Attention Deficit Hyperactivity Disorder (update)
Consultation on draft scope
Stakeholder comments table

8 January 2016 – 5 February 2016

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
East Kent Hospitals University NHS Foundation Trust	General	General	The 2008 guidelines do not directly address the issue of inattentive ADHD. I suspect this is probably because ICD-10 only really thinks in terms of hyperactive and impulsive symptoms, and as such misses out on the inattentive children, whereas DSM-5 acknowledges that this is a significant issue. It looks as if inattention is being put into ICD-11, but possibly as a separate construct. The inattentive children can have major academic problems, often have social and coordination difficulties, are frequently overlooked or described as being lazy or lacking ability, and generally have been getting a raw deal because they are not presenting as an "in-your-face" problem. This needs to be redressed. Many can be helped with understanding and stimulant medication. It should also be noted that most non-pharmacological interventions are geared towards managing behaviour and therefore not relevant to these children as many do not have any behaviour problems.	Thank you for your comment. We agree and section 3.2 of the scope describes the difference in symptoms required for diagnosis between ICD-10 and DSM-5. When reviewing the evidence for pharmacological and non-pharmacological interventions hyperactivity and inattention will be identified as subgroups where considered appropriate by the guideline committee. The guideline committee will then be able to consider any identified differences in the evidence for the effectiveness interventions for these groups.
Association of Educational Psychologists	General	General	I am writing on behalf of the Professional Policies Subcommittee of the Association of Educational Psychologists. We welcome the opportunity to give feedback on the scope consultation on the review of the ADHD guidelines. 1. We think that reference should be made, when referring to the role of psychologists, to the role of educational psychologists as well as clinical psychologists. 2. We think that it should be made clear that the scope will include a new look at the appropriate balance between and priority of psychological and pharmacological interventions, with psychological work taking precedence, before, during and after any medication. 3. We think that there should be a confirmation of both the diagnostic age and the intervention floor of age >6+ for the identification and consideration of medication of ADHD. 4. Further, there should be a scope for further clarifying the differential diagnosis of ADD as distinct from ADHD.	Thank you for your comments. 1. Both clinical and educational psychologists have been included in the guideline committee constituency and both views will be represented during the development process. 2. Sections 1.3 and 1.5 of the scope outlines that the evidence for the effectiveness of pharmacological and non-pharmacological interventions will be reviewed. This includes the most effective combination and sequencing of these interventions. 3. Diagnosis is not included in the scope for the update of this guideline. Intervention floor-age will be considered by the guideline committee in the review of the evidence for the pharmacological interventions. 4. The diagnosis of ADHD or any differential

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				diagnosis is not being addressed in this update.
Association for Family Therapy and Systemic Practice in the UK	General	General	I would like it to be noted that there is a whole alternative narrative to the medico-diagnostic dominant idea about ADHD being "real" and being located in the mind of the patient. In my 25 years experience of this I have never met a single ADHD diagnosed person who does not have a life story to explain his (sic) symptoms. Therapeutic focus therefore should be systemic, working with the sufferer's family or carers, or taking account of other significant factors in his life which will have contributed to his distress. It is particularly important with this diagnosis to carefully consider the contexts (current and historical) in which inattention, hyperactivity and impulsivity occur, and to tailor interventions accordingly. There needs to be scope within any treatments or treatment programmes for the particular difficulties experienced by the particular child / young person / adult and their family and the contexts within which these occur, to be the focus of interventions rather than interventions designed to treat a diagnosis which is contentious. The NICE guideline scope document notes that *"Research indicates that at least 70% of people with ADHD have at least 1 other comorbidity"* page 8 lines 227-228. This again would support a highly personal contextual focus to intervention.	Thank you for your comment. We agree and Section 1.3 of the scope includes both pharmacological and non-pharmacological interventions and section 1.5 includes draft questions for the guideline committee to consider which address the sequencing and combinations of interventions. When considering the evidence the guideline committee will be able to consider the impact on different subgroups of people. In addition NICE guidelines note that clinicians should always consider the individual circumstances and take these into account when deciding on treatment.
Eli Lilly and Company	General	General	The diagnosis of ADHD should be updated and reference made clearly to the changes from DSM4 to DSM 5.	Thank you for your comment. The diagnosis of ADHD is not being addressed in this update. The surveillance review undertaken as part of the NICE update process did not identify any additional evidence that would impact on the current diagnosis section of the guidelines. This has been confirmed by stakeholders at the stakeholder workshop. However references to DSM-4 will be amended to DSM-5 where appropriate. Section 3.2 of the scope clarifies the changes from DSM-4 to DSM-5.
Eli Lilly and Company	General	General	In all sections especially pharmacological interventions distinctions should be clearly drawn to separate out adult and child ADHD data and recommendations.	Thank you for your comment. We agree and where appropriate in the evidence reviews and if possible adult and child data will be evaluated separately.
Eli Lilly and Company	General	General	Sections should be included on relapse prevention by medication and importantly the subsequent implications of stopping medications.	Thank you for your comment. We agree and Section 1.3 of the scope includes both pharmacological and non-pharmacological interventions and section 1.5 includes draft

