NICE guideline: Attention deficit hyperactivity disorder (upate)
Scoping workshop: notes

11/12/15 10:00 – 13:00
Avonmouth House, 6 Avonmouth Street, London, SE1 6NX

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Group 1

ADHD: scope workshop discussions Date: Friday 11 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Children aged 3 years and older, young people and adults with a diagnosis of ADHD and related diagnoses: hyperkinetic disorder (ICD-10) will be considered, along with the three DSM-5 ADHD presentations. • The specific management of ADHD in those individuals who also have: – a defined neurological disorder – a comorbid mental health disorder (including depression, and anxiety disorders). **Groups that will not be covered:** • Children younger than 3 years.	• Is the population appropriate? • Are the exclusions appropriate for the guideline? • Are there any specific subgroups that have not been mentioned (in either list)?	• People with learning disabilities should be included as a group for specific management. • People who misuse substances should be considered a subgroup as they require different management. • Older people with comorbid conditions should be considered a subgroup as they require different management. • Important when looking at studies to define the population of each study as the definition of ADHD varies by culture and country. • Highlighted transition from CAMHS to adults as an area for cross-referral.
1.2. Settings • care in general practice and NHS community care • hospital outpatient and inpatient care • primary/secondary interface of care	• Are the listed settings appropriate? • Are there other settings that should be considered?	• Highlighted prisons as a setting for consideration, or cross-reference the Prisons guideline currently in development.

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1.3 Activities, services or aspects of care: **Key areas that will be covered:** ***Areas from the published guideline that will be updated*** **Pharmacological interventions** The appropriate use of pharmacological interventions, for example initiation and duration of treatment, management of side effects and discontinuation. Specific pharmacological treatments considered will include: • methylphenidate (including modified-release preparations) • atomoxetine (currently licensed for treatment of ADHD in children, and in adults if treatment was initiated in childhood) • guanfacine • dexamphetamine, including lisdexamfetamine dimesylate • tricyclic and other antidepressants • bupropion • nicotine (as skin patches) • atypical antipsychotics • modafinil • clonidine What pharmacological treatments are clinically and	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned?	<u>Pharmacological interventions</u> • 'Atypical' antipsychotics is not a useful clinical term and suggest removing it. • The following pharmacological interventions should be added for consideration: riboxitine, anti-epileptics, mood stabilisers, buspirone, selegiline, MAOIs. • Highlighted combined pharmacological therapies as an area for inclusion. Also noted the importance of titration, and different types of discontinuation (weening versus stopping). <u>Psychological interventions</u> • Skills building groups for children based on age should be included, though this may be covered by parental training. Skills training for adults could also be included. • The term 'parental training' should be changed to 'behaviour management' or 'skills training' to be more inclusive. If parent training is used then it should be 'parent or carer', to include children in care homes and foster carers. • Exercise has been shown to be more effective than relaxation and should be included in the list of interventions. They noted that there are data in this area. • Mindfulness and meditation should be added to the list of interventions.

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cost-effective for people with ADHD whose response to methylphenidate is inadequate? **Psychological interventions** Psychological and behavioural interventions, including: • Cognitive behavioural therapy and other behavioural approaches • Parental training programmes • Family interventions • Neurofeedback • Physical therapies (such as relaxation) **Combined interventions** Sequencing and combination of pharmacological and psychological treatments. **Areas that will not be covered:** • The separate management of comorbid conditions.		• Importance of psycho-education. • Identified classroom support assistants of ADHD mentors in the classroom for children with ADHD as an important intervention.
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing	• The wider costs to society of unemployment, sickness leave and school exclusions as a result of unmanaged or poorly managed ADHD should be captured in the economic analysis. • Highlighted different drug manufacturing processes related to how the drugs release and the potential cost impact of

