissioners' basic remit to get patients seen. This is a counterproductive false-economy: crucial leaps in efficiency and smarter methods of treatment will simply be lost if clinics stay the same, or even if they just scale up to do more of the same thing. An Adult ADHD clinic should not simply do the same thing as it does now- we need to predict what is coming and refine our processes deal with future increases in need, by working *smarter*, using emerging research from evidence-based technologies like remote reviews, online progress capture tools, media-based learning, etc. We suggest a measure to identify rates of detection of ADHD to match and plan clinic activity more dynamically to upturns in expected referrals. The proportion of people identified with ADHD in a general population, versus the amount actually out in the population who may not know their problems are due to ADHD, can be calculated as: Actual Rate of referral(adults per week) identified with ADHD diagnosis in any county (numerator) Expected rate of referral of adults in that	

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					population based on prevalence figures (denominator)	
002	70	British Association for Community Child Health	Quality statement 1		This is an acceptable statement and is measurable	Thank you for your comment.
003	71	British Medical Association	Quality statement 1		Whilst we agree that referring adults with suspected ADHD to an ADHD specialist is important, it is made difficult by a lack of specialists locally.	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. A supporting document has been published alongside the standard reviewing the potential cost impact and implications for commissioners and service providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
004	72	Flynn Pharma	Quality statement 1		Statement covers only newly diagnosed adults and not those previously diagnosed and transitioning. Statement is aspirational and ignores the reality of a limited number of adult services and adult ADHD experts in the UK.	This area was discussed by the QSAC and an additional statement has been developed. The statement is: Adults who were diagnosed with and treated for ADHD as children or young people and present with symptoms of continuing ADHD are referred to general adult psychiatric services.
012	73	Janssen-Cilag Ltd	Quality statement 1		Many adults who were previously diagnosed with ADHD in childhood may face interruptions/disruptions in care as they transition from paediatric to adult health services. We propose that, rather than postponing until a future ADHD Quality Standards is issued (as noted in Section 7.2/ Page 21) NICE should include in these *currently* proposed Quality Standards an additional Quality Statement related to the identification, assessment, and	This area was discussed by the QSAC and an additional statement has been developed. The statement is: Adults who were diagnosed with and treated for ADHD as children or young people and present with symptoms of continuing ADHD are referred to general adult psychiatric services.

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					medication review of adults previously diagnosed with ADHD in childhood to ensure continuity of care.	
012	74	Janssen-Cilag Ltd	Quality statement 1		NICE may wish to also include a specific provision under this Quality Standard which ensures that people in prison are assessed for ADHD as they are an under-diagnosed and undertreated group of people	The QSAC considered equality issues throughout development of the quality standard. A section on 'Diversity, equality and language' can be found in the final quality standard. The quality standard also contains an equality and diversity considerations section for specific statements.
001	75	Lilly UK	Quality statement 1		As there are very few pure ADHD specialists this may limit the number of patients referred on to secondary care for assessment. We believe that a more appropriate descriptor of an ADHD specialist is used by NICE CG72, section 6.4 (p.139) and we have incorporated this into QS 1: Adults who present with symptoms of ADHD, who do not have a childhood diagnosis of ADHD, are referred for assessment to a specialist in adult mental health with the training to diagnose and advise on ADHD.	A definition of an ADHD specialist is included in the final quality standard within the definitions of this quality statement.
001	76	Lilly UK	Quality statement 1		We feel that it would improve patient care if there was a timeframe for referral incorporated within QS1.	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.
018	77	Nottinghamshire Healthcare NHS Trust	Quality statement 1		Page 7, box 4This should read 'referred to' not 'referred by'	Thank you for your comment.
022	78	RCGP	Quality statement 1		MH-. Currently it is difficult to find a specialist to assess an adult with ADHD. The Adult Mental Health Service may not classify this as a "severe mental health disease". It often requires	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. A supporting document

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					the GP to applying to the PCT/CCG for exceptional funding	has been published alongside the standard reviewing the potential cost impact and implications for commissioners and service providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
014	79	Royal College of Paediatrics and Child Health	Quality statement 1		This is an acceptable statement and is measurable	Thank you for your comment.
014	80	Royal College of Paediatrics and Child Health	Quality statement 1		Page 8, line 1: Under “definitions” an ADHD specialist is a mental health clinician or paediatrician with interest in ADHD	A definition of an ADHD specialist is included in the final quality standard within the definitions of this quality statement.
014	81	Royal College of Paediatrics and Child Health	Quality statement 1		Page 8, line 4: Parent training / individual counselling should be offered to any child with mild to moderate ADHD	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
015	82	Royal College of Psychiatrists in Wales	Quality statement 1		In Wales, and possibly in England, there are very few ‘Adult ADHD specialists’. Having dedicated ADHD specialist has implications for training and job planning as most adult psychiatrists have little experience in diagnosing ADHD and there would be an expectation for	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. A supporting document has been published alongside the standard reviewing the potential cost impact and

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					these specialists to see all serious mental illness along with ADHD. What is of equal concern is that most adult psychiatrists have little experience in diagnosing ADHD, and many view ADHD and similar conditions as not part of their remit. We believe that the acute lack of clinicians with an interest and/or experience in managing adult ADHD is the largest problem we face. If routine interventions at primary care fail, then the patient can be referred to an ADHD specialist. This is the case with all other mental disorders and the Quality Standards appear to be creating a sub –speciality. However, there may still be a need for ADHD specialists for the complex cases with co morbidity e.g. autism, psychosis	implications for commissioners and service providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
019	83	UK Adult ADHD Network	Quality statement 1		UKAAN endorses this quality statement. The number of adult ADHD clinics in the UK has increased from only 2 in 2003 to more than 40 in 2013. There are still regions in the country, where access to a specialist in adult ADHD is very difficult and existing services for adults with ADHD are often underfunded. This quality statement would help to improve the funding situation throughout the UK. UKAAN is developing a certification process for adult ADHD services with a strong focus on NICE guideline compliance and minimum requirements for specialist training of clinicians working in those services.	Thank you for your comment.
004	84	Flynn Pharma	Quality statement 1	Audience	The challenge is to whom such patients will present. How will HCPs in primary care assist this process? Will they be provided secondary care links /support for adults with ADHD? There is a marked lack of relevant services.	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other

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					In terms of diagnosis, will guidance be offered to HCPs and will it be based on DSM5 (scheduled for release May 2013) rather than DSM-IV? Consideration for the on-going care and management of ADHD in adults and the development of adult services across the UK; investment in service development and staff training will be required.	related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
015	85	Royal College of Psychiatrists in Wales	Quality statement 1	Audience	There is a typographical error on page 7. "Adults who present with……are referred **to** (instead of **by**) an ADHD specialist for assessment."	Thank you for your comment.
020	86	NICE Implementation	Quality statement 1	Definitions	For clarity I think it would be useful if the symptoms of ADHD were added to the definitions section.	A definition of the symptoms of ADHD is included in the final quality standard within the definitions of this quality statement.
004	87	Flynn Pharma	Quality statement 1	Measure	The quality measure requires "referral" of new diagnosed adults. Who would do this? Who (with sufficient expertise to suspect ADHD) would a patient present to in the first instance? Presumably they are not all in adult psych services for treatment of other mental health disorders. To have any real impact the denominator would be' the estimated number of adult ADHD patients in the UK' and the numerator 'number of patients presenting who are subsequently referred, assessed and diagnosed'. If the primary route of referral is going to be primary care (GPs) provision for training and education of GPs (and primary care staff) needs to be put in place to identify adult patients with suspected ADHD to enable referral to specialist service for formal diagnosis and treatment. The benchmark should consider looking at the rate of diagnosis and treatment in the area covered by	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard. NICE has now produced the support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk

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					the service, and compare this to National figure for diagnosis and treatment. Patient should not be assessed in isolation of parents/offspring/siblings/carers.	
015	88	Royal College of Psychiatrists in Wales	Quality statement 1	Measure	As an Outcome, “rates of new diagnosis” would presume a proper process and outcome measure. It is important that the rates of new diagnosis reflect “appropriately defined” new diagnosis. Increased diagnostic rates are not necessarily a reflection of quality (e.g. could reflect demand and poor practice, inadequate assessment and over-diagnosis) so the process also needs to be carefully specified (e.g. rates of new diagnosis based on X criteria or measure). We believe that a more appropriate health care outcome measure would be the number of psychiatrists in each trust/area with experience and a willingness to work with adult ADHD patients.	Thank you for your suggestions. Outcome measures are stated where the topic expert group felt these were appropriate, measureable and specifically attributable to the action stated in the statement. In addition to this, each statement is followed by a rationale section which provides a brief explanation for why the statement is important with some reference to the outcomes that the action referred to in the statement has a potential causal link to.
017	89	British Psychological Society	Quality statement 1	Question 1	The Society suggests that a potential healthcare outcome for this quality standard should include the number of adults not only receiving ADHD diagnosis, but also who is able to access appropriate treatment. There is great debate in the literature regarding both the diagnosis and the complexities of diagnosing ADHD in adults (e.g. Asherson, et al., 2007) and the appropriate treatment for adults diagnosed with ADHD (for a summary see Nutt et al., 2007) and this is even more complex in settings such as prisons (e.g. Young et al;., 2011). It will impact on the healthcare outcomes of adults with ADHD much more significantly if appropriate treatment is ensured, and hence measured as an outcome,	Thank you for your suggestions. Outcome measures are stated where the topic expert group felt these were appropriate, measureable and specifically attributable to the action stated in the statement. In addition to this, each statement is followed by a rationale section which provides a brief explanation for why the statement is important with some reference to the outcomes that the action referred to in the statement has a potential causal link to.

