National Institute for Health and Care Excellence

Draft for Consultation

Attention deficit hyperactivity disorder (update)

[B] Evidence reviews for Information and support for people with ADHD

NICE guideline CG72

Evidence review

September 2017

Draft for Consultation

This evidence review was developed by the
National Guideline Centre

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1.1 Review question: What are the information and support needs of children, young people and adults with ADHD and their family and carers after diagnosis?

1.2 Introduction

The NICE guidelines on service user experience in adult mental health and patient experience in adult NHS services outline the key principles of general care. It is also important to identify and address the unique needs of specific conditions and following a diagnosis of ADHD, children, young people and adults, and their carers and families require up-to-date, relevant information about ADHD in formats to suit their individual needs. Post-diagnostic advice is in particular an important part of the assessment process. It is important that people with ADHD and their families have accurate detailed knowledge about ADHD to raise self-awareness and reduce the stigma associated with the condition. Information and support can increase adherence to treatment and help people to develop constructive coping strategies to manage their symptoms and reduce the impact these symptoms can have on their everyday lives. Accurate information is helpful for people with ADHD to use when informing people around them about the ways that their ADHD may affect them and how this should be taken into account. This review identifies and outlines the information and support needs of people after being given a diagnosis of ADHD.

1.3 Characteristics table

For full details see the review protocol in appendix A.

Table 1: Characteristics of review question

Objective	To identify what information and support should be provided to people with ADHD and to people close to them after receiving a diagnosis of ADHD.
Population and setting	• Children, young people and adults with ADHD. • Family and carers of people with ADHD • Teachers/professionals involved in education and employers • Healthcare professionals involved in the care of people with ADHD (primary, professionals that deliver treatment, and social care)
Context	Any themes that emerge relating to the information and support needs of the target population. Information that describes how information is delivered.
Review strategy	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches);.

1.4 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual.[144] 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; [2,8,12,14,27,30,34,35,37,41,44,49,56,60,65,67,71-75,77,80,83-87,91,94,96,99,105,108,111,112,114,119,123,127,131,134,137,138,142,145-147,149,153,156,157,161,163,166-169,174,181,184,185,188,189,191,192,198,199,201] these are summarised in Table 2 below.

Fifteen studies focused on the views of adults with ADHD. Forty studies focused on the views of children and young people with ADHD and their families or carers. Four studies focused on the views of healthcare professionals dealing with ADHD. Four studies focused on the views of teachers. Six studies involved the views of a mix of people with ADHD, their families, healthcare professionals or teachers.

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 50 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 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
Bartlett 2010[8]	Interviews (analysis type not specified)	16 young adult college students (aged 18 – 25 years)	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	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	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	
Charach 2006[27]	Focus groups and interpretive interactionist framework analysis	17 mothers and fathers of 14 children with ADHD (aged 7 to 15 years)	To explore parents' attitudes towards medicating their child	Canada
Cheung 2015[30]	Interviews and grounded theory	40 young adults (aged 16 to 23 years (20 patients 16-17 and 20 18+ years))	Explore young adults experiences in accessing treatment and services	Hong Kong
Coletti 2012[34]	Focus groups and grounded theory	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 (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	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[41]	Interviews (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 2010[44]	Interviews and grounded theory	48 parents of children with ADHD, drawn from an urban area with a large proportion of low income, African-American residents (ages 6 to 18 years)	To explore the experiences of parents with a child with ADHD	USA
Einarsdottir 2008[49]	Interviews and phenomenology approach to analysis	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
Flannagan 2002[56]	Interviews,	40 mothers and	Explore the	USA

Study	Design	Population	Research aim	Setting
	analysis type not specified	their children with ADHD (aged 8 to 11 years)	experiences of mothers with children with ADHD	
Gallichan 2008[60]	Interviews and grounded theory	12 young people with ADHD (aged 10 to 17 years)	Explore young peoples' perspectives of ADHD	UK
Ghosh 2016[65]	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[67]	Interviews and interpretive phenomenological analysis	6 parents with children diagnosed with ADHD (age not specified)	Explore parental views of the impact of having a child with ADHD	UK
Hallberg 2008[71]	Interviews and grounded theory	12 parents of adolescents with ADHD (age not specified)	To explore the experiences of parents with teenage daughters with ADHD	Sweden
Hallerod 2015[73]	Interviews and phenomenographical analysis	21 adults with ADHD (aged 18+)	Explore patients' experiences of being diagnosed with ADHD	Sweden
Hansen 2006[72]	Interviews and phenomenological approach	10 parents of children with ADHD (aged 8 to 22 years)	Explore parents' experiences of medicating their child with ADHD	Canada
Harazni 2016[74]	Interviews and phenomenological approach	4 mothers and 12 teachers (4 children with ADHD) (aged 7 to 10 years)	Investigate the experiences of adults that interact with school aged children with ADHD	Palestine
Hassink-Franke 2016[77]	Interviews and constant comparative analysis	15 GPs treating children with ADHD (age not specified)	Explore GPs experiences of children with ADHD	Netherlands
Henry 2011[80]	Interviews	9 woman over the age of 62 diagnosed with ADHD after the age of 60	To explore the experiences of older woman with ADHD	USA
Ho 2011[192]	Interviews and content analysis	12 parents of children with ADHD (age not specified)	To explore parents' perceptions of their child with ADHD	China

