

Attention deficit hyperactivity disorder (update)

**Consultation on draft guideline - Stakeholder comments table
6 September – 18 October 2017**

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Adult Attention Deficit Disorder UK (AADD-UK)	Short	7	4	Some physical health conditions may also be linked with ADHD e.g. asthma and obesity	Thank you for your comment. The purpose of this section was not to define conditions that are common in people with ADHD but define conditions (or situations) which may identify groups for primary healthcare professionals as being at high risk of having ADHD.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	7	14	In addition to epilepsy we feel it's important to include, maybe on additional lines, specific sleep disorders (e.g. restless leg syndrome, periodic limb movement during sleep & circadian rhythm sleep disorder) and obesity	Thank you for your comment. The lists of conditions are those prioritised by the committee for investigation (see the protocol for evidence report A) and in which either evidence was identified or based on the committee's experience and consensus.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	7	18	We feel it would be more helpful to include more than one example of mental health conditions to give people a better appreciation of the range of conditions that may mask undiagnosed ADHD. We would suggest including eating disorders & disordered eating, personality disorders, and self-harm, as well as psychosis.	Thank you for your comment. The lists of conditions are those prioritised by the committee for investigation (see the protocol for evidence report A) and in which either evidence was identified or based on the committee's experience and consensus. The single example has been removed to avoid giving a false sense of specificity.

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Adult Attention Deficit Disorder UK (AADD-UK)	Short	7	22	We are pleased that this has been included but in part this is why we feel it is important to include our suggested additions listed above especially eating disorders, obesity & self-harm (although we recognise that boys & men may also experience these.	Thank you for your comment. The lists of conditions are those prioritised by the committee for investigation (see the protocol for evidence report A) and in which either evidence was identified or based on the committee's experience and consensus. The single example has been removed to avoid giving a false sense of specificity.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	7	24	We feel that it's necessary to add here that girls/women may exhibit different symptoms from boys/men and possibly different patterns of comorbidities as this will help people understand why girls/women are less likely to be referred. We also understand that current diagnostic criteria are derived from predominantly male samples and since that could be one reason why fewer girls/women are referred it would be worth noting this in the guidelines to alert professionals to this bias. It would be useful to note too that girls/women with ADHD (particularly those with the combined sub-type) are more likely to have poor social skills with the result that they have few or no friends &	Thank you for your comment. Further information has been added to the committee's discussion of evidence in report A.

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				are more likely to be victims of bullying all of which can lead to a very negative impact upon self-esteem which can negatively affect scholastic achievement and workplace performance to say nothing about the development of comorbidities. Finally, it would be worth considering when devising a treatment plan for girls/women that hormonal fluctuations may have a negative impact upon ADHD symptoms as they go through adolescence, the reproductive years, pregnancy & childbirth, perimenopause and menopause	
Adult Attention Deficit Disorder UK (AADD-UK)	Short	11	5	A description of assessments is missing from this short version and whilst we appreciate that you have put a link to CG 136 which has a general section about assessments, it would be as well to remember that many of the readers of this short version will be people who are currently undiagnosed and untreated so there is a real possibility that they may overlook clicking through on links. It would be most helpful, if you could include at a minimum an expanded version of the first	Thank you for your comment. It is not clear where in the short guideline the additional recommendation would be useful. NICE methodology is not to reproduce recommendations in other guidelines as should the source guidelines be updated, the recommendations that are reproduced may no longer be up to date.

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				bullet point at 1.3.2 of CG 136 (for speed of reference here it is: "the process of assessment and how long the appointment will last"). We are suggesting this because these two matters, process & length, are very frequently raised as questions.	
Adult Attention Deficit Disorder UK (AADD-UK)	Short	11	12	It might be a good idea to bold the word 'not' just to help combat the stigma that ADHD is about naughty boys.	Thank you for your comment.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	11	16	We suggest you include the word 'written' in the first sentence and then in the examples you also need to include something about providing information about any relevant medical issues that may have been uncovered during the assessment process	Thank you for your comment. The information is not intended solely to be written. The wording of this recommendation has been amended for clarity.

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Adult Attention Deficit Disorder UK (AADD-UK)	Short	11	30	This reads as if the diagnosis leads to a “greater tendency for impulsive behaviour” so we’re wondering if you accidentally left off “than people without ADHD”	Thank you for your comment. The committee’s view is that the current wording is sufficiently clear.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	12	7-9	We feel that this section would be clearer and more informative if education and employment could be separated e.g. Education (for example, choice of courses, rights to reasonable adjustments at school, college & university). Employment & career choices (for example, receiving treatment for ADHD is a disqualifier for pilot training & the armed forces) and issues (for example, rights to reasonable accommodations)	Thank you for your comment. The recommendation has been amended and the bullet point separated.
Adult Attention Deficit Disorder	Short	12	25-26	We feel that information should also be provided in different languages as needed.	Thank you for your comment. This is a generic point not specific to ADHD and is covered in the patient experience guideline: https://www.nice.org.uk/guidance/cg138 .

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Adult Attention Deficit Disorder UK (AADD-UK)	Short	12	1	See comment for page 11, line 30	Thank you for your comment. The committee's view is that the current wording is sufficiently clear.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	12	11	We are not sure what is meant by a "shared treatment plan" so we feel this needs a brief explanation.	Thank you for your comment. This has been added to the terms used in this guideline section.
Adult Attention Deficit Disorder	Short	12	12	We feel that it is important to not just "tell" people" but to also provide written information	Thank you for your comment. We have amended the wording and changed 'tell' to 'inform' to make this more inclusive of all forms of communication. The following recommendation clarifies that information

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UK (AADD-UK)					should be given in a form that is tailored to the individual's needs.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	12	16	Insert at the beginning of this line 'Sources of more information about' because that will help to distinguish this section from the discussion topic listed on lines 7-9 above	Thank you for your comment. The wording has been amended.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	12	17	As in our previous points, we feel written information would be very useful and not just in this section but throughout whenever the provision of information is mentioned.	Thank you for your comment. This guideline references the NICE patient experience guideline CG138, which provides recommendations related to methods of information and support (see section 1.4 Information and support). The committee recommended that information related to both ADHD and its treatment should be tailored to the individual and their family or carers. The committee agreed that the evidence did not support the use of any one particular method of providing information, and that information should

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					always be provided in a format suitable for each person and their family or carers.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	13	17	We're not sure why universities are missing from this section particularly since in line 30 on page 19 of Evidence Review B it says one of the things that parents worry about is "coping at university". Admittedly it's more practical (assertive) for the prospective student to be involved with a university but nevertheless it would be very helpful if information could be provided to the student and/or the parents about how to access help and support at universities so that they can be effective self-advocates.	Thank you for your comment. This has been added.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	18	10	We feel that if it's appropriate and hasn't already been done, screening for a specific sleep disorder (e.g. RLS) should also be considered because that too can exacerbate ADHD symptoms & make medication less effective.	Thank you for your comment. The committee agrees that sleep is an important issue in people with ADHD. An assessment of sleep disorder should be part of the discussion about planning and choosing treatments between the person with ADHD and their ADHD specialist. The discussion of the risks and benefits is

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					outlined in the recommendations on planning treatment.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	19	28	We feel that you need to clarify whether or not you are referring to people who already have a diagnosis and are being reassessed as this line would not apply to people who are newly diagnosed.	Thank you for your comment. This recommendation applies to people about to start medication. In the majority of cases this will be either after environmental modifications or non-pharmacological treatment has been tried, in which case it is important to determine if they still need and meet the criteria for treatment.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	20	8	Screening for a specific sleep disorder could additionally be inserted here	Thank you for your comment. The committee agrees that sleep is an important issue in people with ADHD. An assessment of sleep disorder should be part of the discussion about planning and choosing treatments between the person with ADHD and their ADHD specialist. The discussion of the risks and benefits is outlined in the recommendations on planning treatment.
Adult Attention	Short	22	5	This is an area of concern because it needs to be noted that due in part to restricted access (e.g. self-	Thank you for your comment. It is not clear what the concern relates to. The planning section recommends that

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Deficit Disorder UK (AADD-UK)				payers limited by financial considerations) to services as well as to incomplete funding of access by some CCG's (only funded for a few appointments) people with ADHD are turning to online support groups for answers to questions about their medication. This puts moderators of online support groups in the position of having to field questions about medications for which they know they are not qualified to answer.	treatment decisions should always be made collaboratively between people with ADHD and their healthcare professionals. The committee cannot condone alternative access to medication. The recommendations in the guideline that address medication management may be useful in the situation you describe for supporting individuals.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	25	3	We feel that in order to help improve adherence the following (or similar) should be inserted: 'ensure the person understands fully the process'	Thank you for your comment. The committee agree that it is critical that the person understands fully the process and have emphasised the importance of informed and shared treatment decision making throughout the guideline including in the adherence section.
Adult Attention Deficit Disorder	Short	26	13	This is too vague i.e. as it is currently written it is not clear who will determine the level of severity. If you mean that people with ADHD should be able to ask for a review when they feel it's needed rather than wait, as in the past, for the annual review appointment to roll	Thank you for your comment. The guideline does not specify any one person or method of determining the severity of ADHD, so it would be inappropriate to specify so in this recommendation. Throughout the guideline the committee has emphasised the

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UK (AADD-UK)				around, it would be as well to so this. If you mean that the consultant will be the one to determine the severity of the condition and thus the timing of reviews, then we feel that that will not work since for many of us the severity of our symptoms seems to vary in accordance with the number & type of stressors we're encountering. See also our comment below: 18, page 31, line 3.	importance of informed and shared treatment decision making throughout the guideline. People with ADHD and the ADHD specialists who are assessing symptoms will be aware of possible fluctuations in severity and the timing of any reviews.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	28	21	We are concerned that agitation, irritability, emotional lability, suicidal thinking and self-harming behaviour are missing from section 1.8. We would suggest adding them here as examples.	Thank you for your comment. The committee agree that there other examples that could be added but have highlighted the ones they think are most pertinent.
Adult Attention Deficit Disorder	Short	29	10	Some people develop doubts or become disillusioned about the efficacy of the medication simply because they do not understand or misunderstand the titration process. When they start on the low dose, they feel disappointed that it doesn't seem to work, and then	Thank you for your comment. This information has been added into the committee's discussion of the evidence in evidence report D.

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UK (AADD-UK)				begin to doubt that any medication will help. It might help improve adherence if this process is explained clearly.	
Adult Attention Deficit Disorder UK (AADD-UK)	Short	31	3	We feel that that the recommendation in this section (review ADHD medication at least once a year) and the recommendation under page 26, line 13 (review and follow-up according to the severity of their condition, regardless of whether or not they are taking medication) could be better reconciled because the way they are currently written they appear to contradict each other if they're not read carefully.	Thank you for your comment. The committee agree that people with ADHD should be followed up if they are being treated with medication to assess and monitor the impact of the medication. It is also important that people with ADHD who are not on medication have the opportunity for regular review. The committee do not believe the recommendations contradict each other.
Adult Attention Deficit Disorder UK (AADD-UK)	Short	31	18	If the person has not already been screened for sleep disorders, we feel it should be considered here.	Thank you for your comment. The committee agrees that sleep is an important issue in people with ADHD. An assessment of sleep disorder should be part of the discussion about planning and choosing treatments between the person with ADHD and their ADHD specialist. The discussion of the risks and benefits is outlined in the recommendations on planning treatment.

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Adult Attention Deficit Disorder UK (AADD-UK)	Short	32	4	We would suggest adding 'repositioning desks at work, and/or switching to a sit stand desk' so that this section includes adult needs. Also, "changes to lighting" seems rather vague since it's probably impractical to consider changing overhead lighting in a situation where others will be affected such as in a classroom or office setting. It might be better to suggest getting a lamp or repositioning a lamp or moving desks away from a sunlit window. Also, we feel it would be more helpful to say something like "using headphones to reduce external sounds" rather than "changes . . . to noise" since it's not always possible to control noise. It would also be helpful to add 'decluttering workspaces to reduce distractions.'	Thank you for your comment. Further examples have been added to the explanation of environmental modifications.
Adult Attention Deficit Disorder	Short	34	24-26	We feel that the second sentence of this section could be made clearer by first placing the word 'referral' before 'diagnosis' which would be the natural course. Secondly, the use of the phrase 'these should be accurate' needs clarification as at the moment we are not sure if it is only looking back to the referrals (i.e.	Thank you for your comment. The wording has been amended.

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UK (AADD-UK)				the referrals need to be accurate) or if the phrase is looking back to both referrals and rates of diagnosis in which case it feels as if there is some information missing after the word "therefore".	
Adult Attention Deficit Disorder UK (AADD-UK)	Your question 1 above			Question 1: We are very pleased that you have emphasised other groups of people including girls and women but it may prove difficult to persuade commissioners of adult ADHD services that it would be cost effective to provide more funding for ADHD services at a time when funding seems to be scarce right across the NHS. It's been 9 years and 7 months since we submitted our response to the original consultation in which we described the grinding frustration felt by adults who wanted to contribute to society but instead were forced to expend energy just managing symptoms. During those 9 years there have been some improvements; more adult ADHD specialists, more adult ADHD services, more awareness of adult ADHD, although the latter has brought its own problems. But given that 9 years have	Thank you for your comment. The committee hope that the updated recommendations strengthen the case for providing appropriate ADHD services. It is not within NICE's remit to enforce the implementation of recommendations within their guidelines. The committee have made a number of research recommendations in areas in which further research would be particularly useful for strengthening existing recommendations or making new recommendations. The information will be passed onto our resource impact team for their information.

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				<p>passed there has not been enough improvement. A few areas are still without ADHD services, some services were set up without enough funding, some only offer medication and nothing else, some have long waiting lists (in one known instance the wait is one year!), some services have tried to stop new referrals and others have tried to close. It's been 9 years since we pointed out that leaving ADHD untreated would lead to much higher health & societal costs and here we are 9 years later faced with the reality that funding for ADHD services has not increased at a rate that's commensurate with increased awareness while worrying that, rightly, extending recognition of ADHD to include other groups will only cause disappointment when people realise that it's difficult to access existing services. There has been, however, a steady growth in one area and that's the growth of independent ADHD services. We are disappointed that we are watching the development of an unequal ADHD health care system. It's a two-tier system where those that can pay are assessed,</p>	

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				diagnosed and improving their lives whilst those that can't pay must wait (which potentially could be a breach of their rights under the terms of the Equalities Act 2010). And sometimes, it has to be said, people are waiting to see the same consultant that those who can pay have already seen. To help counter all of this, we strongly recommend that research be conducted which will provide rigorous and robust evidence proving the case (at both national and local levels) for providing ADHD services that meet the standards as laid out in the Guidelines which will in turn help eliminate inequality of access.	
Adult Attention Deficit Disorder UK (AADD-UK)	Your question 2 above			Question 2: See our answer to your question 1.	Thank you for your comment.

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Adult Attention Deficit Disorder UK (AADD-UK)	Your question 3 above			Question 3: We have two suggestions: First, it would be very helpful to publish open-access (i.e. easily available to the public) examples of good practice where relevant evidence-based guidance and standards, from NICE as well as other expert and professional bodies, are used in developing services, recognising at risk groups, and providing assessments and accurate diagnoses with appropriate treatment and monitoring. Second: we would like to suggest that NICE and/or other relevant professionals/organisations work with the CQC to have ADHD services recognised as a core service that will always be included, by name, in inspections both for the NHS and the independent sector. We feel this is needed to help ensure adherence to standards and guidelines for referrals, assessments and treatment across the NHS & independent sector (ADHD is difficult to diagnose accurately, can be masked by co-morbidities, is linked with lower quality of life with higher risk of mortality); to ensure smooth transitions between CAMHS & AMHS, using agreed standards; to ensure better	Thank you for your comment. Unfortunately your suggestions are not within the remit of NICE. NICE guidelines are often used to inform criteria for audit of services. Shared learning examples of implementing NICE guidance into practice can be submitted to NICE. More information is available from: https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies .

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				<p>communications between different specialities (i.e. with those that deal with disorders that can be comorbid with ADHD); to ensure better collaboration between the NHS, government departments, schools, colleges, universities, local authorities, and voluntary services as needed; and to allow for the introduction of standard waiting times, which should help improve levels of funding for NHS services, which in turn will ensure equality of access to ADHD services. Lastly, we suggest this since it will reduce challenges that users have to overcome (they already have enough of their own) including we hope stigma since it should help demonstrate the integration of scientific evidence with the lived experience of people with ADHD. It will help users understand what to expect from ADHD services, & evaluate the quality of services which will help those choosing an independent provider, & provide appropriate feedback as necessary, & advocate for improvements where needed.</p>	

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Association for Family Therapy and Systemic Practice in the UK			Supporting parents to support children (e.g. to take medication)	<p>Who is going to provide this? My experience with ADHD families is that often (not always) they are as disorganised as their children and therefore, should support be more directed in these families to supporting the parents become more organised in their lives, thereby supporting children indirectly??</p> <p>This recommendation needs to be widened from taking medication to all aspects of parenting at home and all aspects of educating at school.</p>	<p>Thank you for your comment. The recommendation about the needs of parents with ADHD has been moved to the general information and support section on supporting families and carers to remove the emphasis on supporting medication adherence. In addition, the recommendation has been broadened to include daily school routines.</p> <p>We anticipate this support and information would be provided alongside the information and support given to the child or young person with ADHD.</p>
Association for Family			After enviro	What are the environmental modifications? I believe that the 2008 still make the most sense if we want to	Thank you for your comment. Environmental modifications are defined in, 'terms used in this guideline' section and

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Therapy and Systemic Practice in the UK			mental modifications...	avoid an explosion in prescribing the way America has gone.	additional detail and example of modifications have been added.
Association for Family Therapy and Systemic Practice in the UK			Adults / CBT	One member voluntarily supports adults with ADHD, and they greatly value both the drugs and the coping / organisational skills they are asked to identify and then to develop.' From what my adults with ADHD tell me, adult mental health only offers medication. They contact me because they have literally nowhere else to go'.	Thank you for your comment. The committee agree it is important for adults to have access to non-pharmacological support when appropriate. The recommendations on when to consider non-pharmacological therapy and its minimum components in the managing ADHD section reflect this.
Association for Family Therapy and	Short		Collaboration /	We welcome a positive shift towards a more collaborative way of planning and delivering care, but it depends on how it is weighted. Ideally professionals involved in these discussions should have the	Thank you for your comment. The recommendations throughout the information and support section, in the planning part of the managing ADHD section and in the review of medication and

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Systemic Practice in the UK			reviews	experience and confidence to state that this is a contested area rather than present ADHD as a medical truth. Both sides should be presented including the importance of context and environment. It is crucial to state that carers will greatly affect the treatment and management of ADHD in their child by how they respond and behave, regardless of what we think of its validity.	discontinuation reinforce the need to discuss the person's experience of ADHD and how this impacts on them. The information and support section has separate recommendations that are directed at supporting families and carers and eliciting their views and concerns.
Association for Family Therapy and Systemic Practice in the UK	Short		1.5.12	CBT is not the only (or even the most applicable) psychological intervention which could be offered, here. The 'Common Factors' literature demonstrates that there is nothing CBT specific that makes CBT work. The 2008 wording 'psychological therapy' is preferable to the updated version One member working clinically in this area felt that services are so stretched that to be able to offer CBT to these patients as well is very difficult. There is very little out there directly for young people with ADHD. Social skills should always be taught in the place the young person or child is most likely to use them – usually at school (because this is often where	Thank you for your comment. The committee looked for evidence supporting the efficacy of a range of non-pharmacological treatments (see the review protocols for more information). The body of evidence in general showed parent training and CBT to be the most effective of the non-pharmacological interventions, hence their inclusion in the recommendations. The committee agree that there may be some non-specific effects of CBT that may be of use, which could be observed across other forms of non-pharmacological treatment for ADHD

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				problems occur most frequently). Family/Systemic therapy is useful in helping a family re-orientate themselves to the diagnosis and to come to an understanding that everyone has a hand in making things better/worse and not just the young person with the diagnosis. Family Therapy also has a major part to play in network meetings with family and school.	and have worded the recommendations to try and reflect this.
Association for Family Therapy and Systemic Practice in the UK	Short		1.5.16	Why should non-pharmacological intervention only be considered in combination with medication for those who are deemed to have benefitted from medication? Again this implies medication as the best 'treatment' but does not say anything about those who have not responded to medication. Also how to judge a 'response' where 'significant impairment' remains?	Thank you for your comment. The recommendation on combination treatment is intended to prevent people having a combination of treatments when medication has clearly had no effect at all. Combination should only be considered when medication appears to have some benefit but is not sufficient. The judgement of response and persistent significant impairment is challenging and has to be done on an individual basis in discussion with the person with ADHD. It is important the clinician has a good relationship with the person and can assess their change in symptoms and impairment relative to the

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					baseline. For this reason the committee did not consider it was possible to include more generic recommendations on this topic. Further text has been added to the committee's discussion of the evidence section in evidence report C. A shared treatment and person centred approach is reinforced throughout the guideline.
Association for Family Therapy and Systemic Practice in the UK	Short	13	1.4.11	We appreciate the recommendation to pay attention to making sure parents do not feel blamed by services, as this can be a common experience of parents, and is unlikely to be helpful to anyone.	Thank you for this feedback.
Association for Family Therapy and	Short	15	1.5.4	'the importance of adherence to treatment and any factors that may affect this (for example it may be difficult to take medication at school or work)'. Again, here, there is an implicit assumption that medication is	Thank you for your comment. This recommendation reflects findings from the qualitative review of adherence, within which the evidence was limited for non-

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Systemic Practice in the UK				the best or only 'treatment'. This is not the same situation as insulin for type 1 diabetes, it is closer to antidepressant medication for the treatment of depression, which is one, not the only, intervention, and individuals should be supported to make a free, informed (not biased) choice.	pharmacological interventions. Our definition of 'treatment' within this recommendation covers both pharmacological and non-pharmacological interventions. Difficulty in remembering appointments has been added as an example that is more pertinent to adherence in non-pharmacological treatments.
Association for Family Therapy and Systemic Practice in the UK	Short	15	1.5.6	We appreciate the reassurance that decisions can be revisited at any time, however this is at odds with the implicit bias towards medication in several places in this document.	Thank you for this feedback. The committee considered the evidence base for both pharmacological and non-pharmacological treatments. The recommendations reflect the evidence identified throughout the guideline process and the guideline committee's consensus decisions on the clinical and cost effectiveness.
Association for Family Therapy	Short	16	1.5.8	The 2008 recommendation that drug treatment is not recommended for pre-school children with ADHD was a preferable statement to the updated version which	Thank you for your comment. The recommendations are clear that ADHD-focused group parent-training programme to parents or carers is first-line treatment

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and Systemic Practice in the UK				<p>implies that medication could be recommended. Members expressed concerns about this. As above, if the emphasis is away from condition and disease, and towards context and environmental factors then medication should be used sparingly if at all. We know that Ritalin slows people down and may aid concentration, but it does so with all young people (my children took it at exam time!) so proves nothing. The idea of medicating under 5's is abhorrent to me. This makes a disease out of normal childhood. Yearly reviews are not enough, especially for young people.</p> <p>This has to be very carefully monitored. For example, what if the parent says they don't/can't attend a parent training programme because they will lose their job (and they are the only working parent)?? If it is explicit, no meds for under 5's, then this is easier, whereas if the door is opened, without a doubt, we will see a rise in prescribing under 5's. One member</p>	<p>for children under 5 years with ADHD. The other recommendation specifically directed at children under 5 years is about obtaining specialist for advice. The committee do not believe these recommendations will result in increased prescribing in the under 5 age group as any other treatment decisions in this age group would be made under the care of a specialist. The committee discussed at length the pharmacological treatment of children under 5 years and were in consensus that there could be exceptional situations where medication was appropriate (see the committee's discussion of the evidence in evidence report C). The 2008 guideline did not recommend drug treatment but also did not go as far as to tell prescribers never to prescribe drug treatment, also allowing for these exceptional situations. After noting the stakeholder comments the committee agreed to add recommendation clarifying that medication should only be</p>

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				<p>working in the area clinically had talked to children who have been given medication and what it is like for them and had been struck by what a difference it made to them Another member felt children under 5 years old should not be prescribed medication but instead should be offered free or subsidised day care tailored to their needs. One member with personal experience of having a child with a diagnosis of ADHD found facilitated individually-tailored play very helpful, without prescription of medication.</p>	<p>prescribed in this age group when a second opinion from a specialist ADHD service with expertise in ADHD in young children (ideally tertiary) has been obtained.</p> <p>A following recommendation in the managing ADHD section makes it clear individual training programmes are appropriate in certain situations for all age groups.</p>
Association for Family Therapy and Systemic Practice in the UK	Short	16	1.5.9	<p>It is good to involve parents and carers in the treatment of young people for whom they have parental responsibility. This is basic systemic theory in practice. The running of these proposed groups however is the crucial question. If they are presented as looking after their children who have “a condition” or a disease then as above, it can only be limited in efficacy. It would be preferable to have groups (for all</p>	<p>Thank you for your comments Based on the clinical and cost effectiveness, the committee could not make any recommendations on how to deliver the training programmes or to be specific about the components. The committee acknowledge in their discussions in evidence report E that</p>

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				<p>ages) where the emphasis is on helping carers to understand behaviours as communication, and for carers to be helped to see their role in this. If the disease model is avoided then 1-2 sessions could make a big difference, but ideally more would be better.</p> <p>One member has run 2 full day and 5 half day parent ADHD parent groups and parents prefer the 5 half day groups compared to the 2 full day ones. It gives them also time to develop relationships with other parents which has led to parents setting up a Whatsapp or facebook group for parental support.</p> <p>Groups could be highly valued by parents if the facilitators allow the parents to co-lead the programme. Where professionals take the 'we know best/we know what works' approach then parents will resist the programme and will be put off from accessing other supports they need. This is about sharing power to decide what is relevant, not about with-holding</p>	<p>ADHD-focused support will be different depending on the local area and can have different delivery methods.</p>

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				<p>knowledge and expecting parents to work everything out without support and information. From experience, parents are rarely happy to just meet for support for just one or two sessions. Whilst some do, most do not. If this idea makes its way into the revised guideline the effect will tend to be to authorise CAMHS etc. to only offer a maximum of 2 sessions to all parents.</p>	
Association for Family Therapy and Systemic Practice in the UK	Short	17	1.5.11	<p>What happens when these groups are not available? Usually provided by local authorities (certainly in my area) and currently, we have no staff to run the groups.</p>	<p>Thank you for your comment. The committee consider this to be an appropriate recommendation, where these services are not available the guidelines should serve as a tool to help promote further development of services.</p>
Association for Family Therapy and Systemic	Short version	general	general	<p>We note that the conceptualisation of ADHD in this draft guidance uses an individualised deficit-based model / medical model. Several of our members felt this particular model of understanding does not adequately represent their clinical experience with</p>	<p>Thank you for your comment. The diagnosis of ADHD was not included in this update of the guideline. The committee agree that it is important to consider the systemic model when managing ADHD.</p>

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Practice in the UK				children, young people and adults who have received a diagnosis of ADHD. Members wanted to draw attention to the way that this model focuses clinicians upon ideas of individual brain 'abnormalities' and medical (pharmaceutical) treatments and focuses them away from the importance of life events and environments. For example, children who have had experiences of abuse, neglect, witnessing violence or other overwhelming experiences are likely to have difficulties paying attention and concentrating, and controlling their behaviour which can be better explained by ideas of hypervigilance to threats; where environments place too much stress and expectation on children, without sufficient support for their developmental level this can also have similar effects. An individual deficit-based model of understanding can have an effect on the system, of which a child or young person is part, and may work towards protecting the environment, or people who have relatively more power in the environment, from engaging in positive	The committee have made a number of recommendations in order to promote this (for example, on environmental modifications, the role of parent training, supporting families with ADHD).

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				<p>change, instead the onus for change also becomes focused on the individual and their 'deficits'.</p> <p>Furthermore, there was concern that this model could also contribute towards less understanding and tolerance of the range of child and young adult behaviours (potentially pathologizing childhood), which could interfere with the willingness and capacity of adults to help children and young adults make sense of their relational interactions in a way that helps them develop towards what is important to them in life. The idea of individual pathology suggests 'solutions' as ways to 'fix' an individual, rather than affording children and young people the continued opportunity for developing greater understanding of their impact on others and their environment in order to help them develop a path in accordance with their goals and values, using the relationships which are important to them. The portrayal of a child or young person as 'abnormal' or 'deficient' in something which society values has the potential for enormous harm to children</p>	

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				<p>and young people who may internalise these labels and start to see themselves within a frame of deficiency and not being 'good enough' (this would be compounded where a greater number of adults around them use this frame of understanding, and where there may be other difficulties in relationships (care-giving or educational relationships).</p> <p>Where a deficit-based model is used then it becomes very important to emphasize and support strengths and abilities. The more this can be embedded into systems surrounding children and young people (health professional, including those organised around the idea of 'ADHD', educational environments and home environments) the greater the potential for support. As well as the importance of strengths and positive qualities being an important aspect within any assessment organised around the idea of ADHD diagnosis, a solution-focused approach was suggested as a way to help mitigate against these risks, e.g. http://sfwork.com/pdf/SFEducation.pdf and the SF</p>	

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				<p>studies found within Appendix 1 of https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/184113/DFE-RR179.pdf</p>	
Association for Family Therapy and Systemic Practice in the UK	Short version	7	1.2.2	<p>We note that NICE have decided to highlight 'under-recognition' of ADHD in girls, despite not having evidence to support this. Without evidence to support this, we would question the wisdom of including this, since it is likely to have the effect of increasing diagnosis and medication rates, both of which may have adverse consequences for the children and young people concerned. We are concerned that mental health professionals, instead of being supported to use their training and experience to understand the complexities and contexts of the concerns people bring, a simplified diagnostic-based understanding is being pushed, which is not the only way of helping and supporting families.</p> <p>If this must be included then it should be worded alongside a statement highlighting the lack of evidence</p>	<p>Thank you for your comment. The wording of these recommendations has been amended to reflect the evidence base. The committee agrees that correctly identifying ADHD in girls and women is an important and complex matter. The new recommendation on raising awareness about the under recognition of ADHD in girls and women should help to address this inequality.</p> <p>The recommendation does highlight that ADHD may be under-recognised in girls and women and that they are less likely to be referred for assessment for ADHD, more likely to have undiagnosed ADHD and more likely to receive an incorrect</p>

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				found, and that this is based upon the opinion of the committee.	diagnosis of another mental health or neurodevelopmental condition. Evidence report A gives further details in the committee's discussion on the reasons for the under recognition of ADHD in girls and women.
Association for Family Therapy and Systemic Practice in the UK	Short version	11	1.4.4	We welcome the recommendation to have a fuller discussion around diagnosis, highlighting both positive and negative impacts of a diagnostic label. However this section confounds a discussion about diagnostic labelling (which in our view helps the people concerned to think about their relationship with a diagnostic label, and develop a relationship which works for them) with a list of exclusively negative issues portrayed as if they are experiences that people will inevitably have, if they receive a diagnostic label. By all means discuss these issues (as recommended in 1.5.4), but not as if they are inevitable 'symptoms' of a 'disease'. Possible medication effects are also	Thank you for this comment. The committee have made a series of recommendations throughout the guideline that emphasise the importance of discussing the impact of ADHD and the potential outcomes of any treatments. These are highlighted in the areas of the guideline where the topic would be appropriate. The examples of the areas to discuss have been identified in the evidence reviews on information and support in evidence review B and in managing treatment in evidence review H and taken from the guideline committee's experience. A shared treatment and person

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				included here, as if this is also an 'inevitable' part of agreeing to take on a diagnostic label. Again if a person is taking or considering medication then a full discussion should be had about positive and negative effects should take place, but this should be in this circumstance, not part of a universal post-diagnosis information-sharing	centred approach is reinforced throughout the guideline.
Association of School and College Leaders	Short	General	General	There is little reference throughout to liaison work with educational providers including nursery provision. Given the amount of time that young people spend in educational establishments engaging with those who have significant contact time with young people with ADHD in a non-clinical setting would we consider be beneficial.	Thank you for your comment. There are recommendations to encourage healthcare professionals to involve schools, colleges and universities including but not limited to discussing environmental modifications and asking for feedback from schools, colleges and universities.
Association of School and College Leaders	Short	General	General	Recognising that we are now talking about 'Care' excellence rather than only specifically the clinical side there is a case for examining how brief guidance for schools and colleges relating to the management of young people with ADHD.	Thank you for your comment. The committee agree it is very important that schools and colleges have the guidance to support children and young people with ADHD. There are recommendations in the information and support section that

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					directly address this and how healthcare professionals can involve educators in the care of individuals with ADHD.
Association of School and College Leaders	Short	General	General	We would suggest that a reminder note of the key elements of this guidance which is relevant to schools, including nurseries, is produced for those establishments.	Thank you for your comment. Unfortunately, NICE no longer produce quick reference guides for education settings.
Association of School and College Leaders	Short	4	17	There is no mention of direct communication with the educational provision	Thank you for your comment. This is set out in the involving schools, colleges and universities section of information and support recommendations.
Association of School and College Leaders	Short	6	20	Good to see the engagement here with educational providers	Thank you for your comment.
Association of School	Short	6	28	The Teaching Agency as such no longer exists as its work is subsumed in the work of the DfE and NCTL.	Thank you for your comment. This section was not identified as requiring an update

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and College Leaders				The point made is a very good one and particularly given the plethora of routes into teaching it is important that some central coordination of training materials is in place.	during the scoping phase of the guideline so we are unable to make the change you suggest.
Association of Youth Offending Team Managers	Short	General	General	In this response, AYM are particularly thinking about children and young people aged 8-18, which is our primary age group. Within that, the majority of young people who offend are aged 15-17 and often display complex and problematic behaviour which is difficult for professionals to address.	Thank you for your comment.
Association of Youth Offending Team Managers	Short	General	General	We would draw attention to the needs of young people with ADHD. There is some evidence that dealing with the underlying causes of a child's behaviour is more effective than using medication. http://www.care2.com/causes/why-are-adhd-rates-20-times-higher-in-the-us-than-in-france.html	Thank you for your comment. Throughout the guideline development process, the committee has considered the evidence of both pharmacological and non-pharmacological treatment (including behavioural interventions) and their role in the treatment options of ADHD symptoms. Overall the evidence identified in the reviews in this guideline did not show clear evidence that behavioural interventions were more effective than medication. The

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					committee have made their recommendations for each treatment option on the basis of the evidence identified and their consensus and clinical experience. Behavioural interventions in the form of environmental modifications, parent support groups and in some cases more established programmes or CBT have been recommended in this guideline.
Association of Youth Offending Team Managers	Short	7	4	<p>Section 1.2.1</p> <p>We would suggest the priority recognition groups should be expanded to people known to the Youth Justice System (Youth Offending Teams/Services) and the adult Criminal Justice System. The reoffending rate of people following custody is very high and addressing their needs is extremely difficult, so they need access to services well before that damaging stage. We welcome the inclusion of looked after children and those in the secure estate in this list, but this needs to be broader.</p>	Thank you for your comment, this recommendation has been amended.

