National Institute for Health and Care Excellence

Final

Attention deficit hyperactivity disorder (update)

[G] Evidence reviews for Adherence to treatment (pharmacological and non-pharmacological)

NICE guideline NG87

Evidence review

March 2018

Final

This evidence review was developed by the National Guideline Centre

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive. All NICE guidance is subject to regular review and may be updated or withdrawn.

Contents

1 Adherence to treatment (pharmacological and non-pharmacological) 5

1.1 Review question: What factors do people with ADHD believe affect their adherence to pharmacological or non-pharmacological treatment for ADHD? 5

1.2 Introduction 5

1.3 Characteristics table 5

1.4 Methods and process 6

1.5 Qualitative evidence 6

1.5.1 Included studies 6

1.5.2 Excluded studies 6

1.5.3 Summary of qualitative studies included in the evidence review 6

1.5.4 Qualitative evidence synthesis 8

1.5.5 Qualitative evidence summary 13

1.6 Economic evidence 22

1.6.1 Included studies 22

1.6.2 Excluded studies 22

1.7 Resource impact 23

1.8 Evidence statements 23

1.8.1 Clinical evidence statements 23

1.8.2 Health economic evidence statements 23

1.9 The committee's discussion of the evidence 23

1.9.1 Interpreting the evidence 23

1.9.2 Cost effectiveness and resource use 25

1.9.3 Other factors the committee took into account 25

Appendices 42

Appendix A: Review protocols 42

Appendix B: Literature search strategies 46

B.1 Clinical search literature search strategy 46

B.2 Health Economics literature search strategy 49

Appendix C: Qualitative study selection 53

Appendix D: Qualitative evidence tables 54

Appendix E: Health economic evidence study selection 65

Appendix F: Health economic evidence tables 67

Appendix G: Excluded studies 68

G.1 Excluded qualitative studies 68

G.2 Excluded health economic studies 72

1

1 Adherence to treatment (pharmacological and non-pharmacological)

1.1 Review question: What factors do people with ADHD believe affect their adherence to pharmacological or non-pharmacological treatment for ADHD?

1.2 Introduction

Supporting adherence to treatment in people with ADHD has unique challenges. Non-adherence has been conceptualised as falling into two categories – intentional and unintentional (see NICE's guideline on medicines adherence). Intentional non-adherence occurs when someone makes a decision not to follow the treatment recommendations and unintentional adherence happens when the individual is willing to follow an agreed treatment, but obstacles and problems beyond their control stop them from doing so. Non-adherence should not be seen as the person's problem. It represents a fundamental limitation in the delivery of healthcare, often because of a failure to fully agree the prescription in the first place or to identify and provide the support that patients need later on. Given the difficulties people with ADHD may have with forgetfulness in everyday activities or in relation to organising tasks, they may be particularly prone to non-adherence of the non-intentional type. For example, they may plan to take their medication but forget to do so, or forget to fill the prescription, or lose the prescription in the interim between receiving it from their doctor and taking it to the chemist. In the case of non-pharmacological treatments they may forget when the appointment is or get distracted on the way to the session. The presence of co-existing mental health or neurodevelopmental conditions may also impact adherence.

The key principles of medicine management are well established and set out clearly in the NICE guideline on medicines adherence. These include ensuring people are involved in discussions about treatment and can make informed decisions about their care. While there are universal principles of care it is important that practitioners are aware of ways to support people with ADHD to be adherent to treatment plans and this chapter considers the factors that people with ADHD believe influence their adherence to both pharmacological and non-pharmacological treatment for their condition.

This review should be read alongside evidence report H on managing treatment and evidence report B on information and support.

1.3 Characteristics table

For full details see the review protocol in appendix A.

Table 1: Characteristics of review question

Objective	To investigate the factors that may affect adherence to treatment, so as to inform guidance to people with ADHD on receiving treatment
Population and setting	Children, young people and adults with ADHD who are receiving treatment (pharmacological or non-pharmacological) and their healthcare professionals, teachers, family and carers.
Context	Any themes that emerge relating to the adherence of treatment for people with ADHD
Review strategy	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data from questionnaires will only be considered if insufficient

qualitative evidence is identified

1.4 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual.[142] Methods specific to this review question are described in the review protocol in appendix A.

Declarations of interest were recorded according to NICE's 2014 conflicts of interest policy.

1.5 Qualitative evidence

1.5.1 Included studies

Fifteen qualitative studies were included in the review; Ahmed 2013[1]; Brinkman 2008[14]; Charach 2006[27]; Charach 2014[29]; Coletti 2012[34]; Gallichan 2008[60]; Ibrahim 2016[88]; Lefler 2016[111]; Matheson 2013[125]; Meaux 2006[133]; Meaux 2009[132]; Mills 2011[135]; O'Callaghan 2014[144]; Sikirica 2014[164]; Swift 2013[178] these are summarised in Table 2 below. Key themes from these studies are summarised in Section 1.5.2 below. See also the study selection flow chart in appendix C, study evidence tables in appendix D, and excluded studies lists in appendix G.

1.5.2 Excluded studies

See the excluded studies list in appendix G.

1.5.3 Summary of qualitative studies included in the evidence review

Table 2: Summary of studies included in the review (pharmacological adherence)

Study	Design	Population	Research aim	Setting
Ahmed 2013[1]	Focus groups and a framework method of analysis.	16 parents of children with ADHD (aged 3 to 12 years)	To explore factors influencing parents' decisions to adhere and persists with ADHD medication	Australia
Brinkman 2008[14]	Focus groups with open-ended questions and grounded theory analysis.	52 parents of children with ADHD (aged 6 to 17 years)	To explore how parents make decisions about treatment for their children with ADHD	USA
Charach 2006[27]	Semi-structured focus groups and thematic analysis.	17 mothers and fathers of 14 children with ADHD (aged 7 to 15 years)	To explore parents' attitudes towards medicating their child	Canada
Charach 2014[29]	Semi-structured interviews and interpretive interactionist framework analysis	12 children with ADHD (aged 12 to 15 years)	Exploring young people's and parents' attitudes towards stimulant treatment	Canada
Coletti 2012[34]	Semi-structured	27 parents of	To explore parent	USA

Study	Design	Population	Research aim	Setting
	focus groups and an inductive approach to analysis, using grounded theory.	children diagnosed with ADHD (aged 5 to 12 years)	perspectives on the decision to initiate medication treatment for ADHD	
Gallichan 2008[60]	Open-ended interviews and grounded theory analysis.	12 young people with ADHD (aged 10 to 17 years)	Explore young peoples' perspectives of ADHD	UK
Ibrahim 2016[88]	Semi-structured interviews and grounded theory analysis.	8 GPs, 8 consultants, 5 teachers and 5 mothers (of children and young people, age not specified)	Examine the experiences of drug holidays from caregivers and healthcare professionals	UK
Lefler 2016[111]	Semi-structured focus groups and idiographic inductive analysis.	36 college students with ADHD (aged >18 years)	To explore the experiences of college students living with ADHD	USA
Matheson 2013[125]	Semi structured interviews and thematic analysis.	15 adults diagnosed with ADHD in childhood, and 15 diagnosed in adulthood (aged >18 years)	Explore adults experiences with ADHD	UK
Meaux 2006[133] (Meaux 2009[132])	Semi-structured interviews and content analysis.	15 college students with ADHD (aged >18 years)	To gain insight about medication use among young people with ADHD	USA
Mills 2011[135]	Semi-structured interviews and constant comparative analysis	19 families (representing 30 children with ADHD) (aged not specified)	To understand how parents decide to medicate their child	USA
O'Callaghan 2014[144]	Semi-structured telephone interviews and thematic analysis.	18 adults with ADHD	To explore the context that influences stimulant medication adherence	USA
Sikirica 2014[164]	Telephone interviews and thematic analysis.	38 caregivers (of ages 6 to 17 years) and 28 young people (13 to 17 years)	To explore the unmet needs of young people with ADHD and their caregivers	Mixed European countries (including UK)
Swift 2013[178]	Semi-structured interviews and thematic analysis.	10 young adults with ADHD (aged 17-18)	Patient experiences of ADHD, particularly around transitioning	UK

Study	Design	Population	Research aim	Setting
			services	

Table 3: Summary of studies included in the review (non-pharmacological adherence)

Study	Design	Population	Research aim	Setting
Smith 2014[171]	Semi-structured focus groups and thematic analysis.	19 practitioners running services for preschool children with ADHD, and 13 parents of children with ADHD (aged Pre-schoolers). Parents were all undertaking group parent training	Understanding the reasons of low uptake and completion of parent interventions for ADHD	UK

See appendix D for full evidence tables.

1.5.4 Qualitative evidence synthesis

Table 4: Review themes

Main themes	Statement of theme
Understanding drug efficacy	Young people have a better understanding of the efficacy of their medication as they get older, and so adhere to it
Perceived benefit/lack of benefit	People on medication are more likely to adhere to their medication if they perceive it to be improving their symptoms.
Side effects	Side effects of medication were described as main reasons for not adhering to it.
Loss of identity	People reported that they didn't feel like themselves whilst on medication
Forgetting to take medication and time management	People with ADHD have difficulty remembering to take their medication and organising appointments.
Willingness to take medication	Children hide their medication from parents, or refuse to take it
Patient self-management	Young people and adults reduce their dosages or have drug holidays without consulting healthcare professionals.
Parental self-management	Parents reduce their child's dosage or have drug holidays without consulting healthcare professionals.
Difficulty accessing prescriptions	Adults report being unable to access treatment due to GPs or pharmacists refusing prescriptions.
Discontinuation when transitioning to adult services	Adults report long periods of treatment cessation when they are transferred to adult services
Barriers to treatments (non-pharmacological)	There are a range of psychological, situational and socioeconomic barriers to non-pharmacological treatment

1.5.4.1 Narrative summary of review themes

Review theme 1: Understanding drug efficacy

Young people felt that as they got older, they realised that their treatment was effective and useful for them. When they were younger, they made attempts to not take their medication, such as hiding their pills or refusing to take them. They gradually learned why they needed to take their medication, and so they adhered more to it as they got older.

Explanation of quality assessment: minor methodological limitations in the contributing studies; moderate concerns about coherence of the theme with review theme 7 showing conflicting results (patients making their own treatment plans without consulting healthcare professionals); partial concerns about applicability with one study being conducted in Canada, and the other in the UK; Moderate concerns about adequacy as data was not detailed. There was a judgement of moderate confidence in this theme due to the concerns regarding the applicability of the data and the adequacy

Review theme 2a: Perceived benefit/lack of benefit (pharmacological treatment)

People on medication are more likely to adhere to their medication if they perceive it to be improving their symptoms. Parents are more likely to consistently adhere to treatment if they feel the improvements extend beyond ADHD symptoms, to functional improvements for all areas of their child's life, such as mood, sleep and social functioning. Adherence is also better when improvements from the medication outweighed side effect; when side effects are worse, this can lead to a lack of adherence. Young people also stop taking their medication if they don't feel like it is helping them.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about coherence of the theme; partial concerns about applicability with only 2/6 studies conducted in the UK; no concerns about adequacy. There was a judgement of moderate confidence in this theme due to the concerns regarding the applicability of the data and the adequacy

Review theme 2b: Perceived benefit/lack of benefit (non-pharmacological treatment)

Parents were more likely to drop out of parent training if they did not see improvement they expected quickly enough. This was combated by setting realistic expectations and in helping parents to see small improvements.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about coherence of the theme; no concerns about applicability; moderate concerns about adequacy due to only one contributing study. There was a judgement of moderate confidence in this theme due to the concerns regarding adequacy of the data

Review theme 3: Side effects

Adherence to medication is impacted by the level of side effects experienced by people with ADHD. Those that perceive a high level of side effects are less likely to adhere to their medication, especially if side effects are seen to outweigh the benefit gained from symptom improvement.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about coherence of the theme; partial concerns about applicability due to only 1 of the 3 studies being conducted in the UK; minor concerns about adequacy, as data was not rich but had moderate quantity. There was a judgement of moderate confidence in this theme due to the concerns regarding the relevance of the data.

Review theme 4: Loss of identity

Adherence to medication is affected by a loss of 'sense of self' in young people. They felt that the medication changed their identity by affecting their personality and the way in which they interact with the world around them.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about coherence of the theme; partial concerns about applicability due to one study being conducted in Canada and one in the UK; moderate concerns about adequacy due to only two contributing studies, with limitations around data richness. There was a judgement of low confidence in this theme due to the concerns regarding the relevance and adequacy of the data.

Review theme 5: Forgetting to take medication and time management

People with ADHD do not feel equipped to successfully stick to their treatment plan. They can forget to take their medication, which is a problem that impacts on their adherence to treatment. In addition they feel unable to keep monthly appointments for medication management. Parents often support their child by ensuring they take their medication, and by organising their appointments for them.

Explanation of quality assessment: moderate methodological limitations in the contributing studies (many limitations within the studies, such as issues with richness of the data, and details provided about data analysis, data collection, and the role of the researcher. No concerns about coherence of the theme; partial concerns about applicability; minor concerns about adequacy. There was a judgement of low confidence in this theme due to the concerns regarding the methodological limitations of the data and concerns about applicability.

Review theme 6: Willingness to take medication

It can be difficult to give ADHD medication to children. Some children attempt to not take their medication by hiding it from their parents, and actively fight to not take their medication. This can make it difficult for parents to ensure their children adhere to treatment.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about coherence of the theme; partial concerns about applicability (one study conducted in the UK, one in Canada); moderate concerns about adequacy due to only 2 contributing studies. There was a judgement of moderate confidence in this theme due to the concerns regarding the adequacy of the data and concerns about applicability.

Review theme 7: Patient self-management

People with ADHD sometimes take their medication at their own direction, without consulting healthcare professionals. They take 'drug holidays' depending on when they feel they need to take their medication, and when they don't. This is mainly for work or education purposes, such as periods of high work-load and exams. Others reduce their dosage or do not take their medication on the weekend because they don't want the effects of the treatment over this time.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about coherence of the theme; partial concerns about applicability (one study in the UK, three in the USA); no concerns about adequacy. There was a judgement of moderate confidence in this theme due to the concerns regarding the applicability of the data.

Review theme 8: Parental self-management

Parents of children and young people with ADHD often felt solely responsible for managing and monitoring their child's medication. Some parents could cope with their children not taking medication out of school hours, and felt it important to do so due to their concerns about side effects and the long-term impacts of medicating their child. Other parents felt

unequipped to do this and so their children were more likely to fully adhere to treatment. Parents also modify dosages or utilising drug holidays of medication when they are concerns about side effects. Although some parents consulted healthcare professionals before doing so, others did not.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about coherence of the theme; partial concerns about applicability (two studies in the UK, two in Australia and one in mixed countries); no concerns about adequacy. There was a judgement of moderate confidence in this theme due to the concerns regarding the applicability of the data.