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					rather than just observing the number of diagnoses made. The complexities of diagnosis also need to be kept in mind when considering who would be qualified to initially note the symptoms present and submit the referral for the screening (Nutt et al., 2007) and it may be that significant training of primary care professionals, specifically General Practitioners, are necessary to facilitate this (Young & Toone, 2000). Asherson, P., Chen, W., Craddock, B., & Taylor, E. (2007). Adult attention-deficit hyperactivity disorder: recognition and treatment in general adult psychiatry. *The British Journal of Psychiatry*, ***190*****(1)**, 4-5. Nutt, D. J., Fone, K., Asherson, P., Bramble, D., Hill, P., Matthews, K., Morris, K.A., Sonuga-Barke, E., Taylor, E., Weiss, M. & Young, S. (2007). Evidence-based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology. *Journal of Psychopharmacology*, ***21*****(1)**, 10-41. Young, S J., Adamou, M., Bolea, B., Gudjonsson, G., Müller, M., Pitts, M. Thome, J. and Asherson. P. (2011) "The identification and management of ADHD offenders within the criminal justice system: a consensus statement from the UK Adult ADHD Network and criminal justice agencies." *BMC Psychiatry* **11**: 32. Young, S., & Toone, B. (2000). Attention deficit hyperactivity disorder in adults: clinical issues. A report from the first NHS clinic in the UK. *Counselling Psychology Quarterly,* **13***,* 313–319	
017	90	British Psychological Society	Quality statement	Question 2	It is now well established that there is a disproportionately high prevalence of ADHD	The QSAC considered equality issues throughout development of the quality

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			1		within the prison population and yet it remains clear that the needs of adult prisoners are not met (Young, S., et al., 2011). In the prison estate, there are limited special provisions either for the assessment or treatment of prisoners exhibiting the symptoms of ADHD and at present. It is not typically a part of the standard assessment when offenders enter custody and as a result ADHD is likely to be either undiagnosed or misdiagnosed and inappropriate treatment, e.g. major tranquillisers, may be initiated, or no treatment at all, with the result that a prisoner with ADHD sufferer is treated as "refractory" and the impact of the ADHD on the offending behaviour continues (Young, S., et al, 2011). UK prison studies have indicated that 24% of male adults screen positive for a childhood history of ADHD, 14% of whom had persisting symptoms (Young et al., 2009). Those with persisting symptoms accounted for eight times more aggressive incidents than other prisoners and six times more than prisoners with Antisocial Personality Disorder. They had a significantly younger onset of offending by around 2.5 years (16 vs. 19.5 years); and they had a significantly higher rate of recidivism (Young et al., 2010). ADHD was the most important predictor of violent offending, even above substance misuse. Currently the National Criminal Justice Board meets regionally and nationally, with representation by the courts, police, probation and prison services. Screening systems already exist in CJS services and but there have not yet been identify and agreed ways of building on	standard. A section on 'Diversity, equality and language' can be found in the final quality standard. The quality standard also contains an equality and diversity considerations section for specific statements.

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					these systems to incorporate screening for ADHD (Young et al., 2011). From all of this data it is clear that the needs of prisoners with ADHD need to be recognised and appropriate interventions offered. We recommend that the quality standard be extended accordingly. This is also the case within forensic mental health services where whilst routine screening is conducted on admission to forensic inpatient services, this is not routinely conducted in community services where the majority of ADHD offenders with mental disorder are likely to be found. Existing screening procedures, where provided, are unlikely to include ADHD, and in some cases ADHD may be misdiagnosed (e.g. as personality disorder), thus emphasising the importance of training for professionals in ADHD assessment and diagnosis, which does not currently feature in generic training curricula (Young et al., 2011). Young, S J., Adamou, M., Bolea, B., Gudjonsson, G., Müller, M., Pitts, M. Thome, J. and Asherson. P. (2011) "The identification and management of ADHD offenders within the criminal justice system: a consensus statement from the UK Adult ADHD Network and criminal justice agencies." *BMC Psychiatry* **11**: 32. Young, S., Gudjonsson, G., Wells, J., Asherson, P., Theobald, D., Oliver, B., Scott, C., Mooney, A,. (2009) Attention Deficit Hyperactivity Disorder and critical incidents in a Scottish prison population. Personality and Individual Differences. ; **46(3)**:265–269. Young, S., Wells, J., Gudjonsson, G., (2010) Predictors of offending among prisoners: the	

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					role of Attention Deficit Hyperactivity Disorder (ADHD) and substance use. Journal of Psychopharmacology. Published online.	
004	91	Flynn Pharma	Quality statement 1	Rationale	If this is the case then HCPs treating the comorbidities (presumably adult psychiatrists) would have to be sufficiently trained/familiar with ADHD symptoms to suspect ADHD and refer on to appropriate colleagues and services	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. A supporting document has been published alongside the standard reviewing the potential cost impact and implications for commissioners and service providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
016	92	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 2		There's an assumption under Rationale that those professionals in primary care, be that school nurses, HV, teachers etc, all have the basic skills to recognise the possibility of children having undiagnosed ADHD. In our experience this is so far from the truth!! One of the biggest problems that parents face, day in and day out, is to get teachers to recognise the fact that the condition exists! We are also concerned that parents will be sent off on specific parent ADHD training techniques, only to find an assessment in secondary care does not confirm that diagnosis. The diagnosis has to come first but primary care professionals have to be educated so they can recognise the possibility of ADHD in a child. Under “Draft quality measure” in addition to “evidence of local arrangements” there needs to be evidence that ADHD specialists have received proper training because our experiences show that within any group of ADHD specialists there is a wide	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. A supporting document has been published alongside the standard reviewing the potential cost impact and implications for commissioners and service providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.

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					variation of expertise. There also needs to be evidence that teachers have received training. Teachers play an equally important role in supporting the child to achieve to the best of their ability and getting through into adulthood with good mental health.	
009	93	Association for Family Therapy and Systemic Practice	Quality statement 2		The use of the term "confirmed" in this statement, as in: '*Evidence of local arrangements to ensure that children and young people with suspected ADHD have their diagnosis confirmed by an ADHD specislist'* ... is potentially confusing as it implies a child can have ADHD attributed to them prior to a full assessment.	Thank you for your comment, the QSAC determined the final wording of this quality statement as, Children and young people with symptoms of ADHD are referred to an ADHD specialist for assessment.
009	94	Association for Family Therapy and Systemic Practice	Quality statement 2		This states service providers should ensure systems are in place for children and young people with suspected ADHD to have their diagnosis confirmed. AFT requests that service providers also ensure services are in place to support those young people with 'suspected ADHD', whether or not they receive a diagnosis. Otherwise, professionals and families may be placed in the painful position of 'needing a diagnosis' to gain access to effective services.	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. A supporting document has been published alongside the standard reviewing the potential cost impact and implications for commissioners and service providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
006	95	Association of School and College Leaders	Quality statement 2		The wording of the statement does not seem to allow for the possibility that those with suspected ADHD do not in fact have the condition.	Thank you for your comment, the QSAC determined the final wording of this quality statement as, Children and young people with symptoms of ADHD are referred to an ADHD specialist for assessment.
006	96	Association of School and College Leaders	Quality statement 2		School leaders report that there are instances of parents who from their own weakness or alienation condone the bad behaviour of their children claiming ADHD as an excuse. ADHD is	Thank you for your comment.