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	practice? • Which area of the scope is likely to have the most marked or **biggest health implications** for patients? • How would you **rank the areas to be prioritised** for economic analysis? • Do you have any further comments on economics?	swapping between drugs, which the group felt in their clinical experience is often problematic to patients. • There may be a cost implication for increased numbers of medication reviews when switching between drugs. • Potential cost-saving impact of certain self-management techniques, for example detachable yellow-tinted screens for LEDs, screen adjustment, adjusting daily routines and good sleep hygiene. • Combined pharmacological and psychological interventions should be a priority for modelling. Related to this, sequencing of medication is an important area for cost-effectiveness analysis. • Frequency of monitoring for concurrent physical health conditions and monitoring of medication is a cost implication. The current frequency of such monitoring is felt in current practice to be unachievable.
1.5 Key issues and questions 1 What is the clinical and cost effectiveness of methylphenidate (including modified-release preparations), atomoxetine, dexamphetamine, guanfacine, tricyclic and other antidepressants, bupropion, nicotine (as skin patches), atypical antipsychotics, modafinil and clonidine when compared to waiting lists, placebo, other drug (head to head trials),	• Would you like to add any additional questions to this list?	• A question could be added on support and information for patients, families and/or carers. • The following information is particularly applicable: online training programmes (already available but not NHS), sharing strategies, long-term planning including family planning, addiction and substance abuse.

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psychological interventions and parent training and does this depend on: ADHD subtype, associated disorder, social context, age, gender and severity, delivery systems?		
2 What pharmacological treatments are clinically and cost-effective for people with ADHD whose response to methylphenidate is inadequate?		
3 What is the clinical and cost effectiveness of cognitive behavioural therapy (CBT), behavioural approaches, parent (effectiveness) training, multimodal interventions, neurofeedback, physical therapies (relaxations etc.) and other approaches when compared to no intervention, waiting lists, 'standard care', other psychological interventions and medication for ADHD and does this depend on: ADHD subtype, associated disorder, social		

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Scope details	**Questions for discussion**	**Stakeholder responses**
context, age, gender and severity, delivery systems? 4 What is the clinical and cost effectiveness of combined treatment (medication for ADHD plus psychological interventions)?		
1.6 Main Outcomes • Quality of life • ADHD symptoms • Cognitive outcomes • Functional status • Associated mental health problems • Peer relationships • Academic outcomes, including school learning and progress • Family relationships • Care needs • Self-esteem • Perceived control of symptoms • Safety	• Is the list of outcomes appropriate? Are any key outcomes missing? • Please identify the top 5 outcomes.	• Mentioned the following as additional outcomes: outcomes of treatment; effect on employment, including absenteeism and presenteeism; recurrence of ADHD; emotional dysregulation; addiction; self-medication, risk-taking behaviour; criminality/convictions/imprisonment; suicide and self-harm; eating disorders (due to the adverse effect of some ADHD medication on appetite); sleep deprivation; transition from university to work, physical health (weight, accidents, heart rate, blood pressure etc.); impact on families.
GC Membership • Educational specialist • Pharmacologist/pharmacist	• Do you have any comments on the proposed membership of the committee?	• One of the psychiatrists should have experience of working with people with ADHD in prisons. • One member should have experience of working people with

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• Paediatric neurologist • Psychiatrist (1 adult and 1 children) • Psychologist • Community paediatrician • General Practitioner • Specialist nurse (1 adult and 1 children) • Lay members (1 adult with ADHD, 1 young adult with ADHD and one carer/parent)		ADHD and learning disabilities. • An occupational physician should be included, as distinct from an occupational therapist. • There should be two young people on the group, one male and one female.