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Association of Youth Offending Team Managers	Short	14	15	<p>Section 1.5.2</p> <p>The treatment plan should also take into account the management of appointments with services provided. Children and young people in the Youth Justice System often fail appointments, even though they need the support and have complex needs. This should not result in services being removed for non-compliance. Instead, plans should include measures to encourage and facilitate attendance, and to understand the difficulties they have in keeping appointments. It is not a reflection of their need, but rather a symptom of the chaotic and unstructured lives they live, and of the damage they have experienced psychologically, emotionally and physically.</p> <p>It is worth noting that the NHS staff seconded to YOTs are key contacts for professionals working with ADHD young people at risk or in the youth justice system. They can support the young people, as well as raising the knowledge level of health colleagues about the</p>	Thank you for your comment. Additional text on this recommendation has been added to the committee's discussion of the evidence in evidence report B and G.

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				needs of the individual young person. So they are a useful resource for all involved with young people who offend and who experience ADHD.	
Association of Youth Offending Team Managers	Short	16	13	Section 1.5.9 We recognise that the age group of 5-17 that you use is based upon medication authorisation, but this age grouping does not appear to recognise the range of children involved. The development of children between 5 and 17 is vast and consideration is needed at each stage to encourage the active involvement of children in their treatment. The needs of a 5-year old will be totally different to a 17-year old, and so differing approaches will be required to achieve full engagement.	Thank you for your comment. The committee agree that there will be different needs throughout the 5 to 17 age group. The recommendations appropriate for adults may also be relevant for 'older' young people. The committee included a recommendation on CBT for young people to highlight this. NICE recommendations are intended to be interpreted in the context of the individual. Throughout the guideline the committee highlight in the recommendations the importance of involving people with ADHD in decisions about their treatment and that treatment should be appropriate to their individual circumstances.
Association of Youth Offending	Short	17	16	Section 1.5.13	Thank you for your comment.

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Team Managers				We welcome the approach of individualised programmes where needs of young people and their families are complex.	
Association of Youth Offending Team Managers	Short	18	21	Section 1.6.1 We would suggest the addition of 'and their families and carers' as diet, nutrition and exercise will be encouraged if it applies to the whole family.	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.
Association of Youth Offending Team Managers	Short	29	10	Section 1.9.2 The symptoms of ADHD can lead to children and young people adhering to treatment plans, as you state, so it is critical that our point about not removing services for non-compliance should be included and addressed here.	Thank you for your comment. Additional text on this recommendation has been added to the committee's discussion of the evidence in evidence report B.
Association of Youth	Short	30	21	Section 1.9.7	Thank you for your comment. Additional text on this recommendation has been

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Offending Team Managers				The paragraph about strategies to deal with identified barriers needs to include our point about gaining adherence to appointments, rather than blaming or withdrawing appointments for non-attendance.	added to the committee's discussion of the evidence in evidence report B.
Association of Youth Offending Team Managers	Short	34	16	The later diagnosis of children and adults in the secure estate is rightly quoted. We would suggest the priority recognition groups should be expanded to all those in the Criminal Justice System, as the reoffending rate of people following custody is very high and addressing their needs is extremely difficult at that late stage.	Thank you for your comment. The wording has been amended.
Association of Youth Offending Team Managers	Short	36	24	We agree young people should have 'as much support as they need' but the issue of missed appointments and services being withdrawn is missing from this guidance. We see many young people whose inability to keep appointments leads to the withdrawal of services.	Thank you for your comment. Additional text on this recommendation has been added to the committee's discussion of the evidence in the in evidence report B and H.
Bradford District Care NHS	Short	7	2	An acknowledgment that increased awareness and recognition will have resource implications for existing specialist ADHD services, most of which are running	Thank you for your comment. This potential impact is discussed in the 'Impact of the

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Foundation Trust				on minimal resources (due to the potential increase in number of referrals). There are long waiting lists already. It remains an uphill struggle to get funding from commissioners	<p>recommendations on practice' section in evidence report A.</p> <p>The committee recognise that the recommendation raising awareness of ADHD in certain populations may result in an increase in referrals to specialists. However, the committee agreed that many of the people that will be referred as result of this guideline will have been given an alternative diagnosis or would have received a late diagnosis of ADHD. They are likely to be already accessing services. Referral as a result of raised awareness from this guideline should result in people receiving the right diagnosis as soon as possible and the appropriate support for ADHD.</p> <p>We will pass this information to our resource impact team for their information.</p>

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Bradford District Care NHS Foundation Trust	short	22	6	<p>There is no compelling evidence that lisdexamfetamine is superior to methylphenidate in adults. Methylphenidate remains first line for children. It is true that lisdexamfetamine has a license for treating adults but this is due to the fact that the pharmaceutical company has actively pursued for this. Methylphenidate has been in use for longer periods of time and has a much robust evidence base in children. The only advantage I note is that Lisdexamphetamine has a license for use in adults but this should not be sole reason for recommending this as first line. Cost effectiveness of lisdexamphetamine is based on one study in adults. I would like the sequencing recommendation be removed but offer clinicians and the patients the option to choose. Stimulants can remain as first line but the choice of either methylphenidate or lisdexamphetamine should be made following a discussion between patient and clinician.</p>	<p>Thank you for your comment. After taking into consideration the stakeholders' comments on this issue the committee agreed that methylphenidate should be included alongside lisdexamphetamine as an option for the first line medication treatment in adults.</p> <p>Clinical evidence was identified in adults for methylphenidate, lisdexamphetamine, and dexamphetamine all compared to placebo so it was difficult to compare active drugs directly. Drug costs using BNF doses also show that a maximum dose of lisdexamphetamine is less costly than maximum doses of extended release methylphenidate formulations. This needs to be weighed up against the clinical benefit of both drugs and this was difficult without a network meta-analysis which was not possible due to the data available (see</p>

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					the methodology chapter and individual reviews for more information).
British Academy of Childhood Disability	Short version	General	General	<p>We would like to compliment the GDG on producing an overall extremely balanced and useful Guideline.</p> <p>The biggest challenge to services for children and young people with ADHD is the still increasing number of referrals and complexity of patients being seen. Current services are already under strain. This is not due to over diagnosis overall as the expected prevalence has not been reached.</p> <p>The increased awareness and e.g. the section on Risk Factors is welcome, however it must be recognised that this could increase referrals and complexity still further.</p> <p>After diagnosis most children/YP need ongoing monitoring which means more follow up appointments.</p>	<p>Thank you for your comments. The committee recognise that the recommendation raising awareness of ADHD in certain populations may result in an increase in referrals to specialists. However, the committee agreed that many of the people that will be referred as result of this guideline will have been given an alternative diagnosis or would have received a late diagnosis of ADHD. They are likely to be already accessing services. Referral as a result of raised awareness from this guideline should result in people receiving the right diagnosis as soon as possible and the appropriate support for ADHD.</p>

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				<p>The role of primary care in monitoring is not discussed fully or the roles of different team members. Nationally we have many different service models and some case examples of good practice would be helpful to clinicians and commissioners.</p>	<p>Section 1.1 was not included in this update of the guideline and the recommendations supporting shared care arrangements with primary care remain in the guideline. Section 1.10 is clear that an ADHD specialist should review ADHD medication at least once a year. The other recommendations on the monitoring and maintenance of treatments in section 1.8 are not as specific about who should be responsible and the committee recognise there are different service models and this could be undertaken in primary care.</p> <p>The section, 'other factors the committee took into account' in evidence report H provide further detail about the committee's experience of good practice in monitoring. Further discussion on the committee's recommendations about shared care arrangements have been added to the</p>

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					“why the committee made these recommendations” section of evidence report H.
British Academy of Childhood Disability	Appendix B	21	Line 14	Event = “even”	Thank you for your comment. The typographical error has been corrected.
British Academy of Childhood Disability	Appendix B	21	31.5.4 .1.3	There is an error/omission on Theme 3: Challenges for parents Although some parents felt they have adequate support from their families, healthcare professionals and teachers, other parents reported a lack of support mainly from spouses and other family members, and from both healthcare and educational professionals.	Thank you for your comment. This wording has been amended.
British Academy of	Appendix B	25	Line 2	Parents felt that teachers were unsympathetic in their	Thank you for your comment. This wording has been amended.

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Childhood Disability				<p>attitudes, and felt that teachers neglected their children as a result.</p> <p>They were that teachers (what should this say?)</p> <p>had a 'blasé' attitude towards ADHD, which resulted in their child not receiving adequate help.</p>	
British Academy of Childhood Disability	Appendix B	Page 25	Line 25	<p>This section is an example of language which I feel is not helpful:</p> <p>I have suggested changes. The comments should not be implied to refer to all cases.</p> <p>Review theme 27: Communication</p> <p>Some parents/carers and teachers reported conflict with each other, and difficulties in discussing the child with ADHD. Parents/carers reported communication difficulties with schools and teachers, which resulted in them feeling distressed. When teachers tried to</p>	<p>Thank you for your comment. This wording has been amended to note that our review findings refer to parents because the studies contributing to these findings were conducted with parents and not carers.</p>

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				<p>discuss a child's behaviour with families some perceived this negatively. Teachers also found it difficult to</p> <p>discuss children's behavioural issues with families, and found that they often had different opinions of the behaviour of the child. Those who did receive support from teachers did not always feel that this greatly impacted the child's behaviour, but it did improve the family's peace of mind</p>	
British Academy of Childhood Disability	Appendix B	Page 56	Line 34	<p>'the possible effect on driving (for example, some ADHD medication may impact on a person's fitness to drive and people with ADHD must declare their diagnosis to the DVLA if it affects their driving)'</p> <p>This is a misleading comment. Regular use of medication for ADHD will improve driving.</p> <p>I suggest it should read:</p>	Thank you for your comment. The wording of this recommendation has been amended to clarify that driving may be affected by ADHD symptoms. The committee has added 'and ADHD medication may improve this'. The recommendation notes that there is a responsibility to inform the DVLA if there are safety concerns about their ability to drive.

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				The possible effect of ADHD symptoms on driving. If needed, appropriate and regular use of medication can improve fitness to drive although some medications can cause drowsiness.) Individuals with ADHD must inform the DVLA of their diagnosis and a report may be requested from their clinicians.	
British Academy of Childhood Disability	Evidence Review A Risk Factors		General	This is excellent and the recommendations are very useful and important to raise awareness of risk factors	Thank you for your comment.
British Academy of Childhood Disability	Evidence Review B		General	<p>However I feel some of the language used should be changed.</p> <p>Firstly a significant number of children/young people are not in the care of their parents and this should either be commented on at the top of the section or the term carer should be added throughout.</p>	<p>Thank you for your comment. The wording in the review findings reflects the evidence, and in cases where review findings refer to parents, this is because evidence was only found on this population.</p> <p>In terms of your comment relating to GPs and teachers, where possible we avoid quantifying results as GRADE CERQual's</p>

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				<p>Secondly there is inappropriate generalisation throughout which carers, GPs etc will not find helpful. The word 'some' is used frequently but actually not often enough. Perhaps many could be used when this is a frequent finding and a few when only a minority or several. Basically parents or teachers or GPs or health professionals is often used as though the following statement applies to ALL when it does not.</p> <p>Also I suggest a change in wording in some of the Tables as currently they are not going to be read positively by GPs and Teachers some of whom know a great deal about ADHD and work effectively with specialists</p> <p>e.g. Table 6.</p> <p>'GPs had difficulty in recognising ADHD' could be 'some' or 'Many' depending on the results</p>	<p>methodology notes this to be misleading. Qualitative reviews do not quantify findings in this way but give insight to themes experienced by the population of interest. Instead, we provide information on the number of studies that contributed to a particular review finding. Our quality assessment also includes a domain on 'coherence', where the quality of a finding would be downgraded if any conflicting review findings were found. Please see the quality assessment section for this level of detail.</p>

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				<p>Attitudes</p> <p>GPs had negative attitudes towards ADHD ditto</p> <p>GPs had limited understanding of their role in treatment management and again.</p> <p>The same applies to Table 7 about teachers</p>	
British Academy of Childhood Disability	General	Training		BACD in partnership with Sheffield Children's NHS Foundation Trust has developed online training on ADHD and comorbid/coexisting conditions. This is being accessed by Specialist Nurses and by medical staff learning about the area. This could also be useful to GPs who would value additional training	Thank you for your comment. We will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement .
British Academy of Childhood Disability	Short version	Service Organisation	General	It would be helpful to consider the role of a neurodevelopmental service with input from Paediatrics and CAMHS rather than assuming Services will be ADHD services. The high degree of overlap in coexisting conditions means that a joint service can provide assessment and diagnosis for the	Thank you for your comment. The committee have been mindful of the impact of coexisting conditions throughout the guideline. The development of joint services is beyond the scope of this guidance.

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				many children with multiple needs without waiting lists and barriers between different assessments and the need for follow up by different teams. Joint working can enable services to manage greater demand better.	
British Academy of Childhood Disability	Short version	General	General	Whilst moving age for diagnosis and medication from 6 to 5 years may be clinically appropriate. There is concern regarding the impact on service provision. For example: in one paediatricians trust - CAMHS have based their ADHD service on premise they will not see anyone below 6 in view of the previous guideline. Whilst CDCs see younger children, the trust says we are not commissioned to see or diagnose children for ADHD, let alone medicate. Whilst local policy may not be right it is based on previous NICE guideline and potentially puts services at risk, especially in current financial climate when we are told there is no new money to facilitate expansion of current services. There is also an issue over access to clinicians with appropriate competencies to manage ADHD in younger children, as many CDCs do not see	<p>Thank you for your comment. The committee acknowledges the challenges of the current financial climate; however, the recommendations are based on the committee consensus over what is most clinically appropriate and cost effective. The committee hope that the recommendations will be a prompt to commissioners to aid expansion of services where appropriate.</p> <p>We will pass this information to our resource impact team for their information.</p>

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				so will not be skilled for the under 6s where CAMHS no longer see	
British Academy of Childhood Disability	Short version	General	General	No guidance for classroom management in schools.	Thank you for your comment. NICE guidelines are written for services commissioned by the NHS. The committee were unable to make recommendations about classroom management in the schools.
British Academy of Childhood Disability	Short version	General	General	No focus on management of sleep as a part of symptom management	Thank you for your comment. The committee agrees that sleep is an important issue in people with ADHD. An assessment of sleep disorder should be part of the discussion about planning and choosing treatments between the person with ADHD and their ADHD specialist. The discussion of the risks and benefits is outlined in the recommendations on planning treatment.
British Academy of	Short Version	8	4	SENCO offering parent training, while this is welcomed as a recommendation, in reality however, we are not sure if education systems are aware or have capacity	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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Childhood Disability				to do this additional work. How can the implementation of this be influenced from a health perspective.	
British Academy of Childhood Disability	Short version	8	Line 24 and 25	I welcome this recommendation that suggests ADHD focused input BEFORE a formal diagnosis is made	Thank you for your comment.
British Academy of Childhood Disability	Short version	9	5	This would be better if it read: Observer reports and assessment of ADHD symptoms and possible comorbid conditions (rather than 'the person's mental state')	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.
British Academy of Childhood Disability	Short version	Page 10	section 1.3.2	It would be better to recommend questionnaires of ADHD core symptoms and questionnaires assessing general behaviour and well being, rather than specifically Conners and SDQ as others are equally good and do not cost to use	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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British Academy of Childhood Disability	Short version	Page 11	section 1.4.4 Line 20 onwards	This whole section is an excellent addition in guiding ongoing support	Thank you for this feedback.
British Academy of Childhood Disability	Short version	Page 12	section 1.4.6	This is very important but seems to make the same point repetitively. Could be shortened and still cover the same issues	Thank you for your comment. The committee think the recommendations as they stand are sufficiently concise and could not be shortened covering the same issues.
British Academy of Childhood Disability	Short version	Page 12	Section 1.4.7 onwards	This section on supporting families and carers is excellent	Thank you for this feedback.

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British Academy of Childhood Disability	Short version	8 – 9	Pg. 8 line 23 onwards	<p>Need to consider the thresholds for referral vs watchful waiting.</p> <p>Watchful waiting for 10 weeks should not be considered if the effects are severe. Families are already waiting long periods for assessment. A judgement needs to be made.</p> <p>Perhaps this should say if the adverse impact is mild consider watchful waiting. If adverse impact is moderate to severe initiate referral. In this situation there also needs to be clarity with respect to how primary care services can assess the impact/severity.</p> <p>This should be highlighted at the beginning of this section and not left as an add-on at the end.</p>	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.
British Academy of Childhood Disability	Short version	Page 20	Baseline assessment	<p>Baseline assessment section: Include full cardiac clinical examination.</p> <p>Heart sounds should be listened to before starting ADHD medication and referral made if significant</p>	Thank you for your comment. The committee have added a cardiac examination to the baseline assessment. The committee recognise that coarctation could be a rare finding but did not consider the case for feeling for femoral pulses was

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				<p>murmurs are audible. (possible aortic stenosis, cardiomyopathy etc)</p> <p>There is also a case for feeling femoral pulses as we have picked up 2 cases of undiagnosed coarctation of the aorta needing treatment before medication for ADHD and BP was normal.</p>	<p>strong enough to include another element to the examination.</p>
British Academy of Childhood Disability	Short version	Page 20	1,2 and 3	<p>I am concerned that this could lead to individuals with severe ADHD waiting long periods of time for additional assessments e.g. for ASD, before medication is trialled</p> <p>This could be avoided by creating neurodevelopmental teams with CAMHS expertise in addition to reduce barriers and waits and promote joint working to optimise family support</p>	<p>Thank you for your comment. The committee do not consider that this will lead to long waits for additional assessments. It is not within the remit of the guideline committee to recommend the creation of neurodevelopmental teams with CAMHS expertise.</p>
British Academy of	Short version	Page 21	Section 1.7.4	<p>Clinicians may have reasons to use other medications as first line. (e.g. parental choice – as in previous guideline)</p>	<p>Thank you for your comment. Patient/parental choice will always feature in medication decisions; however, the purpose of the NICE recommendations is to highlight the most appropriate</p>

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Childhood Disability			– 1.7.7	<p>For example:</p> <p>Guanfacine as first line could be considered in children and</p> <p>young people with high blood pressure (clearly the cause for high BP needs ascertaining first)</p> <p>Also for some children with severe tics.</p> <p>Some clinicians offer atomoxetine to children with significant anxiety symptoms and also to families who feel they can't cope with the 'up and down' effect of stimulants and prefer a more sustained symptom control over the whole day.</p>	<p>medication stages in the majority of people. The recommendations in the general prescribing information section highlight that co-existing conditions like anxiety disorders, tic disorders and autism spectrum disorder are not reasons to automatically deviate from the use of stimulants.</p>
British Academy of Childhood Disability	Short Version	22		<p>a) there should be a mention of considering length of time in the day cover is needed by the child/YP.</p>	<p>Thank you for your comment. The wording of this recommendation has been amended for clarity.</p>

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				b) lines 3 and 4 may encourage prescribers to try several MPH preparations inappropriately before changing to lisdexamfetamine.	
British Academy of Childhood Disability	Short version	24	Section 1.7.18	<p>Several BACD members highlight significant concern with this statement.</p> <p>It should not be in the short guideline with no further discussion and no comment about side effects, pre assessment and on treatment monitoring. As written it is potentially dangerous.</p> <p>Consideration of risperidone in addition to stimulants fits well with a mental health model of adhd, but using drugs like risperidone in isolation would be poor practice. Hopefully the new transformation model will lead to better joint working, between CAMHS and Paedatric services, but there should be clinical caution with use of risperidone and there is resource implication with respect to monitoring.</p>	Thank you for your comment. The recommendations state that an antipsychotic should only be used in addition to stimulants and not in isolation.

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British Academy of Childhood Disability	Short version	25	2	please add cardiac problems	Thank you for your comment. Cardiac problems has been added as you suggest.
British Academy of Childhood Disability	Short version	25	5	This could just say a scale measuring ADHD core symptoms and not specify Conners, SNAP IV is almost identical and free to use	Thank you for your comment, this has been amended.
British Academy of Childhood Disability	Short version	27	1.8.10	Referral for increased BP assessment is not to a cardiologist in many areas but to a paediatric nephrologist. It is also helpful to agree with your local cardiologist and/or nephrologist whether any investigations should be arranged prior to the appointment e.g. feeling femoral pulses and checking BP in other limbs would mean referral for raised BP should be to a cardiologist not a nephrologist. Urine testing is simple and helpful	Thank you for your comment, the wording of this recommendation has been amended.

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				Prior to referral to cardiologist ECG maybe helpful including 24 hour ECG (e.g. for tachycardia or irregular pulse)	
British Academy of Childhood Disability	Short version	31	Section 1.10.1	Please mention the need to consider non pharmacological support for comorbid neurodevelopmental and mental health difficulties as part of monitoring	Thank you for your comment. The recommendations here are focused specifically on ADHD; however, text around this issue has been added to the committee's discussion of the evidence in evidence report H.
British Academy of Childhood Disability	Short version	31	9	could say throughout the day. This would emphasise the need to assess whether an individual has adequate cover throughout the day as they get older.	Thank you for your comment, the wording has been amended as you suggest.
British Academy of Childhood Disability	Short version	49		'the possible effect on driving (for example, some ADHD medication may impact on a person's fitness to drive and people with ADHD must declare their diagnosis to the DVLA if it affects their driving) '	Thank you for your comment. The wording of this recommendation has been amended to clarify that driving may be affected by ADHD symptoms. The committee has added 'and ADHD medication may improve

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				<p>This is a misleading comment. Regular use of medication for ADHD will improve driving.</p> <p>I suggest it should read:</p> <p>The possible effect of ADHD symptoms on driving. If needed, appropriate and regular use of medication can improve fitness to drive (although some medications can cause drowsiness.) Individuals with ADHD must inform the DVLA of their diagnosis and a report may be requested from their clinicians.</p>	<p>this'. The recommendation notes that there is a responsibility to inform the DVLA if there are safety concerns about their ability to drive.</p>
British Academy of Childhood Disability	Short version	64		This should include listening to heart sounds	Thank you for your comment. This has been added.
British Academy of	Short version	65		Referral for raised BP should more commonly be to a nephrologist rather than a cardiologist unless femoral pulses are weak/impalpable	Thank you for your comment. This has been amended and another recommendation added to make it clear a child or young person should be referred to a paediatric specialist in hypertension. The

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Childhood Disability					committee noted that a hypertension specialist might not always be a nephrologist.
British Academy of Childhood Disability	Short version	67		Auscultation is needed (by someone)	Thank you for your comment. This has been added.
British Academy of Childhood Disability	Short version	70		Clinicians would still find discussion of dosage helpful for initiation and optimisation guidance. Why was this omitted?	Thank you for your comment. The guideline section managing treatment, medication choice, considerations when prescribing ADHD medication and dose titration outlines that prescribers should be knowledgeable about the medication they are prescribing. Prescribers are also directed to the BNF for dosing information.
British Academy of Childhood Disability	Short version	79		Conners should be replaced by short questionnaire on core ADHD features	Thank you for your comment. This has been amended.

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British Academy of Childhood Disability	Short version	50 and 53		These sections on Improving communication are repetitive and could be said in a more concise and understandable way whilst still including all the issues.	Thank you for your comment. The section you are referring to demonstrates changes from the previous guideline. The committee considers the wording of the specific recommendations you highlight to be sufficiently concise.
British Academy of Childhood Disability	Short version	71 and 72, 73 and 74		same as previous comments	Thank you for your comment
British Academy of Childhood Disability	Short version	General	General	The emphasis on access to behaviour management, talking therapies, parenting is very welcome. There are cost implications for service provision as access to these is very variable nationally and in many areas will need significant investment across agencies at a time when austerity has led to major cuts in service provision eg from social care and education (and NHS)	Thank you for your comment. The committee agree that services should be commissioned in a way that facilitates care provision according to the NICE recommendations. The information will be passed onto our resource impact team for their information.

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British Academy of Childhood Disability	Short version	Page 16	Line 7 section 1.5.8	Specialist advice for tertiary service ADHD for under 5 is resource limited in many areas of the UK, with very patchy based provision. In each area, there are different service models between CAMHS and community paed. There is a need for clinical co-ordination of services. With current resource adherence to this recommendation may be limited; although this guidance may help to drive resource allocation and co-ordination of care.	Thank you for your comment. The committee agree that services should be commissioned in a way that facilitates care provision according to the NICE recommendations. The information will be passed onto our resource impact team for their information.
British Dietetic Association	Short version	12	1	Important comment to discuss issues around substance misuse and self medication but important to mention discussion on use of self restricted unproven diets as well.	Thank you for your comment. Dietary advice is covered in detail in a separate section that was not updated here.
British Dietetic Association	Short version	15	15	Benefits of healthy lifestyle including exercise - also add and well balanced diet	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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British Dietetic Association	Short version	26	17	Welcome guideline on routine weight/height/growth monitoring in children and BMI monitoring in adults. However, particularly in young children < 5 years 6 monthly monitoring is too infrequent to highlight any early concerns regarding growth and this should be perhaps be 3 monthly. Acknowledge statement to review more frequently where there is concern but poor growth needs to be highlighted early to prevent further deterioration in young children	Thank you for the comment. Additional information on monitoring weight has been added to the committee's discussion of the evidence in evidence report D to clarify when weight loss is of concern.
British Dietetic Association	Short version	27	5	Obtaining dietary advice. Ensure this is from an appropriate health professional by referring to dietitian	Thank you for your comment. The recommendations here are focused specifically on ADHD; however, text around this issue has been added to the committee's discussion of the evidence in evidence report D
British Dietetic Association	Short version	42	5	As previously highlighted - welcome the acknowledgement and importance of weight and growth monitoring for patients taking medication	Thank you for this feedback.

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British Dietetic Association	Short version	42	10	Concern that 6 monthly growth monitoring in children, especially under 5 years is too infrequent and should be 3 monthly	Thank you for your comment. Additional information on monitoring has been added to the committee's discussion of the evidence in the evidence report D to clarify when weight loss is of concern.
British Psychological Society		General	General	Evidence reviews were critically undermined: very few long-term studies cited by the guidance. Majority of pharmacological and non-pharmacological studies are very short in duration – with an approximate mean average of 15 weeks, for age groups under-5, over-5 and adult.	<p>Thank you for your comment. The protocols were agreed by the committee and the studies with longer follow-up did not meet the inclusion criteria for study design in the reviews comparing treatments. The protocols provide further detail about the inclusion criteria.</p> <p>In response to stakeholder comments non comparative longer term studies have been added to the review on adverse effects.</p> <p>The committee acknowledges the short duration of the majority of included studies and reports this limitation of the evidence in the following evidence reports C,D,E and F</p>

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					<p>in ‘the committee’s discussion of the evidence’ section.</p> <p>The committee recognised there is an absence of good quality evidence on adverse events and in particular they acknowledged the concern about potential negative long term effects on growth. The committee also acknowledged the long lasting negative impacts of untreated ADHD on a person’s life. For example, academic, interpersonal, occupational, personal, substance use and driving impacts. People with ADHD are over represented in the criminal justice system.</p> <p>The committee agreed that medication offers a good balance of benefits and costs for people experiencing persistent significant impairment from ADHD</p>
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					symptoms so the committee recommended medication in specific circumstances.
British Psychological Society	Appendices C, E, and F: Evidence review(s) for	General	General	Evidence reviews were critically undermined: diagnosis criteria for ADHD depend on core behavioural symptoms of 'hyperactivity', 'impulsivity', and 'inattention'.	Thank you for your comment. The protocols were agreed by the committee and they agreed that the diagnostic criteria for the study population should be the DSM-III, ICD-10 or later versions. The methodology chapter outlines how the committee assesses clinical improvement

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	efficacy of non-pharmacological treatment + pharmacological treatments			No differential quantitative baselines were provided for 'normal activity', 'normal impulsivity' and 'normal concentration' in any of the guidance, evidence reviews or other appendices. This means that 'improvement over baseline' by any treatment can never be scientifically established in any age group in any context, e.g. home or education, in any study. This is a significant methodological limitation in all studies cited.	in the evidence reviews. The committee's discussion of the evidence in the evidence reviews on pharmacological and non-pharmacological treatment describe the committee decision making on whether the evidence showed improvement. The methodology chapter includes more information on how importance was determined, in brief – anchor-based values from the literature were prioritised if available for any individual symptom scale, if unavailable the committee consensus was that a difference greater than 20% of the baseline symptom score represented a clinically important difference between interventions. If this information was unavailable, standard default differences of 0.5 x the SD was used. These rules of thumb were used as systematic starting points, but the committee were able to deviate from this where their clinical experience and consensus justified.