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					now well-known as a condition and is also likely to be suspected in many inappropriate instances by over-anxious parents.	
006	97	Association of School and College Leaders	Quality statement 2		There is a danger of medicalising 'normal', if inappropriate, behaviour. The American experience suggests that there is a danger of over-diagnosis of disorders such as autism, especially when the observational analysis is carried out by people who are not always fully qualified or who have a particular focus in their work[1]. We need experts such as educational psychologists who have a practical understanding of what is possible within a standard mainstream educational setting and who direct their proposals to that. The danger of private educational psychologists who are not regularly engaged in educational work is that they may make recommendations that are achievable in ideal circumstances with perfect teachers, small classes, lavish resources and an unstressed school, but not in the real world. [1]Current edition of 'Diagnostic and Statistical Manual of Mental Disorders', American Psychiatric Association	Thank you for your comment.
006	98	Association of School and College Leaders	Quality statement 2		It might be helpful to indicate in the standard whose suspicion of ADHD is to be acted on.	The rationale section of this statement states who would identify symptoms of ADHD.
006	99	Association of School and College Leaders	Quality statement 2		Schools and colleges are happy to make such referrals provided that there are suitable agencies to which the referrals can be made. In some areas CAMHS is under very great pressure and not apparently able to respond quickly to such referrals. This situation could be made worse if the volume of referrals were to	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. A supporting document has been published alongside the standard reviewing the potential cost impact and implications for commissioners and service

[1] Current edition of 'Diagnostic and Statistical Manual of Mental Disorders', American Psychiatric Association

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					rise – see the previous three points.	providers, however, the configuration of services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
010	100	Autism Rights Group Highland	Quality statement 2		Draft Quality statements 2 & 3 only mention Children and young people why does it not mention adults?	It is not expected that all statements would apply to all groups covered by the scope.
008	101	British Association for Adoption and Fostering (BAAF)	Quality statement 2		The wording of this should be changed. As stated there is an inherent presumption that those with suspected ADHD will have the diagnosis confirmed by an ADHD specialist, whereas the intent outlined in the rationale is for the specialist to carry out a full assessment to determine the diagnosis – which may or may not be ADHD!	Thank you for your comment, the QSAC determined the final wording of this quality statement as, Children and young people with symptoms of ADHD are referred to an ADHD specialist for assessment.
002	102	British Association for Community Child Health	Quality statement 2		This is an acceptable statement and is measurable. However taking statements 1 and 2 together, there needs to be a third statement stating that there should be an agreed transition pathway into adult services for those young people with ADHD who need to remain on treatment beyond childhood. We are aware that such transition is not available in many areas leading to paediatricians continuing to treat young adults, for which they are not trained and which is not appropriate. (Para 1.6 P35 of the Guideline)	This area was discussed by the QSAC and an additional statement has been developed. The statement is: Adults who were diagnosed and treated for ADHD as children or young people and present with symptoms of continuing ADHD are referred to general adult psychiatric services.
003	103	British Medical Association	Quality statement 2		Similarly, whilst we agree that referring children to ADHD specialists is important, there is also a lack of ADHD specialists working with children. Many children who would otherwise be referred to an ADHD specialist are currently given a general Child and Adolescent Mental Health referral, and some have to be referred to non-specialised Adult Mental Health Services.	NICE quality standards are intended to demonstrate what high quality care looks like for a particular topic based on the best available evidence. A supporting document has been published alongside the standard reviewing the potential cost impact and implications for commissioners and service providers, however, the configuration of

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						services will be determined locally. Supporting documents are available from www.nice.org.uk. We hope this will help to address your concerns.
007	104	East and North Hertfordshire NHS Trust	Quality statement 2		Comment about quality statement 2: The definition of an ADHD specialist is unclear as most Paediatricians are not mental health specialist however they do carry out diagnostic assessments for ADHD. Previous Nice Guidelines was clear in stating that assessment should be done by Child Psychiatrist or Paediatrician with expertise in assessing children for ADHD. There needs to be further clarification of the professionals that should carry out the diagnostic assessment for ADHD. Should the ADHD Nurse Specialist carry out a diagnostic assessment?	A definition of ADHD specialist is included in the final quality standard within the definitions of this quality statement.
007	105	East and North Hertfordshire NHS Trust	Quality statement 2		Comment about quality statement 2: There are lots of issues with children who have ADHD and comorbid mental health problems not having access to a Child Psychiatrist to assess their mental health problems. I feel the quality standards should reflect that children who have ADHD and comorbidity should have access to further assessment by a Child Psychiatrist	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
007	106	East and North Hertfordshire NHS Trust	Quality statement 2		Comment about quality statement 2: There should be a measure of the number of children with ADHD and comorbid mental health problems who have further assessment of their co morbidities by the Child Psychiatrist.	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard. NICE has now produced the support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk
004	107	Flynn Pharma	Quality		To “suspect” ADHD a parent, family,	The quality standards advisory committee

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			statement 2		teacher/other would require sufficient knowledge of ADHD symptoms to make the referral. Is guidance to be offered based on diagnosis using DSM5 criteria rather than DSM-IV? (DSM-V is expected to publish May 2013 and includes new and important diagnostic frameworks for children and adults).	identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
001	108	Lilly UK	Quality statement 2		As there are very few pure ADHD specialists this may limit the number of patients referred on to secondary care for assessment. We believe that a more appropriate descriptor of an ADHD specialist is used in the NICE CG72, Quick Reference Guide (p.10) and we have incorporated this into QS 2: Children and young people with suspected ADHD have the diagnosis confirmed by a specialist psychiatrist, paediatrician or other healthcare professional with training and expertise in the diagnosis of ADHD	A definition of ADHD specialist is included in the final quality standard within the definitions of this quality statement.
001	109	Lilly UK	Quality statement 2		We feel that it would improve patient care if there was a timeframe for referral incorporated within QS2.	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard. NICE has now produced the support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality

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						standard, available from www.nice.org.uk
014	110	Royal College of Paediatrics and Child Health	Quality statement 2		This is an acceptable statement and is measurable. However taking statements 1 and 2 together, there needs to be a third statement stating that there should be an agreed transition pathway into adult services for those young people with ADHD who need to remain on treatment beyond childhood. We are aware that such transition is not available in many areas leading to paediatricians continuing to treat young adults, for which they are not trained and which is not appropriate. (Paragraph 1.6 page 29 of the NICE Guideline)	This area was discussed by the QSAC and an additional statement has been developed. The statement is: Adults who were diagnosed with and treated for ADHD as children or young people and present with symptoms of continuing ADHD are referred to general adult psychiatric services.
014	111	Royal College of Paediatrics and Child Health	Quality statement 2		The standard focuses on *who* is doing the assessment, which is defined by professional group, but fails to address the issue of *what* is done. We are concerned that the new NHS competition regime will encourage shorter, less comprehensive assessments, leading to inaccurate diagnosis by missing out crucial developmental, family dynamic or mental health factors. We would recommend that the standard specify a *comprehensive* assessment by a specialist.	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
015	112	Royal College of Psychiatrists in Wales	Quality statement 2		"Suspected ADHD" is an ambiguous term. We require further clarity around who suspects the symptoms, whether the symptoms are pervasive, the severity of the child's condition, and the impact of the condition on the day-to-day life of the child. These are all important factors to be considered otherwise there is a risk that every child with suspected ADHD, be it by the parent, teacher or GP, is referred to a specialist CAMHS, which would flood the service with referrals.	Thank you for your comment, the QSAC determined the final wording of this quality statement as, Children and young people with symptoms of ADHD are referred to an ADHD specialist for assessment.

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010	114	Autism Rights Group Highland	Quality statement 2	Definitions	Considerations of and assessment of parents / carers mental health is an essential part of supporting a young person with ADHD as well as the wider family. However, this will have to be dealt with extremely sensitively; compelling parents / carers to have their own mental health assessed may make them feel blamed or "on trial" as a parent / carer, causing them to withdraw their children into an environment of secrecy, isolation and a lasting fear of seeking help, instilling associations of stigma and loss of control, liberty and personal choice.	A definition of assessment is included in the final quality standard within the definitions for this quality statement.
004	115	Flynn Pharma	Quality statement 2	Measure	Benchmark the level of adult ADHD diagnosis for individual services with the UK to ensure appropriate levels of diagnosis are being made by individual services; diagnosis levels should be within a specified range of the mean levels of diagnosis. No outcome measure specified	Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. It is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full.
017	116	British Psychological Society	Quality statement 2	Question 2	Whilst the Society welcomes the emphasis on referral to an ADHD specialist within secondary care in order to confirm the diagnosis, we believe that the required assessment would normally be most appropriately conducted by a multi-professional team as opposed to a single healthcare professional as implied by the standard. Furthermore, we believe that the assessments conducted in secondary care must be comprehensive and include a range of social situations and a range of opinions sought. In particular we advise that it is important that the perspectives of parents about the child's behaviour at home are supplemented by the perspectives of teachers about behaviour at	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.