Study	Design	Population	Research aim	Setting
Hong 2008[83]	Interviews (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[84]	Interviews	18 mothers of children with ADHD (age not specified)	To explore parental involvement in their child's schooling	Finland
Honkasilta 2016[85]	Interviews and narrative approach to analysis	13 young people with ADHD (aged 11 to 16 years)	To explore teachers' classroom management strategies for ADHD	Finland
Hughes 2007[86]	Interviews (analysis type not specified)	9 clinicians, 14 children with ADHD and their parents and teachers. (aged 7 to 12 years)	Explore experiences of clinicians, children, parents and teachers involved in ADHD	UK
Hughes 2009[87]	Interviews (analysis type not specified)	9 clinicians, 14 children with ADHD and their parents and teachers (aged 7 to 11 years)	How to support children with ADHD in their learning environment	UK
Jones 2014[91]	Semi structured interview and content analysis	9 young people between 15 and 21 with a diagnosis of ADHD. Substance abuse was an exclusion criterion. (aged 5 to 18 years)	To develop an understanding of the meaning and consequences of an ADHD diagnosis for young people	Denmark
Kendall 2003[94]	Interviews and constant comparative 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[96]	Interviews and thematic analysis	28 stakeholders consisting of 7 mental health professionals, 2 teachers, 7 parents/carers, and 5 children referred for an ADHD assessment	Explore stakeholders' thoughts concerning ADHD in the context of CAMHS	UK
Klasen 2000[99]	Interviews and grounded hermeneutic analysis	10 GPs and 29 parents of hyperactive children (aged)	To investigate parents' and GPs' views on hyperactivity	UK

Study	Design	Population	Research aim	Setting
Kovshoff 2012[105]	Interviews and thematic analysis	50 clinicians (28 from Belgium and 22 from UK, consisting of psychiatrists and paediatricians) (age not specified)	Explore clinicians experiences and attitudes to the diagnosis and management of ADHD	UK and Belgium
Larson 2011[108]	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[111]	Interviews and grounded theory	10 teachers of pre-Kindergarten through to 3rd grade classrooms. (preschool - 3rd grade)	Explore teachers' experiences and perspectives of children with ADHD	USA
Lefler 2016[112]	Focus groups and idiographic inductive analysis	36 college students with ADHD (aged >18 years)	To explore the experiences of college students living with ADHD	USA
Leslie 2007[114]	Interviews and grounded theory	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[119]	Interviews and Colaizzi’s approach to 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
Ma 2016[123]	Interviews and systemic theory analysis	15 of 44 families that took part in a family intervention with a child with ADHD (31 fathers, 42 mothers, one grandmother, 44 children with ADHD, 18 siblings). All had been recommended for the study by social workers.	To learn about the lived experiences surrounding maltreatment in parent-child relationships	China

Study	Design	Population	Research aim	Setting
		Age of children not specified		
Matheson 2013[127]	Interviews and thematic analysis	15 adults diagnosed with ADHD in childhood, and 15 diagnosed in adulthood (aged >18 years)	Explore adults experiences with ADHD	UK
McIntrye 2012[131]	Interviews and thematic analysis	18 parents of children diagnosed with ADHD (aged 7 to 12 years)	Explore parents' experiences of ADHD	UK
Meaux 2009[134]	Interviews and content analysis	15 college students with ADHD (aged 18 to 21 years)	Explore college students experiences of ADHD	USA
Mills 2011[137]	Interviews and constant comparative analysis	19 families (representing 30 children with ADHD) (age not specified)	To understand how parents decide to medicate their child	USA
Moen 2011[138]	Interviews and Colaizzi's approach to 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
Mychailyszyn 2008[142]	Interviews and grounded theory	34 parents whose children were diagnosed with ADHD (aged 6 to 18 (mean age 8.5 years))	Explore parents views of ADHD and mental health care services	USA
Nehlin 2015[145]	Interviews and narrative psychological 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[146]	Interviews and thematic analysis	18 adults with ADHD (aged >18 years)	To explore the context that influences stimulant medication adherence	USA
Olaniyan 2007[147]	Focus groups and thematic analysis	31 parents, only 3 had children with an ADHD diagnosis (Mean 9 (7.8) years)	Explore perspectives of ADHD and behavioural problems among African American parents	USA

Study	Design	Population	Research aim	Setting
Perry 2005[149]	Interviews (analysis type not specified)	26 Latino parents of children with ADHD (aged 6 to 19 years)	To explore Latino families' experiences with ADHD	USA
Reid 1996[153]	Interviews and grounded theory analysis	20 parents of children with ADHD (aged 5 to 18 years)	To explore parents' experiences of support from school systems	USA
Russell 2016[156]	Interviews and focus groups, 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)	Explore educational practitioners views of ADHD	UK
Salt 2005[157]	Interviews, analysis type not specified	13 GPs (plus 93 completing a questionnaire)	To explore GPs' perceptions of the management of ADHD in primary care	UK
Schrevel 2015[161]	Focus groups and conventional coding analysis	52 adults with ADHD (aged 21+)	To assess the perspectives, problems and needs of adults with ADHD	UK
Segal 2001[163]	Interviews and comparative analysis	25 mothers of children with ADHD (age not specified)	Explore mothers' experiences raising children with ADHD	USA
Shaw 2003[166]	Interviews, analysis type not specified	28 GPs caring for people with ADHD	Explore GPs attitudes towards ADHD	Australia
Sikirica 2014[167]	Interviews and thematic analysis	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[168]	Focus groups and thematic analysis	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[169]	Interviews and thematic analysis	22 fathers of children with ADHD (aged 7 to 12 years)	Explore fathers' perspectives of ADHD symptoms, diagnosis and	UK