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British Psychological Society	C.	p.6	ll.21-23	Evidence reviews were critically undermined. To quote the committee: "Despite a large treatment literature supporting the short-term benefits of stimulant medication in children with ADHD, uncertainty still surrounds the quality of evidence and the balance of risks and benefits of long-term drug treatment for ADHD in children and young people."	<p>Thank you for your comment. The committee agrees that long-term evidence is lacking in the current evidence base. On consideration of all available evidence in line with their experience and previous recommendations the committee agreed that the current recommendations were appropriate.</p> <p>The committee recognised there is an absence of good quality evidence on adverse events and in particular they acknowledged the concern about potential negative long term effects on growth. The committee also acknowledged the long lasting negative impacts of untreated ADHD on a person's life. For example, academic, interpersonal, occupational, personal, substance use and driving</p>

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					<p>impacts. People with ADHD are over represented in the criminal justice system.</p> <p>The committee agreed that medication offers a good balance of benefits and costs for people experiencing persistent significant impairment from ADHD symptoms so the committee recommended medication in specific circumstances.</p> <p>The committee has noted the need for long term data collection in the design of the research recommendations evaluating all types of treatments.</p> <p>The committee has also included recommendations for close monitoring of medication and review of the need for medication in order to guard against inappropriate prescribing.</p>

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British Psychological Society	C., E., F.		General	Evidence reviews were critically undermined: there are no long term (2 years plus) follow-up studies cited, for age groups under-5, over-5 and adult.	<p>Thank you for your comment. The protocols were agreed by the committee and the studies with longer follow-up did not meet the inclusion criteria for study design in the reviews comparing treatments. The protocols provide further detail about the inclusion criteria.</p> <p>In response to stakeholder comments non comparative longer term studies have been added to the review on adverse effects.</p> <p>The committee acknowledges the short duration of the majority of included studies and reports this limitation of the evidence in the following evidence reports C,D,E and F in 'the committee's discussion of the evidence' section.</p> <p>The committee recognised there is an absence of good quality evidence on</p>

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					<p>adverse events and in particular they acknowledged the concern about potential negative long term effects on growth. The committee also acknowledged the long lasting negative impacts of untreated ADHD on a person's life. For example, academic, interpersonal, occupational, personal, substance use and driving impacts. People with ADHD are over represented in the criminal justice system.</p> <p>The committee agreed that medication offers a good balance of benefits and costs for people experiencing persistent significant impairment from ADHD symptoms so the committee recommended medication in specific circumstances.</p>

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British Psychological Society	E	p.117	11.30-31	Evidence reviews were critically undermined. To quote the committee: "The committee noted that the majority of evidence for this review was generally low or very low quality."	<p>Thank you for your comment. The protocols were agreed by the committee and the studies with longer follow-up did not meet the inclusion criteria for study design in the reviews comparing treatments. The protocols provide further detail about the inclusion criteria.</p> <p>In response to stakeholder comments non comparative longer term studies have been added to the review on adverse effects.</p> <p>The committee acknowledges the short duration of the majority of included studies and reports this limitation of the evidence in the following evidence reports C,D,E and F in 'the committee's discussion of the evidence' section.</p> <p>The committee recognised there is an absence of good quality evidence on</p>

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					<p>adverse events and in particular they acknowledged the concern about potential negative long term effects on growth. The committee also acknowledged the long lasting negative impacts of untreated ADHD on a person's life. For example, academic, interpersonal, occupational, personal, substance use and driving impacts. People with ADHD are over represented in the criminal justice system.</p> <p>The committee agreed that medication offers a good balance of benefits and costs for people experiencing persistent significant impairment from ADHD symptoms so the committee recommended medication in specific circumstances.</p>

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British Psychological Society	F	p. 107	ll.14-17	Evidence reviews were critically undermined. To quote the committee: "The committee noted that the body of evidence for this review was typically low or very low quality. There was no evidence in children under the age of 5 for this review. There was larger body of evidence for children aged 5 to 18 than for adults over the age of 18. While there were a large number of studies meeting the criteria for the review, in general they were small studies providing imprecise results and only single studies per outcome."	<p>Thank you for your comment. The protocols were agreed by the committee and the studies with longer follow-up did not meet the inclusion criteria for study design in the reviews comparing treatments. The protocols provide further detail about the inclusion criteria.</p> <p>In response to stakeholder comments non comparative longer term studies have been added to the review on adverse effects.</p> <p>The committee acknowledges the short duration of the majority of included studies and reports this limitation of the evidence in the following evidence reports C,D,E and F in 'the committee's discussion of the evidence' section.</p> <p>The committee recognised there is an absence of good quality evidence on</p>

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					<p>adverse events and in particular they acknowledged the concern about potential negative long term effects on growth. The committee also acknowledged the long lasting negative impacts of untreated ADHD on a person's life. For example, academic, interpersonal, occupational, personal, substance use and driving impacts. People with ADHD are over represented in the criminal justice system.</p> <p>The committee agreed that medication offers a good balance of benefits and costs for people experiencing persistent significant impairment from ADHD symptoms so the committee recommended medication in specific circumstances.</p>

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British Psychological Society	NICE guideline: short version, 2017:	p.37-38	General	The Society is concerned that the change from 'Drug treatment is not recommended for the under-5s' in the 2008 guidelines to the first-line use of ADHD-focused group parent training programmes whilst laudable as a first step may inadvertently and unintentionally lead to an increase in prescribing medications to pre-school children to the lack of availability of such training packages in some regions of the country and the potential post-code lottery effect in fairly delivering such a response. This in turn we believe may well result in an increased rate of prescribing to pre-school children in those disadvantaged areas due to the resource limitations.	Thank you for your comment. The recommendations are clear that ADHD-focused group parent-training programme to parents or carers is first-line treatment for children under 5 years with ADHD. The other recommendation specifically directed at children under 5 years is about obtaining specialist for advice from and ADHD specialist. The committee do not believe these recommendations will result in increased prescribing in the under 5 age group as any other treatment decisions in this age group would be made under the care of a specialist. The committee discussed at length the pharmacological treatment of children under 5 years and agreed with consensus that, although unusual, there could be exceptional situations where medication was appropriate (see the Committee's discussion of the evidence in evidence report C). The 2008 guideline did not recommend drug treatment but also did not go as far as to tell prescribers never to

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					<p>prescribe drug treatment, also allowing for these exceptional situations. After noting the stakeholder comments, the committee agreed to add a recommendation clarifying that medication should only be prescribed in this age group when a second opinion from a specialist ADHD service with expertise in ADHD in young children (ideally tertiary) has been obtained.</p>
British Psychological Society	NICE guideline: short version, 2017:			<p><u>References</u></p> <p>Brinkman, W.B., Sherman, S.N., Zmitrovich, A.R., Visscher, M.O., Crosby, L.E., Phelan, K.J. & Donovan, E.F. (2012). In their own words: Adolescent views on ADHD and their evolving role managing medication. <i>Academic Pediatrics</i>, 12(1), 53–61</p> <p>‘Children and Young People with Neurodisabilities in the Criminal System’ (2015).</p>	Thank you for providing these references.

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				<p>Gillberg, C. (2010) 'The essence in child psychiatry: Early symptomatic syndromes eliciting neurodevelopment' <i>Research in Developmental Disabilities</i>, 31, 1543–1551;</p> <p>Gillberg, C., Gillber, I.C., Rasmussen, P., Kadesjo, B., Soderstom, H., Rastam, M. Johnson, M., Rothenberger, A., & Niklasson, L., (2004) 'Co-existing disorders in ADHD – implications for diagnosis and intervention' <i>European Child and Adolescent Psychiatry</i>, 1(1). 180-192</p> <p>Gillberg, C., 2010; Lundstrom, S., et al, 2015). Autism spectrum disorders and co-existing disorders in a nationwide Swedish twin study. <i>Journal of Child Psychology and Psychiatry</i>, 56(6), 702–710</p>	

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				<p>Hughes, N, Williams, W.H. et al (2012) 'Nobody made the connection. The prevalence of neurodisability in young people who offend'</p> <p>Lundstrom, S., Reichenberg, A., Melke, J., Rastam, M., Kerekes, N., Lichtenstein, P. Gillberg, C. & Anckarsater, H. (2015). Autism spectrum disorders and co-existing disorders in a nationwide Swedish twin study. <i>Journal of Child Psychology and Psychiatry</i>, 56(6), 702–710.</p>	
British Psychological Society	NICE guideline: short version, 2017:	p.37-38	ll. 11-18	We value elements of the safeguarding agenda and the clarification of the significant impact in at least one domain of their everyday life but do still have concerns that the proposed changes to first-line intervention may result in an increase of inappropriate prescribing of psychostimulants and anti-psychotic medications.	Thank you for your comment. The evidence indicated that some parents and carers of children and young people aged 5 years and over can benefit from group support (see evidence reports B and E). After discussion of current good practice and consideration of the balance of benefits and costs, the committee decided to recommend offering additional support that could be group-based and is ADHD-

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					<p>focused (this may be as few as 1 or 2 sessions) for parents and carers of all children and young people with ADHD. Evidence showed the benefit of medication in this age group and this was in line with the committee’s experience. The committee discussed at length the impact of the short term adverse effects of medication and acknowledged the concerns around the uncertainty about the long term effects. They particularly discussed the concerns about the impact of stimulants on growth. The committee noted that untreated ADHD can have long reaching negative impacts on a person’s life.</p> <p>After taking this into account the committee agreed that medication offered a good balance of benefits and costs and the committee agreed to recommend this when ADHD symptoms are still having a persistent significant impact on at least one domain of everyday life after environmental</p>
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					<p>modifications have been implemented (see committee's discussion of the evidence in the evidence report C).</p> <p>The committee agreed with consensus that this would not result in a significant increase in prescribing. After considering the stakeholder comments the committee agreed to add the word 'still' to the recommendation to clarify that medication was only appropriate after parents had received information and been offered additional ADHD-focused support and after environmental modifications have been implemented and reviewed. Combining a full parent-training programme with medication did not offer a good balance of benefits and costs for all children and young people in this age group and the committee agreed not to make a recommendation for this (see committee's</p>

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					<p>discussion of the evidence in the evidence reports E and F).</p> <p>Some evidence showed a benefit of cognitive-behavioural therapy (CBT) in young people with ADHD. The committee agreed that this should be considered when a young person has benefited from medication but still have symptoms that are having a persistent significant impact on their lives. They used their experience to recommend areas that a programme should address (see the committee's discussion of the evidence in the evidence reports E and F).</p>
British Psychological Society	NICE guideline: short version, 2017:	p.16-17	ll. 2-10	The Society recommends that consideration be given to forbidding the prescribing of stimulant-medication to children under the age of 6 years unless there is significant distress caused to the child by their own presenting behaviours, and that medication is	Thank you for your comment. The recommendations are clear that ADHD-focused group parent-training programme to parents or carers is first-line treatment for children under 5 years with ADHD. The other recommendation specifically directed

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				<p>supported by a second opinion from parent(s) and a tertiary service. We believe that psychological and psycho-educational programmes are advantageous to children of this age and that psychotropic medications are unnecessarily risky, unethical and of limited efficacy. This is therefore a safeguarding issue. In other European countries such as France medication is not recommended under the age of 7 years.</p>	<p>at children under 5 years is about obtaining advice from an ADHD specialist. The committee do not believe these recommendations will result in increased prescribing in the under 5 age group as any other treatment decisions in this age group would be made under the care of a specialist. The committee discussed at length the pharmacological treatment of children under 5 years and agreed with consensus that, although unusual, there could be exceptional situations where medication was appropriate (see the committee's discussion of the evidence in the evidence report C). The 2008 guideline did not recommend drug treatment but also did not go as far as to tell prescribers never to prescribe drug treatment, also allowing for these exceptional situations. After noting the stakeholder comments the committee agreed to add a recommendation clarifying that medication should only be prescribed in this age group</p>

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					when a second opinion from a specialist ADHD service with expertise in ADHD in young children (ideally tertiary) has been obtained.
British Psychological Society	NICE guideline: short version, 2017:	p. 37-38	ll.16-22	The Society believes that it is potentially dangerous to proffer stimulant-medication to the under-5 age group because of the scant evidence of efficacy. Stimulant medication used with under 5s is therefore antithetical to safeguarding them. We would recommend a stronger recommendation on not offering medication to the under 5's unless there are extreme circumstances and a consensus of more than one medical opinion. There is a large body of professional opinion in the child mental health field and amongst some parents that has concerns about the risk of serious side effects such as sudden heart failure due to overstimulation and are aware of reported cases where children have collapsed in school and been hospitalised as a result.	Thank you for your comment. The recommendations are clear that ADHD-focused group parent-training programme to parents or carers is first-line treatment for children under 5 years with ADHD. The other recommendation specifically directed at children under 5 years is about obtaining specialist for advice. The committee do not believe these recommendations will result in increased prescribing in the under 5 age group as any other treatment decisions in this age group would be made under the care of a specialist. The committee discussed at length the pharmacological treatment of children under 5 years and agreed with consensus that, although unusual, there could be exceptional situations where medication was appropriate (see the committee's

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				These are rare cases but still clearly significant in safeguarding terms.	discussion of the evidence in the evidence report C). The 2008 guideline did not recommend drug treatment but also did not go as far as to tell prescribers never to prescribe drug treatment, also allowing for these exceptional situations. After noting the stakeholder comments the committee agreed to add a recommendation clarifying that medication should only be prescribed in this age group when a second opinion from a specialist ADHD service with expertise in ADHD in young children (ideally tertiary) has been obtained.
British Psychological Society	NICE guideline: short version, 2017:	p.11	l. 9	The Society is concerned that the guidance from adults is being applied downwards to children, young people and their families. The ways in which children, young people and their families access healthcare is different and the issues are different. For example the 'Patient experience' document specifies that practitioners should, for example, 'develop an understanding of the patient as an individual, ask the patient about and take into account factors such as	Thank you for your comment. The committee agree that children and young people are not little adults and recommendations throughout the guideline reflect key differences of care needs for children, young people and adults where appropriate. Separate evidence reviews were conducted for different age groups to support the committee in evaluating the evidence base for the specific age groups

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				domestic, social and work situation...' etc. For children and young people their presentation and care needs need to be in the context of their family, school and wider social systems. Children and young people are not simply little adults.	and to tailor the recommendations accordingly. The committee agreed that the patient experiences guideline had key principles of care that also apply to children, young people and their parents or carers. As with all recommendations, interpretation should be made on an individual basis and the situational factors and context of each child or young person needs to be taken into account.
British Psychological Society	NICE guideline: short version, 2017:	p.12	I. 24	The Society welcomes the reference of positive aspects of having a diagnosis and the need for people receiving a diagnosis being given appropriate information, and the requirement for this to be at an age / development appropriate level.	Thank you for your comment.
British Psychological Society	NICE guideline: short	p.15	II. 11	We welcome the inclusion of: "the benefits of a healthy lifestyle, including exercise". There is significant evidence not cited that supports the systematic use of physical activity prior to a decision to medicate a child to assess a beneficial effect on the	Thank you for your comment. The committee looked for and evaluated the evidence on the benefits of exercise in people with ADHD. A small low quality body of evidence was identified (see

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	version, 2017:			presenting pattern of behaviours. In France, for example, doctors use 'social prescribing' - the state pays for the membership of a sports club for a year to measure if this has any beneficial impact on non-compliant behaviour.	evidence report E). This was not sufficient to make stronger, more specific recommendations. This area has been included as a research recommendation.
British Psychological Society	NICE guideline: short version, 2017:	p.16	I. 3	The Society welcomes the inclusion of offering an ADHD focussed Parent Training Programme at this stage for children under 5 years of age, providing that it is informed by evidenced psychological principles, e.g. CBT.	Thank you for your comment.
British Psychological Society	NICE guideline: short version, 2017:	p.31	II. 3	The Society would recommend that if a patient has been prescribed stimulant medication, the review period should be a minimum of twice yearly because of the seriousness of side-effects, and the importance of patient empowerment and informed decision-making.	Thank you for your comment. The recommendation on the review of medication proposes that people with ADHD should have their medication reviewed at least once a year. This recommendation acknowledges there should be flexibility for people to be seen more frequently if this is appropriate. The committee experience is that not all people will need to be seen more than once a year (for example those with stable symptoms

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					that are well controlled but still justify the use of medication) and it is important that NICE recommendations do not add to the treatment burden for people with chronic conditions.
British Psychological Society	NICE guideline: short version, 2017:	p.37	ll. 12	Under 5s, note: "There was limited evidence on the efficacy of medication and because of concerns about medication in very young children, the committee agreed to recommend a group-based parent training programme as first line treatment." The Society welcomes this guidance and recommends that it would be a significant safeguarding-risk to vulnerable young children to offer medication in the light of this note. We also feel that better safeguarding of children under the age of 5 may provide a significant cost-saving outcome by reducing prescriptions where a significant amount of money saved could be spent on other clinical interventions for children with medical needs.	Thank you for your comment. The recommendations are clear that ADHD-focused group parent-training programme to parents or carers is first-line treatment for children under 5 years with ADHD. The other recommendation specifically directed at children under 5 years is about obtaining specialist for advice.

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British Psychological Society	NICE guideline: short version, 2017:	p. 2	I. 26	The Society believes that reference should be made to co-occurring (comorbid) conditions here since evidence suggests that receiving more than one neurodevelopmental diagnosis is the norm. (Gillberg, C. et al, 2004)	Thank you for your comment. The wording of this section has been amended for clarity.
British Psychological Society	NICE guideline: short version, 2017:	p. 6	I. 19	The Society believes that this implies trainee teachers are most in need of training in this area. More balance should be applied and that indeed the training of a variety of new professionals entering public sector jobs including those in health and education may benefit from evidence-based and policy informed training regarding ADHD within their training. (E.g. SALT, OT, Physio, School nurse, Portage...)	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.
British Psychological Society	NICE guideline: short	p. 7	II. 22-27	Teachers and parents have been aware that as a general rule girls are much more behaviourally compliant than boys in both educational and home settings but to suggest that girls are more likely to be of the 'inattentive' type means that the guidance would	Thank you for your comment. The recommendations are aimed at raising awareness of ADHD in populations where there is a delayed or misdiagnosis. Women and girls were suggested at the

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	version, 2017:			contradict DSM-5 and ICD-11 in suggesting that there are sub-categories of ADHD. This is a complex issue and we believe the different socialisation process for girls in our society, differences in biological make up such as the role of male hormones etc may well be part of the explanation and we should not be seeking to address a perceived imbalance in prescribing rates when there may indeed be other possible hypotheses to explain the current differential diagnosis rates.	stakeholder workshop as a group that may have been overlooked for a diagnosis of ADHD and this can be because girls with ADHD present differently. The recommendations here are based on the consensus of the committee. Referral as a result of raised awareness from this guideline should result in women and girls receiving the right diagnosis as soon as possible and the appropriate support for ADHD.
British Psychological Society	NICE guideline: short version, 2017:	p. 7	l. 9	We believe that this should read 'children and young people diagnosed with oppositional defiant disorder or conduct disorder'; the terms 'oppositional defiant disorder' and 'conduct disorder' are labels applied to children and young people, not things that they 'have'. The language used in line 13 ('a close family member diagnosed with ADHD') should be used as the model throughout when talking about diagnoses.	Thank you for your comment. The wording has been amended as you suggest.

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British Psychological Society	NICE guideline: short version, 2017:	p. 7	I. 21	The Society welcomes the inclusion of 'people with acquired brain injury' and of children with identified 'attachment disorders', as the evidence for these groups being at increased risk of receiving a diagnosis of ADHD is growing, and represents clinical experience.	Thank you for your comment.
British Psychological Society	NICE guideline: short version, 2017:	p. 10	II. 20-24	The Society believes that cognitive or neuropsychological assessment might clarify co-occurring conditions that may give rise to attentional difficulties for other reasons (e.g., dyslexia, dyspraxia, autism spectrum disorder or sensory processing disorder. It would also differentiate out the possibility of brain injury. This may then identify dysexecutive function, manifesting as ADHD.	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.
British Psychological Society	NICE guideline: short version, 2017:	p. 11	I. 21	"Following a diagnosis of ADHD it is important to have a structured discussion with people (and their families or carers as appropriate)". The Society believes that it needs to be recognised that for children and young people, a discussion with parents is required, as	Thank you for your comment. The guideline committee agreed that post-diagnostic advice was an important area of the guideline to update. The new recommendations highlight the importance

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				parents are generally the carers for their children; similarly, it is important for the discussion not just to be with parents when the child in question is very young, since all children have the right to know about any health conditions they may have, in an age appropriate format.	of discussions involving people with ADHD, and their families or carers when this is appropriate. Throughout the guideline the committee highlight in the recommendations the importance of involving people with ADHD in decisions about their treatment and that this information should be appropriate to their individual circumstances.
British Psychological Society	NICE guideline: short version, 2017:	p. 11	l. 21	The Society welcomes the recognition that family and carers are a crucial part of the support process for children and young people, but we would like to see this extended to young people over 16 if this is what the young person would like. We have some concern that there should be an expectation that young people aged over 16 are able to, or may want to be solely responsible for their healthcare. This is certainly not the case for young people aged over 16 with complex presentations of neuro-developmental disorders, such as ADHD, where co-occurrence of neuro-	Thank you for your comment. The definition of 'young people' across the guideline includes young people up the age of 18 and this is set out in the review protocols. The committee agree and throughout the guideline have highlighted in the recommendations the importance of involving the family, carers and friends of people with ADHD in decisions about their treatment where this is appropriate to their individual circumstances. In the managing

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				developmental conditions is the norm (Gillberg, C., 2010; Lundstrom, S., et al, 2015) or where the young person has intellectual difficulties. We would also argue that young people over 16 should be explicitly asked if they want their parents or carers to continue to be involved in their healthcare management as they navigate the transition to adult mental health services, rather than it being assumed that they do not; this is especially the case for young people with any degree of vulnerability.	ADHD section under planning treatment this recommendation, 'Ask young people and adults with ADHD if a parent, partner, close friend or carer could join discussions on treatment and adherence' specifically addresses your concern.
British Psychological Society	NICE guideline: short version, 2017:	p. 14	l. 13	The Society believes that reference needs to be made to the need for continuity at the point of transition from child to adult services. We would strongly welcome more clarity or guidance in the document about how this should happen. It is all too familiar to hear from young people of a complete breakdown in provision as they move from paediatric focused services with a philosophy of care that involves the young person and	Thank you for your comment. Transition to adult services is referred to in the service organisation section of the guideline.

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				their family, to adult services where provision is focused only on the individual.	
British Psychological Society	NICE guideline: short version, 2017:	p. 15	l. 4	The Society welcomes the need to encourage children and young people to give their own account of how they feel. We do have some concerns about the lack of self report measures of 'ADHD symptoms'; evidence suggests that young people can feel detached from the management of ADHD with important implications for treatment compliance. It is important young people are able to give their account to give a fuller picture of the distress and difficulty experienced by children and young people who have a diagnosis of ADHD. (Brinkman, et al, 2012).	Thank you for your comment. We agree that it is important that children and young people are given the opportunity to give an account of how they feel and to understand how their experience will impact on their potential adherence to treatment. The committee are not aware of any self-report measures that could support this recommendation. The recommendation has been amended to reinforce the importance of understanding a person's experience of being diagnosed with ADHD.
British Psychological Society	NICE guideline: short version, 2017:	p. 16	ll. 18-21	The Society welcomes the recommendation that group based ADHD parent-training should be offered first, however, we have concerns that medication should then be offered 'if ADHD symptoms are having a persistent significant impact in at least one domain of their everyday life after environmental modification'.	Thank you for your comment. The importance of environmental modifications has been further emphasised in the recommendations. The importance of environmental modifications has been added to the recommendation on supporting people with ADHD. The

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				<p>There is a step missing here, since environmental modifications should be explicitly trialled, their impact monitored and reviewed as a distinct and definitive step. Clinical experience is that parents may be asked if environmental changes have been tried, but because children with ADHD can be challenging, parents very often say these things have been tried when, in reality they have not been implemented in any systematic way, and have not been subject to any review. Medication may be helpful for children and young people, but so might properly implemented environmental interventions (including at school), but these are often not given a chance to work before medication is tried. No change of medication should be considered until medication has been stopped for a period of time and a systemic psychological intervention tried instead in school or in the home.</p>	<p>recommendations referring to environmental modifications in the managing ADHD section now includes the wording 'after environmental modifications have been implemented and reviewed'. The importance of ensuring environmental modifications are systematically implemented and evaluated has been added to the Rationale and impact section of evidence report H.</p>

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British Psychological Society	NICE guideline: short version, 2017:	p. 17	I. 7	The Society welcomes the recommendation to include the use of evidence based CBT treatment for children and would urge that consideration is given to it being used to reduce anxiety etc. prior to medication being offered.	Thank you for your comment. The committee considered the appropriate timing of interventions, there was little evidence to justify a particular sequence of events and the opposite point to yours could be made (e.g. medication may reduce symptoms, allowing for CBT to be more effective). Overall the committee felt it was not possible to make a recommendation that CBT should be offered prior to medication.
British Psychological Society	NICE guideline: short version, 2017:	p. 17	I. 16	We welcome the inclusion of the option of individual parent training interventions for parents who cannot attend group based approaches. Clinical experience is that parents are often lost to services when they cannot access the one size fits all service that is on offer.	Thank you for your comment.
British Psychological Society	NICE guideline: short	p. 18	II. 21-23	The Society believes that reference to bespoke plans needs to be made for children and young people around responsibility for taking their own medication, since it would not be appropriate for a very young child to be in charge of taking stimulant medication. This	Thank you for your comment. In NICE guidelines the word 'people' is used to refer to adults, young people and children and where there are important principles of care that can apply to everyone the

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	version, 2017:			point is mentioned further in the document, but it would be helpful if the document did not read like a document for adults, with children and young people as an afterthought.	<p>recommendation refers to people. It is important in NICE guidelines to make them succinct and user friendly.</p> <p>The committee agree that the needs of children and young people can be different to adults. Where this is appropriate recommendations throughout the guideline reflect key differences of care needs for children, young people and adults. Separate evidence reviews were conducted for different age groups to support the committee in evaluating the evidence base for the specific age groups and to tailor the recommendations accordingly. As you note one example of this distinction is made in the adherence section of the guideline advising that parents and carers oversee the medication needs of children and young people.</p>

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British Psychological Society	NICE guideline: short version, 2017:	p. 18	l. 2	The Society would welcome non-pharmacological treatment offered to children and young people on the same basis as they are offered to adults, e.g. when they have made an informed choice not to have medication. Competent children and young people are able to make this choice and should, therefore, be offered it. Similarly, some children and young people are unable to tolerate the side effects of medication.	Thank you for your comment. The first recommendation in the managing ADHD, children and young people aged 5 years and over, section offers information and additional ADHD focused support to all children and young people. As with adults, pharmacological treatment is recommended in specific circumstances. Any decision about initiating any treatment is made in discussion with the person with ADHD: the committee have stated the importance of discussing the risks and benefits of any treatments. In the maintenance, follow-up and monitoring section there are three recommendations about the monitoring of adverse effects and in the review of medication and discontinuation a comprehensive review of adverse effects is recommended.
British Psychological Society	NICE guideline: short	p. 21	l. 6	The Society is concerned about the removal of psychological interventions from the 2008 Guidelines as the first line of intervention for children and young people and the replacement with methylphenidate, a	Thank you for your comment. All children under 5 are still offered ADHD focused parent training as the first line intervention. This was supported by clinical

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	version, 2017:			stimulant-medication as the first-line intervention. We have concerns that in children where the drug does not have a calming effect that it acts as it is designed to stimulate the central nervous system causing major sleep disturbance and other well evidenced side effects such as growth retardation and weight / appetite loss which can not be beneficial to the children affected. We have great concerns that this change could lead to a dramatic increase in false positives and overprescribing; and attendant economic risks to the public purse.	and cost effectiveness evidence and in the context of treatment options for this age group. Uncertainty around the clinical and cost effectiveness of formal parent training programmes for children over 5 years and young people meant that the committee were unable to confidently recommend this as a treatment. The committee has recommended additional support that could be group-based and is ADHD-focused (this may be as few as 1 or 2 sessions) for parents and carers of all children and young people with ADHD.

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					<p>Medication is recommended for children and young people in specific circumstances and the committee have made detailed recommendations on the initiation of medication, the monitoring and review of the effectiveness and the documentation of adverse effects.</p> <p>The committee believe these sections of the guideline should address the concern that children are prescribed medication that is ineffective (and avoiding an increase in false positives) or has intolerable side effects.</p>
British Psychological Society	NICE guideline: short	p. 27	l. 18	All side effects, for example tics, weight loss and height retardation, should be viewed as serious and the prescribing doctor should always consider cessation of stimulant medication as a first response.	Thank you for your comment. The committee agree that all adverse effects should be viewed as serious. The cessation of medication in the context of adverse effects is an important discussion with the prescriber and the person with

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	version, 2017:				ADHD. It is important to consider that inappropriate cessation could also be harmful and should not always be a first response.
British Psychological Society	NICE guideline: short version, 2017:	p. 29	ll. 17	We welcome the development of the patient's autonomy and decision-making so that the person diagnosed with ADHD makes a significant contribution to their own treatment plan, including the cessation of their treatment / medication as part of their own informed decision making.	Thank you for your comment.
British Psychological Society	NICE guideline: short version, 2017:	p. 29	l. 26	The Society believes that a patient taking medication should be encouraged to identify, measure, record and monitor their side effects in order that they can properly contribute to the regular twice-yearly review of their treatment plan and this needs to be reflected in the guidance.	Thank you for your comment. An additional recommendation encouraging people with ADHD to monitor and record their own adverse effects has been added to the maintenance, follow-up and monitoring section.
British Psychological Society	NICE guideline: short	p. 34	ll. 12-21	The rates of neurodisability disorders are typically much higher in offenders than non-offender groups, (Hughes, N, Williams, W.H. et al, 2012) This was also described in the British Psychological Society	Thank you for your comment. This group has been listed in the recommendation raising awareness of groups that may have a delayed or a misdiagnosis.

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	version, 2017:			publication 'Children and Young People with Neurodisabilities in the Criminal System' (2015).	
British Psychological Society	NICE guideline: short version, 2017:	p. 34	ll. 18-19	<p>The guidance reports: "No evidence was found on the increased risk of missing a diagnosis of ADHD in girls."</p> <p>The Society acknowledges that girls are less likely to be diagnosed with ADHD, However, we are concerned about the conclusion of the guidance. The fact that females are under-represented in diagnosed ADHD group is not a reason to diagnose more. This is a statistically spurious argument and not born out by the experience of mental health professionals including psychologists.</p>	<p>Thank you for your comment. The wording of these recommendations has been amended to reflect the evidence base. The committee agree there is an absence of evidence and the recommendation that identifies girls and women as a population that are underdiagnosed or misdiagnosed is based on the committee's clinical experience and consensus. It is in line with current thinking, women and girls were identified at the stakeholder workshop as a group that have been overlooked for considering a diagnosis of ADHD and this could be because girls with ADHD present differently.</p> <p>In the committee's experience the impact of having a delayed or misdiagnosis can be far reaching. The lack of access to appropriate support and treatment, such as</p>

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					educational interventions, can result in poor long term outcomes. Referral as a result of raised awareness from this guideline should result in women and girls receiving the right diagnosis as soon as possible and the appropriate support for ADHD.
British Psychological Society	NICE guideline: short version, 2017:	p. 35	ll. 11-15	The Society believes that Schools and colleges should be encouraged to continually scrutinise and challenge diagnoses of ADHD in the fullest consideration of their safeguarding procedures.	Thank you for your comment. The recommendations are directed at health and social care professionals providing care funded by the NHS. The recommendations involving schools and colleges are important to ensure that children and young people have the support they need at school. It is important to note that in the evidence report B children and young people with ADHD and their parents found the questioning of their diagnosis to be unhelpful and the committee have made several recommendations addressing the stigma attached to ADHD.

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British Psychological Society	NICE guideline: short version, 2017:	p. 36	l. 12	We welcome the notion of 'holistic' but note that throughout the guidance, a medical 'within-child' model as opposed to a 'systemic' model is used to understand a patient and their ADHD.	Thank you for your comment. The committee agree that it is important to consider the systemic model when managing ADHD. The committee have made a number of recommendations in order to promote this (for example, on environmental modifications, the role of parent training, supporting families with ADHD).
British Psychological Society	NICE guideline: short version, 2017:	p. 52	ll. 1 - 10	The Society is concerned that the box from the 2008 guidance, noting the precedence of the Mental Health Act (2007) and the Children Act (2007) has been deleted from the 2017 guidance.	Thank you for your comment. This is directly referred to in NICE's guideline on antisocial behaviour and conduct disorders in children and young people in the general principles section and linked to from this guideline in the information and support section.
British Psychological Society	Short + appendices	General + p.45 p. 46	General + ll. 27-28 +	The guidance was critically undermined: diagnosis criteria for ADHD depend on core behavioural symptoms of 'hyperactivity', 'impulsivity', and 'inattention'. No differential baseline is provided for 'normal activity', 'normal impulsivity' and 'normal concentration' in any of the guidance, evidence reviews or other appendices for any or all age ranges.	Thank you for your comment. The table you are commenting on is included just to identify where recommendations have been amended from the previous version of the guideline. The guideline committee prioritised outcomes that are commonly accepted as the most appropriate for determining ADHD symptom response. We

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			ll. 6 - 9	This means that 'improvement over baseline' by any treatment can never be scientifically established in any age group in any context, e.g. home, clinic or educational setting.	acknowledge your point though we do not think it prevents the committee from determining whether there were clinically meaningful differences between treatments/between a treatment and placebo in terms of overall effect on ADHD symptoms.
British Psychological Society	Short version + appendices	General	General	<p>The Society would recommend the following points in relation to the 2017 updated NICE guidance on ADHD and its treatment:</p> <ol style="list-style-type: none"> 1. We are concerned that the guidance is now recommending that stimulus-medication can be used as the first-line treatment for ADHD above the age of 5 years prior to psychological interventions prior to parent-training, CBT, behaviour management and systemic multi-agency work have been properly planned, executed and the outcomes measured. 	<p>Thank you for your comments.</p> <p>Comments 1 and 3</p> <p>The recommendations are clear that ADHD-focused group parent-training programme to parents or carers is first-line treatment for children under 5 years with ADHD. The other recommendation specifically directed at children under 5 years is about obtaining specialist for advice. The committee do not believe these recommendations will result in increased prescribing in the under 5 age group as any other treatment decisions in this age group would be made under the care of a</p>

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				<p>2. There is implication that more females – children and adults - require an ADHD diagnosis and treatment because they are 'missed' by clinicians. We believe that this is a statistically spurious argument and ethically questionable in terms of the safeguarding agenda.</p> <p>3. The Society is concerned that the guidelines state that under-5s can be more routinely diagnosed as having ADHD and prescribed stimulant-medication such as methylphenidate (Ritalin) contrary to manufacturer's licences and guidance. We believe that psychological interventions such as parent-training, CBT, behaviour management and systemic multi-agency work should always be used first. This will better safeguard the under-5 child population.</p> <p>4. The Society is concerned that ethical considerations of ADHD diagnosis and treatment have not been discussed in this guidance. The symptoms of ADHD are</p>	<p>specialist. The committee discussed at length the pharmacological treatment of children under 5 years and agreed with consensus although unusual there could be exceptional situations where medication was appropriate (see the committee's discussion of the evidence in the evidence report C). The 2008 guideline did not recommend drug treatment but also did not go as far as to tell prescribers never to prescribe drug treatment, also allowing for these exceptional situations. After noting the stakeholder comments the committee agreed to add recommendation clarifying that medication should only be prescribed in this age group when a second opinion from a specialist ADHD service with expertise in ADHD in young children (ideally tertiary) has been obtained.</p>

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				<p>behavioural (hyperactive behaviour, impulsive behaviour, inattentive behaviour). The use of medication to control, change and/or manage the autonomous social-behaviour of children and young people – particularly when the behaviour is not causing the medicated person distress – is ethically contentious and can be viewed as impinging on children's and young people's basic human rights. What constitutes properly informed consent and involvement in decision-making is also ethically contentious and particularly impinges on the safe-guarding of children and young people.</p>	<p>Comment 2.</p> <p>The committee disagree there is an implication that more females require an ADHD diagnosis. The recommendation does highlight that ADHD may be under-recognised in girls and women and that they are less likely to be referred for assessment for ADHD, more likely to have undiagnosed ADHD and more likely to receive an incorrect diagnosis of another mental health or neurodevelopmental condition. Referral as a result of raised awareness from this guideline should result in women and girls receiving the right diagnosis as soon as possible and the appropriate support for ADHD. The committee's discussion of the evidence in Evidence report A gives further details of</p>

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					<p>the committee's discussion on the under recognition of ADHD in girls and women.</p> <p>Comment 4.</p> <p>The committee agree that it is important to consider both pharmacological and non-pharmacological interventions to address ADHD symptoms and that there are important ethical considerations in this discussion. Overall the opinion of the committee was that there is sufficient evidence of a benefit of medication for children to justify the recommendations made here, which are to use medication but only when environmental modifications have failed to prevent symptoms from having a persistent impact on children and then to monitor regularly and consider whether or not there is an ongoing need for medication.</p>

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British Psychological Society	Short version + versions	General	General	The Society welcomed the Autism guidelines from 2013, in respect of promoting a multi-agency care-pathway for the diagnosis and systemic treatment of people with an autism spectrum condition and believes that this should not have been omitted in the current guidelines.	Thank you for your comment. The section on diagnosis was out of the scope of this update. The committee has endeavoured to promote multi-agency work throughout the recommendations included in this update.
Buzz Consulting	Short	24	1.7.19-24	I as a GP would like to ensure that 'Healthcare professionals' explicitly includes mental health nurses trained in caring for ADHD, and thus able to diagnose, prescribe, monitor and share care with GP, but oversee initiation of medication and annual follow up. There is no reason that a psychiatrist needs to do this for many ADHD patients, and without explicit statement, people will assume 'Health care professionals' 1.7.19 will be psychiatrists. Bracketed examples of others who can do this would be very beneficial for allowing future development of services). Waiting lists could be reduced dramatically for patient benefit.	Thank you for your comment. Healthcare professionals does include mental health nurses, the wording has been amended to reflect the key issue being expertise in ADHD.