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					school which may differ. We believe that the contributions of teachers and other relevant education professionals are invaluable in arriving at a diagnosis and should be taken into consideration routinely when confirming a diagnosis.	
015	117	Royal College of Psychiatrists in Wales	Quality statement 2	Rationale	There is a need for clarity around the referral process, including patient pathways and the role of primary care services in this process. The assessment of co morbid mental health and developmental problems in children and young people needs to be flagged up explicitly with examples including autistic spectrum disorder, intellectual Disability, mood Disorders including bipolar disorder. Co morbidity is the rule rather than the exception and those assessing ADHD need to be trained and have skills in assessing these conditions and not simply be experts on ADHD in isolation. There is a lack of service for children with ADHD and co-morbid learning disability as the ADHD symptoms are often explained on the basis of masking or diagnostic overshadowing whereby these children are rarely offered appropriate assessments or interventions. (Attached paper in press on these issues)	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. NICE has now produced the support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk
016	118	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 3		This statement does not include provisions for severely affected adults with ADHD whose families and carers could also benefit from psychological treatment and other help. Please see our draft quality statement 14 for our recommendations for this group. From our experiences it seems that many trusts don't appear to have accurate numbers for children actually diagnosed with ADHD. Given	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important

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					that, we are not sure that Trusts will be able to accurately measure (and include under "Denominator", not only those diagnosed, but also those who are suspected of having ADHD. We feel that it would be more meaningful if the quality statement focused on getting Trusts to identify and using the number of children actually diagnosed (as an aside without that information, MHT's and commissioners can't even begin to look at planning an Adult ADHD service!) "Process" and "Outcomes" should be more specific as follows: Parents who have received targeted ADHD parent training should be asked to provide 3 monthly feedback to measure whether or not the training continues to meet their needs. This feedback would help develop programmes which would address shortfalls in the original training programme. Authorities would have to show how they have used that feedback to arrange further targeted training – thus a continuous learning cycle is developed.	to measure the quality statements in the final standard.
009	119	Association for Family Therapy and Systemic Practice	Quality statement 3		There needs to be explicit recognition within the quality statements that some parents of children who have a diagnosis of 'ADHD' plus 'Conduct Disorder' / 'Oppositional Defiant Disorder' / severe challenging behaviour, and/or who have serious parental or family relationship difficulties and/or mental health difficulties may require a more specialist therapeutic service than a parent training programme. Such families benefit from Systemic Family Therapy. There is also a growing evidence for the usefulness of systemic Multi-FamilyTherapy. Engaging, collaborative and effective, Multi-	The QSAC identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.

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					FamilyTherapy groups in schools and other non-stigmatising settings are supporting children and families experiencing emotional, behavioural and social problems, including families with children with a diagnosis of ADHD. Marlborough Model of Multiple Family Therapy Groups in Schools Context, Issue 123 / October 2012: Multi-family therapy: Challenging behaviour in educational settings	
006	120	Association of School and College Leaders	Quality statement 3		This is particularly welcome. Schools and colleges are happy to make such referrals provided that there are suitable agencies to which the referrals can be made.	Thank you for your comment.
010	121	Autism Rights Group Highland	Quality statement 3		We are concerned about the wording: 'parent training and education', whilst it is necessary to be explicit and unambiguous with language these terms could be seen to imply that parents are at fault or to blame. For example, parent support and education may be less likely to imply attached blame. Training / education should also be given to staff / carers in out of home settings, for example at home for looked after children and to schools for all children.	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
010	122	Autism Rights Group Highland	Quality statement 3		Draft Quality statements 2 & 3 only mention Children and young people why does it not mention adults?	It is not expected that all statements would apply to all groups covered by the scope.
002	123	British Association for Community Child Health	Quality statement 3		This is an acceptable statement and is measurable	Thank you for your comment.
003	124	British Medical	Quality		We are unsure whether there are adequate	Thank you for your comment. NICE has now

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		Association	statement 3		places in appropriate education services, but if these do exist, we would be happy for the diagnosing specialist to make this referral for parents.	produced the support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk
007	125	East and North Hertfordshire NHS Trust	Quality statement 3		There is lack of clarity on what an education programme is. Majority of the schools have no education programme in place for children with ADHD. There needs to be more clarity about what a parent training or education programme should provide.	A definition of education programme is included in the final quality standard within the definitions for this quality statement.
004	126	Flynn Pharma	Quality statement 3		Important to differentiate between mild/moderate and severe ADHD/impairment – NICE recommends the first intervention for the latter group is pharmacological. Training needs of other responsible adults such as teachers who come into contact with children with ADHD must be considered/addressed to ensure consistency of messages.	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes. NICE has now produced the support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk
014	127	Royal College of Paediatrics and Child Health	Quality statement 3		This is an acceptable statement and is measurable	Thank you for your comment.
015	128	Royal College of Psychiatrists in Wales	Quality statement 3		The availability of these programmes tends to be variable depending on the local resources and services. Even if available, the uptake by parents is often poor.	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes. NICE has now produced the support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk
004	129	Flynn Pharma	Quality statement	Audience	Service Providers and HCPs need to validate the success of the programmes they	NICE has now produced the support document to help commissioners and others

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			3		commission, parent/ carer completer rates or measures of improvements in ADHD symptoms or parent/ carer QoL should be accessed and measured.	consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk
004	130	Flynn Pharma	Quality statement 3	Measure	Outcome - This would require an assessment form/process (ideally standardised) and sufficiently comprehensive to capture both negative and positive feedback. Additionally, this is a purely subjective outcome measure with inherent bias/ unreliability. The number of parents/carers referred should be compared with the number who actually start a course and the number of starters needs to be compared with the number of course completers; this gives a better indication of the perceived value, effectiveness and use of the training offered. Need a more objective measure as to the success of the training offered, possibly using a rating scale equating improvement in symptoms of ADHD or parents QoL measure – tools that are currently used to access the impact of psychological interventions.	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard. Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. It is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full.
017	131	British Psychological Society	Quality statement 3	Question 1	The Society believes that in addition to whether families had been offered programmes and parent satisfactions an appropriate health outcome would also be the percentage attendance in terms of those offered (to ensure concerns listed in 'equality and diversity considerations' are met) as, of course, the positive impact comes from attendance at courses rather than having been offered a place. Services need to take responsibility for making such programmes accessible to all families. In 2012, the Society published a discussion paper *Technique is not enough* emphasizing that parenting programmes must be socially inclusive	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.

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					otherwise they run the risk of failing to attract or retain participants. *Technique is not enough* is designed to ensure that parenting programmes engage those most likely to benefit. It argues that if all programmes adopted its framework, participation rates could increase dramatically. Additionally we would strongly suggest that health outcomes be measured by objective changes either in symptomology by a measure such as the Conners' Rating Scales (Conners, 2004) or parental stress levels such as the Parental Stress Index (Abidin, 1983). Conners, C. K. (2004). *Conners' Rating Scales-Revised: CRS-R*. MHS, Multi-Health Systems. Abidin, R. R. (1983). Parenting Stress Index: Manual, Administration Booklet [and] Research Update. British Psychological Society (2012). *Technique is not enough.* Leicester: British Psychological Society	
017	132	British Psychological Society	Quality statement 3	Question 4	Whilst we warmly welcome the inclusion of the offer of parent training/education programme, as a standard, we would suggest the inclusion of the term 'evidenced based' in relation to parenting training and education programme. There is significant data to indicate which components of ADHD parent training programmes are effective in long term outcomes for young people (e.g. Wyatt, Kaminski et al., 2008) and it is important that programmes offered are evidenced based so as to best enhance the lives of children, young people and their families. For example, it is known in one contributors' current work place that a one-day education programme is offered to families who	A definition of parent training programme is included in the final quality standard within the definitions for this quality statement.

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					have had a child/young person diagnosed with ADHD but this covers only psycho-education and not the more key components to parental training and so measuring alone whether this programme is offered would not fully clarify that the standard had been met in terms of the young people's outcomes. Wyatt Kaminski, J., Valle, L. A., Filene, J. H., & Boyle, C. L. (2008). A meta-analytic review of components associated with parent training program effectiveness. *Journal of abnormal child psychology*, ***36*****(4)**, 567-589	
016	133	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 4		Rationale: Good in as far as it goes. However, psychological treatment should also be looking to help children and young people educate themselves about their condition, with a view to encouraging them to begin to take ownership of their condition. After all, for many children, this will be a condition which affects them over the lifespan. Any government document stresses the importance of early intervention, so why not start the "education" process at an early stage, so these young people can put in place strategies which will help them in adulthood. Alongside this, the evidence should also be measuring the number of young people, who at 18, have successfully moved into either employment or some form of continuing education.	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway. The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.