Study	Design	Population	Research aim	Setting
			treatment	
Smith 2014[174]	Focus groups and thematic analysis	19 practitioners running services for preschool children with ADHD, and 13 parents of children with ADHD (Pre-schoolers)	Understanding the reasons of low uptake and completion of parent interventions for ADHD	UK
Swift 2013[181]	Interviews and thematic analysis	10 young adults with ADHD (aged 17-18 years)	Patient experiences of ADHD, particularly around transitioning services	UK
Taylor 2006[184]	Interviews and grounded theory	33 parents of children with ADHD (aged 22 primary school, 11 teenagers)	How to parents reach a decision to medicate their children or not	Australia
Waite 2010[188]	Interviews and conceptual coding analysis	16 women with ADHD (aged 18+ years)	To explore the experiences of women with ADHD	USA
Wallace 2005[189]	Interviews and grounded theory	10 parents of children with ADHD (age not specified)	Explore the perception of mothers of sons with ADHD	Australia
Wiener 2015[191]	Interviews and grounded theory	12 adolescents with ADHD (aged 14 to 16 years)	Explore school experiences of adolescents with ADHD	Canada
Williams 2014[185]	Interviews and grounded theory	16 parents of children with ADHD (aged 5 to 13 years)	To explore parent's perspectives of parenting a child with ADHD	Australia
Wolpert 2004[75]	Interviews and grounded theory	10 parents of children with ADHD (aged 8 to 11)	To investigate how parents make sense of the different aetiological models	UK
Wright 1997[198]	Interviews	16 parents of children with ADHD (aged 5-15 years (mean 10.2))	Explore experiences of parents whose children were taking Ritalin	UK
Young 2008[199]	Semi structured interview and interpretative phenomenological analysis	8 people diagnosed with ADHD in adulthood (aged >18 years)	To explore the experience of receiving a diagnosis of ADHD in adulthood	UK

Study	Design	Population	Research aim	Setting
Young 2009[201]	Semi structured interview and ideographic approach to 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

See appendix D for full evidence tables.

1.5.4 Qualitative evidence synthesis

Table 3: Review themes: Diagnosis

Main themes	Statement of theme
Benefit	People felt a sense of relief, elation, improved self-esteem and reduction in feelings of guilt
Harm	People felt that a diagnosis led to stigma, feelings of embarrassment and 'not belonging'
Doubt	Some people questioned the existence of ADHD
Missed diagnosis	People felt many negative impacts of their behaviour could have been avoided if they were diagnosed earlier in their lives

Table 4: Review themes: Challenges for people with ADHD

Main themes	Statement of theme
Recognition	Teachers were not aware of inattentive symptoms of ADHD or found this behaviour difficult to pinpoint
Academic and employment impact	ADHD symptoms negatively impacted on academic achievement and employment
Psychosocial impact	ADHD had negative impacts on emotional wellbeing and social functioning
Bullying	Children and young people reported being bullied as a result of their symptoms
Impact on life	ADHD has a huge impact on people's day to day lives
Substance use	People with ADHD felt inclined to use substances such as nicotine and alcohol
Driving skills	People with ADHD felt that their symptoms impacted on their driving ability
Experiences of support	People with ADHD needed more support from their family, teachers and healthcare professionals
Conflict	People with ADHD and their parents reported that conflict could result in physical abuse

Table 5: Review themes: Challenges for parents

Main themes	Statement of theme
Experiences of support	Parents needed more support from healthcare professionals, teachers and family members
Psychosocial impact	Having a child with ADHD had negative impacts on emotional wellbeing and social functioning

Main themes	Statement of theme
High demand	Bringing up a child with ADHD can be highly demanding and cause high levels of emotional and physical exhaustion
Employment/education	Parents had to reduce their working hours, stop working entirely, and put educational opportunities on hold to care for their child
Access to services	Parents had difficulty in accessing services
Information needs	Parents felt they required more information about the causes, mechanisms, and functional implications of ADHD

Table 6: Review themes: Healthcare professionals

Main themes	Statement of theme
Diagnosis	Healthcare professional's experiences, perspectives and understanding of ADHD impacted whether someone would receive a diagnosis
Recognition	GPs had difficulty in recognising ADHD
Attitudes	GPs had negative attitudes towards ADHD
Management	GPs had limited understanding of their role in treatment management

Table 7: Review themes: Schools

Main themes	Statement of theme
Challenges for teachers	Teachers found it difficult to support children and young people with ADHD
Teachers' attitudes	Some teachers displayed negative attitudes towards the condition
Parents' attitudes	Parents felt behavioural problems were a result of poor teaching and were insulted by teachers suggesting visiting the doctor
Communication	Parents and teacher often conflicted when discussing the child's behavioural difficulties
Factors influencing the classroom experience	Children benefited from small classes with minimized distractions and good teaching techniques and support

Table 8: Review themes: Services

Main themes	Statement of theme
Experiences of service use	People experienced delayed services with long diagnostic processes and a lack of follow up care
Transition to adult services	People found a delay in referral to adult services
Improving the treatment pathway	Healthcare professionals felt interventions could be improved with initial home visits and addressing parents' own mental health conditions.

Table 9: Review themes: Methods of providing information and support

Main themes	Statement of theme
Support groups	People wanted access to support groups to talk to other people in similar situations
Written and oral presentations	People felt detailed written information about ADHD or oral summaries would be most useful
The internet	People felt direction on which internet sources to use

Main themes	Statement of theme
	would be helpful, and GPs found online training materials to be useful
Methods for children	People felt that care needed to be taken when explaining ADHD to children

1.5.4.1 Narrative summary of review themes

1.5.4.1.1 Theme 1: Diagnosis

Review theme 1: Benefits of diagnosis

People with ADHD and their parents and carers noted many benefits to receiving a diagnosis. They felt a sense of relief and elation that their behaviour was not their fault; they felt a diagnosis helped to explain the difficulties they had previously faced throughout their lives. Both parents and people with ADHD saw improvements to self-esteem, due to the legitimization of their difficulties; they thought more highly of themselves, and felt that others did too. People with ADHD felt they had a better understanding of themselves following a diagnosis. Parents felt that the diagnosis reduced stigma against their child. They also felt it reduced a sense of guilt that they themselves had, as they had attributed their child's behaviour to their own parenting. Some reported an improvement in the parent-child relationship due to realising that their child needed help and support. A diagnosis also gave access to coping strategies to deal with symptoms, and a range of ways to improve behaviour through pharmacological and non-pharmacological interventions.

Explanation of quality assessment: minor methodological limitations in the contributing studies; moderate concerns about the coherence of the theme with conflicting evidence that lowers our confidence, due to evidence that a diagnosis can also cause harm; partial relevance due to the contributing studies being conducted mainly outside of the UK; minor concerns about inadequacy as the evidence is not sufficiently deep. There was a judgement of moderate confidence in this theme due to concerns regarding the coherence of the theme.

Review theme 2: Harm of diagnosis

People felt that a diagnosis led to stigma and discrimination from others. For children, this effect was seen both inside and outside of school. For example in school they felt that they were often blamed for things that they had not done. Similarly, parents felt stigmatised by teachers, their own family, people they didn't know in public places, and other parents. Many felt fearful of stigma; some people did not tell people about their diagnosis and isolated themselves as a result. Others opted to act as their own advocate and explain their condition to people they came across in their day-to-day lives. Many felt like they 'didn't belong' in society due to their diagnosis, felt 'abnormal', embarrassed and ashamed at being diagnosed with ADHD

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 mainly being conducted outside of 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 coherence of the theme.

Review theme 3: Doubt of diagnosis

People diagnosed with ADHD had varying degrees of doubt around their diagnosis. Some questioned the existence of ADHD, some questioned whether they had it, and others reported loved ones being sceptical.

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 outside of 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.

Review theme 4: Missed diagnosis

People that had been diagnosed with ADHD later on in their lives regretted that they had not been diagnosed sooner and questioned if their lives could have been better if they had. They felt that not being diagnosed had many negative impacts on many aspects of their life. For example, difficulty and failure in employment and education could have been avoided. This led to an accumulated sense of failure, with many reporting losing their jobs or getting into trouble for reasons related to their symptoms. Emotional wellbeing could have also been improved with a diagnosis. Some reported psychological breakdown and suicidal ideation as a result of their symptoms. Others felt their symptoms led to substance abuse, which could have been avoided. Others felt that relationship problems were worsened as a result of their missed diagnosis.

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 outside of the UK; minor 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 applicability of the data.

1.5.4.1.2 Theme 2: Challenges for people with ADHD

Review theme 5: Recognition

Teachers felt that inattentive behaviour is as problematic as hyperactive behaviour but difficult to pinpoint. Some teachers were not aware of these symptoms of ADHD, which could impact the support this subgroup receive during school time.

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 study being conducted outside of 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.

Review theme 6: Academic and employment impact

ADHD is often related to academic impairment. People reported an inability to listen in class and carry out work both inside and outside of school. People reported not having clear techniques of how to organise and carry out their schoolwork. They had difficulty juggling multiple tasks and in making decisions related to work. They found reading comprehension difficult, reported motivational problems and found they got easily distracted. Many didn’t feel that they could discuss accommodations with their teachers, and felt ashamed when they did have to utilise accommodations, such as taking tests in disability centres. Adults with ADHD reported difficulty in finding suitable work roles, with some being unemployed due to this.

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 outside of 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 adequacy of the data and methodological limitations.