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Buzz Consulting	Short	31	1.10.1	'An ADHD Specialist' should again be able to be a mental health nurse (appropriately trained), to allow for <u>annual</u> review not to require consultant psychiatrist review. Working to protocol, most nurses who are correctly trained in this field, would be able to do this annual review of medication, and thus free up the consultant psychiatrist for other, more complex, patients. The whole guideline needs to reflect the changing nature of the NHS workforce, and be crystal clear in stating that health care professionals can include appropriately trained nurses.	Thank you for your comment. The committee agree that an ADHD specialist is not limited to a consultant psychiatrist and could include nurse specialists who are correctly trained. Recommendation 1.1.3 that was not updated describes an ADHD specialist as someone who is an appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD. Using the term ADHD specialists reflects this rather than stating a professional role.
Citizens Commission on Human Rights (United Kingdom)	Short	General	General	The Citizens Commission on Human Rights (CCHR) in the United Kingdom is keen to submit a number of salient points to the consultation in view of the controversy that accompanies the diagnosis for ADHD. Having previously raised concerns with NICE about the unscientific nature of ADHD, it is acknowledged that this is not an issue that NICE would take up.	Thank you for your comment. The section on diagnosis of ADHD was not updated in this guideline. The recommendations in the guideline on treatment options are based on the best available evidence. All recommendations have been developed with an aim to improve the welfare of children in a clinically and cost effective manner. The evidence indicated that some parents and carers of children and young people

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				<p>There is however a fundamental inconsistency when addressing 'ADHD' and the associated difficulties with psychiatric drugs.</p> <p>While it cannot be denied that some children and adolescents experience difficulties in learning, and that some can be boisterous, argumentative or even disruptive, the taming of such difficulties with psychiatric drugs is frowned upon and could be considered chemical restraint.</p> <p>Physical tests are not available to provide empirical evidence for the existence of ADHD. No biological markers exist for the condition. It is therefore an anomaly to deploy biological interventions for what are essentially behavioural and emotional characteristics.</p> <p>It can be observed by teachers that chemical interventions can restrain an exuberant child or adolescent in an academic setting and could thus be considered efficacious. This could however be</p>	<p>aged 5 years and over can benefit from group support (see evidence reports B and E). After discussion of current good practice and consideration of the balance of benefits and costs, the committee decided to recommend offering additional support that could be group-based and is ADHD-focused (this may be as few as 1 or 2 sessions) for parents and carers of all children and young people with ADHD.</p> <p>Evidence showed the benefit of medication in this age group and this was in line with the committee's experience. The committee discussed at length the impact of the short term adverse effects of medication and acknowledged the concerns around the uncertainty about the long term effects. They particularly discussed the concerns about the impact of stimulants on growth. The committee</p>

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				<p>observed as sedation and should not and should never be the purpose for drugging young people.</p> <p>We are aware the draft consultation Committee will be viewing ADHD as an actual condition. The following information is therefore being submitted in regards to the well being of children and adolescents and from the viewpoint of protection.</p>	<p>noted that untreated ADHD can have long reaching negative impacts on a person's life.</p> <p>After taking this into account the committee agreed that medication offered a good balance of benefits and costs and the committee agreed to recommend this when ADHD symptoms are still having a persistent significant impact on at least one domain of everyday life after environmental modifications have been implemented (see committee's discussion of the evidence in the evidence report C).</p>
Citizens Commission on Human Rights	Short	General	General	<p><u>Psychiatric Drugs</u></p> <p>A number of recommendations were made by the United Nations Committee on the Rights of the Child (CRC) in 2016 that are directly relevant to and impact</p>	<p>Thank you for your comment. A number of your suggestions are outside of the remit of the guideline committee (for example, reassessing the diagnostic criteria for ADHD and ongoing monitoring of prescription rates). Other suggestions have been incorporated into the</p>

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(United Kingdom)				<p>upon some of the NICE proposed amendments published in September 2017.</p> <p>The proposed amendment to make psychiatric drugs a 'first line' treatment directly conflicts with the CRC recommendations.</p> <p>The United Nations CRC published the following on 12 July 2016:</p> <p style="padding-left: 40px;">"62. The Committee welcomes the publication by the National Institute for Health and Care Excellence of new guidelines for the diagnosing and management of attention deficit and hyperactivity disorder and related disorders. The Committee is, however, concerned that:</p> <p style="padding-left: 80px;">(a) The actual number of children that are given methylphenidate or other psychotropic drugs is not available;</p>	<p>recommendations. For example, the guideline recommends that before starting any treatment there is a full baseline assessment of any child and a full discussion about the likely benefits and harms of any treatment option.</p>

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				<p>(b) There has reportedly been a significant increase in the prescription of psychostimulants and psychotropic drugs to children with behavioural problems, including for children under 6 years of age, despite growing evidence of the harmful effects of these drugs.</p> <p>63. The Committee recommends that the State party:</p> <p>(a) Regularly collect data on the amount and regularity of psychotropic drugs (Ritalin, Concerta, etc.) being prescribed to children, and make the data transparent;</p> <p>(b) Ensure that the prescription of drugs is used as a measure of last resort and only after an individualized assessment of the best interests of that child, and that children and their parents are properly informed about the possible</p>	

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				<p>side effects of such medical treatment and about non-medical alternatives;</p> <p>(c) Establish a system of independent expert monitoring of diagnoses of or related to attention deficit and hyperactivity disorders, and undertake a study on the root causes of their increase, also aimed at improving the accuracy of diagnoses.”ⁱ</p> <p>It would appear the proposed NICE amendment would conflict with the UN CRC recommendations and we would ask the Committee to consider this matter and review its proposal.</p>	
Citizens Commission on Human Rights	Short	General	General	<p><u>Medication</u></p> <p>The BNF category 4.4 lists the CNS stimulants and drugs used for ADHD, which includes methylphenidate.</p>	Thank you for your comment. The recommendations in the guideline to use CNS stimulants are based on randomised controlled trials suggesting these drugs have clinically important benefit on ADHD symptoms. The committee agree that the evidence base has limitations and have

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(United Kingdom)				<p>Offering stimulant drugs to children and adolescents who are presenting with emotional and behavioural difficulties is paradoxical and irresponsible. It's a statement indicative of a pharmaceutical commercial objective rather than the resolution of difficulties that are affecting children academically or personally.</p> <p>There is no justification for the introduction of psychiatric drugs to resolve emotional and behavioural difficulties.</p> <p>There is every reason to carry out the full physical examination to find any undiagnosed physical condition that may be manifesting as so-called 'ADHD'. Again, if a physical condition was found and treated, and the person was no longer experiencing the difficulties associated with so-called 'ADHD', the doctor may be saving a person from a lengthy spell, is not a lifetime, of taking psychiatric drugs.</p>	<p>included recommendations on appropriate monitoring and the need for the review of ongoing requirement for medication. The committee agree that stimulants should not be considered before a full baseline assessment, including determining whether or not symptoms are having a persistent significant impact on a child, and before a full discussion of the likely benefits and harms of any treatment option. The recommendations also only consider medication after environmental modifications and, in the case of children, ADHD focused support, education and information on parenting strategies.</p>

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Citizens Commission on Human Rights (United Kingdom)	Short	General	General	<p><u>Addition to the Guidelines</u></p> <p>CCHR proposes an additional paragraph that would be in line with the above-mentioned UN CRC recommendations. This would be as follows:</p> <p style="padding-left: 40px;">1.10.4 NICE recommends to the government to regularly collect data on the amount and regularity of psychotropic drugs (Ritalin, Concerta, etc.) being prescribed to children, and make the data transparent.</p>	Thank you for your comment. This type of recommendation is outside of the remit of the guideline development process.
Citizens Commission on Human Rights (United Kingdom)	Short	4	15	<p><u>Management</u></p> <p>We fully acknowledge the problems experienced by children, adolescents and parents in connection with emotional and behavioural difficulties. The management of these difficulties has been responsible for a lot of the controversy surrounding 'ADHD'. One of the major divides concerning management has been the introduction of psychiatric drugs, some of which are pharmacologically similar to cocaine.</p>	Thank you for your comment. This guideline does reference the NICE guideline on Patient experience in adult NHS services: improving the experience of care for people using adult NHS services (CG138, see section 1.4 Information and support). The committee agreed that information related to both ADHD and its treatment should be tailored to the individual and their family or carers. The

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				<p>Regarding management, paragraph 1.5.4 of the draft consultation states the following:</p> <p>Before starting any treatment for ADHD, discuss the following with the person, and their family or carers as appropriate, encouraging children and young people to give their own account of how they feel:</p> <ul style="list-style-type: none"> the benefits and harms of non-pharmacological and pharmacological treatments (for example, the efficacy of medications compared with no treatment or non-pharmacological treatments, potential side effects and non-response rates) <p>When discussing the benefits and harms of treatments, a conflict of interest can arise. An independently compiled, easy-to-read summary of data would again be advantageous, so that the parents or the person themselves can make a fully informed choice about whether to agree to treatment or not. The</p>	<p>evidence did not support the use of any one particular method of providing information. Information should always be provided in a format suitable for each person and their family or carers.</p>

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				summary of data would not be assembled by those with vested interests, such as pharmaceutical companies who manufacture the drugs being prescribed.	
Citizens Commission on Human Rights (United Kingdom)	Short	7	22	<p><u>Recognition</u></p> <p>As noted above, there are no physical tests for 'ADHD' and there are no biological markers to recognise an abnormality. It would appear to be a subjective argument concerning under-recognition of 'ADHD' in girls and women.</p> <p>Paragraph 1.2.2 states the following:</p> <p style="padding-left: 40px;">Be aware that ADHD is thought to be under-recognised in girls and women and that they are:</p> <ul style="list-style-type: none"> - less likely to be referred for assessment for ADHD - more likely to have undiagnosed ADHD 	<p>Thank you for your comment. The first paragraph referenced is the recommendation agreed by the guideline committee.</p> <p>The second statement is from the rationale section explaining how the committee came to their conclusion (see the rationale and impact section of evidence report A). The committee made their recommendations based on consensus and their clinical experience. The recommendation and the statement are not contradictory.</p> <p>Women and girls were identified at the stakeholder workshop as a group that has been overlooked for a diagnosis of ADHD</p>

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				<ul style="list-style-type: none"> - more likely to receive an incorrect diagnosis of another mental health or neurodevelopmental condition. [2018] <p>With this in mind, a contradictory statement is included later in the draft consultation, which states:</p> <ul style="list-style-type: none"> - No evidence was found on the increased risk of missing a diagnosis of ADHD in girls. <p>The paragraph should therefore be reviewed and even deleted as it is ambiguous and misleading. It would be advantageous if the Committee considered the diagnostic criteria used in arriving at the conclusion a person has 'ADHD.' Controversy surrounds the diagnosis as the criteria are reflective of what are generally accepted as normal childhood characteristics and behaviour.</p> <p>This would also align with paragraph 63 (c) of the UN CRC recommendations to "Establish a system of independent expert monitoring of diagnoses..."</p>	<p>and this may be because girls with ADHD present with different symptoms.</p> <p>Referral as a result of raised awareness from this guideline should result in women and girls receiving the right diagnosis as soon as possible and the appropriate support for ADHD.</p>

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Citizens Commission on Human Rights (United Kingdom)	Short	11	21	<p><u>Support</u></p> <p>Since the diagnostic criteria for 'ADHD' reflect emotional and behavioural characteristics that are normal in children and adolescents, any structured discussions should be aimed at allowing the parents or the person themselves to make a fully informed choice. This should occur at the point of diagnosis rather than following the diagnosis.</p> <p>Regarding support, paragraph 1.4.4 of the draft states the following:</p> <p style="padding-left: 40px;">Following a diagnosis of ADHD, have a structured discussion with people (and their families or carers as appropriate) about how ADHD could affect their life. This could include:</p> <ul style="list-style-type: none"> • the positive impacts of receiving a diagnosis, such as: 	<p>Thank you for your comment. The scope for the update of this guideline did not include the section on diagnosis or prior to diagnosis: the recommendations are relevant to situations after a diagnosis has been made and accepted.</p>

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				<ul style="list-style-type: none"> - improving their understanding of symptoms - identifying and building on individual strengths - improving access to services • the negative impacts of receiving a diagnosis, such as stigma and labelling <p>Allowing the parent or the person to make a fully informed choice is imperative since the ramifications of accepting an 'ADHD' diagnosis are considerable, especially as it could result in the introduction of psychiatric drugs.</p> <p>We are in favour of support but this must occur prior to any diagnosis so that the parent or the person is made aware of the division of medical opinion that exists around 'ADHD.'</p> <p>We are also in favour of an independently compiled summary that can be presented to parents or the person themselves, that covers all aspects of the</p>	

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				diagnosis as well as the controversial nature of the diagnosis, which would then allow for a fully informed choice. This would also include information about the effects of psychiatric drugs that can be easily understood by any reader.	
Citizens Commission on Human Rights (United Kingdom)	Short	15	19	<p><u>Dietary Advice</u></p> <p>It is noted the draft consultation has attempted to make less of dietary factors that may affect emotion and behaviour. Paragraph 1.6.2 of the draft consultation states the following:</p> <p style="padding-left: 40px;">Do not advise elimination of artificial colouring and additives from the diet as a generally applicable treatment for children and young people with ADHD.</p> <p>Also of note, paragraph 1.6.4 states:</p> <p style="padding-left: 40px;">Do not advise or offer dietary fatty acid supplementation for treating ADHD in children and young people.</p>	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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				This should be removed from the draft consultation so that those who follow the guidelines are not misled into thinking that diet is not a contributory factor in the presentation of emotional and behavioural difficulties.	
Citizens Commission on Human Rights (United Kingdom)	Short	26	19	<p><u>Assessment</u></p> <p>If a child or adolescent is experiencing emotional or behavioural difficulties, they are referred for an assessment. Paragraph 1.7.2 of the draft consultation states the following:</p> <p>Before starting medication, people with ADHD should have a full assessment, which should include:</p> <ul style="list-style-type: none"> • a review to confirm they continue to meet the criteria for ADHD and need treatment • ... • a review of physical health, including: 	Thank you for your comment. The recommendation you have highlighted is not intended to look for underlying conditions that could manifest in a similar way to ADHD. This is a recommendation to assess the safety and appropriateness of starting medication. The current update of this guideline is also not covering diagnosis, which is where this issue you have highlighted would fit. The committee, along with topic experts and stakeholders during the scoping process, did not feel that there is evidence to indicate a need to assess for undiagnosed conditions, such as allergies. Other conditions such as these would be covered in other guidelines or policies.

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				<ul style="list-style-type: none"> - a medical history, taking into account conditions that may be contraindications for specific medicines - current medication - height and weight (measured and recorded against the normal range for age, height and sex) - baseline pulse and blood pressure (measured with an appropriately sized cuff and compared with the normal range for age) - an ECG if the treatment may affect the QT interval (for example, tricyclics and monoamine oxidase inhibitors). [2018] <p>While the assessment covers the basic information, there is a need for a more comprehensive assessment to find undiagnosed physical conditions that may be manifesting as a so-called mental disorder. By completing a battery of tests, undiagnosed physical conditions, when treated, could result in the resolution of the perceived difficulties.</p>	

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				<p>CCHR therefore proposes to add the following:</p> <ul style="list-style-type: none"> - “A full physical examination to find undiagnosed physical conditions which would include, but is not limited to the testing for allergies, as well as environmental factors that may be adversely affecting a person’s health. 	
Department for Education	Short	6 and 92	27-30	<p>Our comment relates to this text:</p> <p>“1.1.9 The Department for Education should consider providing more education to trainee teachers about ADHD by working with the Teaching Agency and relevant health service organisations to produce training programmes and guidance for supporting children with ADHD. [2008, amended 2018]”</p> <p>We would like this text to be removed, for three reasons:</p> <ul style="list-style-type: none"> • This is a guideline for an organisation that is not a Health body and it doesn’t seem to fit on 	Thank you for your comment. This recommendation has been removed.

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				<p>the context of this document. With the former guideline 1.5.2.3 you have decided to delete it because 'the guideline is directed at people providing services for the NHS' (see page 58). The same logic would seem to apply here.</p> <ul style="list-style-type: none"> • The recommendation was time-specific. The Department considered the guideline at the time. We have extensive arrangements for the training of teachers, including in relation to how to identify and meet the Special Educational Needs of pupils. For the guideline to remain will have no impact on those arrangements. • The legal framework around Special Educational Needs already imposes a range of duties on education providers, complemented by statutory guidance. So again, the guideline will not lead to any change in practice. 	
Department of Health				<p>Thank you for the opportunity to comment on the draft for the above clinical guideline.</p> <p>I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.</p>	Thank you for your comment.

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Faculty of Dental Surgery of Royal College of Surgeons of England	Short	12	25	Good to see recommendation for Individual information is tailored to needs of each person.	Thank you for this feedback.
Faculty of Dental Surgery of Royal College of Surgeons of England	Short	12	28	Excellent to see recommending opportunities for families and carers to discuss their concerns.....'and to be listened to and acted upon wherever possible'.	Thank you for this feedback.
Faculty of Dental Surgery of Royal College of	Short	13	11/12	Excellent to see that recommend advice is given on how ADHD affects person's functioning and that structure is important.	Thank you for this feedback.

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Surgeons of England					
Faculty of Dental Surgery of Royal College of Surgeons of England	Short	13	27	Value of feedback from schools and colleges to people with ADHD and their healthcare professionals – please include dental team within these health care providers.	Thank you for your comment. The term healthcare professionals is used to include all relevant specialties, including the dental team.
Faculty of Dental Surgery of Royal College of Surgeons of England	Short	14	13	Recommendation for healthcare providers to ensure continuity of care – this is so important and not always available in the dental situation. Families and children would benefit so much from continuing care with the same dental team.	Thank you for this feedback.
Faculty of Dental Surgery of	Short	14	25	Being involved in decision making – totally support this recommendation!	Thank you for this feedback.

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Royal College of Surgeons of England					
Faculty of Dental Surgery of Royal College of Surgeons of England	Short	17	7	Really good to see that a course of CBT should be considered.	Thank you for your comment.
Faculty of Dental Surgery of Royal College of Surgeons of England	Short	19	26	Have a full physical view of health – could include dental too?	Thank you for your comment. This information has been added to the committee's discussion of the evidence in evidence report D.

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Faculty of Dental Surgery of Royal College of Surgeons of England	Short	89	Table	Good to see Transition arrangements should be in place but this is so critical that it maybe could do with more emphasis?	Thank you for your comment. The table you are commenting on is included just to identify where recommendations have been amended from the previous version of the guideline.
Flynn Pharma Ltd.	3	108	9 (table 54)	The description provided in the text, Table 54: UK costs of ADHD drugs for children, indicates it contains drugs commonly used to treat ADHD in children. In May, 2016 Medikinet® XL had a market share of 19% (NHS PCA; May, 2016) making it a commonly used extended-release preparation of methylphenidate for the treatment of ADHD and as such, it should be included in table 54. This is particularly pertinent as using the methodology NICE have followed to complete the UK costs of ADHD drugs for children table, it demonstrates how a significant cost saving to the NHS over other extended-release preparations of methylphenidate (and lisdexamfetamine) may be	Thank you for your comment. Prices demonstrated in the guideline are based on the drug tariff prices. As advised by the NICE guidelines manual (https://www.nice.org.uk/process/pmg20/apter/incorporating-economic-evaluation), different brands of the same dose of drug are all the same price according to the drug tariff. While it is accepted that drug prices may vary depending on local arrangements, the drug tariff is used in the guideline as it is a published national

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				<p>achieved by careful selection of an extended-release methylphenidate preparation (with Medikinet® XL).</p> <p>Additional comments related to the table include:</p> <p>Inclusion of Medikinet® XL at low dose 20mg per day (£28.86 cost per pack of 30 – giving monthly and annual cost of £29.26 and £351.13 respectively) and high dose 60mg per day (£67.32 cost per pack of 30 – giving monthly and annual cost of £68.26 and £819.06 respectively) results in significant cost savings for the NHS (as suggested above).</p> <p>Given the availability of a 20mg preparation of Equasym® XL (with the respective cost of £30.00 for a pack of 30 – giving monthly and annual costs of £30.42 and £365 respectively), the decision to base the costs of Equasym® XL 20mg on taking x2 Equasym® XL 10mg capsules actively disadvantages and misleads as to the real cost of a 20mg preparation of extended-release methylphenidate; unless the</p>	<p>source thereby ensuring consistency in the prices that products are available for across the country.</p> <p>The recommendations do not name individual products. The costing tables have also been made clearer by only including the name of the drug itself and not any brand names so as not to name any particular branded product available.</p> <p>Costing illustrations have also been amended to a dose of once a day to fit in with licensing as stated, unless the drug tariff price was not available for a higher dose formulation in which case a smaller dose was used requiring more tablets.</p>

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				<p>recommendation is for the out of licence use of BD dosing.</p> <p>Dexamfetamine hasn't been shown as a range (high and low doses) only the maximum licensed dose of 20mg has been shown for cost comparison; it is not immediately clear why a range hasn't been shown. Whilst the BNF and Drug Tariff price for generic dexamfetamine have been indicated to be £24.75 for 28 tablets giving the monthly and annual figures shown, the branded generic product (Amfexa[®]) available at the time of compiling the table has been excluded from the cost analysis. This exclusion actively disadvantages dexamfetamine (as a class) in any price comparison of ADHD drugs. Amfexa[®] costs £19.98 for 30 tablets making the monthly and annual costs of 5mg of Amfexa[®] £20.17 and £242.00 (low dose) and £80.67 and £967.98 (high dose); as per the 10mg tablet shown. The exclusion of dexamfetamine as a standard treatment option in the draft guidance will make realising future cost savings by the NHS</p>	<p>A range of costs have been demonstrated for dexamfetamine and lisdexamfetamine as suggested for consistency. All dosing illustrations are also now taken from the BNF for consistency so that one source was used.</p>

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				<p>associated with generic price reductions difficult to achieve.</p> <p>With regard to lisdexamfetamine, it isn't immediately clear why only a single dose of this product is looked at in the price comparison table rather than the low and high dose approach used for other products, particularly given the prominent inclusion of this product within the guidelines will have implications for the cost of treating patients with ADHD, it would have been more appropriate to look at a low 30mg (giving pack, monthly and annual costs of £58.24 (28's), £59.05 and £708.59 respectively) and high 70mg (giving pack, monthly and annual costs of licenced doses of £83.16 (28's), £90.34 and £1084.05 respectively) doses of this product. Being aware of the range of costs is pertinent given the frequency of prescribing of the original presentations (30, 50 & 70mg) is reasonably consistent across the dose range</p>	

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				and this allows fair and appropriate cost comparisons to be made across products.	
Flynn Pharma Ltd.	3	109	8 (table 55)	For any cost comparison it is important for that comparison to be fair to all products and produce an unbiased answer, comparisons should be based upon either the licensed dose range of the given product or guidance from an authoritative body such as the BNF. With this in-mind, it is not immediately obviously how the maximum dose of methylphenidate of 120mg per day was chosen or decided upon. This is significantly above the recommended licensed dosage of the products and outside of the range specified in the BNF (100mg). Using the calculations for monthly and annual costs the price of methylphenidate, following the guidance in the BNF (edition 73) would cost £ £55.36 and £664.30 respectively (based upon a pack of 30 x 20mg tablets costing £10.92); the decision to select 120mg as a maximum is also out of line with the recommendation to use other, extended-release,	<p>Thank you for your comment. For some drugs, the source of dosing was initially taken from RCTs identified in the clinical review. Where data on a drug was not available from the clinical review, the doses have been taken from the BNF. Based on your comments and acknowledging that RCTs may use high doses to show effectiveness, the BNF has been used for the source of all doses.</p> <p>The drug tariff prices have been used as is stated in the NICE guidelines manual, therefore reference to all branded products is not necessary because different brands of the same dose are the same price. While it is accepted that drug prices may vary depending on local arrangements, the drug tariff is used in the guideline as it is a published national source thereby ensuring</p>

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				<p>preparations of methylphenidate at lower maximal doses.</p> <p>The exclusion of Medikinet® XL from the analysis is unjustified as a commonly prescribed preparation of extended-release methylphenidate (19% of prescriptions NHS PCA data; May, 2016) and this exclusion has the effect of making extended-release preparations of methylphenidate 'appear' more expensive than it needs to be for the NHS (inclusion of Medikinet® XL at low dose 40mg per day £57.72 cost per pack of 30 – giving monthly and annual cost of £58.52 and £702.26 respectively).</p> <p>Dexamfetamine is presented as a single dose (40mg) for use in adults, a dose that whilst in-line with the maximum dosage in the BNF, is a dose that according to the label would only be used on occasion. The 40mg dosage used for the cost comparison unnecessarily doubles the cost of the medication. Forty milligrams is also double the mean dosage</p>	<p>consistency in the prices that products are available for across the country. The drug unit cost tables in the guideline have been updated and all references to brand names have been removed. The doses are based on the BNF, and ranges of costs for illustrative high and low doses have been used for all the main ADHD drugs (including dexamfetamine and lisdexamfetamine) for consistency.</p> <p>The costings are illustrations and are not an attempt to demonstrate cost of different products to reach equivalent effectiveness.</p> <p>Thank you for noting the error in the table. You are correct that the 10mg comes in packs of 30. This has been corrected and the cost also amended where this was an error.</p>

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				<p>prescribed in the UK NHS based upon average prescription size (PCA, 2016). It would represent a more balanced review of the data if, as for lisdexamfetamine, a range of doses and the associated costs was presented in the table.</p> <p>It is not apparent in the review as to how there is justification for requiring methylphenidate and dexamfetamine to be prescribed at above the maximum licensed dose and in some cases above the maximum recommended doses in the BNF whilst the maximum dose of Elvanse® listed is that from the SmPC. This becomes more perplexing as we consider the active ingredient for lisdexamfetamine is dexamfetamine (and lisdexamfetamine and dexamfetamine can be regarded as pharmacodynamically identical; EMA report 353952/2014 – 22nd May, 2014). When prescribing Elvanse® 70mg (lisdexamfetamine), the preparation contains 20.8 mg of active dexamfetamine base. This is considered an appropriate maximum dose of</p>	

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				<p>dexamfetamine base however when prescribing dexamfetamine sulfate, the authors believe they require approx. 29.2mg dexamfetamine base to achieve (what one assumes is) the same clinical response; approx. 30% more active which also reflects a significant increase in the apparent cost for using this product. This is an unfair and unjustified comparison.</p> <p>There is an error on the tablet volume as the 10mg tablets are supplied in packs of 30's.</p>	
Flynn Pharma Ltd.	6	92	30 (table 39)	<p>The description provided in the text, Table 39: UK costs of ADHD drugs for children, indicates it contains drugs commonly used to treat ADHD in children. In May, 2016 Medikinet® XL had a market share of 19% (NHS PCA; May, 2016) making it a commonly used extended-release preparation of methylphenidate for the treatment of ADHD and as such, it should be included in table 54. This is particularly pertinent as using the methodology NICE have followed to complete the UK costs of ADHD drugs for children</p>	<p>Thank you for your comment.</p> <p>Prices demonstrated in the guideline are based on the drug tariff prices. As advised by the NICE guidelines manual (https://www.nice.org.uk/process/pmg20/chapter/incorporating-economic-evaluation), different brands of the same dose of drug are all the same price according to the drug tariff. While it is accepted that drug prices may vary depending on local</p>

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				<p>table, it demonstrates how a significant cost saving to the NHS over other extended-release preparations of methylphenidate (and lisdexamfetamine) may be achieved by careful selection of an extended-release methylphenidate preparation (with Medikinet® XL).</p> <p>Additional comments related to the table include:</p> <p>Inclusion of Medikinet® XL at low dose 20mg per day (£28.86 cost per pack of 30 – giving monthly and annual cost of £29.26 and £351.13 respectively) and high dose 60mg per day (£67.32 cost per pack of 30 – giving monthly and annual cost of £68.26 and £819.06 respectively) results in significant cost savings for the NHS (as suggested above).</p> <p>Given the availability of a 20mg preparation of Equasym® XL (with the respective cost of £30.00 for a pack of 30 – giving monthly and annual costs of £30.42 and £365 respectively), the decision to base the costs of Equasym® XL 20mg on taking x2 Equasym® XL 10mg capsules actively disadvantages</p>	<p>arrangements, the drug tariff is used in the guideline as it is a published national source thereby ensuring consistency in the prices that products are available for across the country.</p> <p>The recommendations do not name individual products. The costing tables have also been made clearer by only including the name of the drug itself and not any brand names.</p> <p>Costing illustrations have also been amended to a dose of once a day to fit in with licensing as stated. If the drug tariff price was not available for a higher dose formulation a smaller dose was used but with more tablets.</p>

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				<p>and misleads as to the real cost of a 20mg preparation of extended-release methylphenidate; unless the recommendation is for the out of licence use of BD dosing.</p> <p>Dexamfetamine hasn't been shown as a range (high and low doses) only the maximum licensed dose of 20mg has been shown for cost comparison; it is not immediately clear why a range hasn't been shown. Whilst the BNF and Drug Tariff price for generic dexamfetamine have been indicated to be £24.75 for 28 tablets giving the monthly and annual figures shown, the branded generic product (Amfexa[®]) available at the time of compiling the table has been excluded from the cost analysis. This exclusion actively disadvantages dexamfetamine (as a class) in any price comparison of ADHD drugs. Amfexa[®] costs £19.98 for 30 tablets making the monthly and annual costs of 5mg of Amfexa[®] £20.17 and £242.00 (low dose) and £80.67 and £967.98 (high dose); as per the 10mg tablet shown. The exclusion of dexamfetamine</p>	<p>A range of costs have been demonstrated for dexamfetamine and lisdexamfetamine as suggested for consistency. In addition, all dosing illustrations are also now taken only from the BNF.</p>

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				<p>as a standard treatment option in the draft guidance will make realising future cost savings by the NHS associated with generic price reductions difficult to achieve.</p> <p>With regard to lisdexamfetamine, it isn't immediately clear why only a single dose of this product is looked at in the price comparison table rather than the low and high dose approach used for other products, particularly given the prominent inclusion of this product within the guidelines will have implications for the cost of treating patients with ADHD, it would have been more appropriate to look at a low 30mg (giving pack, monthly and annual costs of £58.24 (28's), £59.05 and £708.59 respectively) and high 70mg (giving pack, monthly and annual costs of licenced doses of £83.16 (28's), £90.34 and £1084.05 respectively) doses of this product. Being aware of the range of costs is pertinent given the frequency of prescribing of the original presentations (30, 50 & 70mg) is reasonably consistent across the dose range</p>	

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				and this allows fair and appropriate cost comparisons to be made across products.	
Flynn Pharma Ltd.	6	93	5 (table 40)	For any cost comparison it is important for that comparison to be fair to all products and produce an unbiased answer, comparisons should be based upon either the licensed dose range of the given product or guidance from an authoritative body such as the BNF. With this in-mind, it is not immediately obviously how the maximum dose of methylphenidate of 120mg per day was chosen or decided upon. This is significantly above the recommended licensed dosage of the products and outside of the range specified in the BNF (100mg). Using the calculations for monthly and annual costs the price of methylphenidate, following the guidance in the BNF (edition 73) would cost £ £55.36 and £664.30 respectively (based upon a pack of 30 x 20mg tablets costing £10.92); the decision to select 120mg as a maximum is also out of line with the recommendation to use other, extended-release,	<p>Thank you for your comment. For some drugs, the source of dosing was initially taken from RCTs identified in the clinical review. Where data on a drug was not available from the clinical review, the doses have been taken from the BNF. Based on your comments and acknowledging that RCTs may use high doses to show effectiveness, the BNF has been used for the source of all doses.</p> <p>The drug tariff prices have been used as is stated in the NICE guidelines manual, therefore reference to all branded products is not necessary because different brands of the same dose are the same price. While it is accepted that drug prices may vary depending on local arrangements, the drug tariff is used in the guideline as it is a published national source thereby ensuring</p>