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009	134	Association for Family Therapy and Systemic Practice	Quality statement 4		This refers to 'psychological group treatment programme'. It would be useful if this were described in more detail. AFT alerts the QS consultation to the usefulness of Multi-Family Therapy for families with children with a diagnosis of ADHD or presenting with symptoms that might be described as such (see Statement 2+3, above). What is the alternative recommendation for those families and children for whom a group programme is not appropriate, or who feel unable to participate in a group? There is a robust evidence base for systemic family interventions with this client group. Lange, G., Sheerin, D., Carr, A., Dooley, B., Barton, V., Marshall, D., Mulligan, A., Lawlor, M., Belton, M. and Doyle, M. (2005), Family factors associated with attention deficit hyperactivity disorder and emotional disorders in children. Journal of Family Therapy, 27: 76–96. doi: 10.1111/j.1467-6427.2005.00300.x Stratton, P (2010). The Evidence Base Of Systemic Family and Couples. Therapy. Association for Family Therapy, UK	A definition of psychological group treatment programme is included in the final quality standard within the definitions for this quality statement.
009	135	Association for Family Therapy and Systemic Practice	Quality statement 4		The 'rationale' states that 'ADHD affects many aspects of the lives of children and young people'. Yes, and the lives of children and young people also affects their behaviours. This glaring obvious statement is important to include in the rationale, if service providers and practitioners are to be supported to consider explanations other than 'ADHD'. It will also support provision of effective interventions for families and children struggling with aspects of their lives,	Thank you for your comment.

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					relationships and behaviours, with or without a diagnosis.	
006	136	Association of School and College Leaders	Quality statement 4		This is welcome. Schools and colleges are happy to make such referrals provided that there are suitable agencies to which the referrals can be made.	Thank you for your comment.
010	137	Autism Rights Group Highland	Quality statement 4		There are many instances in which group treatment would not be beneficial or may be rejected by an individual, for Example pushing children or young people into group sessions may be traumatic for them as in many cases their difficulties are likely to have made them vulnerable to bullying in peer groups. Draft quality statement 4: Psychological treatments for children and young people with ADHD, definitions, suggests individual psychological interventions for older adolescents, we would like to see this extended to all age groups if requested / appropriate.	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
002	138	British Association for Community Child Health	Quality statement 4		This is an acceptable statement and is measurable	Thank you for your comment.
003	139	British Medical Association	Quality statement 4		We are unsure whether there are adequate places in appropriate psychological group treatment programmes, but if these do exist, we would be happy for those with ADHD to be referred to it as part of the specialist diagnosis and management.	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. NICE has now produced the support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality

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						standard, available from www.nice.org.uk
013	140	Royal College of Nursing	Quality statement 4		We would be interested to know which effective evidenced based and specific programme that is being considered here for this group and what it consists of in terms of CBT and psychological interventions. We are aware of the parenting training i.e. Tripple P and Webster Stratton which is manualised and researched. We are unaware of any for ADHD.	A definition of psychological group treatment programme is included in the final quality standard within the definitions for this quality statement.
014	141	Royal College of Paediatrics and Child Health	Quality statement 4		This is an acceptable statement and is measurable	Thank you for your comment.
015	142	Royal College of Psychiatrists in Wales	Quality statement 4		Group-based treatment for some (for example those with autism, specific language impairments, anxiety disorder, intellectual disability-group-based interventions) might not be possible or suitable. These again are variable according to local resources, and often engagement by children and young people is poor. These services are variable in different parts of the country in terms of provision and access.	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
019	143	UK Adult ADHD Network	Quality statement 4		UKAAN would like to suggest the extension of this statement to adults with ADHD. There is increasing evidence from high quality clinical trials that CBT, both group and individual formats, improves symptoms and functioning, particularly when combined with medication (for review see Mongia & Hechtman 2012, Young & Bramham 2013).	It is not expected that all statements would apply to all groups covered by the scope.
009	144	Association for Family Therapy and Systemic Practice	Quality statement 4	Equality and diversity	There needs to be an explicit recognition within the quality statements that some children who have a diagnosis of 'ADHD' and 'Conduct	The quality standards advisory committee identified the development sources they felt

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				considerations	Disorder'/ 'Oppositional Defiant Disorder'/ severe challenging behaviour, may require a more specialist therapeutic service. Consideration needs to be given to therapeutic approaches such as Systemic Family Therapy and systemic Multi-Family Therapy Marlborough Model of Multiple Family Therapy Groups in Schools Context, Issue 123 / October 2012: Multi-family therapy: Challenging behaviour in educational settings Lange, G., Sheerin, D., Carr, A., Dooley, B., Barton, V., Marshall, D., Mulligan, A., Lawlor, M., Belton, M. and Doyle, M. (2005), Family factors associated with attention deficit hyperactivity disorder and emotional disorders in children. Journal of Family Therapy, 27: 76–96. doi: 10.1111/j.1467-6427.2005.00300.x Stratton, P (2010). The Evidence Base Of Systemic Family and Couples. Therapy. Association for Family Therapy, UK	were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
004	145	Flynn Pharma	Quality statement 4	Measure	There is no outcome measure here. According to NICE Quality Statements must be measureable. Is the denominator quantifiable? Should specify a minimal number or levels of patients expected to enrole with and complete the programme. Also a minimal level of improvements in ADHD symptoms should be considered to access the efficacy of the psychological treatment being offered.	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.
017	146	British Psychological Society	Quality statement 4	Question 2	It states in equality and diversity that consideration should be given to young people with co-morbid difficulties such as conduct disorders, mood disorders and learning disabilities. We feel it is important to clarify that	Thank you for your comment.

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					these are areas for consideration, not exclusion to ensure that young people are not inadvertently excluded from a service. These young people should still be offered services under this quality standard as there are very serious consequences for individuals with ADHD and other co-morbid disorder, especially conduct disorders, not receiving appropriate treatment (e.g. Harpin, 2005). Harpin, V. A. (2005). The effect of ADHD on the life of an individual, their family, and community from preschool to adult life. *Archives of disease in childhood*, *90*(suppl 1), i2-i7.	
017	147	British Psychological Society	Quality statement 4	Question 4	We would ideally suggest the inclusion of the potential for individual treatment as well as group treatment under quality standard 4 in line with NICE guideline recommendation for evidence based treatments for this group. We would not however, suggest this as an alternative but only as an addition to the current quality standards. National Institute for Clinical Excellence Guideline: Attention deficit hyperactivity disorder (ADHD) (CG72)	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
016	148	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 5		Rationale. There's an emphasis here that monitoring the effects of titration is solely down to the prescriber and for side effects alone. However parents/ adults should be given some kind of tool which will help them self-monitor the effects of titration not only for side effects but	Thank you for your comment.

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					also for benefits. Without that we are left in a position whereby the prescriber appears to be the only person who can judge the effectiveness of titration. This surely can't be right. There has to be some sense that this is a partnership arrangement between parent/child/young person/adult.	
009	149	Association for Family Therapy and Systemic Practice	Quality statement 2&3		There needs to be explicit recognition within the quality statements that some parents of children who have a diagnosis of 'ADHD' plus 'Conduct Disorder' / 'Oppositional Defiant Disorder' / severe challenging behaviour, and/or who have serious parental or family relationship difficulties and/or mental health difficulties may require a more specialist therapeutic service than a parent training programme. Such families benefit from Systemic Family Therapy. There is also a growing evidence for the usefulness of systemic Multi-FamilyTherapy. Engaging, collaborative and effective, Multi-FamilyTherapy groups in schools and other non-stigmatising settings are supporting children and families experiencing emotional, behavioural and social problems, including families with children with a diagnosis of ADHD. Marlborough Model of Multiple Family Therapy Groups in Schools Context, Issue 123 / October 2012: Multi-family therapy: Challenging behaviour in educational settings	The quality standards advisory committee identified the development sources they felt were most relevant to developing the standard, within the framework of the Quality Standards development process. Other related quality standards are referenced in the published standard. The key development sources will typically be NICE guidance and the diagnostic manuals referenced within it. Other NICE accredited sources, where available, may be used when existing NICE guidance does not cover a part of the patient pathway.
006	150	Association of School and College Leaders	Quality statement 5		Not for ASCL to comment on.	Thank you for your comment.
021	151	Avon and Wiltshire NHS Trust Adult ADHD clinic	Quality statement		Monitoring for side effects is not a direct measure of treatment efficacy and initial	The QSAC prioritised areas of care where practice is variable, or where implementation

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<tr><td></td><td></td><td></td><td>5</td><td></td><td>escalation rates may be too aggressive.

