Topic proposal

I understand that this proposal will be retained by the SIGN Programme Lead and be made available on the SIGN website for time period that the proposal is being considered. **Only proposals with a completed Declaration of Interests for the principal proposer will be considered**	
1.	**What is the problem/need for a guideline/clinical scenario?**
	SIGN Guideline 112 October 2009 "Management of Attention Deficit and Hyperkinetic Disorders in Children and Young People" requires updating to take into account recent developments and management strategies, including newer medications, - this guideline now considered to be outdated. In proposing this topic, we suggest our guideline could cover adults and children but appreciate that there could be separate guidelines for young people and adults.
2.	**Burden of the condition**
	Mortality Not known but low. Nevertheless, ADHD (which is characterised by poor levels of impulse control) is an important contributing factor to many illnesses which are important causes of increased mortality in Scotland, including alcohol misuse, smoking and obesity. In particular, ADHD impacts upon the ability to follow preventative health advice.
	Incidence N/A
	Prevalence ADHD is condition which has a normally distributed level of severity in the population. Like problems such as obesity or hypertension, its prevalence depends upon the point at which the degree of abnormality is considered to warrant diagnosis, based on an assessment of related impairment. ADHD diagnosed according to DSM-IV criteria has a higher prevalence than the Hyperkinetic disorders diagnosed using stricter. ICD-10 criteria. The most accurate and comprehensive study conducted in the UK revealed a prevalence of hyperkinetic disorder in the UK to be 2.7% (The Mental Health of Children and Adolescents of Great Britain, a report by the Office for National Statistics [2005], Green, H yet al.; Palgrave MacMillan ISBN 1-4039-8637-1). According to Health Improvement Scotland Attention Deficit and Hyperkinetic Disorders over Scotland (ADHDSOS) Final Report , November 2012, the worldwide prevalence of ADHD is around 5% - citing Polanczzyk G et al "The worldwide prevalence of ADHD: a Systematic Review and metaregression analysis" Am. J. Psychiat. 2007. 164 (6) 942-8 One meta-analysis reports prevalence of ADHD **in adults** of 2.5% (Simon et al [2009], British Journal of Psychiatry 194, 204–211. doi: 10.1192/bjp.bp.107.048827)
3.	**Variations**
	In practice in Scotland <u>Diagnosis (under diagnosis) and diagnostic criteria used:</u> The diagnostic criteria in use across Scotland vary between ICD-10 and DSM-IV The ADHDSOS Final Report indicated an administrative prevalence for ADHD of 0.6% , commenting in particular about under-diagnosis versus expectation, alongside wide variations in reported prevalence across health board areas , ranging from 0.21 to 1.17%

Service provision

Service varies widely by which services and disciplines are employed to conduct assessment and treatment. Disciplines employed to conduct assessment and treatment include child and adolescent psychiatrists, specialist paediatric and community paediatrics, specialist ADHD nurses, generic CAMHS clinicians, and clinical psychology.

Little is clearly known about provision of adult services for ADHD across the country – to our knowledge the task is usually absorbed by generic general adult psychiatric services.

Variability in service provision is likely to be reflected in variation in prescribing rates.

Prescribing

Medical prescribing is initiated by specialist physicians (psychiatrist and paediatricians) with broad range of follow-up and monitoring. Expectation is that specialist services should review the prescription at least 6 monthly. It is very unclear to what extent this occurs.

ISD reports wide variations in prescribing rates of stimulants across health boards. In 2016/17 (even excluding islands with very limited services), there were five-fold differences across health boards, ranging from 5-7 doses/1000 in Lanarkshire and Ayreshire, to 20-25 doses/1000 in Tayside and Borders. (http://www.isdscotland.org/Health-Topics/Prescribing-and-Medicines/Publications/2017-10-10/2017-10-10-PrescribingMentalHealth-Report.pdf?)

Transition

The ADHDSOS Report noted the position re transition in 2012:

"At the time of this follow-up review, not all NHS boards had a formal transition protocol in place. Six NHS boards reported that a generic CAMHS transition protocol was either in place or was in development, and a few of these made specific reference to transition arrangements for young people with ADHD."