Review theme 9: Difficulty accessing prescriptions

Adults with ADHD reported healthcare professionals and pharmacists as barriers to their treatment. They sometimes reported difficulty in accessing repeat prescriptions due to pharmacists being unwilling to dispense the treatment, or GPs being unwilling to prescribe medication. These sometimes cause long periods of treatment cessation, lasting from days to years, which is highly distressing for patients.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; no concerns about coherence of the theme; minor concerns about applicability; no concerns about adequacy. There was a judgement of moderate confidence in this theme due to the concerns regarding methodological limitations.

Review theme 10: discontinuation when transitioning to adult services

People with ADHD reported long delays in transitions to adult services from child services. This sometimes resulted in discontinuation of support and as a result caused periods of treatment cessation.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about coherence of the theme; no concerns about applicability; moderate concerns about adequacy (only one contributing study). There was a judgement of low confidence in this theme due to the concerns regarding adequacy of the data.

Review theme 11: barriers to adhering to services (non-pharmacological)

Many barriers for patients in accessing non-pharmacological treatment exist. Psychological barriers included feelings of shame, embarrassment and fear of being judged. Situational barriers included time commitments, inconvenient session times and location and child care issues. Practitioners also feel that a lack of education, cultural issues, domestic violence and financial difficulties impacted on adherence.

Explanation of quality assessment: minor methodological limitations in the contributing study; no concerns about coherence of the theme; moderate concerns over applicability due to study being based only on group parent training interventions; moderate concerns about adequacy due to only one contributing study. There was a judgement of low confidence in this theme due to the concerns regarding adequacy of the data and applicability.

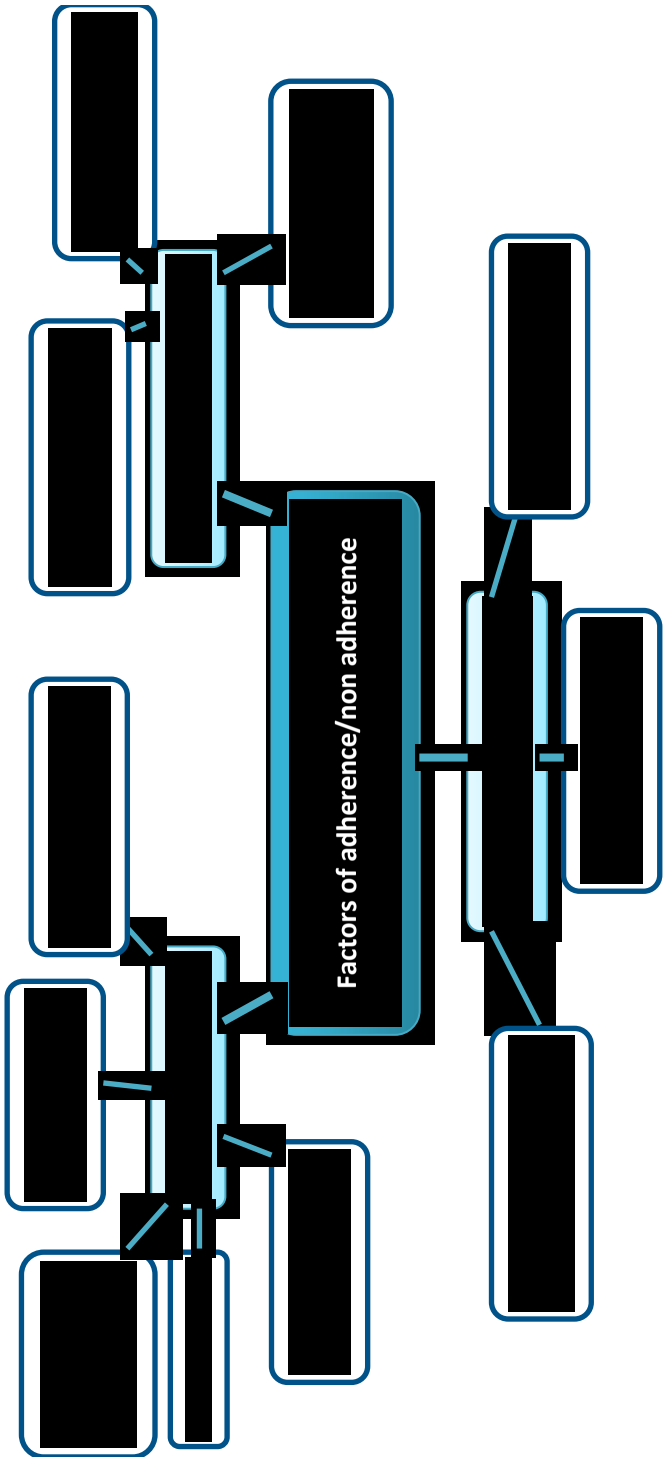


Figure 1: Diagram of review themes

1.5.5 Qualitative evidence summary

1.5.5.1 Theme 1: Psychological factors

Table 5: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
Review theme 1: understanding drug efficacy (young people)					
2	2 interviews (1 UK; 1 Canada)	Young people have a better understanding of the efficacy of their medication as they get older, and so adhere to it	Limitations	minor limitations	LOW
			Coherence	moderate concerns about coherence	
			Relevance	partially relevant	
			Adequacy	Moderate concerns about adequacy	

Table 6: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
Review theme 2a: perceived benefit/lack of benefit (pharmacological; all age groups)					

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
5	1 Focus group 4 Interviews (3 USA,1 UK; 1 Canada) (3 children, 2 young people, 1 adult)	People on medication are more likely to adhere to their medication if they perceive it to be improving their symptoms. People are less likely to adhere to their medication when they do not perceive a benefit	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	No concerns about adequacy	

Table 7: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
Review theme 2b: perceived benefit/lack of benefit (non-pharmacological; pre-schoolers; parent training)					
1	Interviews (UK)	Parents were more likely to drop out of parent training if they did not see improvement they expected quickly enough.	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

Table 8: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
Review theme 3: Side effects; all age groups					
3	2 interviews 1 focus group (1 UK; 1 USA; 1 Canada)	Side effects of medication were described as a main reason for not adhering to it.	Limitations	minor limitations	MODERATE
			Coherence	no concerns about coherence	
			Relevance	partially applicable	
			Adequacy	no concerns about adequacy	

Table 9: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
Review theme 4: Loss of sense of self (young people)					
2	2 interviews (1 UK; 1 Canada)	People reported that they didn't feel like themselves whilst on medication	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

Table 10: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
Review theme 5: Forgetting to take medication and time management (all age groups)					
4	3 interviews 1 focus group	People with ADHD have difficulty remembering to take their medication and organising appointments.	Limitations	moderate limitations	LOW
			Coherence	no concerns about	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
	(1 UK; 3 USA)			coherence	
			Relevance	Partially applicable	
			Adequacy	minor concerns about adequacy	

1.5.5.2 Theme 2: Self-management

Table 11: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 6: Willingness to take medication (children)					
2	1 interview 1 focus group (1 UK; 1 Canada)	Children can actively fight to not take their medication, or hide their medication from their parents.	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
			Adequacy	moderate concerns about adequacy	

Table 12: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 7: patient self-management (young people and adults)					
4	3 interviews 1 focus group (1 UK; 3 USA)	Young people and adults reduce their dosages or have drug holidays without consulting healthcare professionals.	Limitations	minor limitations	MODERATE
			Coherence	no concerns about coherence	
			Relevance	partially applicable	
			Adequacy	no concerns about adequacy	

Table 13: Summary of evidence

Study design and sample size	Themes	Quality assessment

No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 8: Parent self-management (children and young people)					
5	3 interviews 2 focus groups (2 UK; 2 Australia; 1 mixed European countries including the UK)	Parents reduce their child's dosages or utilise drug holidays without consulting healthcare professionals.	Limitations	minor limitations	MODERATE
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	no concerns about adequacy	

Table 14: Summary of evidence

Study design and sample size			Quality assessment		
No of studies contributing to the theme	**Design**	**Themes**	**Criteria**	**Rating**	**Overall assessment of confidence**
Review theme 9: Difficulty accessing prescriptions (adults)					
3	3 interviews (2 UK; 1 USA)	Adults report being unable to access treatment due to GPs or pharmacists refusing to write prescriptions or dispense medication.	Limitations	moderate limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	minor	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
				concerns about adequacy	

1.5.5.3 Theme 3: Services

Table 15: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 10: Discontinuation when transitioning to adult services					
1	Interviews (UK)	Adults report long periods of treatment cessation when they are transferred to adult services	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

Table 16: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
Review theme 11: Barriers to non-pharmacological treatment					
1	Interviews (UK)	Psychological barriers (feelings of shame, embarrassment and fear of being judged) Situational barriers (time commitments, inconvenient session times and location and child care issues) Socioeconomic barriers (lack of education, cultural issues, domestic violence and financial difficulties)	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

1.6 Economic evidence

1.6.1 Included studies

No relevant health economic studies were identified.

1.6.2 Excluded studies

No health economic studies that were relevant to this question were excluded due to assessment of limited applicability or methodological limitations.

See also the health economic study selection flow chart in appendix E

1.7 Resource impact

We do not expect recommendations resulting from this review area to have a significant impact on resources.

1.8 Evidence statements

1.8.1 Clinical evidence statements

- See section 1.5.4.1

1.8.2 Health economic evidence statements

- No relevant economic evaluations were identified.

1.9 The committee's discussion of the evidence

1.9.1 Interpreting the evidence

1.9.1.1 The quality of the evidence

All the evidence was of low to moderate quality. The majority of subthemes had minor methodological limitations in the contributing studies. There were mainly only minor concerns about the coherence of the themes. Many of the studies had moderate concerns about relevance and adequacy. The studies were all conducted in a population of people with ADHD, or in carers or healthcare professionals who supported people with ADHD. For some subthemes, only a small amount of evidence was identified. The majority of studies were conducted within Canada, the USA, Australia and the UK. Although Canada and Australia have similar healthcare systems to the UK, the USA does not. This was taken into account when assessing the applicability of the themes around the delivery of services. The committee were in agreement that the subthemes presented were consistent with their own clinical experiences.

1.9.1.2 Themes identified in the evidence synthesis

The review identified a number of factors that influence adherence to pharmacological treatment in people with ADHD. These included psychological factors, self-management behaviours, and service barriers.

The perception of the benefit of treatment and side effects were found to influence adherence. People were found not to adhere to treatment if they did not perceive it to be improving their symptoms. Parents were also more likely to adhere to treatment if they felt the improvements extended beyond ADHD symptoms, to functional improvements for all areas of their child's life, such as mood, sleep and social functioning. In addition, adherence was found to be better when improvements from the medication outweighed side effects; when side effects were worse, this led to a lack of adherence.

The committee agreed that healthcare professionals should discuss with children, young people and adults with ADHD and their parents or carers the impact that medication can have on individuals, and how this can be managed. In addition, the committee noted that healthcare professionals should explain the process of achieving an optimal balance between efficacy of treatment and side effects, ways to reduce side effects (with particular emphasis on titration periods), the importance of adherence to treatment, and how parents or

carers could help to improve treatment adherence. The committee noted that healthcare professionals should fully disclose possible side effects with people with ADHD and their carers. The committee also agreed that in young people and adults with ADHD, support groups could be a useful way for patients to gain support by discussing experiences with treatment with others. This evidence supported the recommendations made in the management of treatment and information and support sections.

The committee noted the importance of providing clear instructions, which should be individualized into the appropriate format for that person. They agreed that in families where parents or carers also have ADHD, healthcare professionals needed to be aware of the needs of parents and how they might require additional support to help their children adhere to treatment.

The committee discussed the monitoring of treatment, and agreed that healthcare professionals should endeavour to understand how the medication impacts the patients' life. They felt that in adults with ADHD, it may be useful to have someone else present during conversations.

Age was also found to influence adherence. Some people with ADHD began to understand why they needed to take medication as they got older, and so adhered to treatment. For others, they began to take control of their treatment and establish autonomy over decisions to take medication; in some cases only taking their medication when they felt they needed it, such as during times of high workload. The committee agreed that both of these circumstances arise, and they highlighted the importance of recognising young people's increased involvement in medication decision-making.

The evidence suggested that people were not adhering to treatment when they felt that it was causing a loss of identity or change in personality. The committee noted that they had often come across this in their own clinical experiences. They discussed the importance of healthcare professionals recognising these concerns, particularly in young people that have an increased autonomy over their medication decisions.

The evidence suggests that people with ADHD have difficulty remembering to take their treatment, and difficulty in arranging and organising appointments with healthcare professionals in order to monitor treatment. The committee discussed ways to reduce problems related to forgetting to take medication, such as obtaining batch prescriptions from pharmacies. The committee agreed that healthcare professionals should discuss techniques that could be used to support planning and management of medication taking. They noted that simple drug regimens should be used (for example, once daily modified release doses), in order to aid adherence.

The review identified barriers to services that are experienced by adults with ADHD. The evidence suggested that adults could find difficulty in accessing prescriptions, due to uncertainty from healthcare professionals and pharmacists. The committee discussed ways to improve these experiences for people with ADHD. They suggested that healthcare professionals should discuss these issues with people with ADHD. They agreed that people with ADHD providing documentation could help, which could be particularly useful when travelling abroad, as difficulty could arise due to carrying a control drug.

The evidence suggested that young adults may be unable to access treatment whilst they are transitioning from paediatric to adult services. The committee noted the importance of a shared care arrangement over primary and secondary care that could be continued at a time young people transition to adult services. They felt that this would improve the confidence of primary healthcare professionals in continuing to prescribe medication.

1.9.2 Cost effectiveness and resource use

No economic evidence was identified on the adherence to treatment in people with ADHD, as this was a qualitative review and therefore did not look at the clinical effectiveness or cost effectiveness of interventions.

The recommendations made by the committee are not expected to have any major cost implications as they indicate what elements have to be considered by healthcare professionals in the discussion of treatment with the patients and all interventions that are mentioned are considered to already be best clinical practice. This review aims at changing the content of discussions around treatment, rather than the quantity or intensity of the treatment reviews. Improved treatment adherence would lead to more efficient care and decision making further down the line with the aim of reducing treatment burden and adverse events, which would create some cost savings to the NHS.

1.9.3 Other factors the committee took into account

Based on their experience, the committee discussed what should be discussed between the person with ADHD, the parent or carer, and the healthcare professional. They felt that it should cover managing expectations of treatment and helping patients to understand the benefit and harm of treatment, and the impact on their lives as a whole. Healthcare professionals should relate this information to the importance of adherence to treatment. The titration process should be discussed, with particular emphasis on achieving an optimal balance between the efficacy and side effects of the treatment. The committee also felt that healthcare professionals should discuss with parents or carers issues around children hiding medication, or refusing to take it.