For our most commonly prescribed agent, Concerta XL, this is the breakdown of dosage in our current stabilised patients:
<table><tr><th>Dosage</th><th>#</th><th>%</th></tr><tr><td>18mg</td><td>40</td><td>19.8</td></tr><tr><td>27mg</td><td>22</td><td>10.9</td></tr><tr><td>36mg</td><td>122</td><td>60.4</td></tr><tr><td>54mg</td><td>5</td><td>2.5</td></tr><tr><td>72mg</td><td>13</td><td>6.4</td></tr><tr><td></td><td>202</td><td>100</td></tr></table>
In adult patients, our experiences would guide us to recommend a much longer period of treatment initiation and stabilisation than the stated 4 to 6 weeks. In adults we recommend 3 to 6 months, and rate of titration should be slow, only increasing after the 1 month point.

The reasons are as follows:
<u>1. The psychosocial effects of new diagnosis in adulthood.</u>
Doses of medication on our caseload are certainly lower than childhood doses, probably due to both organic and psychological reasons. We have observed that many such patients have downstream effects of drug initiation:

i) they do well on lower doses if those lower doses are left with an individual to form their own views over 2-3 months, rather than more aggressive escalation

ii) Getting a new diagnosis in itself constitutes</td><td>could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.

The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.</td></tr>
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					initiates a substantial internal treatment effect through processes of self-education, accommodation, automatically initiated compensations, greater wellbeing due to greater self knowledge etc. Aggressive increases in dose may land the patient on an unnecessarily high dose, and distract from the side-effect free gains made by these processes. Also, a slower titration period in itself helps manage expectations of impulsive adults who are over-focussed on medication as the curative agent. **2. Efficacy, tolerability, and time to switch** Although stimulants have a low NNT for ADHD, there are still significant numbers of patients for whom they don't work for any reason (efficacy, tolerability etc). The 4-6 week period is not long enough to consider the switch to second or third line agents, and in the second and third line agents typically atomoxetine or bupropion, evidence of efficacy is only reached in a minimum of 4-6 weeks. Thereafter, there is commonly a period of at least another 4 to 6 weeks, during which optimum dosing of that 2nd/ 3rd line agent is sought. **3. Commissioning service specifications may set 6-8 weeks as the upper limit for a patient to be exclusively in the care of specialist service. This is not long enough.** Commissioning groups are in practice likely to set service specifications to expect patients to be diagnosed and stabilised within a certain period. This period is commonly the time in	

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					which they expect most patients to be settled on a medication. 6-8 weeks is not a sufficient time to expect any complete specialist service to have done much beyond just the first pharmacological steps: i) Psychological skills groups etc tend to run once a patient is stabilised on medication, often from week 8 onwards (starting psychological treatment before then may not have as much impact considering the nature of the disorder). Commissioners in our area have been historically reluctant to fund these groups, preferring to focus on medication. For example, there is still no such funded psychological work for ADHD patients who are in transit to adulthood in the Bristol area. ii) **6-8 weeks is not long enough to create a coherent for dialogue with GPs new to ADHD**. GPs in all areas are still relatively hesitant to take on shared care prescribing. From the time a new patient gets seen to the time they are stabilised, there also suns a parallel educational process when the clinic discusses and negotiates longer term support for the patient. This often takes a few months in our experience., iii) **Patients stabilised too early in a chronic condition may not be truly stabilised**. also more likely to require reassessment, switching and ad-hoc adjustment etc. They often experience some latent or milder downstream effects of the drug (sexual side effects, slow weight loss etc). They more often need to be re-	

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					evaluated by coming back to clinic- this may necessitate extra admin and unnecessary extra appointment time, and this in itself may need requests for further funding etc which would cause delays in serving the patient's needs.	
021	152	Avon and Wiltshire NHS Trust Adult ADHD clinic	Quality statement 5		Adults with ADHD are naturally more autonomous than children. They have very disparate and often very specific aims for treatment which are difficult to capture with extant standardised instruments, and our observations are that side effects are less problematic overall, but benefits are both more subjective and more specific. We strongly suggest incorporating PROMS (patient specified / patient rated outcome measures) and/or evidence-based measures of well-being (eg. The recovery star) as part of measurement of outcome and progress in dose adjustment response in adults. This has been a highly successful strategy locally. It allows patients to be specific and pragmatic about what they feel is actually helped. As an example of PROMS inpractice, we ask all patients to fill out standardised symptom forms at assessment and review (e.g. Barkley Scales) but we also add to the bottom of those forms, a customised section as follows: See proforma for full table Besides being highly satisfactory for patients, collecting this data allows adult ADHD services to form themes for future service development, avenues for research, and opportunities for education in this rapidly growing field, in a way	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. It is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full.

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					that is integrated with day to day practice.	
002	153	British Association for Community Child Health	Quality statement 5		This is an acceptable statement but we have concerns about how this could be recorded and measured at a national level.	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard. Examples of existing national data collection which may be relevant, in part at least, to the quality measure are referenced where appropriate. It is expected that local data sources and audits where appropriate will be considered in order to measure the quality statements in full.
003	154	British Medical Association	Quality statement 5		Given our concerns about the numbers of specialists, we are unsure that this statement can be practically put into action, but we would agree that specialists should supervise and assess the medication dose. However, given the low levels of specialists available across the country, we would argue that it would be difficult for a patient to see their specialist frequently enough for the specialist to calibrate their medication within 4-6 weeks and would suggest a longer time-scale would be more realistic. After the medication has been calibrated, we would argue strongly that there should be a period of stabilisation of at least 12 weeks before any contemplation of passing prescribing on under any shared care arrangements that might exist locally for the ongoing prescribing.	NICE has now produced the support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk

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007	155	East and North Hertfordshire NHS Trust	Quality statement 5		Comments about quality statement 5: The standard states that people starting their ADHD treatment should have their initial dose adjustment over 4-6 weeks by an ADHD specialist. Comment: There should be more clarification about how this should be done. Will it be acceptable to review patients by telephone only over the whole 6 weeks period or review them at least once in a face to face consultation? There should be more clarification regarding minimum standards in this area.	A definition of dose adjustment is included in the final quality standard within the definitions for this quality statement.
012	156	Janssen-Cilag Ltd	Quality statement 5		Janssen agrees that monitoring unwanted sides effects in the early weeks following treatment initiation is important. However, we also believe that once an optimal dose has been determined, specific standards should also be developed to monitor and encourage patient adherence to medication, and to monitor the beneficial effects of treatment, such as symptom improvement, quality of life improvement, etc over the course of the treatment cycle/year.	Thank you for your comment.
001	157	Lilly UK	Quality statement 5		We agree that it is appropriate to titrate methylphenidate and dexamfetamine over 4 to 6 weeks, however, this recommendation should not extend to atomoxetine as it does not reflect the atomoxetine licence or the correct dosing guidance in NICE Guideline CG72. CG72, sections 1.8.2.3 and 1.8.3.4 include the correct initial titration recommendations for atomoxetine in children and adults respectively: *1.8.2.3 If using atomoxetine in children and young people with ADHD aged 6 years and older:*	Thank you for your comment. The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.

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					• *For those weighing up to 70 kg, the initial total daily dose should be approximately 0.5 mg/kg; the dose should be increased after 7 days to approximately 1.2 mg/kg/day* • *For those weighing more than 70 kg, the initial total daily dose should be 40 mg; the dose should be increased after 7 days up to a maintenance dose of 80 mg/day.* *1.8.3.4 If using atomoxetine in adults with ADHD:* • *For people with ADHD weighing up to 70 kg, the initial total daily dose should be approximately 0.5 mg/kg; the dose should be increased after 7 days to approximately 1.2 mg/kg/day* • *For people with ADHD weighing more than 70 kg, the initial total daily dose should be 40 mg; the dose should be increased after 7 days up to a maintenance dose of 100 mg/day.* We suggest that the statement is, therefore, amended to incorporate wording around efficacy and/or outcomes e.g. 1) People with ADHD who are starting drug treatment have their initial drug dose adjusted by a mental health specialist with the training to diagnose and advise	