Review theme 7: Psychosocial impact

People felt that ADHD was greatly impacting their psychosocial functioning. Young people with ADHD often did not have many friends or take part in social activities. They felt that their friendships often didn’t last long, and they reported not spending time with friends outside of school. People felt that they had a low tolerance for others behaviour, which impacted on their ability to take part in social activities. People also reported a range of negative emotional difficulties related to their behavioural problems and the way others reacted to them. They felt sad, angry, frustrated and ashamed at their behaviour.

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 outside of 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 adequacy of the data and methodological limitations.

Review theme 8: Bullying

Children and young people with ADHD reported that they had been bullied by their classmates. They felt that this was due to symptoms such as poor social skills, low self-esteem and aggression.

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 outside of 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 adequacy of the data.

Review theme 9: Impact on life

People with ADHD reported that their symptoms had a huge impact on their day-to-day lives. They felt that their symptoms greatly impacted their ability to undertake everyday tasks. Some felt 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. Parents worried about the impact that this would have in the long time, such as coping at university, managing money and driving.

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 outside of 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 adequacy of the data.

Review theme 10: Substance abuse

People with ADHD felt that they had addictive personalities, which resulted in substance use. Some had got into trouble with their schools as a result of substance misuse. Others felt that their substance use was a way of trying to minimise their symptoms and feel ‘normal’. Some drank alcohol to bring a feeling of calm. Whereas others felt that nicotine from smoking helped to improve their symptoms.

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 outside of 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 adequacy of the data.

Review theme 11: Driving

People with ADHD felt that their symptoms impacted on their ability to drive, as they were easily distracted and not as careful as they should be.

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 study being conducted outside of 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: Experience of support

Young people felt that their parents' lack of understanding or knowledge of ADHD made life more difficult for them and left them feeling frustrated. Some did feel in control of their symptoms and didn't need additional help from family members or healthcare professionals, whereas some required a large amount of support to stay on track. They also reported limited support from teachers, and felt that they needed more guidance at school, but there was a lack of available support. In addition, people with ADHD felt that doctors needed to explain ADHD better, particularly during childhood, to help patients understand their condition better.

For those that had the support of their families, they reported that they found their parents' ability to create a structured environment and teaching strategies of coping to be useful. However, they also felt that their parent's attitudes towards the diagnosis influenced their own. For example, they felt that their parents own worries greatly influenced their own fears and worries about the condition. Some reported being told misleading information by parents, such as that they would 'grow out' of their condition; they felt that this information was misleading.

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 study being conducted outside of 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 applicability of the data and methodological limitations.

Review theme 13: Conflict

Children and parents reported incidences of child maltreatment, in the form of parents harming their children, as a result of their child's behaviour and the conflict that arose from this. Conflict often arose as a result of homework supervision, parent's demands when the child was playing, parents misunderstanding their child's behaviour, and parents threatening to remove their child from their home

Parents also reported serious incidences of being physically abused by their children, during times of aggressive and disruptive behaviour. They specified being hit and having their hair pulled out, along with verbal abuse. Conflict often arose as a result of homework supervision, parent's demands when the child was playing, parents misunderstanding their child's behaviour, and parents threatening to remove their child from their home.

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 study being conducted outside of 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 applicability of the data and methodological limitations.

1.5.4.1.3 *Theme 3: Challenges for parents*

Review theme 14: Experiences of support

Although some parents felt they have adequate support from their families, healthcare professionals and teachers, parents in reported a lack of support mainly from spouses and other family members, and from both healthcare and educational professionals. They felt that these professionals had a poor understanding of the nature of ADHD and a lack of skills to help to manage their children, and felt that their concerns were being dismissed. Parents reported having to battle to gain support from professionals, particularly with teachers that could not manage their child's behaviour.

Parents reported a lack of support from schools and teachers. They felt they were being blamed for their child's ADHD and had a lack of support from the school system. They felt that event when schools were trying to be supportive, they did not consider the needs of the child properly. Some parents felt that teachers did not have enough of an understanding of ADHD, which led to these discrepancies in support needed and support given. Issues included disagreements around treatment and behaviour, poor communication, and a lack of understanding for the parents' difficult situation.

Parents wanted healthcare professionals to listen to them more and offer more support. They felt that some did not give support and advice specific to their situation, and found some were unwilling to take any responsibility in order to support their child. In some cases they felt that they were made out to be the expert in the management of their child, but many parents felt that this were not the case. In addition, Mothers also reported that fathers were not supportive in the care of their children. They felt that in some cases, fathers played a negative role in the management of child care. This resulted in difficulties in their marriage. Some did not understand their child's symptoms, and were reluctant to believe the diagnosis was real.

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; 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 adequacy of the data and methodological limitations.

Review theme 15: Psychosocial impact

Parents described vast and severe psychosocial implications of their child having ADHD. They reported high emotional distress. This was a result of the difficulties they experienced in parenting their children, their worry about their child's behaviour, difficulty in tracking their child's academic success and keeping them focused on school work, and difficulties in helping their children undertake daily tasks. Feelings of frustration and worry were also apparent when parents could not find alternative treatments to medication. They felt their treatment decisions would always negatively impact their child, regardless of their choice.