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				questions for the guideline committee to consider which address adherence issues in this population and issues around stopping medication.
British Academy of Childhood Disability (BACD)	General	General	There is an opportunity to address assessment and management of ADHD when it, as it very frequently does, co-occurs with Autistic Spectrum Disorder (ASD). This is a complex area as both can appear very similar. There is also a big issue for this group in parts of the country where ASD comes under Child Development Centres (paediatrics) and ADHD (Child & Adolescent Mental Health Services) as the child often ends up under both services due to service specs and commissioning practice, for what is in reality part of one neuro-developmental disorder (or mental health disorder!) in that child. Guidance from NICE could really help to improve the patient and family journey for this group of children.	Thank you for your comment. We agree that people with ADHD often have concurrent conditions and Section 1.1 of the scope identifies the population as 'children and young people and adults with a diagnosis of attention deficit disorder hyperactivity disorder (ADHD). This includes people with a co morbid condition such as: • a defined neurological disorder • a mental health disorder • another neurodevelopmental disorder. The guideline committee will consider the evidence within this context.
British Academy of Childhood Disability (BACD)	General	General	It seems a pity if Qb testing isn't included in the review. It is rapidly coming into use and a review of the evidence for it would be useful.	Thank you for your comment. The diagnosis of ADHD is not being addressed in this update.
British Psychological Society	General	General	We are pleased with the widening scope and positive intent of this new guideline. We do feel that the term 'Psychological Wellbeing' should be included on at least the one occasion identified above as there is growing evidence of the psycho-social variables that impact on both the onset of such conditions and on the individuals psychological resilience to develop 'coping strategies.' This is both for the condition and the side effects of the chosen drug treatment.	Thank you for your comment. Wellbeing is a broad concept and in the list of main outcomes (section 1.6) there are outcomes to measure aspects of wellbeing. These include quality of life, peer and family relationships, self-esteem and perceived control of symptoms. In addition the list of outcomes is not an exhaustive list. The guideline committee will consider and prioritise outcomes for each review question which could include outcomes that are specific to each question.
British Association for Adoption and Fostering	General	General	This response is being submitted on behalf of the CoramBAAF Health Group, which is also a special interest group of the Royal College of Paediatrics and Child Health (RCPCH). The Health Group was formed to support health professionals working with children in the care system, through training, the provision of practice guidance and lobbying to promote the health of these children. With over 500 members UK-wide, an elected Health Group Advisory Committee with representation from community paediatricians working as medical advisers for looked after children	Thank you for your comment. We agree these are a vulnerable group and looked after children have been included in the equalities impact assessment for the guideline and will be given consideration throughout the development process. Where appropriate, the guideline committee may decide to include this population as a subgroup when developing protocols for review questions.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			and adoption panels, specialist nurses for looked after children, psychologists and psychiatrists, the Health Group has considerable expertise and a wide sphere of influence. Our area of concern is the particularly vulnerable group comprised of looked after and adopted children and young people.	
Royal College of Pathologists	General	General	I am writing to inform you that the Royal College of Pathologists does not have any comments to make.	Thank you.
Royal College of Nursing	General	General	The Royal College of Nursing welcomes proposals to update this guideline. The RCN invited members who care for people with this condition to comment on the draft scope. The comments below reflect their views.	Thank you.
Royal College of Nursing	General	General	The draft scope seems comprehensive.	Thank you.
Royal College of Paediatrics and Child Health	General		Treatment personalised to the childs /young persons needs will have the best outcome	Thank you for your comment. We agree and NICE guidelines note that clinicians should always consider the person's individual circumstances and take these into account when deciding on treatment.
Royal College of Paediatrics and Child Health	General		There is an opportunity to address assessment and management of ADHD when it, as it very frequently does, co-occurs with Autistic Spectrum Disorder (ASD). This is complex area as both can appear very similar. There is also big issue for this group in parts of country where ASD comes under Child Development Centres (CDCs) (paediatrics) and ADHD under Child & Adolescent Mental Health Services (CAMHS) as the child often ends up under both services due to service specs and commissioning practice, for what is in reality part of one neuro-developmental disorder (or mental health disorder!) in that child. Guidance from NICE could really help to improve the patient and family journey for this group of children.	Thank you for your comment. We agree that people with ADHD often have concurrent conditions and Section 1.1 of the scope identifies the population as 'children and young people and adults with a diagnosis of attention deficit disorder hyperactivity disorder (ADHD). This includes people with a co morbid condition such as: • a defined neurological disorder • a mental health disorder • another neurodevelopmental disorder. The guideline committee will consider the evidence within this context.
Royal College of Psychiatrists	General	General	What is the most clinically and cost-effective non-pharmacological treatment for individuals with ADHD	Thank you for your comment. This question has been prioritised for inclusion of this guideline update.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Royal College of Psychiatrists	General	General	Evidence base for combinations of treatments in ADHD: combination of stimulants and non-stimulants	Thank you for your comment. The committee will review the available evidence with relation to treatment combinations for ADHD and if appropriate the combinations of stimulants and non- stimulants.
Royal College of Psychiatrists	General	General	Will the guidance mention psycho-education as a treatment, children and families and schools need to adjust to the diagnosis and guidance on best way to provide this	Thank you for your comment. Section 1.3 includes non-pharmacological interventions; the list is not intended to be exhaustive and will be reviewed with the guideline committee. The importance of the education system in the treatment of children and young people is acknowledged in the scope under 'who this guideline is for'.
Royal College of Psychiatrists	General	General	While use of dsm5 alongside ICD 10 is understandable for reasons of Systematic Review in the update, the differences in diagnostic criteria in both systems needs to be emphasised.	Thank you for your comment. The differences between in the ICD-10 and DSM-5 diagnostic criteria are noted in section 3.2 of the scope.
HQT Diagnostics	General	General	Dietary Fatty Acids were specifically excluded in the previous guideline CG72 of September 2008 There is evidence that a higher level of certain Fatty Acids reduces the level of ADHD Dietary Fatty Acids should be reviewed as part of this update Evidence: http://www.expertomega3.com/ http://www.fatsoflife.com/	Thank you for your comment. The clinical and cost effectiveness of dietary interventions for ADHD were reviewed separately and updated advice was published in February 2016 on the NICE website. Dietary interventions are not included in the scope for this update. Section 1.3 of the scope clarifies that if appropriate combinations of treatments will be reviewed and his may include dietary interventions combined with pharmacological treatment.
HQT Diagnostics	General	General	There is evidence that a higher level of Vitamin D and Magnesium reduces the level of ADHD Vitamin D and other Vitamins, Minerals and Supplements should be reviewed as part of this update Evidence: http://www.vitamindwiki.com/ADHD+and+Vitamin+D+Deficiency http://www.vitamindcouncil.org/	Thank you for your comment. The clinical and cost effectiveness of dietary interventions for ADHD were reviewed separately and updated advice was published in February 2016 on the NICE website. Dietary interventions are not included in the scope for this update. Section 1.3 of the scope clarifies that if appropriate combinations of treatments will be reviewed and his may include dietary interventions combined with pharmacological treatment.
Neonatal &	General	General	We have no comments on this scope at present.	Thank you.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Paediatric Pharmacists Group (NPPG)				
Tees, Esk and Wear Valleys NHS Foundation Trust	General		What is the most clinically and cost-effective non-pharmacological treatment for individuals with ADHD.	Thank you for your comment. This question has been prioritised for inclusion of this guideline update.
Tees, Esk and Wear Valleys NHS Foundation Trust	General		Evidence base for combinations of treatments in ADHD: combination of stimulants and non-stimulants.	Thank you for your comment. This question has been prioritised for inclusion of this guideline update.
Tees, Esk and Wear Valleys NHS Foundation Trust	General		Will the guidance to include best ways of swapping from 1 medication to another and best practice for timescales to do this?	Thank you for your comment. Section 1.3 of the scope states that sequencing of pharmacological interventions will be reviewed. The draft questions for the guideline committee to consider include the sequencing of treatment.
Tees, Esk and Wear Valleys NHS Foundation Trust	General		Will the guidance mention psycho-education as a treatment, children and families and schools need to adjust to the diagnosis and guidance on best way to provide this.	Thank you for your comment. Section 1.3 includes non-pharmacological interventions; the list is not intended to be exhaustive and will be reviewed with the guideline committee. The importance of the education system in the treatment of children and young people is acknowledged in the scope under 'who this guideline is for'.
Shire Pharmaceutical Contract LTD.	Workshop note P11	Scope details column	• The workshop notes, page 11 classify lisdexamfetamine dimesylate (LDX) as a dexamphetamine, however, Shire believes LDX should be included as a separate group. LDX has different mode of action from dexamphetamine, in which lisdexamfetamine dimesylate (LDX) contains a pharmacologically inactive prodrug – after oral administration, the inactive molecule lisdexamfetamine dimesylate is rapidly absorbed from the gastrointestinal (GI) tract and hydrolysed primarily by red blood cells to the active molecule, d-amfetamine. This mode of action allows LDX to be a long acting compound (up to 14 hours), while	Thank you for your comment. Section 1.3 of the scope, under pharmacological interventions in specific treatments to be considered, lisdexamfetamine, dimesylate and dexamphetamine are listed separately.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			dexamphetamine is considered a short acting stimulant. • The mode of action could also be linked to the increase in abuse potential for dexamephetamin.	
Shire Pharmaceutical Contract LTD.	General	General	• Will the available licensed/unlicensed stimulants and non-stimulants dose / combination and add-on therapy treatment be considered for the purpose of this review? • Will this be reviewed in the health economic review?	Thank you for your comment. Section 1.3 of the scope, under pharmacological interventions lists a number of treatments. The list is not intended to be exhaustive and will be reviewed with the guideline committee. Where appropriate additional treatments could be included in the reviews, this may include treatments outside their licensed indications. All the interventions that are considered in the guideline will also be assessed for their cost effectiveness in a health economic literature review.
Shire Pharmaceutical Contract LTD.	General	General	Shire would like to thank NICE for engaging with the stakeholders involved in this review. We appreciate the amount of time and effort invested to speed up the review process. However, we believe that this review should be completed within a shorter time frame than envisaged and would like to ask that these be brought forward. The projected publication timeline for the final document is 2018, which represents a long wait for patients and clinicians, particularly when taking into consideration the fast moving developments and changes in the available licensing and reimbursed products for ADHD, which did not exist at the time of writing the previous guidelines. These include three new pharmaceutical products from Shire alone. Therefore, we believe it would be of great benefit if the timelines for reviews were shorter than the current projection.	Thank you for your comment. The development time for guidelines is determined through NICE processes and is dependent on the size and scope of the topic being covered.
Shire Pharmaceutical Contract LTD.	General	General	• Shire would like to explore the possibility of setting a definition around outcomes that most clinicians should expect from treatment, e.g. would it be possible to aim for the gold standard of remission (. what would NICE define as remission).	Thank you for your comment. The guideline committee considers the most appropriate outcomes to measure effectiveness of the treatments when reviewing the evidence. The committee will define how the data for these outcomes should be extracted (for example at specific time points). The list