It is unclear what progress has in actuality been achieved re transition since this time in the absence of data.

In health outcomes in Scotland

No clear outcome data is available specific to Scotland.

However, there are wide variations in health outcomes across boards for a wide variety of health indicators affected by ADHD, given that ADHD places children and adults at risk for multiple adverse health outcomes, with increases in mental illness and physical illness in adult life, as well as poor social function and increased criminality.

Just some of the well-documented risks include:
Reduced academic performance and outcomes; smoking, substance misuse and addiction; antisocial behaviour, bulimia and borderline personality disorder; increased accidents and head injuries (including road traffic accidents), obesity, decreased occupational opportunity, reduced self-esteem, and poor peer relationships.

ADHD is a significant risk factor for the major health risk factors of smoking, obesity and alcohol misuse.

4.	Areas of uncertainty to be covered
	We are proposing that the previous SIGN guidelines are reviewed to consider new evidence that has arisen since previous publication and also to consider the place of new treatments that have come available since the previous publication. **Key question 1: New drug treatment options** Since previous publication, new treatments that have become available include Lisdexamphetamine (Elvanse) and Guanfacine (Slow-Release). Systemic reviews have been published considering the varying effectiveness of the different treatment options that are likely to influence the guidelines. Should methylphenidate still be considered 'first-line?' (NICE guidance does not consider these treatment options). **Key Question 2: Co-morbidity with Autism Spectrum Disorder (ASD)** ASD has a prevalence of approximately 0.5% to 1.0% and so ADHD co-morbid with autism occurs in at least 0.2% of children and adolescents. What is the evidence to support the treatment of ADHD when co-occurring with a diagnosis of an autism spectrum disorder, and what management strategies are most effective in order to reduce core ADHD symptoms in this situation? Since publication of the previous SIGN guidelines clinical trials have been conducted to examine this question (again not answered by NICE guidelines). **Key question 3: General Co-morbidities including sleep disorders** Similarly, has new evidence been published to advise on the treatment of ADHD when occurring with other co-morbidities such as anxiety disorders or tic disorders? Currently, about £5million/ year is spent in Scotland on melatonin. Much of this is probably for young people with ADHD and sleep problems and the evidence base for this would seem to be minimal. What is the most appropriate way to manage increased sleep latency and other sleep disorders in ADHD? (to include psychological/behavioural approaches as well as medication) **Key question 4: Adult ADHD** What is available in the literature regarding how adults should be assessed for ADHD, how such a de novo diagnosis is made and what is the best evidence for the treatment of ADHD in adults? **Key question 5: Transition between child and adult services** What should be included in guidance regarding the need for transition of young people to either adult mental health services or primary care for ongoing monitoring of ADHD and their medication? At what age and by what process do young people with ADHD best transition from paediatric to adult care (either adult mental health services or primary care), to allow for continued engagement in adult healthcare to allow ongoing monitoring of ADHD and their medication? Compare transition without a structured process and different models of structured transition. This topic needs to include geographical transition as young people move away from home to further education elsewhere. **Key question 6: Behavioural interventions and parent-training** What behavioural interventions are effective and when should they be used? What novel evidence has emerged since the previous guideline e.g. Daley,D. et al., (2017). Practitioner Review: Current best practice in the use of parent training and other behavioural interventions in the treatment of children and adolescents with ADHD. Journal of Child Psychology and Psychiatry. DOI: 10.1111/jcpp.12825

Key Question 7: Long-term treatment outcomes
Is there any new evidence concerning long-term outcomes and benefits, risks or costs of treatment e.g. Humphreys KLet al. (2013). Stimulant medication and substance use outcomes: a meta-analysis. Journal of American Medical Association-Psychiatry 70, 740–749.? When should pharmacological therapy be stopped?

Key Question 8: Service Organisation
How are services best organised to ensure:

a) Regular and effective monitoring of routine treatment
b) Appropriate use of highly limited professional resources
c) Health professionals carry out tasks relevant to their skills.
d) Access to more complex treatment programmes for treatment resistance
e) Appropriate delivery of behavioural and psychosocial programmes of treatment alongside drug treatments.
f) Inter-agency collaboration, getting input from schools and social services in both assessment and treatment.
g) Monitoring and measurement of treatment and service effectiveness.