The committee also highlighted the importance of good communication and involvement of the child wherever possible, and for this to be appropriate to the developmental level of the child. They also emphasised the importance of individualising this for each patient or family, depending on their care needs. For example, the instructions should be in the appropriate format for that individual. This may be written instructions, instructions using pictures, or could use different methods based on the persons' needs, and appropriate to the development level of the person with ADHD. These discussions were based partly on their experience but also informed by the themes relating to the types of information people preferred. In addition, the committee noted that separate recommendations may be needed for families with ADHD, where the parents also have ADHD, or other behaviour or mental health conditions. Here, parents might need additional support in helping their children in adhering to their medication. This support should be individualised to the needs of both the parent and the child. There may be different communication issues that exist for children and adults, and so the committee felt recommendations should be made separately for each age strata.

The committee highlighted that providing immediate information on side effects was important, in order to give patients and their carers advice on what to do and how best to manage these. The committee highlighted that there may not currently be someone identified to do this, and that it is important to identify a specific healthcare professionals that could be contacted, in order to help with the optimization process. The committee highlighted that currently, services were discharging children back to their GPs, and GPs often do not provide the level of information on side effects that patients and their parents or carers require.

The committee highlighted that a shared care protocol was required to better equip GPs with the information needed to continue prescribing treatment. The committee noted that a number of the qualitative reviews in this guideline identified situations in which the interface between primary and secondary care was contributing to the variations in care. . The evidence showed that people with ADHD thought secondary services should be involved in distributing shared care plans. The committee felt that GPs had a responsibility of care to

prescribe medication to people with ADHD, but had a lack of training or awareness in the area. Currently, some CDCs discharge young people with ADHD back to primary care before they transition to adult services, without full guidance on the treatment requirements necessary for the person with ADHD.

The committee highlighted that the needs of children and young people with ADHD could vary greatly, and that monitoring and managing adherence should take this into account. There could be a variety of responses to medication which relates to the child's increased role in decision making. For example sometimes, young people may need to stop their medication to understand the benefits they were receiving from it. The GC highlighted the importance of 'watchful waiting' in these cases. Other children may be known to be lively and socially active. If their medication subdues them, they may be at risk of feeling like their medication has changed them too much to adhere to. The committee emphasised the importance of individualising treatment management and support to each persons' own situation.

The committee noted that in their experience shared decision making between the person with ADHD, the parents or carers, and the healthcare professional, could be difficult. Parents find their children's increased involvement difficult and the healthcare professional may find it difficult to determine the level of involvement from both patients and parents. The committee noted there should be clarity of what should be considered for children, young people and adults taking into the account the changing involvement of young people in their treatment. They noted that more involvement in decision making could occur from early on in adolescence and needs to be recognised by healthcare professionals. The committee felt it was important not to overlook the fact that they might need to give young people similar information to that they are giving adults.

The committee had concerns that the ADHD population may be more likely to be self-medicating and buying drugs illegally. In addition, they noted that some people with ADHD may be selling their medication and apparent adherence to treatment may be masking that the person with ADHD is selling on their medication. Issues around self-medication and selling of ADHD medication were identified in the review. The committee agreed that this is important for healthcare professionals to be aware of.

The committee discussed many ways to help people to remember to take their medication or order their next prescription. They highlighted the importance of clear instructions and the need for them to with the medication. This could be a sticker on the side of the packet, the committee noted that separate pieces of paper given at the same time as the prescription would be likely to be lost or forgotten.

Based on their own experience, the committee discussed the use of apps, and medicine boxes that use smart technology that will indicate whether or not you have taken your medication. For example, there are barcode scanning apps that will only allow a phone to be unlocked when the barcode on the medication has been scanned. The committee noted it would be useful to have a system in place to remind patients to reorder their medication when it's almost finished. Pharmacies can also be supportive obtaining repeat prescription from GPs, or access batch prescriptions which will help the person with ADHD to access treatment. They also noted other techniques to help planning, such as the use of dosset boxes so it is easy to tell how long ago the pill bottle was open, pill boxes should be labelled with days of the week. The committee were keen to illustrate the unique difficulties that people with ADHD have in adhering to medication and the story below, brought to the committee's attention by one of the lay members, reflects their experience and underpins the importance of these recommendations,

'Every morning the dreaded question: "Did I take my meds already?"

It is unavoidable no matter what trick I try to use.

This morning however the situation almost took a turn for the worse.

I was being my usual self, getting ready, making my lunch while putting on deodorant and checking reddit all at once, you know how it is.

Usually I stop when I see my pill bottle and have to wonder whether or not I've taken it, I realize I hadn't and take my medication out of the bottle. I then remember that I needed to give the dog her epilepsy meds as well, so I took her pill out the bottle. I then realized I didn't have the candy things they use to give her her meds, so I turn around to go to the cupboard and get them.

I get back to the counter, take a bite of my bagel, try to remember if the deodorant is out because I wanted to put it on or if I had just left it there. Anyways, grab the pill, put it in the candy thing for the dog, give it to the dog.

Did I take my meds yet?

Look on the counter, all that's there is the tiny epilepsy pill... oh no.

Chase the dog, grab the dog, get the stupid candy thing out of her mouth, break it open, there's my pill! Realize I would've killed the dog, get angry at myself, grab another candy thing give her the right pill.

Realise I'm gonna miss the bus, grab my lunch, out the door.

Get on the bus, wait... did I take my meds?'

The committee noted the importance of healthcare professionals bearing in mind the impact of ADHD on people's abilities to engage with services and keep appointments. They agreed that more so than in other conditions, failure to attend appointments is frequently a sign of the impact of a person's condition rather than a lack of interest or importance placed on attendance.

References

1. Ahmed R, Borst J, Wei YC, Aslani P. Parents' perspectives about factors influencing adherence to pharmacotherapy for ADHD. Journal of Attention Disorders. 2017; 21(2):91-99

2. Ahmed R, Borst JM, Yong CW, Aslani P. Do parents of children with attention-deficit/hyperactivity disorder (ADHD) receive adequate information about the disorder and its treatments? A qualitative investigation. Patient Preference & Adherence. 2014; 8:661-670

3. Ahmed R, McCaffery KJ, Aslani P. Factors influencing parental decision making about stimulant treatment for attention-deficit/hyperactivity disorder. Journal of Child and Adolescent Psychopharmacology. 2013; 23(3):163-178

4. Ansari NJR, Dhongade RK, Lad PS, Borade A, Suvarna YG, Yadav V et al. Study of parental perceptions on health & social needs of children with neuro-developmental disability and it's impact on the family. Journal of Clinical and Diagnostic Research. 2016; 10(12):SC16-SC20

5. Arango C. To treat or not to treat? and How to treat? Two questions whose answers are far removed from evidence informed practice in child psychiatry. European Child and Adolescent Psychiatry. 2013; 22(9):521-522

6. Bachman JA, Brennan PF, Patrick TB, Cole M. A World Wide Web-based health resource. Survey of Missouri school nurses to determine priority health information resources for SchoolhealthLink. Journal of School Nursing. 2000; 16(1):28-33

7. Ball C. Attention-deficit hyperactivity disorder and the use of methylphenidate: A survey of the views of general practitioners. Psychiatric Bulletin. 2001; 25(8):301-304

8. Bartlett R, Rowe TS, Shattell MM. Perspectives of college students on their childhood ADHD. MCN, American Journal of Maternal Child Nursing. 2010; 35(4):226-231

9. Bekle B. Knowledge and attitudes about attention-deficit hyperactivity disorder (ADHD): a comparison between practicing teachers and undergraduate education students. Journal of Attention Disorders. 2004; 7(3):151-161

10. Berger I, Dor T, Nevo Y, Goldzweig G. Attitudes toward attention-deficit hyperactivity disorder (ADHD) treatment: Parents' and children's perspectives. Journal of Child Neurology. 2008; 23(9):1036-1042

11. Berger NP. The creative use of the ADHD diagnosis in probationers' self-narratives. Journal of Scandinavian Studies in Criminology and Crime Prevention. 2015; 16(1):122-139

12. Bringewatt EH. Negotiating narratives surrounding children's mental health diagnoses: Children and their contribution to the discourse. Children and Youth Services Review. 2013; 35(8):1219-1226

13. Brinkman WB, Epstein JN. Treatment planning for children with attention-deficit/hyperactivity disorder: treatment utilization and family preferences. Patient Preference & Adherence. 2011; 5:45-56

14. Brinkman WB, Sherman SN, Zmitrovich AR, Visscher MO, Crosby LE, Phelan KJ et al. Parental angst making and revisiting decisions about treatment of attention-deficit/hyperactivity disorder. Pediatrics. 2009; 124(2):580-589

15. Brinkman WB, Sherman SN, Zmitrovich AR, Visscher MO, Crosby LE, Phelan KJ et al. In their own words: adolescent views on ADHD and their evolving role managing medication. Academic Pediatrics. 2012; 12(1):53-61

16. Brodin J, Ljusberg AL. Teaching children with attention deficit hyperactivity disorder in remedial classes. International Journal of Rehabilitation Research. 2008; 31(4):351-355

17. Brook U, Boaz M. Attention deficit and hyperactivity disorder (ADHD) and learning disabilities (LD): adolescents perspective. Patient Education and Counseling. 2005; 58(2):187-191

18. Brook U, Watemberg N, Geva D. Attitude and knowledge of attention deficit hyperactivity disorder and learning disability among high school teachers. Patient Education and Counseling. 2000; 40(3):247-252

19. Brown O, Howcroft G, Muthen T. Resilience in families living with a child diagnosed with hyperactivity/attention deficit disorder. South African Journal of Psychology. 2010; 40(3):338-350

20. Bussing R, Koro-Ljungberg M, Noguchi K, Mason D, Mayerson G, Garvan CW. Willingness to use ADHD treatments: a mixed methods study of perceptions by adolescents, parents, health professionals and teachers. Social Science and Medicine. 2012; 74(1):92-100

21. Bussing R, Mason D, Garvan CW, Gurnani T, Koro-Ljungberg M, Noguchi K et al. Willingness to use ADHD self-management: mixed methods study of perceptions by adolescents and parents. Journal of Child & Family Studies. 2016; 25(2):562-573

22. Bussing R, Schoenberg NE, Perwien AR. Knowledge and information about ADHD: evidence of cultural differences among African-American and white parents. Social Science and Medicine. 1998; 46(7):919-928

23. Butler AM, Titus C. Systematic review of engagement in culturally adapted parent training for disruptive behavior. Journal of Early Intervention. 2015; 37(4):300-318

24. Canela C, Buadze A, Dube A, Eich D, Liebrenz M. Attitudes toward stimulant treatment of offspring of adult patients with attention-deficit/hyperactivity disorder. Journal of Child and Adolescent Psychopharmacology. 2017; Epublication

25. Carpenter-Song E. Familial responses to ADHD and bipolar spectrum disorders: Perspectives from a diverse group of families in the United States. Directions in Psychiatry. 2010; 30(1):53-62

26. Carter SL. College students' acceptance of potential treatments for ADHD. Psychological Reports. 2005; 97(1):258-264

27. Charach A, Skyba A, Cook L, Antle BJ. Using stimulant medication for children with ADHD: what do parents say? A brief report. Journal of the Canadian Academy of Child & Adolescent Psychiatry. 2006; 15(2):75-83

28. Charach A, Volpe T, Boydell KM, Gearing RE. A theoretical approach to medication adherence for children and youth with psychiatric disorders. Harvard Review of Psychiatry. 2008; 16(2):126-135

29. Charach A, Yeung E, Volpe T, Goodale T, Dosreis S. Exploring stimulant treatment in ADHD: narratives of young adolescents and their parents. BMC Psychiatry. 2014; 14:110

30. Cheung KK, Wong IC, Ip P, Chan PK, Lin CH, Wong LY et al. Experiences of adolescents and young adults with ADHD in Hong Kong: treatment services and clinical management. BMC Psychiatry. 2015; 15:95

31. Clarke JN. Surplus suffering: The search for help when a child has mental-health issues. Child & Family Social Work. 2013; 18(2):217-225

32. Clarke JN, Lang L. Mothers whose children have ADD/ADHD discuss their children's medication use: An investigation of blogs. Social Work in Health Care. 2012; 51(5):402-416

33. Clay D, Farris K, McCarthy AM, Kelly MW, Howarth R. Family perceptions of medication administration at school: errors, risk factors, and consequences. Journal of School Nursing. 2008; 24(2):95-102

34. Coletti DJ, Pappadopulos E, Katsiotas NJ, Berest A, Jensen PS, Kafantaris V. Parent perspectives on the decision to initiate medication treatment of attention-deficit/hyperactivity disorder. Journal of Child and Adolescent Psychopharmacology. 2012; 22(3):226-237

35. Cooper P, Shea T. Pupils' perceptions of AD/HD. Emotional & Behavioural Difficulties. 1998; 3(3):36-48

36. Corcoran J, Schildt B, Hochbrueckner R, Abell J. Parents of children with attention deficit/hyperactivity disorder: A meta-synthesis, part I. Child & Adolescent Social Work Journal. 2016:1-55

37. Cormier E. How parents make decisions to use medication to treat their child's ADHD: a grounded theory study. Journal of the American Psychiatric Nurses Association. 2012; 18(6):345-356

38. Couture C, Royer E, Dupuis FA, Potvin P. Comparison of Quebec and British teachers' beliefs about, training in and experience with attention deficit hyperactivity disorder. Emotional and Behavioural Difficulties. 2003; 8(4):284-302

39. Darredeau C, Barrett SP, Jardin B, Pihl RO. Patterns and predictors of medication compliance, diversion, and misuse in adult prescribed methylphenidate users. Human Psychopharmacology. 2007; 22(8):529-536

40. Davis-Berman JL, Pestello FG. Medicating for ADD/ADHD: Personal and social issues. International Journal of Mental Health and Addiction. 2010; 8(3):482-492

41. Davis CC, Claudius M, Palinkas LA, Wong JB, Leslie LK. Putting families in the center: family perspectives on decision making and ADHD and implications for ADHD care. Journal of Attention Disorders. 2012; 16(8):675-684

42. Deane H, Young S. Navigating adolescence: an epidemiological follow-up of adaptive functioning in girls with childhood ADHD symptoms and conduct disorder. Journal of Attention Disorders. 2014; 18(1):44-51

43. Dennis T, Davis M, Johnson U, Brooks H, Humbi A. Attention deficit hyperactivity disorder: parents' and professionals' perceptions. Community Practitioner. 2008; 81(3):24-28

44. DosReis S, Barksdale CL, Sherman A, Maloney K, Charach A. Stigmatizing experiences of parents of children with a new diagnosis of ADHD. Psychiatric Services. 2010; 61(8):811-816

45. DosReis S, Mychailyszyn MP, Evans-Lacko SE, Beltran A, Riley AW, Myers MA. The meaning of attention-deficit/hyperactivity disorder medication and parents' initiation

and continuity of treatment for their child. Journal of Child and Adolescent Psychopharmacology. 2009; 19(4):377-383