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				of main outcomes in section 1.6 of the scope is not an exhaustive list but the main outcomes that are expected to be used within the guideline.
Shire Pharmaceutical Contract LTD.	General	General	• Shire believes that it would be helpful if the guideline had greater details on selection, initiation, titration, monitoring, risks and decision for pharmacological treatments.	Thank you for your comment. Section 1.3 of the scope under the section for pharmacological interventions includes these areas. The draft questions for the guideline committee to consider listed in section 1.5 also include these areas.
Shire Pharmaceutical Contract LTD.	Reference	References	1. Biederman *et al*. J Clin Psychiatry, 2006 2. Young *et al*. Personality and Individual Differences, 2003 3. Pitts M, *et al.* Arch Psychiatr Nurs, 2015 4. 4. Brod M, *et al.* Health Qual Life Outcomes, 2012 5. NICE. ADHD costing report, 2008 6. Moore *et al*. J Atten Disord 2013 7. Ginsberg *et al*. BMC Psychiatry, 2010 8. Rösler *et al*. Eur Arch Psychiatry Clin Neurosci, 2009 9. Lichtenstein *et al*. New Engl J Med, 2012 10. Young SJ, *et al*. BMC Psychiatry, 2011 11. Torgersen T, *et al*. Nord J Psychiatry, 2006 12. Barkley RA, *et al*. J Int Neuropsychol Soc, 2002 13. Barkley RA. The ADHD Report, 2006 14. Knecht C, *et al.* Int J Adolesc Med Health, 2014 15. Biederman *et al*. J Clin Psychiatry, 2006 16. Brod *et al*. Health Qual Life Outcomes, 2012 17. Pitts M, *et al.* Arch Psychiatr Nurs, 2015	Thank you for these references.
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	1	29	The draft scope excludes deaf children and adolescents who have a diagnosis of ADHD. Deaf children are more likely to develop mental health difficulties yet they often struggle to access or receive appropriate assessment and treatment from mainstream mental health services. On the basis of equality, deaf children are a marginalised and vulnerable group.	Thank you for your comment. Deaf children are included in the scope of the guideline update. In addition where appropriate, the guideline committee may decide to include subgroups when developing protocols for review questions.
Shire Pharmaceutic	Draft guideline	Page 4	• The draft scope pages 4 states that all economics evidence will be reviewed and included in the future guidelines. We	Thank you for your comment. The economic implications of alternative interventions will be considered in the guideline. We

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
al Contract LTD.	s Section 1.4 (economic aspects)		would like to clarify if the updated guidelines will include the economics and societal impact. Shire believes that the impact that ADHD has a significant impact on society, we have listed below 3 illustrate: 1) Employment, ADHD is associate with Higher turnover of jobs and periods of unemployment[1,2,3,] it also causes a greater work difficulties – disorganisation, forgetfulness, impulsive talking, problems with authority, inattentiveness/distractibility, confusion anxiety, fatigue and inability to begin or prioritise[3,4] Adult ADHD patients also tend to have their occupation frequently changed and careers rarely developed[2]. Treatment can increase work productivity and performance[5]. 2) Crime rate: The prevalence of ADHD has been estimated to be 10–40% among adult prisoners[6,7,8.] UK prison studies indicate that 24% of male adults screen positive for a childhood history of ADHD[10.] Symptoms of ADHD in adults are associated with higher levels of criminality, arrests and traffic violations, compared with controls[9,11-12.] Data suggest that the rate of adult inmates with ADHD far exceeds that reported in the general population as an underdiagnoses is common. Research reports that criminality may be reduced by one-third if ADHD is treated [9] Relationships impact: ADHD patients have greater difficulties with social functioning and a wide range of relationships compared with controls[15-17.] They are less likely to have good relationship, fit in with peers, have higher divorce rates and will be less satisfied with their social life. Research also shown that genetic link may mean adults with ADHD have family members who also have ADHD, which will have an impacting on how the	will adopt an NHS and Personal and Social Services perspective when assessing the cost and cost effectiveness of interventions; however, we will also consider intervention costs falling on the education sector. We will not include productivity costs since if they were included in NICE Guidelines, those interventions aimed at the working population would be favoured and we would discriminate against the elderly, children, unemployed people and people who are unable to work. Other non-health related outcomes will be looked at in the clinical reviews; in fact our list of main outcomes in section 1.6 of the scope does include social aspects such as relationships and risky behaviour.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			family functions and the degree of support it may need[16] Based on the examples above, Shire believes that ADHD patients will have a significant impact on the social care system. Therefore, we would like to propose adding more details linked to this topic.	
Adult Attention Deficit Disorder UK (AADD-UK)	2	32	We would like to see older adults included as a group to be considered as an equality issue. Older people (aged 50 years and older) are now seeking assessments for ADHD but are experiencing considerable difficulty accessing treatment due to their age. Also, it is our experience that currently NHS ADHD services focus on providing treatment for adults of working age (65 or less). ADHD symptoms do persist into older age in many people (although prevalence rate is currently unknown due to a lack of research) and we feel it is a discriminatory practice to restrict treatment for people who could benefit based upon an outdated and arbitrary age limit. Services for older age people should be recommended based upon individual circumstances and on a properly individualised risk-benefit analysis. In addition, we would also like to point out that there is now some evidence that some older adults who have been assessed for early dementia may actually have undiagnosed ADHD.	Thank you for your comment. We agree and have included adults and older adults (50 years and over) in the equalities impact assessment for the guideline update.
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	2	36	There is greater risk of ADHD in deaf children as risk factors are also linked to the cause of deafness. For example, CMV, congenital rubella. Deafness is also associated with pervasive brain damage e.g. intrauterine viral infections, complications due to severe prematurity, neonatal meningitis. Ref: Hindley and Kroll, 1998. Theoretical and epidemiological aspects of ADHD in deaf children. In Journal of Deaf Studies, 64-72	Thank you for your comment. We agree there is a lack of awareness around some groups of people who may at risk of ADHD. Under section 1.3 of the scope, areas not in the published guideline that will be included in the update, is the identification of people who may have ADHD (risk factors).
East Kent Hospitals University NHS	2	40	Should read "a mental health or *other* neurodevelopmental disorder" (ADHD is a neurodevelopmental disorder)	Thank you for your comment. We agree and have amended the text as below:

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Foundation Trust				*"This includes people with a co morbid condition such as:* • *a defined neurological disorder* • *a mental health disorder* • *another neurodevelopmental disorder"*
Royal College of Paediatrics and Child Health	2	40	It is unclear where the dividing line comes between a neuro developmental disorder and learning disability, or which diagnosis determines the pathway. Indeed, it is hard to understand why there are 2 sets of guidelines. There is a risk that individuals with complex problems will end up without a service .	Thank you for your comment. We agree that people with ADHD often have concurrent conditions including learning disabilities. Section 1.1 of the scope identifies the population as 'children and young people and adults with a diagnosis of attention deficit disorder hyperactivity disorder (ADHD). This includes people with a co morbid condition such as: • a defined neurological disorder • a mental health disorder • another neurodevelopmental disorder. People with learning disabilities will be considered in this context and the guideline will cross refer to the NICE guidance on mental health problems with learning disabilities where appropriate. NICE guidelines note that clinicians should always consider the person's individual circumstances and take these into account when deciding on treatment.
Royal College of Paediatrics and Child Health	2	41	We would not advise excluding this group. Their needs and management may be different form non LD children /adults The MHLD guideline would have to provide a comprehensive section on the management of ADHD if it is to be the main source of information for this group. Is that the case? The MHLD is likely to be covering a wide range of conditions and not be able to go into the relevant detail for the audience in practice that this guideline is aimed at. Please don't let this group fall between guidelines	Thank you for your comment. This group are not excluded and we have removed this text from the scope. Section 1.1 of the scope identifies the population as 'children and young people and adults with a diagnosis of attention deficit disorder hyperactivity disorder (ADHD). This includes people with a co morbid condition such as: • a defined neurological disorder • a mental health disorder • another neurodevelopmental disorder. People with learning disabilities will be considered in this context and the guideline will cross refer to the NICE guidance on mental health problems with learning disabilities where appropriate. NICE guidelines note that clinicians should always consider the