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				<p>preparations of methylphenidate at lower maximal doses.</p> <p>The exclusion of Medikinet® XL from the analysis is unjustified as a commonly prescribed preparation of extended-release methylphenidate (19% of prescriptions NHS PCA data; May, 2016) and this exclusion has the effect of making extended-release preparations of methylphenidate 'appear' more expensive than it needs to be for the NHS (inclusion of Medikinet® XL at low dose 40mg per day £57.72 cost per pack of 30 – giving monthly and annual cost of £58.52 and £702.26 respectively).</p> <p>Dexamfetamine is presented as a single dose (40mg) for use in adults, a dose that whilst in-line with the maximum dosage in the BNF, is a dose that according to the label would only be used on occasion. The 40mg dosage used for the cost comparison unnecessarily doubles the cost of the medication. Forty milligrams is also double the mean dosage</p>	<p>consistency in the prices that products are available for across the country. The drug unit cost tables in the guideline have been updated and all references to brand names have been removed. The doses are based on the BNF, and ranges of costs for illustrative high and low doses have been used for all the main ADHD drugs (including dexamfetamine and lisdexamfetamine) for consistency.</p> <p>The costings are illustrations and are not an attempt to demonstrate the cost of different products needed to reach equivalent effectiveness.</p> <p>Thank you for noting the error in the table. You are correct that the 10mg comes in packs of 30. This has been corrected and the cost also amended where this was an error.</p>

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				<p>prescribed in the UK NHS based upon average prescription size (PCA, 2016). It would represent a more balanced review of the data if, as for lisdexamfetamine, a range of doses and the associated costs was presented in the table.</p> <p>It is not apparent in the review as to how there is justification for requiring methylphenidate and dexamfetamine to be prescribed at above the maximum licensed dose and in some cases above the maximum recommended doses in the BNF whilst the maximum dose of Elvanse® listed is that from the SmPC. This becomes more perplexing as we consider the active ingredient for lisdexamfetamine is dexamfetamine (and lisdexamfetamine and dexamfetamine can be regarded as pharmacodynamically identical; EMA report 353952/2014 – 22nd May, 2014). When prescribing Elvanse® 70mg (lisdexamfetamine), the preparation contains 20.8 mg of active dexamfetamine base. This is considered an appropriate maximum dose of</p>	

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				<p>dexamfetamine base however when prescribing dexamfetamine sulfate, the authors believe they require approx. 29.2mg dexamfetamine base to achieve (what one assumes is) the same clinical response; approx. 30% more active which also reflects a significant increase in the apparent cost for using this product. This is an unfair and unjustified comparison.</p> <p>There is an error on the tablet volume as the 10mg tablets are supplied in packs of 30's.</p>	
Flynn Pharma Ltd.	NICE CG72	34	General	Footnote 5 on page 34 of the current NICE Guideline 72 relating to the prescribing of methylphenidate and stimulant dose equivalents has been omitted. This is important information for the prescriber to be aware of how the different preparations of methylphenidate compare, and the clinical response they may expect if they switch between the 12-hour and 8-hour extended-release preparations. This is particularly important as there are now a number of branded generic versions of	Thank you for your comment. The current recommendation on pharmacological treatment refers only to methylphenidate and as you have noted there are an increasing number of branded generic versions of methylphenidate available. As another brand is introduced, this footnote becomes more out of date and inaccurate and disadvantages the newer brands. It was not in the remit of the committee to provide this very specific prescribing information. NICE expect that prescribers

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				12-hour extended-release methylphenidates available in the UK.	of any medication would be fully aware of the different preparations and the appropriateness to the person the drug is being prescribed for.
Flynn Pharma Ltd.	Short	21	6-7	The emphasis on using the most cost-effective treatments has been over-looked in the draft guideline by the non-inclusion of supporting information from the analysis of economic data reviewed on page 144 and page 152 of Evidence Review 3. These data indicate that use of Equasym® XL or Medikinet® XL represent cost savings being achievable for the NHS with the use of these products over the use of Concerta® XL, when an extended-release methylphenidate preparation is required.	Thank you for your comment. The recommendations do not state specific branded products to allow flexibility. The tables you refer to reflect that those economic evaluations specifically used those drugs in their comparison and so the extraction has also used the specific names, however there was a lack of clinical evidence comparing between different modified release preparations and so it was not felt specific names could be recommended.
Flynn Pharma Ltd.	Short	21	8	Positioning lisdexafetamine over dexamfetamine is inconsistent with current evidence summaries and given the costs of lisdexamfetamine (a branded patent protected medication) and dexamfetamine (available	Thank you for your comment. The recommendations in children to have lisdexamfetamine prior to dexamfetamine

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				<p>as generic and branded generic preparations) is a concern both clinically and from a cost effectiveness perspective. EMA report 353952/2014 – 22nd May, 2014 – Assessment Report For Dexamed (dexamfetamine sulfate) 5mg tablets and associated names. P6. notes as follows: 'Lastly, it is noted that lisdexamfetamine is an inactive prodrug which is absorbed to the bloodstream where it is gradually converted to dexamfetamine. lisdexamfetamine was recently approved in some Member States as part of a comprehensive treatment programme for ADHD in children aged 6 years of age and over when response to previous methylphenidate treatment is considered clinically inadequate. lisdexamfetamine and dexamfetamine can be regarded as pharmacodynamically identical, therefore to grant a marketing authorisation for dexamfetamine as second line ADHD treatment would be consistent with the recent approval of lisdexamfetamine for use in the same population.' An evidenced based review concludes these products are pharmacodynamically</p>	<p>in the sequence was down to more factors than just cost. There was one cost effectiveness analysis comparing lisdexamfetamine to atomoxetine to children with an inadequate response to methylphenidate which found lisdexamfetamine to be cost effective. As the doses are lower for children then there is less cost difference between lisdexamfetamine and dexamfetamine than in adults. However, the committee also took the clinical evidence (for example there were direct comparisons of methylphenidate and lisdexamfetamine in children) and their own experience into account, and felt that lisdexamfetamine is a pro-drug of dexamphetamine, and has a longer effect profile, and that the only situation in which they would recommend dexamphetamine would be when the person has responded very well to</p>

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				<p>identical and are therefore equally appropriate for use as second-line agents. 'Consensus' based upon current generic pricing is an unacceptable reason for the exclusion of dexamfetamine in preference to lisdexamfetamine in these guidelines.</p>	<p>lisdexamfetamine but is unable to tolerate its longer effect profile. Lisdexamfetamine is also a newer drug that was not available at the time of the previous guideline. The stigma of taking multiple doses a day of a short acting stimulant for example is another patient factor that was considered.</p>
Flynn Pharma Ltd.	Short	22	6-7	<p>It should be made clear that the recommendation for lisdexamfetamine is for <i>de novo</i> (new) adult patients and not for all patients over 18 years of age. It needs to be explicit in so far as those stabilised on methylphenidate as children (less than 18 years of age), as they transition into adulthood should be maintained on, assuming they are achieving appropriate benefit, their existing medication as they transition into adulthood and onwards. It should be noted not all preparations of methylphenidate are licensed for continued use into adulthood and the prescriber should be aware of preparations that are licensed for 'transition' use. This latter consideration</p>	<p>Thank you for your comment. This is stated in the licencing information detailed in the footnotes about lisdexametamine in the guideline.</p> <p>After taking into consideration the stakeholders' comments on this issue the committee agreed that methylphenidate should be included alongside lisdexamfetamine as an option for the first line medication treatment in adults</p>

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				may have implications for shared-care agreements put in-place with primary care groups.	
Flynn Pharma Ltd.	Short	40	13-15	The rising cost of dexamfetamine was cited as the rationale for the selection of lisdexamfetamine over dexamfetamine and indeed the near exclusion of dexamfetamine from the draft guidance. As a generic product, whilst the cost of dexamfetamine has gone up recently, costs can and do go down; indeed, there have been recent reductions in the Drug Tariff price of some presentations of dexamfetamine. The launch of a branded generic version of dexamfetamine sulfate (5mg; Amfexa [®]) has been omitted from the analysis; this product was available to the NHS at an approx. 25% reduction to the current Drug Tariff price. The apparent high costs are more due to tariff pricing rather than actual drug acquisition costs. It should also be noted that the Drug Tariff price for 10mg preparation of dexamfetamine sulfate (Amfexa [®]) has been updated and included in Evidence Reviews 3 and 6. By excluding a generic product with accepted	Thank you for your comment. The drug tariff is used for drug costs in NICE guidelines as stated in the NICE guidelines manual. This national source of drug costs is used for consistency as this is the cost at which products should be available for the whole country and the cost at which pharmacists are reimbursed. As mentioned in your comment, costs can change over time and, due to uncertainty in the availability and duration of the discounted prices, these prices are not used in NICE guidelines currently. Prescribers should aim to be cost conscious if differently priced generics are available.

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				<p>efficacy and long-term safety data to support its inclusion (dexamfetamine sulfate), the NHS is potentially going to be denied the opportunity to make cost savings in the future. Indeed, the potential for the NHS to realise potential cost savings is further exacerbated by the exclusion of dexamfetamine for the branded pro-drug (of dexamfetamine) lisdexamfetamine. This is particularly of note given the Department of Health, MHRA and NHS England are in the process of bring into place legislation to control the cost of generic medications moving forwards.</p>	<p>There were other factors as to why in children lisdexamfetamine was placed above dexamfetamine as well as cost; clinical evidence (for example there were direct comparisons of methylphenidate and lisdexamfetamine in children), and their own experiences - because lisdexamfetamine is a pro-drug of dexamphetamine, and has a longer effect profile. The committee agreed, based on consensus, that the only situation in which they would recommend dexamfetamine would be when the person has responded very well to lisdexamfetamine but is unable to tolerate its longer effect profile. The stigma of taking multiple tablets a day for ADHD is also a patient factor.</p> <p>For adults, there are fewer licensed products and current NICE practice is to</p>

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					recommend licensed products first where available and supported by the evidence.
Flynn Pharma Ltd.	Short	40	5-6	The document misses the statement out that there is proven clinical efficacy for dexamfetamine, the granting of a marketing authorisation is indicative of the efficacy of the medication. Further to this, recently dexamfetamine was reviewed by the EMA in an EMA report 353952/2014 dated 22 nd May, 2014 – Assessment Report For Dexamed (dexamfetamine sulfate) 5mg tablets and associated names. P6 of the report notes as follows: 'Lastly, it is noted that lisdexamfetamine is an inactive prodrug which is absorbed to the bloodstream where it is gradually converted to dexamfetamine. Lisdexamfetamine was recently approved in some Member States as part of a comprehensive treatment programme for ADHD in children aged 6 years of age and over when response to previous methylphenidate treatment is considered clinically inadequate. <i>Lisdexamfetamine and dexamfetamine can be regarded as</i>	Thank you for your comment. The recommendations in children to have lisdexamfetamine prior to dexamfetamine in the sequence, was down to many factors. The committee took the clinical evidence into account; for example, there were direct comparisons of methylphenidate and lisdexamfetamine in children, and their own experience, and felt that lisdexamfetamine is a pro-drug of dexamphetamine, and has a longer effect profile, and that the only situation in which they would recommend dexamphetamine would be when the person has responded very well to lisdexamfetamine but is unable to tolerate its longer effect profile. There was also one cost effectiveness analysis

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				<i>pharmacodynamically identical</i> , therefore to grant a marketing authorisation for dexamfetamine as second-line ADHD treatment would be consistent with the recent approval of lisdexamfetamine for use in the same population.' Given the EMA sees these products as therapeutically equivalent, it would be amiss and contradictory for NICE to fail to acknowledge their therapeutic equivalence.	comparing lisdexamfetamine to atomoxetine in children with an inadequate response to methylphenidate which found lisdexamfetamine to be cost effective. As the doses are lower for children, there is less cost difference between lisdexamfetamine and dexamfetamine than in adults.
Flynn Pharma Ltd.	Short	69	Box 3 of the table	'1.5.5.6 If there is a choice of more than one appropriate drug, the product with the lowest cost (taking into account the cost per dose and number of daily doses) should be prescribed' has been removed from the draft guidance and replaced with the comment 'This recommendation has been deleted because this is implicit in the cost effectiveness decision making'. Removal of this instruction is a concern for the NHS due to the flaws in the cost effectiveness evaluations carried out in Evidence Review 3, tables 54 and 55 and Evidence Review 6, tables 39 and 40 where a significant product	Thank you for your comment. The costs used in table 54 and 55 are for illustrative purposes. No specific brands are referred to in the recommendations, as the NICE guideline manual states that the Drug Tariff should be used for costs as this represents the costs that pharmacists will be reimbursed. Therefore, different generic branded products of the same drug for the same dose are reimbursed at the same price.

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				(Medikinet® XL) was omitted from the cost analysis and from the data reviewed on pages 144 and 152 of Evidence Review 3.	With regards to published economic evaluations that included Medikinet as an intervention, it is recognised in the health economic evidence statements that modified release methylphenidate was dominant compared to immediate release methylphenidate, and specifically that the Medikinet/Equasym strategy was dominant compared to methylphenidate Osmotic-Release Oral System (OROS). Specific branded products or a distinction between types of modified release preparations are not referred to in the recommendations beyond a distinction between 'short or long acting' (recommendation 1.7.7.7 for example) as this is leaving it up to the clinician and the patient to find the formulation that works for them.

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Neonatal and Paediatric Pharmacists Group (NPPG)	Short	General	General	NPPG welcomes the update to this standard.	Thank you for your comment.
Neonatal and Paediatric Pharmacists Group (NPPG)	Short	21-22	6-4	Recommendations 1.7.4 – 1.7.7 We welcome the clearer prioritisation of pharmacological interventions in the update of this standard.	Thank you for your comment.
Neonatal and Paediatric Pharmacists Group (NPPG)	Short	21	7	BNFC dose recommendations are for children ≥6 years. If the data supports use for children ≥5 years, we would recommend the experts collaborating with the BNFC to review the BNFC dosing recommendations in order to minimise confusion for prescribers.	Thank you for your comment. The committee made the recommendations for 5 years and over based on the decision on school age in England and Wales. There is limited evidence in this age group and the committee extrapolated from the published evidence. The footnotes in the guideline make the licensing status of the ADHD medications more explicit.

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Neonatal and Paediatric Pharmacists Group (NPPG)	Short	21	8	BNFC dose recommendations are for children ≥6 years. If the data supports use for children ≥5 years, we would recommend the experts collaborating with the BNFC to review the BNFC dosing recommendations in order to minimise confusion for prescribers.	Thank you for your comment. The committee made the recommendations for 5 years and over based on the decision on school age in England and Wales. There is limited evidence in this age group and the committee extrapolated from the published evidence. The footnotes in the guideline make the licensing status of the ADHD medications more explicit.
Neonatal and Paediatric Pharmacists Group (NPPG)	Short	21	11	BNFC dose recommendations are for children ≥6 years. If the data supports use for children ≥5 years, we would recommend the experts collaborating with the BNFC to review the BNFC dosing recommendations in order to minimise confusion for prescribers.	Thank you for your comment. The committee made the recommendations for 5 years and over based on the decision on school age in England and Wales. There is limited evidence in this age group and the committee extrapolated from the published evidence. The footnotes in the guideline make the licensing status of the ADHD medications more explicit.
Neonatal and Paediatric Pharmacists	Short	21	14	BNFC dose recommendations are for children ≥6 years. If the data supports use for children ≥5 years, we would recommend the experts collaborating with the BNFC to review the BNFC dosing	Thank you for your comment. The committee made the recommendations for 5 years and over based on the decision on school age in England and Wales. There is limited evidence in this age group and the committee extrapolated from the published

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s Group (NPPG)				recommendations in order to minimise confusion for prescribers.	evidence. The footnotes in the guideline make the licensing status of the ADHD medications more explicit.
Neonatal and Paediatric Pharmacists Group (NPPG)	Short	33	24-28	NPPG welcomes this research recommendation as data are lacking in this age group.	Thank you for your comment.
Northumberland, Tyne and Wear NHS Foundation Trust	short	18	2-4	It is not very clear what environmental modifications would exactly involve and hard to calibrate if these modifications have/not been achieved. Patients with ADHD are often classed non-CPA due to lower level of needs as compared to other SMIs, thus treating clinician being the sole/lead clinician for the patient in most cases. Suggesting this as a requirement to be met prior to medications will therefore be a challenge to ADHD services, with delaying treatment unnecessarily, increasing frustration to service users, influencing disengagement	Thank you for your comment. Further detail on environmental modifications has been added to the 'terms used in this guideline' section. The committee agree it is appropriate for these modifications to be in place and given adequate time for effect before medication is considered.

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				and add pressure on to services and resources due to delays in commencing treatment.	
Northumberland, Tyne and Wear NHS Foundation Trust	short	22	6	<p>We are concerned with the treatment suggestions, in particular Lisdexamfetamine being the first line treatment option. We have read reasons for this recommendation and have the following concerns</p> <ul style="list-style-type: none"> • Methylphenidate IR and XL versions have been regularly and successfully used in adults for ADHD for atleast last 9 years since the last NICE CG72, despite this being an unlicensed use. So why are we concerned about this now? There haven't been any substantial studies in this period which would raise concerns about this prescription. • IR MTP is an extremely effective, safe and cost effective option, so technically should still remain the first line option • Our clinical experience has not shown Lisdexamfetamine to be very effective in comparison to other stimulants, with significant 	<p>Thank you for your comment. After taking into consideration the stakeholders' comments on this issue the committee agreed that methylphenidate should be included alongside lisdexamfetamine as an option for the first line medication treatment in adults.</p>

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				<p>number of patients then choosing to try other MTP medication options and swapping over</p> <ul style="list-style-type: none"> • Bio-availability of this medication (maximum BNF doses) is low, when compared to equivalent doses of other stimulant medication options, thus raising concerns that this may not be effective enough for people with severe ADHD • In clinical practice, we find that best treatment engagement is obtained with a full discussion with the patient of available medication options, the pros and cons and using a person centred approach, rather than one size fits all approach. We are concerned that this recommendation is very restrictive, does not allow for patient choice and optimisation of clinician's experience in negotiating treatment options. • Lisdexamfetamine does have a role for some patients with ADHD, and we would welcome this as one of the options of treatment, and perhaps drug of choice for patients with history of substance misuse and for patients who may have been treated with Adderall in the past. 	

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				<ul style="list-style-type: none"> A considerable number of our existing patients are already stable and well established on non-Lisdexamfetamine medications. We are concerned that this recommendation may cause unnecessary angst among service users and clinicians alike, destabilise existing treatment packages and further add pressure to existing resources that are already stretched. (We will be prepared to attach information about prescription costs and prescribing practice for our service upon request). 	
Northumberland, Tyne and Wear NHS Foundation Trust	short	31	3	Suggestion of ADHD specialist review atleast annually causes considerable challenge to the service resources. Our service has a case load of higher than 1400 with high referral rates (referrals of approximately 25/week). Continuing to provide the annual review longer term indefinitely without an exit strategy to discharge patients to primary care, will cause huge challenges to existing service provision. We do not anticipate any increased funding arrangements for our service in the future, and without the throughput, we	Thank you for your comment. Section 1.1 was not included in this update of the guideline and the recommendations supporting shared care arrangements with primary care remain in the guideline. Section 1.10 is clear that an ADHD specialist should review ADHD medication at least once a year. The other recommendations on the monitoring and maintenance of treatments in section 1.8 are not as specific about who should be responsible and the committee recognise

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				<p>may not be able to provide assessments and treatments for undiagnosed patients in the community. We have very long waiting lists (of more than 12 months), and this will cause huge pressures further on the waiting lists. We believe that our service is not unique in regards to all of these issues.</p> <p>Would the NICE be able to recommend discharge to primary care after 2/3 years of stability within specialist services as a reasonable mid-point?</p> <p>Training of primary care and robust liaison arrangements with secondary services for trouble-shooting purposes may be a reasonable recommendation to ensure smooth and safe transition of patients between services.</p>	<p>there are different service models in and this could be undertaken in primary care. The committee discussed that it was important that specialist services remained aware of people with ADHD so they could have rapid access back to the services in time of crises.</p> <p>The committee's discussion of the evidence in evidence report D and H provide further detail about the committee's experience of good practice in monitoring. Further discussion on the committee's recommendations about shared care arrangements have been added to the "Why the committee made these recommendations" section of evidence report H. The committee agreed that it was important for people still on ADHD medication to be reviewed at least once a year to consider primarily whether they still need to continue the medication. If medication can be stopped, this may well</p>

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					be an opportunity to reduce the need for further appointments with either primary or secondary care.
Northwest Boroughs Healthcare NHS Foundation Trust				Regarding choice of medications, Elvanse (lisdexamphetamine) has been proposed as first line. As clinicians working in adults with ADHD we feel that Elvanse should be at par with other stimulant medication options (modified release or immediate release methylphenidate) and not necessarily ahead as 'first line'.	Thank you for your comment. After taking into consideration the stakeholders' comments on this issue, the committee agreed that methylphenidate should be included alongside lisdexamfetamine as an option for the first line medication treatment in adults.
Northwest Boroughs Healthcare NHS Foundation Trust				There should be further emphasis on timely transition of patients between paediatric and CAMHS services to adult services with comments on an acceptable waiting time.	Thank you for your comment. Transition to adult services is referred to in the service organisation section of the guideline.
Northwest Boroughs Healthcare				Needs further emphasis on providers being able to offer psychosocial interventions.	Thank you for your comment.

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NHS Foundation Trust					
Planet Autism	[A] Evidence reviews for risk factors for ADHD	06/07/17	23 (PICO table)	<p><i>("Prognostic variables under consideration" • females* *Only missed diagnosis outcome to be extracted for gender risk, as increased prevalence in boys/men compared to girls/women is an accepted aspect of ADHD epidemiology and not priority for this review)</i></p> <p>It is of great concern that there is a widespread lack of recognition of female ADHD presentation. It results in clinical ignorance which leads to missed diagnosis. It is very similar to the situation with ASD, whereby an assumption, which is now thankfully being challenged, that there is a male preponderance of the condition means that many females remain undiagnosed and struggling. Research will show that there is no gender</p>	<p>Thank you for your comment. The committee agrees that correctly identifying ADHD in girls and women is an important and complex matter. The recommendation on raising awareness about the under recognition of ADHD in girls and women should help to address this inequality.</p> <p>The recommendation does highlight that ADHD may be under-recognised in girls and women and that they are less likely to be referred for assessment for ADHD, more likely to have undiagnosed ADHD and more likely to receive an incorrect diagnosis of another mental health or neurodevelopmental condition.</p>

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				<p>disparity, there are an equal number of males and females.</p> <p>Saying 'it is an accepted aspect of ADHD epidemiology' rules out discussion or investigation of the issue of females being undiagnosed and this directly impacts the guidance. There is seemingly increased recognition of this issue in the USA and the UK needs to become part of this recognition process. Here is a wealth of information regarding females with ADHD:</p> <p>Females are much more likely to mask their ADHD in settings such as school making them harder to recognise:</p>	<p>The committee's discussion of the evidence in Evidence report A gives further details of the committee's discussion on the under recognition of ADHD in girls and women.</p> <p>The study you reference (a narrative review of the field) did not meet the inclusion criteria of the review which sought quantitative evidence on the occurrence of missed diagnoses in women and girls.</p> <p>The line you reference is from the protocol and is included to shape the evidence</p>

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				<p>http://adhd-edu.be/Web/index.php?toPage=Mjl=</p> <p>"Children and adolescents with masked AD/HD include the following:</p> <ul style="list-style-type: none"> • Boys with inattentive type AD/HD. • Girls with all types of AD/HD. • Boys and girls with borderline AD/HD and another condition or conditions. • Girls and boys with a learning disability and/or another condition on the autistic spectrum who also have AD/HD. • Gifted girls and boys with AD/HD." <p>http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4195638/</p> <p><u>"A Review of Attention-Deficit/Hyperactivity Disorder in Women and Girls: Uncovering This Hidden Diagnosis"</u></p>	<p>review: it is not a recommendation or definitive statement.</p>

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				<p><i>"Results: Attitudes about ADHD among individuals with ADHD and knowledgeable informants (families, teachers, colleagues) vary on the basis of the diagnosed individual's gender. The ADHD prevalence rates are higher among boys than girls. A low index of clinical suspicion exists for girls; their presentation is considered "subthreshold" because inattentiveness is more prominent than hyperactivity/impulsivity. Females with ADHD may develop better coping strategies than males to mask their symptoms. Lastly, anxiety and depression, common comorbidities in female patients with ADHD, can lead to missed or misdiagnosis. If not properly diagnosed and treated, girls with ADHD experience the same negative consequences as boys, including poor academic performance and behavioral problems. Unique issues related to hormonal effects on ADHD expression and treatment response are also experienced by women and girls.</i></p> <p><i>Conclusions: Accurate ADHD diagnosis in women and girls requires establishing a</i></p>	

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				<p><u>symptom history and an understanding of its gender-specific presentation. Coexisting anxiety and depression are prominent in female patients with ADHD; satisfactory academic achievement should not rule out an ADHD diagnosis."</u></p> <p><u>http://www.additudemag.com/adhd/article/1626.html</u> (interview with Patricia Quinn, M.D., director of the National Centre for Gender Issues and ADHD & Sharon Wigal, Ph.D., associate clinical professor of pediatrics at the University of California)</p> <p><u>http://www.additudemag.com/adhd/article/740.html</u> (interview with Fred Reimherr, M.D., director of the University of Utah Mood Disorders Clinic)</p> <p><i>"Underdiagnosis of ADD in women has its roots in childhood. Girls with ADD tend</i></p>	

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				<p><i>to try harder than their male counterparts to compensate for and cover up symptoms. To keep up their grades, girls are often more willing to put in extra hours of studying and to ask their parents for help.</i></p> <p><i>In addition, girls are more likely to be "people pleasers," doing all they can to fit in—even when they know they are "different."</i></p> <p><i>http://www.thewire.com/national/2013/04/its-different-girls-adhd/63746/ (Dr Ellen Littman, clinical psychologist, author of <i>Understanding Girls with ADHD</i>)</i></p> <p><i>"ADHD does not look the same in boys and girls. Women with the disorder tend to be less hyperactive and impulsive, more disorganized, scattered, forgetful, and introverted. "They've alternately been anxious or depressed for years," Littman</i></p>	

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				<p><i>says. "It's this sense of not being able to hold everything together."</i></p> <p>http://www.science20.com/science_motherhood/girls_add_why_it_so_ofen_missed</p> <p><i>"A girl with ADD has fewer learning problems in early grades than her male counterparts. Boys often get diagnosed through evaluation of learning problems. Girls with ADD, especially those with high intelligence, may actually be good students and/or well-behaved - and as a result raise absolutely no alarms that anything may be amiss."</i></p> <p>http://qz.com/592364/decades-of-failing-to-recognize-adhd-in-girls-has-created-a-lost-generation-of-women/?utm_source=FBP011916_1</p> <p><i>"Unlike boys, many of whom show hyperactivity, girls' symptoms veer more toward inattentiveness and disorganization. Girls tend to develop ADHD later than boys."</i></p>	

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				<p><i>They frequently mask it in an attempt to conform to society's expectation that they be on the ball and organized.</i> <i>"research is almost exclusively focused on boys (1% is specific to girls, Littman says)."</i></p> <p>http://www.addiss.co.uk/ADHDNews20.pdf</p> <p>"Adolescent girls with ADHD Suffering in Silence by Dr Nikos Myttas"</p> <p><i>"Girls of this type daydream more, appear passive and academically withdrawn, are shy, timid and easily overwhelmed, they rarely act out, they may have difficulty verbalising their thoughts and feelings, they can be easily discouraged and may appear "sluggish" and lethargic. These girls are often more conscientious and guilt-ridden and they work harder in order to hide their academic difficulties and to conform to their teachers' and parents' expectations. They come to the attention of mental health services later than</i></p>	

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				<p><i>boys and they are more likely to be diagnosed as anxious and/or depressed (Biederman et al, 1994). Despite numerous discussions for a need to have gender-based diagnostic criteria for ADHD, mental health professionals continue to rely on behaviour criteria that better identify disruptive boys.</i></p> <p><i>Many adolescent girls with ADHD anxiously comply, sometimes obsessively, to these expectations in an attempt to gain some acceptance and respect from their family and teachers, so as to compensate for the disappointments they experience in their peer group. They may try hard to be fashionable and well dressed, but they are let down by their inability to organise their rooms and life so as to have, and be able to find in the chaos of their room, clean and colour-coordinated clothes on school mornings so they can avoid the sneers and caustic remarks coming from</i></p>	

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				<p><i>their peers. The self-doubts, competitiveness, abruptness and irritability so common among adolescent girls are often more intense for girls with ADHD. They get much more easily hurt and these painful feelings can rapidly escalate into impulsive remarks, verbal or physical over-reactions. However, as soon as the drama is over and the curtain has fallen, they are often ready to forgive and forget. Following the storm, they behave as if nothing has happened and they are surprised and bewildered when those they have stung with their comments remain bruised and intolerant of further temper explosions."</i></p> <p>https://www.additudemag.com/add-in-women/</p> <p>"ADHD Is Not a Male Disorder</p> <p>ADHD impacts both genders equally, but outdated stereotypes leave too many women undiagnosed and feeling hopelessly ditzy, dumb, or depressed. The fact is that ADHD looks different in girls, and many</p>	

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				<p><i>clinicians still don't know that, which is irresponsible at best and dangerous at worst."</i></p> <p>https://www.additudemag.com/adhd-in-girls-women/?utm_source=eletter&utm_medium=email&utm_campaign=august&utm_source=ADDitude+Master+List&utm_campaign=1b91983513-EMAIL_CAMPAIGN_2017_08_25&utm_medium=email&utm_term=0_d9446392d6-1b91983513-289819149&mc_cid=1b91983513&mc_eid=7861ef0880</p> <p><i>"Late Diagnosis, Little Treatment: What ADHD Looks Like in Girls and Women</i></p> <p><i>Many young girls and women with ADHD — most with inattentive symptoms — are being drowned out by loud, hyperactive boys who demonstrate the condition's stereotypical behavior. Learn how to recognize symptoms and turn around this unfair unbalance for your daughter or yourself."</i></p>	

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				<p>http://www.yakimaherald.com/lifestyle/health/delayed-adhd-autism-diagnoses-can-hurt-girls/article_30496b38-3755-11e6-8999-d35804dd680e.html</p> <p><i>"Delayed ADHD, autism diagnoses can hurt girls"</i></p> <p><i>Therefore it is vital that the NICE guidance makes a clear statement on females with ADHD and ADD to avoid this group continuing to be overlooked and underdiagnosed.</i></p>	
Royal College of General Practitioners		General	General	Overall it appears informative and useable. It would be useful to have more detailed guidance on the monitoring of medication. What aspects could be done primary care? Could this guideline suggest a check list for the 6 month and 12 month reviews?	Thank you for your comment. The committee are unaware of any existing checklist. The committee considered providing more detailed guidance but concerns were raised that the information could rapidly become out of date, In addition the committee were aware of the variation in local arrangements and the difficulty in selecting specific practices to highlight. After taking this into account they

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					committee were unable to set out more detailed guidance on monitoring.
Royal College of General Practitioners	Short	5	6-21	Consider updated section 1.2.1 to include the study showing that people with EDS also have a relative risk of ADHD of 5.6 compared with matched comparison individuals, at least in the Swedish population. https://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-016-0922-6	Thank you for your comment. The committee did not prioritise Ehlers–Danlos syndrome as a condition of interest for assessment in terms of ADHD risk. Please see the protocol for this review for the full list of conditions considered.
Royal College of General Practitioners	Short	8	16-19	Is there a standardised tool primary care practitioners should use to determine severity and extent of pervading different domains and settings? If recommendations are made according to whether symptoms are mild/moderate/severe there must be an objective and universally used tool to guide categorisation.	Thank you for your comments. The committee are unaware of a tool and agree this is an important area of research and have made an additional research recommendation on this topic.
Royal College of General	Short	9	22-23	What are the definitions for moderate or severe impairment?	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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Practitioners					
Royal College of General Practitioners	Short	15	9	Need a stronger phrase as well as side effects to reflect seriousness of some biological effects e.g. stunted growth.	Thank you for your comment. The committee think the current wording is appropriate taking into account the evidence base identified on adverse effects of medication and their clinical experience.
Royal College of General Practitioners	Short	18	4	Environmental modifications specified anywhere.	Thank you for your comment. Environmental modifications are defined in, 'terms used in this guideline section' and additional detail and example of modifications have been added.
Royal College of General Practitioners	Short	21	8-10	It would be helpful to have timescale specified for adequate response – also what is considered adequate x% reduction in symptom intensity/frequency? Or just patient report?	Thank you for your comment. No evidence was identified to support a specific time point and the 6-week trial decision was based on the committee's experience and agreed through consensus. The committee agree that it is difficult to generalise and to define a specific time

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					<p>point. All treatment decisions should be made with the person taking medication and take into account how they feel the medication is having an impact on their ADHD symptoms. The committee agreed that 6 weeks is enough time to optimise the medication and to know if it is reducing any impairment. Six weeks allows the time to titrate medication and to avoid rapid decision making in changing medication but equally is not a prolonged time on a medication that may not be effective. There is additional information in the initiation and titration section of the guideline.</p> <p>The committee also agree the assessment of response is challenging. The committee noted that it is important that any treatment decision is made with the person taking the medication. It is important that the clinician has a good relationship with the person</p>

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					and can assess their change in symptoms and impairment relative to the baseline. For this reason, the committee did not consider it was possible to include more generic recommendations on this topic: further text has been added to the committee's discussion of the evidence section in evidence report C.
Royal College of General Practitioners	Short	22	8-9	It would be helpful to have timescale specified for adequate response – also what is considered adequate x% reduction in symptom intensity/frequency? Or just patient report?	Thank you for the comment. No evidence was identified to support a specific time point and the 6-week trial decision was based on the committee's experience and agreed through consensus. The committee agree that it is difficult to generalise and to define a specific time point when to consider switching to different medications. All treatment decisions should be made with the person taking medication and take into account how they feel their medication is having an impact on their ADHD symptoms. The judgement of response and persistent

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					<p>significant impairment is challenging and has to be done on an individual basis in discussion with the person with ADHD. It is important the clinician has a good relationship with the person and can assess their change in symptoms and impairment relative to the baseline.</p> <p>There is additional information in the dose titration section of the guideline.</p>
Royal College of General Practitioners	Short	23	16-17	How can diversion for cognitive enhancement be monitored/managed especially in primary care? Many of the adult patients with ADHD, Gps are looking after, have been put on medication in other countries or by private doctors – there is very little evidence that they ever met diagnostic criteria but they can't do their high functioning jobs without it. This can potentially put considerable financial pressures on the NHS budget and resources.	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so the committee are unable to make any recommendations.
Royal College of	Short	24	6-7	There is a need to specify appropriate timescale for trial of behavioural interventions and some way of	Thank you for your comment. The committee agree that timescale for

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General Practitioners				assessing fidelity of the intervention – was it attempted but not completed? If so were resources available to support full implementation, especially for parents.	assessment and fidelity of interventions are important issues; however, it is not possible to make generalised recommendations on these topics given the wide range of interventions that may be offered.
Royal College of General Practitioners	Short	42	1-15	Whilst some of atomoxetine side effects are specified it would be useful for the guideline to specify which side effects relate to which medication.	Thank you for your comment. The side effects that are specific to any one drug or drug class are made explicit in the recommendations.
Royal College of Nursing		22-Onwards		We have received no adverse comments from our members regarding the medication discussed	Thank you for your comment.
Royal College of Nursing	1.1	4	13-22	It is essential that there are effective services for all age groups and a particular difficult period is transition. We welcome that integration is mentioned and this needs to be a must do as currently not a consistent provision.	Thank you for your comment.