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					on ADHD, to ensure effective response to medication is achieved and unwanted effects are minimised.	
018	158	Nottinghamshire Healthcare NHS Trust	Quality statement 5		Please add that for those with LD it is recommended to titrate drugs over a longer period eg three months due to underreporting of side effects.	Thank you for your comment.
022	159	RCGP	Quality statement 5		CB - 4-6 weeks is insufficient time to stabilise the person on the correct dose of appropriate medication. It is too soon to hand the prescribing over to the none specialist. In the case of adults this would often be the GP. The wording should not specify a time, it should have a more rigorous statement of what constitutes a stable preparation and dose. For example: the specialist should ensure the person with ADHD is on the most appropriate type of medication in terms of preparation and dose before transferring the prescribing to primary care. When primary care is being asked to take over the prescription there should be a shared care protocol which clearly states the aims and objectives of treatment, potential side effects, monitoring requirements, duration of treatment and when referral back to specialist services is appropriate.	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.
014	160	Royal College of Paediatrics and Child Health	Quality standard 5		Page 16, line 5 Nurse prescriber specialising in ADHD may write a prescription for repeat medication (this line should be added to make it clearer).	Thank you for your comment.
014	161	Royal College of Paediatrics and Child Health	Quality statement 5		This is an acceptable statement but we have concerns about how this could be recorded and measured at a national level.	Thank you for your comment. NICE has now produced the support document to help commissioners and others consider the commissioning implications and potential

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						resource impact of this quality standard, available from www.nice.org.uk
014	162	Royal College of Paediatrics and Child Health	Quality statement 5		Parents (or other carers), should be given time to consider information about proposed drug treatment which should only be started at a subsequent clinic visit.	Thank you for your comment.
011	163	Sussex Partnership NHS Foundation Trust	Quality statement 5		No specific mention of the importance of physiological assessment of the patient before initiating ADHD medication therapy. (Lead CAMHS & Early Intervention Pharmacist)	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
011	164	Sussex Partnership NHS Foundation Trust	Quality statement 5		No specific mention of which side effects and what monitoring is required when initiating ADHD medication therapy. (Lead CAMHS & Early Intervention Pharmacist)	A definition of how drug dose should be adjusted is included in the final quality standard within the definitions for this quality statement.
019	165	UK Adult ADHD Network	Quality statement 5		UKAAN endorses dose titration by an ADHD specialist or “under direction of a specialist” (as recommended by the British National Formulary). In our understanding, a specialist in adult ADHD is a suitably trained psychiatrist or nurse practitioner who participates in regular CPD on adult ADHD and peer supervision. In the interest of feasibility we would like to suggest an extended period of initial dose titration of 4-12 weeks. Weekly (or even more frequent) contacts with patients are difficult to organise in busy general adult mental health services (community mental health teams).	Thank you for your comment.
004	166	Flynn Pharma	Quality	Measure	Ensure that a range of pharmacotherapies are	The QSAC reviewed all measures in the draft

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			statement 5		used by individual services and that treatments are regularly reviewed and adjusted to meet individual patient requirements and therapeutic needs (this should be accessed by clinical audit). Improvement in ADHD treatment could be assessed by improvement in symptoms; this is a better measure, used alone or in conjunction with assessment of side-effects. All prescribing is a balance between risk and benefit. AE's needs to be recorded by incidence, type and severity for each active agent and for each patient group. This is paramount given the introduction of new drugs and indications. Additionally, it is important to monitor both safety *and* efficacy given that clinicians will need to establish a balance of the two.	quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.
015	167	Royal College of Psychiatrists in Wales	Quality statement 5	Measure	Using drug-related side effects is problematic- this could reflect the clinic population (e.g. those with autism and intellectual disability have higher rates of side effects) or under-treatment (e.g. staying on a very low dose and not titrating upwards).	Thank you for your comment.
004	168	Flynn Pharma	Quality statement 5	Rationale	Is the outcome an accurate measure of the QS? Recently introduced products for ADHD may well increase the number of SEs reported without reflecting an increase in monitoring.	The QSAC reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.
016	169	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 6		Rationale. NICE are right to insist people who are taking drug treatment are reviewed at least annually. However, there's a huge difference between those people who have been diagnosed long enough to be experienced patients and in addition are well settled on drug treatment, from those who are relatively new to	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.

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					the diagnosis. It is our experience that too many people, after the initial titration period are then left on their own until they are due for an annual review. We suggest that newly diagnosed people should be offered 3 monthly reviews in their 1st year of treatment so they have the opportunity to take stock of the impact of the diagnosis and discuss what additional areas of concern need to be addressed and what support can be accessed. A quality standard measurement for this would be the number of people still taking medication after the 1st year. It should also be recognised and included within the quality statement that those people who were once stable on medication may no longer be so, and may also have stopped taking drug treatment without the prescribers' knowledge. This could be due not just to side effects but to breakdowns in supporting structures due to unavoidable changes in life circumstances, or changes in health conditions, or to difficulties in accessing prescriptions because of lack of or breakdowns in shared care agreements amongst other things. Under these circumstances there should be enough flexibility in an ADHD service's capacity to allow people to have reviews before their annual review is due.	
009	170	Association for Family Therapy and Systemic Practice	Quality statement 6		AFT is concerned that the emphasis seems to be on reviewing medication alone. Reviews, at a frequency agreed according to clinical need rather than service systems, need to also consider other possible treatments, including systemic psychological interventions, and to actively consider the possibility of explanations other than ADHD for people's struggles. Children and young people in particular will need	A definition of a specialist review is included in the final quality standard within the definitions for this quality statement.

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					drug treatments reviewed more regularly than 'at least annually'. In cash strapped services, 'minimums' have a habit of becoming practice standards.	
006	171	Association of School and College Leaders	Quality statement 6		Not for ASCL to comment on.	Thank you for your comment.
002	172	British Association for Community Child Health	Quality statement 6		This statement does not seem to be in accordance with NICE guidance, which says that people on treatment should have their blood pressure measured every three months (Para 1.8.4.6 P45 of the Guideline), and that children on treatment should be weighed and measured at least every six months (Para 1.8.4.2 P44)	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
003	173	British Medical Association	Quality statement 6		It must be made clear in the statement that the review of the drug treatment and its continuing need is a specialist responsibility and non-transferrable. Initial discussions of possible adverse drug reactions noted by patients/carers would fall to the prescriber but annual assessments would be covered by existing shared care arrangements and must be for specialists to complete.	Thank you for your comment. A definition of a specialist review is included in the final quality standard within the definitions for this quality statement.
004	174	Flynn Pharma	Quality statement 6		EU safety referral (Article 31) and methylphenidate SmPCs (some generally for all stimulants and atomoxetine) specify 6 monthly review (for paediatrics to include CV, weight and growth).	Thank you for your comment.
012	175	Janssen-Cilag Ltd	Quality statement 6		Janssen agrees that monitoring unwanted sides effects in the early weeks following treatment initiation is important. However, we also believe that once an optimal dose has been determined, specific standards should also be developed to monitor and encourage patient adherence to medication, and	Thank you for your comment.

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					to monitor the beneficial effects of treatment, such as symptom improvement, quality of life improvement, etc over the course of the treatment cycle/year.	
001	176	Lilly UK	Quality statement 6		We feel that it is important to highlight that essential safety reviews for all treatments are carried out more frequently (every 3 to 6 months in some circumstances). A useful table (table 3) in the CG72 Quick Reference Guide includes monitoring guidance for methylphenidate, atomoxetine and dexamfetamine in areas such as cardiac function and blood pressure, height, weight etc. This table could prove a helpful addition to the quality standard.	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
022	177	RCGP	Quality statement 6		Needs to specify who should be doing the annual review. As with statement 5 above, clear guidance to primary care is essential. At present we have a considerable number of adults who remain on Methylphenidate (Ritalin) after being discharged from adult services. There is lack of guidance and support for primary care who are required to supply the drug to the adults and face issues such as interactions with other medications (SSRIs) and alcohol as well as advising re pregnancy.	Thank you for your comment. A definition of a specialist review and who should do it is included in the final quality standard within the definitions for this quality statement.
014	178	Royal College of Paediatrics and Child Health	Quality standard 6		Page 17, line 27 People with severe ADHD.....	Thank you for your comment.
014	179	Royal College of Paediatrics and Child Health	Quality statement 6		This statement does not seem to be in accordance with NICE guidance, which says that people on treatment should have their blood pressure measured every three months (Paragraph 1.8.4.6, page 37 of the NICE Guideline), and that children on treatment should be weighed and measured at least every	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.