Some also had feelings of embarrassment and disappointment when their children didn't act like others their age. This was mostly apparent in fathers that wanted their children to be involved in athletic activities. Parents also reported feelings of guilt and remorse for not having recognised the symptoms earlier. They often attributed their parenting as the cause of the problems their child was facing, which resulted in further guilt. Parents reported having no social lives, with their lives completely taken over by their child. Their child's behaviour often meant that it was difficult to find babysitters, or parents would not be comfortable leaving their child. In addition, their concerns over their child's behaviour meant that they would avoid taking them to social events.

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 and of high quantity. There was a judgement of moderate confidence in this theme due to the concerns regarding the methodological limitations.

Review theme 16: High demand

Parents reported that bringing up children with ADHD was highly demanding, and caused high levels of exhaustion, both emotionally and physically. Parents felt they needed more information on how they could manage their child's symptoms, particular around mood swings and what to do in certain situations. Parents had to constantly structure and monitor their child's daily routine, and assist them in their activities. This caused feelings of guilt as they had less time to care for their other children. Parents reported having to make many sacrifices in order to care for their child adequately, such as reducing their working hours or stopping work entirely. They did not feel other people were equipped to look after their children safely, including close family members. This is because they didn't understand the extent of the behavioural issues the child exhibited.

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 mainly being conducted outside of 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 adequacy of the data.

Review theme 17: Employment/education

Parents reported having to reduce their working hours or stop working entirely to care for their child. They often put their career or educational opportunities on hold as they committed themselves to caring for their child

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 outside of 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.

Review theme 18: Access to services

Parents had difficult experiences in accessing the services they needed. Some found that when their child was initially diagnosed, it was hard for them to understand what they should do or where they should get assistance. Others reported not being offered non-pharmacological treatment options. Some felt that they had to push for a diagnosis and subsequent treatment. However, others felt unable to push for the care they required, which led to delays in diagnosis, feelings of disempowerment and distress for the entire family.

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 outside of 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.

Review theme 19: Information needs

Parents felt they had a limited understanding of ADHD. They reported wanting more information on the causes, mechanisms, and functional implications of ADHD. Some parents felt that their parenting skills were to blame for their children's symptoms. They felt that healthcare professionals needed to explain ADHD better, particularly during childhood, to help patients understand their condition and therefore manage it. Parents also felt that there was a need for professionals to have more information and training for themselves too, in order to provide them with support.

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 outside of 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.

1.5.4.1.4 Theme 4: Healthcare professionals

Review theme 20: Diagnosis

Healthcare professional's personal perspectives were a factor for whether or not a child would receive a diagnosis, with some feeling that ADHD is over diagnosed, and some not feeling comfortable in making a diagnosis. They reported that they often took into account the wishes of the family, and the impact that a diagnostic label could have, when deciding to make the diagnosis. They also found it difficult to interpret the family and child difficulties in each consultation, feeling that they were attempting to separate cases out into 'real' ADHD and 'pseudo' ADHD.

GPs in particular did not feel competent in diagnosing ADHD, due to a lack of knowledge and experience, and due to having too little time to do some. They felt that they did not have adequate training in the assessment of ADHD. Parents felt that healthcare professionals were acting like their child's behaviour was normal, which delayed them receiving a diagnosis. In addition, some GPs were unaware of where they could refer patients to.

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 outside of 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 21: Recognition

GPs found the recognition of ADHD difficult, with some not knowing the difference between 'normal' and 'abnormal' behaviour. Some felt that they did not have adequate training in the recognition of ADHD. Some noted similarities in levels of hyperactivity across mainly families, but noted that some parents would not mind this level of hyperactivity, whereas others would seek help for the symptoms. GPs also emphasised the view that family dysfunction could lead to problem behaviour or to a 'dysfunctional' family seeking help for their child.

Explanation of quality assessment: severe methodological limitations in the contributing studies; minor concerns about the coherence of the theme with nothing to lower our confidence; partial relevance due to some of the contributing studies being conducted outside of 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 the applicability of the data.

Review theme 22: Attitudes

Some GPs had negative attitudes towards ADHD. They felt that a diagnosis could do more harm than good. 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. In addition, parents found GP's attitudes to be dismissive and disempowering; with some finding that GPs did not believe that their child had hyperactivity problems. GPs felt that often ADHD symptoms were caused by difficult family situations and poor parenting, often feeling that labelling the symptoms was not helpful.

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

Review theme 23: Management

Some GPs understood their role in treatment management for children with ADHD. However, others felt that they did not have adequate training to do so, or had little interest in being the primary care provider for children with ADHD. Some GPs had taken part in an online training course in ADHD, and felt more confident in managing patients with ADHD as a result. Others reported that they would be more willing to be involved in the care of children if they received more training to do so. In addition, GPs displayed limited knowledge and understanding of the side effects that could present with ADHD medication. Some felt that stimulants did not have many side effects, and others felt there were a few but couldn't remember what they were.

Explanation of quality assessment: minor methodological limitations in the contributing studies; moderate concerns about the coherence of the theme with conflicting evidence; partial relevance due to some of the contributing studies being conducted outside of 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 the applicability of the data.