46. dosReis S, Mychailyszyn MP, Myers M, Riley AW. Coming to terms with ADHD: how urban African-American families come to seek care for their children. Psychiatric Services. 2007; 58(5):636-641

47. dosReis S, Myers MA. Parental attitudes and involvement in psychopharmacological treatment for ADHD: a conceptual model. International Review of Psychiatry. 2008; 20(2):135-141

48. Edwards C, Howlett E. Putting knowledge to trial: 'ADHD parents' and the evaluation of alternative therapeutic regimes. Social Science and Medicine. 2013; 81:34-41

49. Einarsdottir J. Teaching children with ADHD: Icelandic early childhood teachers' perspectives. Early Child Development and Care. 2008; 178(4):375-397

50. Eisenberg D, Schneider H. Perceptions of academic skills of children diagnosed with ADHD. Journal of Attention Disorders. 2007; 10(4):390-397

51. Elias R, White SW. Autism goes to college: understanding the needs of a student population on the rise. Journal of Autism and Developmental Disorders. 2017; Epublication

52. Emilsson M, Gustafsson PA, Ohnstrom G, Marteinsdottir I. Beliefs regarding medication and side effects influence treatment adherence in adolescents with attention deficit hyperactivity disorder. European Child and Adolescent Psychiatry. 2017; 26(5):559-571

53. Faber A, Kalverdijk LJ, de Jong-van den Berg LT, Hugtenburg JG, Minderaa RB, Tobi H. Parents report on stimulant-treated children in the Netherlands: initiation of treatment and follow-up care. Journal of Child and Adolescent Psychopharmacology. 2006; 16(4):432-440

54. Fiks AG, Hughes CC, Gafen A, Guevara JP, Barg FK. Contrasting parents' and pediatricians' perspectives on shared decision-making in ADHD. Pediatrics. 2011; 127(1):e188-196

55. Firmin MW, Phillips A. A qualitative study of families and children possessing diagnoses of ADHD. Journal of Family Issues. 2009; 30(9):1155-1174

56. Flannagan D, Pillow DR, Wise JC. Perceptions and communications about ADHD and ODD behaviors in children with combined type attention deficit hyperactivity disorder. Children's Health Care. 2002; 31(3):223-236

57. Fleischmann A, Miller EC. Online narratives by adults with ADHD who were diagnosed in adulthood. Learning Disability Quarterly. 2013; 36(1):47-60

58. Frank E, Ozon C, Nair V, Othee K. Examining why patients with attention-deficit/hyperactivity disorder lack adherence to medication over the long term: a review and analysis. Journal of Clinical Psychiatry. 2015; 76(11):e1459-1468

59. Friars P, Mellor D. Drop-out from parenting training programmes: a retrospective study. Journal of Child & Adolescent Mental Health. 2009; 21(1):29-38

60. Gallichan DJ, Curle C. Fitting square pegs into round holes: the challenge of coping with attention-deficit hyperactivity disorder. Clinical Child Psychology and Psychiatry. 2008; 13(3):343-363

61. Garro LC, Yarris KE. "A massive long way": interconnecting histories, a "special child," ADHD, and everyday family life. Culture, Medicine and Psychiatry. 2009; 33(4):559-607

62. Gau SS, Chiu CD, Shang CY, Cheng AT, Soong WT. Executive function in adolescence among children with attention-deficit/hyperactivity disorder in Taiwan. Journal of Developmental and Behavioral Pediatrics. 2009; 30(6):525-534

63. Gerdes AC, Lawton KE, Haack LM, Schneider BW. Latino parental help seeking for childhood ADHD. Administration and Policy in Mental Health. 2014; 41(4):503-513

64. Ghanizadeh A, Zarei N. Are GPs adequately equipped with the knowledge for educating and counseling of families with ADHD children? BMC Family Practice. 2010; 11:5

65. Ghosh M, Fisher C, Preen DB, Holman CD. "It has to be fixed": a qualitative inquiry into perceived ADHD behaviour among affected individuals and parents in Western Australia. BMC Health Services Research. 2016; 16:141

66. Ginsberg ML. Attention-deficit/hyperactivity disorder: a personal perspective. Adolescent Medicine. 2008; 19(2):339-351, xi-xii

67. Goodwillie G. Protective vigilance: A parental strategy in caring for a child diagnosed with ADHD. Journal of Family Therapy. 2014; 36(3):255-267

68. Gwernan-Jones R, Moore DA, Cooper P, Russell AE, Richardson M, Rogers M et al. A systematic review and synthesis of qualitative research: the influence of school context on symptoms of attention deficit hyperactivity disorder. Emotional and Behavioural Difficulties. 2016; 21(1):83-100

69. Gwernan-Jones R, Moore DA, Garside R, Richardson M, Thompson-Coon J, Rogers M et al. ADHD, parent perspectives and parent–teacher relationships: grounds for conflict. British Journal of Special Education. 2015; 42(3):279-300

70. Hack S, Chow B. Pediatric psychotropic medication compliance: a literature review and research-based suggestions for improving treatment compliance. Journal of Child and Adolescent Psychopharmacology. 2001; 11(1):59-67

71. Hallberg U, Klingberg G, Reichenberg K, Möller A. Living at the edge of one's capability: Experiences of parents of teenage daughters diagnosed with ADHD. International Journal of Qualitative Studies on Health and Well-being. 2008; 3(1):52-58

72. Hansen DL, Hansen EH. Caught in a balancing act: parents' dilemmas regarding their ADHD child's treatment with stimulant medication. Qualitative Health Research. 2006; 16(9):1267-1285

73. Hansson Hallerod SL, Anckarsater H, Rastam M, Hansson Scherman M. Experienced consequences of being diagnosed with ADHD as an adult - a qualitative study. BMC Psychiatry. 2015; 15:31

74. Harazni L, Alkaissi AAE. Experience of mothers and teachers of attention deficit/hyperactivity disorder children, and their management practices for the behaviors of the child: a descriptive phenomenological study...Middle Eastern Nurses Uniting in Human Caring, Third Annual Middle East Conference; Aqaba, Jordan, February 20-21, 2015. International Journal for Human Caring. 2015; 19(4):78-78

75. Harborne A, Wolpert M, Clare L. Making sense of ADHD: A battle for understanding? Parents' views of their children being diagnosed with ADHD. Clinical Child Psychology and Psychiatry. 2004; 9(3):327-339

76. Harvey WJ, Reid G, Bloom GA, Staples K, Grizenko N, Mbekou V et al. Physical activity experiences of boys with and without ADHD. Adapted Physical Activity Quarterly. 2009; 26(2):131-150

77. Hassink-Franke LJ, Janssen MM, Oehlen G, van Deurzen PA, Buitelaar JK, Wensing M et al. GPs' experiences with enhanced collaboration between psychiatry and general practice for children with ADHD. European Journal of General Practice. 2016; 22(3):196-202

78. Hazell P, Lewin T, Sly K. What is a clinically important level of improvement in symptoms of attention-deficit/hyperactivity disorder? Australian and New Zealand Journal of Psychiatry. 2005; 39(5):354-358

79. Hebert J, Polotskaia A, Joober R, Grizenko N. Adherence to psychostimulant medication in children with attention-deficit/hyperactivity disorder: the role of attitudes. Journal of the Canadian Academy of Child & Adolescent Psychiatry 2013; 22(4):317-323

80. Henry E, Jones SH. Experiences of older adult women diagnosed with attention deficit hyperactivity disorder. Journal of Women and Aging. 2011; 23(3):246-262

81. Hill V, Turner H. Educational psychologists' perspectives on the medicalisation of childhood behaviour: A focus on attention deficit hyperactive disorder (ADHD). Educational and Child Psychology. 2016; 33(2):12-29

82. Ho SW, Chien WT, Wang LQ. Parents' perceptions of care-giving to a child with attention deficit hyperactivity disorder: an exploratory study. Contemporary Nurse. 2011; 40(1):41-56

83. Hong Y. Teachers' perceptions of young children with ADHD in Korea. Early Child Development and Care. 2008; 178(4):399-414

84. Honkasilta J, Vehkakoski T, Vehmas S. Power struggle, submission and partnership: Agency constructions of mothers of children with ADHD diagnosis in their narrated school involvement. Scandinavian Journal of Educational Research. 2015; 59(6):674-690

85. Honkasilta J, Vehkakoski T, Vehmas S. 'The teacher almost made me cry' Narrative analysis of teachers' reactive classroom management strategies as reported by students diagnosed with ADHD. Teaching and Teacher Education. 2016; 55:100-109

86. Hughes L. The reality of living with AD/HD: children's concern about educational and medical support. Emotional & Behavioural Difficulties. 2007; 12(1):69-80

87. Hughes L. Engaging students with ADHD in mainstream education: Lessons from children, parents and teachers. The International Journal of Emotional Education. 2009; 1(1):108-117

88. Ibrahim K, Vogt C, Donyai P. Caught in the eye of the storm: A qualitative study of views and experiences of planned drug holidays from methylphenidate in child and adolescent adhd treatment. Child and Adolescent Mental Health. 2016; 21(4):192-200

89. Ide-Okochi A, Tadaka E. A hybrid concept analysis of children of concern: Japanese healthcare professionals' views of children at a high risk of developmental disability. BMC Pediatrics. 2016; 16 171

90. Jackson D, Peters K. Use of drug therapy in children with attention deficit hyperactivity disorder (ADHD): maternal views and experiences. Journal of Clinical Nursing. 2008; 17(20):2725-2732

91. Kean B. The Risk Society and attention deficit hyperactivity disorder (ADHD): a critical social research analysis concerning the development and social impact of the ADHD diagnosis. Ethical Human Psychology and Psychiatry. 2005; 7(2):131-142

92. Kendall J. The use of qualitative methods in the study of wellness in children with attention deficit hyperactivity disorder. Journal of Child and Adolescent Psychiatric Nursing. 1997; 10(4):27-38

93. Kendall J, Hatton D, Beckett A, Leo M. Children's accounts of attention-deficit/hyperactivity disorder. Advances in Nursing Science. 2003; 26(2):114-130

94. Kendall L. 'The teacher said I'm thick!' Experiences of children with attention deficit hyperactivity disorder within a school setting. Support for Learning. 2016; 31(2):122-137

95. Kildea S, Wright J, Davies J. Making sense of ADHD in practice: a stakeholder review. Clinical Child Psychology and Psychiatry. 2011; 16(4):599-619

96. King K, Alexander D, Seabi J. Siblings' perceptions of their ADHD-diagnosed sibling's impact on the family system. International Journal of Environmental Research and Public Health. 2016; 13(9):13

97. Kisely S, Ong G, Takyar A. A survey of the quality of web based information on the treatment of schizophrenia and Attention Deficit Hyperactivity Disorder. Australian and New Zealand Journal of Psychiatry. 2003; 37(1):85-91

98. Klasen H, Goodman R. Parents and GPs at cross-purposes over hyperactivity: a qualitative study of possible barriers to treatment. British Journal of General Practice. 2000; 50(452):199-202

99. Knipp DK. Teens' perceptions about attention deficit/hyperactivity disorder and medications. Journal of School Nursing. 2006; 22(2):120-125

100. Ko CH, Yen JY, Chen CS, Chen CC, Yen CF. Psychiatric comorbidity of internet addiction in college students: an interview study. CNS Spectrums. 2008; 13(2):147-153

101. Koerting J, Smith E, Knowles MM, Latter S, Elsey H, McCann DC et al. Barriers to, and facilitators of, parenting programmes for childhood behaviour problems: a qualitative synthesis of studies of parents' and professionals' perceptions. European Child and Adolescent Psychiatry. 2013; 22(11):653-670

102. Kollins SH. A qualitative review of issues arising in the use of psycho-stimulant medications in patients with ADHD and co-morbid substance use disorders. Current Medical Research and Opinion. 2008; 24(5):1345-1357

103. Koro-Ljungberg M, Bussing R, Williamson P, Wilder J, Mills T. African-American teenagers' stories of attention deficit/hyperactivity disorder. Journal of Child and Family Studies. 2008; 17(4):467-485

104. Kovshoff H, Williams S, Vrijens M, Danckaerts M, Thompson M, Yardley L et al. The decisions regarding ADHD management (DRAMa) study: uncertainties and complexities in assessment, diagnosis and treatment, from the clinician's point of view. European Child and Adolescent Psychiatry. 2012; 21(2):87-99

105. Kronenberg LM, Slager-Visscher K, Goossens PJ, van den Brink W, van Achterberg T. Everyday life consequences of substance use in adult patients with a substance use disorder (SUD) and co-occurring attention deficit/hyperactivity disorder (ADHD) or autism spectrum disorder (ASD): a patient's perspective. BMC Psychiatry. 2014; 14:264

106. Kutuk MO, Durmus E, Gokcen C, Toros F, Guler G, Evegu E. Determination of beliefs, attitudes of consulting teachers towards mental diseases, and referral reasons of their students to a child and adolescent psychiatrist. Düşünen Adam: Journal of Psychiatry and Neurological Sciences. 2016; 29(3):227-236

107. Larson JJ, Yoon Y, Stewart M, dosReis S. Influence of caregivers' experiences on service use among children with attention-deficit hyperactivity disorder. Psychiatric Services. 2011; 62(7):734-739

108. Laugesen B, Lauritsen MB, Jorgensen R, Sorensen EE, Rasmussen P, Gronkjaer M. Living with a child with attention deficit hyperactivity disorder: a systematic review. International Journal of Evidence Based Healthcare. 2016; 14(4):150-165

109. Lee H, Causgrove Dunn J, Holt NL. Youth sport experiences of individuals with attention deficit/hyperactivity disorder. Adapted Physical Activity Quarterly. 2014; 31(4):343-361

110. Lee K. ADHD in American early schooling: From a cultural psychological perspective. Early Child Development and Care. 2008; 178(4):415-439

111. Lefler EK, Sacchetti GM, Del Carlo DI. ADHD in college: A qualitative analysis. Attention Deficit and Hyperactivity Disorders. 2016; 8(2):79-93

112. Leggett C, Hotham E. Treatment experiences of children and adolescents with attention-deficit/hyperactivity disorder. Journal of Paediatrics and Child Health. 2011; 47(8):512-517

113. Leslie LK, Plemmons D, Monn AR, Palinkas LA. Investigating ADHD treatment trajectories: listening to families' stories about medication use. Journal of Developmental and Behavioral Pediatrics. 2007; 28(3):179-188

114. Lewis-Morton R, Dallos R, McClelland L, Clempson R. “There is something not quite right with Brad...”: The ways in which families construct ADHD before receiving a diagnosis. Contemporary Family Therapy. 2014; 36(2):260-280

115. Lewis EM, Feely M, Seay KD, Fedoravicis N, Kohl PL. Child welfare involved parents and pathways Triple P: perceptions of program acceptability and appropriateness. Journal of Child & Family Studies. 2016; 25(12):3760-3770

116. Lewis EM, Feely M, Seay KD, Fedoravicius N, Kohl PL. "Child welfare involved parents and pathways Triple P: Perceptions of program acceptability and appropriateness": Erratum. Journal of Child and Family Studies. 2016; 25(12):3782

117. Liebrenz M, Fisher CE, Nellen R, Frei A, Biechl A-C, Hiestand N et al. Adult attention-deficit/hyperactivity disorder and nicotine withdrawal: A qualitative study of patient perceptions. BMC Psychiatry. 2016; 16:11

118. Lin MJ, Huang XY, Hung BJ. The experiences of primary caregivers raising school-aged children with attention-deficit hyperactivity disorder. Journal of Clinical Nursing. 2009; 18(12):1693-1702

119. Ljusberg AL. Children's views on attending a remedial class - because of concentration difficulties. Child: Care, Health and Development. 2011; 37(3):440-445

120. Loe M, Cuttino L. Grappling with the medicated self: The case of ADHD college students. Symbolic Interaction. 2008; 31(3):303-323

121. Lopes T, Eloff I, Howie S, Maree JG. South African teachers' experiences of children in their classrooms who may have ADHD. Journal of Psychology in Africa. 2009; 19(3):347-354

122. Maassen EF, Schrevel SJ, Dedding CW, Broerse JE, Regeer BJ. Comparing patients' perspectives of "good care" in Dutch outpatient psychiatric services with academic perspectives of patient-centred care. Journal of Mental Health. 2017; 26(1):84-94

123. Marcer H, Finlay F, Baverstock A. ADHD and transition to adult services--the experience of community paediatricians. Child: Care, Health and Development. 2008; 34(5):564-566

124. Mathers ME. Aspects of language in children with ADHD: applying functional analyses to explore language use. Journal of Attention Disorders. 2006; 9(3):523-533

125. Matheson L, Asherson P, Wong IC, Hodgkins P, Setyawan J, Sasane R et al. Adult ADHD patient experiences of impairment, service provision and clinical management in England: a qualitative study. BMC Health Services Research. 2013; 13:184

126. Matthys F, Soyez V, van den Brink W, Joostens P, Tremmery S, Sabbe B. Barriers to implementation of treatment guidelines for ADHD in adults with substance use disorder. Journal of Dual Diagnosis. 2014; 10(3):130-138

127. McCarthy AM, Kelly MW, Reed D. Medication administration practices of school nurses. Journal of School Health. 2000; 70(9):371-376

128. McGoron L, Sturner R, Howard B, Barry TD, Seymour K, Tomeny TS et al. Parents' goals for ADHD care in a clinical pediatric sample. Clinical Pediatrics. 2014; 53(10):949-959

129. McIntyre R, Hennessy E. 'He's just enthusiastic. Is that such a bad thing?' Experiences of parents of children with attention deficit hyperactivity disorder. Emotional and Behavioural Difficulties. 2012; 17(1):65-82

130. McKay MM, McCadam K, Gonzales JJ. Addressing the barriers to mental health services for inner city children and their caretakers. Community Mental Health Journal. 1996; 32(4):353-361

131. McMenamy JM, Perrin EC. The impact of experience on children's understanding of ADHD. Journal of Developmental and Behavioral Pediatrics. 2008; 29(6):483-492

132. Meaux JB, Green A, Broussard L. ADHD in the college student: a block in the road. Journal of Psychiatric and Mental Health Nursing. 2009; 16(3):248-256

133. Meaux JB, Hester C, Smith B, Shoptaw A. Stimulant medications: a trade-off? The lived experience of adolescents with ADHD. Journal for Specialists in Pediatric Nursing: JSPN. 2006; 11(4):214-226

134. Michielsen M, de Kruif JT, Comijs HC, van Mierlo S, Semeijn EJ, Beekman AT et al. The burden of ADHD in older adults: a qualitative study. Journal of Attention Disorders. 2015; Epublication

135. Mills I. Understanding parent decision making for treatment of ADHD. School Social Work Journal. 2011; 36(1):41-60

136. Moen OL, Hall-Lord ML, Hedelin B. Contending and adapting every day: norwegian parents' lived experience of having a child with ADHD. Journal of Family Nursing. 2011; 17(4):441-462

137. Morsink S, Sonuga-Barke E, Mies G, Glorie N, Lemiere J, Van der Oord S et al. What motivates individuals with ADHD? A qualitative analysis from the adolescent's point of view. European Child and Adolescent Psychiatry. 2017; Epublication

138. Muhlbacher AC, Slawik L, Kasper J, Nubling M. Patients preferences in adults with ADHD - A discrete choice experiment. Value in Health. 2009; 12 (7):A362

139. Murrell AR, Lester EG, Sandoz EK. Grounding turbulent minds: The challenges of mindfulness-based interventions for college students with ADHD and how to overcome them. Journal of College Student Psychotherapy. 2015; 29(4):314-328

140. Mychailyszyn MP, DosReis S, Myers M. African American caretakers' views of ADHD and use of outpatient mental health care services for children. Families, Systems & Health: The Journal of Collaborative Family HealthCare. 2008; 26(4):447-458

141. Myers K, Stoep AV, Lobdell C. Feasibility of conducting a randomized controlled trial of telemental health with children diagnosed with attention-deficit/hyperactivity disorder in underserved communities. Journal of Child and Adolescent Psychopharmacology. 2013; 23(6):372-378

142. National Institute for Health and Care Excellence. Developing NICE guidelines: the manual. London. National Institute for Health and Care Excellence, 2014. Available from: https://www.nice.org.uk/guidance/pmg20/resources/developing-nice-guidelines-the-manual-pdf-72286708700869

143. Nehlin C, Nyberg F, Oster C. The patient's perspective on the link between ADHD and substance use: a qualitative interview study. Journal of Attention Disorders. 2015; 19(4):343-350

144. O'Callaghan P. Adherence to stimulants in adult ADHD. Attention Deficit and Hyperactivity Disorders. 2014; 6(2):111-120

145. Olaniyan O, dosReis S, Garriett V, Mychailyszyn MP, Anixt J, Rowe PC et al. Community perspectives of childhood behavioral problems and ADHD among African American parents. Ambulatory Pediatrics. 2007; 7(3):226-231

146. Oruche UM, Draucker C, Alkhattab H, Knopf A, Mazurcyk J. Interventions for family members of adolescents with disruptive behavior disorders. Journal of Child and Adolescent Psychiatric Nursing. 2014; 27(3):99-108

147. Perry CE, Hatton D, Kendall J. Latino parents' accounts of attention deficit hyperactivity disorder. Journal of Transcultural Nursing. 2005; 16(4):312-321

148. Ramsay JR. “Without a net”: CBT without medications for an adult with ADHD. Clinical Case Studies. 2012; 11(1):48-65

149. Raskind MH, Margalit M, Higgins EL. "My LD": Children's voices on the internet. Learning Disability Quarterly. 2006; 29(4):253-268

150. Reale L, Frassica S, Gollner A, Bonati M. Transition to adult mental health services for young people with attention deficit hyperactivity disorder in Italy: Parents' and clinicians' experiences. Postgraduate Medicine. 2015; 127(7):671-676

151. Reid R, Hertzog M, Snyder M. Educating every teacher, every year: the public schools and parents of children with ADHD. Seminars in Speech and Language. 1996; 17(1):73-90

152. Rogalin MT, Nencini A. Consequences of the “Attention-Deficit/Hyperactivity Disorder” (ADHD) diagnosis. An investigation with education professionals. Psychological Studies. 2015; 60(1):41-49

153. Russell AE, Moore DA, Ford T. Educational practitioners' beliefs and conceptualisation about the cause of ADHD: A qualitative study. Emotional and Behavioural Difficulties. 2016; 21(1):101-118

154. Salt N, Parkes E, Scammell A. GPs' perceptions of the management of ADHD in primary care: A study of Wandsworth GPs. Primary Health Care Research and Development. 2005; 6(2):162-171

155. Sandler A, Glesne C, Geller G. Children's and parents' perspectives on open-label use of placebos in the treatment of ADHD. Child: Care, Health and Development. 2008; 34(1):111-120

156. Schatz NK, Fabiano GA, Cunningham CE, dosReis S, Waschbusch DA, Jerome S et al. Systematic review of patients' and parents' preferences for ADHD treatment options and processes of care. The Patient: Patient-Centered Outcomes Research. 2015; 8(6):483-497

157. Schreuer N, Dorot R. Experiences of employed women with attention deficit hyperactive disorder: A phenomenological study. Work. 2017; 56(3):429-441

158. Schrevel SJ, Dedding C, van Aken JA, Broerse JE. 'Do I need to become someone else?' A qualitative exploratory study into the experiences and needs of adults with ADHD. Health Expectations. 2016; 19(1):39-48

159. Schubert SJ, Hansen S, Dyer KR, Rapley M. 'ADHD patient' or 'illicit drug user'?: Managing medico-moral membership categories in drug dependence services. Discourse & Society. 2009; 20(4):499-516

160. Segal ES. Learned mothering: Raising a child with ADHD. Child & Adolescent Social Work Journal. 2001; 18(4):263-279

161. Segal R, Frank G. The extraordinary construction of ordinary experience: scheduling daily life in families with children with attention deficit hyperactivity disorder. Scandinavian Journal of Occupational Therapy. 1998; 5(3):141-147

162. Shattell MM, Bartlett R, Rowe T. "I have always felt different": the experience of attention-deficit/hyperactivity disorder in childhood. Journal of Pediatric Nursing. 2008; 23(1):49-57

163. Shaw K, Wagner I, Eastwood H, Mitchell G. A qualitative study of Australian GPs' attitudes and practices in the diagnosis and management of attention-deficit/hyperactivity disorder (ADHD). Family Practice. 2003; 20(2):129-134

164. Sikirica V, Flood E, Dietrich CN, Quintero J, Harpin V, Hodgkins P et al. Unmet needs associated with attention-deficit/hyperactivity disorder in eight European countries as reported by caregivers and adolescents: results from qualitative research. The Patient: Patient-Centered Outcomes Research. 2015; 8(3):269-281

165. Simons L, Valentine AZ, Falconer CJ, Groom M, Daley D, Craven MP et al. Developing mHealth remote monitoring technology for attention deficit hyperactivity disorder: a qualitative study eliciting user priorities and needs. JMIR MHealth and UHealth. 2016; 4(1):e31

166. Singh I. Boys will be boys: fathers' perspectives on ADHD symptoms, diagnosis, and drug treatment. Harvard Review of Psychiatry. 2003; 11(6):308-316

167. Singh I. Will the "real boy" please behave: dosing dilemmas for parents of boys with ADHD. American Journal of Bioethics. 2005; 5(3):34-47

168. Singh I. A disorder of anger and aggression: children's perspectives on attention deficit/hyperactivity disorder in the UK. Social Science and Medicine. 2011; 73(6):889-896

169. Singh SP, Tuomainen H. Transition from child to adult mental health services: Needs, barriers, experiences and new models of care. World Psychiatry. 2015; 14(3):358-361

170. Sleath B, Carpenter DM, Sayner R, Thomas K, Mann L, Sage A et al. Youth views on communication about ADHD and medication adherence. Community Mental Health Journal. 2017; 53(4):438-444

171. Smith E, Koerting J, Latter S, Knowles MM, McCann DC, Thompson M et al. Overcoming barriers to effective early parenting interventions for attention-deficit hyperactivity disorder (ADHD): parent and practitioner views. Child: Care, Health and Development. 2015; 41(1):93-102

172. Soderqvist H, Kajsa E, Ahlstrom BH, Wentz E. The caregivers' perspectives of burden before and after an internet-based intervention of young persons with ADHD or autism spectrum disorder. Scandinavian Journal of Occupational Therapy. 2017; Epublication

173. Solberg BS, Haavik J, Halmoy A. Health care services for adults with ADHD: patient satisfaction and the role of psycho-education. Journal of Attention Disorders. 2015; 18:18

174. Sox CM, Gribbons WM, Loring BA, Mandl KD, Batista R, Porter SC. Patient-centered design of an information management module for a personally controlled health record. Journal of Medical Internet Research. 2010; 12(3):e36

175. Srignanasoundari E, Vijayalakshmi S, Kokilavani N. A study to assess the knowledge on attention deficit hyperactivity disorder among primary school teachers at selected schools of Kancheepuram District, Tamilnadu. International Journal of Nursing Education. 2016; 8(4):66-70

176. Stroh J, Frankenberger W, Cornell-Swanson LV, Wood C, Pahl S. The use of stimulant medication and behavioral interventions for the treatment of attention deficit hyperactivity disorder: A survey of parents? knowledge, attitudes, and experiences. Journal of Child and Family Studies. 2008; 17(3):385-401

177. Surman CB, Thomas RJ, Aleardi M, Pagano C, Biederman J. Adults with ADHD and sleep complaints: a pilot study identifying sleep-disordered breathing using polysomnography and sleep quality assessment. Journal of Attention Disorders. 2006; 9(3):550-555

178. Swift KD, Hall CL, Marimuttu V, Redstone L, Sayal K, Hollis C. Transition to adult mental health services for young people with attention deficit/hyperactivity disorder (ADHD): a qualitative analysis of their experiences. BMC Psychiatry. 2013; 13:74

179. Tatlow-Golden M, Prihodova L, Gavin B, Cullen W, McNicholas F. What do general practitioners know about ADHD? Attitudes and knowledge among first-contact gatekeepers: systematic narrative review. BMC Family Practice. 2016; 17:129

180. Taylor JA, Valentine AZ, Sellman E, Bransby-Adams K, Daley D, Sayal K. A qualitative process evaluation of a randomised controlled trial of a parenting intervention in community (school) settings for children at risk of attention deficit hyperactivity disorder (ADHD). BMC Psychiatry. 2015; 15:290

181. Taylor M, O'Donoghue T, Houghton S. To medicate or not to medicate? The decision-making process of Western Australian parents following their child's diagnosis with an attention deficit hyperactivity disorder. International Journal of Disability, Development and Education. 2006; 53(1):111-128

182. Thiruchelvam D, Charach A, Schachar RJ. Moderators and mediators of long-term adherence to stimulant treatment in children with ADHD. Journal of the American Academy of Child and Adolescent Psychiatry. 2001; 40(8):922-928

183. Travell C, Visser J. ADHD does bad stuff to you': young people's and parents' experiences and perceptions of Attention Deficit Hyperactivity Disorder (ADHD). Emotional & Behavioural Difficulties. 2006; 11(3):205-216

184. Varley CK. Perspectives of adolescents with attention-deficit hyperactivity disorder do matter. Journal of Adolescent Health. 2011; 49(1):1-2

185. Waite R, Tran M. ADHD among a cohort of ethnic minority women. Women and Health. 2010; 50(1):71-87

186. Wallace N. The perceptions of mothers of sons with ADHD. ANZJFT Australian and New Zealand Journal of Family Therapy. 2005; 26(4):193-199

187. Wan ESF, Ma JLC, Lai KYC, Lo JWK. The subjective experiences of attention deficit/ hyperactivity disorder of Chinese families in Hong Kong: co-construction of meanings in multiple family groups. Health and Social Work. 2016; 41(3):164-172

188. Wiener J, Daniels L. School experiences of adolescents with attention-deficit/hyperactivity disorder. Journal of Learning Disabilities. 2016; 49(6):567-581

189. Wilkes-Gillan S, Bundy A, Cordier R, Lincoln M, Hancock N. Parents' perspectives on the appropriateness of a parent-delivered intervention for improving the social play skills of children with ADHD. British Journal of Occupational Therapy. 2015; 78(10):644-652

190. Wilkinson S, Harvey WJ, Bloom GA, Joober R, Grizenko N. Student teacher experiences in a service-learning project for children with attention-deficit hyperactivity disorder. Physical Education and Sport Pedagogy. 2013; 18(5):475-491

191. Williams NJ, Harries M, Williams AM. Gaining control: A new perspective on the parenting of children with AD/HD. Qualitative Research in Psychology. 2014; 11(3):277-297

192. Williamson D, Johnston C. Gender differences in adults with attention-deficit/hyperactivity disorder: A narrative review. Clinical Psychology Review. 2015; 40:15-27

193. Williamson P, Koro-Ljungberg ME, Bussing R. Analysis of critical incidents and shifting perspectives: transitions in illness careers among adolescents with ADHD. Qualitative Health Research. 2009; 19(3):352-365

194. Winter H, Moncrieff J, Speed E. "Because you're worth it": A discourse analysis of the gendered rhetoric of the ADHD woman. Qualitative Research in Psychology. 2015; 12(4):415-434

195. Wright SF. "A little understood solution to a vaguely defined problem": Parental perceptions of Ritalin. Educational and Child Psychology. 1997; 14(1):50-59

196. Young S, Bramham J, Gray K, Rose E. The experience of receiving a diagnosis and treatment of ADHD in adulthood: a qualitative study of clinically referred patients using interpretative phenomenological analysis. Journal of Attention Disorders. 2008; 11(4):493-503

197. Young S, Chesney S, Sperlinger D, Misch P, Collins P. A qualitative study exploring the life-course experiences of young offenders with symptoms and signs of ADHD

who were detained in a residential care setting. Criminal Behaviour and Mental Health. 2009; 19(1):54-63

198. Young S, Gray K, Bramham J. A phenomenological analysis of the experience of receiving a diagnosis and treatment of ADHD in adulthood: a partner's perspective. Journal of Attention Disorders. 2009; 12(4):299-307

199. Zhang D, Chan SKC, Lo HHM, Chan CYH, Chan JCY, Ting KT et al. Mindfulness-based intervention for Chinese children with adhd and their parents: A pilot mixed-method study. Mindfulness. 2016; Epublication

Appendices

Appendix A: Review protocols

Table 17: Review protocol: Adherence to treatment (pharmacological and non-pharmacological)

Field	Content
Review question	What factors do people with ADHD believe affect their adherence to pharmacological or non-pharmacological treatment for ADHD?
Type of review question	Qualitative
Objective of the review	To investigate the factors that may affect adherence to treatment, so as to inform guidance to people with ADHD on receiving treatment
Eligibility criteria – population / disease / condition / issue / domain	Children, young people and adults with ADHD who are receiving treatment (pharmacological or non-pharmacological) and their healthcare professionals, teachers, family and carers. Stratify by age (<5 years old, 5 to 18, >18 years old) and treatment (pharmacological; non-pharmacological).
Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	Not applicable
Eligibility criteria – comparator(s) / control or reference (gold) standard	Not applicable
Outcomes and prioritisation	Themes will be identified from the papers, and not specified in advance. However relevant themes may include: • Self-help tips to improve adherence; for example, use of alarms and reminders, use of technology/apps • Role of parents/partners/carers in promoting adherence • Psychological factors that impact on adherence; for example, self- and social-stigma, beliefs about ADHD and about treatment, comorbid mental health conditions • Dosing schedules, including use of extended release drug preparations
Eligibility criteria – study design	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data from questionnaires will only be considered if insufficient qualitative evidence is identified
Other inclusion exclusion criteria	Exclusions: ADHD diagnosis made not using DSM-III/ICD-10 or later versions of these (note that studies evaluating treatments for ADHD in a population of people with autistic spectrum disorder will be included if no formal diagnosis of ADHD has been made using these, but evidence of moderate to severe symptoms of hyperactivity, impulsivity, and/or inattention is demonstrated according to validated symptom questionnaires)
Proposed sensitivity / subgroup analysis, or meta-regression	Not applicable
Selection process –	No duplicate screening was deemed necessary for this question, for

duplicate screening / selection / analysis	more information please see the separate Methods report for this guideline. Appraisal of methodological quality: The methodological quality of each study will be assessed using NGC checklists. Evidence will be analysed using thematic analysis; findings will be presented narratively and diagrammatically where appropriate. Findings will be reported according to GRADE CERQual standards Additional qualitative studies will be added to the review until themes within the analysis become saturated; i.e. studies will only be included if they contribute towards the development of existing themes or to the development of new themes.
Data management (software)	• Endnote for bibliography, citations, sifting and reference management
Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, CINAHL,PsycINFO Date: All years Health economics search databases to be used: Medline, Embase, NHSEED, HTA Date: Medline, Embase from 2014 NHSEED, HTA – all years Language: Restrict to English only Supplementary search techniques: backward citation searching Key papers: Not known
Identify if an update	Not an update
Author contacts	https://www.nice.org.uk/guidance/cg72
Highlight if amendment to previous protocol	Not an amendment
Search strategy – for one database	For details please see appendix B
Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendix D of the evidence report.
Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables).
Methods for assessing bias at outcome / study level	The risk of bias across all available evidence was evaluated for each outcome according to GRADE CERQual standards.
Criteria for quantitative synthesis	N/A
Methods for quantitative analysis – combining studies and exploring (in)consistency	N/A
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual.
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual and the methods section of this guideline.

Rationale / context – what is known	For details please see the introduction to the evidence review.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Gillian Baird in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, critically appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual and the methods section of this guideline.
Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
PROSPERO registration number	Not registered

Table 18: Health economic review protocol

Review question	All questions – health economic evidence
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	Populations, interventions and comparators must be as specified in the clinical review protocols in appendix A above. Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) Unpublished reports will not be considered unless submitted as part of a call for evidence. Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter – see appendix B. For questions being updated, the search will be run from December 2007, which was the cut-off date for the searches conducted for NICE guideline CG72
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2001, abstract-only studies and studies from non-OECD countries or the USA will also be excluded. Studies published after 2001 that were included in the previous guideline will be reassessed for inclusion and may be included or selectively excluded based on their relevance to the questions covered in this update and whether more applicable evidence is also identified. Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in appendix H of Developing NICE guidelines: the manual (2014).[142] Inclusion and exclusion criteria If a study is rated as both 'Directly applicable' and with 'Minor limitations' then it will be included in the guideline. A health economic evidence table will be completed and it will

Review question	All questions – health economic evidence
	be included in the health economic evidence profile. If a study is rated as either 'Not applicable' or with 'Very serious limitations' then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile. If a study is rated as 'Partially applicable', with 'Potentially serious limitations' or both then there is discretion over whether it should be included. Where there is discretion The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation as excluded health economic studies in appendix G. The health economist will be guided by the following hierarchies. Setting: UK NHS (most applicable). OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden). OECD countries with predominantly private health insurance systems (for example, Switzerland). Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations. Health economic study type: Cost–utility analysis (most applicable). Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis). Comparative cost analysis. Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations. Year of analysis: The more recent the study, the more applicable it will be. Studies published in 2001 or later (including any such studies included in the previous guideline) but that depend on unit costs and resource data entirely or predominantly from before 2001 will be rated as 'Not applicable'. Studies published before 2001 (including any such studies included in the previous guideline) will be excluded before being assessed for applicability and methodological limitations. Quality and relevance of effectiveness data used in the health economic analysis: The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline. Economic evaluations that are based on studies excluded from the clinical review will be excluded.

Appendix B: Literature search strategies

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual, Oct 2014, updated 2017 https://www.nice.org.uk/guidance/pmg20/resources/developing-nice-guidelines-the-manual-pdf-72286708700869

For more detailed information, please see the Methodology Review.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 19: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1948 – 28 April 2017	Exclusions Patient views/qualitative studies
Embase (OVID)	1974– 28 April 2017	Exclusions Patient views/qualitative studies
CINAHL (EBSCO)	Inception– 28 April 2017	Exclusions Patient views/qualitative studies
PsycINFO (ProQuest)	Inception– 28 April 2017	Exclusions Patient views/qualitative studies

Medline (Ovid) search terms

1.	"attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	(((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*)).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	letter/
11.	editorial/
12.	news/
13.	exp historical article/
14.	Anecdotes as Topic/
15.	comment/
16.	case report/
17.	(letter or comment*).ti.

18.	or/10-17
19.	randomized controlled trial/ or random*.ti,ab.
20.	18 not 19
21.	animals/ not humans/
22.	Animals, Laboratory/
23.	exp animal experiment/
24.	exp animal model/
25.	exp Rodentia/
26.	(rat or rats or mouse or mice).ti.
27.	or/20-26
28.	9 not 27
29.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
30.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
31.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
32.	or/29-31
33.	28 and 32

Embase (Ovid) search terms

1.	attention deficit disorder/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	(((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*)).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	letter.pt. or letter/
11.	note.pt.
12.	editorial.pt.
13.	case report/ or case study/
14.	(letter or comment*).ti.
15.	or/10-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animal/ not human/
19.	nonhuman/
20.	exp Animal Experiment/

21.	exp Experimental Animal/
22.	animal model/
23.	exp Rodent/
24.	(rat or rats or mouse or mice).ti.
25.	or/17-24
26.	9 not 25
27.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
28.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
29.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
30.	or/27-29
31.	26 and 30

CINAHL (EBSCO) search terms

S1.	(MH "Attention Deficit Hyperactivity Disorder")
S2.	((attenti* or disrupt*) n3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*))
S3.	adhd or addh or ad hd or ad/hd
S4.	attenti* n3 deficit*
S5.	(((hyperkin* or hyper kin*) n1 (syndrome* or disorder*)) or hkd)
S6.	(minimal brain n2 (dysfunct* or disorder*))
S7.	S1 OR S2 OR S3 OR S4 OR S5 OR S6
S8.	(MH "Qualitative Studies+")
S9.	(MH "Qualitative Validity+")
S10.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S11.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S12.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* n3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)
S13.	S8 OR S9 OR S10 OR S11 OR S12
S14.	S7 AND S13
S15.	PT anecdote or PT audiovisual or PT bibliography or PT biography or PT book or PT book review or PT brief item or PT cartoon or PT commentary or PT computer program or PT editorial or PT games or PT glossary or PT historical material or PT interview or PT letter or PT listservs or PT masters thesis or PT obituary or PT pamphlet or PT pamphlet chapter or PT pictorial or PT poetry or PT proceedings or PT “questions and answers” or PT response or PT software or PT teaching materials or PT website
S16.	S14 NOT S15 Limiters - English Language; Exclude MEDLINE records

PsycINFO (ProQuest) search terms

1.	SU.EXACT.EXPLODE("Attention Deficit Disorder") OR TI((attenti* OR disrupt*) NEAR/3 (adolescent* OR adult* OR behav* OR child* OR class OR classes OR classroom* OR condition* OR difficult* OR disorder* OR learn* OR people OR person* OR poor OR problem* OR process* OR youngster*)) OR AB((attenti* OR disrupt*) NEAR/3 disorder*) OR TI,AB(adhd OR addh OR ad-hd OR ad??hd) OR TI,AB(attenti* NEAR/3 deficit*) OR TI,AB(((hyperkin* OR (hyper-kin*)) NEAR/1 (syndrome* OR disorder*)) OR hkd) OR TI,AB(minimal NEAR/1 brain NEAR/2 (dysfunct* OR disorder*))
2.	SU.EXACT("Qualitative Research") OR (SU.EXACT("Narratives") OR SU.EXACT("Interviews")) OR (SU.EXACT("Questionnaires") OR SU.EXACT.EXPLODE("Surveys")) OR (qualitative OR interview*) OR (focus-group* OR theme*) OR (questionnaire* OR survey*) OR (metasynthes* OR meta-synthes*) OR (metasummar* OR meta-summar*) OR (metastud* OR meta-stud*) OR (metathem* OR meta-them*) OR ethno* OR (emic OR etic) OR (phenomenolog* OR "grounded theory") OR (constant-compar* OR thematic* NEAR/3 analys*) OR (theoretical-sampl* OR purposive-sampl*) OR (hermeneutic* OR heidegger*) OR (husserl* OR colaizzi*) OR (van-kaam* OR van-manen*) OR (giorgi* OR glaser*) OR (strauss* OR ricoeur*) OR (spiegelberg* OR merleau*)
3.	1 AND 2
4.	NOT (Dissertations & Theses AND Books)
5.	English

B.2 Health Economics literature search strategy

Health economic evidence was identified by conducting a broad search relating to ADHD population in NHS Economic Evaluation Database (NHS EED – this ceased to be updated after March 2015) and the Health Technology Assessment database (HTA) with no date restrictions. NHS EED and HTA databases are hosted by the Centre for Research and Dissemination (CRD). Additional searches were run on Medline and Embase.

Table 20: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline	2014 – 28 April 2017	Exclusions Health economics
Embase	2014 – 28 April 2017	Exclusions Health economics
Centre for Research and Dissemination (CRD)	HTA - 2008 – 28 April 2017 NHSEED - 2008 to March 2015	None

Medline (Ovid) search terms

1.	"attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	(((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*)).ti,ab.
8.	or/1-7

9.	limit 8 to English language
10.	letter/
11.	editorial/
12.	news/
13.	exp historical article/
14.	Anecdotes as Topic/
15.	comment/
16.	case report/
17.	(letter or comment*).ti.
18.	or/10-17
19.	randomized controlled trial/ or random*.ti,ab.
20.	18 not 19
21.	animals/ not humans/
22.	Animals, Laboratory/
23.	exp animal experiment/
24.	exp animal model/
25.	exp Rodentia/
26.	(rat or rats or mouse or mice).ti.
27.	or/20-26
28.	9 not 27
29.	Economics/
30.	Value of life/
31.	exp "Costs and Cost Analysis"/
32.	exp Economics, Hospital/
33.	exp Economics, Medical/
34.	Economics, Nursing/
35.	Economics, Pharmaceutical/
36.	exp "Fees and Charges"/
37.	exp Budgets/
38.	budget*.ti,ab.
39.	cost*.ti.
40.	(economic* or pharmaco?economic*).ti.
41.	(price* or pricing*).ti,ab.
42.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
43.	(financ* or fee or fees).ti,ab.
44.	(value adj2 (money or monetary)).ti,ab.
45.	or/29-44
46.	exp models, economic/
47.	*Models, Theoretical/
48.	*Models, Organizational/
49.	markov chains/
50.	monte carlo method/
51.	exp Decision Theory/
52.	(markov* or monte carlo).ti,ab.