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				person's individual circumstances and take these into account when deciding on treatment.
East Kent Hospitals University NHS Foundation Trust	2	42	Children with learning disabilities should be included. They are already potentially disadvantaged by virtue of their learning disability, if they have ADHD as well they may have huge problems. Intellectual (learning) disability is a neurodevelopmental disorder (as classified by DSM-5), therefore it should be included, as stated in line 40.	Thank you for your comment. This group are not excluded and we have removed this text from the scope. Section 1.1 of the scope identifies the population as 'children and young people and adults with a diagnosis of attention deficit disorder hyperactivity disorder (ADHD). This includes people with a co morbid condition such as: • a defined neurological disorder • a mental health disorder • another neurodevelopmental disorder. People with learning disabilities will be considered in this context and the guideline will cross refer to the NICE guidance on mental health problems with learning disabilities where appropriate. NICE guidelines note that clinicians should always consider the person's individual circumstances and take these into account when deciding on treatment**.**
Royal College of Paediatrics and Child Health	2	42	A child with ASD and an IQ of 75 would fall into this set of guidelines and a child with ASD and an IQ of 69 would come under the guidelines for learning disability. Why? Within this guideline it should be clarified where the advice is relevant to individuals with LD and where it is not, and why not/ or what would be pertinent to individuals with LD instead	Thank you for your comment. Children with an IQ of 69 are not excluded from this guideline. Section 1.1 of the scope identifies the population as 'children and young people and adults with a diagnosis of attention deficit disorder hyperactivity disorder (ADHD). This includes people with a co morbid condition such as: • a defined neurological disorder • a mental health disorder • another neurodevelopmental disorder. People with learning disabilities will be considered in this context and the guideline will cross refer to the NICE guidance on mental health problems with learning disabilities where appropriate. NICE guidelines note that clinicians should always consider the person's individual circumstances and take these into account when deciding on treatment.
Royal College	2	42	(-45)	Thank you for your comment. This group are not excluded and

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
of Psychiatrists			ADHD with comorbid presence of LD will not be addressed by the update. This is owing to the guidance being developed on mental health problems in people with learning disabilities. The concern is that this guidance about mental health problems might not adequately address issues of a condition such as ADHD, which can be seen as a common developmental comorbidity in individuals with LD.	we have removed this text from the scope. Section 1.1 of the scope identifies the population as 'children and young people and adults with a diagnosis of attention deficit disorder hyperactivity disorder (ADHD). This includes people with a co morbid condition such as: • a defined neurological disorder • a mental health disorder • another neurodevelopmental disorder. People with learning disabilities will be considered in this context and the guideline will cross refer to the NICE guidance on mental health problems with learning disabilities where appropriate. NICE guidelines note that clinicians should always consider the person's individual circumstances and take these into account when deciding on treatment**.**
Tees, Esk and Wear Valleys NHS Foundation Trust	2	42	(-45) ADHD with comorbid presence of LD will not be addressed by the update. This is owing to the guidance being developed on mental health problems in people with learning disabilities. The concern is that this guidance about mental health problems might not adequately address issues of a condition such as ADHD, which can be seen as a common developmental comorbidity in individuals with LD.	Thank you for your comment. This group are not excluded and we have removed this text from the scope. Section 1.1 of the scope identifies the population as 'children and young people and adults with a diagnosis of attention deficit disorder hyperactivity disorder (ADHD). This includes people with a co morbid condition such as: • a defined neurological disorder • a mental health disorder • another neurodevelopmental disorder. People with learning disabilities will be considered in this context and the guideline will cross refer to the NICE guidance on mental health problems with learning disabilities where appropriate. NICE guidelines note that clinicians should always consider the person's individual circumstances and take these into account when deciding on treatment**.**
Royal College of Psychiatrists	2	43	Term learning disabilities may need to be respecifed (eg generalized intellectual disability)	Thank you for your comment. The guideline committee will consider the most appropriate terms to be used in the guideline throughout development and prior to publication.
East Kent Hospitals	2	44	By saying it is covered by this guideline implies that ADHD is a	Thank you for your comment. To clarify this we have amended

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
University NHS Foundation Trust			mental health disorder. It is not, it is a neurodevelopmental disorder, which may have mental health co-morbidity	the text as below: *"This includes people with a co morbid condition such as:* • *a defined neurological disorder* • *a mental health disorder* • *another neurodevelopmental disorder"*
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	2	44	We would propose that new guidance is developed to specifically address the mental health needs of deaf children and young people as is being done with people with learning disabilities (due to be published Sept 2016).There is a growing body of evidence and a specialist mental health service (NDCAMHS) is now commissioned centrally by NHS England in recognition that deaf children and young people present differently and often have complex needs than their hearing peers. Ref: Gentili & Holiwell, 2011. Mental health in children with a severe hearing impairment. In Advances in Psychiatric Treatment, 17 (1) 54-62 Sibley, 2015. ADHD and Hearing Loss: A Study examining the Co-occurence of the Two Disorders.	Thank you for your comment. The commissioning of new guidance is outside of the remit of this scope and cannot be addressed here.
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	2	49	Currently does not include specialist NDCAMHS provision	Thank you for your comment. Section 1.2 of the scope states all services commissioned by the NHS are covered by this guideline.
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	2	53	Currently does not attend to the specific needs of deaf children	Thank you for your comment. Deaf children are not excluded from the scope and where appropriate, the guideline committee may decide to include subgroups for specific attention when developing protocols for review questions.
Adult Attention	2	54	We would like to see Annual Reviews listed here: From our combined experience of running support groups, we've found that	Thank you for your comment. Annual reviews as an aspect of post-diagnostic service delivery are included in the existing

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Deficit Disorder UK (AADD-UK)			many people get no follow ups, and the term 'annual review' has, in practice, been rather loosely interpreted. Some GPs interpret it to mean that they, despite lack of relevant experience/qualifications, should do the annual review. One CCG has interpreted the term to mean 'one review, one year after the diagnosis, and no more'.	guideline and will not reviewed as part of the update.
East Kent Hospitals University NHS Foundation Trust	3	55	Dual pharmacological therapy should also be considered	Thank you for your comment. Consideration of dual pharmacological treatment is included under combined interventions in Section 1.3 of the scope.
Royal College of Psychiatrists	3	58	(-62) Contra-indications/cautions for use of Methylphenidate, Dexamfetamine, Atomoxetine and Lisdexamfetamine where depression/suicidality is comorbid to the ADHD.	Thank you for your comment. Consideration of the safety and adverse effects of pharmacological treatments will be included in the evidence reviews on the clinical and cost effectiveness of treatments.
Royal College of Psychiatrists	3	58	(-60) Contra-indications/cautions for use of Methylphenidate, Dexamfetamine and Lisdexamfetamine where psychosis is comorbid to the ADHD. Interventions using stimulants in individuals with high-risk for development of psychosis needs to be described.	Thank you for your comment. Consideration of the safety and adverse effects of pharmacological treatments will be included in the evidence reviews on the clinical and cost effectiveness of treatments.
Royal College of Psychiatrists	3	64	(-65) Serotonergic noradrenergic and reuptake inhibitors SNRIs also have a useful place.	Thank you for your comment. Section 1.3 of the scope, under pharmacological interventions lists a number of treatments. The list is not intended to be exhaustive and will be reviewed with the guideline committee. Where appropriate additional treatments could be included in the reviews
Royal College of Psychiatrists	3	64	(-71) There needs to be clarity that the psychotropic drugs mentioned are not indicated for treatment of ADHD. They are rather options of intervention for difficulties and conditions that could be co-morbidly present alongside ADHD	Thank you for your comment. The pharmacological interventions listed in the section 1.3 of the scope have been identified as interventions that are currently used in the treatment of ADHD.
East Kent Hospitals University NHS Foundation Trust	3	73	The best treatment for ADHD is a good school. There are a wealth of management strategies that can have an enormous impact on children's academic and social progress in school. These are, unlike many other interventions, often as equally relevant for inattentive ADHD as for combined and hyperactive-impulsive types.	Thank you for your comment. Educational interventions will be covered in the non-pharmacological section of the guideline (section 1.3 of the scope).
National Deaf Child and Adolescent Mental Health	3	73	(-82) Does not acknowledge the need to adapt non-pharmacological interventions to fit the needs of deaf children and young people. With particular attention given to the children's language and communication needs; ensuring full access to	Thank you for your comment. Where appropriate, the guideline committee may decide to include subgroups when developing protocols for review questions to evaluate the impact on different populations. NICE guidelines note that clinicians should always