Further questions:	Stakeholder responses
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	• Identified misdiagnosis as an area that has not been covered. • Noted sleep as an important aspect that has not been included. Sleep deprivation, management plans and sleep hygiene clinics could come under this. • The side effect of medication on motivation was considered an important clinical issue. • Noted overtreatment as a key clinical issue. • Identified combination of medications and switching preparations as a clinical issue. • Noted important self-management areas which have a great impact on people with ADHD, for example the negative effect of internet gaming across time zones.
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	None identified.
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	• Physical health monitoring and medication monitoring was felt to be an area of diverse practice, in spite of the 3 month frequency specified in the existing guidance.
4. Are there any areas that you think should be	• Service delivery arrangements are currently diverse and potentially lacking.

Further questions:	Stakeholder responses
included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	• There needs to be a shared care agreement between primary and secondary care. • The coordination of care was felt to be diverse with potential impacts on patient care. There is a need for a single point of contact for patients, particularly among psychiatrists.
5. Any other issues raised during subgroup discussion for noting:	• The group raised the following issues for consideration of equal access: culture, gender, learning disabilities, language, African-Caribbean background.

Group 2

ADHD: scope workshop discussions – Group 2 Date: Friday 11 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Children aged 3 years and older, young people and adults with a diagnosis of ADHD and related diagnoses: hyperkinetic disorder (ICD-10) will be considered, along with the three DSM-5 ADHD presentations. • The specific management of ADHD in those individuals who also have: – a defined neurological disorder – a comorbid mental health disorder (including depression, and anxiety disorders). **Groups that will not be covered:** • Children younger than 3 years.	• Is the population appropriate? • Are the exclusions appropriate for the guideline? • Are there any specific subgroups that have not been mentioned (in either list)?	• Patients should be grouped by age, and different age groups would have different disorders, problems and comorbidities. For example, treatment algorithms would be different for children and adults. Though management for people who are 18 and above is generally different in NHS however because people with ADHD develop slower compared with other populations so the management between 18 and 25 might be crucial. They suggested that preferential treatments might be different for different age groups due to comorbidities and controversial treatment effects. However other stakeholders worried whether enough evidences could be found if we stratify the population into many age groups. • Cover a broader range of comorbidities, e.g. personality disorders. • The term "neurological disorder" is misleading on what it covers, suggested using the term "neuro-developmental disorder" instead. • Physical health for ADHD population is generally worse than general population as well.
1.2. Settings • care in general practice and NHS community care • hospital outpatient and inpatient care • primary/secondary interface of care	• Are the listed settings appropriate? • Are there other settings that should be considered?	• School/educational settings should also be included in the scope. For some of the ADHD related problems, it is hard to classify whether it is a health related issue or education related issue, thus where the funding should come from. This might create barriers of implementations.

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Scope details	Questions for discussion	Stakeholder responses
		• Employment, prisons, residential placement, social care to adults' settings was also mentioned in the meeting.
1.3 Activities, services or aspects of care: **Key areas that will be covered:** ***Areas from the published guideline that will be updated*** **Pharmacological interventions** The appropriate use of pharmacological interventions, for example initiation and duration of treatment, management of side effects and discontinuation. Specific pharmacological treatments considered will include: • methylphenidate (including modified-release preparations) • atomoxetine (currently licensed for treatment of ADHD in children, and in adults if treatment was initiated in childhood) • guanfacine • dexamphetamine, including lisdexamfetamine dimesylate • tricyclic and other antidepressants • bupropion • nicotine (as skin patches) • atypical antipsychotics • modafinil	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned?	• Combine methylphenidate and dexamphetamine into one category, as well as combining atomoxetine and guanfacine into one category. • Include prescription algorithms into the guideline: ○ When patient does not respond to one of the drugs there are generally two choices: increase the dose or try another drug. Currently there is no instruction on how to select between these two options ○ They suggested that most of the drugs are licenced as monotherapy, and there is no instruction on combined therapies ○ Choice of stimulants and non-stimulants between different sub-populations, and what to do if a patient does not respond to either ○ When comorbidities such as anxiety needed to be treated at the same time, what is the best way to sequence and/or combine treatments. • More guidance on intolerance is required. • Different algorithms should be given to adults and children due to:

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Scope details	**Questions for discussion**	**Stakeholder responses**
• clonidine What pharmacological treatments are clinically and cost-effective for people with ADHD whose response to methylphenidate is inadequate? **Psychological interventions** Psychological and behavioural interventions, including: • Cognitive behavioural therapy and other behavioural approaches • Parental training programmes • Family interventions • Neurofeedback • Physical therapies (such as relaxation) **Combined interventions** Sequencing and combination of pharmacological and psychological treatments. **Areas that will not be covered:** • The separate management of comorbid conditions.		○ First line and second line drugs could be different in these two sub-populations ○ Licencing is different in these two sub-populations. • Change the topic "psychological interventions" to "non-pharmacological interventions". • The following interventions were suggested: ○ Adult DBT ○ Coaching for adults and children ○ Exercise ○ Play based therapy and social therapy ○ Occupational therapy ○ Environment changing: current environment might be too stressful to patients, changing environment might be more helpful than treating patient symptoms ○ Therapist support ○ Support in transition environment (e.g. from primary school to high school) ○ Adherence to intervention protocol ○ Psycho-education.

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		• Relaxation is not appropriate as an example for physical therapies.
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice? • Which area of the scope is likely to have the most marked or **biggest health implications** for patients? • How would you **rank the areas to be prioritised** for economic analysis? • Do you have any further comments on economics?	• Include cost savings from crime reduction and traffic accident reduction in the analysis, as well as cost savings to society resulting from a potentially better employment rate. • Cost reduction in special education and replacement could also be included in analysis. • Costs associated with wrong treatments should be included in the analysis. • Previous studies indicated ADHD patients generally have worse physical health status and the mortality rate in ADHD is doubled due to physical health issues. • Currently it is not clear what services should be provided by primary care and what should be provided by secondary care services. • The training effect could reduce after patients moved from training environment to their living environment. • It is important to include adherence to protocol into analysis, and how other support such as primary care or therapist could potentially increase the adherence rate. • The treatment effect in group treatment might not be as good as individual treatment because it doesn’t teach individualised

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		skills.
1.5 Key issues and questions 5 What is the clinical and cost effectiveness of methylphenidate (including modified-release preparations), atomoxetine, dexamphetamine, guanfacine, tricyclic and other antidepressants, bupropion, nicotine (as skin patches), atypical antipsychotics, modafinil and clonidine when compared to waiting lists, placebo, other drug (head to head trials), psychological interventions and parent training and does this depend on: ADHD subtype, associated disorder, social context, age, gender and severity, delivery systems? 6 What pharmacological treatments are clinically and cost-effective for people with ADHD whose response to methylphenidate is inadequate? 7 What is the clinical and cost effectiveness of cognitive behavioural therapy (CBT), behavioural approaches, parent	• Would you like to add any additional questions to this list?	• Include delivery and social context in the scope, including family situation, living, school/employment, family education. • Concern about generalisation of studies. Generally people involved in those studies are more aware of ADHD compared with other people with ADHD. • Include living conditions in the guideline, for example, stability, crowded environment etc. • Include sub-types in the scope, including symptom domains and dimensions, treatment efficacy to different sub-types and how to target sub-types differently. • The entire age range should be covered and different genders should be treated differently. • Care pathways should be included in the scope and the content on pathways in the previous guideline was not adequate. • Patient’s experience with treatment should be included in analysis. • Guiding principles on treatment delivery should be included in the scope.