5.	**Areas that will not be covered**
	Educational and school-based management strategies, preschool behaviour management programmes. Neuroimaging, neuropsychological and genetic studies.
6.	**Aspects of the proposed clinical topic that are key areas of concern for patients, carers and/or the organisations that represent them**
	We lack primary data on this topic but clinical experience points to the issues above: access to diagnosis and treatment, long waiting times, transition, long-term outcomes, sleep problems, co-morbidity. This includes an expressed concern that treatment with stimulant drugs might increase risk of substance misuse in later life.
7.	**Population**
	Included: Children and adults. We do not anticipate work with the elderly.
	Not included: Infants and younger children under 5 yrs of age
8.	**Healthcare setting**
	Included: NHS in Scotland. Services to secure settings should also be considered, given the high prevalence of ADHD in looked-after children and prisoners.
	Not included: Practice outside of Scotland and private practice. We do not anticipate including care for the elderly.
9.	**Potential**
	ADHD is a very common health problem with high morbidity and yet available evidence suggests that it remains under-diagnosed and undertreated in Scotland, with poor transition to adult services, poor coordination of services, and poor utilisation of resources. Effective

	treatment requires to take place over the long-term, and requires effective integration of different agencies and disciplines. Guidelines are required in order to utilise existing evidence to advise on the best way to structure care-pathways to: • Make best use of limited resources and expertise • Optimise treatment choices leading to improved symptom control • Guide the training of non-medical practitioners to deliver more services, • Achieve wider dissemination of models of best-practice • Achieve wider diagnosis • Maximise retention of patients in treatment over the long-term, and minimise drop-out from treatment, especially at transition points. • Achieve greater uniformity and coverage of practice within Scotland Whilst we are not so naïve to think that SIGN guidelines will solve all the problems, we do consider that they are a necessary to provide a better foundation upon which to build improved services.
	Potential impact on important health outcomes (name measureable indicators) Better diagnosis and treatment will result in reduced utilisation of primary and secondary healthcare for other reasons due to improved mental and physical health. This will be reflected in reduced visits to general practice, hospitals (including A&E Departments) and mental health services for reasons other than ADHD treatment. Outside of health, measureable indicators will include: improved academic outcomes, improved school attendance, reduced school exclusions, decreased crime rates (including prosecutions for drug misuse).
	Potential impact on resources (name measureable indicators) Early diagnosis and appropriate intervention/management has the potential to create long term saving by reducing the prevalence of adverse outcomes as noted above.
10.	**What evidence based guidance is currently available?**
	None
	Out-of-date (list) SIGN 112: Management of attention deficit and hyperkinetic disorders in children and young people (October 2009)(withdrawn)
	Current (list) Attention deficit hyperactivity disorder: diagnosis and management. NICE CG72 (September 2008, updated: February 2016) https://www.nice.org.uk/guidance/cg72/chapter/Recommendations#diagnosis-of-adhd
11.	**Relevance to current Scottish Government policies**
	Concordant with the Mental Health Strategy Priorities for Child and Adolescent Mental Health . Scottish Gov. 2017- 2017
12.	**Who is this guidance for?**
	Clinical Practitioners in Child and Adolescent Health, Specialist Paediatrics and their clinical teams including Clinical Psychologists and Specialist ADHD Nurse practitioners

13.	**Implementation**
	Links with existing audit programmes http://www.healthcareimprovementscotland.org/our_work/mental_health/adhd_service_improvement/stage_3_adhd_final_report.aspx Medicines used in Mental Health - BNF Section 4.4 - CNS stimulants and other drugs used for attention deficit hyperactivity disorder (Data collected by ISD) MHAIST Data Workstream Group is currently underway with the objective of collecting mental health service data at the person level.
	Existing educational initiatives None known
	Strategies for monitoring implementation Should HIS re-visit/follow up on ADHD SOS 2012?
14.	**Primary contact(s) for topic proposal**
	Dr Justin Williams (justin.williams@abdn.ac.uk) Dr Christopher Steer (christopher.steer@nhs.net)
15.	**Group(s) or institution(s) supporting the proposal**
	Royal College of Psychiatry Child and Adolescent Faculty Royal College of Paediatrics and Child Health