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Royal College of Nursing	1.1	5	8	We agree that having a multi-agency group in each area is important to oversee implementation of these guidelines. Funding will also need to be provided to facilitate the training recommendations of this guideline.	Thank you for your comment.
Royal College of Nursing	1.1	6	27	We welcome ensuring appropriate education for teachers and wider team.	Thank you for your comment.
Royal College of Nursing	1.2	8	23	May be better to say 'no more than 10 weeks' as a delay longer may cause issues and may be beneficial that support within this period may be required especially for families in crisis.	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.
Royal College of Nursing	1.3	(General)	20	We welcome physical assessment being raised and feel this is an important as often contributing elements. Public health and life style assessment should be included with appropriate early intervention.	Thank you for your comment.

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Royal College of Nursing	General			Overall we are supportive of these updated guidelines and they appear concise and supportive of a holistic and multi-disciplinary approach	Thank you for your comment.
Royal College of Occupational Therapists	Short	18	14-16	<p>"1.5.17 When non-pharmacological treatment is indicated for adults with ADHD,</p> <p>offer the following as a minimum:</p> <p><input type="checkbox"/> a structured supportive psychological intervention focused on ADHD"</p> <p>There are other interventions which can support adults with ADHD including occupational therapy. Could this recommendation be altered to state "a structured supportive intervention focused on ADHD" so that a multi-professional approach may be considered?</p>	Thank you for your comment. The clinical and cost effectiveness for the non-pharmacological treatments did not identify any one treatment or any components that the committee could confidently recommend for treatment. The minimum requirement of, 'a structured supportive psychological intervention focused on ADHD" allows for flexibility and does promote a multi-professional approach.
Royal College of Occupation	Short	32	2-4	"Environmental modifications	Thank you for your comment. The committee agree that the social environment is important but were unable

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al Therapists				<p>Changes that are made to the physical environment, for example, changes to seating arrangements at school, changes to lighting and to noise.”</p> <p>Should this definition be extended to the social environment? Changes made to the attitudes and perceptions of people (e.g. in the school or work setting) through education programmes can have a significant impact on the ability and functioning of children and adults.</p>	<p>on the basis of the topics and the evidence they had reviewed to make a recommendation in this area.</p>
Royal College of Occupational Therapists	Short	32	5	<p>“Recommendations for research”</p> <p>There are other non-pharmacological approaches to supporting people with ADHD which go beyond psychological interventions (e.g. occupational therapy – see example references below). An additional research recommendation to consider the viability of alternative forms of intervention would support a multi-professional approach to supporting people with ADHD.</p>	<p>Thank you for your comment. The committee agreed that there are other non-pharmacological approaches to supporting people with ADHD and the evidence review (see evidence report E) searched for this information to support the committee's decision making. The committee recommends a structured supportive psychological approach as a minimum and does not exclude other non-pharmacological treatments. The committee have noted the lack of good</p>

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				<p>Soraya Gharebaghy, Mehdi Rassafiani & Debra Cameron (2015) Effect of Cognitive Intervention on Children with ADHD, Physical & Occupational Therapy In Pediatrics, 35:1, 13-23</p> <p>To link to this article: http://dx.doi.org/10.3109/01942638.2014.957428</p> <p>Wilkes-Gillan, Sarah & Bundy, Anita & Cordier, Reinie & Lincoln, Michelle. (2014). Eighteen-month follow-up of a play-based intervention to improve the social play skills of children with attention deficit hyperactivity disorder. Australian Occupational Therapy Journal. 61. . 10.1111/1440-1630.12124.</p>	<p>quality evidence in the area of non-pharmacological treatments and the need for further research without specifying one intervention. The studies you reference did not meet the protocol for inclusion in the relevant evidence reviews in this guideline. The committee have made research recommendations on interventions they considered worthy of further study that did not currently have a sufficient evidence base to warrant recommendations (see the evidence reports for more information).</p>
Royal College of Paediatrics and Child Health	Short version	General	General	<p>We would like to compliment the GDG on producing an overall extremely balanced and useful Guideline.</p> <p>The biggest challenge to services for children and young people with ADHD is the still increasing number of referrals and complexity of patients being seen. Current services are already under strain. This is not</p>	<p>Thank you for your comments. The committee recognise that the recommendation raising awareness of ADHD in certain populations may result in an increase in referrals to specialists. However, the committee agreed that many of the people that will be referred as result of this guideline will have been given an</p>

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				<p>due to over diagnosis overall as the expected prevalence has not been reached.</p> <p>The increased awareness and e.g. the section on Risk Factors is welcome, however it must be recognised that this could increase referrals and complexity still further.</p> <p>After diagnosis most children/YP need ongoing monitoring which means more follow up appointments.</p> <p>The role of primary care in monitoring is not discussed fully or the roles of different team members. Nationally we have many different service models and some case examples of good practice would be helpful to clinicians and commissioners.</p>	<p>alternative diagnosis or would have received a late diagnosis of ADHD. They are likely to be already accessing services. Referral as a result of raised awareness from this guideline should result in people receiving the right diagnosis as soon as possible and the appropriate support for ADHD.</p> <p>Section 1.1 was not included in this update of the guideline and the recommendations supporting shared care arrangements with primary care remain in the guideline. Section 1.10 is clear that an ADHD specialist should review ADHD medication at least once a year. The other recommendations on the monitoring and maintenance of treatments in section 1.8 are not as specific about who should be responsible and the committee recognise there are different service models and this could be undertaken in primary care. The section, 'Other factors the committee took into account' in evidence report H</p>

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					provide further detail about the committee's experience of good practice in monitoring. Further discussion on the committee's recommendations about shared care arrangements have been added to the "Why the committee made these recommendations" section of evidence report
Royal College of Paediatrics and Child Health		Page 56	7 onwards	Again: This is clumsy and repetitive and could be condensed without losing all the relevant point	Thank you for your comment. This wording refers to the table detailing the changes from the last guideline. This is a recommendation that has been deleted.
Royal College of Paediatrics and Child Health	1.4.4	12	2	Need to clarify that inattention, as well as medication, might impact on driving: otherwise a risk that young people might come off medication in an attempt to improve their driving or chance of getting a licence!	Thank you for your comment. The wording of this recommendation has been amended to clarify that driving may be affected by ADHD symptoms. The committee has added 'and ADHD medication may improve this' to the recommendation. The recommendation notes that there is a responsibility to inform the DVLA if there

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					are safety concerns about their ability to drive.
Royal College of Paediatrics and Child Health	Appendix B	21	Line 14	<p>Parents felt that teachers were unsympathetic in their attitudes, and felt that teachers neglected their children as a result.</p> <p>They were that teachers (what should this say?)</p> <p>had a 'blasé' attitude towards ADHD, which resulted in their child not receiving adequate help.</p>	Thank you for your comment. This wording has been amended.
Royal College of Paediatrics and Child Health	Appendix B	21	31.5.4 .1.3	<p>There is an error/omission on</p> <p>31.5.4.1.3 Theme 3: Challenges for parents</p> <p>4 Review theme 14: Experiences of support</p> <p>5 Although some parents felt they have adequate support from their families, healthcare</p>	Thank you for your comment. This wording has been amended.

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				<p>6 professionals and teachers, other parents reported a lack of support mainly from spouses and</p> <p>7 other family members, and from both healthcare and educational professionals.</p>	
Royal College of Paediatrics and Child Health	Appendix B	Page 25	Line 25	<p>This section is an example of language which I feel is not helpful:</p> <p>I have suggested changes. The comments should not be implied to refer to all cases.</p> <p>Review theme 27: Communication</p> <p>Some parents/carers and teachers reported conflict with each other, and difficulties in discussing the child with ADHD. Parents/carers reported communication difficulties with schools and teachers, which resulted in them feeling distressed. When teachers tried to discuss a</p>	Thank you for your comment. This wording has been amended to note that our review findings refer to parents because the studies contributing to these findings were conducted with parents and not carers.

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				<p>child's behaviour with families some perceived this negatively. Teachers also found it difficult to</p> <p>discuss children's behavioural issues with families, and found that they often had different opinions of the behaviour of the child. Those who did receive support from teachers did not always feel that this greatly impacted the child's behaviour, but it did improve the family's peace of mind</p>	
Royal College of Paediatrics and Child Health	Appendix B	Page 56	Line 34	<p>'the possible effect on driving (for example, some ADHD medication may impact on a person's fitness to drive and people with ADHD must declare their diagnosis to the DVLA if it affects their driving)'</p> <p>This is a misleading comment. Regular use of medication for ADHD will improve driving.</p> <p>I suggest it should read:</p> <p>The possible effect of ADHD symptoms on driving. If needed, appropriate and regular use of medication can</p>	Thank you for your comment. The wording of this recommendation has been amended to clarify that driving may be affected by ADHD symptoms. The committee has added 'and ADHD medication may improve this'. The recommendation notes that there is a responsibility to inform the DVLA if there are safety concerns about their ability to drive.

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				improve fitness to drive (although some medications can cause drowsiness.) Individuals with ADHD must inform the DVLA of their diagnosis and a report may be requested from their clinicians.	
Royal College of Paediatrics and Child Health	Evidence Review A Risk Factors		General	This is excellent and the recommendations are very useful and important to raise awareness of risk factors	Thank you for your comment.
Royal College of Paediatrics and Child Health	Evidence Review B		General	<p>However we feel some of the language used should be changed.</p> <p>Firstly a significant number of children/young people are not in the care of their parents and this should either be commented on at the top of the section or the term carer should be added throughout.</p> <p>Secondly there is inappropriate generalisation throughout which carers, GPs etc will not find helpful. The word 'some' is used frequently but actually not</p>	<p>Thank you for your comment. The wording in the review findings reflects the evidence, and in cases where review findings refer to parents, this is because evidence was only found on this population.</p> <p>In terms of your comment relating to GPs and teachers, where possible we avoid quantifying results as GRADE CERQual's methodology notes this to be misleading. Qualitative reviews do not quantify findings in this way but give insight to themes</p>

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				<p>often enough. Perhaps many could be used when this is a frequent finding and a few when only a minority or several. Basically parents or teachers or GPs or health professionals is often used as though the following statement applies to ALL when it does not.</p> <p>Also I suggest a change in wording in some of the Tables as currently they are not going to be read positively by GPs and Teachers some of whom know a great deal about ADHD and work effectively with specialists</p> <p>e.g. Table 6.</p> <p>'GPs had difficulty in recognising ADHD' could be 'some' or 'Many' depending on the results</p> <p>Attitudes</p> <p>GPs had negative attitudes towards ADHD ditto</p>	<p>experienced by the population of interest. Instead, we provide information on the number of studies that contributed to a particular review finding. Our quality assessment also includes a domain on 'coherence', where the quality of a finding would be downgraded if any conflicting review findings were found. Please see the quality assessment section for this level of detail.</p>

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				<p>GPs had limited understanding of their role in treatment management and again.</p> <p>The same applies to Table 7 about teachers</p>	
Royal College of Paediatrics and Child Health	General	Training		BACD in partnership with Sheffield Children's NHS Foundation Trust has developed online training on ADHD and comorbid/coexisting conditions. This is being accessed by Specialist Nurses and by medical staff learning about the area. This could also be useful to GPs who would value additional training	Thank you for your comment. We will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement .
Royal College of Paediatrics and Child Health	short	general	general	It would be helpful if a list of differential diagnoses for ADHD was added.	Thank you for your comment. Diagnosis and differential diagnosis were not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.
Royal College of Paediatrics	Short 1.2.1	7	6	Foetal alcohol spectrum disorder should be added to list of predisposing conditions	Thank you for your comment. No evidence was identified in the evidence report A and the guideline committee did not prioritise this as a risk factor to consider in the evidence review, the list is not intended to

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and Child Health					be comprehensive and cover all risk factors.
Royal College of Paediatrics and Child Health	Short 1.8.15	28	18	It is unfortunate that managing sleep does not seem to be well covered in the guidance, this is often one of the major issues which families bring to us, and sleep deprivation itself can increase hyperactivity in children, setting up a vicious cycle. The impact on sleep of medication was discussed when discussing choices with families, who sometimes make atomoxetine their own preference ahead of methylphenidate as a result. (See Sangal RB et al, Effects of atomoxetine and methylphenidate on sleep in children with ADHD. Sleep 2006 29(12):1573-85	Thank you for your comment. The committee agrees that sleep is an important issue in people with ADHD. An assessment of sleep disorder should be part of the discussion about planning and choosing treatments between the person with ADHD and their ADHD specialist. In the committee's discussion of the evidence of evidence report D the committee note the importance of monitoring the impact of medication on sleep and noting the baseline. The committee have not provided any specific examples noting that any adjustment in dosing or timing would be tailored to the individual.

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Royal College of Paediatrics and Child Health	Short version	Service Organisation	General	It would be helpful to consider the role of a neurodevelopmental service with input from Paediatrics and CAMHS rather than assuming Services will be ADHD services. The high degree of overlap in coexisting conditions means that a joint service can provide assessment and diagnosis for the many children with multiple needs without waiting lists and barriers between different assessments and the need for follow up by different teams. Joint working can enable services to manage greater demand better.	Thank you for your comment. The committee have been mindful of the impact of coexisting conditions throughout the guideline. The development of joint services is beyond the scope of this guidance.
Royal College of Paediatrics and Child Health	Short version	General	General	Whilst moving age for diagnosis and medication from 6 to 5 years may be clinically appropriate. There is concern regarding the impact on service provision. For example: in one paediatricians trust - CAMHS have based their ADHD service on premise they will not see anyone below 6 in view of the previous guideline. Whilst CDCs see younger children, the trust says we are not commissioned to see or diagnose children for ADHD, let alone medicate. Whilst local policy may not be right it is based on previous NICE guideline and	Thank you for your comment. The committee acknowledges the challenges of the current financial climate; however, the recommendations are based on the committee consensus over what is most clinically appropriate and cost effective. The committee hope that the recommendations will be a prompt to commissioners to aid expansion of services where appropriate.

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				potentially puts services at risk, especially in current financial climate when we are told there is no new money to facilitate expansion of current services. There is also an issue over access to clinicians with appropriate competencies to manage ADHD in younger children, as many CDCs do not see so will not be skilled for the under 6s where CAMHS no longer see	We will pass this information to our resource impact team for their information.
Royal College of Paediatrics and Child Health	Short version	General	General	No guidance for classroom management in schools.	Thank you for your comment. NICE guidelines are written for services commissioned by the NHS. The committee were unable to make recommendations about classroom management in the schools.
Royal College of Paediatrics and Child Health	Short version	General	General	No focus on management of sleep as a part of symptom management	Thank you for your comment. The committee agrees that sleep is an important issue in people with ADHD. An assessment of sleep disorder should be part of the discussion about planning and

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					<p>choosing treatments between the person with ADHD and their ADHD specialist.</p> <p>In the committee's discussion of the evidence of evidence report D the committee note the importance of monitoring the impact of medication on sleep and noting the baseline. The committee have not provided any specific examples noting that any adjustment in dosing or timing would be tailored to the individual.</p>
Royal College of Paediatrics and Child Health	Short Version	8	4	SENCO offering parent training, while this is welcomed as a recommendation, in reality however, we are not sure if education systems are aware or have capacity to do this additional work. How can the implementation of this be influenced from a health perspective.	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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Royal College of Paediatrics and Child Health	Short version	8	Line 24 and 25	We welcome this recommendation that suggests ADHD focused input BEFORE a formal diagnosis is made	Thank you for your comment.
Royal College of Paediatrics and Child Health	Short version	9	5	This would be better if it read: Observer reports and assessment of ADHD symptoms and possible comorbid conditions (rather than 'the person's mental state')	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.
Royal College of Paediatrics and Child Health	Short version	Page 10	section 1.3.2	It would be better to recommend questionnaires of ADHD core symptoms and questionnaires assessing general behaviour and wellbeing, rather than specifically Conners and SDQ as others are equally good and do not cost to use	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.
Royal College of Paediatrics	Short version	Page 11	section 1.4.4	This whole section is an excellent addition in guiding ongoing support	Thank you for this feedback.

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and Child Health			Line 20 onwards		
Royal College of Paediatrics and Child Health	Short Version	11	11	We are concerned about the reference to the antisocial behaviour/conduct disorder guideline being so directly linked to management in ADHD. We think service users might find this confusing and/or offensive. By reorganising the order of this paragraph, the message is still clearly stated but with less of an obvious parallel being brought between ADHD and antisocial behaviour/conduct disorder. For example: 'The general principles of care for managing children and young people with ADHD are the same as those for managing antisocial behaviour/conduct disorder in children and young people. Therefore, we recommend healthcare professionals follow the recommendations in NICE's guideline on antisocial behaviour/conduct disorder.' Same applies to page 8, line 8.	Thank you for your comment. The committee discussed this and have noted in the recommendation that this does not mean that all children and young people with ADHD have coexisting antisocial or conduct disorder but the general principles of care apply. The committee think this is clear.

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Royal College of Paediatrics and Child Health	Short Version	11	16	It may be difficult to implement giving information on support groups unless another specific diagnosis is reached. We struggled to think of support groups that are not diagnosis specificok. We propose that it would be more useful here to emphasise that even when patients do not meet the diagnostic threshold or have a unifying diagnosis, they will still require support and intervention which is needs based. In the case of children and young people with ADHD, these needs should continue to be addressed by school and locality involvement even without a diagnostic label. Cambridgeshire Community Services have a good approach to this.1	Thank you for your comment. The wording of this recommendation has been amended to reflect your point on the lack of specific diagnoses and support groups and to emphasise the general need for information and support.
Royal College of Paediatrics and Child Health	Short version	Page 12	section 1.4.6	This is very important but seems to make the same point repetitively. Could be shortened and still cover the same issues	Thank you for your comment. The committee think the recommendations as they stand are sufficiently concise and could not be shortened covering the same issues.

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Royal College of Paediatrics and Child Health	Short version	Page 12	Section 1.4.7 onwards	This section on supporting families and carers is excellent	Thank you for this feedback.
Royal College of Paediatrics and Child Health	Short Version	12	11	It would be useful to have an explanation of what the shared treatment plan is here or a link to a separate part of the document where the shared treatment plan is described.	Thank you for your comment. An explanation has been added to the terms used in this guideline section.
Royal College of Paediatrics and Child Health	Short Version	13	1	We agree that addressing the needs of parents/carers/family members of those with ADHD is important. It would be useful here to give examples of where they could have their needs assessed. Otherwise, we foresee that many healthcare professionals will default to recommending seeking GP assessment. This could lead to a significantly increased workload for GPs.	Thank you for your comment. Recommending where parents/carers/family members of those with ADHD could have their needs assessed was not in the remit of the guideline committee. This recommendation was supported by evidence from the evidence report on B and how the service delivery of this was not evaluated.

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Royal College of Paediatrics and Child Health	Short version	Page 16	Line 7 section 1.5.8	Specialist advice for tertiary service ADHD for under 5 is resource limited in many areas of the UK, with very patchy based provision. In each area, there are different service models between CAMHS and community paed. There is a need for clinical co-ordination of services. With current resource adherence to this recommendation may be limited; although this guidance may help to drive resource allocation and co-ordination of care.	Thank you for your comment. The committee agree that services should be commissioned in a way that facilitates care provision according to the NICE recommendations. We will pass this information to our resource impact team for their information.
Royal College of Paediatrics and Child Health	Short version	8 – 9	Pg. 8 line 23 onwards	Need to consider the thresholds for referral vs watchful waiting. Watchful waiting for 10 weeks should not be considered if the effects are severe. Families are already waiting long periods for assessment. A judgement needs to be made. Perhaps this should say if the adverse impact is mild consider watchful waiting. If adverse impact is moderate to severe initiate referral. In this situation	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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				<p>there also needs to be clarity with respect to how primary care services can assess the impact/severity.</p> <p>This should be highlighted at the beginning of this section and not left as an add-on at the end.</p>	
Royal College of Paediatrics and Child Health	Short version	Page 20	Baseline assessment	<p>Baseline assessment section: Include full cardiac clinical examination.</p> <p>Heart sounds should be listened to before starting ADHD medication and referral made if significant murmurs are audible. (possible aortic stenosis, cardiomyopathy etc)</p> <p>There is also a case for feeling femoral pulses as we have picked up 2 cases of undiagnosed coarctation of the aorta needing treatment before medication for ADHD and BP was normal.</p>	<p>Thank you for your comment. The committee have added a cardiac examination to the baseline assessment. The committee recognise that coarctation could be a rare finding but did not consider the case for feeling for femoral pulses was strong enough to include another element to the examination.</p>
Royal College of Paediatrics	Short version	Page 20	1,2 and 3	<p>We are concerned that this could lead to individuals with severe ADHD waiting long periods of time for</p>	<p>Thank you for your comment. The committee do not consider that this will lead to long waits for additional assessments. It is not within the remit of</p>

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and Child Health				<p>additional assessments e.g. for ASD, before medication is trialled</p> <p>This could be avoided by creating neurodevelopmental teams with CAMHS expertise in addition to reduce barriers and waits and promote joint working to optimise family support</p>	the guideline committee to recommend the creation of neurodevelopmental teams with CAMHS expertise.
Royal College of Paediatrics and Child Health	Short version	Page 21	Section 1.7.4 – 1.7.7	<p>Clinicians may have reasons to use other medications as first line. (e.g. parental choice – as in previous guideline)</p> <p>For example:</p> <p>Guanfacine as first line could be considered in children and</p> <p>young people with high blood pressure (clearly the cause for high BP needs ascertaining first)</p> <p>Also for some children with severe tics.</p>	<p>Thank you for your comment.</p> <p>Patient/parental choice will always feature in medication decisions; however, the purpose of the NICE recommendations is to highlight the most appropriate medication stages in the majority of people.</p> <p>The recommendations in the general prescribing information section highlight that co-existing conditions like anxiety disorders, tic disorders and autism spectrum disorder are not reasons to automatically deviate from the use of stimulants.</p>

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				Some clinicians offer atomoxetine to children with significant anxiety symptoms and also to families who feel they can't cope with the 'up and down' effect of stimulants and prefer a more sustained symptom control over the whole day.	
Royal College of Paediatrics and Child Health	Short Version	22		a) there should be a mention of considering length of time in the day cover is needed by the child/YP. b) lines 3 and 4 may encourage prescribers to try several MPH preparations inappropriately before changing to lisdexamfetamine.	Thank you for your comment. The wording of this recommendation has been amended for clarity.
Royal College of Paediatrics and Child Health	Short version	24	Section 1.7.18	Several BACD members highlight significant concern with this statement. It should not be in the short guideline with no further discussion and no comment about side effects, pre assessment and on treatment monitoring. As written it is potentially dangerous.	Thank you for your comment. The recommendations state that an antipsychotic should only be used in addition to stimulants and not in isolation.

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				Consideration of risperidone in addition to stimulants fits well with a mental health model of adhd, but using drugs like risperidone in isolation would be poor practice. Hopefully the new transformation model will lead to better joint working, between CAMHS and Paediatric services, but there should be clinical caution with use of risperidone and there is resource implication with respect to monitoring.	
Royal College of Paediatrics and Child Health	Short version	25	2	please add cardiac problems	Thank you for your comment. Cardiac problems has been added as you suggest.
Royal College of Paediatrics and Child Health	Short version	25	5	This could just say a scale measuring ADHD core symptoms and not specify Conners, SNAP IV is almost identical and free to use	Thank you for your comment, this has been amended.

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Royal College of Paediatrics and Child Health	Short Version	25	6	We do not have experience in starting medication for managing ADHD. However, we are concerned that the recommended weekly telephone contact with the specialist for monitoring during the titration phase may be difficult to implement in the time and resource limited NHS setting. We would be interested to know if healthcare professionals involved in this part of the process (for example, CAMHS doctors) would find this sustainable or too time-consuming to routinely implement.	<p>Thank you for your comment.</p> <p>The committee acknowledges the challenges of the current financial climate; however, the recommendations are based on the committee consensus over what is most clinically appropriate and cost effective. The committee hope that the recommendations will be a prompt to commissioners to aid expansion of services where appropriate.</p> <p>We will pass this information to our resource impact team for their information</p>
Royal College of Paediatrics and Child Health	Short version	27	1.8.10	<p>Referral for increased BP assessment is not to a cardiologist in many areas but to a paediatric nephrologist.</p> <p>It is also helpful to agree with your local cardiologist and/or nephrologist whether any investigations should</p>	Thank you for your comment, the wording of this recommendation has been amended.

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				<p>be arranged prior to the appointment e.g. feeling femoral pulses and checking BP in other limbs would mean referral for raised BP should be to a cardiologist not a nephrologist. Urine testing is simple and helpful</p> <p>Prior to referral to cardiologist ECG maybe helpful including 24 hour ECG (e.g. for tachycardia or irregular pulse)</p>	
Royal College of Paediatrics and Child Health	Short version	31	Section 1.10.1	Please mention the need to consider non pharmacological support for comorbid neurodevelopmental and mental health difficulties as part of monitoring	Thank you for your comment. The recommendations here are focused specifically on ADHD; however, text around this issue has been added to the committee's discussion of the evidence in evidence report H.
Royal College of Paediatrics and Child Health	Short version	31	9	<p>could say throughout the day.</p> <p>This would emphasise the need to assess whether an individual has adequate cover throughout the day as they get older.</p>	Thank you for your comment, the wording has been amended as you suggest.

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Royal College of Paediatrics and Child Health	Short Version	38	11	<p>We are concerned that offering CBT may not be an achievable recommendation in some regions. Waiting lists for NHS funded CBT are long nationwide. The guideline suggests that CBT for children with ADHD needs to address specific relevant areas. We are unsure if such tailored programmes are available in most regions. Establishing new CBT programmes in these areas would likely be expensive. This financial challenge could be partially addressed through introducing computerised CBT programmes. There is some evidence that computerised CBT is effective in treating anxiety and depression in 12-25 year olds but benefits in the younger population are less clear². This approach relies on the service user population having computer access and computer literacy and this could be a stumbling block.</p> <p>1 Information to school referrers to Cambridge Community Paediatrics for the assessment of</p>	<p>Thank you for your comment.</p> <p>The committee acknowledges the challenges of the current financial climate; however, the recommendations are based on the committee consensus over what is most clinically appropriate and cost effective. The committee hope that the recommendations will be a prompt to commissioners to aid expansion of services where appropriate.</p> <p>We will pass this information to our resource impact team for their information.</p>

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				<p>Neurodevelopmental conditions. Website: cambcommunityservices.nhs.uk.</p> <p>2 Pennant ME, Loucas CE, Whittington C et al. Computerised therapies for anxiety and depression in children and young people: a systematic review and meta-analysis. Behav Res Ther 2015 Apr;67:1-18</p>	
Royal College of Paediatrics and Child Health	Short version	49		<p>'the possible effect on driving (for example, some ADHD medication may impact on a person's fitness to drive and people with ADHD must declare their diagnosis to the DVLA if it affects their driving) '</p> <p>This is a misleading comment. Regular use of medication for ADHD will improve driving.</p> <p>We suggest it should read:</p> <p>The possible effect of ADHD symptoms on driving. If needed, appropriate and regular use of medication can improve fitness to drive (although some medications can cause drowsiness.) Individuals with ADHD must</p>	<p>Thank you for your comment. The wording of this recommendation has been amended to clarify that driving may be affected by ADHD symptoms. The committee has added 'and ADHD medication may improve this'. The recommendation notes that there is a responsibility to inform the DVLA if there are safety concerns about their ability to drive.</p>

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				inform the DVLA of their diagnosis and a report may be requested from their clinicians.	
Royal College of Paediatrics and Child Health	Short version	64		This should include listening to heart sounds	Thank you for your comment. This has been added.
Royal College of Paediatrics and Child Health	Short version	65		Referral for raised BP should more commonly be to a nephrologist rather than a cardiologist unless femoral pulses are weak/impalpable	Thank you for your comment. This has been amended as you suggest.
Royal College of Paediatrics and Child Health	Short version	67		Auscultation is needed (by someone)	Thank you for your comment. This has been added.

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Royal College of Paediatrics and Child Health	Short version	70		Clinicians would still find discussion of dosage helpful for initiation and optimisation guidance. Why was this omitted?	Thank you for your comment. The guideline section on managing treatment, medication choice, considerations when prescribing ADHD medication and dose titration outlines that prescribers should be knowledgeable about the medication they are prescribing. Prescribers are also directed to the BNF for dosing information.
Royal College of Paediatrics and Child Health	Short version	79		Conners should be replaced by short questionnaire on core ADHD features	Thank you for your comment. This has been amended.
Royal College of Paediatrics and Child Health	Short version	50 and 53		These sections on Improving communication are repetitive and could be said in a more concise and understandable way whilst still including all the issues.	Thank you for your comment. The section you are referring to demonstrates changes from the previous guideline. The committee considers the wording of the specific recommendations you highlight to be sufficiently concise.
Royal College of	Short version	71 and		same as previous comments	Thank you for your comment

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Paediatrics and Child Health		72, 73 and 74			
Royal College of Paediatrics and Child Health	Short version	General	General	The emphasis on access to behaviour management, talking therapies, parenting is very welcome. There are cost implications for service provision as access to these is very variable nationally and in many areas will need significant investment across agencies at a time when austerity has led to major cuts in service provision e.g. from social care and education (and NHS)	Thank you for your comment. The committee agree that services should be commissioned in a way that facilitates care provision according to the NICE recommendations. The information will be passed onto our resource impact team for their information.
Royal college of Psychiatrists	Evidence review D (Pharmacological safety)	82	25	There are difficulties checking BP and heart rate in patients with severe ADHD and Intellectual disability prior to starting ADHD treatment due to their severe hyperactivity and inability to tolerate the process of checking BP/HR. Most of the time, Psychiatrists who are confident in treating ADHD start ADHD medication if there are no cardiovascular risks and family history of sudden deaths. Once patient's ADHD	Thank you for your comment. The committee agree that in some situations it may be difficult to assess BP and HR. However, in the committee's experience it is rarely impossible and this should not prevent BP and HR assessment from being part of the general baseline assessment for ADHD medication. Additional information

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				is controlled with medication, then clinicians are able to check BP and HR in most cases. Inability to check BP and HR stops many psychiatrists prescribing appropriate ADHD medications. So it will be clinically useful to make a statement on this as this prevents patients receiving appropriate ADHD medications which can make a difference to their symptoms and associated behaviours. This will also prevent patients been receiving treatments that are not effective such as antipsychotics for their ADHD symptoms.	has been added to the Committee's discussion of the evidence in this review.
Royal college of Psychiatrists	Short	General	General	The association with suicide should be noted.	Thank you for your comment.
Royal college of Psychiatrists	Short	17	7=15	While this recommendation, for a course of CBT, is clinically appropriate, it is doubtful if it can be achieved given that CBT is a limited resource. It will require a degree of investment that does not seem likely to transpire.	Thank you for your comment. This information has been passed onto our resource impact team for their information.