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(effectiveness) training, multimodal interventions, neurofeedback, physical therapies (relaxations etc.) and other approaches when compared to no intervention, waiting lists, 'standard care', other psychological interventions and medication for ADHD and does this depend on: ADHD subtype, associated disorder, social context, age, gender and severity, delivery systems? 8 What is the clinical and cost effectiveness of combined treatment (medication for ADHD plus psychological interventions)?		
1.6 Main Outcomes • Quality of life • ADHD symptoms • Cognitive outcomes • Functional status • Associated mental health problems • Peer relationships • Academic outcomes, including school learning and progress	• Is the list of outcomes appropriate? Are any key outcomes missing? • Please identify the top 5 outcomes.	• Reduce the total number of outcomes to 4-5 and aggregate some of the current listed outcomes. • The peer relationships and family relationships could be aggregated into one. • Remove cognitive outcomes. • These outcomes were also suggested by the group: ○ Emotional liability

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Scope details	**Questions for discussion**	**Stakeholder responses**
• Family relationships • Care needs • Self-esteem • Perceived control of symptoms • Safety		○ Occupation ○ Criminality, social behaviour ○ Self-knowledge. • The most important outcomes identified by this group are: ○ Function status ○ Quality of life.
GC Membership • Educational specialist • Pharmacologist/pharmacist • Paediatric neurologist • Psychiatrist (1 adult and 1 children) • Psychologist • Community paediatrician • General Practitioner • Specialist nurse (1 adult and 1 children) • Lay members (1 adult with ADHD, 1 young adult with ADHD and one carer/parent)	• Do you have any comments on the proposed membership of the committee?	• The group made the following suggestions on the GC: ○ Include one occupational therapist for adult and one for children in the GC ○ Include one adult ADHD specialist in the GC ○ Include a psychiatrist specialising in substance abuse in the GC ○ Include one adult female ADHD specialist in the GC.

Further questions:	Stakeholder responses
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	None identified.

Further questions:	Stakeholder responses
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	None identified.
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	None identified.
4. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	None identified.
5. Any other issues raised during subgroup discussion for noting:	None identified.

Group 3

ADHD: scope workshop discussions – Group 3 Date: Friday 11 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Children aged 3 years and older, young people and adults with a diagnosis of ADHD and related diagnoses: hyperkinetic disorder (ICD-10) will be considered, along with the three DSM-5 ADHD presentations. • The specific management of ADHD in those individuals who also have: – a defined neurological disorder – a comorbid mental health disorder (including depression, and anxiety disorders). **Groups that will not be covered:** • Children younger than 3 years.	• Is the population appropriate? • Are the exclusions appropriate for the guideline? • Are there any specific subgroups that have not been mentioned (in either list)?	• There are many other comorbidities, and all need to be included. ADHD without a comorbidity is relatively unusual. Other common comorbidities include: ○ Autism (new area) ○ Ticks and Tourette's ○ FASD (Foetal alcohol spectrum disorder) ○ ODD ○ Sleep disorder. • High risk groups include: children in care; suicidal/self-harming people. • ADHD and comorbid psychosis is a small but significant group, especially over 16 years of age. May be triggered by the ADHD medication. • Early childhood attachment and neglect important, but being covered by another guideline. • Comorbidity makes diagnosis and treatment more complicated. • May be more than one comorbidity at a time, so could be difficult to separate out. • Important to ask about substance abuse/exposure during pregnancy as this can affect response to pharma treatment.

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		• Pathways may be different for different comorbidities. • Including DSM-V will lead to an increase in diagnosis and medication. • DSM-V categorisation of mild, moderate and severe can be problematic, not clearly defined.
1.2. Settings • care in general practice and NHS community care • hospital outpatient and inpatient care • primary/secondary interface of care	• Are the listed settings appropriate? • Are there other settings that should be considered?	• Much of ADHD is managed in education and similar, not NHS. Although this is out of the remit, collaboration needs to be emphasised. • There are no educational guidelines for management of ADHD – left out of new code of conduct. • School clinics may be involved with initial investigation, but not actual diagnosis.
1.3 Activities, services or aspects of care: **Key areas that will be covered:** ***Areas from the published guideline that will be updated*** **Pharmacological interventions** The appropriate use of pharmacological interventions, for example initiation and duration of treatment, management of side effects and discontinuation. Specific pharmacological treatments	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned?	• Would be helpful to look at diet in combination with other treatments. • Sleep interventions. Lots of new evidence, and new SR, see also EUSOM. • Sleep is also an issue as it interacts with medication. • Lisdexamfetamine is currently licensed for second line treatment only in children, can be first line treatment in adults. • Guanfacine also licensed as a second line treatment.