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Service (NDCAMHS)			resources; increased empha sis on the visual modality; acknowledging the presence of social and emotional developmental delay often seen in deaf children; additional executive functioning difficulties.	consider the person's individual circumstances and take these into account when deciding on treatment.
Royal College of General Practitioners	3	73	Non-pharmaceutical intervention consideration should be given information available on websites for families and carers of ADHD sufferers. There is potential for charities to provide considerable practical guidance and signpost resources. At the same time, because these organisation may rely on pharmaceutical company funding, there can be potential conflicts of interest. Similarly there are smart phone apps for ADHD sufferers that focus on awareness of time. Whilst MHRA are understandably reluctant to look at endorsing products, my research around the use of apps to help should be evaluated.	Thank you for your comment. Improving adherence to both pharmacological and non-pharmacological interventions is included in the scope for the update of the guideline. Specific interventions or strategies maybe evaluated but modes of delivery will not be reviewed.
BrainTrain UK	3	78	(-79) We note that the words '(using technology to help the person understand and train the way their brain reacts)' has been added after 'Neurofeedback', presumably with the intention to clarify what Neurofeedback is to those unfamiliar. We believe this sentence is superfluous and as written is inaccurate. It is inaccurate because Neurofeedback is not a process that requires a person to 'understand' the way their brain works in a conscious way. We would suggest that either i. the words '(using technology to help the person understand and train the way their brain reacts)' is removed; ii. the sentence is replaced with 'Neurofeedback (Electroencephalogram (EEG) biofeedback), both terms which are readily understood from the literature;	Thank you for your comment. We have removed this definition and replaced it with, '(using Electroencephalogram (EEG) biofeedback to train the brain towards better function)'.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			iii. or if it is believed that a descriptive sentence is really necessary within this document, we suggest: • 'Neurofeedback (using Electroencephalogram (EEG) biofeedback to train the brain towards better function)'; or • Electroencephalogram (EEG) biofeedback (using technology to train the brain towards better function).'	
Royal College of Psychiatrists	3	80	Do physical interventions include autonomic biofeedback training cf neurofeedback	Thank you for your comment. Section 1.3 of the scope, under areas from the published guideline that will be covered, lists neurofeedback as an example of non-pharmacological interventions that will be included in the evidence reviews. The list is not meant to be exhaustive and does not imply any order or category of interventions.
Adult Attention Deficit Disorder UK (AADD-UK)	3	83	In addition to the non-pharmacological interventions already included we would like to see the following added as recommendations: coaching, occupational therapy, and support groups	Thank you for your comment. The current list of non-pharmacological interventions is not intended to be exhaustive and will be reviewed by the Guideline Committee.
British Psychological Society	3	83	Add - Mindfulness training (Body of research to support inclusion)	Thank you for your comment. The current list of non-pharmacological interventions is not intended to be exhaustive and will be reviewed by the Guideline Committee.
Royal College of Paediatrics and Child Health	4	57	Would be useful to divide the pharmacological treatment in stimulant and non stimulant group to make it easier for clinicians	Thank you for your comment. The pharmacological interventions listed in section1.3 of the scope have been grouped according to their mechanism of action after feedback from the stakeholder workshop.
Eli Lilly and Company	4	87	(-91) It should be made clear in the guideline which, if any, recommendations fall outside licensed indications, as well directing prescribers to drug SPC. Consideration should also be given to excluding non-licensed treatments from recommendations so prescribers are clear which interventions would be considered cost-effective, if the prescriber does not wish to consider non-licensed	Thank you for your comment. Any recommendations that may include treatments that fall outside licensed indications will include appropriate information for prescribers. All the interventions that are considered in the guideline will also be assessed for their cost effectiveness in a health economic

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			treatments.	literature review.
British Association for Adoption and Fostering	4	93	We welcome the inclusion of identification of people who may have ADHD in the guidance. Relative to the general paediatric population looked after and adopted children have a considerably higher prevalence of ADHD. These children have a high burden of health inequalities which predispose them to ADHD and discussion of the risk factors for ADHD will assist health and social care practitioners to recognise individual children. It will be helpful for the guidance to explicitly state that looked after children are at high risk of developing ADHD.	Thank you for your comment. We agree there is a lack of awareness around some groups of people who may at risk of ADHD. Under section 1.3 of the scope, areas not in the published guideline that will be included in the update, is the identification of people who may have ADHD (risk factors).
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	4	93	Deaf children would fall into this category. See comment 2	Thank you for your comment. We agree there is a lack of awareness around some groups of people who may at risk of ADHD. Under section 1.3 of the scope, areas not in the published guideline that will be included in the update, is the identification of people who may have ADHD (risk factors).
Royal College of Nursing	4	94	(& 96) The draft scope excludes the diagnosis of ADHD and comorbidity in the planned guideline update. This seems at odd with the information in line 36 which suggests that the scope will cover people with a diagnosis of ADHD including people with comorbidity. It is important that there are guidelines on related diagnosis as well as comorbidity, in particular the increased evidence in the area of Developmental Trauma and Complex Trauma in Children and Young people should form part of the diagnostic process. The evidence of Hypervigilance and Hyperkinesis responses should include trauma history as part of the diagnostic process.	Thank you for your comment. The guideline update will cover people with an existing diagnosis of ADHD, including those with a diagnosed comorbid condition; however the diagnosis of ADHD or other comorbid conditions is not being addressed.
College of Occupational Therapists	4	95	As ADHD is a lifelong condition. Thus, it is suggested that the scope also includes adults and older adults. Even if the evidence is patchy for this age group, highlighting any research needs will also be important. For example: Miranda A, Berenguer C, Colomer C, Roselló R. Psicothema (2014)	Thank you for your comment. Section 1.1 of the scope states that the guideline will cover 'children, young people and adults with a diagnosis of attention deficit hyperactivity disorder (ADHD)'. Adults and older adults have been included in the equalities impact assessment for the guideline update.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			Influence of the symptoms of Attention Deficit Hyperactivity Disorder (ADHD) and comorbid disorders on functioning in adulthood. *Psicothema, 26(4):*471-6. doi: 10.7334/psicothema2014.121.	
Royal College of Paediatrics and Child Health	4	99	Is the diagnostic process unchanged? The increasing numbers being diagnosed warrants confirmation and clarification of diagnostic approaches. The difficulties and questions about the accuracy of the diagnosis in the very large number of children with ADHD like symptoms and major environmental contributory factors warrants an evidence base and evidence review / update re are these children different from core organic ADHD (classic organic : now the minority in Camhs practice) and do they respond as well to the usual medication and are environmental approaches effective, as important , more important , less effective etc	Thank you for your comment. The surveillance review undertaken as part of the NICE update process did not identify any additional evidence that would impact on the current diagnosis section of the guidelines. This has been confirmed by stakeholders at the stakeholder workshop.
Royal College of Psychiatrists	4	99	Given concerns about the rise in medication use, and more ADHD being initially assessed outside CAMHS, minimal standards for diagnosing ADHD for children, adolescents and adults require stating (this is relevant to thresholds for using medication and a rise in prescribing).	Thank you for your comment. The surveillance review undertaken as part of the NICE update process did not identify any additional evidence that would impact on the current diagnosis section of the guidelines. This has been confirmed by stakeholders at the stakeholder workshop. The current recommendations in CG72 will be carried over when this update is published.
Royal College of Psychiatrists	4	108	(-115) Guidance should comment on cost of not identifying ADHD and thus losing opportunity for early interventions	Thank you for your comment. Diagnosis of ADHD is an area that will not be updated in this guideline update, therefore the cost impact of a late diagnosis will not be assessed. However some considerations on the opportunity cost of identifying ADHD may be made when looking at the risk factors for ADHD.
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	5	109	Addressing the specific needs of deaf children will mean that this population receive timely, effective and value for money interventions at an earlier stage thus reducing the risk of 'revolving door referrals' and lack of access to appropriate treatment. It needs to be highlighted that deaf children may be misdiagnosed with ADHD when the under-lying cause of the behaviour is as a	Thank you for your comment. Under section 1.3 of the scope, areas not in the published guideline that will be included in the update, is the identification of people who may have ADHD (risk factors). The guideline committee will reviewing the evidence to identify groups that would fall into this category and benefit from an early diagnosis. Considerations on the opportunity cost of identifying ADHD may