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					six months (Para 1.8.4.2 page 36)	
015	180	Royal College of Psychiatrists in Wales	Quality statement 6		It is unclear who should carry out the review. If it is the prescriber, will this be patient's GP? If so, it would be important to analyse the rates of prescriptions from GPs, from CMHTs, and from specialist clinics.	Thank you for your comment. A definition of a specialist review and who should do it is included in the final quality standard within the definitions for this quality statement.
011	181	Sussex Partnership NHS Foundation Trust	Quality statement 6		I feel that there needs to be more emphasis on the review looking at whether medication remains an appropriate treatment as ideally we would be looking to help young people to be able to manage their behaviour as they get older without having to rely on mediation. We also need to acknowledge that this might not always be possible. (Consultant Nurse, CAMHs)	Thank you for your comment. A definition of a specialist review is included in the final quality standard within the definitions for this quality statement.
011	182	Sussex Partnership NHS Foundation Trust	Quality statement 6		There is a lack of mention of requirement for physical health monitoring (BP, pulse, height & weight) at least every 6 months. when taking ADHD medications. (Lead CAMHS & Early Intervention Pharmacist)	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
011	183	Sussex Partnership NHS Foundation Trust	Quality statement 6		There could be more emphasis of the importance of medication breaks at least annually, particularly with the stimulant medications. (Lead CAMHS & Early Intervention Pharmacist)	The QSAC prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators.
019	184	UK Adult ADHD Network	Quality statement 6		UKAAN endorses this quality statement. There is an ongoing debate between secondary (and tertiary) mental health services and primary care about the responsibility for (and funding of) the annual review. In the new NHS many patients with a diagnosis of ADHD who are functioning well on a stable dose of ADHD medication will be discharged to primary care.	Thank you for your comment. A definition of a specialist review and who should do it is included in the final quality standard within the definitions for this quality statement.

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					UKAAN would like to suggest that annual reviews of non-complicated patients with ADHD can be performed by GPs with some minimum training in ADHD to ensure they have the relevant experience, knowledge and skills to do so. Ideally, annual reviews of stable patients could be performed by ADHD specialists and GPs in alternating years. However, where GPs feel they are not able to review patients then such patients should have access to specialist review within secondary (or tertiary) mental health services. The NICE 2008 guideline recommends that “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” in people on ADHD medication (1.8.4.6). It is not clear where this recommendation comes from. In the SPC for Concerta XL (which has a carry-on license for adults) it says (and this is the recommendation for children and adolescents): "Cardiovascular status should be carefully monitored. Blood pressure and pulse should be recorded on a centile chart at each adjustment of dose and then at least every 6 months." UKAAN would like to suggest an extension of the blood pressure / pulse monitoring interval from 3 to 6 months. Centile charts do not make sense in adults and should not be recommended for adults with ADHD.	
010	185	Autism Rights Group Highland	Quality statement 6	Definitions	"People with ADHD should have access to an interpreter or advocate if needed" should be if Requested. who decides need?	Thank you for your comment.

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013	186	Royal College of Nursing	Quality statement 6	Description	Who is the annual review by – GP or primary care as this seems to contradict the guideline Section 10.18.11 (pages 311 and 312).	Thank you for your comment. A definition of a specialist review and who should do it is included in the final quality standard within the definitions for this quality statement.
004	187	Flynn Pharma	Quality statement 6	Measure	Clarity of what a medication review should be looking for and warning signs associated with misuse; medication audit carried out annually by services prescribing medications; type of medication, dose, prescribing frequency, control and side effects to be considered.	Thank you for your comment. A definition of a specialist review and who should do it is included in the final quality standard within the definitions for this quality statement.
012	188	Janssen-Cilag Ltd	Quality statement 6	Rationale	NICE may also wish to note in this Quality Statement that extended release (XL) forms of ADHD medications may have reduced potential for abuse.	Thank you for your comment.
013	189	Royal College of Nursing	Quality statement 6	source clinical guideline references	For ease of reference, it would be helpful to include the references from the Full Guideline i.e. the summary of recommendation section 12 (page 380).	Thank you for your comment.
016	190	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 7		Quality statement: Practitioner competence: Practitioners delivering pharmacological, psychological or psychosocial interventions for people with ADHD receive regular supervision that ensures they are competent in delivering interventions of appropriate content and duration in accordance with NICE guidance. Structure: a) Evidence of local arrangements for the regular monitoring and supervision of practitioners delivering pharmacological, psychological or psychosocial interventions for people with ADHD. b) Evidence of local arrangements for regular monitoring of compliance with applicable competencies for practitioners delivering pharmacological, psychological or psychosocial	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations

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					interventions. c) Evidence that services are commissioned to provide pharmacological, psychological or psychosocial interventions of content and duration in accordance with NICE guidance for people with ADHD. d) Evidence of local implementation of current guidance from the Royal College of Psychiatrists, UKAAN, and other bodies as appropriate on training and competence for doctors working in ADHD. e) Evidence of local arrangements to ensure that care coordination with other agencies (for example, housing, employment and social care) is delivered by appropriately trained and competent staff.	continue to be implemented.
016	191	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 8		Quality statement 8: Recording health outcomes. Structure: Evidence of systems in place to monitor health outcomes for people with ADHD at each appointment and use the findings to adjust delivery of interventions	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
016	192	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 9		Quality statement 9: Collaborative care. People with ADHD with co-morbidities that have associated functional impairments, and/or chronic physical health problems receive collaborative and coordinated care. Structure: a)	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is

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					Evidence of local arrangements in specialist ADHD services to provide collaborative care to people with ADHD with co-morbidities that have associated functional impairments and/or chronic physical health problems; b) Evidence of local arrangements in specialist ADHD services for effective coordination with other agencies relevant to adult service users;	potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
016	193	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 10		Quality statement 10: Coordinated care through the exchange of patient information. Quality statement Patients experience coordinated care with clear and accurate information exchange between relevant health and social care professionals. Structure: Evidence of local arrangements to support coordinated care through clear and accurate information exchange between relevant health and social care professionals. Outcome: Evidence from patient experience surveys and feedback that patients feel that information about their care was shared clearly and accurately with the least possible delay or disruption between relevant health and social care professionals.	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
016	194	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 11		Quality statement 11: Lack of response to both initial and subsequent treatments. Structure: Evidence of local arrangements to identify people with ADHD that have not responded adequately both to initial treatment and subsequent treatments and to review treatment plans.	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were

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						discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
016	195	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 12		Quality statement 12: Written and verbal information. People newly diagnosed with ADHD and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area. Structure: Evidence of local arrangements to ensure written information on ADHD is available to staff	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
016	196	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 13		Quality statement 13: Awareness training for health and social care staff. Quality statement Health and social care staff receive awareness training that promotes respectful, non-judgmental care of people with ADHD. Structure: a) Evidence of local arrangements to ensure that ADHD awareness training that promotes respectful, non-judgmental care is delivered to all health and social care staff who potentially	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were

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					work with patients or service users with ADHD (e.g. GP's, addiction services, sexual health, housing, schools, etc.) b) Evidence of local arrangements to ensure that local patient and service user feedback, in the form of surveys and complaints, is collected, analysed and acted upon within all health and social care settings.	inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.
016	197	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 14		Quality statement 14: Families and carers. Quality statement: Families and carers of adults with ADHD have their own needs identified, including those associated with risk of harm, and are offered information and support. Structure: a) Evidence of local arrangements to ensure that local services use promotional materials to encourage families and carers of people with ADHD to access information and support. b) Evidence of local arrangements to ensure that families and carers of people with ADHD are offered written and verbal information on ADHD and its management. c) Evidence of local arrangements to ensure those at risk of harm, including domestic violence, are offered information, advice and referral to other services where appropriate. d) Evidence of local arrangements to ensure that services are compliant with current national guidance on safeguarding children. e) Evidence of local arrangements to ensure that carers' assessments are offered to eligible carers of people with ADHD. f) Evidence of local arrangements to ensure provision of guided self-help for families and carers of people with ADHD, including facilitating contact with support groups. g) Evidence of local arrangements to ensure provision of family meetings for families	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.

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					and carers with significant problems, the meetings to consist of sessions providing information, identifying sources of stress and exploring coping behaviours.	
016	198	Adult Attention Deficit Disorder – UK (AADD-UK)	Quality statement 15		Quality statement 15: Combating stigma; People with ADHD feel less stigmatised in the community and NHS, including in GP surgeries, mental health services, social services, and any other relevant agencies. Structure: Evidence of local arrangements to ensure that a strategy is developed with other local organisations to combat stigma in the community, the NHS, mental health services, social services, GP surgeries, and any other relevant agencies. Outcome: Evidence from experience surveys and feedback that people with ADHD feel less stigmatised in the community, in the NHS, in mental health services, social services, and other relevant agencies.	The quality standards advisory committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. All suggestions for additional statements were discussed by the quality standards advisory committee who considered they were inappropriate for inclusion (for example, outside the scope of the quality standard), or already covered by existing statements. The quality standard contains key markers of clinical and cost effective care across a care pathway. It remains important that other evidence-based guideline recommendations continue to be implemented.

These organisations were approached but did not respond: