National Institute for Health and Care Excellence

Final

Attention deficit hyperactivity disorder (update)

[H] Evidence reviews for the principles for discussion when starting, adjusting and discontinuing pharmacological treatment for ADHD

NICE guideline NG87

Evidence review

March 2018

Final

This evidence review was developed by
the National Guideline Centre

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1.1 Review question: What principles should clinicians follow when discussing decisions to start, adjust, or discontinue pharmacological treatment for people with ADHD?

1.2 Introduction

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 in this guideline on ADHD to identify and draw attention to topics and issues that are specific to people with ADHD. This review identifies and outlines the specific areas that clinicians should address when discussing decisions about initiating or reviewing medicines. This review should also be read alongside evidence report G on adherence to treatment.

1.3 Characteristics table

For full details see the review protocol in appendix A.

Table 1: Characteristics of review question

Objective	To identify the issues that are important to people with ADHD when considering whether to start, adjust, or discontinue treatment for ADHD to inform discussions between clinicians and people with ADHD
Population and setting	• Children, young people and adults with ADHD • Parents of children with ADHD • Teachers/professionals involved in education • Healthcare professionals
Context	• Any themes that emerge relating to the principles around starting, adjusting and discontinuing pharmacological treatment for the population
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.[141] 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

Sixty-nine qualitative studies were included in the review;[1,2,8,12,14,15,27,29,30,34,35,37,40,44,45,47,52,54,58,63,65,69-73,75,81,82,86,89,92,94,97,98,103,106,109-112,117,119,124,128,132,134,135,142,143,145,149,151,152,156,158,161-164,175,178,182,183,185,186,192,193,195] 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.

As a large number of papers were identified for this review, inclusion was halted once saturation was reached. Saturation is the point at which no new information emerged from studies that were found to match the review protocol. These five studies are listed in Table 40 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

Study	Design	Population	Research aim	Setting
Ahmed 2006[2]	Focus groups and framework method of analysis	16 parents of children with ADHD (aged 3-12 years)	To determine if parents of children with ADHD receive adequate information about the disorder and its treatments	Australia
Ahmed 2013[1]	Focus groups and framework method of analysis	16 parents of children with ADHD (aged 3 to 12 years)	To explore factors influencing parents' decisions to adhere and persist with ADHD medication	Australia
Bartlett 2010[8]	Interviews and content analysis	16 young adult college students (aged 18 - 25)	To determine what successful young adults perceive was helpful to them when they had difficulties with their symptoms as children	USA
Bringewatt 2013[12]	Interviews and grounded theory analysis	42 young adults with ADHD (aged 18 to 22 years)	Explore young adults' experiences of their ADHD	USA
Brinkman 2008[14]	Focus groups 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	USA

Study	Design	Population	Research aim	Setting
			ADHD	
Brinkman 2012[15]	Focus groups and inductive coding analysis	44 adolescents with ADHD between 13-18 years. (aged 13-18 years)	To investigate how adolescents with ADHD contribute to medication treatment decisions	USA
Charach 2006[27]	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]	Interviews and interpretive interactionist framework	12 children with ADHD (aged 12 to 15 years)	Exploring adolescents and parents' attitudes towards stimulant treatment	Canada
Cheung 2015[30]	Interviews and grounded theory analysis	40 young adults (aged 16 to 23 years (20 patients 16-17 and 20 18+))	Explore young adults experiences in accessing treatment and services	Hong Kong
Coletti 2012[34]	Focus groups and grounded theory analysis	27 parents of children diagnosed with ADHD (aged 5 to 12 years)	To explore parent perspectives on the decision to initiate medication treatment for ADHD	USA
Cooper 1998[35]	Interviews and analysis not specified	16 young people attending a school for students with learning and behavioural conditions. (aged 11-16 years)	Explore students' experiences with their ADHD	UK
Cormier 2012[37]	Interviews and grounded theory analysis	13 parents of children with ADHD (aged 6 to 12 years)	To understand how parents decide to medicate their child and explore factors of adherence	USA
Davis-Berman 2012[40]	Interviews and analysis not specified	28 families with a child with ADHD (aged 6 to 15 years)	To examine treatment making decisions of parents with a child with ADHD	USA
DosReis 2007[44]	Interviews and grounded theory analysis	26 African-American parents of children with ADHD (aged 6 to 18 years)	To explore parents' reasons for seeking treatment for their child	USA
Dosreis 2008[45]	Interviews and	20 college	To explore	USA

Study	Design	Population	Research aim	Setting
	grounded theory analysis	students with ADHD (age not specified)	experiences of taking medication for ADHD	
Einarsdottir 2008[47]	Interviews and phenomenology methodology	8 playschool teachers and 8 first grade teachers with 7-30 years of teaching experience.	Explore early childhood teachers' experiences and perspectives of children with ADHD	Iceland
Fiks 2010[52]	Interviews and grounded theory analysis	60 parents of children with ADHD and 30 clinicians (aged 6 to 12 years)	Compare how parents and clinicians understand shared decision making	USA
Flannagan 2002[54]	Interviews and analysis not specified	40 mothers and their children with ADHD (aged 8 to 11 years)		USA
Gallichan 2008[58]	Interviews and grounded theory analysis	12 young people with ADHD (aged 10 to 17 years)	Explore young peoples' perspectives of ADHD	UK
Ghosh 2016[63]	Interviews and thematic analysis	8 parents of children with ADHD. 4 had ADHD themselves and 1 had no children with ADHD (aged 3-23 years)	To explore parent experiences with ADHD	Australia
Goodwillie 2014[65]	Interviews and interpretive interactionist framework	6 parents with children diagnosed with ADHD (aged children' not specified)	Explore parental views of the impact of having a child with ADHD	UK
Hallberg 2008[69]	Interviews and grounded theory analysis	12 parents of adolescents with ADHD (aged Adolescent)	To explore the experiences of parents with teenage daughters with ADHD	Sweden
Hallerod 2015[71]	Interviews and phenomenology methodology	21 adults with ADHD (aged 18+)	Explore patients' experiences of being diagnosed with ADHD	Sweden
Hansen 2006[70]	Interviews and phenomenology methodology	10 parents of children with ADHD (aged 8 to 22 years)	Explore parents' experiences of medicating their child with ADHD	Canada
Harazni 2016[72]	Interviews and phenomenology methodology	4 mothers and 12 teachers (4 children with ADHD) (aged 7 to 10 years)	Investigate the experiences of adults that interact with school aged	Palestine

Study	Design	Population	Research aim	Setting
			children with ADHD	
Hassink-Franke 2016[75]	Interviews and constant comparative analysis	15 GPs treating children with ADHD (aged Not specified)	Explore GPs experiences of children with ADHD	Netherlands
Ho 2011[186]	Interviews (and survey) and content analysis	12 parents of children with ADHD (aged Children (not specified))	To explore parents' perceptions of their child with ADHD	China
Hong 2008[81]	Interviews and analysis not specified	8 kindergarten teachers, 2 day care teachers, 1 occupational therapist, 12 school teachers	Explore teachers' experiences and perspectives of children with ADHD	Korea
Honkasilta 2014[82]	Interviews and critical discourse analysis	18 mothers of children with ADHD (aged Not specified)	To explore parental involvement in their child's schooling	Finland
Ibrahim 2016[86]	Semi structured interview and analysis not specified	8 GPs, 8 consultants, 5 teachers and 5 mothers (aged children and adolescents)	Examine the experiences of drug holidays from caregivers and healthcare professionals	UK
Jones 2014[89]	Interviews and grounded theory analysis	9 young people between 15 and 21 with a diagnosis of ADHD. Substance abuse was an exclusion criteria. (aged 5 to 18 years)	To develop an understanding of the meaning and consequences of an ADHD diagnosis for young people	Denmark
Kendall 2003[92]	Interviews and thematic analysis	39 children and adolescents with ADHD (aged 6 to 17 years (mean 11.2))	Explores children's' perspectives on the authenticity of ADHD	USA
Kildea 2011[94]	Interviews and content analysis	28 stakeholders consisting of 7 mental health professionals, 2 teachers, 7 parents/carers, and 5 children referred for an ADHD assessment (age not specified)	Explore stakeholders' thoughts concerning ADHD in the context of CAMHS	UK
Klasen 2000[97]	Interviews and constant comparative analysis	10 GPs and 29 parents of hyperactive children (age	To investigate parents' and GPs' views on hyperactivity	UK

Study	Design	Population	Research aim	Setting
		not specified)		
Knipp 2006[98]	and thematic analysis	15 adolescents with ADHD (aged 14 to 17 years)	To explore adolescent perceptions of ADHD and medications	USA
Kovshoff 2012[103]	Interviews and grounded hermeneutic procedures	50 clinicians (28 from Belgium and 22 from UK, consisting of psychiatrists and paediatricians) (aged N/)	Explore clinicians experiences and attitudes to the diagnosis and management of ADHD	UK and Belgium
Larson 2011[106]	Interviews and grounded theory	Caregivers of 48 children with ADHD (aged 5 to 16)	How prior experiences of caregivers of children with ADHD leading up to treatment related to later service use	USA
Lee 2008[109]	Focus groups and content analysis	10 teachers of pre-Kindergarten through to 3rd grade classrooms. (aged preschool - 3rd grade)	Explore teachers' experiences and perspectives of children with ADHD	USA
Lefler 2016[110]	Interviews and grounded theory analysis	36 college students with ADHD (aged >18 years)	To explore the experiences of college students living with ADHD	USA
Leggett 2011[111]	Interviews and analysis not specified	33 parents of children with ADHD (aged 6 to 17 years)	To gain insight into the treatment experiences of children with ADHD	Australia
Leslie 2007[112]	Interviews and idiographic inductive analysis	28 families with a child with ADHD (aged 6 to 15 years)	Investigate contextual mechanisms that may explain differences in medication use among youths with ADHD	USA
Lin 2009[117]	Interviews and thematic analysis	10 mothers of children diagnosed with ADHD (aged 8 to 13 years)	To understand the experiences of primary caregivers who are bringing up children with ADHD	Taiwan
Loe 2008[119]	Interviews and grounded theory analysis	16 college students with ADHD (aged 18+)	To understand how college students construct and	USA

Study	Design	Population	Research aim	Setting
			manage identity in the context of pharmaceutical use	
Matheson 2013[124]	Interviews and Colaizzi's approach used for analysis	15 adults diagnosed with ADHD in childhood, and 15 diagnosed in adulthood (aged >18 years)	Explore adults experiences with ADHD	UK
McIntrye 2012[128]	Interviews and analysis not specified	18 parents of children diagnosed with ADHD (aged 7 to 12 years)	Explore parents' experiences of ADHD	UK
Meaux 2006[132]	Interviews and thematic analysis	15 college students with ADHD (aged 18+)	To gain insight about medication use among adolescents with ADHD	USA
Mills 2011[134]	Interviews and thematic analysis	19 families (representing 30 children with ADHD) (aged Not specified)	To understand how parents decide to medicate their child	USA
Moen 2011[135]	Semi structured interview and thematic analysis	9 parents (5 mothers and 4 fathers) from 7 families participated (aged 8 to 14 years)	Gain an understanding of the lived experience of having a child with ADHD	Norway
Nehlin 2015[175]	Interviews and content analysis	14 adults with ADHD, under the age of 30 with self-defined problematic alcohol/drug use (aged >18 years)	To investigate how adults with ADHD perceive the role of substance abuse and drugs in their lives	Sweden
O'Callaghan 2014[142]	Focus groups and constant comparative analysis	18 adults with ADHD (aged >18 years)	To explore the context that influences stimulant medication adherence	USA
Olaniyan 2007[143]	Interviews and Colaizzi's approach used for analysis	31 parents, only 3 had children with an ADHD diagnosis (mean age 9 (7.8) years)	Explore perspectives of ADHD and behavioural problems among African American parents	USA
Perry 2005[145]	Interviews and grounded theory analysis	26 Latino parents of children with ADHD (aged 6 to 19 years)	To explore Latino families' experiences with ADHD	USA

Study	Design	Population	Research aim	Setting
Reid 1996[149]	Interviews and focus groups and narrative psychological analysis	20 parents of children with ADHD (aged 5 to 18 years)	To explore parents' experiences of support from school systems	USA
Russell 2016[151]	Interviews and thematic analysis	41 educational practitioners that work with young people with ADHD, recruited from primary and secondary schools, and pupil referral units. (aged 11 to 18 years)	Explore educational practitioners views of ADHD	UK
Salt 2005[152]	Focus groups and thematic analysis	13 GPs (plus 93 completing a questionnaire) (age not specified)	To explore GPs' perceptions of the management of ADHD in primary care	UK
Schrevel 2014[156]	Interviews and coding used for analysis	52 adults with ADHD (aged 21+)	To assess the perspectives, problems and needs of adults with ADHD	The Netherlands
Segal 2001[158]	Interviews and grounded theory analysis	25 mothers of children with ADHD (age not specified)	Explore mothers' experiences raising children with ADHD	USA
Shaw 2003[161]	Interviews and thematic analysis	28 GPs caring for people with ADHD (age not specified)	Explore GPs attitudes towards ADHD	Australia
Sikirica 2014[162]	Focus groups and analysis not specified	38 caregivers (of ages 6 to 17 years) and 28 adolescents (13 to 17 years) with ADHD took part (aged 6 to 17 years)	To explore the unmet needs of adolescents with ADHD and their caregivers	Mixed European countries
Simons 2016[163]	Interviews and analysis not specified	59 participants (adults and young people with ADHD, parents of children with ADHD, and healthcare professionals)	To explore attitudes towards a remote monitoring technology for ADHD	UK
Singh 2003[164]	Interviews and grounded theory analysis	22 fathers of children with ADHD (aged 7 to 12 years)	Explore fathers' perspectives of ADHD symptoms, diagnosis and treatment	UK
Taylor 2006[178]	Interviews and analysis not	33 parents of children with	How to parents reach a decision	Australia

Study	Design	Population	Research aim	Setting
	specified	ADHD (22 primary school age, 11 teenagers)	to medicate their children or not	
Waite 2010[182]	Interviews and thematic analysis	16 women with ADHD (aged 18+)	To explore the experiences of women with ADHD	USA
Wallace 2005[183]	Interviews and thematic analysis	10 parents of children with ADHD (age not specified)	Explore the perception of mothers of sons with ADHD	Australia
Wiener 2015[185]	Interviews and grounded theory analysis	12 adolescents with ADHD (aged 14 to 16 years)	Explore school experiences of adolescents with ADHD	Canada
Wolpert 2004[73]	Interviews and thematic analysis	10 parents of children with ADHD (aged 8 to 11)	To investigate how parents make sense of the different aetiological models	UK
Wright 1997[192]	Semi structured interview and thematic analysis	16 parents of children with ADHD (aged 5-15 years (mean 10.2))	Explore experiences of parents whose children were taking Ritalin	UK
Young 2009[195]	Semi structured interview and grounded theory analysis	Partners of 8 people diagnosed with ADHD in adulthood (aged >18 years)	To explore the experience of living with a person who has undergone a diagnosis of ADHD in adulthood	UK
Young 2008[193]	Focus groups and framework method of analysis	8 people diagnosed with ADHD in adulthood (aged >18 years)	To explore the experience of receiving a diagnosis of ADHD in adulthood	UK

See appendix D for full evidence tables.

1.5.4 Qualitative evidence synthesis

Table 3: Theme 1: Starting treatment

Main themes	Statement of theme
Acceptance	Parents needed to accept their children’s diagnosis in order to make treatment choices
Influence of others	Parents treatment decisions were influenced by others
What’s best for the child	Parents wanted treatment decisions to be based solely on what was best for their child

Main themes	Statement of theme
Last resort	Parents decided to medicate their child when it was the last resort
Impact of symptoms	Medication was initiated when symptoms were severe, impacting on quality of life and functioning.
Role of healthcare professionals	Poor relationships, poor communication or a lack of information from healthcare professionals could delay initiation of treatment
Uncertainty/concerns	Parents had a range of concerns about medicating their children
Delayed services	Delayed services caused a delay in initiating treatment

Table 4: Theme 2: Monitoring treatment

Main themes	Statement of theme
Revisiting decision	Parents often doubted their decision to medicate their child and revisited their decision regularly.
Self-management	People adjusted their medication without consulting healthcare professional.
Reluctance of healthcare professionals	GPs had reservations about prescribing ADHD medication
Substance misuse	People with ADHD are approached by people wanting to take their medication

Table 5: Theme 3: Decision-making

Main themes	Statement of theme
Conflict	People involved in treatment decisions had conflicting opinions
Shared decision making	Experiences of decision-making ranged across parents and people with ADHD
Role of young people	Young people become increasingly involved in decision making as they get older

Table 6: Theme 4: Stopping of treatment

Main themes	Statement of theme
Side effects	People discontinued treatment due to side effects
Balance of benefit vs. side effects	People discontinued treatment when side effects outweighed the benefit of treatment
Changed sense of self	People discontinued treatment when they felt it was changing their ‘sense of self’, causing a loss of identity
Healthcare professional involvement	People did not tell their healthcare professionals when stopping treatment, or felt they did not have adequate support during cessation periods.
Negative experiences	Treatment was discontinued in patients that had negative experiences within the healthcare system
Trialling withdrawal	People wanted to trial life without medication in order to decide whether to discontinue

Table 7: Theme 5: Experiences of medication

Main themes	Statement of theme
Balance of benefit and side effects	People described how they interpreted the balance of benefit and side effects of treatment
Side effects	A range of side effects were described for people

Main themes	Statement of theme
	taking medication
Benefit	A range of benefits were described for people taking medication
Sense of self	People described the loss of identity experienced when taking medication
Worry/concerns	People had concerns about the long term impact of medication, addiction and
Stigma	People experienced stigma as a result of taking medication
Understanding	Children displayed an understanding of why they take medication

1.5.4.1 Narrative summary of review themes

1.5.4.1.1 Theme 1: Initiation of treatment

Review theme 1: Acceptance

Parents needed to reach an acceptance that their child had ADHD, and understand what this meant for them before being willing to medicate. Parents needed a reasonable amount of time to come to terms with their situation. They felt that consultations were too brief, and decisions to medicate their child were too hasty. Some parents were in denial that their children’s behaviour was a problem, and some were sceptical of the existence of ADHD, and needed to accept this in order to feel medicating their child was necessary.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies being conducted in Australia, USA and Canada, and evidence was only identified for parents of children with ADHD and not on the people with ADHD themselves; minor concerns about inadequacy as the evidence is not sufficiently deep, although the quantity of data was moderate. There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme and the adequacy of the data.

Review theme 2: Influence of others

Parent’s treatment choices were directly influenced by the opinion and actions of others. This included family members, teachers and people in their social circles. Teachers were sometimes the ones to identify the child’s behavioural problems and recommend seeking help, which parents felt helpful. However, some parents felt that teachers were pressurising them to medicate their children.

When parents had support from their family members and social circles in medicating their child, they found this helped them to make a decision and that the decision was made easier. Additionally, when parents knew someone that had chosen to medicate their child, it made them feel less averse to doing the same. However, when parents didn’t have the support of family members or social circles, they found the decision more difficult due to the pressure this caused, and the judgement they felt from others. This led to feelings of isolation in parents.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies being conducted in Australia and the USA, and evidence was only identified for parents of children with ADHD and not on the people with ADHD themselves; minor concerns about inadequacy as the evidence is sufficiently deep (themes provided with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme and the methodological limitations.

Review theme 3: What's best for the child

Parents put their child first when it came to decisions around whether or not to medicate them. They wanted this decision to solely be about what was best for their child, and not about taking 'the easy way out'. If their child's behaviour was sustainably managed by parents, they were less likely to decide to medicate their child. If medication was seen as the option that would help their child the most, parents chose this; many of these parents reported high levels of distress and exhaustion prior to making this decision. This was also with the caveat that they would do what was best within the constraints of their money and resources.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies being conducted in Australia and the USA, and evidence was only identified for parents of children with ADHD and not on the people with ADHD themselves; minor concerns about inadequacy as the evidence is moderately deep (themes provided with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme and the methodological limitations.

Review theme 4: Last resort

Parents decided to medicate their child when it was the last option available. They tried a range of non-pharmacological and alternative treatments available, and if these were all ineffective, they would then choose to medicate their child. Often parents were still reluctant, but contributing to this choice was seeing their child suffer with their symptoms. At this point, parents felt they had reached a point in which they could no longer cope with their situation. Some reported feeling guilty about their negative feelings towards their child, and felt unable to parent their child any longer without medication.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies being conducted in Australia, Canada and the USA, and evidence was only identified for parents of children with ADHD and not on the people with ADHD themselves; minor concerns about inadequacy as the evidence is not hugely rich, but of moderate quantity. There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme.

Review theme 5: Impact of symptoms

Parents decided to medicate their child when their symptoms were severe and impacted on their daily lives, or when their behaviour was out of context for what was expected compared to the child's peers of their age. In these situations, the child's impairments exceeded what the parents could manage, with or without alternative treatments. In addition, when symptoms were more manageable and were not impacting on the child's education or social functioning, parents were less likely to seek treatment. Similarly, people with ADHD also sought treatment when their symptoms were impacting on their quality of life.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies being conducted in Australia, Sweden and the USA; minor concerns about inadequacy as the evidence is not hugely rich, but of moderate quantity. There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme.

Review theme 6: Communication with healthcare professionals

Both people with ADHD and their parents were more reluctant to initiate treatment if the relationship with their healthcare professional, communication with them, and information provided by them was poor or insufficient. Some parents felt that their healthcare professional did not support them, and they did not trust them to make treatment decisions as a result. In some cases they felt ignored and intimidated. Others emphasised the importance of healthcare professionals giving them full details of all available treatment options. Those who “pushed” medication were responded to negatively by parents. Other parents viewed professionals negatively when they were seen to be focusing too much on parental skills or family dysfunction, which impacted on the parent’s willingness to follow the treatment pathway through. Other parents felt that consultations were too brief and that they needed more detailed information to make decisions to medicate their child. Those that felt confused by the information they had received were more apprehensive about making treatment decisions as a result. In addition, people with ADHD also reported that positive or negative interactions with doctors influenced whether or not they would start medication. Those with good relationships with their doctors felt more in control and less frustrated. When doctors referred to medication initiation as ‘trials’, parents felt more willing to try the medication.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies being conducted in the USA and Canada, with one being conducted in the UK. Minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme.

Review theme 7: Concerns with medication

Many parents felt fearful or were concerned about medicating their children, due to possible impacts of doing so. Their concerns included harmful side effects and changing their children’s ‘identity’. Others were concerned about the long term impact of medication, and the possibility of drug addiction. Worries about stigma and isolation were also strong concerns for parents. This perception of drug treatments had come from stories they had heard from others, and the media. In addition, some African-American parents were suspicious of medication, due to overarching concerns related to racial social control.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies only representing the experience of parents of children with ADHD, and most of the studies not being conducted in the UK; minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme.

Review theme 8: Delayed services

People with ADHD experienced some difficulty in accessing treatment, due to having to wait a long time during the referral process. This caused a delay in initiation of treatment. For some, this made them feel frustrated and have negative attitudes towards receiving care.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to only one study being conducted in the UK and one in Hong Kong; moderate concerns about inadequacy as the evidence is not sufficiently deep (provide themes, with elaborations and examples). There was a judgement of low confidence in this theme due to the concerns regarding the partial applicability of the theme and concerns around adequacy of the data.

1.5.4.1.2 *Theme 2: Monitoring treatment*

Review theme 9: Revisiting decisions

Parents often doubted their decision to medicate their child and revisited this decision regularly. They constantly examined the costs and benefits of their child's medication, in order to determine whether or not to continue the treatment. The decision was related mainly to the effectiveness of the treatment, which was judged based on whether it was having a positive impact on the child's behaviour and academic performance.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies only representing the experience of parents in the USA; moderate concerns about inadequacy as the evidence is not sufficiently deep. There was a judgement of low confidence in this theme due to the concerns regarding the partial applicability of this theme and the adequacy of the data.

Review theme 10: Self-management

People with ADHD and their parents modify their treatment plans, often doing so without consulting with a healthcare professional. This mainly included decreasing in dosages in response to side effects; people experimented with dosages until they found the optimal balance between benefit and side effects. Some also utilised 'drug holidays' without consulting with a healthcare professional, often due to adverse events. Many felt that there was a lack of support and guidance from healthcare professionals in relation to medication adjustments. Some people desired more support from healthcare professionals, reporting feelings of abandonment during these periods; they found it difficult to make decisions about medication on their own, especially when they were not warned by healthcare professionals about side effects. In addition, some patients reported not telling GPs about adverse events for fear that this would cause them to halt their medication. Healthcare professionals reported that it was difficult to monitor titration periods weekly, due to time constraints and high workloads.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies being conducted mainly in other countries; minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding methodological limitations.

Review theme 11: Reluctance of healthcare professionals

GPs felt resistant to prescribing medication, particularly stimulants, for children with ADHD. They felt that they shouldn't have to do this, were wary of doing so, and unsure of when they should cease treatment. Some were happy to continue repeat prescriptions for patients but had reservations about initially prescribing stimulants to children.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; high relevance due to the contributing studies being conducted in the UK; moderate concerns about inadequacy as the evidence is not sufficiently deep. There was a judgement of low confidence in this theme due to the concerns regarding the adequacy of the data.

Review theme 12: Substance misuse

Some people reported that they, or others that they knew, had been approached by people wanting to take their medication

Explanation of quality assessment: minor methodological limitations in the contributing studies; moderate concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies not being conducted in the UK; moderate concerns about inadequacy as the evidence is not sufficiently deep or of high quantity. There was a judgement of low confidence in this theme due to the concerns regarding the adequacy of the data and methodological limitations.

1.5.4.1.3 Theme 3: Decision-making

Review theme 13: Conflict

People involved in treatment decisions were found to have conflicting opinions on whether medication is needed, if adjustments need to be made or if different treatments should be trialled. This often arose between parents and children, spouses, other family members and healthcare professionals. When it came to decisions around discontinuation of treatment, healthcare professionals found that a good compromise was to ‘trial’ life without treatment, before more making permanent decisions.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to most of the contributing studies not being conducted in the UK; moderate concerns about inadequacy as the evidence is not sufficiently deep or of high quantity. There was a judgement of moderate confidence in this theme due to the concerns regarding the adequacy of the data and the applicability of the data.

Review theme 14: Shared decision-making

Most people with ADHD and their parents valued shared decision making between themselves and their healthcare professionals, but actual involvement ranged greatly. Some wanted to be involved in decision making, but wanted the healthcare professional to use their expertise to make the final decision; they felt unqualified to make their own decisions and so trusted healthcare professionals to do so. Others felt that their own involvement was inadequate and wanted to be listened to more, feeling that healthcare professionals needed to acknowledge that the parents were the primary decision makers and the experts on their children, whereas others felt they had control of their treatment decisions. In addition, some people felt that they had too much control over treatment decisions, and wanted healthcare professionals to be more involved.

Healthcare professionals utilised shared decision making, some feeling that this was a useful way for parents to accept the clinician’s preferred treatment option, without it seeming like a command.

Explanation of quality assessment: minor methodological limitations in the contributing studies; moderate concerns about the coherence of the theme with many conflicting experiences of patients; partial relevance due to the studies not being conducted in the UK; minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of low confidence in this theme due to the concerns regarding the partial applicability of this theme and the coherence of it.

Review theme 15: Involvement of young people

Young people become increasingly involved in treatment decisions as they get older. As a result, the role of parents in decision making often decreases, or conflict arises in decisions.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies only representing the experience of women from sub-Saharan Africa which is only a sub-set of the global focus of the review question and the only people represented by the evidence are the women themselves as no evidence was found of partners and health providers perceptions; moderate concerns about inadequacy as the evidence is not sufficiently deep. There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme to the global question.

1.5.4.1.4 Theme 4: Discontinuation of treatment

Review theme 16: Side effects

Side effects were reported to be a main reason for stopping treatment for ADHD. This included side effects of decreased appetite, sedation and emotional problems.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to most of the contributing being conducted outside the UK; moderate concerns about inadequacy as the evidence is not sufficiently deep. There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme to the global question.

Review theme 17: Balance of benefit and side effects

People discontinued treatment when side effects outweighed the benefit of medication. In some cases, even if the benefit of medication was perceived high, if side effects were severe then treatment would be halted. In other cases, the benefit was insufficient and so even minor side effects would result in discontinuation of treatment. Others found that initially the benefit of treatment outweighed side effects, but as the efficacy of treatment decreased it became less worthwhile to continue treatment.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing mainly being conducted outside the UK; moderate concerns about inadequacy as the evidence is not sufficiently deep. There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of the theme and inadequacy of the data.

Review theme 18: Changed sense of self

People with ADHD were found to discontinue treatment when it was impacting on their ‘sense of self’. In these cases they didn’t feel like themselves and feel treatment is causing a ‘loss of identity’.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the some of the contributing studies being conducted outside the UK; moderate concerns about inadequacy as the evidence is not sufficiently deep. There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of the theme and inadequacy of the data.

Review theme 19: Involvement of healthcare professionals

People reported not discussing cessation attempts with their healthcare professionals. Some felt that they required support during attempts to withdraw from treatment, as they found it difficult to judge whether or not treatment should be continued.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies being conducted both in the UK and the USA; moderate concerns about inadequacy as the evidence is not sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability and adequacy of the data.

Review theme 20: Trialling withdrawal

People wanted to trial life without medication, before deciding whether or not to discontinue treatment permanently. Some found that behaviour was manageable without treatment, and so discontinued treatment. Others displayed negative behaviour and continued with treatment.

Explanation of quality assessment: minor methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing study being conducted in the UK; moderate concerns about inadequacy as the evidence is not sufficiently deep or of high quantity. There was a judgement of low confidence in this theme due to the concerns regarding the partial applicability of this theme and concerns regarding adequacy.

1.5.4.1.5 *Theme 5: Experiences of medication*

Review theme 21: Balance of benefit and side effects

People with ADHD and their parents described the process in which they determined whether the benefit of treatment was sufficient enough to continue it, or whether side effects outweighed the benefit. Generally, they described a benefit of medication when there were behavioural and cognitive improvements, both at school and at home. This included reduced aggressive behaviour and increased calmness, improved concentration and improvements in school work, and an effect that lasted throughout the day. They wanted to find a balance between ensuring behavioural changes were sufficient enough, without ‘overmedicating’ their child or increasing side effects. They cited long term academic goals as justification for why these changes in behaviour were important for their children’s wellbeing. Although parents had judged benefit of treatment to outweigh side effects, they were often worried about the impact of these, and found them difficult to manage. Parents were frustrated that they had to interpret efficacy and side effects themselves, without the support of healthcare professionals.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies mainly being conducted outside the UK; minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme.

Review theme 22: Benefit

A range of benefits were described by people with ADHD, their parents, teachers and healthcare professionals. This included a range of positive behaviours, which were noted both at home and at school and were seen to improve day to day activities and overall quality of life. Academic improvements were seen due to increased concentration and attention span. Behavioural improvements were seen such as reduced hyperactivity and a reduction in disruptive behaviour; this led to improved relationships with parents and teachers, and a reduction in stress for parents. Emotional improvements included improved emotional stability, feeling more ‘normal’ and having increased confidence. Functional improvements included improved ability to take part in sports and other activities, and improved driving skills.

Parents felt that all these benefits allowed their children to reach their full potential. However, they felt that the treatment should not be seen as a ‘cure’; these improvements were not the full picture, and that other aspects of the child’s behaviour and functioning required additional support. Many noted that the benefit of treatment wore off quickly, and symptoms returned when children returned home from school. Some noted that symptoms could return rapidly, and were sometimes worse than before medication was taken.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies mainly being conducted outside of the UK; minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme and methodological limitations.

Review theme 23: Side effects

Taking ADHD medications resulted in a range of side effects. People reported a general feeling of 'dullness' and 'numbness', feeling 'zombie' like. As a result people took less enjoyment out of their daily activities, and often socialised less. Other side effects reported included appetite problems and weight loss, and sleep disturbances. Even though many of these side effects were reported as being severe and difficult to manage, many patients continued on treatment.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing mainly being conducted outside of the UK; minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme to the global question.

Review theme 24: Sense of self

Children and young people with ADHD reported not feeling like themselves on medication. They felt withdrawn, and felt that medication had 'dampened' their personality. They felt uninterested in activities they would usually take enjoyment out of, and didn't like feeling that they were being controlled by their medication.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing mainly being conducted outside of the UK; minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme to the global question.

Review theme 25: Concerns

Parents reported a high level of distress when contemplating their child's future on the medication. They had concerns about the long term impact of medication on their child, particularly around the possibility of addiction and abuse during the adolescent years. Others were concerned about the long term impact of side effects, such as decreased appetite. Generally, parents were worried due to the possibility of damaging their child's health rather than improving it, although they continued to accept the decisions of healthcare professionals to continue treatment.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing studies being mainly conducted outside the UK; minor concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability of this theme to the global question.

Review theme 26: Stigma

Parents felt that most people they knew didn't understand ADHD or why they had chosen to medicate their child, and felt that it was mainly due to poor parenting techniques. Children and young people with ADHD reported being made fun of when they had to leave classes to take medication, although others reported not feeling stigmatised whilst doing so. For those that did, they experienced feelings of sadness, frustration, anger and embarrassment due to the stigma it evoked.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; moderate concerns about the coherence of the theme as conflicting themes were found within the theme; partial relevance due to the contributing studies being conducted outside the UK; moderate concerns about inadequacy as the evidence is sufficiently deep (provided themes, with elaborations and examples). There was a judgement of low confidence in this theme due to multiple concerns.

Review theme 27: Children's understanding

Children understood that the medication they were taking was a way of helping them with the problems they were having.

Explanation of quality assessment: moderate methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to the contributing being conducted in the USA; minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this theme due to the concerns regarding the partial applicability and methodological limitations.

1.5.5 Qualitative evidence summary

1.5.5.1 Theme 1: Starting treatment

Table 8: 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**
Acceptance					
6 Children and young people	3 focus groups; 3 interview (1 Canada; 2 USA; 3 Australia)	Parents needed to accept their children's diagnosis in order to make treatment choices	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 9: 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**

Study design and sample size			Quality assessment		
No of studies contributing to the theme	**Design**	**Themes**	**Criteria**	**Rating**	**Overall assessment of confidence**
Influence of others					
9 Children and young people	2 focus groups; 1 interview (6 USA; 3 Australia)	Parents treatment choices were influenced by others Teachers could encourage or discourage medication Family members and social networks could support or criticise treatment choices	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 10: 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**
What is best for the child					
3 Children and young people	1 focus groups; 2 interviews (2 USA; 1	Parents wanted treatment decisions to be based solely on what was best for their child	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns about coherence	

Study design and sample size			Quality assessment		
No of studies contributing to the theme	Design	Themes	Criteria	Rating	Overall assessment of confidence
	Australia)		Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 11: 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
Last resort					
6 Children and young people	2 focus groups; 3 interviews (4 USA; 1 Australia; 1 Canada)	Parents decided to medicate their child when they had tried all other options and medication was the last resort	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 12: 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**
Impact of symptoms					
7 5 Children and young people 2 Adults	2 focus groups; 5 interviews (5 USA; 1 Australia; 1 Sweden)	People with ADHD and parents initiated medication when symptoms were severe, impacting on quality of life and functioning.	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 13: 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**
Role of healthcare professionals					
8 6 children and young	5 focus groups; 3 interviews	Poor relationships, poor communication or a lack of information from healthcare professionals could delay initiation of treatment.	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about	

Study design and sample size			Quality assessment		
No of studies contributing to the theme	**Design**	**Themes**	**Criteria**	**Rating**	**Overall assessment of confidence**
people 2 adults	(5 USA; 1 UK; 1 Canada; 1 Canada)			coherence	
			Relevance	partially relevant	
			Adequacy	minor 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**
Uncertainty and concerns					
11 Children and young people	4 focus groups; 7 interviews (6 USA; 1 UK; 1 Canada; 3 Australia)	Parents had concerns about medication which delayed initiation of treatment: Side effects Loss of identity, isolation and stigma Long term impact and drug addiction	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 15: 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**
Delayed services					
2 Children and young people	2 interviews (1 UK 1 Hong Kong)	Delays in accessing services resulted in delays in accessing treatment	Limitations	minor limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

1.5.5.2 Theme 2: Monitoring treatment

Table 16: 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**
Revisiting decisions					
4 Children and	3 focus groups; 1 interview	Parents often doubted their decision to medicate their child and revisited their decision regularly.	Limitations	minor limitations	LOW
			Coherence	minor	

Study design and sample size			Quality assessment		
No of studies contributing to the theme	**Design**	**Themes**	**Criteria**	**Rating**	**Overall assessment of confidence**
young people	(3 USA; 1 Australia)			concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 17: 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**
Self-management					
10 6 adults; 4 children and young people	2 focus groups; 5 interviews (4 USA; 3 UK; 3 Australia)	People adjusted their medication without consulting healthcare professional. Some felt support was lacking and desired more support Healthcare professionals felt they didn't have enough time to do so	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns	

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

Table 18: 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
GP reluctance					
3	3 interviews (2 UK; 1 Netherlands)	GPs had reservations about prescribing ADHD medication	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	fully relevant	
			Adequacy	moderate concerns about adequacy	

Table 19: 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
GP reluctance					
1	Interviews (USA)	People with ADHD are approached by people wanting to take their medication People involved in treatment decisions had conflicting opinions	Limitations	moderate limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

1.5.5.3 Theme 3: Decision-making

Table 20: 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**
Conflict					
4	Interviews (1 USA; 1 UK; 2 Canada)	People involved in treatment decisions had conflicting opinions Parent-child conflict Spouses Other family members Healthcare professionals	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	

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

Table 21: 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**
Shared decision-making					
6 3 children and young people 3 adults	(1 focus group; 4 Interviews) (4 USA; 1 Hong Kong; 1 UK)	Experiences of shared decision making varied Inadequate patient involvement Inadequate healthcare professional involvement Parents wanting more/less control	Limitations	minor limitations	LOW
			Coherence	moderate concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 22: 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**
Young peoples' role					
2 Children and young people	(2 Interviews) (1 Hong Kong; 1 Canada)	Young people become increasingly involved in treatment decisions as they get older	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

1.5.5.4 Theme 4: Stopping treatment

Table 23: 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**
Side effects					
4	(1 focus group; 3 Interviews)	People discontinued their treatment due to side effects	Limitations	minor limitations	MODERATE
			Coherence	minor	

Study design and sample size			Quality assessment		
No of studies contributing to the theme	**Design**	**Themes**	**Criteria**	**Rating**	**Overall assessment of confidence**
Side effects					
Adults	(2 UK; 1 USA; 1 Canada)			concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 24: 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**
Balance of benefit and side effects					
8 4 children and young people 4 adults	(1 focus group; 7 Interviews) (3 UK; 2 USA; 2 Canada; 1 Mixed European	People discontinued their treatment when side effects outweighed the benefit of treatment	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate	

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

Table 25: 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
Sense of identity					
3 2 children and young people 1 adults	(3 Interviews) (2 UK; 1 Canada)	People discontinued treatment when they felt it was changing their 'sense of self', causing a loss of identity	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 26: 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
Healthcare professional involvement					
3 2 children and young people 1 adults	(3 Interviews) (1 UK; 1 USA; 1 Canada)	People did not tell their healthcare professionals when stopping treatment, and felt they required more support during withdrawal attempts.	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 27: 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**
Trialling withdrawal					
1 Adults	(1 focus group) (1 USA)	People trialled life without treatment before deciding whether to discontinue	Limitations	minor limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	

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

1.5.5.5 Theme 5: Experiences of medication

Table 28: 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**
Balance of benefit and side effects					
9 Children and young people	(8 interviews; 1 focus group) (1 Norway; 2 Canada; 1 Australia; 2 UK; 3 USA)	Parents described a range of benefits that outweighed side effects due to functional improvements both inside and outside of school	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 29: 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**
Benefits					
24 21 children and young people 3 adult	(21 Interviews; 3 focus group) (7 USA; 7 UK; 1 Hong Kong; 5 Canada; 2 Australia; 1 Korea; 1 Mixed European countries)	Benefits included functional and behavioural improvements across many aspects of people's lives, and were seen to improve quality of life Wore off by the end of the day Symptoms worse when they return Not the full picture	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 30: 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**
Side effects					
11 8 children	(11 interviews)	Medication were associated with a range of side effects that impacted on functioning 'Zombie' like	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns	

Study design and sample size			Quality assessment		
No of studies contributing to the theme	**Design**	**Themes**	**Criteria**	**Rating**	**Overall assessment of confidence**
and young people 3 adult	(7 USA 1 Iceland; 2 UK; 1 Australia)	Appetite changes and weight loss Sleep disturbances		about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 31: 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**
Sense of self					
9 8 children and young people 1 adult	(9 interviews) (4 USA; 1 Canada; 3 UK; 1 Mixed European Countries)	People felt they had lost their identity, and that their personality had changed as a result of taking medication	Limitations	minor limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about	

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

Table 32: 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
Concerns					
9 Children and young people	(2 focus group; 7 Interviews) (3 Australia; 2 Canada; 1 Hong Kong; 1 USA; 1 UK; 1 mixed European countries)	Parents were concerned about the long term impact of medicating their children	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor concerns about adequacy	

Table 33: 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
Stigma					
4 2 children and young people 2 adults	(1 focus group; 3 Interviews) (3 USA; 1 Canada)	People with ADHD and their parents experienced stigma as a result of taking medication.	Limitations	moderate limitations	LOW
			Coherence	moderate concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 34: 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
Children's' understanding					
1	(Interview) (USA)	Children understood that medication was a way of helping them with the problems they were having	Limitations	moderate limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	

Study design and sample size			Quality assessment		
No of studies contributing to the theme	**Design**	**Themes**	**Criteria**	**Rating**	**Overall assessment of confidence**
			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 G.

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 for the narrative summaries

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

For many of the subthemes, a large amount of evidence was identified. All of the evidence was of low to moderate quality. There were mainly only minor concerns about the coherence of the themes and methodological limitations. Many of the themes had moderate concerns about the adequacy of the data. Many of the themes were only partially applicable to the population and setting of this review. The studies were all conducted in a population of people with ADHD, or in carers, healthcare professionals or teachers who supported people with ADHD. 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 GC were in agreement that the subthemes presented were consistent with their own clinical experiences.

1.9.1.2 Themes identified in the evidence synthesis

Initiation

The evidence identified that initiation of treatment was often delayed due to the availability of services or healthcare professionals and that initiating pharmacological treatment was a difficult decision for people with ADHD and their parents. The evidence identified that parents would often initiate treatment when this was best for their child and if their child's symptoms were too severe for them to manage. However, choosing to initiate medication required much discussion and was a difficult decision to come to regardless of the benefits for the child. This is due to the concerns parents had about medication, which mainly related to harmful side effects and concerns about the long term impact. The committee agreed that in their experience parents often had considerable concerns about medication. For example they felt that many had concerns about addiction, and that some were worried about the possibility of addiction to the ADHD medication itself, or that taking medication could lead to addiction to illicit substances. The review also highlighted that people sometimes felt that discussions around initiating medication were too brief or rushed and that no matter how good the consultation skills of a healthcare professional it can take time for a person to accept the need for medication, hence the importance of allowing people to revisit decisions. The committee recommended that healthcare professionals discuss concerns about medication and ensure that revisiting decisions did not unduly delay initiation of treatment.

Some saw medication only as a last resort whereas others were keen to follow any option that was definitively ‘what was best for the child’. The committee noted that there is no one definitive option that will best for every child and reflected this in their recommendations around when to use pharmacological vs non-pharmacological treatments, however they also agreed that in general the evidence in other reviews supported pharmacological treatment as likely being more effective at treating core ADHD symptoms. Taking all of this together, the committee recommended that regardless of the main treatment choices made by people with ADHD, it is important that all have a treatment plan that addresses the psychological, behavioural and occupational or educational needs and is not purely medication focused.

The committee noted that discussions around initiating treatments bring together many points of view and as identified by the evidence this can often cause conflict and potentially delay treatment. The evidence highlighted that parents’ decisions to medicate their child could be influenced by the opinion and actions of others. The review identified a number of situations in which healthcare professionals, teachers, parents and other family members had varying opinions on the need for medication and the benefits and challenges presented by these many inputs. However these discussions are important and if not addressed openly then they can lead to people not using medication as prescribed or not adhering. The committee therefore recommended that healthcare professionals should encourage these discussions to occur openly and before initiation in order to insure that shared decision making in the best interests of the person or child with ADHD can occur.

The review highlighted that initiation of treatment could be impacted by a person’s communication with their healthcare professional. People were less happy to initiate treatment when their relationship with their healthcare professional, and information provided by them was insufficient. Some parents felt that they did not have the support of their healthcare professional and did not trust them to make important decisions about medication as a result. Others felt that healthcare professionals were too quick to push for medication and were responded to negatively as a consequence. The committee agreed that the guideline should cross refer to the NICE guideline on antisocial behaviour and conduct disorders in children and young people for principles of care such as developing a trusting relationship with people with ADHD and their families.

The evidence identified that some people reported a sense of changed identity while using medication for ADHD and this was a reason for their discontinuation of treatment. The committee agreed that in their experience some people did report this fear and that it was important to discuss this to support adherence to medication (for more information, see evidence report G on adherence to treatment). Once these fears were discussed people could be reassured that their personality would not change and the medication was to support them in managing situations they found difficult.

Monitoring

The evidence identified that some people with ADHD experienced delays in care and problems with monitoring when their primary healthcare professionals were uncomfortable prescribing medication for ADHD. The committee noted that this was a common theme in their own experience and reinforced the previous recommendation that while primary care practitioners should not start medication, after titration and dose stabilisation prescribing should be carried out under a shared care arrangement between primary and secondary care. The committee also emphasised that healthcare providers should ensure continuity of care for people with ADHD.

Stopping

The review highlighted that people would stop their treatment when the harm of medication outweighed the benefits they felt they were receiving. The committee noted that people commonly reported altering their medication dose or stopping medication altogether without input from healthcare professionals. The committee recommended that healthcare professionals encourage open discussion about discontinuation to avoid people from stopping their medication without at least discussing the implications with a healthcare professional. The evidence also indicated that people would prefer trial periods of dose reduction or discontinuation rather than abrupt stopping without a plan to monitor or reinitiate treatment. These themes were incorporated into the committee's recommendations on discontinuation of treatment (see review I Withdrawal and drug holidays).

1.9.2 Cost effectiveness and resource use

No economic evidence was identified for this question.

The clinical review for this question was a thematic analysis to identify issues important to people around starting, adjusting or discontinuing treatment. Resources that might be involved include staff time to provide the relevant advice and support to patients.

The committee considered the evidence and felt that themes that came out of the review were consistent with their own experiences in clinical practice.

On a consensus basis the committee decided to draft recommendations around good practice that should take place in terms of what they should consider and also what should be discussed with patients/families/carers in order to provide the best level of care and information to patients when they are starting or making changes to their treatment.

This recommendation is not likely to have a resource impact.

1.9.3 Other factors the committee took into account

The committee considered that in coming to a decision to initiate any specific treatment for ADHD the severity of symptoms, degree and pervasiveness of impairment of the individual, and the individual and family's own views were all important to consider and discuss. The committee agreed that all options, benefits and harms should be fully explained and discussed. These discussions should also take into account specific medical factors which may influence decisions (for example cardiac conditions).The committee also noted that it was important to discuss treatment options with women trying to conceive or during pregnancy and whilst breastfeeding.The committee noted that ADHD frequently co-exists with other neurodevelopmental or mental health conditions. While this guideline focuses specifically on ADHD, the committee agreed that it is important for healthcare professionals to consider the need for support relating to co-existing conditions as part of the ongoing monitoring process.

While very little evidence was identified on the practicalities of initiation and monitoring, the committee chosen to make consensus based updates to the previous recommendations about how to initiate and monitor ADHD medication. These recommendations were also informed by the pharmacological efficacy and adverse events reviews. The committee wanted to be clear that decisions about the mode of delivery of the preparations (such as liquid or tablet) should be made carefully with the person with ADHD.

The committee wanted to note that the continuity of care and regular contact is crucial to keeping people informed and supported about their treatment. In the committee’s experience a healthcare professional (such as an ADHD specialist nurse) can have a positive impact on the management and adherence of treatment. The committee noted in children and young people with ADHD that the availability of someone to communicate with the school and to provide a route for feedback was invaluable in supporting the management of treatment. The committee reinforced the previous recommendations on shared care arrangements.

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 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

41. 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

42. 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

43. 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

44. 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

45. 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

46. 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

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

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

49. 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

50. 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

51. 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

52. 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

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

54. 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

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

56. 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

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

58. 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

59. 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

60. 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

61. 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

62. 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

63. 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

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

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

66. 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

67. 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

68. 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

69. 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

70. 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

71. 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

72. 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

73. 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

74. 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

75. 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

76. 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

77. 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

78. 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

79. 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

80. 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

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

82. 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

83. 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

84. 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

85. 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

86. 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

87. 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

88. 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

89. Jones S, Hesse M. Adolescents with ADHD: experiences of having an ADHD diagnosis and negotiations of self-image and identity. Journal of Attention Disorders. 2014; Epublication

90. 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

91. 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

92. 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

93. 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

94. 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

95. 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

96. 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

97. 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

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

99. 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

100. 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

101. 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

102. 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

103. 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

104. 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

105. 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

106. 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

107. 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

108. 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

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

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

111. 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

112. 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

113. 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

114. 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

115. 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

116. 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

117. 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

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

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

120. 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

121. 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

122. 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

123. 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

124. 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

125. 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

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

127. 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

128. 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

129. 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

130. 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

131. 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

132. 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

133. 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

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

135. 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

136. 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

137. 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

138. 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

139. 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

140. 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

141. 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

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

143. 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

144. 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

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

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

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

148. 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

149. 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

150. 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

151. 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

152. 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

153. 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

154. 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

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

156. 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

157. 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

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

159. 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

160. 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

161. 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

162. 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

163. 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

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

165. 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

166. 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

167. 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

168. 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

169. 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

170. 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

171. 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

172. 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

173. 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

174. 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

175. 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

176. 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

177. 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

178. 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

179. 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

180. 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

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

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

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

184. 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

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

186. 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

187. 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

188. 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

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

190. 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

191. 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

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

193. 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

194. 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

195. 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

196. 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 35: Review protocol: Managing treatment

Field	Content
Review question	What principles should clinicians follow when discussing decisions to start, adjust, or discontinue pharmacological treatment with people with ADHD?
Type of review question	Qualitative
Objective of the review	To identify the issues that are important to people with ADHD when considering whether to start, adjust, or discontinue treatment for ADHD to inform discussions between clinicians and people with ADHD
Eligibility criteria – population / disease / condition / issue / domain	• Children, young people and adults with ADHD • Parents of children with ADHD • Teachers/professionals involved in education • Healthcare professionals involved in the care of people with ADHD
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 derived from the evidence identified for this review, and not pre-specified by the guideline committee in advance. However, relevant themes may include: • The attitudes of people with ADHD towards the balance between side effects and symptom reduction • What people with ADHD think is a meaningful change in symptoms • The factors that contribute to choice of treatment in people with ADHD • The factors that contribute to people’s adherence (or non-adherence) of treatment. This may include the way in which medication is prescribed • The factors that contribute towards people’s decision to initiate or discontinue treatment, including parents’ considerations in children with ADHD
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	Not applicable

meta-regression	
Selection process – duplicate screening / selection / analysis	No duplicate screening was deemed necessary for this question, for 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) or F (health economic 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	Not applicable
Methods for quantitative analysis – combining studies and exploring (in)consistency	Not applicable
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.
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 36: 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).141 Inclusion and exclusion criteria

Review question	**All questions – health economic evidence**
	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 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 37: 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 38: 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.

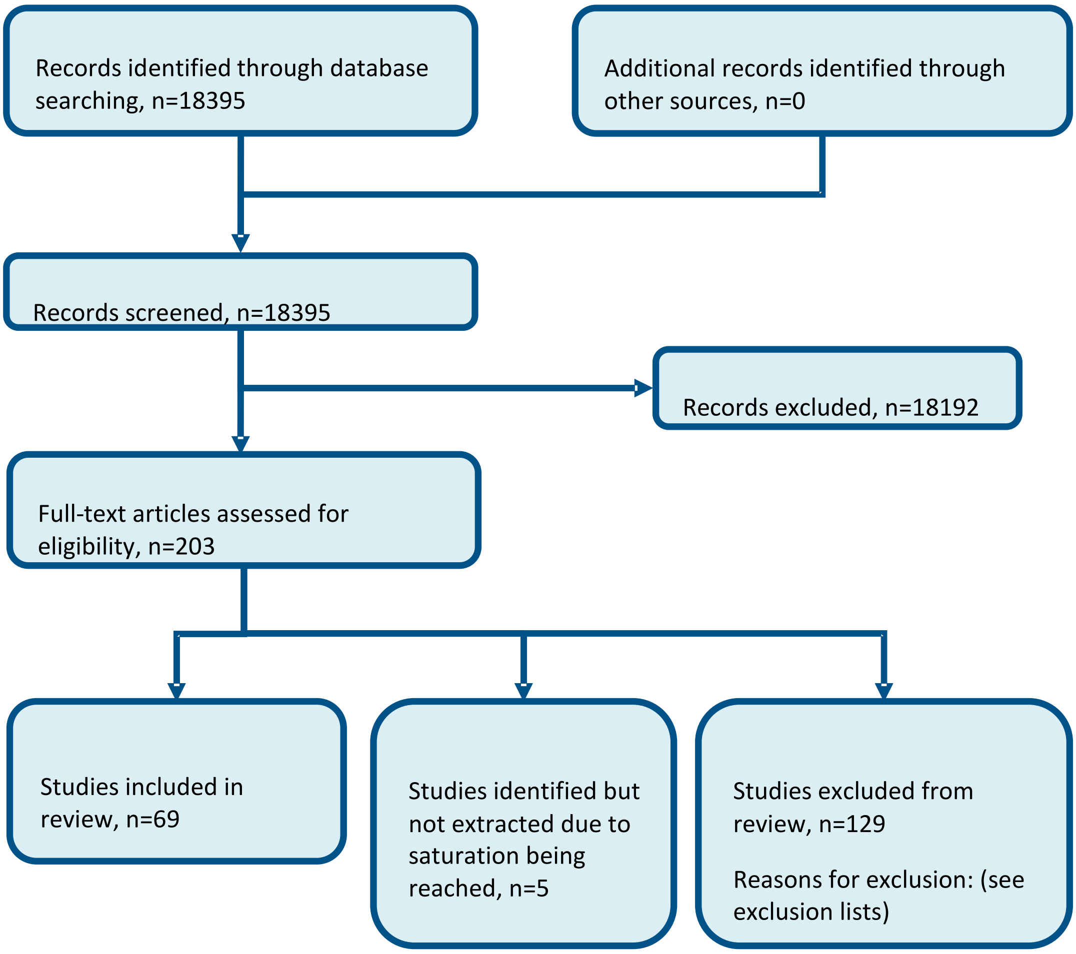
37.	econom* model*.ti,ab.
38.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
39.	or/29-38
40.	*health economics/
41.	exp *economic evaluation/
42.	exp *health care cost/
43.	exp *fee/
44.	budget/
45.	funding/
46.	budget*.ti,ab.
47.	cost*.ti.
48.	(economic* or pharmaco?economic*).ti.
49.	(price* 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 1: Flow chart of clinical article selection for the review of managing treatments



Appendix D: Qualitative evidence tables

Study	Ahmed 2006[2]
Aim	To determine if parents of children with ADHD receive adequate information about the disorder and its treatments
Population	16 parents of children with ADHD (aged 3-12 years)
Setting	Australia
Study design and methodology	Focus groups were facilitated by one of the researchers experienced in conducting focus groups, and each lasted between 1 - 1.5 hours. Questions were open ended to encourage detailed answers. Analysis was conducted using a framework method of analysis. Notes were made about the themes emerging, when investigators had read and listened to the focus group data numerous times. Themes were discussed with the full research team.
Themes with findings	Information needs •Some parents felt confused or frustrated by the information they received and were apprehensive about making treatment decisions as a result •Parents felt information given by GPs was too brief, and found conflicting information from other sources •Parents wanted more information on the biological mechanisms of ADHD •Parents wanted access to information about adults who were effected by ADHD as children, to determine the impact of the condition, specifically around the impact of medication •Parents wanted more information on the long term outlook of the condition, and the long term impact of medication, and the duration of medicating that might be necessary •Parents wanted more information on how they could manage their child’s ADHD, particularly around mood swings and what to do in certain situations
	Information sources •Most parents reported the diagnosing clinician to be their main source of information •Parents found information from the internet was too excessive to be helpful •Parents felt that information on real life experiences of other families would be a useful way to understand the condition and the management of it •Parents felt it would be helpful to be referred to support groups to speak to other parents, and learn ways to manage their children from them. Harm of medication •Parents read many horror stories about medication on the internet, which put them off of medicating their child

Study	**Ahmed 2006[2]**
	Support needs After diagnosis, parents reported a huge amount of paperwork that needed to be filled in for various health and educational reasons. They felt the HCPs should help or advise with what needed to be done.
Limitations	Minor limitations related to the richness of the data
Applicability of evidence	Partially; conducted in Australia. Information applicable to the experiences of parents of children with ADHD

Study	**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 and methodology	Focus groups lasted from 1 to 1.5 hours and ware 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 with findings	Harm of medication •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. Drug holidays •Many participants reported utilising drug holidays to reduce unwanted side effects, without consulting HCPs Reasons for initiating treatment •Parents identified factors that encouraged them to initiate treatment. The main factor was concerns about poor academic performance. Other factors included relying on advice of HCPs, and listening to other parents' experiences with children on medication Continuing treatment •Parents reported continuing treatment when the treatment was clearly having a positive impact on the child's behaviour and academic performance Long term impact of medication •Parents had concerns about the long-term impact of medication on their child, particularly around the possibility of addiction and abuse during the adolescent years. Stigma experienced by parents •Parents faced many criticisms from family members and those in their social circle for choosing to medicate their child. Parents

Study	Ahmed 2013[1]
	described feelings of isolation and lack of support as a result
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Applicability of evidence	Partially; conducted in Australia. Information applicable to the experiences of parents of children with ADHD

Study	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 and methodology	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 the transcripts, identified emerging themes, and labelled themes to construct a codebook.
Themes with findings	"Factors of adherence •Parents reported that their children sometimes forgot to take their medication" "Emotional impact for parents •Parents described great difficulties in parenting their children, which caused daily emotional distress" "Pressure from teachers •Parents felt that teachers were pressurising them to medicate their children" "Conflict between parents •Many parents reported contrasting opinions between them and their partner, regarding whether a diagnosis is helpful for their child and whether medication is needed." "Emotional impact of decision making •Parents reported reaching a point, emotionally, in which they could no longer cope with their situation. They reported feeling too guilty about their negative feelings towards their child, and feeling unable to attempt to parent their child any longer"
	"Factors supporting initiation of treatment

Study	**Brinkman 2008[14]**
	•Parents recognised that their child's functional impairments were severe and were impacted every aspect of their life, and so felt medication was necessary" •Parents reported feeling comfortable with initiating medication when it was referred to as a 'trial' in which they could terminate if they felt necessary." •Parents reported that teachers identified that their child might have behavioural problems, which led to a diagnosis and treatment" •Parents that had friends or family members that had chosen to medicate their children, made them feel less adverse to doing the same" •Parents reported that having a positive relationship with their doctor helped them to decide on the initiation of treatment" •Parents reported that having extended family support helped them to in their decision making" •Some parents saw medication as a last resort, after other medications had been ineffective" Factors that delay initiation of medication •Parents felt that before deciding to medicate their child, there were in denial that there was a problem, or were not confident in the diagnosis" •Parents reported that poor communication with teachers led to a delay in treatment" •Parents had heard ""horrors stories"" about ADHD medication side effects, which made them not want to medicate their child" •Parents did not want their child to be a victim of stigma, as a result of receiving medication" •Parents felt fearful of medicating their child due to side effects, the possibility of drug addiction, and an overreliance on medication to fix things"
Limitations	Minor limitations related to the richness of the data
Applicability of evidence	Partially; conducted in the USA and limited to the experiences of parents of children with ADHD.

Study (ref id)	**Brinkman 2012[15]**
Aim	To investigate how adolescents with ADHD contribute to medication treatment decisions
Population	44 adolescents with ADHD between 13-18 years. (aged 13-18 years)
Setting	USA
Study design and methodology	7 focus groups with a mean duration of 1.5 hours were led by an experienced focus group facilitator. Prompting questions we developed by all investigators and informed by the literature. Inductive coding of transcripts was used, followed by focused coding
Themes with findings	"Driving skills •Many participants were unaware of the increased risk for automobile accidents with ADHD, and the impact of medication on this"

Study (ref id)	**Brinkman 2012[15]**
	"Medication side effects •Participants noted side effects as a major reason for discontinuing medication" "Impact of medication •Participants noted the range of medication impacts on schoolwork, personality, relationships but this varied among participants. Participants displayed a range of personal opinions around the psychosocial impacts of medication" "Involvement in decision making •Some participants felt their involvement in decisions was inadequate, whereas others felt they were listened to and had control"
Limitations	Moderate limitations related to the role of the researcher and the context of the study
Applicability of evidence	Partially; conducted in the USA and limited to the experiences of young people with ADHD

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 and methodology	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 with findings	"Decision on medication •An important aspect of this decision making was the willingness of the child to take medication. Some children actively fought to not take medication"
	"Stigma •Parents reported that most people they know did not understand ADHD and most thought it was down to poor parenting." "Conflict with teachers •Parents reported negative interactions with teachers when parents were confronted by their child's poor behaviour." "Lack of support •Many parents felt consultations with HCPs were brief and that decisions to medicate their child were too hasty. They reported needing time to take in the information they had been given" "Negative impact of medication •Parents felt that they had failed by needing to medicate their child"

Study (ref id)	Charach 2006[27]
	"Fears about medication •Many parents had fears about the safety of medication, and had heard 'horror stories' from other people." "Conflict in families •Parents reported conflict with other family members who had strong opinions about how they should manage their child, which often conflicted with advice from HCPs" "Decision on medication •Parents viewed this as a decision of balancing costs against the benefits of medication." "Decision on medication •Parents withdrew medication when the side effects were worse than the benefit of treatment"
Limitations	Minor limitations related to the richness of the data
Applicability of evidence	Partial applicability due to being conducted outside of the UK and applicable to the experiences of mothers

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 and methodology	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 with findings	"Decision on medication •An important aspect of this decision making was the willingness of the child to take medication. Some children actively fought to not take medication"
	"Stigma •Parents reported that most people they know did not understand ADHD and most thought it was down to poor parenting." "Conflict with teachers •Parents reported negative interactions with teachers when parents were confronted by their child's poor behaviour." "Lack of support

Study (ref id)	**Charach 2006**[27]
	•Many parents felt consultations with HCPs were brief and that decisions to medicate their child were too hasty. They reported needing time to take in the information they had been given" "Negative impact of medication •Parents felt that they had failed by needing to medicate their child" "Fears about medication •Many parents had fears about the safety of medication, and had heard 'horror stories' from other people." "Conflict in families •Parents reported conflict with other family members who had strong opinions about how they should manage their child, which often conflicted with advice from HCPs" "Decision on medication •Parents viewed this as a decision of balancing costs against the benefits of medication." "Decision on medication •Parents withdrew medication when the side effects were worse than the benefit of treatment"
Limitations	Minor limitations related to the richness of the data
Applicability of evidence	Partial applicability due to being conducted outside of the UK and applicable to the experiences of mothers

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 and methodology	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 with findings	"Decision on medication •An important aspect of this decision making was the willingness of the child to take medication. Some children actively fought to not take medication"
	"Stigma

Study (ref id)	**Charach 2006[27]**
	•Parents reported that most people they know did not understand ADHD and most thought it was down to poor parenting." "Conflict with teachers •Parents reported negative interactions with teachers when parents were confronted by their child's poor behaviour." "Lack of support •Many parents felt consultations with HCPs were brief and that decisions to medicate their child were too hasty. They reported needing time to take in the information they had been given" "Negative impact of medication •Parents felt that they had failed by needing to medicate their child" "Fears about medication •Many parents had fears about the safety of medication, and had heard 'horror stories' from other people." "Conflict in families •Parents reported conflict with other family members who had strong opinions about how they should manage their child, which often conflicted with advice from HCPs" "Decision on medication •Parents viewed this as a decision of balancing costs against the benefits of medication." "Decision on medication •Parents withdrew medication when the side effects were worse than the benefit of treatment"
Limitations	Minor limitations related to the richness of the data
Applicability of evidence	Partial applicability due to being conducted outside of the UK and applicable to the experiences of mothers

Study	**Cooper 1998[35]**
Aim	Explore students' experiences with their ADHD
Population	16 young people attending a school for students with learning and behavioural conditions. (aged 11-16 years)
Setting	UK
Study design and methodology	Interviews conducted with an emphasis on the interviewee's individual manner of recalling and construing issues and events of concern. The interviewer acted by gently guiding the focus of the interview, through the use of a loose interview structure. All participants were interviewed twice within a period of several days. Each interview lasted for 30 to 45 minutes
	Harm of diagnosis

Study	**Cooper 1998**[35]
	•Children had either neutral or negative opinions of their diagnosis. Many felt it had a stigmatising effect both inside and outside of school.
	Benefit of medication •Children reported being able to concentrate more in school and experiencing higher academic success.
	Lost sense of self •Many children felt that they weren't themselves on their medication
Limitations	Minor limitations
Applicability of evidence	Partial applicability

Study	**Cormier 2012**[37]
Aim	To understand how parents decide to medicate their child and explore factors of adherence
Population	13 parents of children with ADHD (aged 6 to 12 years)
Setting	USA
Study design and methodology	Semi-structured interviewed lasted for approximately 60 to 90 minutes, conducted by the principle investigator and a research assistant experienced in qualitative research. An interview guide was used, with broad and open ended questions. Questions became more focused as the interview process progressed. Data were analysed using grounded theory. Transcripts were first analysed in an iterative process that involved 3 levels of coding; line by line coding of concepts, comparison of 1st level codes and identifying links between categories in order to form themes
	Decision on medication •Investigators found that parents chose to medicate their child when this was seen as the option that would help the most. Parents in this situation reported high levels of distress and exhaustion prior to deciding this
	Delay in treatment •Parents reported resisting medicating their child due to uncertainty about their effects, negative stigma, feeling blamed, and concerns about side effects.
	Delay in treatment •Some parents delayed treating their child's ADHD in the hope that they would grow out of it
	Trying different treatments •Parents reported wanting to try every option before medicating their child
	Gaining advice and support •Many parents felt dissatisfied and frustrated with the lack of support and guidance they received.

Study	**Cormier 2012[37]**
	Decision on medication •When parents decided to medicate their child, they felt their impairments exceeded what they could manage, with or without alternative treatments
	Harm of medication •Parents reported a range of side effects that were difficult to manage, such as appetite reduction and sleep disturbances. They felt the benefits of the medication greatly outweighed this
	Harm of medication •Parents raised concerns about the long term impact of medicating their child, and this was constantly weighed up against the benefits
Limitations	Moderate limitations related to data richness and the findings
Applicability of evidence	Partial applicability

Study	**Davis-Berman 2012[40]**
Aim	To examine treatment making decisions of parents with a child with ADHD
Population	28 families with a child with ADHD (aged 6 to 15 years)
Setting	USA
Study design and methodology	Interviews lasted from 1.5 to 2 hours. Codes were identified throughout the transcripts which formed the themes of the study (type of analysis not stated)
Themes with findings	Decision making •Most parents wanted decision making to be shared between them and the consultant HCP
	Factors relating to attitudes to treatment •Parents' attitudes to treatment were impacted by the attitudes of those in their social network
	Distress for parents •Parents reported symptoms of stress and worry as a result of their child’s behaviour, leading to emotional/mental health problems
	Harm of medication •Many presents reported harm from medication that was a concern for them, such as appetite changes and sleep problems
	Treatment goals •families wanted interventions that didn't just address core ADHD symptoms, but the issues that extended beyond this.
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Applicability of	Partial applicability

Study	**Davis-Berman 2012[40]**
evidence	

Study	**dosReis 2010[43] (dosReis 2007[44])**
Aim	To explore parents' reasons for seeking treatment for their child
Population	26 African-American parents of children with ADHD (aged 6 to 18 years)
Setting	USA
Study design and methodology	Semi-structured interviews were conducted and lasted between 30 to 60 minutes. Data were analysed using grounded theory methods. Initially transcripts were coded line by line, to categorize the text by themes. This was an iterative process that used the constant comparative method. As more data were coded, the dimensional properties of each theme emerged.
Themes with findings	Seeking treatment •African-American parents identified their children’s behaviour as out of context for what was expected of peers their age, which caused them to seek treatment for their behaviour
Limitations	Minor limitations related to the richness of the data
Applicability of evidence	Partial applicability

Study	**DosReis 2008[45]**
Aim	To explore experiences of taking medication for ADHD
Population	20 college students with ADHD (aged Not specified)
Setting	USA
Study design and methodology	Interviews lasted approximately 1 hour. Topic guide was used. Themes were identified from transcripts by each investigator independently. The themes chosen for analysis were derived inductively through a grounded theory approach, and analytic categories were identified as they arose
Themes with findings	Stigma •Participants did not feel stigmatised as a result of taking stimulants. Stigma •Some participants felt embarrassed to take medication throughout the day Harm of medication •Participants reported a range of side effects and had tried numerous different treatments and dosages to find the best balance of benefit to side effects.

Study	**DosReis 2008[45]**
	Change of self •Participants reported that they did not feel like themselves on their medication Drug abuse •Some participants reported that they, or others that they knew, had been approached by people wanting to take their medication
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Applicability of evidence	Partial applicability

Study	**Einarsdottir 2008[47]**
Aim	Explore early childhood teachers' experiences and perspectives of children with ADHD
Population	8 playschool teachers and 8 first grade teachers with 7-30 years of teaching experience.
Setting	Iceland
Study design and methodology	Phenomenology methodology was used to analyse data. Interviews lasting from 40 to 90 minutes. Questions asked are described in methodology but unclear if this was an interview schedule
Themes with findings	Transition to school •Teachers felt that the transition from playschool to primary school could be difficult for children with ADHD, due to the size of classes and less personal relationships with teachers and families Benefit of diagnosis •Teachers emphasised that a diagnosis helped them to support children with behavioural problems. Harm of medication •Teachers found that children taking medication became 'dull' and 'numb'
Limitations	Moderate limitations related to data richness, the role of the researcher
Applicability of evidence	Partial applicability

Study	**Fiks 2010**[52]
Aim	Compare how parents and clinicians understand shared decision making
Population	60 parents of children with ADHD and 30 clinicians (aged 6 to 12 years)
Setting	USA
Methods and analysis	Semi-structured interview were carried out using an interview guide developed from exploring the literature. A grounded theory approach was used to code the interviews inductively, without using an a priori set of codes. The process was iterative which allowed the regular reviewing of codes.
Limitations	Minor limitations related to the richness of the data
Themes	Information on treatment options •Parents emphasised the important of HCPs giving them full details of all available treatment options. They reported acting negatively to doctors who "pushed" medication.
	Decision on medication •Parents reported wanting to participate in decision making relating to treatment, but they wanted the HCP to make the final decision "for" them.
	Decision on medication •Clinicians felt that shared decision making was a way to get parents to accept the clinicians' preferred treatment option

Study	**Gallichan 2008**[58]
Aim	Explore young peoples' perspectives of ADHD
Population	12 young people with ADHD (aged 10 to 17 years)
Setting	UK
Methods and analysis	One on one open-ended interview ranged from 25 minutes to 1 hour and 15 minutes. Grounded theory was used to analyse the data.
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Avoiding medication •Children reported attempting to not take their medication and hide this from parents. However, older adolescents reported understanding why they needed to take their medication as they got older
	Negative sense of self •Children with ADHD felt unworthy and 'bad'
	Benefit of medication

Study	**Gallichan 2008[58]**
	•Children reported a benefit of medication, stating that they calmed them down and allowed them to take exams
	Sense of self •Children reported not feeling like themselves on their medication
	Support from schools •Children reported finding smaller classes in learning support units beneficial

Study	**Ghosh 2016[63]**
Aim	To explore parent experiences with ADHD
Population	8 parents of children with ADHD. 4 had ADHD themselves and 1 had no children with ADHD (aged 3-23 years)
Setting	Australia
Methods and analysis	Semi-structured face-to-face interviews conducted with key questions to guide the interview sessions. Each interview lasted approximately for 1 hour. Thematic analysis used to analyse data.
Limitations	N/A
Themes	Positives of ADHD •Parents felt their children were fun, had a lot of energy and high cognitive abilities
	Negatives of ADHD •Parents felt children with ADHD were very challenging and this impacted on the school and social lives.
	Benefit of diagnosis •Participants felt a diagnosis allowed a sense of relief that the condition was not 'their fault and that they were not bad parents', and a relief that help was available.
	Benefit of medication •Improved academic outcomes, focus, improved relationships with teachers, and improved quality of life were emphasised. Medication was felt to be an important part of ADHD treatment, but not the only part
	Cue to action •Parents reported hesitance in agreeing to stimulant medication due to health concerns, debates in the media about over diagnosis and treatment of ADHD, and feeling strange about medicating their children. However parents felt it was their responsibility to improve their children's ability to fit into society.
	Cue to action •Some parents reported not diagnosing their other children, in whom they noticed ADHD symptoms, because it was not affecting their education or social lives.

Study	**Hallerod 2015[71]**
Aim	Explore patients' experiences of being diagnosed with ADHD
Population	21 adults with ADHD (aged 18+)
Setting	Sweden
Methods and analysis	Open ended exploratory interviews, analysed with a qualitative phenomenographical approach
Limitations	Minor limitations related to the richness of the data
Themes	Benefit of diagnosis •Patients felt their diagnosis gave an explanation of the difficulties they had previously faced throughout their life, and felt more highly valued due to legitimizing their difficulties. They found that this lead to people not thinking of them as badly
	Doubt of diagnosis •Patients had varying degrees of doubt around their ADHD diagnosis. Some questioned the existence of ADHD; some questioned whether they had it and reported loved ones being sceptical.
	Benefit of diagnosis •Patients felt they gained a better understanding of themselves following the diagnosis
	Harm of diagnosis •Patients disliked feeling different to the general population and being vulnerable to stigma, and feeling like they don't belong
	Cue to action •Patients' realised that their quality of life was being affected by their symptoms and so sought help
	Substance abuse •One patient reported pretending to be an alcoholic in order to receive help from healthcare professionals, prior to their ADHD diagnosis
	Benefit of diagnosis •Patients reported that their diagnosis allowed them to search for strategies to cope with their symptoms
	Lack of access to treatment •Participants reported receiving no treatment once they had been diagnosed with ADHD

Study	**Hansen 2006[70]**
Aim	Explore parents' experiences of medicating their child with ADHD
Population	10 parents of children with ADHD (aged 8 to 22 years)
Setting	Canada

Study	Hansen 2006[70]
Methods and analysis	Interviews lasted for 1.5 to 2 hours. An interview guide was developed drawing from many different sources and the existing literature. Analysis took a phenomological approach, using a method of reduction. Statements were selected and transferred into condensation tables and later categorised according to themes that developed in the data.
Limitations	Minor limitations related to the richness of the data
Themes	Balancing improvements and side effects •Parents focused mainly on behavioural and cognitive improvements (both at school and at home) versus biological side effects in determining how to medicate their child.
	Benefit of medication •Parents reported that their home life was greatly improved by their child's medication. They reported that this had reduced their own stress levels
	Harm of medication •Parents reported many side effects of medication, such as reduced appetite, difficulty sleeping and a 'zombie' effect on their child
	Balancing improvements and side effects •Parents found it difficult to decide whether or not to keep their children on medication. Academic goals, both present and future, were cited as justification for keeping their child on medication
	Balancing improvements and side effects •Some parents wanted to give a dosage that was high enough to ensure a good functional effect throughout the day, but at the same time not risk the adverse consequences of 'overmedicating' to satisfy teachers
	Decision on medication •Many parents were worried about the long term impact of taking medication
	Support for parents •Parents worried about the difficulties that lied ahead for their children, such as coping at university, managing money, and driving

Study	Harazni 2016[72]
Aim	Investigate the experiences of adults that interact with school aged children with ADHD
Population	4 mothers and 12 teachers (4 children with ADHD) (aged 7 to 10 years)
Setting	Palestine
Methods and analysis	Semi structured interviews using a guide with themes and underlying issues to discuss. This was used as a checklist to assure all themes were brought up. Each interview was between 45 and 60 minutes. Data was analysed using a phenomenological approach of reduction: a descriptive analysis requires bracketing as a first step, and presenting data as it presents itself.
Limitations	Minor limitations related to the role of the researcher

Study	**Harazni 2016**[72]
Themes	Burden for parent’s •Parents described facing many difficulties in tracking their child's academic success and helping with daily tasks. This often resulted in emotional distress caused by frustration and anger of the difficulties they face
	Inadequate support •Mothers felt that they did not have support from fathers of their children, and in some cases the fathers played a negative role in the management of child care
	Fathers understanding •Mothers felt that fathers in particular did not understand their child’s symptoms
	Lack of support from schools •Some mothers found that schools were unsympathetic in their attitudes; as a result teachers neglect their children.
	Lack of information for teachers •Teachers reported feeling unequipped to support children with ADHD, due to having no training or information provided about the condition
	Time restraints •Teachers reported having a lack of time to fully support children with ADHD

Study	**Hassink-Franke 2016**[75]
Aim	Explore GPs experiences of children with ADHD
Population	15 GPs treating children with ADHD (aged Not specified)
Setting	Netherlands
Methods and analysis	GP interviews lasted for approximately 30 minutes, conducted via telephone. An interview guide was used and analysis was conducted as an iterative process; relevant topics were added to the guidebook after a preliminary analysis of each interview. The principles of constant comparative analysis were used, whereby transcripts are coded thematically and reread to identify the themes.
Limitations	Minor limitations related to the richness of the data
Themes	Lack of training •GPs did not feel competent in diagnosing ADHD, due to a lack of knowledge and experience, and having too little time
	Attitudes towards medication •GPs felt resistant to prescribing stimulants for children with ADHD
	Treatment management •GPs understood their role in treatment management for children with ADHD
	GP training

Study	**Hassink-Franke 2016[75]**
	•GPs felt more confident in managing patients with ADHD after taking part in an online training course

Study	**Henry [78] (#2011)**
Aim	To explore the experiences of older woman with ADHD
Population	9 woman over the age of 62 diagnosed with ADHD after the age of 60
Setting	USA
Methods and analysis	Interviews, data analysed using non-specified coding techniques
Limitations	Minor
Themes	Older woman reported the benefit of talking to others in similar situations

Study	**Hughes 2009[85]**
Aim	How to support children with ADHD in their learning environment
Population	
Setting	UK
Methods and analysis	Semi structured interviews conducted. Adults were interviewed on 3 occasions and children on average 6 times over a period of 4 months. Each interview lasted approximately 60 minutes. Analysis type not stated
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Consistency of support in school •Teachers felt that using supply teachers had a negative impact on children with ADHD and caused them to behave more disruptively. This was improved by consistently using the same supply teacher when necessary
	Type of teacher •Children with ADHD reported that they preferred teachers that were strict and could control the class

Study	**Hughes 2007[84]**
Aim	Explore experiences of clinicians, children, parents and teachers involved in ADHD
Population	9 clinicians, 14 children with ADHD and their parents and teachers. (aged 7 TO 12 YEARS)
Setting	UK
Methods and analysis	Cognitive interview techniques were used to unveil information with children. No further details
Limitations	Severe limitations related to data richness, the role of the researcher and the context of the study
Themes	Conflicting perspectives •Teachers and parents had different perspectives of the cause of children's' symptoms, which could have a negative impact on the child
	Balance of improvement vs. side effects •Some parents felt that the medication improved their child's behaviour, but they were worried about the long term implications of side effects

Study	**Ibrahim 2016[86]**
Aim	Examine the experiences of drug holidays from caregivers and healthcare professionals
Population	8 GPs, 8 consultancies, 5 teachers and 5 mothers (aged children and adolescents)
Setting	UK
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.
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Medication out of school hours •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
	Adolescent decision making •Adolescents want to stop their medication to feel like themselves and because they don't feel like the medication is helping
	Benefit of medication •Teachers, parents and HCPs reported the benefit of medication on core symptoms, improving behaviour at home and at school
	Difficulties with appetite •Parents reported difficulties in getting their child to eat, with only a small window of time once he's taken his medication
	Loss of identity

Study	**Ibrahim 2016**[86]
	•Teachers reported that medication dampened the personality of children
	GP doubts •GPs felt that they shouldn't have to prescribe ADHD medication, were wary of doing so, and unsure of when they should cease treatment
	Drug holidays •Drug holidays were viewed by teachers as being useful in managing psychological and physiological side effects of medication. HCPs felt this particularly important in children with appetite problems

Study	**Jackson 2008**[88]
Aim	Explore maternal views and experiences of medication in children with ADHD
Population	11 mothers of children diagnosed with ADHD (aged 7 to 18 years)
Setting	Australia
Methods and analysis	Interviews were 'conventionally' styled and lasting between one to two hours. Interviews were analysed thematically
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Worrying about medication •Parents worried about the long term impact of taking medication
	Decisions on medication •Parents reported that the decision to medicate their child was made more difficult due to pressure and judgement from family members and social circles. On the other hand some reported pressure from HCPs and teachers to medicate their children
	Decisions on medication •Parents reported that they wanted to try all other options before medicating their child
	Decisions on medication •Some mothers were sceptical about ADHD as a diagnosis, which delayed them trying medication
	Decisions on medication •Some parents decided not to medicate their child because of side effects and concerns that the medication was changing their 'whole personality'
	Decisions on medication •Parents reported the decision was made easier when loved ones were supportive

Study	**Jones 2014**[89]

Study	**Jones 2014[89]**
Aim	To develop an understanding of the meaning and consequences of an ADHD diagnosis for young people
Population	9 young people between 15 and 21 with a diagnosis of ADHD. Substance abuse was an exclusion criterion. (Aged 5 to 18 years)
Setting	Denmark
Methods and analysis	Semi-structured interviews with pre-defined areas of interest, carried out by single interviewer at a hospital. Deductive, directed content analysis was used to extract themes under the defined areas of interest.
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Benefits of diagnosis •Participants felt that the diagnosis of ADHD gave them an explanation for their feelings of being "abnormal" which came as a relief for some
	Harm of diagnosis •Participants felt that the diagnosis of ADHD gave them an explanation for their feelings of being "abnormal" which for some felt like it cemented the fact that they were abnormal

Study	**Kendall 2003[92]**
Aim	Explores children's' perspectives on the authenticity of ADHD
Population	39 children and adolescents with ADHD (aged 6 to 17 years (mean 11.2))
Setting	USA
Methods and analysis	Semi structured interviews carried out by 2 researchers with expertise in mental health services. Interviews explore experiences of ADHD within their everyday lives. Interviews lasted from 15 to 45 minutes. Constant comparative analysis used to generate conceptual categories and their properties from the data. This began with open coding
Limitations	#N/A
Themes	Stigma of diagnosis •Participants reported being blamed and accused of things they had not done.
	Emotional aspects of ADHD •Many participants reported feeling sad, mad, frustrated and ashamed, mainly of their learning and behavioural problems, and of others negative reactions to them.
	Negative implications of drug treatment •Participants reported being made fun of when they had to leave classes to take medication
	Identity •Many participants spoke about ADHD as if it defined them, rather than talking about the symptoms they experienced.

Study	Kendall 2003[92]
	Understanding of medication •Children understood that the medication was a way of helping them with the problems they were having
	Benefit of medication •Participants felt it helped them to behave and concentrate at school when they would usually not be able to concentrate
	Negative implications of drug treatment •Participants displayed fear associated with taking pills to control their behaviour; they felt that the medication changed them negatively, in terms of being uninterested in fun activities and feeling 'depressed'.

Study	Knipp 2006[98]
Aim	To explore adolescent perceptions of ADHD and medications
Population	15 adolescents with ADHD (aged 14 to 17 years)
Setting	USA
Methods and analysis	Semi structured interviews were conducted and analysed using content analysis. No further details
Limitations	Moderate limitations related to data richness, the role of the researcher and the context of the study
Themes	Negative experiences with medication •Adolescents reported many negative memories associated with taking medication. They found it a hassle, disliked the side effects and disliked having a lack of social skills. However, they reported that they eventually found a medication that suited them best
	Benefit of medication •Participants reported improved academic achievement after taking medication

Study	Klasen 2000[97]
Aim	To investigate parents' and GPs' views on hyperactivity
Population	10 GPs and 29 parents of hyperactive children (aged)
Setting	UK
Methods and analysis	Semi-structured interviews of 1-2 hours. Interviews were analysed by content analysis using grounded hermeneutic procedures.
Limitations	Severe limitations related to richness of data, context of the study and methodology
Themes	Understanding of ADHD

Study	**Klasen 2000[97]**
	•Parents felt it was a biological and not a psychological condition
	Difficulties gaining support •Parents reported GPs not believing their children had hyperactivity problems
	GPs lack of understanding •GPs reported not knowing the difference between 'normal' and abnormal behaviour, due to some parents not minding that their children were hyperactive, and others seeking help for the symptoms
	Benefit of diagnosis •Parents felt that a diagnosis improved the parent-child relationship due to realising their child needed help and support
	GPs views of diagnosis •GPs reported feeling that a diagnosis did more harm than good with ADHD. They reported seeing ADHD as an artificial, ill-defined and overused category. GPs felt that parents seeking support were attempting to avoid dealing with possible shortcomings of their parenting
	Cause of ADHD •GPs emphasised the view that family dysfunction could lead to problem behaviour or to a 'dysfunctional' family seeking help for their chid
	Parent support •Parents reported feeling exhausted and isolated due to their children's' behaviour and the negative reactions loved ones had towards them
	GP training •GPs felt they did not have adequate training in the treatment and assessment of hyperactivity
	GP training •GPs were unaware of where they could refer patients to

Study	**Larson [106] 2011**
Aim	Examine how prior experiences of caregivers of children with ADHD leading up to treatment related to later service use
Population	Caregivers of children with ADHD
Setting	USA
Methods and analysis	Semi structured interviews ranged from 30 minutes to over an hour and were conducted by one author and trained research assistants. Interviewers followed a field guide containing questions about parent's experiences. Data were analysed using grounded theory analysis. The research team discussed theoretical dimensions of each theme through a consensus process, and developed a coding manual that defined each thematic code. This was used to analysis the remaining interviews, and any new codes that emerged were added on the basis of consensus.

Study	**Larson [106] 2011**
Limitations	Minor limitations
Themes	Parents reported being extremely distressed as a result of their child's behaviour. Parents reported seeing other children go through the side effects of medication, which put them off medicating their child

Study	**Lee 2008[109]**
Aim	Explore teachers' experiences and perspectives of children with ADHD
Population	10 teachers of pre-Kindergarten through to 3rd grade classrooms. (Aged preschool - 3rd grade)
Setting	USA
Methods and analysis	Interviews were conducted by a graduate assistant and took about 1 hour. Data was analysed by searching for emergent themes and patterns from the interview data. The author looked for culturally learned and taken-for-granted assumptions that the teacher made about children with ADHD.
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Inattentive symptoms •Teachers felt that inattentive behaviour is as problematic as hyperactive behaviour but difficult to pinpoint.
	Teachers understanding •Some teachers were not aware of inattentive types of ADHD, which could impact the support this subgroup receive during school time
	Teachers understanding •Teachers understanding of race/ethnicity, age, gender and socio-economic status varied among teachers
	Teacher-parent relationship •Some teachers found it difficult to confront parents about behavioural issues of their children, and found they often had conflicted opinions on the behaviour
	Benefit of medication •Teachers found that medication calmed children down, helped them to manager their anger and behaviour, allowed them to focus, decreased disruptive behaviour, helped them to get work done, and enabled children to fulfil their potential.
	Harm of medication •Teachers reported students that lost their appetite and felt lethargic due to their medication
	Benefit of medication for teachers •Some teachers felt that medication was helpful in making their job easier, however others felt it was wrong to want to medicate children just to make teachers' jobs easier

Study	**Lefler 2016[110]**
Aim	To explore the experiences of college students living with ADHD
Population	36 college students with ADHD (aged >18 years)
Setting	USA
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. Either a clinical psychologist or a student training to be a clinical psychologist facilitated focus groups. Idiographic inductive analysis was used.
Limitations	N/A
Themes	Benefit of diagnosis •Students felt a diagnosis helped them to achieve a good education, and allowed them to cope with their symptoms
	Harm of diagnosis •Students reported that the label caused limitations for them, due to the stigma it encompasses
	Impact of ADHD on decisions •Student reported that their symptoms impacted the path that their life has taken, and they have made decisions based on the best environments and activities for their symptoms
	Impact of ADHD on academic achievement •Students reported struggling with organisation, juggling multiple tasks and difficulty in making decisions. They also found reading comprehension difficult, reported motivational problems and found they get easily distracted
	Stigma of seeking help •Students did not feel they could easily discuss accommodations with professors, and felt ashamed when fellow class mates noted these accommodations, such as taking tests in a disability centre
	Benefits and harm of medication •Many students reported that their medication had benefited them greatly, although they did not like taking it and did not like how it made them feel
	Medication changes •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

Study	**Leggett 2011[111]**
Aim	To gain insight into the treatment experiences of children with ADHD
Population	33 parents of children with ADHD (aged 6 to 17 years)

Study	**Leggett 2011[111]**
Setting	Australia
Methods and analysis	Interviews were conducted and coded data was categorised into themes. No further details
Limitations	Moderate limitations related to data richness, the role of the researcher and the context of the study
Themes	Harm of medication •Parents reported negative side effects of their children’s' medication, but most did not cease treatment
	Harm of medication •Parents reported that their children were too passive and 'vegetative'

Study	**Leslie 2007[112]**
Aim	Investigate contextual mechanisms that may explain differences in medication use among youths with ADHD
Population	28 families with a child with ADHD (aged 6 to 15 years)
Setting	USA
Methods and analysis	Semi structured interviews were conducted. Open-ended questions were used. Interviews lasted between 1.5 to 2 hours. Data were analysed using grounded theory. An initial coding schema was developed based on a priori hypotheses. Interviews were coded through a process of on-going comparisons, in an iterative fashion. Categories were further and further condensed into broad themes.
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Decisions on medication •Parents reported that extended social networks had a role in either encouraging or discouraging medication treatment.
	Methods of information giving •Some parents felt that being able to speak to other parents in similar situations would be helpful, especially when it came to deciding whether or not to medicate their child

Study	**Loe 2008[119]**
Aim	To understand how college students construct and manage identity in the context of pharmaceutical use
Population	16 college students with ADHD (aged 18+)
Setting	USA
Methods and analysis	Interviews lasted from 30 to 90 minutes. Transcripts were analysed by coding and identifying themes (analysis type not specified).

Study	**Loe 2008[119]**
Limitations	Minor limitations
Themes	Seeking treatment •Authors felt that participants were seeking treatment due to an inability to meet the demands of social environments
	Harm of medication •Many students reported a loss of their sense of identity due to taking medication

Study	**Matheson 2013[124]**
Aim	Explore adults experiences with ADHD
Population	15 adults diagnosed with ADHD in childhood, and 15 diagnosed in adulthood (aged >18 years)
Setting	UK
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
Limitations	Minor limitations relating to the richness of data
Themes	Accessing services •Getting diagnosis and accessing care was a long and frustrating process for many. Patients perceived this to be due to the negative and sceptical attitudes towards ADHD.
	Accessing services •The stress of accessing services caused feelings of disempowerment and helplessness, which in some led to reduced functioning.
	Cue to action •Some participants with negative experiences within the healthcare system considered stopping their attempts at accessing services, due to the stress it caused
	Lack of support •lack of support from healthcare professionals resulted in feelings of abandonment in those that desired support, especially in adjusting medication doses. Patients reported not telling GPs about adverse events for fear they would halt their medication
	Treatment choices •Some participants wanted a more active role in choice of treatment and a choice to try a larger range of medication
	ADHD specialist care •Patients accessing specialist care felt more supported by healthcare professionals
	Treatment choices •Patients felt they needed more information on the short term and long term effects of medication, and felt some healthcare professionals were reluctant to discuss risks of treatment

Study	**Matheson 2013**[124]
	Adjusting doses •Patients reported wanting more support in adjusting dosages to the optimal amount, feeling that some healthcare professionals were unwilling to help with this
	Missed diagnosis •Patients diagnosed in adulthood felt that an earlier diagnosis would have positively impacted their psychosocial wellbeing and stopped the accumulated sense of failure due to job, education and relationship problems.
	Missed diagnosis •Patients reported that the emotional impact of living with undiagnosed ADHD had led some to psychological breakdown and suicidal ideation.
	Impact of ADHD •Both for patients diagnosed in childhood and adulthood, ADHD was reported to have a huge impact on their day to day lives
	Impact of ADHD •Participants reported difficulties in finding suitable work roles, with some being unemployed due to this
	Benefit of medication •Participants reported medication improving their day to day lives and ability to concentrate
	Negative medication beliefs •Participants reported difficulty with side effects and often withdrawal effects when medication wore off.
	Negative medication beliefs •Participants perceived a lack of long term effective of drug treatment
	Beliefs about medication •Participants felt that medication helped but was not the 'full picture' and that other aspects of the condition required other treatment and support
	Psychosocial support •Participants felt that non-pharmacological interventions were useful in helping patients to learn coping strategies and deal with the psychosocial burden. The social element of group therapy was also highly valued

Study	**Meaux 2006**[132]
Aim	To gain insight about medication use among adolescents with ADHD
Population	15 college students with ADHD (aged 18+)
Setting	USA
Methods and	Semi structured interviews were conducted by the principal investigator. Initial interviews lasted from 1 to 1.5 hours and follow up

Study	**Meaux 2006**[132]
analysis	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
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Treatment cessation •Many participants reported deciding to halt their medication without consulting HCPs
	Stigma •Students reported that having to take medication throughout the school day involved feelings of sadness, frustration, anger and embarrassment due to the stigma it evoked
	Harm of medication •Participants felt that taking Ritalin made them much less sociable and less likely to interact with others
	Harm of medication •Participants reported a range of side effects such as reduced appetite, inability to sleep, emotional problems and feeling 'drugged' or 'zoned out'.
	Benefit of medication •All participants felt their medication improved their ability to function academically
	Support from healthcare professionals •Students reported no involvement of HCPs in decisions around starting, stopping and changing medication.
	Forgetting to take medication •Students reported they often forgot to take their medication
	Drug holidays •Students reported that they not only take their medication when they need to, which generally was just when they had a large workload.

Study	**Meaux 2009**[131]
Aim	Explore college students experiences of ADHD
Population	15 college students with ADHD (aged 18 to 21 years)
Setting	USA
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.
Limitations	Moderate limitations related to data richness, the role of the researcher and the context of the study
Themes	Hiding the diagnosis

Study	**Meaux 2009**[131]
	•College students reported not wanting others to find out about their diagnosis to avoid being labelled as different
	Parents lack of understanding •Participants reported that their parents' lack of understanding or knowledge of ADHD made life more difficult and left them feeling frustrated.
	The internet as a resource •Participants reported learning about their condition by accessing information on internet sites
	ADHD symptoms •People reported that symptoms impacted their academic achievement at college.
	Difficulty driving •Participants felt that their driving skills were impacted by being easily distracted, and that they were not as careful as they should be
	Alcohol abuse •College students reported that their addictive personalities resulted in alcohol abuse, with some having received violations from the college.
	Benefit of medication •Participants felt that stimulants improved their academic success, ability to focus during school and other activities, including during sport and when driving.
	Self-autonomy •Participants reported feeling in control of their ADHD and not needing additional help from family members or healthcare professionals, whereas some required support from teaching staff and friends in order to stay on track
	Adherence to medication •Most participants were not taking their medication on a regular basis, as they didn't like how the side effects made them feel.

Study	**Mills 2011**[134]
Aim	To understand how parents decide to medicate their child
Population	19 families (representing 30 children with ADHD) (aged Not specified)
Setting	USA
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
Limitations	Minor
Themes	Reasons for delay in medicating

Study	**Mills 2011**[134]
	•Many parents reported being hesitant to use medication due to the representation this medication had in the media
	Decision on medication •Seeing their children suffer and having exhausted all other options were the motivating factors to attempt medication trials.
	Benefit of medication •Parents reported the main benefit of medication as academic success, as well as social acceptance and overall emotional stability.
	Family stress •Parents reported being emotionally and physically exhausted due to demands from their child
	Benefit of diagnosis •Parents reported a great sense of 'relief' at having an explanation for their child’s behaviour
	Stigma •Parents reported a great deal of stigma and judgement from those in their social circles
	Decision on medication •The decision to keep a child on their medication was related mainly to the effectiveness of the treatment.

Study	**Moen 2011**[135]
Aim	Gain an understanding of the lived experience of having a child with ADHD
Population	9 parents (5 mothers and 4 fathers) from 7 families participated (aged 8 to 14 years)
Setting	Norway
Methods and analysis	Initial interview question about parent experiences was followed by follow up questions. Interviews lasted approximately 1 hour to 90 minutes. Data were analysed using Colaizzi's (1978) method. Analytical steps were followed as closely as possible; clusters of themes were labelled into themes and main themes.
Limitations	Moderate limitations related to data richness, the role of the researcher and the data analysis
Themes	Delayed diagnosis •Parents reported that HCPs acted like the child's behaviour was normal, thus delaying receiving a diagnosis
	Emotional impact on parents •Parents reported distress involved in receiving a diagnosis of ADHD
	Benefit of diagnosis •Parents reported a seen of relief from receiving a diagnosis with biological explanations for their child’s behaviour
	Views of others •Parents reported that having a social network of support was important, but some found that those close to them didn't understand their situation, and were sometimes intolerant. This caused distress for parents

Study	**Moen 2011**[135]
	Help from professional's •Parents reported that health and education professionals were often unhelpful and unwilling to take any responsibility in order to support their child.
	Help from professionals •Parents reported that professionals did not give support and advice specific to their unique situation, and often found them patronizing
	Balance of improvement vs. side effects •Parents felt frustrated that they had to interpret the efficacy, and difficulty with side effects, of medication without support of healthcare professionals. They worried about the impact of side effects

Study	**O'Callaghan 2014**[142]
Aim	To explore the context that influences stimulant medication adherence
Population	18 adults with ADHD (aged >18 years)
Setting	USA
Methods and analysis	Semi structured telephone interviews lasted an average of 45 minutes. Notes were manually recorded and transcriptions analysed using thematic analysis.
Limitations	N/A
Themes	Barriers to stimulant medication •Participants reported many barriers in their experiences with stimulant medication, including: side effects, psychological side effects and lack of effectiveness. Other barriers mentioned included cost of drugs, fear of cardiac side effects
	Harm of medication •Participants reported not feeling themselves on the medication
	Harm of medication •Participants reported weight loss as a problem with the medication, although they felt this was something they could control if mindful.
	Benefit of medication •Participants reported an increase in positive behaviours and decrease in negative behaviours associated with ADHD
	Difficulties of lack of diagnosis •Participants reported struggling with their day to day lives particularly within work and education settings, with some reporting losing their job or getting into trouble for reasons relating to ADHD symptoms
	Cue to action •Participants reported that positive/negative interactions with doctors influenced whether or not they started stimulant medication. Those with good relationships with their doctors felt more in control and less frustrated

Study	**O'Callaghan 2014[142]**
	Stopping medication •Participants stopped medication when the costs outweighed the benefits of the treatment.
	Barriers to stimulant medication •Participants reported difficulty getting a prescription refilled due to suspicious questions asked by pharmacists
	Ability to adhere to treatment •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.

Study	**Olaniyan 2007[143]**
Aim	Explore perspectives of ADHD and behavioural problems among African American parents
Population	31 parents, only 3 had children with an ADHD diagnosis (aged Mean 9 (7.8) years)
Setting	USA
Methods and analysis	5 focus groups led by an experienced African American facilitator. Sessions began with the scenario of a child who is disruptive in school hypothetically. Pre-written open-ended questions were used to guide discussions around parents' perceptions of behavioural problems. Sessions lasted between 60 to 90 minutes. Analysed using thematic analysis
Limitations	Minor
Themes	Causes of behavioural problems •Many participants attributed behavioural problems to bad parenting, and that children looked to parents as role models.
	Views of ADHD as a diagnosis •Many participants felt ADHD was merely a label and not an illness, and was used to allow the medical treatment of children in order to get them to behave
	Views of medication •Many parents described feeling suspicious of medication, with emphasis on racial concerns and social control. Negative opinions of medication were prevalent across focus groups. Many felt that the black community in particular were wary of medication, due to issues around drug addiction.
	The role of teacher’s •Many felt that behavioural problems at school were a result of poor teaching methods and impatience with 'slow' children. Parents felt dissatisfied and insulted by teachers suggesting medication and doctor referrals.

Study	**Perry 2005[145]**

Study	**Perry 2005**[145]
Aim	To explore Latino families' experiences with ADHD
Population	26 Latino parents of children with ADHD (aged 6 to 19 years)
Setting	USA
Methods and analysis	Semi structured interviews were conducted by research assistants. An interview guide was used and interviews lasted from 60 to 90 minutes. Each family received 100 dollars for participation. Data were initially analysed using line-by-line open coding, followed by combining these into broader axial codes, and finally selective coding to capture the emerging themes.
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Emotional impact for parents •Parents reported a range of difficulties they experienced prior to their child receiving a diagnosis of ADHD
	Decision on medication •Parents often had initial concerns about medicating their children, but many found the consequences of not using them were worse
	Cultural difficulties •Parents felt that the Latino culture was less open to talking about family difficulties, which made the process of seeking help difficult
	Explaining the diagnosis to the child •Parents reported finding it difficult to find a way to explain ADHD to their child
	Information needs •Parents identified the need for more information about ADHD from health professionals and teachers, and felt that there was a need for professionals to have more information and training for themselves too.
	Support from healthcare professionals •Parents wanted healthcare professionals to listen to them more and offer more support. They felt that HCPs often made out that the parents were the expert in the management of their child, but often parents felt this were not the case

Study	**Salt 2005**[152]
Aim	To explore GPs' perceptions of the management of ADHD in primary care
Population	13 GPs (plus 93 completing a questionnaire) (aged Not specified)
Setting	UK
Methods and analysis	An interview topic guide was created to explore key issues identified from the literature. No details of analysis
Limitations	Minor limitations related to the richness of the data
Themes	GP training needs

Study	**Salt 2005**[152]
	•GPs did not feel that they had adequate training in the recognition of ADHD, and felt specialist involvement was crucial
	Understanding of side effects •Several GPs felt there were little side effects of stimulant medication, and some felt there were a few but couldn't remember what they were.

Study	**Segal 1998**[159]
Aim	To examine the adaptations of families with children that have ADHD
Population	
Setting	Canada
Methods and analysis	Interview guides were used to ask non-directive questions and encourage parents to talk. Themes in the data were derived through rigorous comparative analysis. Families were interviewed together, and interviews lasted for 1.5 to 5 hours.
Limitations	Moderate limitations related to the role of the researcher and the context of the study
Themes	Benefit of medication •Parents reported that their holds' academic success had improved from taking medication

Study	**Segal 2001**[158]
Aim	Explore mothers' experiences raising children with ADHD
Population	25 mothers of children with ADHD (aged not specified)
Setting	USA
Methods and analysis	Semi-structured interviews. 15 mothers were interviewed twice. Questions were modified depending on initial answers to the initial question 'what is your experience as a mother of a child with ADHD?' Transcripts were analysed using grounded theory.
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Difficulties with diagnosis •Older children with ADHD were harder to diagnose than younger children. Mothers reported not knowing what to do and what was wrong
	Benefit of diagnosis •Mothers were grateful to receive a diagnosis that could help relieve the difficulties their child was facing
	Difficulties for parent's •Mothers explained how hard it is to raise e a child with ADHD, some putting their career and/or educational opportunities on hold as

Study	**Segal 2001**[158]
	they committed themselves to their child.
	Role of parents •Parents reported having to constantly structure and monitor their child's daily routine
	Finding resources •Some parents were able to find out how to help their child, battle schools to get support and push for a diagnosis and treatment. However, others felt unable to do this, which resulted in delayed diagnosis and stress for the family
	Difficulties for parents •Parents reported feeling isolated and ignored by loved ones due to their child’s diagnosis
	Difficulties for parents •Parents reported difficulties in their marriage due to their child’s diagnosis

Study	**Sikirica 2014**[162]
Aim	To explore the unmet needs of adolescents with ADHD and their caregivers
Population	38 caregivers (of ages 6 to 17 years) and 28 adolescents (13 to 17 years) with ADHD took part (aged 6 to 17 years)
Setting	Mixed European countries
Methods and analysis	Experienced interviewers, who took part in a training seminar including mock interviews, conducted One to one telephone 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 adolescents lasted from 30 to 60 minutes. Thematic analysis was used to identify themes; an initial code system was developed which were organised into themes.
Limitations	Minor limitations related to the richness of the data
Themes	Difficulties of diagnosis •Most caregivers reported that it was difficult to get their child a diagnosis of ADHD, with lengthy waiting periods and visits to multiple doctors.
	Harm of diagnosis •Adolescents with ADHD expressed concerns about their diagnosis, such as embarrassment, shame and annoyance at having ADHD
	Impact of ADHD •ADHD symptoms had an impact on school performance despite children being on medication
	Concerns about treatment •Caregivers had a number of concerns about medication, such as side effects, the possibility of addiction, long-term impact.
	Concerns about treatment •Parents reported that their children’s treatment had worn off by the afternoon, which caused difficulties at home

Study	**Sikirica 2014[162]**
	Reasons for discontinuing •Participants reported the main reasons for discontinuing being due to side effects and decreased efficacy.
	Concerns about treatment •Some adolescents felt unhappy about taking their medication over a long period of time, didn't like being 'controlled by medications' or felt they were losing their 'self' to medication
	Impact for parent's •Parents reported having to reduce their working hours or stop entirely to care for their child. Most parents felt they had to provide constant supervision for their child.
	Impact for parent's •Parents reported feeling exhausted, helpless, guilty and both emotionally and physically drained. Many felt they needed additional support and assistance from their healthcare providers.
	Support for parents •Parents felt additional therapy would be helpful in managing everyday issues related to their child's ADHD. They also felt they needed more government support and financial assistance, and felt teachers and the general public needed educational support about ADHD
	Drug holiday's •Participants reported allowing their children to deviate from their treatment and take breaks from their medication.

Study	**Simons 2016[163]**
Aim	To explore attitudes towards a remote monitoring technology for ADHD
Population	59 participants (adults and young people with ADHD, parents of children with ADHD, and healthcare professionals) (aged Mixed)
Setting	UK
Methods and analysis	2 members of the research team facilitated each focus group. The facilitators were 'background figures' in the group that guided the process rather than leading it. A topic schedule was used. Thematic analysis was used to analyse the data. An initial coding frame was developed by 2 researchers, which allowed the constant comparison of data, which was eventually refined, framed and organised into themes.
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Difficulties for HCPs •HCPs reported that it was difficult to monitor titration weekly, due to time constraints and workload
	Difficulty in getting a diagnosis •Participants reported a frustrating and lengthy process in gaining a diagnosis, which caused severe emotional distress. They reported long waiting times, logistical issues, unpredictable communication and inconsistent doctors.

Study	**Singh 2003[164]**
Aim	Explore fathers' perspectives of ADHD symptoms, diagnosis and treatment
Population	22 fathers of children with ADHD (aged 7 TO 12 YEARS)
Setting	UK
Methods and analysis	Interviews conducted using the grounded theory approach. Open-ended formal interviews were conducted using pictures chosen by participants from a standardized set of magazines. This was used to allow interviewees to feel in control of the subject matter and enrich their verbal narratives. They were asked to leaf through magazines to collect pictures in response to a broad question on methylphenidate use. Interviews lasted between one and three hours.
Limitations	Minor limitations related to the richness of the data
Themes	Family support •Fathers were heavily involved in the diagnostic process and many were reluctant to believe the diagnosis.
	Attitudes towards medication •Fathers felt medication of their child caused stigma and isolation for them, and were unsure as to whether they needed it or not
	Emotional implications •Fathers felt embarrassed and disappointment when their son did not act likes other children their age, especially in terms of athletic ability.

Study	**Swift 2013[176]**
Aim	Patient experiences of ADHD, particularly around transitioning services
Population	10 young adults with ADHD (aged 17-18)
Setting	UK
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
Limitations	Minor limitations related to the richness of the data
Themes	Transition to adult services •Patients did not feel that their age should impact on the care they receiving, feeling that child services still provided the support they required
	Responsibility of care •Patients reported that their parents or other family members were often involved in support, helping with medication and clinic appointments, where some people with ADHD struggle

Study	**Taylor 2006[178]**
Aim	How to parents reach a decision to medicate their children or not
Population	33 parents of children with ADHD (aged 22 primary school, 11 teenagers)
Setting	Australia
Methods and analysis	Semi structured interviews with specific questions developed. Interviews lasted between 45 and 60 minutes. 8 interviews were face to face and the remaining 25 were conducted by telephone. Grounded theory was used for analysis, which involved constant comparisons of the data and deciphering the properties of each piece of data, which forms the basis of data categories. Note: participants were sent the interview questions 6 weeks prior to the interview
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Doubt around ADHD •Some parents doubted the existence of ADHD and did not feel their child needed a label
	Before medicating •Parents tended to seek alternative treatment options to medication, unwilling to accept that medication is the only option, although they were sceptical of the long term benefits of non-pharmacological treatments. The cost of these treatments is the main reason parents could not continue them
	GP attitudes •Parents found dismissive attitudes of GPs to be disempowering
	Emotional distress •Parents feel frustrated and worried when they cannot find an alternative treatment to medication
	Worrying about treatment •Parents felt highly distressed when contemplating their child's future on the medication. And worried about the long term impact of this on their health and behaviour
	Emotional impact of decision making •Parents felt that whatever they decide for their child’s treatment, there would always be a highly negative impact
	Emotional distress •parents feel guilty and express remorse for not have acted differently or recognised their child’s symptoms earlier. They often attribute their parenting to the cause of the problems their child is facing
	Stigma •Parents struggle with teachers, family members, friends and acquaintances judging them for deciding to medicate their child.
	Teachers attitudes •Parents felt teachers adopt a 'blasé' attitude towards ADHD due to the diagnosis being so common, which resulted in their child not receiving adequate help

	Decision on medication •Parents decide whether to medicate their child or not based solely on what is best for their child within the constraints of their money and resources
	Monitoring treatment •Parents feel they are solely responsible for monitoring the titration of their child's medication to achieve the most positive outcome
	Monitoring titration •Parents adopt a trial and error approach to managing treatment titration to reduce side effects. They feel that they haven't received adequate advice from their doctors
	Lack of advice around titration •Parents felt that they are not given adequate advice on the administration of medication.
	Lack of advice around titration •Parents felt that they were not warned of the reaction their child might have to medication

Study	**Wright 1997[192]**
Aim	Explore experiences of parents whose children were taking Ritalin
Population	16 parents of children with ADHD (aged 5-15 years (mean 10.2))
Setting	UK
Methods and analysis	Semi-structured interviews included questions on ADHD, Ritalin, and management and monitoring. No further details
Limitations	Severe limitations related to data richness, the role of the researcher, the context of the study and the design
Themes	Benefit of medication •Parents emphasised that their child was calmer, concentration was better, and aggressive behaviour had diminished. Parents were happy that this impact was beneficial enough vs. side effects to keep their children on the medication
	Support for parents •Parents felt it was useful to have a HCP that listened to them and supported them
	Benefit of diagnosis •Parents felt their diagnosis reduced stigma against their child, for having bad behaviour
	Liaison between professionals •Parents felt that schools and HCPs were helpful and supportive

Study	**Young 2009[195]**

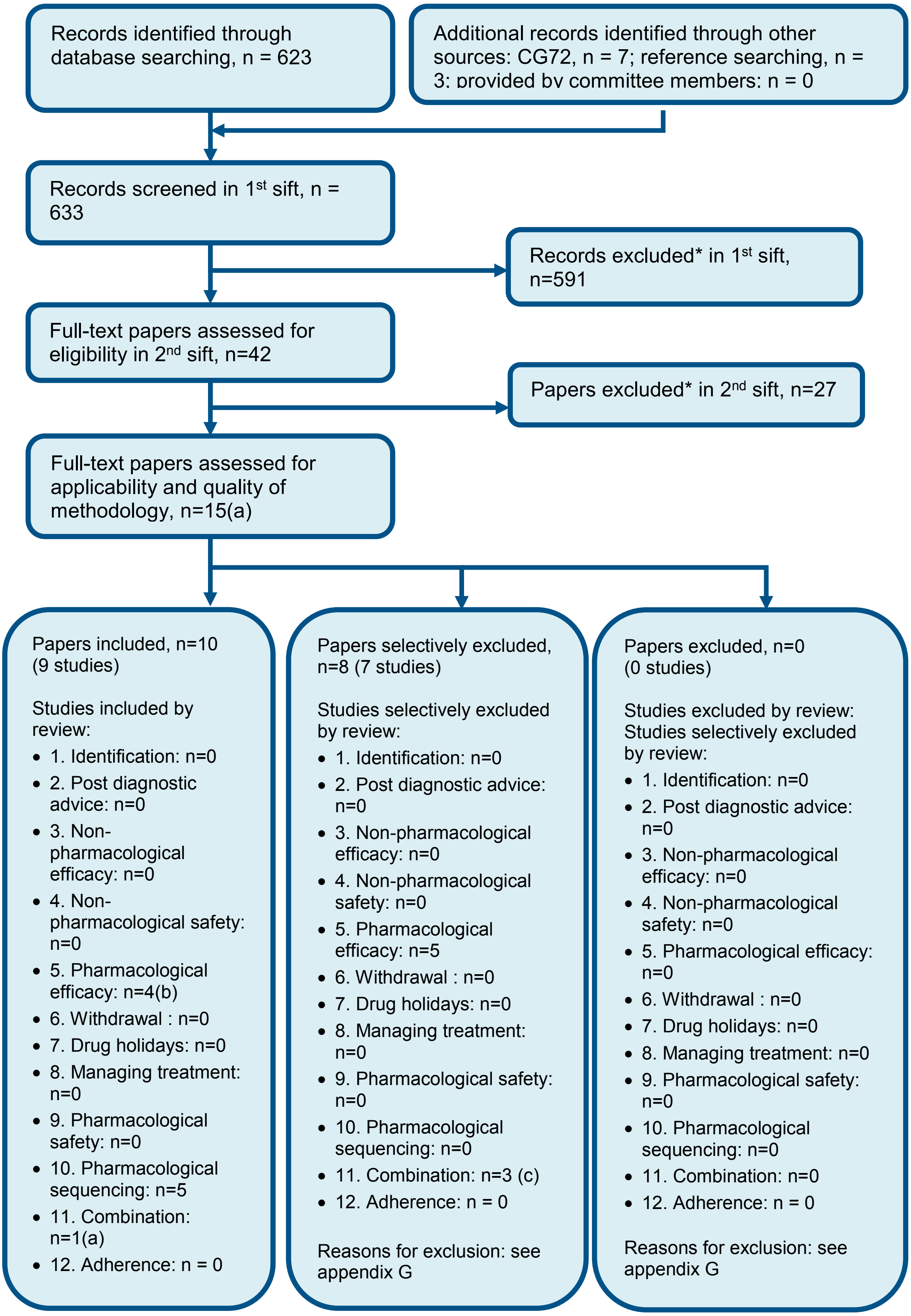
Study	**Young 2009**[195]
Aim	To explore the experience of living with a person who has undergone a diagnosis of ADHD in adulthood
Population	Partners of 8 people diagnosed with ADHD in adulthood (aged >18 years)
Setting	UK
Methods and analysis	Individual interviews conducted by assistant psychologist trained in qualitative methodology, ranged from 60 to 90 minutes. Interpretative phenomenological approach to analysis, extracting themes from each interview with subsequent grouping and categorising into master and subordinate.
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Benefits of diagnosis •Partners felt that the diagnosis of ADHD gave people an explanation for some of their difficulties and alleviated some guilt
	Benefits of drug treatment •Partners felt that initially treatment improved personal and interpersonal functioning
	Short-lived and limited benefits of drug treatment •Partners talked about the limitations of medication and that it was not a cure-all, they also noted that symptoms rapidly returned when the medication had worn off

Study	**Young 2008**[193]
Aim	To explore the experience of receiving a diagnosis of ADHD in adulthood
Population	8 people diagnosed with ADHD in adulthood (aged >18 years)
Setting	UK
Methods and analysis	Individual interviews conducted by assistant psychologist trained in qualitative methodology, ranged from 60 to 90 minutes. Interpretative phenomenological approach to analysis, extracting themes from each interview with subsequent grouping and categorising into master and subordinate.
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Missed diagnosis •Being diagnosed as adults left people regretting that they had not been diagnosed sooner and questioning if their lives could have been better if they had
	Long term impact of diagnosis •Participants noted that they soon realised that the diagnosis was a chronic one that they would live with for the rest of their lives which brought on some mild anxiety at least initially
	Stigma of diagnosis •Participants reported an awareness of a stigma surrounding ADHD which led them to tell less people of their diagnosis than they might

Study	**Young 2008[193]**
	otherwise
	Benefits of diagnosis •Participants felt that the diagnosis of ADHD gave them an explanation for many of their difficulties and it had a large emotional impact on them
	Short-lived and limited benefits of drug treatment •Participants noted that the medication did not cure everything and they experienced symptoms perhaps more acutely than before, when it wore off

Study	**Young 2009[194]**
Aim	Explore the experiences of young offenders with symptoms of ADHD
Population	
Setting	UK
Methods and analysis	Semi structured interviews using an interview schedule. 3 main sections on the consideration of life course, exploration of identities, and expectations for the future. Interviews lasted between 35 and 50 minutes. Initial analysis used an ideographic approach whereby an initial transcript was examined and notes made of all words and phrases relating to the research question. This supplied a list to support analysis of the remaining transcripts. Themes were grouped based on conceptual similarities.
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Family disruption •All young offenders had experienced a form of severe family disruption, and used this to justify their current situation.
	Causes of behaviour •None of the young offenders showed evidence of thinking about how their choices and behaviours had impacted upon their confinement. They all felt their behaviour was caused by experiences of loss and family disruption
	Impact of confinement •The young offenders felt that their confinement provided structure, clear expectations of behaviour with rules and sanctions. Some felt that this allowed them to reflect on their behavioural problems
	Impact of confinement •Young offenders felt that they greatly benefited from the small group sizes of classes

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

ave 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 39: Studies excluded from the qualitative review

Reference	Reason for exclusion
Ahmed 2013[3]	Systematic review
Andrews 2015[189]	Incorrect study design
Ansari 2016[4]	Survey
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
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
Carpenter-Song 2010[25]	Article
Carter 2005[26]	Survey
Charach 2008[28]	Incorrect study design
Clarke 2012[32]	Incorrect study design
Clarke 2013[31]	Incorrect population
Clay 2008[33]	Wrong population
Corcoran 2016[36]	Systematic review
Couture 2003[38]	Questionnaire
Darredeau 2007[39]	Survey
Deane 2012[41]	Incorrect population
Dennis 2008[42]	Literature review
Dosreis 2008[45]	Incorrect study design
Edwards 2013[46]	Wrong population
Eisenberg 2007[48]	Survey
Elias 2017[49]	Incorrect population
Emilsson 2016[50]	Survey
Faber 2006[51]	Incorrect study design

Reference	Reason for exclusion
Firmin 2009[53]	No relevant themes
Flannagan 2002[54]	No relevant themes
Fleishcmann 2013[55]	Survey
Frank 2015[56]	Incorrect study design
Friars 2009[57]	No relevant themes
Garro 2009[59]	Article
Gau 2009[60]	Incorrect study design
Gerdes 2014[61]	Incorrect study design - questionnaire
Ghanizadeh 2010[62]	Questionnaire
Ginsberg 2008[64]	Incorrect study design
Goodwillie 2014[65]	No relevant themes
Gwernan-Jones 2015[67]	Literature review
Gwernan-Jones 2016[66]	Systematic review
Hack 2001[68]	Incorrect study design
Harazni 2016[72]	No relevant themes
Harvey 2009[74]	Wrong population, incorrect study design
Hazell 2004[76]	No qualitative results reported
Hebert 2013[77]	Survey
Henry 2011[78]	No relevant themes
Hill 2016[79]	Survey
Ho 2011[186]	No relevant themes
Honkasilta 2014[82]	No relevant themes
Honkasilta 2016[83]	No relevant themes
Ide-Okochi 1016 [87]	Article
Kean 2005[90]	Incorrect study design
Kendall 1997[91]	Incorrect study design
Kildea 2011[94]	No relevant themes
King 2016[95]	Incorrect population
Kisely 2002[96]	Survey
Ko 2008[99]	Questionnaire
Koerting 2013[100]	Review
Kollins 2008[101]	Review
Kovshoff 2012[103]	No relevant themes
Kronenberg 2014[104]	Incorrect population
Kutuk 2016[105]	Survey
Laugesen 2016[107]	Unable to access
Laugesen 2016[107]	Systematic review
Lee 2014[108]	No relevant themes

Reference	Reason for exclusion
Lewis 2016[114]	No relevant themes
Lewis 2016[115]	Erratum
Lewis-Morton 2014[113]	No relevant themes
Lin 2009[117]	No relevant themes
Ljusberg 2011[118]	No relevant themes
Lopes 2009[120]	Incorrect population
Maassen 2016[121]	No relevant themes
Marcer 2008[122]	Questionnaire
Mathers 2006[123]	Incorrect study design
Matthys 2014[125]	No relevant themes
McCarthy 2000[126]	Survey
McGoron 2014[127]	Questionnaire
McIntrye 2012[128]	No relevant themes
McKay 1996[129]	Wrong population
McMenamy 2008[130]	Wrong population
Michielsen 2015[133]	Wrong population
Mills 2008[102]	Abstract
Morsink 2017[136]	No relevant themes
Muhlbacher 2009[137]	Abstract
Muhlbacher 2009[137]	Abstract
Murrell 2015[138]	Incorrect study design
Mychailyszyn 2008[139]	No relevant themes
Myers 2013[140]	Incorrect study design
Nehlin 2015[175]	No relevant themes
Oruche 2014[144]	Wrong population
Ramsay 2012[146]	Incorrect study design
Raskind 2006[147]	Survey
Reale 2015[148]	Survey
Reid 1996[149]	No relevant themes
Rogalin 2015[150]	No relevant themes
Russell 2016[151]	No relevant themes
Sandler 2007[153]	No relevant themes
Schatz 2015[154]	Systematic review
Schreuer 2017[155]	No relevant themes
Schrevel 2014[156]	No relevant themes
Schubert 2009[157]	No relevant themes
shattell 2008[160]	No relevant themes
Shaw 2003[161]	No relevant themes

Reference	Reason for exclusion
Singh 2005[165]	Article
Singh 2011[166]	Article
Singh 2015[167]	Article
Sleath 2016[168]	Survey
Smith 2014[169]	No relevant themes
Solberg 2015[171]	Incorrect study design - questionnaire
Sox 2010[172]	Incorrect study design
Srignanasoundari 2017[173]	No relevant themes
Stroh 2008[174]	Survey
Surman 2006[175]	Incorrect study design
Tatlow-Golden 2016[177]	Systematic review
Thiruchelvam 2001[179]	Incorrect study design
Travell 2006[180]	Analysis
Varley 2011[181]	Article
Waite 2010[182]	No relevant themes
Wallace 2005[183]	No relevant themes
Wiener 2015[185]	No relevant themes
Wilkes-Gillan 2015[80]	No relevant themes (parental intervention)
Wilkinson 2013[187]	No relevant themes
Williams 2014[188]	No relevant themes
Williams 2014[188]	No relevant themes
Williamson 2009[190]	Incorrect study design
Winter 2015[191]	Incorrect study design
Wolpert 2004[73]	No relevant themes
Zhang 1017[196]	No relevant themes

Table 40: Studies identified but not included in the qualitative review due to saturation being reached

Reference
Canela 2017[24]
Kendall 2016[93]
Liebrenz 2016[116]
Soderqvist 2017[170]
Wan 2016[184]

G.2 Excluded health economic studies

None.