53.	econom* model*.ti,ab.
54.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
55.	or/46-54
56.	28 and (45 or 55)

Embase (Ovid) search terms

1.	attention deficit disorder/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	(((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*)).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	letter.pt. or letter/
11.	note.pt.
12.	editorial.pt.
13.	case report/ or case study/
14.	(letter or comment*).ti.
15.	or/10-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animal/ not human/
19.	nonhuman/
20.	exp Animal Experiment/
21.	exp Experimental Animal/
22.	animal model/
23.	exp Rodent/
24.	(rat or rats or mouse or mice).ti.
25.	or/17-24
26.	9 not 25
27.	statistical model/
28.	exp economic aspect/
29.	27 and 28
30.	*theoretical model/
31.	*nonbiological model/
32.	stochastic model/
33.	decision theory/
34.	decision tree/
35.	monte carlo method/
36.	(markov* or monte carlo).ti,ab.

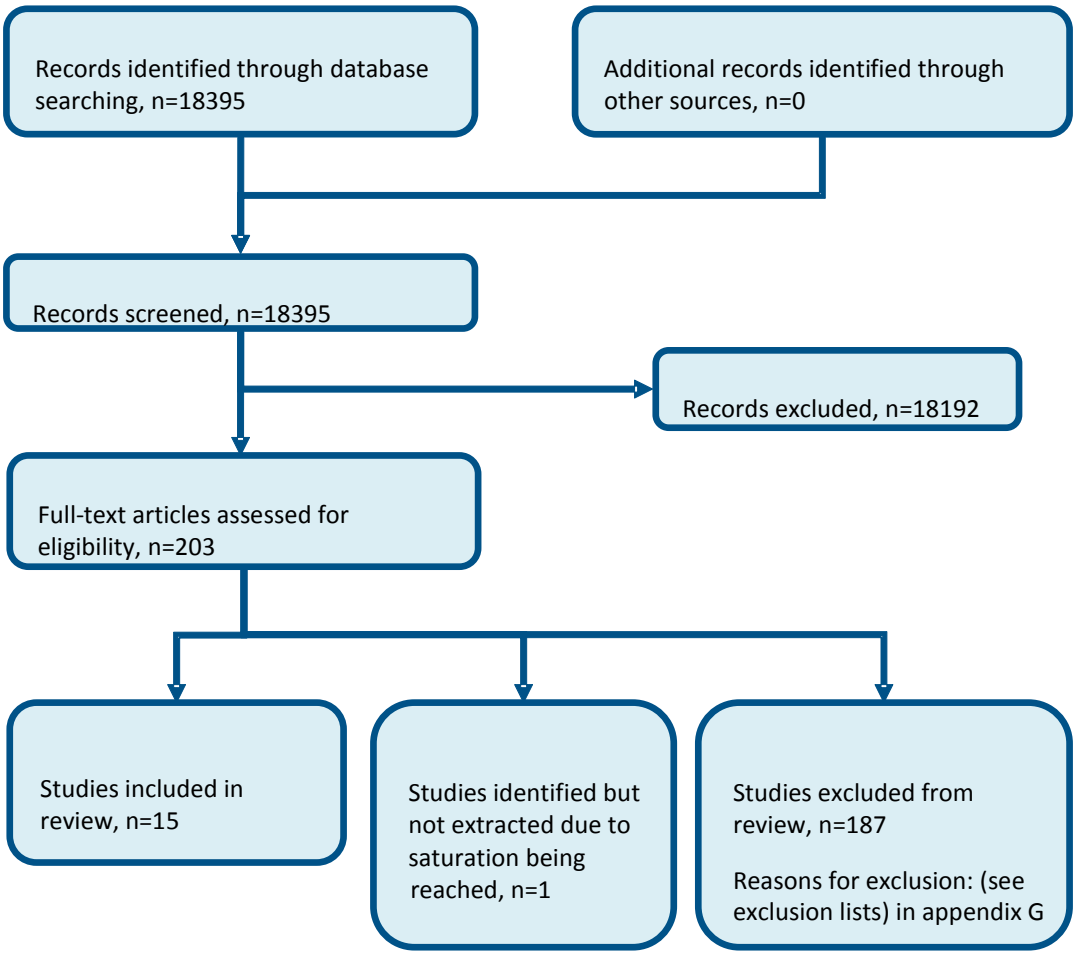
37.	econom* model*.ti,ab.
38.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
39.	or/29-38
40.	*health economics/
41.	exp *economic evaluation/
42.	exp *health care cost/
43.	exp *fee/
44.	budget/
45.	funding/
46.	budget*.ti,ab.
47.	cost*.ti.
48.	(economic* or pharmaco?economic*).ti.
49.	(price* or pricing*).ti,ab.
50.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
51.	(financ* or fee or fees).ti,ab.
52.	(value adj2 (money or monetary)).ti,ab.
53.	or/40-52
54.	26 and (39 or 53)

NHS EED and HTA (CRD) search terms

#1.	MeSH DESCRIPTOR Attention Deficit and Disruptive Behavior Disorders
#2.	MeSH DESCRIPTOR Attention Deficit Disorder with Hyperactivity
#3.	(((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*))):TI
#4.	(((attenti* or disrupt*) adj3 disorder*))
#5.	((adhd or addh or ad hd or ad??hd))
#6.	((attenti* adj3 deficit*))
#7.	((((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd))
#8.	((minimal brain adj2 (dysfunct* or disorder*)))
#9.	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8
#10.	(#9) IN NHSEED, HTA

Appendix C: Qualitative study selection

Figure 2: Flow chart of clinical article selection for the review of adherence



Appendix D: Qualitative evidence tables

Study (ref id)	Ahmed 2013[1]
Aim	To explore factors influencing parents' decisions to adhere and persist with ADHD medication
Population	16 parents of children with ADHD (aged 3 to 12 years)
Setting	Australia
Study design	Qualitative (focus groups)
Methods and analysis	Focus groups lasted from 1 to 1.5 hours and were facilitated by a researcher experienced in conducting focus groups. A guide was used to lead discussions. A framework method of analysis was used whereby a thematic framework was developed based on the major themes identified in the dat.
Themes	Parents were concerned about the side effects of medication, and often modified medication doses due to this. Some consulted with HCPs prior to any modifications, whereas others did not.
	Many parents reported utilising drug holidays to reduce unwanted side effects, without consulting HCPs
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Brinkman 2008[14]
Aim	To explore how parents make decisions about treatment for their children with ADHD
Population	52 parents of children with ADHD (aged 6 to 17 years)
Setting	USA
Study design	Qualitative (focus groups)
Methods and analysis	12 focus groups with an average length of 1.5 hours. Prompting questions were developed by all investigators and were broad, open ended initially, followed by more specific probing questions to clarify responses and narrow the discussion. Recruitment was terminated when the investigators felt data saturation had been reached. Grounded theory was used for analysis, whereby the investigators read

Study (ref id)	Brinkman 2008[14]
	the transcripts, identified emerging themes, and labelled themes to construct a codebook.
Themes	Parents reported that their children sometimes forgot to take their medication
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Charach 2006[27]
Aim	To explore parents' attitudes towards medicating their child
Population	17 mothers and fathers of 14 children with ADHD (aged 7 to 15 years)
Setting	Canada
Study design	Qualitative (focus groups)
Methods and analysis	Focus groups were led by a social worker and a practical nurse specialist who had worked with the families. A semi-structured guide was used; parents were asked to describe their experiences regarding the use of medication. Data was analysed using thematic analysis. Initially analysed by line by line coding, followed by reviewing of these codes by the whole research team. This was followed by clustering codes into themes that best represented the data set.
Themes	An important aspect of this decision-making was the willingness of the child to take medication. Some children actively fought to not take medication
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Charach 2014[29]
Aim	Exploring adolescents and parents' attitudes towards stimulant treatment
Population	12 children with ADHD (aged 12 to 15 years)
Setting	Canada
Study design	Interviews
Methods and analysis	Semi structured interviews with interview questions, lasting between 60 to 90 minutes. Transcripts were analysed using interpretive interactionist framework
Themes	Some patients continued to adhere to treatment as they got older, as they realised the efficacy of the medication
	Children stopped medication due to adverse events, insufficient benefit, feeling that the medication changed their sense of self
Limitations and applicability of evidence	Minor limitations related to the role of the researcher and context of the study

Study (ref id)	Coletti 2012[34]
Aim	To explore parent perspectives on the decision to initiate medication treatment for ADHD
Population	27 parents of children diagnosed with ADHD (aged 5 to 12 years)
Setting	USA
Study design	Qualitative (focus groups)
Methods and analysis	Focus groups were 2 hours in duration and were led by two child psychologists with experience in focus groups. A semi structured guide aided discussions and ensured they were theory driven. An inductive approach was used to analyse transcripts, using grounded theory methods to allow themes to emerge independent of theory.
Themes	Parents that tried to consistently adhere to medicate did so because they felt the improvements extended beyond just ADHD symptoms, and led to

Study (ref id)	Coletti 2012[34]
	functional improvements of mood, sleep, and social functioning. For some parents, behavioural improvements outweighed side effects, and so they adhered to treatment.
Limitations and applicability of evidence	Minor limitations of the evidence

Study (ref id)	Gallichan 2008[60]
Aim	Explore young peoples' perspectives of ADHD
Population	12 young people with ADHD (aged 10 to 17 years)
Setting	UK
Study design	Qualitative (interviews)
Methods and analysis	One on one open-ended interviews ranged from 25 minutes to 1 hour and 15 minutes. Grounded theory was used to analyse the data.
Themes	Young people reported understanding why they needed to take their medication as they got older Children reported attempting to not take their medication and hide this from parents.
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Ibrahim 2016[88]
Aim	Examine the experiences of drug holidays from caregivers and healthcare professionals
Population	8 GPs, 8 consultants, 5 teachers and 5 mothers (aged children and young people)
Setting	UK
Study design	Interviews
Methods and analysis	Semi-structured interviews were carried out by one author using an interview schedule that focused on descriptions of ADHD and referral and diagnosis processes, and experiences with ADHD. Data was analysed using grounded theory.
Themes	Some parents could cope with their child not taking medication out of school hours, and felt it important to do so. However other parents' were unequipped to do this Young people want to stop their medication to feel like themselves and because they don't feel like the medication is helping
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Lefler 2016[111]
Aim	To explore the experiences of college students living with ADHD
Population	36 college students with ADHD (aged >18 years)
Setting	USA
Study design	Focus groups
Methods and analysis	8 2 to 2.5 hour focus groups were conducted, each with 4-5 students. A semi-structured interview schedule was used. Focus groups were facilitated by either a clinical psychologist or a student training to be a clinical psychologist. Idiographic inductive analysis was used.

Study (ref id)	Lefler 2016[111]
Themes	Students took medication holidays at their own direction, such as on the days that they had classes. Some students reported that they would also use more than was prescribed during periods of deadlines and examinations. They also reported frequently breaking pills up to take smaller doses than prescribed
Limitations and applicability of evidence	Minor limitations of the study related to a lack of context provided

Study (ref id)	Matheson 2013[125]
Aim	Explore adults experiences with ADHD
Population	15 adults diagnosed with ADHD in childhood, and 15 diagnosed in adulthood (aged >18 years)
Setting	UK
Study design	Interviews
Methods and analysis	Semi structured face to face interviews were conducted in the participant's home, or at the school of Pharmacy in London. An interview guide was used. Length approximately 1 hour. Thematic analysis used
Themes	Patients reported only taking medication when it was required for work or education purposes
	Participants reported difficulty in accessing prescriptions, with GPs unwilling to prescribe or pharmacists reluctant to stock or dispense the medication.
	Participants reported that a lack of cooperation from pharmacists, GPs, and health trusts resulted in periods of cessation, which lasted from days to years. These periods were distressing for patients
	Many found delays in referral to adult services, discontinuation of support and medication upon turning 18
	Forgetfulness, side effects, uncertainty of effectiveness and a sense of lost identity were reported as the main reasons for treatment cessation

Study (ref id)	Matheson 2013[125]
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Meaux 2006[133]
Aim	To gain insight about medication use among young people with ADHD
Population	15 college students with ADHD (aged 18+)
Setting	USA
Study design	Interviews
Methods and analysis	Semi-structured interviews were conducted by the principal investigator. Initial interviews lasted from 1 to 1.5 hours and follow up interviews lasted between 15 to 30 minutes. Content analysis was used to identify raw data clusters within the coded data. Raw data clusters were then combined to form themes
Themes	Students reported they often forgot to take their medication Many students reported not taking their medication on the weekend when they were younger because they didn't want to 'feel like that' over the weekend Students reported that they not only take their medication when they need to, which generally was just when they had a large workload.
Limitations and applicability of evidence	Moderate limitations related to the role of the researcher and the richness of the data

Study (ref id)	Meaux 2009[132]
Aim	Explore college students experiences of ADHD
Population	15 college students with ADHD (aged 18 to 21 years)

Study (ref id)	Meaux 2009[132]
Setting	USA
Study design	Interviews
Methods and analysis	Semi structured interviews lasting 60 to 90 minutes were conducted. An interview guide was used . Content analysis was used to identify clusters of raw data, which were compared and combined to identify themes. Thematic analysis then allowed for further identification of themes.
Themes	Most participants were not taking their medication on a regular basis as they didn't like how the side effects made them feel.
Limitations and applicability of evidence	Moderate limitations related to the role of the researcher and the richness of the data

Study (ref id)	Mills 2011[135]
Aim	To understand how parents decide to medicate their child
Population	19 families (representing 30 children with ADHD) (aged Not specified)
Setting	USA
Study design	Interviews
Methods and analysis	Semi-structured interviews were conducted. Transcripts were analysed using constant comparative analysis, in order to generate conceptual categories and their properties. Open coding was used initially, followed by axial coding to connect the categories. No further details
Themes	The decision to keep a child on their medication was related mainly to the effectiveness of the treatment.
Limitations and applicability of evidence	Minor limitations related to the context of the study

Study (ref id)	O'Callaghan 2014[144]
Aim	To explore the context that influences stimulant medication adherence