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Scope details	**Questions for discussion**	**Stakeholder responses**
considered will include: • methylphenidate (including modified-release preparations) • atomoxetine (currently licensed for treatment of ADHD in children, and in adults if treatment was initiated in childhood) • guanfacine • dexamphetamine, including lisdexamfetamine dimesylate • tricyclic and other antidepressants • bupropion • nicotine (as skin patches) • atypical antipsychotics • modafinil • clonidine What pharmacological treatments are clinically and cost-effective for people with ADHD whose response to methylphenidate is inadequate? **Psychological interventions** Psychological and behavioural interventions, including: • Cognitive behavioural therapy and other behavioural approaches • Parental training programmes • Family interventions		• Atypical antipsychotics – currently not recommended in CG72. BNF recommend for short term in specific situations/comorbidities. They should not be used where these comorbidities are not present. • Immediate release stimulants need to be included as well. • Clonidine and guanfacine are linked, put them next to each other. • SSRIs should be given only for comorbidities, not for ADHD. • Add melatonin as it is used but should not be. • Primary treatments: methylphenidate, atomoxetine, dexamphetamine. • Second line: lisedxamfetamine, guanfacine, tricyclic, clonidine. • With comorbidities only: atypical, SSRIs, clonidine, tricyclics. • Consider complementary therapies as a specific item – massage, mindfulness, exercise, reiki, etc. • Change text from ‘psychological’ to ‘non-pharmacological’. • Need to have a dialogue about outcomes around harm and using lower evidence for non-pharmacological. • What is right medication for young person with suicidal/self-harm tendencies – many medications are contraindicated here. • Personalised treatment programmes are an emerging area and could perhaps be considered, particularly important for this

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• Neurofeedback • Physical therapies (such as relaxation) **Combined interventions** Sequencing and combination of pharmacological and psychological treatments. **Areas that will not be covered:** • The separate management of comorbid conditions.		population as it is complex and heterogeneous. • Children under six don't have many licensed treatments, so non-pharmacological are important in this group. • There is an evidence gap for children under 6. • Development of psychosis by medication. Methylphenidate and psychosis link. • Management and compliance for pharmacological interventions is an issue. Lots of non-compliance, perhaps due to side-effects, or nature of patient group? Non-compliance might be as high as 50%. May also be some drug diversion. • Include psycho-education as a bullet point under psychological. Helpful especially for adults. Psycho-education targeted at parents and at people with ADHD. Appropriate methods need to be used with children such as storytelling to help them understand. Recognise different learning styles for both child and parent. Importance of clear communication from professionals • Parental self-help groups are often helpful. • Patient/parent choice is important when looking at interventions. • Not all services will be able to offer all interventions, so parents/children don't always get full choice. Informed consent needs all options. Need to be open about success rates and compliance and commitment to treatment.

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		• Medication only improves concentration, does not cure/correct. Holistic treatments may be more curative, but evidence is patchy. • Distinguish between symptom control and condition improvement. • 5 RCTs on homeopathy in India and Switzerland. • Impact of electronic media – blue lights. Evidence around attention, sleep, cognitive performance. Limited screen time etc. • Social media can be empowering and can impact on management. E.g. school-doctor.com. • Use of apps to monitor. May have better uptake by young people. Could fall under psycho-education and compliance. Can save on clinic time. • Many children already use technology as a coping mechanism, needs to be part of the discussion with parents and young people.
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing	• May be some cost effectiveness evidence for psycho-education. • Drugs are expensive, but benefits and cost effectiveness of taking medication are very high in the long term. • Expanding to DSM-V could increase costs.