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Royal college of Psychiatrists	Short	20	15-16	1.17.18 suggests considering the addition of an atypical antipsychotic: might this be a better example of a drug where treatment might affect the QT interval.	Thank you for comment. The committee believe that the drugs given as examples are more likely to be encountered in the ADHD population.
Royal college of Psychiatrists	Short	21	6-15	The clear sequence for introducing drugs does not make any allowance for parental /patient wishes – e.g. someone unwilling to consider stimulants. Might a statement about patient/parental wishes be added?	Thank you for your comment. The committee agrees that personal preferences will feed into decisions about appropriate medications and a shared treatment and person centred approach is reinforced throughout the guideline. The treatment pathway identified by the committee is the most appropriate default set of steps to consider and is based on the clinical and cost effectiveness of the evidence and the committee's experience. Stimulants are the most appropriate first line pharmacological treatment. If a person refuses to use stimulants for whatever reason (including a lack of efficacy/tolerance as specified in the recommendations), it would be appropriate to consider second line treatments (i.e. non-stimulant medications).

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Royal college of Psychiatrists	Short	21	6-15	Many children with autism or severe Intellectual Disability cannot cope with swallowing tablet/capsules/granules. For some, the medication has to be given through a tube. They require a liquid preparation and the alternatives are to use a specially made up preparation of methylphenidate (very expensive) or to use dissolved lisdexamfetamine (where there may be difficulty in achieving a low dose or to use liquid atomoxetine. Might there be a statement about the management of children in these circumstances (as it is an inability to tolerate the solid preparation rather than of the drug itself and so not really covered by 'they cannot tolerate methylphenidate or lisdexamfetamine')?	Thank you for your comment. This information has been added to the committee's discussion of the evidence in evidence report H.
Shire Pharmaceuticals	Evidence review 3	588	12	As above	Thank you for your comment. The heading has been moved as you suggest.

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Shire Pharmaceuticals	Questions from NICE			<p>Shire believes the areas likely to prove the most challenging to implement are:</p> <ul style="list-style-type: none"> • Recognition, Identification and Referral. Understanding of ADHD in primary care is frequently not good and GPs can act as a barrier to referral (see comment 13). NICE should consider what guideline implementation tools could help primary care to better identify people who potentially have ADHD (rec 1.2.1 and 1.2.2). Timely diagnosis and treatment of all age groups is challenging currently. Waiting times for an appointment with a specialist who is able to diagnose and treat ADHD are highly variable and often very long (See note below). Implementation of the recommendations is likely to result in higher numbers of referrals therefore NICE should consider what implementation tools could help CCGs to more accurately forecast demand and to commission appropriate services to meet this demand across all age groups. • Recommendations relating to schools and communication between schools and NHS 	<p>Thank you for your comment. This information has been passed onto the NICE resource impact team for their information.</p> <p>After the publication of this guideline the quality standard will be assessed to see if it needs to be updated and if any changes will need to be made.</p>

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				<p>specialist ADHD services (e.g. 1.2.4, 1.4.12). NICE should consider what guideline implementation tools and information could be targeted specifically towards education professionals to help them understand their role in supporting children with and young people with ADHD.</p> <ul style="list-style-type: none"> • Recommendations relating to provision of psychological treatment for children and young people. According to research conducted by Shire using Freedom of Information requests in October 2016, implementation of the 2008 guideline recommendation on group psychological treatment for children and young people was extremely poor. • Recommendations relating to ADHD specific parent training programmes. Implementation of the recommendations from the 2008 guideline on parent training has been mixed ranging from 100% of parents accessing a programme to there being no local provision. ADHD specific programmes appear to be rare. Parent training programmes are often provided by the local authority, other local services or the voluntary 	

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				<p>sector, sometimes commissioned by the CCG but not always. The draft guideline updates this recommendation to focus the training programmes on ADHD specifically which is very welcome, however in many areas of the country this will require a significant change of approach.</p> <ul style="list-style-type: none"> Measuring performance on implementation. When this guideline is published, the NICE Quality Standard for ADHD will be out of date. The datasets to which it refers no longer exist. Implementation support for the 2018 guideline should therefore consider the most appropriate ways for providers and commissioners to measure their progress in implementing the guideline so that this can be reported and assurance provided in a meaningful way. <p>Supporting information:</p> <p>Between October 2016 and January 2017 research was conducted on behalf of Shire which asked NHS providers for information about their services for</p>	

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				<p>people with ADHD based on the statements included in the NICE Quality Standard for ADHD, which was itself based on the 2008 NICE clinical guideline. NHS Digital does not provide data specific to ADHD therefore the research was conducted using a Freedom of Information Act request. Shire can provide the responses to the FOI questions on request.</p> <p>In summary the results suggested the most challenging areas for children and young people were:</p> <ul style="list-style-type: none"> • Waiting times from referral to first outpatient appointment. Average waiting times ranged from 14 to 187 days, with the longest reported waiting time being 532 days. • Provision of parent training programmes – only 33% reported offering this to all or most parents. • Referral to group psychological treatment programme – only 11% offer this to all or most patients with a further 11% offering it to a very small proportion of patients 	

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				<p>65 trusts provided data on their services for children and young people.</p> <p>The most challenging area for adults was waiting time from referral to first outpatient appointment. Average waiting times ranged from 65 to 388 days, with the longest reported waiting time being 1225 days.</p> <p>22 Trusts provided data on waiting times for adults.</p> <p>Of the 169 trusts which responded to the FOI request, 63 provided information on transition (37%) from children and young people's services to adult services. Responses were highly varied making conclusions challenging to draw. 13 of the 169 Trusts that responded reported there is no transition service or pathway with no further information. The remainder provided some information about a transition service or pathway in existence or in development, some areas explained that there is no ADHD adult service to transition to and several areas refer ADHD patients</p>	

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				back to the GP. Some areas only have a non-ADHD specific transition pathway.	
Shire Pharmaceuticals Limited	Evidence review 3	587	14	The main heading of the section suggests this is for Adults but the title of the forest plot says children and Shire believes the forest plots refer to children so the Adults heading should be moved to section E.2.8 page 592.	Thank you for your comment. The heading has been moved as you suggest.
Shire Pharmaceuticals Limited	Short	11-14	1.4	The guidance should use this section to reiterate the point that patients and parents should be involved in treatment decisions.	Thank you for your comment. Recommendations related to treatment decisions and discussions are reflected within section 1.5. Recommendations are not repeated within the guideline to ensure guidance is clear and accessible. A shared treatment and person centred approach is reinforced throughout the guideline.
Shire Pharmaceuticals Limited	Short	11-12	1.4	Shire welcomes the recommendations on information and support provided to people following a diagnosis of ADHD. People diagnosed with ADHD as adults may struggle emotionally as a result of the diagnosis previously	Thank you for your comment. This detail, relating to the importance of supporting newly diagnosed adults with ADHD, has been added to the committee's discussion of the evidence in evidence report B. The

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				<p>being missed and the recognition that the negative impacts of ADHD they have experienced could have been avoided (as discussed in the evidence review for this section, review theme 4, page 18, lines 7-23). While the recommendation for a structured discussion at the time of diagnosis is welcome, the guidelines should recognise that this may not be sufficient for everyone. A recommendation for further follow up a few weeks after diagnosis to check how the patient is coping, offer emotional support and determine whether they are accessing signposted services should be considered.</p> <p>Newly diagnosed adults may also benefit from other forms of practical support in addition to what is recommended, for support with basic housekeeping, life skills, household budgeting and entering the workplace.</p>	<p>committee emphasise the importance of making sure that the person's care is tailored to their needs at all stages of their care. The clinical and cost effectiveness of the evidence did not support a general recommendation increasing appointment frequency within this group.</p>
Shire Pharmaceu	Short	11-12	1.4.4	This recommendation should more strongly indicate that after the structured discussion, patients and	Thank you for your comment. This guideline does reference CG138 (see section 1.4 Information and support). The

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tics Limited				parents should receive the same information in a written format. This is also in line with recommendations from CG138 'Patient experience' which state that patients should be given both oral and written information (recommendation 51) and it is particularly necessary for this patient group.	committee agreed that information related to both ADHD and its treatment should be tailored to the individual and their family or carers. The evidence did not support the use of any one particular method of providing information. Information should always be provided in a format suitable for each person and their family or carers.
Shire Pharmaceu ticals Limited	Short	25-26	1.7.26	The recommendation should also include the option of switching to lisdexamfetamine	Thank you for your comment. The wording of this recommendation has been amended.
Shire Pharmaceu ticals Limited	Short	11-12	1.4.4 – 1.4.5	Shire welcomes the recommendations to increase the level of dialogue and support provided to patients and their families. In addition to providing information about local support groups (etc), the guideline should also make clear the other types of practical and emotional support that may be needed following diagnosis. For example, support	Thank you for your comment. This detail, relating to the importance of supporting newly diagnosed adults with ADHD, has been added to the committee's discussion of the evidence in evidence report C. The committee emphasise the importance of making sure that the person's care is tailored to their needs at all stages of their care. The clinical and cost effectiveness of

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				<p>with basic housekeeping, life skills, household budgeting, entering the workplace.</p> <p>The guidance should encourage the ADHD team to monitor uptake of these wider support services by checking in with the patient in the weeks following diagnosis to see how they are coping and whether they are accessing the right kinds of support.</p>	<p>the evidence did not support a general recommendation increasing appointment frequency within this group.</p>
Shire Pharmaceuticals Limited	Short	21-22	1.7.4 to 1.7.7	<p>Shire suggests the following:</p> <ul style="list-style-type: none"> To include a reference to the importance of taking into account patient and parental preference between stimulants and non-stimulants (Van Brunt K, Matza LS, Classi PM, Johnston JA. Preferences related to attention-deficit/hyperactivity disorder and its treatment. <i>Patient preference and adherence</i>. 2011;5:33-43. doi:10.2147/PPA.S6389) As per TA98 the individual preference of the child or adolescent and/or their family or carer should be considered when choosing a treatment 	<p>Thank you for your comment. The committee agrees that personal preferences will feed into decisions about appropriate medications and a shared treatment and person centred approach is reinforced throughout the guideline. The treatment pathway identified by the committee is the most appropriate default set of steps to consider and is based on the clinical and cost effectiveness of the evidence and the committee's experience, recommendations are intended to be</p>

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				<ul style="list-style-type: none"> To include a reference to the importance of taking into account patient and parental preference between different non-stimulants and being aware of drivers of patient preference. A phase 3 study (A Hervas et al, Efficacy and safety of extended-release guanfacine hydrochloride in children and adolescents with attention-deficit/hyperactivity disorder: A randomized, controlled, Phase III trial, In European Neuropsychopharmacology, Volume 24, Issue 12,2014, 1861-1872) showed the onset of treatment action observed more rapid with GXR than ATX. GXR achieved a statistical separation from placebo at Week 1 (p=0.001) versus Week 3 for ATX (p=0.024), as measured by the ADHD-RS-IV score. Evidence suggests that GXR may be preferred to ATX due to its faster speed of onset which is valued by children, young people and parents (Flood E. et al. (2015), 'Preferences for ADHD non-stimulant treatment characteristics among children and adolescents with ADHD and their caregivers', JHEOR, 3(1):56-72.) As per TA98 the individual preference of the child or 	<p>interpreted in the context of each individual person</p> <p>The committee agree the assessment of response is challenging. The committee noted that it is important that any treatment decision is made with the person taking the medication. It is important that the clinician has a good relationship with the person and can assess the change in symptoms and impairment relative the baseline. For this reason the committee did not consider it was possible to include more generic recommendations on this topic, further text has been added to the committee's discussion of the evidence section in evidence report C.</p>

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				<p>adolescent and/or their family or carer should be considered when choosing a treatment.</p> <ul style="list-style-type: none"> To provide a definition of adequate response to MPH that helps clinicians determine when to consider LDX. <p>To provide a definition of adequate response to LDX that helps clinicians determine when to consider non-stimulants.</p>	
Shire Pharmaceuticals Limited	Short	21/22	1.7.5 & 1.7.7	<p>Further clarity should be given what constitutes non-response in recommendations 1.7.5 & 1.7.7 to support clinician switch decision. In clinical trials response to treatment was defined as a $\geq 30\%$ reduction from Baseline in ADHD-RS-IV Total Score and a CGI-I value of 1 or 2 (reference Elvanse SPC). In addition, 1.7.7 recommends a trial period of 6 weeks and the same should be considered for 1.7.7. Also there should be a consideration in 1.7.5 of reason for inadequate response. If patient is showing some response to methylphenidate but the effects do not last long enough then it may be appropriate to consider a longer acting methylphenidate or lisdexamfetamine. If</p>	<p>Thank you for your comment.</p> <p>The committee agree the assessment of response or non-response is challenging. The committee noted that it is important that any treatment decision is made with the person taking the medication and take into account how they feel their medication is having an impact on their symptoms. It is important that the clinician has a good relationship with the person and can assess the change in their symptoms and impairment relative to the baseline. For this reason the committee did not consider</p>

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				<p>a patient fails to show adequate symptom improvement during the period of the day methylphenidate has an effect then a switch to lisdexamfetamine may be more appropriate (Arnold L.E. (2000), 'Methylphenidate vs. amphetamine: Comparative review', Journal of Attention Disorders. 3(4): 200-211.)</p> <p>As per TA98 the individual preference of the child or adolescent and/or their family or carer should be considered when choosing a treatment. When considering patient preference, a non-stimulant may be considered prior to a stimulant in certain situations. In addition, the attributes of each treatment, such as onset of action, may influence patient preference and ultimately influence overall adherence to treatment. Guanfacine XR may be considered prior to Atomoxetine when taking into account a shorter onset of action as a patient preference (A Hervas et al, Efficacy and safety of extended-release guanfacine hydrochloride in children and adolescents with</p>	<p>it was possible to include more generic recommendations on this topic, further text has been added to the committee's discussion of the evidence section in evidence report C.</p> <p>The committee agrees that personal preferences will feed into decisions about appropriate medications and a shared treatment and person centred approach is reinforced throughout the guideline. The treatment pathway identified by the committee is the most appropriate default set of steps to consider and is based on the clinical and cost effectiveness of the evidence and the committee's experience. Recommendations are intended to be interpreted in the context of each individual person.</p>

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				attention-deficit/hyperactivity disorder: A randomized, controlled, Phase III trial, In European Neuropsychopharmacology, Volume 24, Issue 12,2014, 1861-1872).	The committee agrees that personal preferences will feed into decisions about appropriate medications and a shared treatment and person centred approach is reinforced throughout the guideline. The treatment pathway identified by the committee is the most appropriate default set of steps to consider and is based on the clinical and cost effectiveness of the evidence and the committee's experience, Recommendations are intended to be interpreted in the context of each individual person.
Shire Pharmaceuticals Limited	Short	7	1.2.1	Shire welcomes this addition to the draft guidance, but recommends that the guideline should include some further detail to improve recognition and identification. In particular, where there are difficulties treating mental health conditions such as depression, anxiety and bipolar in adult patients, clinicians should use the ASRS screening tool to identify adult patients who may	Thank you for your comment. Evaluation of screen tools or diagnosis were not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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				<p>have comorbid ADHD or in whom ADHD is the primary diagnosis precipitating other mental health problems. (Masi L and Gignac M. (2015), 'ADHD and Comorbid Disorders in Childhood Psychiatric Problems, Medical Problems, Learning Disorders and Developmental Coordination Disorder', Clinical Psychiatry, 1(5): 1-9.)</p>	
Shire Pharmaceuticals Limited	Short	7	1.2.2	<p>Shire recommends that this list should be expanded to include a bullet to note that these patients are more likely to self-harm and make suicide attempts. (Hinshaw et al Journal of Consulting and Clinical Psychology © 2012 American Psychological Association 2012, Vol. 80, No. 6, 1041–1051). This should also include a bullet to highlight the increased risk of eating disorders among adolescent girls with ADHD.</p> <p>(Mikami, A. Y., Hinshaw, S. P., Patterson, K. A., & Lee, J. C. (2008). Eating pathology among adolescent girls with attention-deficit/hyperactivity disorder. Journal of Abnormal Psychology, 117(1), 225-235;</p>	<p>Thank you for your comment. This section of recommendations was only included to identify at risk groups and did not look at the risk of other diagnoses in people with ADHD or the risk of self-harm or suicide attempts.</p>

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				and Are Girls with ADHD at Risk for Eating Disorders? Results from a Controlled, Five-Year Prospective Study, Joseph Biederman, Sarah W. Ball, Michael C. Monuteaux, Craig B. Surman, Jessica L. Johnson, Sarah Zeitlin, J Dev Behav Pediatr 28:302–307, 2007)	
Shire Pharmaceuticals Limited	Short	7	13	Shire recommends that the guideline should replace “close” with “biological” to provide clarity, as it is understood that there is a genetic link. (Blum K et al. (2008), ‘Attention-deficit-hyperactivity disorder and reward deficiency syndrome’, Neuropsychiatry Disease and Treatment; 4(5): 893-918.)	Thank you for your comment. The committee agrees that there is likely to be a genetic link in ADHD but considers “close” to be the most appropriate wording for this recommendation given the evidence identified and the role of environmental factors serving as risk markers.
Shire Pharmaceuticals Limited	Short	7	18	Shire recommends that this bullet should be expanded to include adults diagnosed with anxiety, depression or bipolar disorder as these are the more common comorbidities in adults with ADHD. See Kessler RC, Adler L, Barkley R, et al. The prevalence and correlates of adult ADHD in the United States: Results	Thank you for your comment. The lists of conditions are those prioritised by the committee for investigation (see the protocol for evidence report A) and in which either evidence was identified or based on the committee's experience and consensus. The single example has been

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				from the National Comorbidity Survey Replication. <i>The American journal of psychiatry</i> . 2006;163(4):716-723. doi:10.1176/appi.ajp.163.4.716.	removed to avoid giving a false sense of specificity.
Shire Pharmaceuticals Limited	Short	12	2	The discussion should also include information also on the positive effect that ADHD treatment can have on driving (Russell A. Barkley, Daniel Cox, A review of driving risks and impairments associated with attention-deficit/hyperactivity disorder and the effects of stimulant medication on driving performance, In <i>Journal of Safety Research</i> , Volume 38, Issue 1, 2007, Pages 113-128)	Thank you for your comment. The wording of this recommendation has been amended to clarify that driving may be affected by ADHD symptoms. The committee has added 'and ADHD medication may improve this'. The recommendation notes that there is a responsibility to inform the DVLA if there are safety concerns about their ability to drive.
Shire Pharmaceuticals Limited	Short	12	11	Shire would welcome some clarification on the shared treatment plan. Shire believes there should be a written plan that is communicated to parents and GP within the next working week after the appointment where the treatment plan is discussed; this can be facilitated by technology and it is not perceived as unrealistic. Currently there is virtually no documentation sent out by secondary care which	Thank you for your comment. This has been added to the terms used in this guideline section.

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				makes it extremely difficult for parents to gain support from schools or to support requests for Education Health and Care plans for their children. It is important that the plan is communicated to parents in writing so that both secondary care and parents are aware.	
Shire Pharmaceuticals Limited	Short	13	1.4.12	Shire welcomes this recommendation. The guidance should also ensure that any interaction with schools or colleges is shared with the family in a timely way.	Thank you for this feedback. Any interaction with schools or colleges is with the child or young person's consent, this usually involves the person's parents or carers. This requisite for consent in the recommendation should ensure that any interaction is shared with the family as it occurs.
Shire Pharmaceuticals Limited	Short	13	1.4.8	Shire recommends the following statement should be added: in particular consider the parents and family's higher risk of having ADHD.	Thank you for your comment. The increased risk of ADHD in the close family of people diagnosed with ADHD is noted in the recognition, identification and referral recommendations.
Shire Pharmaceuticals Limited	Short	14	1.4.13	This recommendation should be clarified to include the patient's GP. People with ADHD frequently report lack	Thank you for your comment. This recommendation is specific to the situation

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ticals Limited				of understanding of the condition by their GP, and in some cases active denial that ADHD exists. In a recent survey initiated by Shire (March-April 2017) carried out of 72 guardians/carers of children with ADHD and 32 adult patients with ADHD, almost one in four (22%) patients experienced doubt from their GPs about whether ADHD is a real condition. Two thirds (66%) felt as though they had little or no positive support from their GP about their / their child's ADHD symptoms.	in which a person with ADHD is newly diagnosed with a co-existing condition and is being cared for by a new healthcare professional. The importance of co-ordination between the person diagnosing ADHD and primary care is emphasised in other recommendations.
Shire Pharmaceu ticals Limited	Short	14	1.5.1	Shire welcomes this recommendation for continuity of care but seeks greater clarity in the guideline on what this means in practice – for example in relation to frequency of follow up, continuity of team involved in a patient's care, joined up working between different agencies and consistent support throughout the transition to adult services.	Thank you for your comment. The different sections of the guideline, such as the one on follow up, include recommendations that clarify how continuity of care can be addressed. The service and organisation section that was not updated has recommendations about transition to adult services.
Shire Pharmaceu	Short	14	1.5.1	The guideline should clarify that if patients are stabilised on treatment they should be able to continue care even if they move areas or transition services eg	Thank you for your comment. This recommendation underpins the importance of continuity of care from or between any area, service or organisation. The service

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ticals Limited				child to adult, students moving to university (missing an academic year whilst waiting for referral into system to continue treatment is unacceptable), patients in prison being released back to community, etc.	and organisation section that was not updated has recommendations about transition to adult services.
Shire Pharmaceuticals Limited	Short	14	1.5.2 – 1.5.4	<p>Shire welcomes the recommendation for a comprehensive, shared treatment plan. The guidance should also indicate who the treatment plan should be shared with and within what timeframe.</p> <p>Shire recommends adding the following into the recommendation:</p> <ul style="list-style-type: none"> - the treatment plan should be individualised based on the criteria set out on p14. - Patient and parent treatment preference should be included as an additional criterium - The shared treatment plan must be documented and sent to parents or patient within the next working week after the consultation <p>Information about treatment options should be provided in a written format to patients; this is in line</p>	Thank you for the comment. Additional information about a shared treatment plan has been added into the terms used in this guideline section.

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				with recommendations from CG138 'Patient experience' which state that patients should be given both oral and written information and this is particularly important in this patient group.	
Shire Pharmaceuticals Limited	Short	16	1.5.9	Shire recommends that a timeline be attached to this; Shire would suggest a place on a group-based ADHD-focused support is offered within 6 weeks from referral.	Thank you for your comments Based on the clinical and cost effectiveness the committee could not make any recommendations on how or when to deliver the training programmes or to be specific about the components. The committee acknowledge in the committee's discussion of the evidence in the evidence report E that ADHD-focused support will be different depending on the local area and can have different delivery methods.
Shire Pharmaceuticals Limited	Short	17	1.5.13	The recommendation should also mention parents who work and are unable to attend group sessions which are invariably held during the working week office hours.	Thank you for your comments. Parents who work and are unable to attend group sessions are included in the first bullet point, when 'there are particular difficulties for families in attending group sessions'.

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Shire Pharmaceuticals Limited	Short	21	1.7.5	<p>This recommendation does not address what time frame constitutes nonresponse.</p> <p>Consider that a recommendation should be made in the same way as it has been for 2nd line medication as per 1.7.7 [switch when] their symptoms have not responded to separate 6-week trials of lisdexamfetamine and methylphenidate, having tried alternative formulations and adequate doses.</p> <p>This recommendation does not make mention of the need to avoid methylphenidate cycling. We suggest clarifying that long-acting lisdexamfetamine should be considered in place of trying multiple MPH cycles.</p>	<p>Thank you for your comment.</p> <p>No evidence was identified to support a specific time point and the 6-week trial decision was based on the committee's experience and agreed through consensus. The committee agree that it is difficult to generalise and to define a specific time point when to consider switching to different medications. All treatment decisions should be made with the person taking medication and take into account how they feel their medication is having an impact on their ADHD symptoms. The judgement of response and persistent significant impairment is challenging and has to be done on an individual basis in discussion with the person with ADHD. It is important the clinician has a good relationship with the person and can assess their change in symptoms and</p>

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					impairment relative to the baseline. Taking this into account should avoid methylphenidate cycling. There is additional information in the dose titration section of the guideline.
Shire Pharmaceuticals Limited	Short	22	1.7.8 to 1.7.11	Shire welcomes the adult treatment pathway. However, the guidance should be strengthened to include the importance of patient preference within treatment decisions between stimulants and non-stimulants. Patient choice is sometimes restricted because patients do not have all the information they need to make an informed choice or develop their preferences. The guideline should stipulate that the role the clinician is to inform and empower the patient in relation their options, so that they can make choices, if that is their wish.	Thank you for your comment. NICE guidelines are intended to highlight the most appropriate default treatment decisions but should be considered in the context of the individual. This context will include the preferences of the person with ADHD and their family. The committee agreed that the clinical and cost effectiveness evidence indicated that stimulants are the most appropriate first line treatment. If a person does not wish to use stimulants for whatever reason (including a lack of efficacy/tolerance as specified in the recommendations) it would be appropriate to consider the second line of treatments (i.e. non-stimulant medications). The guideline includes a

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					number of recommendations for healthcare professionals to fully discuss the benefits and harms of all treatment options.
Shire Pharmaceuticals Limited	Short	23	1.5.8 1.7.12 1.7.13	The guideline should provide a definition of what constitutes a tertiary service.	Thank you for your comment. It is commonly accepted that a tertiary service is one that provides specialised consultative care, usually on referral from healthcare professionals working in primary or secondary services.
Shire Pharmaceuticals Limited	Short	25	1.7.23	The guidance should include a clearer definition of what is meant by 'dose optimisation' in terms of patient outcomes. A definition of adequate response is required in this section. Standard scales should be used consistently to objectively measure progress against remission (so that a response for a patient is evaluated regularly using the same scale). The phrase "reduced symptoms" is not an effective measure of adequate response and should be amended to "remission".	Thank you for your comment. No evidence was identified to support a specific time point and the 6-week trial decision was based on the committee's experience and agreed through consensus. The committee agree that it is difficult to generalise and to define a specific time point when to consider switching to different medications while optimising medication. All treatment decisions should be made with the person taking medication and take into account

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					<p>how they feel their medication is having an impact on their ADHD symptoms. The judgement of response and significant impairment is challenging and has to be done on an individual basis in discussion with the person with ADHD. It is important the clinician has a good relationship with the person and can assess their change in symptoms and impairment relative to the baseline.</p> <p>There is additional information in the dose titration section of the guideline. The committee considers that the current wording of the recommendation 'reduced symptoms, positive behaviour change, improvements in education, employment and relationships, with tolerable side effects' adequately describes dose optimisation.</p>

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Shire Pharmaceuticals Limited	Short	27	1.8.6	This section should specify 'inappropriate weight loss'.	Thank you for your comment. Additional information on monitoring weight has been added to the committee's discussion of the evidence in the in evidence report D to clarify when weight loss is of concern.
Shire Pharmaceuticals Limited	Short	27	1.8.7	Shire suggests rewording as expected height or weight for their baseline centiles - for example in a pre-term child or a child who is genetically small like biological parents.	Thank you for your comment. The committee believe that the current wording is clear.
Shire Pharmaceuticals Limited	Short	28	1.8.16	Primary care practitioners should be supported to monitor worsening behaviour and adjust medication accordingly. The role of primary care practitioners should be clarified in the guideline. The role of specialist nurses (including community psychiatric nurses) in the diagnosis and treatment of ADHD should be clarified in the guidance.	Thank you for your comment. The service and organisation section that was not updated emphasises the importance of shared care arrangements with primary care. The committee's discussion of the evidence in the evidence report D and H has further detail on the experience of the committee on the role of primary care

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					practitioner and specialist nurses in follow up and monitoring.
South London & Maudsley NHS Foundation Trust	Short	General	General	We are aware that this document is noted to be specifically for patients/carers/patient, and health and social care professionals, however so much of the guidance is predicated on the commissioning of required services, with sufficient funding to be able to offer the examples of good practice which this document describes so well. Therefore we would be keen for the document to explicitly state that this needs to be used by commissioners to inform the local service provision that they offer within their area, or are required purchase from out of area providers.	Thank you for your comment. This has been added to the front of the guideline in the section outlining who the guideline is for.
South London & Maudsley NHS Foundation Trust	Short	12	3	It may be beneficial to note that ADHD medication could have positive or negative impacts on fitness to drive, eg improved attention or reduced distraction or impulsivity could be beneficial, side-effects or on/off effects as the medication wears off could be detrimental. In addition patients may need direct	Thank you for your comment. The wording of this recommendation has been amended to clarify that driving may be affected by ADHD symptoms. The committee has added 'and ADHD medication may improve this'. The recommendation notes that there

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				advice on driving on days where they chose to omit their medication, eg where they are on leave from work/studies, or medication has worn off, eg driving late at night. This may affect treatment choices for the patient.	is a responsibility to inform the DVLA if there are safety concerns about their ability to drive.
South London & Maudsley NHS Foundation Trust	Short	14	13	As noted in our first comment, healthcare providers are facilitated/inhibited by the budget and specifications for services that they have been commissioned to provide. Eg child/paediatric healthcare providers have limited ability to ensure continuity of care for young people reaching adulthood where there are no adult services commissioned in their area, or where the limited funding for the service means that their transitioning patient faces lengthy delay before being seen by adult services. This should be acknowledged in the guidance, or in an explanatory note about the guidance.	Thank you for your comment. Your first comment has been passed to the resource impact team and additional text on this recommendation has been added to the committee's discussion of the evidence in evidence report B.
South London &	Short	18	4	It would be helpful to have "environmental modifications" clearly defined, for all age ranges. We	Thank you for your comment. Environmental modifications are defined in, ' terms used in this guideline section' and

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Maudsley NHS Foundation Trust				note that there are examples on p32, but these seem child orientated. We were concerned that having medication treatment commence only after environmental modification has been made could lead to a situation where you are denying someone treatment until such time as they have made changes that medication, and indeed psychological treatment, could assist with. Or a high bar for environmental modification could be set as a means of limiting the number of patients who could go on to be treated with medication, particularly if service provision is limited.	additional detail and example of modifications for all ages have been added. The committee agreed that it was important that environmental modifications should be tried and reviewed and then if a person still is having a persistent significant impact in at least one domain of their everyday life then medication should be considered.
South London & Maudsley NHS Foundation Trust	Short	18	6	We support psychological and pharmacological arms of treatment, and these should be core aspects of any treatment service. However, we are aware that in many areas there is little or no ADHD specific psychological treatment at the present time, and it is not uncommon for secondary care psychological services, or IAPT, to be unwilling or lacking the experience in offering modifications to their treatment packages to suit people with ADHD, or have ADHD as	Thank you for your comment. The committee consider this to be an appropriate recommendation: where these services are not available, the guidelines should serve as a tool to help promote further development of services. This information has been passed on to our resource impact team.

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				an exclusion. This reiterates the need for appropriate commissioning.	Uncertainty around the cost effectiveness of parent training programmes led to a recommendation on ADHD focussed support with less direction on what such a programme may look like, for example, it should include "education and information on the causes and impact of ADHD and advice on parenting strategies". This therefore does not suggest a full course of parent training, and further discussion in evidence report E also talks about the support that might be available through other sectors such as the voluntary sector.
South London & Maudsley NHS	Short	18	9	We recommend an additional bullet point indicating that non-pharmacological treatment should be considered for females during pregnancy and whilst breastfeeding.	Thank you for your comment. The committee agreed that any treatment options for females during pregnancy and whilst breastfeeding should be carefully considered and discussed with the woman. The options should be considered on an

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Foundation Trust					individual basis taking into account the risks and benefits to the person's circumstances. This has been added to the committee's discussion of the evidence in evidence report D and H.
South London & Maudsley NHS Foundation Trust	Short	18	17	This would imply that patients who had completed CBT or other psychological treatment would remain on service caseloads indefinitely, even if treatment had concluded successfully, which is not sustainable.	Thank you for your comment. The service and organisation section that was not updated emphasises the importance of shared care arrangements with primary care. In this example, the person would not stay on service caseloads indefinitely but be managed with primary care. The committee noted that, in their experience, this would enable someone to have rapid access back to a specialist if this was required.
South London & Maudsley NHS Foundation Trust	Short	20	7	We would recommend adding in a point re asking whether a female patient is pregnant, planning to become pregnant, or breastfeeding, to allow risk/benefit analysis of whether to prescribe or delay medication. In addition we would add in the asking about sleep pattern prior to medication being introduced as it is important to differentiate between	Thank you for your comment. The committee agree that, before any medication is prescribed, the risks and benefits should be discussed to allow an informed decision to be made. This would include discussions around potential pregnancy and sleep patterns. This is

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				medication induced sleep problems, and those that have been there longer term.	outlined in the planning treatment section and noted in the committee's discussion of the evidence in evidence report D and H.
South London & Maudsley NHS Foundation Trust	Short	20	28	We have not been able to source centile charts for adults - please provide a reference, or for adults suggest cut off values for BP readings as per NICE guidance on hypertension which has categories of stage 1, stage 2 and severe hypertension.	Thank you for your comment. The wording of this recommendation has been amended.
South London & Maudsley NHS Foundation Trust	Short	22	6	We are surprised that lisdexamfetamine is listed as the first line treatment for adults. It clearly has a place in treatment for adults, with the benefit of a licence, but we would have expected it to have moved to first line alongside methylphenidate preparations, rather than methylphenidate dropping to second place. In practice we find that lisdexamfetamine frequently doesn't last a full working day, and requires the addition of immediate release dexamfetamine, similar to Concerta XL or other brands of methylphenidate XL medication	Thank you for your comment. After taking into consideration the stakeholders' comments on this issue the committee agreed that methylphenidate should be included alongside lisdexamfetamine as an option for the first line medication treatment in adults.