Study (ref id)	O'Callaghan 2014[144]
Population	18 adults with ADHD (aged >18 years)
Setting	USA
Study design	Interviews
Methods and analysis	Semi-structured telephone interviews lasted an average of 45 minutes. Notes were manually recorded and transcriptions analysed using thematic analysis.
Themes	Participants did not feel equipped to successful stick to their treatment plan. This was due to being unable to keep monthly appointments for medication management. It seemed that those that benefited more from the treatment were more likely to adhere to it, with benefits clearly outweighing the harm of treatment.
	Participants reported difficulty getting a prescription refilled due to suspicious questions asked by pharmacists
Limitations and applicability of evidence	Severe limitations relating to the richness of data, data analysis, data collection and the role of the researcher

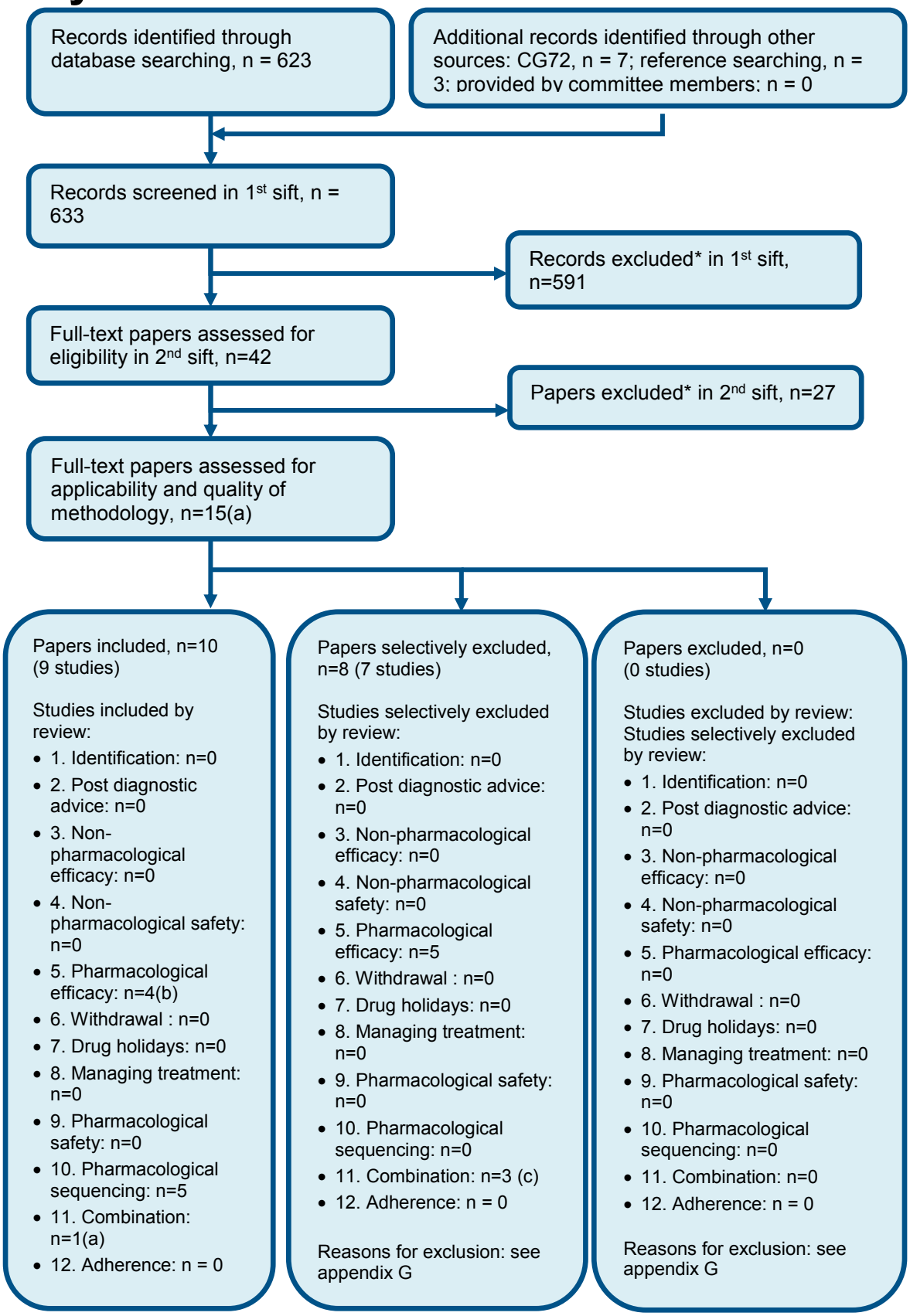
Study (ref id)	Sikirica 2014[164]
Aim	To explore the unmet needs of young people with ADHD and their caregivers
Population	38 caregivers (of ages 6 to 17 years) and 28 young people (13 to 17 years) with ADHD took part (aged 6 to 17 years)
Setting	Mixed European countries (including the UK)
Study design	Interviews
Methods and analysis	One to one telephone interviews were conducted by experienced interviewers, who took part in a training seminar including mock interviews. Each interview followed a standardised semi structured interview guide with open ended questions. Interviews with caregivers lasted between 60 to 90 minutes and interviews with young people lasted from 30 to 60 minutes. Thematic analysis was used to identify themes; an initial code system was developed which were organised into themes.
Themes	Participants reported allowing their children to deviate from their treatment and take breaks from their medication.
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Smith 2014[171]
Aim	Understanding the reasons of low uptake and completion of parent interventions for ADHD
Population	19 practitioners running services for preschool children with ADHD, and 13 parents of children with ADHD (Pre-schoolers)
Setting	UK
Study design	Focus groups
Methods and analysis	semi-structured focus groups using an interview schedule based on themes for a qualitative literature synthesis. Analysed using thematic analysis
Themes	Parents were more likely to drop out if they did not see improvement they expected quickly enough.
	Many barriers for patients in accessing non-pharmacological treatment were reported by parents and healthcare professionals. Psychological barriers included feelings of shame, embarrassment and fear of being judged. Situational barriers included time commitments, inconvenient session times and location and child care issues. Practitioners also feel that a lack of education, cultural issues, domestic violence and financial difficulties impacted on adherence.
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Swift 2013[178]
Aim	Patient experiences of ADHD, particularly around transitioning services
Population	10 young adults with ADHD (aged 17-18)
Setting	UK
Study design	Interviews
Methods and analysis	Semi-structured interviews analysed by thematic analysis. Parents were allowed to be present during the interviews. Set questions were used during the interviews, but the format was flexible
Themes	Patients reported that their parents or other family members were often involved in support, helping with medication and clinic

Study (ref id)	Swift 2013[178]
	appointments, where some people with ADHD struggle
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Appendix E: Health economic evidence study selection



** Non-relevant population, intervention, comparison, design or setting; non-English language*
(a) note that there were 2 original models from the previous guideline (either included or excluded) which is why the numbers add to more than 15.
(b) Two articles identified were applicable to Q5 and Q10, for the purposes of this diagram it has been included under Q5 only.
(c) One of these is a model from the previous guideline that was exclude. Two articles identified were applicable to both Q5 and Q11 and have only been included here under Q11. One paper here was selectively excluded in Q11 but included in Q5 and so is double counted in this flowchart.

Appendix F: Health economic evidence tables

None.

Appendix G: Excluded studies

G.1 Excluded qualitative studies

Table 21: Studies excluded from the qualitative review

Reference	Reason for exclusion
Ahmed 2006[2]	No relevant themes
Ahmed 2013[3]	Systematic review
Andrews 2015[192]	Incorrect study design
Ansari 2016[4]	Survey
Arango 2013[5]	Article
Bachman 2000[6]	Survey
Ball 2001[7]	Survey
Bartlett 2010[8]	No relevant themes
Bekle 2004[9]	Survey
Berger 2008[10]	Survey
Berger 2015[11]	No relevant themes
Bringewatt 2013[12]	No relevant themes
Brinkman 2011[13]	Literature review
Brinkman 2012[15]	No relevant themes
Brodin 2008[16]	No relevant themes
Brook 2000[18]	Survey
Brook 2005[17]	Incorrect study design
Brown 2010[19]	No relevant themes
Bussing 1998[22]	Survey
Bussing 2012[20]	Survey
Bussing 2016[21]	Survey
Butler 2015[23]	Systematic review
Canela 2017[24]	No relevant themes
Carpenter-Song 2010[25]	Article
Carter 2005[26]	Survey
Charach 2008[28]	Incorrect study design
Cheung 2015[30]	No relevant themes
Clarke 2012[32]	Incorrect study design
Clarke 2013[31]	Incorrect population
Clay 2008[33]	Wrong population
Cooper 1998[35]	No relevant themes
Corcoran 2016[36]	Systematic review
Cormier 2012[37]	No relevant themes
Couture 2003[38]	Questionnaire
Darredeau 2007[39]	Survey
Davis-Berman 2010[40]	No relevant themes
Davis-Berman 2012[41]	No relevant themes
Deane 2012[42]	Incorrect population
Dennis 2008[43]	Literature review

Reference	Reason for exclusion
dosReis 2007[46]	No relevant themes
Dosreis 2008[47]	Incorrect study design
dosReis 2009[45]	No relevant themes
dosReis 2010[44]	No relevant themes
Edwards 2013[48]	Wrong population
Einarsdottir 2008[49]	No relevant themes
Eisenberg 2007[50]	Survey
Elias 2017[51]	Incorrect population
Emilsson 2016[52]	Survey
Faber 2006[53]	Incorrect study design
Fiks 2010[54]	No relevant themes
Firmin 2009[55]	No relevant themes
Flannagan 2002[56]	No relevant themes
Fleishcmann 2013[57]	Survey
Frank 2015[58]	Incorrect study design
Friars 2009[59]	No relevant themes
Garro 2009[61]	Article
Gau 2009[62]	Incorrect study design
Gerdes 2014[63]	Incorrect study design - questionnaire
Ghanizadeh 2010[64]	Questionnaire
Ghosh 2016[65]	No relevant themes
Ginsberg 2008[66]	Incorrect study design
Goodwillie 2014[67]	No relevant themes
Gwernan-Jones 2015[69]	Literature review
Gwernan-Jones 2016[68]	Systematic review
Hack 2001[70]	Incorrect study design
Hallberg 2008[71]	No relevant themes
Hallerod 2015[73]	No relevant themes
Hansen 2006[72]	No relevant themes
Harazni 2016[74]	No relevant themes
Harvey 2009[76]	Wrong population, incorrect study design
Hassink-Franke 2016[77]	No relevant themes
Hazell 2004[78]	No qualitative results reported
Hebert 2013[79]	Survey
Henry 2011[80]	No relevant themes
Hill 2016[81]	Survey
Ho 2011[189]	No relevant themes
Hong 2008[83]	No relevant themes
Honkasilta 2014[84]	No relevant themes
Honkasilta 2016[85]	No relevant themes
Hughes 2007[86]	No relevant themes
Hughes 2009[87]	No relevant themes
Ide-Okochi 1016 [89]	Article
Jackson 2008[90]	No relevant themes
Kean 2005[91]	Incorrect study design

Reference	Reason for exclusion
Kendall 1997[92]	Incorrect study design
Kendall 2003[93]	No relevant themes
Kendall 2016[94]	No relevant themes
Kildea 2011[95]	No relevant themes
King 2016[96]	Wrong population
Kisely [97]	Survey
Klasen [98]	No relevant themes
Knipp [99]	No relevant themes
Ko [100]	Questionnaire
Koerting [101]	Review
Kollins [102]	Review
Kovshoff [104]	No relevant themes
Kronenberg [105]	Incorrect population
Kutuk 2016[106]	Survey
Larson [107]	No relevant themes
Laugesen [108]	Unable to access
Laugesen [108]	Systematic review
Lee [109]	No relevant themes
Lee [110]	No relevant themes
Leggett [112]	No relevant themes
Leslie [113]	No relevant themes
Lewis 2016[116]	Erratum
Lewis-Morton [114]	No relevant themes
Liebrenz 2016[117]	No relevant themes
Lin [118]	No relevant themes
Ljusberg [119]	No relevant themes
Loe [120]	No relevant themes
Lopes [121]	Incorrect population
Maassen [122]	No relevant themes
Marcer [123]	Questionnaire
Mathers [124]	Incorrect study design
Matthys [126]	No relevant themes
McCarthy [127]	Survey
McGoron [128]	Questionnaire
McIntrye [129]	No relevant themes
McKay [130]	Wrong population
McMenamy [131]	Wrong population
Michielsen [134]	Wrong population
Mills [103]	Abstract
Moen [136]	No relevant themes
Morsink 2017[137]	No relevant themes
Muhlbacher [138]	Abstract
Muhlbacher [138]	Abstract
Murrell [139]	Incorrect study design
Mychailyszyn [140]	No relevant themes

Reference	Reason for exclusion
Myers [141]	Incorrect study design
Nehlin [143]	No relevant themes
Olaniyan [145]	No relevant themes
Oruche [146]	Wrong population
Perry [147]	No relevant themes
Ramsay [148]	Incorrect study design
Raskind [149]	Survey
Reale [150]	Survey
Reid [151]	No relevant themes
Rogalin [152]	No relevant themes
Russell [153]	No relevant themes
Salt [154]	No relevant themes
Sandler [155]	No relevant themes
Schatz [156]	Systematic review
Schreuer 2017[157]	No relevant themes
Schrevel [158]	No relevant themes
Schrevel [158]	No relevant themes
Schubert [159]	No relevant themes
Segal [160]	No relevant themes
Segal [161]	No relevant themes
Shattell [162]	No relevant themes
Shaw [163]	No relevant themes
Simons [165]	No relevant themes
Singh [167]	Article
Singh [166]	No relevant themes
Singh [168]	Article
Singh [169]	Article
Sleath 2016[170]	Survey
Soderqvist 2017[172]	No relevant themes
Solberg [173]	Incorrect study design - questionnaire
Sox [174]	Incorrect study design
Srignanasoundari 2017[175]	No relevant themes
Stroh [176]	Survey
Surman [177]	Incorrect study design
Tatlow-Golden 2016[179]	Systematic review
Taylor [181]	No relevant themes
Taylor 2015[180] [180]	No relevant themes
Thiruchelvam [182]	Incorrect study design
Travell [183]	Analysis
Varley [184]	Article
Waite [185]	No relevant themes
Wallace [186]	No relevant themes
Wan 2016[187]	No relevant themes
Wiener [188]	No relevant themes
Wilkes-Gillan [82]	No relevant themes (parental intervention)

Reference	Reason for exclusion
Wilkinson [190]	No relevant themes
Williams [191]	No relevant themes
Williamson [193]	Incorrect study design
Winter [194]	Incorrect study design
Wolpert [75]	No relevant themes
Wright [195]	No relevant themes
Young [197]	No relevant themes
Young [196]	No relevant themes
Young [198]	No relevant themes
Zhang 1017[199]	No relevant themes

Table 22: Studies identified but not included in the qualitative review due to saturation being reached

Reference
Lewis 2016[115]

G.2 Excluded health economic studies

None.