Declaration of Interests

Please complete all sections and if you have nothing to declare please put 'N/A

Having read the SIGN Policy on Declaration of Competing Interests I declare the following competing interests for the previous year, and the following year. I understand that this declaration will be retained by the SIGN Programme Lead and be made available on the SIGN website for time period that the proposal is being considered.

Signature:	C.R.Steer
Name:	Dr Christopher Steer
Relationship to SIGN:	Topic proposal primary contact Dr Christopher Steer or Dr Justin Williams
Date:	04/02/2018
Date received at SIGN:	

Personal Interests
Remuneration from employment

	Name of Employer and Post held	**Nature of Business**	**Self or partner/ relative**	**Specific?**
Details of employment held which may be significant to, or relevant to, or bear upon the work of SIGN	Scottish Government	Medical Advisor on Fetal Alcohol Spectrum Disorders and Children and Young People with Disability	N/A	N/A

Remuneration from self employment

	Name of Business	**Nature of Business**	**Self or partner/ relative**	**Specific?**
Details of self employment held which may be significant to, or relevant to, or bear upon the work of SIGN	N/A	N/A	N/A	N/A

Remuneration as holder of paid office

	Nature of Office held	Organisation	Self or partner/ relative	Specific?
Details of office held which may be significant to, or relevant to, or bear upon the work of SIGN	N/A	N/A	N/A	N/A

Remuneration as a director of an undertaking

	Name of Undertaking	Nature of Business	Self or partner/ relative	Specific?
Details of directorship held which may be significant to, or relevant to, or bear upon the work of SIGN	N/A	N/A	N/A	N/A

Remuneration as a partner in a firm

	Name of Partnership	Nature of Business	Self or partner/ relative	Specific?
Details of Partnership held which may be significant to, or relevant to, or bear upon the work of SIGN	N/A	N/A	N/A	N/A

Shares and securities

	Description of organisation	Description of nature of holding (value need not be disclosed)	Self or partner/ relative	Specific?
Details of interests in shares and securities in commercial healthcare companies, organisations and undertakings	N/A	N/A	N/A	N/A

Remuneration from consultancy or other fee paid work commissioned by, or gifts from, commercial healthcare companies, organisations and undertakings

	Nature of work	For whom undertaken and frequency	Self or partner/ relative	Specific?
Details of consultancy or other fee paid work which may be significant of to, or relevant to, or bear upon the work of SIGN	Nil current or planned	N/A	N/A	N/A
Details of gifts which may be significant to, or relevant to, or bear upon the work of SIGN	N/A	N/A	N/A	N/A

Non-financial interests

	Description of interest	Self or partner/ relative	Specific?
Details of non-financial interests which may be significant to, or relevant to, or bear upon the work of SIGN	N/A	N/A	N/A

Non-personal interests

	Name of company, organisation or undertaking	Nature of interest
Details of non-personal support from commercial healthcare companies, organisations or undertakings	N/A	N/A

C.R.Steer

Signature _____ *Date:* *08/02/2018*

Thank you for completing this form.

Please return to
Roberta James
SIGN Programme Lead
SIGN Executive, Healthcare Improvement Scotland,
Gyle Square | 1 South Gyle Crescent | Edinburgh | EH12 9EB

t: **0131 623 4735**
e:**roberta.james@nhs.net**

Data Protection

Your details will be stored on a database for the purposes of managing this guideline topic proposal. We may retain your details so that we can contact you about future Healthcare Improvement Scotland activities. We will not pass these details on to any third parties. Please indicate if you do not want your details to be stored after the proposal is published.