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				<p>in practice often requiring immediate release methylphenidate. This has an impact on the economic argument based on lisdexamfetamine lasting 14 hours, as the cost of adding immediate release dexamfetamine could exceed the costs of adding immediate release methylphenidate to brands of methylphenidate XL medication. Secondly, there is the benefit as regards patient choice - the variety of methylphenidate medications varying in duration of effect, which allows for patients to tailor their treatment to suit their response to medication in terms of duration of effect, or their particular demands, such as those whose work shifts vary in duration, who work nights and will need to be able to alter duration of effect to allow changes in sleep patterns, for example.</p>	
South London & Maudsley NHS	Short	22	12	<p>Add in consideration of dexamfetamine where lisdexamfetamine duration of effect needs extending (as per advice on methylphenidate guidance on p26 lines 1-3), as this is something we have found to be</p>	<p>Thank you for your comment. The recommendation about differing stimulant preparations used together has been amended to make this clearer.</p>

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Foundation Trust				required reasonably frequently in practice when using lisdexamfetamine, as noted above.	
South London & Maudsley NHS Foundation Trust	Short	24	1	Consider moving this line to be the second bullet point, ie swapping order with line 2 of page 24 in the current document. Consider altering to “do not offer any new medication for ADHD until the psychotic or manic episode has resolved/controlled, and then consider on a case by case basis according to risk/benefit, including non-stimulant and psychological treatment options, and referral to a tertiary service for second opinion. Add an additional line, “any subsequent initiation of further pharmacological treatment for ADHD, particularly with stimulants, would be advised to commence at a lower dosage, with slower titration and more frequent monitoring.”	Thank you for your comment. The wording of this recommendation has been amended.
South London & Maudsley NHS	Short	24	2	Consider moving this to be the first bullet point, replacing bullet point in line 1 of page 24 in current document.	Thank you for your comment. The wording of this recommendation has been amended.

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South London & Maudsley NHS Foundation Trust	Short	25	5	In addition to “parents and teachers” add patient, as even children and adolescents can do this. And for adults, add partner, friend, family members, for example, as they often provide beneficial information where a adult patients find it hard to self-monitor, or aren't aware of their behaviours/ramifications of their behaviours.	Thank you for your comment. The recommendation should be interpreted on an individual basis. The examples of parent or teacher rating scales are possible methods of measurement.
South London & Maudsley NHS Foundation Trust	Short	26	1	This could applies equally to lisdexamfetamine, so this line should read “stimulant preparation in the morning and an immediate-release stimulant”. Thereafter, with the change suggest below, the complete sentence would read “Think about using immediate- and modified-release preparations of the same treatment to optimise effect (for example, a modified stimulant preparation in the morning and an immediate-release stimulant preparation at another time of the day to extend the duration of effect).”	Thank you for your comment. The wording of this recommendation has been amended.

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South London & Maudsley NHS Foundation Trust	Short	26	2	This line should read "preparation at another time of the day to extend the". Thus, with the change suggest above, the complete sentence would read "Think about using immediate- and modified-release preparations of the same treatment to optimise effect (for example, a modified stimulant preparation in the morning and an immediate-release stimulant preparation at another time of the day to extend the duration of effect)."	Thank you for your comment. The wording of this recommendation has been amended.
South London & Maudsley NHS Foundation Trust	Short	26	26	Medication often leads to lowering of an existing high body mass index over and above any lowering due to reduction in appetite. For example, as a result of adults being better able to plan a healthy diet and resist impulsive urges to snack or binge. Therefore it is not the lowering of body mass index per se that is of concern, as someone might make these positive dietary habits and move from "overweight" to "normal" BMI category, and stabilise there. The concern would therefore be when the weight loss continues, not stabilising, and the person then falls further into the "underweight" category, or where the person is already	Thank you for your comment. Additional information on monitoring weight has been added to the committee's discussion of the evidence in evidence report D to clarify when weight loss is of concern.

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				in the "normal"/"underweight" category and weight loss follows initiation of treatment.	
South London & Maudsley NHS Foundation Trust	Short	27	20	We have not been able to source centile charts for adults - please provide a reference, or for adults suggest cut off values for BP readings as per NICE guidance on hypertension which has categories of stage 1, stage 2 and severe hypertension.	Thank you for your comment. The wording of this recommendation has been amended.
South London & Maudsley NHS Foundation Trust	Short	28	19	We would suggest adding "NB, always refer back to sleep pattern information gained from patient prior to initiation medication to ensure reported poor sleep is related to medication and not patient reflecting on a longer term problem. And consider referral to a specialists sleep clinic for longer term sleep conditions."	Thank you for your comment. This information has been added to the committee's discussion of the evidence in evidence report D.
South London & Maudsley NHS	Short	29	16	Whilst treatment may not change "personality", it can alter how people present to others, for example with reduced verbosity, or more reserved behaviour in someone who was previously gregarious, and this	Thank you for your comment. Additional text on this recommendation has been

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Foundation Trust				should be acknowledged and discussed with the patient when treatment is reviewed, as it may impact on patient choice in terms of dosing, and discussion may prevent someone stopping treatment if they didn't think this was being acknowledge as "real" by the treating clinician.	added to committee's discussion of the evidence in evidence report B.
South London & Maudsley NHS Foundation Trust	Short	31	3	I would be helpful to define "ADHD specialist", as this may be taken as someone who works in a specialist service. With appropriate training and referral pathways back to specialist services when necessary, reviews could be undertaken by GPs/practice nurses in primary care, or care-coordinators in secondary care, for example. This would enable stable patients to be discharge from caseloads of specialist clinics where they are stable and happy so to do. Without such patients being discharged from specialist services, particularly adult services where treatment may continue for decades, then caseloads will be growing continually, resulting in demand quickly outgrowing supply, ever lengthening waits for new patients to	Thank you for your comment. The committee agree that an ADHD specialist is not limited to a consultant psychiatrist and could include nurse specialists who correctly trained. Recommendation 1.1.3 that was not updated describes an ADHD specialist as someone who is an appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD. Using the term ADHD specialists reflects this rather than stating a professional role.

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				access services, and services which aren't sustainable..	
South London & Maudsley NHS Foundation Trust	Short	32	4	Add in adult focussed suggestions, such as "seating arrangements at school/college or use of quiet areas or separate offices in the workplace, changes to lighting and noise, the use of headphones in the workplace where suitable in order to block out distraction, support to establish routine, access to technology to support academic or work activities, such as electronic diaries, dictation and note taking software, setting boundaries around time or access to mobile devices" for example.	Thank you for your comment. Further examples have been added to the explanation of environmental modifications.
Sussex Partnership NHS Foundation Trust		22	6	We feel the shift from Methylphenidate to Lisdexametamine as first line of treatment is positive.	Thank you for your comment. After taking into consideration the stakeholders' comments on this issue the committee agreed that methylphenidate should be included alongside lisdexamfetamine as an option for the first line medication treatment in adults.

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Sussex Partnership NHS Foundation Trust	Short	General	General	In general we welcome the updates in the guidance.	Thank you for your comment.
Sussex Partnership NHS Foundation Trust	short	7	4	We welcome the increased awareness of high risk groups believe this will lead to improved outcomes and prevent late diagnosis.	Thank you for your comment. .
Sussex Partnership NHS Foundation Trust	short	31	3	We have been implementing medication reviews at least annually in the adult specialist clinic in one part of the Trust and this has led to an increasing caseload which has impacted on the service's capacity to offer sufficient new diagnostic assessments. There is now a significant wait for these. We recognise the importance of the review as a chance to initiate a drug holiday and assess response off of medication and to assess ongoing need for medication. Particularly for older	Thank you for your comment. Section 1.1 was not included in this update of the guideline and the recommendations supporting shared care arrangements with primary care remain in the guideline. Section 1.10 is clear that an ADHD specialist should review ADHD medication at least once a year. The other recommendations on the monitoring and maintenance of treatments in section 1.8 are not as specific about who should be

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				<p>patients taking multiple other meds that potentially interact and impact on physical health. We would be interested in evidence as to the outcomes for patients being reviewed by professionals outside of the specialist team when weighed against the impact for those who are waiting a long time for a diagnosis. Although we agree on the importance of those reviews being undertaken by a specialist, we would be interested in any evidence or advice for our commissioners for some patients being reviewed by professionals outside of the specialist team (with possible consultation from a specialist) when weighed against the impact for those who are waiting a long time for a diagnosis.</p>	<p>responsible and the committee recognise there are different service models in and this could be undertaken in primary care. The committee discussed that it was important that specialist services remained aware of people with ADHD so they could have rapid access back to the services in time of crises.</p> <p>The committee's discussion of the evidence in evidence report D and H provide further detail about the committee's experience of good practice in monitoring. Further discussion on the committee's recommendations about shared care arrangements have been added to the "Why the committee made these recommendations" section of evidence report H.</p>
Tees Esk and Wear Valleys NHS	Short	General		Medication Choice: Lisdexamfetamine is recommended as second medication of choice ahead	Thank you for your comment. The committee agreed that the evidence justified this recommendation, given the effect profile of atomoxetine and the costs

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Foundation Trust				of Dexamfetamine and Atomoxetine. Is evidence robust enough for such a recommendation	of dexamfetamine. More detail on the rationale for these recommendations can be found in the relevant evidence reports.
Tees Esk and Wear Valleys NHS Foundation Trust	Short	General		The Guidance does not refer to comorbidity as an criterion for choice of medication and the first three choices are stimulants- is the evidence robust enough for what seems to be paradigm shift	Thank you for your comment. The section on general prescribing information outlines the importance of considering people with ADHD and co-existing conditions. The committee agrees that personal preferences will feed into decisions about appropriate medications and a shared treatment and person centred approach is reinforced throughout the guideline. The treatment pathway identified by the committee is the most appropriate default set of steps to consider and is based on the clinical and cost effectiveness of the evidence and the committee's experience. Recommendations are intended to be interpreted in the context of each individual person.

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Tees Esk and Wear Valleys NHS Foundation Trust	Short	5	8-24	Evidence on whether the Multi-Agency groups advised in 2008 guidance have been formed in any localities.	Thank you for your comment. The implementation of the 2008 guideline is out of the remit of the committee.
Tees Esk and Wear Valleys NHS Foundation Trust	Short	7	18	Two recent training courses (via UKAAN) suggested ADHD in psychosis is an extremely rare comorbidity – Hence, is 'psychosis' the best example of a comorbid mental health condition in ADHD in this context	Thank you for your comment. The wording of this recommendation has been amended.
Tees Esk and Wear Valleys NHS Foundation Trust	Short	10	13-14	Given the differences in stringency of diagnostic criteria between dsm5 and ICD10, would the guidance recommend any classificatory system over the other.	Thank you for your comment. Diagnosis is not part of this update for the guideline.

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Tees Esk and Wear Valleys NHS Foundation Trust	Short	11	16-19	This is vague – would referral to Adult ADHD support group be appropriate for someone that doesn't meet criteria for diagnosis? - Are there any examples available of the type of 'appropriate' group this refers to?	Thank you for your comment. The wording of this recommendation has been amended.
Tees Esk and Wear Valleys NHS Foundation Trust	Short	12	2-4	This suggests disclosure to DVLA regarding diagnosis is optional only if driving is affected? Our understanding is an ADHD diagnosis is a disclosable condition to the DVLA according to DVLA Website. Requires clarification	Thank you for your comment. The wording of this recommendation has been amended to clarify that driving may be affected by ADHD symptoms. The committee has added and ADHD medication may improve this. The recommendation notes that there is a responsibility to inform the DVLA if there are safety concerns about their ability to drive.
Tees Esk and Wear Valleys NHS	Short	16	18-21	Guidance regarding BNF advice on use of medication over 6 years and guidance recommendation on medication in under 5 year old children.	Thank you for your comment. The committee made the recommendations for 5 years and over based on the decision on school age in England and Wales. There is limited evidence in this age group and the

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Foundation Trust					committee extrapolated from the published evidence. The footnotes in the guideline make the licensing status of the ADHD medications more explicit.
Tees Esk and Wear Valleys NHS Foundation Trust	Short	20	15-16	Clarify that the advice of ECG when Tricyclics and MAO-I are used is in case of adults with ADHD	Thank you for your comment. The recommendation you highlight applies to all age groups.
Tees Esk and Wear Valleys NHS Foundation Trust	Short	22	5-7	Lisdexamfetamine as first choice among medication for adults- Is evidence robust enough for such a recommendation. Cost implication regarding Lisdexamfetamine as first line. Rising cost of Dexamfetamine (Is there a dearth of convincing evidence base available to support this?) Is drug licencing and quicker onset of action strong enough reasons for such a recommendation? Should	Thank you for your comment. The committee agrees that personal preferences will feed into decisions about appropriate medications and a shared treatment and person centred approach is reinforced throughout the guideline. The treatment pathway identified by the committee is the most appropriate default set of steps to consider and is based on the clinical and cost effectiveness of the evidence and the committee's experience. Recommendations are intended to be

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				<p>there have been a greater sophistication of thinking when advising choice of medication.</p> <p>Atomoxetine is only product licensed for initiation and may be preferred choice for some.</p> <p>Patient preference may include not wanting to consider stimulants non-stimulant i.e. Atomoxetine as a first line treatment has proven in our clinical practice area to be very effective option in many cases, including where there has been a comorbid mood or anxiety problem and or risk of misuse/diversion.</p>	<p>interpreted in the context of each individual person.</p> <p>After taking into consideration the stakeholders' comments on this issue, the committee agreed that methylphenidate should be included alongside lisdexamfetamine as an option for the first line medication treatment in adults.</p>
The Association for Child and Adolescent	Methodology	11	3 and following	<p>Search strategy: Searches for evidence were limited to published trials. We were concerned that this may limit the representativeness of the findings especially with regard to unpublished information that could have been requested to drug companies.</p>	<p>Thank you for your comment The committee acknowledge that publication bias may be a concern in ADHD</p>

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Mental Health (ACAMH)					research and that this is not unusual across health related research. NICE have established methods for determining the likely presence of publication bias (please see the methodology section of the guideline) and it is unusual to make requests for additional unpublished information in the absence of definitive publication bias and presence of considerable amounts of published evidence. The committee were aware that the majority of studies included in the pharmacological reviews were funded by pharmaceutical companies and took this into account in their assessment of the evidence.
The Association for Child and Adolescent Mental	Short	N/A	N/A	Access to services for individuals with ADHD are severely restricted in the NHS. Many individuals who need help do not get it and even when referred have to wait a long time for diagnosis and treatment. In a way this issue was the clinical elephant in the room in the guidance. It would have been good to see some recommendations about how it could be addressed.	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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Health (ACAMH)				How can identification be improved, referral processes by made more efficient and waiting	
The Association for Child and Adolescent Mental Health (ACAMH)	Short	22 24 24	2 3 12	<p>Medication</p> <p>In general we felt the recommendations regarding medication were consistent with evidence-based best practice. However, we had a number of concerns.</p> <p>1) Definition of non-response: What is the evidence/rationale for the “6-week” definition of non-response before switching from 3 lisdexamfetamine and methylphenidate?</p> <p>2) Antipsychotics: Atypical antipsychotic (for example, risperidone) are to be considered in addition to stimulants for children aged 5 years when coexisting pervasive aggression, rages or irritability co-present. Many clinicians now prefer aripiprazole: should this be mentioned more clearly?</p> <p>3) Individual differences in drug response: The current description on this matter is vague and not helpful for the clinician. Could the issues relating to</p>	<p>Thank you for your comments</p> <p>Definition of non-response and switching</p> <p>No evidence was identified to support a specific time point and the 6-week trial decision was based on the committee's experience and agreed through consensus. The committee agree that it is difficult to generalise and to define a specific time point when to consider switching. All treatment decisions should be made with the person taking medication and take into account how they feel their medication is having an impact on their ADHD symptoms. The committee agreed that 6</p>

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		28	17	<p>effect size, duration of action and levels of adverse effects be specified more clearly?</p> <p>4) Sleep adverse events: The current advice in terms of monitoring of sleep related adverse events is vague and not helpful to clinicians. It could be improved through elaboration. (e.g., adding small doses of stimulants at night may be beneficial for some patients, if sleep onset delay is caused by ADHD symptoms due to wearing off effects)5.</p>	<p>weeks is enough time to optimise the medication and to know if it is reducing any impairment. Six weeks allows the time to titrate medication and to avoid rapid decision making in changing medication but equally is not a prolonged time on a medication that may not be effective. There is additional information in the dose titration section of the guideline.</p> <p>Antipsychotics</p> <p>This recommendation has been amended and reference to any specific medication has been removed. The committee view was that the evidence did not justify distinguishing between antipsychotics and appropriate choice of prescribing in that context would be down to individual prescribers, as you point out this varies between healthcare professionals.</p>

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					<p>Individual differences in drug response</p> <p>The committee agreed that it was difficult to be precise or generalise about the duration of effect and the recommendation raises awareness to prescribers that individuals respond differently to stimulants and this should be taken into account when initiating and optimising medication. There are further details on the impact of stimulants in the dose titration section, the monitoring sections and in the committee's discussion of the evidence in evidence report D</p> <p>Sleep adverse events</p> <p>In the committee's discussion of the evidence in evidence report D. The committee note the importance of monitoring the impact of medication on sleep. The committee have not provided</p>

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					any specific examples noting that any adjustment in dosing or timing would be tailored to the individual..
The Association for Child and Adolescent Mental Health (ACAMH)	Short	7	22	Under recognition of ADHD in females: It was good to see specific mention of this important issue. However, little is known about why ADHD is under-recognised in females. This seems like an area ripe for study within the NHS	Thank you for your comment. The area you highlight is interesting but was not prioritised by the guideline committee as a research recommendation. Research recommendations in NICE guidelines are intended to identify high priority areas where new recommendations could be generated as a consequence of further research, the committee chose to make consensus based recommendations in this area with the currently available evidence base. The committee focused on treatment options.
The Association for Child and Adolescent Mental	Short	8	8 and following	Acknowledging the growing evidence base on PT and ADHD: As in the previous guidance on matters relating to PT the document repeatedly defers to prior NICE guidance on the management of anti-social behaviour and conduct disorder when talking about PT. This was disappointing as a number of large scale,	Thank you for your comment. The guideline did consider evidence explicitly in the ADHD population for parent training. A number of the trials included in the meta-analysis you reference were included in our own analysis. Please see the relevant reviews for the full list of included studies

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Health (ACAMH)				<p>high quality trials and well conducted systematic reviews and meta-analyses that provide good evidence of the benefits (or not) of PT specifically for children with ADHD, have been published in the last five years¹. Although often comorbid ADHD and conduct disorder are different disorders and disorder specific approaches to PT may be indicated.</p> <p>1.Daley D, Van der Oord S, Ferrin M et al. Behavioral Interventions in Attention-Deficit/Hyperactivity Disorder: A Meta-Analysis of Randomized Controlled Trials Across Multiple Outcome Domains. J Am Acad Child Adolesc Psychiatry 2014;53(8):835-847.</p>	<p>and excluded studies with reasons given. The committee interpreted the evidence in ADHD specific trials in the context of current clinical practice which includes the current NICE recommendations on the management of anti-social behaviour and conduct disorder.</p>
The Association for Child and Adolescent Mental	Short	8	24	<p>Group versus individually delivered PT: As in previous guidance the value of group-based PT is highlighted as the norm repeatedly throughout the document. Individually-based approaches are presented as the exception to be implemented in special circumstances. We assume that this is based on data from RCTs of PT for conduct disorder. There is no evidence that group-based PT is more effective than individually delivered PT and also no evidence</p>	<p>Thank you for your comment. The committee considered the status of group compared to individually delivered programmes as a subgroup analysis across the relevant reviews. There was no evidence identified in any of the reviews that demonstrated heterogeneity within a meta-analysis that was resolved by separation into group and individually</p>

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Health (ACAMH)				<p>that it is less costly. In fact in a recent RCT a group-based PT approach (Incredible Years) was more costly than a individually delivered approach (New Forest Parenting Package) ³. Furthermore many parents expressed a preference for individually delivered over group based approaches. We would suggest highlighting that both forms of PT should be made available.</p> <p>³Sonuga-Barke EJS, Barton J, Daley D, Hutchings J, Maishman T, Raftery J, Stanton L, Laver Bradbury C, Chorozoglou M, Coghill D, Little L, Ruddock M, Radford M, Yao GL, Lee L, Gould L, Shipway L, Markomichal P, McGuirk J, Lowe M, Perez Vallejos E, Lockwood J Thompson MJJ (in press). The clinical effectiveness and cost of specialised individually-delivered and generic, group-based parenting programmes for preschool attention-deficit/hyperactivity disorder: A multi-centre, randomised controlled-trial comparing the New Forest</p>	<p>delivered programmes. The consensus of the committee was that as a starting point, group treatments could be equally effective as individual treatments. However, they recognised that in some situations that may not be the case and made recommendations to consider individual treatments in these situations. The trial you reference was not published prior during the development of this guideline.</p> <p>As there wasn't any evidence to suggest a difference in effectiveness, the least costly would be the dominant intervention. No economic evaluations were identified looking at parent training programmes (the reference mentioned we assume is not published yet as cannot be sourced). Resource use that was costed for either group or individual treatment was elicited from the guideline committee.</p>

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				Parenting Programme and Incredible Years. European Child Adolescent Psychiatry	
The Association for Child and Adolescent Mental Health (ACAMH)	Short	16	13 and following	<p>What is the value of PT when used in the treatment of ADHD? The guidance fails to clearly define the purpose of parent training for ADHD. Recent meta-analyses conducted by the European ADHD Guidelines Group^{1,2} demonstrate that PT does not reduce core ADHD symptoms in the short term (at least as measured by probably blinded raters). However, there is good evidence that PT improves parenting and reduces oppositional and defiant problems¹. The EAGG have therefore argued that PT is an important component of ADHD treatment – given the common co-presentation of conduct problems alongside ADHD. It would be good to clarify this point for clinicians.</p> <p>1.Daley D, Van der Oord S, Ferrin M et al. Behavioral Interventions in Attention-Deficit/Hyperactivity Disorder: A Meta-Analysis of Randomized Controlled</p>	Thank you for your comment. The committee agree that in some situations and analyses as you highlight, parent training was not shown to have a clinically important benefit on some core symptoms, although this was not universal. Overall the committee considered the evidence of parent training's efficacy sufficient to warrant recommendations. The committee's discussion of the evidence in the in evidence report E discusses some of the situations in which non-pharmacological treatment (for example, parent training) may be expected to have particular benefit (for example, for function/behavioural outcomes). The committee acknowledged the importance of

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				<p>Trials Across Multiple Outcome Domains. J Am Acad Child Adolesc Psychiatry 2014;53(8):835-847.</p> <p>2.Sonuga-Barke EJ, Brandeis D, Cortese S et al. Nonpharmacological interventions for ADHD: systematic review and meta-analyses of randomized controlled trials of dietary and psychological treatments. Am J Psychiatry 2013;170(3):275-289</p>	<p>these effects by including it as a treatment recommendation.</p> <p>All the parents and carers of children under 5 years are still offered ADHD focused parent training. This was supported by limited cost effectiveness evidence and the guideline committee's clinical experience.</p> <p>All the parents and carers of children over 5 years and young people also are offered ADHD focused support that can be group based. Uncertainty around the cost effectiveness of parent training programmes led to a recommendation on ADHD focussed support with less direction on what such a programme may look like for example, it should include "education and information on the cause and impact of ADHD and advice on parenting strategies".</p>

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					Different outcomes can capture different components of the condition or wider symptoms outside of the core symptoms – particularly dichotomous outcomes. The parent training models had different base case analyses due to heterogeneity in the data which may in part be due to the outcome measures used and therefore might be capturing some of the issues you refer to and hence why benefit might be picked up more on some measures rather than others.
The Association for Child and Adolescent Mental	Short	18	20 and following	The guidance is largely dismissive of the value of dietary interventions – exclusions and supplements. A number of high quality meta-analyses suggest small but robust effects of Fatty Acid Supplements and suggest overall positive but heterogeneous effects of exclusion diets of various sorts with food intolerant patients ⁴ . It would be good to see the guidance relating	Thank you for your comment. This section was not identified as requiring an update during the scoping phase of the guideline so we are unable to make the change you suggest.

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Health (ACAMH)				<p>to diet to be modified to take this evidence into account.</p> <p>⁴ Stevenson J, Buitelaar J, Cortese S et al. Research Review: The role of diet in the treatment of attention-deficit/hyperactivity disorder - an appraisal of the evidence on efficacy and recommendations on the design of future studies. J Child Psychol Psychiatry 2014.</p>	
UK Adult ADHD Network	Methodology 3	33-42	Table 4	<p>A couple of important RCTs have not been included into this analysis (and no reason is given why not): Huss et al. 2014, Konstantius et al. 2014, Takahashi et al. 2014, Philipsen et al. 2015, Goodman et al. 2017 (see reference list for details).</p>	<p>Thank you for your comment. Huss 2014 was excluded as only the methylphenidate responders entered the double-blind maintenance effect phase, see the excluded studies table. Konstenius 2014 did not provide any data matching our outcomes in a format that we were able to extract and meta-analyse. Philipsen 2015 is included in both the non-pharma and combination reviews but as all of the 4 arms receive some form of non-pharmacological intervention, it was not included here. Takahashi 2014 was previously excluded but, on revisiting of the</p>

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					studies details, the reviewing team agree it is appropriate for inclusion and it has now been added to the review, although this has not substantially affected the evidence base or the recommendations. It is unclear from your comment what study "Goodman 2017" refers to but also given the dates, it is possible that it was published after our final evidence searches.
UK Adult ADHD Network	Methodology 3	6	26-27	We really don't understand what is meant with the statement the use of stimulants "in adults is still limited"? Every clinician who treats adults with ADHD knows that stimulants are one of the best treatments in psychiatry.	Thank you for your comment, the use of limited was meant in comparison to the use of stimulants in children. The text has been amended.
UK Adult ADHD Network	Methodology 3	6	27-28	We agree with the guideline authors that it "remains an anomaly that many drugs that are considered to be safe and effective in children and young people are not licensed for the use in adults" – the logical consequence of this anomaly is that the licensing status of a medication should not be more important than the clinical evidence.	Thank you for your comment. After taking into consideration the stakeholders' comments on this issue the committee agreed that methylphenidate should be included alongside lisdexamfetamine as an option for the first line medication treatment in adults.

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UK Adult ADHD Network	Methodology 3	120	30-32	The cost utility analysis of Zimovetz et al. 2017 has indeed “serious limitations” and it is a wrong conclusion to say that “lisdexamfetamine was dominant” because the costs for LDX and MPH-ER were similar; a difference of £5 per year is negligible and average treatment costs for LDX are higher.	Thank you for your comment. Although the difference in cost is small, it is not wrong to refer to an intervention that is less expensive and more effective as dominant based on the rules of cost effectiveness. Average treatment costs in terms of medication costs are more expensive for Lisdexamfetamine; however, the higher response rate led to lower (albeit just) overall costs because fewer non-responders meant other resource use costs were lower.
UK Adult ADHD Network	Methodology 3	111	14	There is an obvious error in the line: “methylphenidate” should be replaced by “lisdexamfetamine”	Thank you for your comment. We have checked page 111, line 14 of evidence report 3 but cannot find the error that you have identified.
UK Adult ADHD Network	Short	22	6-9	We welcome that lisdexamfetamine (LDX) is now available for the treatment of adults with ADHD. We support that it should be added to the other first-line treatment options, but do not agree that it replaces the	Thank you for your comment. A rating of potentially serious limitations for the Zimovetz study reflects factors such as the conflict of interest and the clinical data in

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				<p>options that have been used for decades and form the mainstay of treatment of ADHD in adults.</p> <p>We are concerned that the decision to recommend LDX as the only first-line treatment for adults with ADHD reduces treatment choices for patients and limits the prescribing practices of clinicians. This "one size fits all" recommendation would make it difficult to develop individualised treatment plans for adults with ADHD. It also undermines a shared-decision making process (between patient and clinician), and would discourage detailed discussions about the different types of medication available for the treatment of ADHD.</p> <p>More importantly the decision to recommend LDX as the only first-line medication is based on (a) questionable evidence, (b) a clearly biased cost-efficiency analysis (Zimovetz et al. 2017) and (c) it is not supported by experienced UK clinicians.</p> <p>(a) There are only 3 published placebo-controlled clinical trials for LDX in adults with ADHD (Adler et al.</p>	<p>the NMA included studies that were not included in our own clinical review. It is also acknowledged that the results showed small incremental costs and QALYs, however as the guideline has not conducted an NMA it is difficult to compare the inputs into the study with the indirect clinical review data to know for certain if there is a bias.</p> <p>Lisdexamfetamine has higher drug costs but as lisdexamfetamine was shown to have a higher response rate, this led to less other resource use costs (associated with fewer non-responders), hence similar costs in the end. The sentence quoted has also been changed to "<i>was likely</i> to be dominant".</p> <p>Drug costs using BNF doses also show that a maximum dose of lisdexamfetamine is less costly than maximum doses of extended release methylphenidate formulations; although, once again this needs to be weighed up against the clinical</p>

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				<p>2008, DuPaul et al. 2012, Adler et al. 2013) compared to more than 29 for methylphenidate (MPH) that have been meta-analysed several times (eg Castells et al. 2011). The evidence presented in this guideline seems to be biased against MPH. It looks like the decision to recommend LDX first-line is mainly based on the fact that LDX has a full adult license rather than being based on evidence from head-to-head RCTs (comparing LDX and MPH) or a network meta-analysis. In our opinion, the evidence for MPH is more solid than for LDX and both medications should be recommended as first-line treatment for adults with ADHD.</p> <p>(b) The draft guideline first states that Zimovetz et al. 2017 “has potentially serious limitations”, but then goes on to make conclusions and recommendations that are based on this paper (“one economic evaluation for adults was identified comparing</p>	<p>benefit of both drugs and this was difficult without a network meta-analysis.</p> <p>After taking into consideration the stakeholders’ comments on this issue the committee agreed that methylphenidate should be included alongside lisdexamfetamine as an option for the first line medication treatment in adults. This was also based on the committee’s clinical experience and they agreed stimulants are the most effective treatment and when medication is required stimulants should be first line.</p>

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				<p>lisdexamfetamine to extended release methylphenidate and atomoxetine, and found that lisdexamfetamine was dominant”). The Zimovetz et al. 2017 cost-efficiency analysis cherry-picks evidence in a biased way in favour of LDX and is not a piece of robust research. The authors (two of them employees of Shire) modelled the costs and benefits for 1 year of treatment with LDX vs extended-release methylphenidate (MPH-ER) vs atomoxetine and found that MPH-ER was £5 more expensive per year than LDX – this is a negligible difference. Average daily treatment costs of LDX are, however, higher than for MPH-ER in the UK (BNF 2017). LDX is more expensive than MPH-ER and has less positive evidence than MPH-ER. In our opinion, the fact that LDX has a full license for use in adults should not outweigh its worse evidence-base and higher costs.</p>	

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				<p>(c) In a symposium on “Medication management in ADHD – key updates” at the UKAAN conference on 23 Oct 2017 draft NICE guideline recommendations were presented to an audience of more than 100 clinicians. Most of these clinicians did not support the recommendation to use LDX as first-line medication for adults with ADHD. There was clear consensus among clinicians that all stimulants (with the exception of Dexamfetamine, due to high price, addictive potential and risk of deviation) should be recommended as first-line medication for adults with ADHD. The draft guideline recommendation is not supported by a representative sample of experienced UK clinicians.</p> <p>While NICE is about to introduce a ground-breaking change to the treatment of ADHD in adults in the UK (and around the world, where NICE guidelines are translated into national guidelines), the recommendation to use LDX first-line is not supported</p>	

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				by sound research evidence and experienced clinicians.	
XCD Consulting Services Ltd, T/A BrainTrainUK	5 - Evidence review E: non-pharmacological efficacy and adverse events	118	32-39	<p>We question whether the committee has sufficient knowledge of current practice or clinical experience of neurofeedback to make the judgement to take 'into account current practice and their clinical experience' when deciding not to make specific recommendations for the use of neurofeedback.</p> <p>We are also concerned that the evidence reviewed does not represent contemporary neurofeedback clinical practice.</p> <p>This is despite our reaching out to leading UK academics including committee membership to offer to provide an overview of current practice and evidence. This offer has been made several times during this evidence-gathering process.</p>	<p>Thank you for your comment. The committee agreed that there was insufficient evidence to recommend the use of neurofeedback for the treatment of ADHD as there were trials in the area but they were small and in general showed no clinically important benefit. Following consultation, the have added a research recommendation to evaluate neurofeedback in further, high quality research.</p> <p>Thank you for your offer of an overview of current practice and evidence, it is outside of the NICE process to accept evidence from specific stakeholders without a call for evidence (see Developing NICE guidelines: the manual for further details). Individual committee members are not in a position to accept approaches from individual stakeholders. The committee also considered that they have a good</p>

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				<p>This offer is still open to the committee and we believe that without this input, this review of guidelines review will not be fair and reasonable.</p> <p>In order to create real-life comparative data we would urge the committee to recommend commissioning 'real-life' trials involving randomised controlled trials of contemporary neurofeedback modalities compared with other established treatment options, including a measure of long-term effects 12 months after treatment ends.</p> <p>We would be pleased to advise and support such trials, and hold ourselves available to provide further information and support as requested.</p>	<p>understanding of current neurofeedback clinical practice and evidence.</p>

ⁱ http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGBR%2fCO%2f5&Lang=en

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