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	practice? • Which area of the scope is likely to have the most marked or **biggest health implications** for patients? • How would you **rank the areas to be prioritised** for economic analysis? • Do you have any further comments on economics?	

Further questions:	Stakeholder responses
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	None identified.
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	None identified.
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	None identified.
4. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	None identified.

Further questions:	Stakeholder responses
5. Any other issues raised during subgroup discussion for noting:	• Important that the voice of the young person or child is always heard. • Informed choice and informed consent are important. • Pregnancy and treatment protocols in pregnancy. • Prevention of ADHD during pregnancy. Probably highly heritable, so ADHD and family members need advice during pregnancy.

Group 4

ADHD: scope workshop discussions – Group 4 Date: Friday 11 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Children aged 3 years and older, young people and adults with a diagnosis of ADHD and related diagnoses: hyperkinetic disorder (ICD-10) will be considered, along with the three DSM-5 ADHD presentations. • The specific management of ADHD in those individuals who also have: – a defined neurological disorder – a comorbid mental health disorder (including depression, and anxiety disorders). **Groups that will not be covered:** • Children younger than 3 years.	• Is the population appropriate? • Are the exclusions appropriate for the guideline? • Are there any specific subgroups that have not been mentioned (in either list)?	• The cut-off age of 3 years in the previous guideline was too young as medication cannot be prescribed at this age. • An age of 3-6 years was considered more appropriate for diagnosis. • The age of diagnosis in the current guideline being stated as 6 years has been used by some clinicians as an excuse not to diagnose earlier.
1.2. Settings • care in general practice and NHS community care • hospital outpatient and inpatient care • primary/secondary interface of care	• Are the listed settings appropriate? • Are there other settings that should be considered?	• It can take 4.5 years to get a diagnosis of ADHD in current settings.
1.3 Activities, services or aspects of care: **Key areas that will be covered:** ***Areas from the published guideline that will be***	These are the key clinical areas that have been prioritised for inclusion in the guideline.	• Dental care should be given attention in overall care of ADHD patients when initially diagnosed to facilitate early

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Scope details	**Questions for discussion**	**Stakeholder responses**
updated **Pharmacological interventions** The appropriate use of pharmacological interventions, for example initiation and duration of treatment, management of side effects and discontinuation. Specific pharmacological treatments considered will include: • methylphenidate (including modified-release preparations) • atomoxetine (currently licensed for treatment of ADHD in children, and in adults if treatment was initiated in childhood) • guanfacine • dexamphetamine, including lisdexamfetamine dimesylate • tricyclic and other antidepressants • bupropion • nicotine (as skin patches) • atypical antipsychotics • modafinil • clonidine What pharmacological treatments are clinically and cost-effective for people with ADHD whose response to methylphenidate is inadequate? **Psychological interventions**	• Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned?	intervention. • Early diagnosis and intervention should include psychological management, early family training with interventions such as parent child games. • In a CAMHS setting, treatment should involve the whole family – lack of involvement by parents/carers can lead to failure of the intervention. CAMHS does not currently have the capacity to do this due to time constraints. • The group discussed the genetic link in ADHD (~70% genetic). Parent diagnosis and treatment should be taken into account and there should be join involvement going forward. • Treatments and services should be integrated. • Important benefits of the DSM-V tool as ASD can be listed as a comorbidity which couldn't be done with DSM-IV.

ADHD: scope workshop discussions – Group 4

Date: Friday 11 December 2015

Scope details	Questions for discussion	Stakeholder responses
Psychological and behavioural interventions, including: • Cognitive behavioural therapy and other behavioural approaches • Parental training programmes • Family interventions • Neurofeedback • Physical therapies (such as relaxation) **Combined interventions** Sequencing and combination of pharmacological and psychological treatments. **Areas that will not be covered:** • The separate management of comorbid conditions.		
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice? • Which area of the scope is likely to have the most marked or **biggest health implications** for patients?	• DSM-V could lead to over-diagnosis and associated cost impacts.