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			result of communication difficulties, a specific language disorder; attachment and emotional regulation difficulties. There will be a group of children who are receiving inappropriate treatment due to misdiagnosis. It is therefore vital that there is better understanding of alternative hypotheses for behaviour that may appear to look like ADHD. Please see Gentili (2011) article. This is of concern not only in terms of the economics but more importantly the risks to children who are in receipt of medication they do not need and are not in receipt of appropriate treatment options that would address the behavioural and learning issues.	be made when looking at the risk factors for ADHD.
British Association for Adoption and Fostering	5	120	As above, the guidance should state that looked after and adopted children are at high risk of developing ADHD.	Thank you for your comment. Under section 1.3 of the scope, areas not in the published guideline that will be included in the update, is the identification of people who may have ADHD (risk factors). The guideline committee will reviewing the evidence to identify groups that would fall into this category and benefit from an early diagnosis. Considerations on the opportunity cost of identifying ADHD may be made when looking at the risk factors for ADHD. Looked after children have also been included in the equalities impact assessment as a group that may have limited access to treatment.
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	5	120	Please see comment 2	Thank you for your comment. We agree there is a lack of awareness around some groups of people who may at risk of ADHD. Under section 1.3 of the scope, areas not in the published guideline that will be included in the update, is the identification of people who may have ADHD (risk factors).
Royal College of Paediatrics and Child Health	5	120	Does this include those with suboptimal environmental factors and if so please consider the questions above re not reviewing diagnosis	Thank you for your comment. The surveillance review undertaken as part of the NICE update process did not identify any additional evidence that would impact on the current diagnosis section of the guidelines. This has been confirmed by stakeholders at the stakeholder workshop. However it was agreed that a lack of awareness around some groups of people