Healthcare Improvement Scotland

SIGN
Scottish Intercollegiate Guidelines Network

Declaration of Interests

Please complete all sections and if you have nothing to declare please score through that section or put 'N/A

Diagnosis of children with fetal alcohol syndrome disorders

Justin Williams

Having read the attached SIGN Policy on Declaration of Competing Interests I declare the following competing interests for the previous year, and the following year. I understand that this declaration will be retained by the SIGN Programme Lead for the lifetime of the guideline, and made available in summary on the SIGN website.

Signature:	
Name:	Justin H G Williams
Relationship to SIGN:	
Date:	27th March 2017
Date received at SIGN:	27·3·17

Personal Interests

Remuneration from employment

	Name of Employer and Post held	Nature of Business	Self or partner/ relative	Specific?
Details of employment held which may be significant to, or relevant to, or bear upon the work of SIGN	University of Aberdeen	Senior Clinical Lecturer in Child And Adolescent Psychiatry	Self	Not specific

Remuneration from self employment

	Name of Business	Nature of Business	Self or partner/ relative	Specific?
Details of self employment held which may be significant to, or relevant to, or bear upon the work of SIGN	St Andrews Psychology Practice	Private Clinical Psychology Practice	Partner	Not specific

Remuneration as holder of paid office

	Nature of Office held	Organisation	Self or partner/ relative	Specific?
Details of office held which may be significant to, or relevant to, or bear upon the work of SIGN	Nil			

Remuneration as a director of an undertaking

	Name of Undertaking	Nature of Business	Self or partner/ relative	Specific?
Details of directorship held which may be significant to, or relevant to, or bear upon the work of SIGN	Nil			

Remuneration as a partner in a firm

	Name of Partnership	Nature of Business	Self or partner/ relative	Specific?
Details of Partnership held which may be significant to, or relevant to, or bear upon the work of SIGN	Nil			

Shares and securities

	Description of organisation	Description of nature of holding (value need not be disclosed)	Self or partner/ relative	Specific?
Details of interests in shares and securities in commercial healthcare companies, organisations and undertakings	Nil			

Remuneration from consultancy or other fee paid work commissioned by, or gifts from, commercial healthcare companies, organisations and undertakings

	Nature of work	For whom undertaken and frequency	Self or partner/ relative	Specific?
Details of consultancy or other fee paid work which may be significant of to, or relevant to, or bear upon the work of SIGN	Nil			

Details of gifts which may be significant to, or relevant to, or bear upon the work of SIGN	Nil			

Non-financial interests

	Description of interest	Self or partner/ relative	Specific?
Details of non-financial interests which may be significant to, or relevant to, or bear upon the work of SIGN	Nil		

Non-personal interests

	Name of company, organisation or undertaking	Nature of interest
Details of non-personal support from commercial healthcare companies, organisations or undertakings	Nil	

Please return to
Gaynor Rattray
Guideline Co-ordinator
SIGN Executive, Healthcare Improvement Scotland,
Gyle Square | 1 South Gyle Crescent | Edinburgh | EH12 9EB

t: **0131 623 4730**
e: **gaynor.rattray@nhs.net**

Initial screen

Purpose: initial screening by SIGN Senior Management Team to exclude proposals that are neither clinical, nor multi-professional, nor appropriate for the SIGN process.

1.	**Is this an appropriate clinical topic for a SIGN guideline?** Is it a clinical topic, what is the breadth of the topic and is there a need for the guideline as identified in the proposal?	
	Yes, it would replace SIGN 12 on management of ADHD in children and young people published in 2009. The topic is very broad and is intended to cover children and adults, however there is a separate topic proposal on ADHD in adults and the Royal College of Psychiatrics in Scotland recently published a guideline on management of adults with ADHD. The remit would need to be more focused for consideration by GPAG.	
2.	**Is there a suitable alternative product which would address this topic?** Would another Healthcare Improvement Scotland product better address the topic?	
	No, although some key questions may not be appropriate or possible to develop within an evidence-based guideline	
3.	**Has this topic been considered before and rejected?** What were the reasons for rejection and are they still applicable	
	No	
4.	**Outcome**	
	Go forward to the next stage of topic selection Suggest meet the proposers to discuss narrowing the remit and avoiding overlap with the proposal for a guideline on ADHD in adults before taking to next stage.	**YES** **18/07/18**
	Reject	

Suitability screen

Purpose: screening by the Guideline Programme Advisory Board to select applications suitable for inclusion in the SIGN topic selection process.