1.5.4.1.5 Theme 5: Schools

Review theme 24: Challenges for teachers

Teachers found it difficult to support children and young people with ADHD. They felt unequipped to do so, having received no training or any information about the condition. They also felt they had a lack of time and resources to fully support children with ADHD. This led to feelings of frustration and helplessness when being unsuccessful in helping or reducing disruptive behaviour in a child with ADHD. In addition, teachers understanding of the prevalence of ADHD across age groups and gender were varied and limited.

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 some of the contributing studies being conducted outside of 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 the methodological limitations.

Review theme 25: Teachers' attitudes

Teachers' attitudes towards ADHD impacted on the support that children received. Some had negative opinions on the causes of ADHD, feeling that it was due to poor parenting skills and home environment; they often framed this attribution negatively, and felt that if it weren't for these factors, the child would not have ADHD. In these cases, they felt that diagnoses should not have been given. Attitudes to medication differed; some felt that it was wrong for teachers to want to medicate children to ‘make their job easier’; whereas others felt that medication was useful in doing so. Parents felt that teachers were unsympathetic in their attitudes, and felt that teachers neglected their children as a result. They were that teachers had a ‘blasé’ attitude towards ADHD, which resulted in their child not receiving adequate help.

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 some of the contributing studies being conducted outside of the UK; minor concerns about inadequacy as the evidence is reasonably deep, with some elaborations and examples. 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 26: Parents’ attitudes

Parents felt that behavioural problems at school were a result of poor teaching methods and impatience with children that were slow at progressing through their work. Parents felt dissatisfied and insulted by teachers suggesting that doctor referrals and medication might be 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 some of the contributing studies being conducted outside of the UK; moderate concerns about inadequacy as the evidence is reasonably deep, with some elaborations and examples. There was a judgement of low confidence in this theme due to the concerns regarding the adequacy of the data and the applicability of the data.

Review theme 27: Communication

Both parents and teachers reported conflict with each other, and difficulties in discussing the child with ADHD. Parents reported communication difficulties with schools and teachers, which resulted in them feeling distressed. When teachers tried to confront parents about their child’s behaviour, parents perceived this negatively. Teachers also found it difficult to confront parents about behavioural issues of their children, and found that they often had conflicting opinions of the behaviour of the child, compared to that of the parents. Those who did receive support from teachers did not feel that this greatly impacted the child’s behaviour, but it did improve the parent’s peace of mind

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 some of the contributing studies being conducted outside of the UK; moderate concerns about inadequacy as the evidence is reasonably deep, with some elaborations and examples. 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 28: Factors influencing the classroom experience

Children and young people reported the variables influencing how they behaved best in classrooms. Some felt that they learnt best in smaller classes, and found learning support units to be beneficial. They felt that classes needed to be a quiet environment that minimized distractions, such as sitting away from the window and having separate desks. They also described their ‘ideal teacher’. Some found teachers most supportive when they helped to teach them strategies for learning, had patience, and were willing to explain things and motivate children. They also felt that they needed a teacher that was strict and could control the class. They also reported that flexibility with deadlines where necessary was beneficial.

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 some of the contributing studies being conducted outside of the UK; moderate concerns about inadequacy as the evidence is reasonably deep, with some elaborations and examples. 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.

1.5.4.1.6 Theme 6: Services

Review theme 29: Experiences of service use

Some people with ADHD had positive experiences of specialist care, and felt supported by healthcare professionals. Others had negative experiences, with parents reporting long and arduous processes to receive a diagnosis of ADHD. They reported that often, the services referred to were far away, didn't provide conclusive treatment plans, offered a lack of follow up care, and elicited too many administrative duties to stay on top of.

Use of services also differed in terms of non-pharmacological interventions. Some people 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. However, healthcare professionals found that some families were reluctant to work on the wider psychological factors, instead just wanting the medical intervention

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 being conducted inside of the UK; moderate concerns about inadequacy as the evidence is not deep. 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 30: Transition to adult services

Many found delays in referral to adult services, and discontinuation of support and medication upon turning 18. People with ADHD did not feel that their age should impact on the care they received, and felt that child services still provided the support they required.

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 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.

Review theme 31: Improving treatment pathway

Healthcare professionals suggested parenting programmes would be better implemented if an initial home visit was carried out, to build trust with the parent and to explain how the programme should be used.

Healthcare professionals also felt that parents' own mental health problems, domestic violence, and low confidence should be recognised and supported by healthcare professionals before referral to parental interventions. They felt it was particularly important to identify and treat depression and ADHD when present 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; high relevance due to the contributing study being conducted inside of the UK;

moderate concerns about inadequacy as the evidence is not deep. There was a judgement of low confidence in this theme due to the concerns regarding the adequacy of the data and the applicability of the data.

1.5.4.1.7 *Theme 7: Methods of providing information and support*

Review theme 32: Support groups

Parents and people with ADHD felt that support groups would be a useful way of gaining information and support. Parents felt it would be helpful to speak to other parents, and learn ways to manage their children from them. They reported often seeking other parents when they had questions about their condition, or decisions around whether or not to medicate their child. Women with ADHD had a strong desire to have access to support groups to help them to learn about other women's experiences of having ADHD.