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				who may at risk of ADHD and are not identified for assessment. Under section 1.3 of the scope, areas not in the published guideline that will be included in the update, is the identification of people who may have ADHD (risk factors).
Royal College of Psychiatrists	5	120	Define and categorise high-risk groups including individuals with high genetic risks as well as individuals with high vulnerability such as children-in-need, looked-after children etc.	Thank you for your comment. The definition and categorisation of high risk groups will be evaluated from the evidence. Evidence reviews will be undertaken to address section 1.3of the scope,' the identification of people who may have ADHD (risk factors).'
Royal College of Psychiatrists	5	120	Risk groups can be considered in terms of causal risks and non causal correlates-perhaps considered as familial/genetic, prenatal, social.	Thank you for your comment. The guideline group will consider this categorisation of risk when developing the protocol for this question.
Royal College of Psychiatrists	5	121	Develop psycho-education material for individuals (Children Adolescents and Adults) with ADHD, carers as well as other agencies such as schools where the individuals with ADHD are supported.	Thank you for your comment. The guideline committee will consider the draft questions in section 1.5 of the scope and may include within the questions on post-diagnostic advice which materials are appropriate and where they should be available.
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	5	122	(-130) It is important that information and support addresses the specific needs of deaf children and their families. Deaf children have different language and communication needs and it is vital that there is a good understanding of the child and family members' preferred method of communication. Some children and parents may be BSL users and so require information to be translated into BSL. Others may use signs alongside speech. They may use a range of technology to assist with residual hearing. It would be important to attend to the format of information/resources. Parenting and behavioural techniques will need be adapted to fit the specific needs of the individual deaf child. As NDCAMH service we would welcome the opportunity to discuss the ways we have developed our clinical practice to better fit the needs of this population. This has included adopting a bi-lingual, bi-cultural approach that acknowledges the need for the deaf perspective alongside the mental health. BSL/English interpreters are integral to the team. As part of our remit we already provide consultation, advice, joint working with mainstream CAMHS	Thank you for your comment. Deaf children are included within the scope of the guideline update and have been added to the equalities impact assessment. Where appropriate, the guideline committee may decide to include subgroups when developing protocols for review questions and may make specific recommendations where the evidence allows.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			colleagues. As a specialist regional service, informal protocols are in place with local CAMH around prescribing arrangements and health checks for deaf children with ADHD known to our service. NDCAMH service is at the forefront of developing research and specialist mental health provision both in the European and Worldwide arena, as identified at the European and World conference for Mental Health and Deafness.	
British Association for Adoption and Fostering	5	126	(-130) The health inequalities including trauma and loss which predispose looked after children and young people to ADHD often also make it more difficult to work with them to provide information, interventions and support. Additionally their experiences in the care system such as changes of placement, school and friendship groups can add to the difficulties. These factors should be explicitly recognised and addressed for both the children and their carers when considering information and support needs, and methods of delivery.	Thank you for your comment. Looked after children have been included in the equalities impact assessment as group that may have limited access to treatment and could require special consideration. Where appropriate, the guideline committee may decide to include subgroups when developing protocols for review questions and may make specific recommendations where the evidence allows.
Association of Child Psychotherapists	5	128	Parents of children diagnosed with ADHD are offered parenting groups as part of the post diagnostic support package/intervention. However the take up by parents of groups is very low and drop out is common. The result is that medication is the sole intervention offered to children. This is problematic a) because for most children diagnosed with ADHD there is no evidence that medication alone has benefits and b) this gives children and their families the erroneous message that ADHD is a mono-causal, purely biological illness and reinforces parents' reluctance to take up interventions which aim to improve parent-child relationships and parenting strategies	Thank you for your comment. Adherence to interventions is included in the scope and the guideline committee will consider the draft questions in section 1.5. Where appropriate when refining the review questions and developing the protocols the committee may decide to include subgroups such as, parents and may make specific recommendations where the evidence allows.
Royal College of Paediatrics and Child Health	5	131	(- 156) Please comment on polypharmacy and the questions this raises about the accuracy of the diagnosis and management . Plus who should initiate and how reviewed , by whom and for how long? Establish quality standards around this – think of the standards expected re Epilepsy and should these be mirrored? We see children on multiple drugs for ADHD and apparent co morbidities that raise huge doubts and sometimes require a lot of effort to unpick. A better balance is required and drugs should not be given	Thank you for your comment. Section 1.3 of the scope includes both pharmacological and non-pharmacological interventions and section 1.5 includes draft questions for the guideline committee to consider which address the initiation and review of interventions. The guideline recommendations from this update will inform the quality standard for ADHD.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			out so readily .	
Royal College of Psychiatrists	5	131	What is the threshold for using medication and how might this be measured (related to diagnostic standards)?	Thank you for your comment. Diagnosis will not be updated in this guideline. The current recommendations on diagnosis will be carried over when the update is published. The threshold for using medication will not be reviewed separately but, in the evidence reviews, the committee may decide to look at diagnostic subgroups and effectiveness.
Royal College of Psychiatrists	5	131	What determines response or side effects of stimulants (eg do individual differences in initial experience of unwanted symptoms e.g. activation or euphoria clinical useful predictors, what determines these responses)	Thank you for your comment. Section 1.5 includes draft questions for the guideline committee to consider which address these topics in relation to pharmacological treatment. When considering the evidence the guideline committee will be able to consider the impact and response on different subgroups of people. In addition NICE guidelines note that clinicians should always consider the individual circumstances and take these into account when deciding on treatment.
Royal College of Psychiatrists	5	131	(-146) Issues around physical health monitoring (who what when) are major part of ADHD management	Thank you for your comment. Section 1.5 includes draft questions for the guideline committee to consider which address these topics in relation to pharmacological treatment. The issue of physical health monitoring will be taken into account when the committee consider the questions.
Association for Family Therapy and Systemic Practice in the UK	5	134	(-135) Reviews show that stimulant medication no longer has a therapeutic effect after 3 years, and there are significant side effects. This suggests use of stimulant medication needs to be used for a time-limited period, whilst systemic therapy helps children and parents to learn skills to manage symptoms. (Carr, 2014) Carr, A. (2014) The evidence base for family therapy and systemic interventions for child-focused problems. Journal of Family Therapy (36) p.107-157	Thank you for your comment and the reference. Section 1.5 includes draft questions for the guideline committee to consider and these include adverse effects and the safety profile of treatments.
Association for Family Therapy and Systemic	5	134	(-135 and 140-141) Positive effects of stimulant medication dissipate when medication ceases unless systemic interventions have been provided concurrently. (Carr 2014)	Thank you for your comment and the reference. Section 1.5 includes draft questions for the guideline committee to consider and these include combination treatments and adverse effects and the safety profile of treatments.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Practice in the UK			Carr, A. (2014) The evidence base for family therapy and systemic interventions for child-focused problems. Journal of Family Therapy (36) p.107-157	
Royal College of Psychiatrists	5	138	(&141) Why focus on starting medications? Blood pressure treatment to maintain people on stimulants need considering as do interactions with eg anti retroviral therapy	Thank you for your comment. Section 1.5 includes draft questions for the guideline committee to consider. The questions will be refined when developing the protocols and will consider this and the issue of long term monitoring.
British Psychological Society	5	139	Add new 10 then renumber - What are the common adverse effects of pharmacological treatment for people with ADHD?	Thank you for your comment. Adverse effects of pharmacological treatment are covered by the update and will form part of the evidence reviewed in assessing the effectiveness of pharmacological treatment. It will also inform proposed questions on safety issues of starting pharmacological treatment as well as treatment adherence. No changes have been made to the scope.
College of Occupational Therapists	5	142	Psychological interventions should be broadened to non-pharmacological interventions. The current title implies a specific professional group at the exclusion of others, such as occupational therapy. Alternative approaches that demonstrate emerging evidence and could be added to the list of interventions include: Cantrill A, Wilkes-Gillan S, Bundy A, Cordier R, Wilson N (2015) An eighteen-month follow-up of a pilot parent-delivered **play-based intervention to improve the social play skills of children with attention deficit hyperactivity disorder** and their playmates. *Australian Occupational Therapy Journal, 62(3):* 197-207. doi: 10.1111/1440-1630.12203. Rosenberg L, Maeir A, Yochman A, Dahan I, Hirsch I (2015) **Effectiveness of a cognitive-functional group intervention among preschoolers with attention deficit hyperactivity disorder: a pilot study**. *American Journal of Occupational Therapy, 69(3): 6903220040,*1-8.	Thank you for your comment. Non-pharmacological interventions are referred to not psychological interventions.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			doi: 10.5014/ajot.2015.014795. Maeir A, Fisher O, Bar-Ilan RT, Boas N, Berger I, Landau YE (2014) **Effectiveness of Cognitive-Functional (Cog-Fun) occupational therapy intervention for young children with attention deficit hyperactivity disorder: a controlled study**. *American Journal of Occupational Therapy, 68(3):* 260-7. doi: 10.5014/ajot.2014.011700. Gharebaghy S, Rassafiani M, Cameron D (2015) **Effect of cognitive intervention on children with ADHD**.*Phys Occup Ther Pediatr, 35(1):*13-23. doi: 10.3109/01942638.2014.957428 Epub 2014 Sep 23.	
Royal College of Psychiatrists	5	144	(-46) Will the guidance include best ways of swapping from 1 medication to another and best practice for timescales to do this?	Thank you for your comment. Section 1.3 of the scope, under areas from the published guideline that will be updated, refers to pharmacological interventions, including starting treatment, managing side effects and stopping treatment, and sequencing.
Royal College of Paediatrics and Child Health	5	146	What is best way of tapering medication and introducing new one ? guidance would be very useful as non stimulants should not be ideally stopped suddenly especially guanfacin as it can effect blood pressure	Thank you for your comment. Section 1.3 of the scope, under areas from the published guideline that will be updated, refers to pharmacological interventions, including starting treatment, managing side effects and stopping treatment, and sequencing.
East Kent Hospitals University NHS Foundation Trust	6	147	Non-pharmacological interventions must be looked at in the context of ADHD type. Many are not relevant for children with inattentive ADHD who may not present with behavioural problems.	Thank you for your comment. When reviewing the evidence for pharmacological and non-pharmacological interventions hyperactivity and inattention will be identified as subgroups where considered appropriate by the guideline committee. The guideline committee will then be able to consider any identified differences in the evidence for the effectiveness interventions for these groups.
Association for Family Therapy and Systemic Practice in the UK	6	150	(-151) Carr (2014) suggests that multi-modal treatments need to span at least 6 months, and then offer sustained but infrequent contact with the multi-disciplinary team e.g. to help the child and family manage transitions such as the child entering a new class or new school. Carr, A. (2014) The evidence base for family therapy and systemic	Thank you for your comment and the reference.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			interventions for child-focused problems. Journal of Family Therapy (36) p.107-157	
Association for Family Therapy and Systemic Practice in the UK	6	154	(-156) A proportion of preschool children with ADHD show significant improvement with behavioural parent training, which suggests for this age group this should be the first line of treatment – then for children who do not respond to these interventions alone, it is suggested that systemic (family / relational) interventions are offered as part of a multi-modal programme then also involving stimulant medication (Carr, 2014) Carr, A. (2014) The evidence base for family therapy and systemic interventions for child-focused problems. Journal of Family Therapy (36) p.107-157	Thank you for your comment and the reference.
Association for Family Therapy and Systemic Practice in the UK	6	158	(-159) For children who do not respond to systemic therapy alone, systemic therapy as part of a multi-modal programme, (e.g. including family therapy or parent training, school-based behavioural programmes, and coping skills training for children, and stimulant medication), have been shown to be effective. (Carr, 2014) Carr, A. (2014) The evidence base for family therapy and systemic interventions for child-focused problems. Journal of Family Therapy (36) p.107-157	Thank you for your comment and the reference.
Eli Lilly and Company	6	160	(-166) Improving adherence should include information on choice of dosage form- e.g. liquid formulations etc. where available.	Thank you for your comment. Section 1.5 includes draft questions for the guideline committee to consider. The questions will be refined when developing the protocols and will consider this when considering the adherence questions and protocols.
Association of Child Psychotherapists	6	164	(-166) Despite the low take-up up of parenting groups, many children presenting at CAMHS with ADHD symptoms are struggling with relationship difficulties hat are not addressed by medication. In particular those children with attachment difficulties and those being	Thank you for our comment. Section 1.5 includes draft questions for the guideline committee to consider. Where appropriate when refining the review questions and developing the protocols the committee may decide to include subgroups such as, parents