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	• How would you **rank the areas to be prioritised** for economic analysis? • Do you have any further comments on economics?	
1.5 Key issues and questions 9 What is the clinical and cost effectiveness of methylphenidate (including modified-release preparations), atomoxetine, dexamphetamine, guanfacine, tricyclic and other antidepressants, bupropion, nicotine (as skin patches), atypical antipsychotics, modafinil and clonidine when compared to waiting lists, placebo, other drug (head to head trials), psychological interventions and parent training and does this depend on: ADHD subtype, associated disorder, social context, age, gender and severity, delivery systems? 10 What pharmacological treatments are clinically and cost-effective for people with ADHD whose response to methylphenidate is	• Would you like to add any additional questions to this list?	• Research recommendations around adult ADHD centres and the effect of ADHD outcomes would be helpful. • There was a query about whether the current guideline addressed transition from child to adult services – there were only two adult centres at the time of publication so there could potentially be more evidence now.

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inadequate? 11 What is the clinical and cost effectiveness of cognitive behavioural therapy (CBT), behavioural approaches, parent (effectiveness) training, multimodal interventions, neurofeedback, physical therapies (relaxations etc.) and other approaches when compared to no intervention, waiting lists, 'standard care', other psychological interventions and medication for ADHD and does this depend on: ADHD subtype, associated disorder, social context, age, gender and severity, delivery systems? 12 What is the clinical and cost effectiveness of combined treatment (medication for ADHD plus psychological interventions)?		
1.6 Main Outcomes • Quality of life • ADHD symptoms • Cognitive outcomes • Functional status	• Is the list of outcomes appropriate? Are any key outcomes missing? • Please identify the top 5 outcomes.	• Antisocial behaviour should be considered as an outcome. • Important to look at the effect of ADHD on the criminal justice system as an outcome as 30% of criminals have ADHD symptoms and criminal activity decreases with medication.

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• Associated mental health problems • Peer relationships • Academic outcomes, including school learning and progress • Family relationships • Care needs • Self-esteem • Perceived control of symptoms • Safety		• Inattentive subscale in girls is important to address. • Longer term outcomes should be looked at. • Other suggestions for important outcomes included: ○ Effect on driving ○ Proportion in university ○ Long term unemployment.
GC Membership • Educational specialist • Pharmacologist/pharmacist • Paediatric neurologist • Psychiatrist (1 adult and 1 children) • Psychologist • Community paediatrician • General Practitioner • Specialist nurse (1 adult and 1 children) • Lay members (1 adult with ADHD, 1 young adult with ADHD and one carer/parent)	• Do you have any comments on the proposed membership of the committee?	• An ADHD specific nurse should be included in the GC. • Both adult and child representation should be present. Suggested a child and adult specialist for each role on the GC.

Further questions:	Stakeholder responses
1. Are there any critical **clinical** issues that have been	• Concern was raised about misdiagnosis or late diagnosis and the impact in terms of disability

Further questions:	Stakeholder responses
missed from the Scope that will make a difference to **patient care**?	and educational setbacks. • Concerns were also raised about how diagnosis should differ for children with ADHD and comorbid conditions in comparison to those with ADHD only. • Concerns around the commissioning and authority to diagnose ADHD, especially around clinicians having the appropriate expertise and experience to diagnose adult ADHD.
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	None identified.
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	None identified.
4. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	• Adult ADHD services have not been implemented in line with the current guideline. • There should be specialised ADHD clinics for adults. • Concerns about the lack of ownership between health bodies and local authorities.
5. Any other issues raised during subgroup discussion for noting:	• Parents who have been through adult ADHD have improved significantly and this has improved care of their children with ADHD.