1.	**Is there an owner for the project?** (preferably an individual)
	Yes
2.	**Is this a clinical priority area for NHSScotland?**
	ADHD (which is characterised by poor levels of impulse control) is an important contributing factor to many illnesses which are important causes of increased mortality in Scotland, including alcohol misuse, smoking and obesity. In particular, ADHD impacts upon the ability to follow preventative health advice.
3.	**Is there a gap between current and optimal practice? OR Is there wide variation in current practice?** (is this an area of clinical uncertainty)
	Service varies widely by which services and disciplines are employed to conduct assessment and treatment:: • variation in prescribing of ADHD medication across boards, with variation in prescribing for children partially accounted for by individual lead clinicians with different approaches • association between prescribing of ADHD medication and deprivation • distribution of prescribing of ADHD medication across age groups • parents' opinions that ADHD diagnosis takes too long • general lack of support for parents (other than medication).
4.	**Is there a suitable guideline already available that could be adapted?** (not necessarily by SIGN)
	There is a NICE guideline for diagnosis and management of ADHD in children and adults which was published in March 2018. This is a comprehensive review of the evidence which includes: • Service organisation and training • Recognition, identification and referral • Diagnosis • Information and support • Non-pharmacological management of ADHD • Dietary advice • Pharmacological management of ADHD • Maintenance and monitoring • Adherence to treatment • Review of medication and discontinuation. The Royal College of Psychiatrists in Scotland guideline for ADHD in adults, published in 2017, includes: • Diagnosis • Pre-referral recommendations • Referrals to mental health services • Assessment • Comorbidity • Specific patient groups • Management of ADHD • Service design • Training • Transition guidance • Comorbidity

	• Self help Royal College of Psychiatrists in Scotland Adult ADHD Working Group has developed standards for transition. This notes that about 50% of children with ADHD do not require transition to adult services, however emphasises the need to align with NICE advice about individualised assessment of need at transition boundaries to ensure continuity of care. NICE has published a commissioning guide to support the development of services for adults with ADHD.
5.	**Is there adequate literature to make an evidence-based decision about appropriate practice?** (is effective intervention proven and would it reduce mortality or morbidity)
	Yes, as evidence by the NICE guideline.
6.	**Would the proposed practice change result in sufficient change in outcomes** (health status, provider and consumer satisfaction and cost) **to justify the effort?**
	Better diagnosis and treatment will result in reduced utilisation of primary and secondary healthcare for other reasons due to improved mental and physical health. This will be reflected in reduced visits to general practice, hospitals (including A&E Departments) and mental health services for reasons other than ADHD treatment. Outside of health, measureable indicators will include: improved academic outcomes, improved school attendance, reduced school exclusions, and decreased crime rates (including prosecutions for drug misuse).
	How big is the gap?
	Not clear
	How much effort will it take to close the gap?
	Not clear
7.	**Is there a perceived need for the guideline, as indicated by a network of relevant stakeholders?**
	Royal College of Psychiatry Child and Adolescent Faculty Royal College of Paediatrics and Child Health
8.	**Is there a reasonable likelihood that NHSScotland could implement the change?**
	Not clear
9.	**Does the proposer have any conflicts of interest? If so how will these be managed?**
	No

10.	**Outcome**	
	Go forward to the next stage of topic selection	
	Reject The conclusion of a multidisciplinary group meeting, held 30 October 2018, including the proposers, and proposers of a guideline on management of ADHD in adults, was that for ADHD, there are real and significant concerns about service delivery and configuration which have been well-described by all those present, however these would not be impacted by a summary of the evidence on interventions (and any evidence needs which may exist currently have been addressed by NICE's comprehensive and up to date review).	**REJECT** **30/01/2019**
11.	**Decision**	
	Rejected by SIGN Council for inclusion on the SIGN guideline development programme	**Date**
	Comment	**13/02/2019**