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			cared for by parents with mental health problems could benefit from their parents being offered bespoke, individual parenting support. This could reduce drop-out and facilitate more families to adhere to the combined treatment model which is most likely to produce optimal results for the child. It may also help some parents develop a more nuanced understanding of their child's difficulties and reduce the often unrealistic expectation that medication is the only/best solution.	and may make specific recommendations where the evidence allows.
British Association for Adoption and Fostering	6	164	(-166) The factors noted above should be considered and addressed when considering treatment adherence for looked after children. They should also be considered and addressed for looked after young people at the time of transition to adult services. It is well recognised that at this time when all young people need additional support, in reality support for those leaving care frequently diminishes leading to serious adverse outcomes. A significant group will leave the shelter of foster care for independent living and thus lose their source of daily support in managing ADHD. Many of them do not meet the thresholds for access to adult mental health services.	Thank you for our comment. Section 1.5 includes draft questions for the guideline committee to consider. Where appropriate when refining the review questions and developing the protocols the committee may decide to include subgroups such as, looked after children and young adults moving to adult services and may make specific recommendations where the evidence allows.
National Deaf Child and Adolescent Mental Health Service (NDCAMHS)	6	169	(-182) It is vital that the needs of deaf children are considered as a group at risk of poorer outcomes. There is evidence that deaf children generally are more likely struggle in peers relations, family relations, have reduced academic success, low self-esteem etc. In the case of children with ADHD there will be an additive effect and they will be at even greater risk of reduced quality of life outcomes if they do not receive the appropriate treatment they require.	Thank you for your comment. Deaf children have not been excluded from the scope of the guideline update. In addition where appropriate, the guideline committee may decide to include subgroups when developing protocols for review questions. Where the evidence allows recommendations can be made for specific groups.
British Psychological Society	6	172	Add new 2 then renumber – Impact on the Psychological Wellbeing of the person.	Thank you for your comment. Wellbeing is a broad concept and in the list of main outcomes (section 1.6) there are outcomes to measure aspects of wellbeing. These include quality of life, peer and family relationships, self-esteem and perceived control of symptoms. In addition the list of outcomes is not an exhaustive list. The guideline committee will consider and prioritise outcomes for each review question which could include

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				outcomes that are specific to each question.
Association of Child Psychotherapists	6	173	There is now some evidence that psychoanalytic treatments can significantly decrease ADHD symptoms (see Leuzinger-Bohleber, M., Laezer, K. L., Pfenning-Meerkoetter, N., Fischmann, T., Wolff, A., & Green, J. (2011). Psychoanalytic treatment of ADHD children in the frame of two extraclinical studies: The Frankfurt Prevention Study and the EVA Study. *Journal of Infant, Child and Adolescent Psychotherapy, 10,* 32–50.)	Thank you for your comment and references.
Royal College of Psychiatrists	7	182	Will this include management issues raised substance misuse?	Thank you for your comment. Risky behaviour is listed as a main outcome and the guideline committee will define further detail the risky behaviours to measure in the evidence reviews.
Royal College of Psychiatrists	7	183	NICE hypertension guidance?	Thank you. This has been added.
College of Occupational Therapists	7	200	The list of interventions should include those which focus on participation in everyday life. Examples are listed above and include: '*occupational performance coaching'*, '*Cognitive orientation to daily occupational performance'*, '*play based interventions'* and '*social skills interventions'*.	Thank you for your comment. This was not meant to be an exhaustive list but an illustration of interventions in the treatment of ADHD.
Department of Health	7	201	(- 202) In between line 201 and 202, we would suggest adding the following in development NICE guidance: <u>The safe use and management of controlled drugs.</u> NICE guideline. Publication expected March 2016.	Thank you. This has been added.
College of Occupational Therapists	8	215	An additional question which relates to the factors contributing to adherence to intervention approaches would be helpful. The effectiveness of interventions may be skewed in the research data as the people who often participate in research projects are often particularly engaged with the intervention approaches. Identifying critical features of interventions which facilitate the engagement of people and their families will provide guidance for the implementation of effective intervention. Examples can be found in this article: Sarah Wilkes-Gillan, Anita Bundy, Reinie Cordier, Michelle Lincoln, and Nicola Hancock (2015) Parents' perspectives on the	Thank you for your comment and reference. Adherence to treatments is included in the scope.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			appropriateness of a **parent-delivered intervention for improving the social play skills** of children with ADHD. *British Journal of Occupational Therapy October 2015 78: 644-652*. First published on June 12, 2015 doi:10.1177/0308022615573453	
Eli Lilly and Company	8	215	(-219) Please clarify if the CG update will replace the guidance in TA78 or if the recommendations from TA78 will be included verbatim in the CG update. Clearly, the NICE pathway should be consistent across CG and TA recommendations and the scope currently does not make clear how the recommendations of TA78 will be used	Thank you for comment. TA78 is 'Fluid-filled thermal balloon and microwave endometrial ablation techniques for heavy menstrual bleeding' and unrelated to ADHD. We believe that your comment refers to TA98 'Methylphenidate, atomoxetine and dexamfetamine for attention deficit hyperactivity disorder (ADHD) in children and adolescents'. We have now proposed that this be included in the scope in section 2.1 under NICE guidance that will be updated by this guideline. This proposal is subject to the review process by NICE's technology appraisals programme.
East Kent Hospitals University NHS Foundation Trust	8	222	Should read "characterised by *inattention and/or hyperactivity/impulsivity*". Children can be diagnosed with ADHD (predominantly inattentive - DSM-5) without symptoms of hyperactivity or impulsivity. Current wording implies all three symptoms are required for diagnosis which is incorrect.	Thank you for your comment. This has been changed.
Royal College of Paediatrics and Child Health	8	227	Reasons for these? Organic brain issues clearly but also environmental ones and the evidence around both and the implications. Care re c o morbidities and their implications. Evidence re whether these co morbidities are likely to be organic primary conditions or reflect complex environmental factors too and hence what is the evidence about and need for environmentally based interventions and resources	Thank you for your comment. This section gives a brief introduction to the reader and is not meant to be a comprehensive background to the ADHD and the complex issues in the area.
Royal College of Paediatrics and Child Health	8	230	Other common comorbid disorders in children are Autism spectrum disorder,sleep disorder,oppositional defiant disorder and conduct disorders which have not been mentioned !	Thank you for your comment. This was not meant to be an exhaustive list but an illustration of comorbid disorders.
College of Occupational Therapists	9	217	Main outcomes should primarily focus on ecologically relevant and meaningful outcomes rather than scales relating to body functions and symptom reduction. For example, following intervention is the person able to participate in school / home / community life.	Thank you for your comment. The list of outcomes is not an exhaustive list the guideline committee will consider and prioritise outcomes for each review question which could include additional outcomes that are specific to each question.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
British Psychological Society	9	237	Add – This variation between the two International Schedules is a cause for concern and further investigation.	Thank you for your comment. This section gives a brief introduction to the reader and is not meant to be a comprehensive background to the ADHD and the complex issues in the area.
Adult Attention Deficit Disorder UK (AADD-UK)	9	251	We would like to see added here that some people are at increased risk of self-harm and suicide.	Thank you for your comment. This section gives a brief introduction to the reader and is not meant to be a comprehensive background to the ADHD and the complex issues in the area. We have included an sentence to clarify the distress that adults with ADHD can experience.
Adult Attention Deficit Disorder UK (AADD-UK)	9	252	(-254) We feel that this section would present a better balanced view if you included an analysis comparing the actual prevalence rate for ADHD with diagnosed rates as well as with the rates of prescribing rather than simply stating the increase in the number of prescriptions. The latter could be an imperfect reflection of the true prevalence rate for ADHD.	Thank you for your comment. This section gives a brief introduction to the reader and is not meant to be a comprehensive background to the ADHD and the complex issues in the area.
British Psychological Society	9	258	Add – There is also concern about the possible financial driver for parents of having a diagnosis for their child as they may benefit financially from receiving Disabled Living Allowance.	Thank you for your comment. This section gives a brief introduction to the reader and is not meant to be a comprehensive background to the ADHD and the complex issues in the area.
Royal College of Paediatrics and Child Health	10	271	Should be DSM V	Thank you for your comment. This has been changed.
Royal College of Paediatrics and Child Health	10	279	What are the implications. Are these emergent primary organic disorders presenting later ? Different groups ?	Thank you for your comment. This section gives a brief introduction to the reader and is not meant to be a comprehensive background to the ADHD and the complex issues in the area.