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 most of the contributing studies being conducted outside of the UK; moderate concerns about inadequacy as the evidence is reasonably deep. 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 33: Written and oral presentation

Parents felt that written detailed information about ADHD would be useful. Other parents wanted concise orally presented summaries of what they needed to know. They didn’t want information to be too technical or too vague.

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 outside of the UK; moderate concerns about inadequacy as the evidence is not deep. There was a judgement of low confidence in this theme due to the concerns regarding the adequacy of the data and the applicability of the data.

Review theme 34: The Internet

People with ADHD reported learning about their condition by accessing information on internet sites, although they felt direction on which websites to use would be helpful. GPs also took part in an online training course, which made them feel more confident in managing patients.

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 most of the contributing studies being conducted outside of the UK; moderate concerns about inadequacy as the evidence is not deep. There was a judgement of low confidence in this theme due to the concerns regarding the adequacy of the data and the applicability of the data.

Review theme 35: Methods for children

Parents felt that healthcare professionals needed to be careful in their approach to discussing ADHD with children. Patients felt that the term 'disorder' should not be used with young children, and that non-medical narratives should be used until the child is older. Young people with ADHD greatly emphasised the need for parents, healthcare professionals and teachers to assure them not to be ashamed of their symptoms or diagnosis. They also emphasised the need to not speak about the condition negatively.

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 most of the contributing studies being conducted outside of the UK; moderate concerns about inadequacy as the evidence is not deep. There was a judgement of low confidence in this theme due to the concerns regarding the adequacy of the data and the applicability of the data.

1.5.5 Qualitative evidence summary

1.5.5.1 Theme 1: Diagnosis

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**
Benefit of diagnosis					
15 10 children and young people 5 adults	(13 interviews; 2 focus groups) (4 UK; 6 USA; 1 Iceland, 1 Australia, 1 Sweden, 1 Denmark, 1 Norway)	People reported a sense of relief, elation, reduction of guilt and improved relationships and self-esteem following a diagnosis	Limitations	minor limitations	MODERATE
			Coherence	moderate concerns about coherence	
			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**

Harm of diagnosis					
11 6 children and young people 5 adults	(10 interviews; 1 focus groups) (3 UK; 4 USA; 1 Ireland, 1 Sweden, 1 Denmark, 1 mixed European countries)	People experienced stigma and feelings of isolation, embarrassment, anxiousness and shame following a diagnosis	Limitations	minor limitations	MODERATE
			Coherence	moderate 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**
Doubt of diagnosis					
1 Adults	Interviews (Sweden)	People had varying degrees of doubt around their diagnosis and the existence of ADHD	Limitations	minor limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate 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**
Missed diagnosis					
4 Adults	Interviews (2 UK; 1 USA; 1 Sweden)	If diagnosed earlier, people felt negative impacts of their behaviour could have been avoided. Education and employment Emotional wellbeing Relationships	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

1.5.5.2 Theme 2: Challenges for people with ADHD

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**
Recognition					
1 Children and	Interview	Teachers were not aware of inattentive symptoms of ADHD or found this behaviour difficult to pinpoint	Limitations	moderate limitations	LOW
			Coherence	minor	

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

Table 15: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Academic and employment impact					
7 3 children and young people 4 adults	5 Interviews; 2 focus groups (2 UK; 2 USA; 1 Canada; 1	ADHD symptoms negatively impacted on academic achievement and employment	Limitations	minor limitations	MODERATE
			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**
	Hong Kong; 1 Australia)		Adequacy	moderate concerns about adequacy	

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**
Psychosocial impact					
6 5 children and young people 1 adults	5 interviews; 1 focus group (2 USA; 1 Canada; 1 Hong Kong; 1 Korea; 1 Australia	ADHD had negative impacts on emotional wellbeing and social functioning	Limitations	minor limitations	MODERATE
			Coherence	minor 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**
Bullying					
3 Children and young people	Interviews (Hong Kong; Australia; Canada)	Children and young people reported being bullied as a result of their symptoms	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 18: 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 on life					
4 1 children and young	2 interviews; 2 focus groups	ADHD has a huge impact on people's lives Ability to undertake tasks Impact on life decisions Long term impact	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 3 adults	(2 UK; 1 USA; 1 Canada)			coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 19: 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**
Substance use					
3 Adults	Interviews (1 USA; 2 Sweden)	People with ADHD felt inclined to use substances such as nicotine and alcohol	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate 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 20: 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
Driving skills					
1 Adults	Interviews USA	People with ADHD felt that their symptoms impacted on their driving ability	Limitations	moderate limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 21: 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
Experiences of support					
5 2 children and young people 3 adults	Interviews (1 Hong Kong; 3 USA; 1 Finland)	People with ADHD needed more support from their family, teachers and healthcare professionals	Limitations	moderate limitations	MODERATE
			Coherence	minor 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
Conflict					
1 Children and their parents	1 interview China	Conflict arose between parents and their children, which sometimes involved physical abuse of either the parent or the child.	Limitations	moderate limitations	MODERATE
			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	minor concerns about adequacy	

1.5.5.3 Theme 3: Challenges for parents

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
Experiences of support					
15 Children and young people	Interviews (4 USA; 5 UK; 1 Palestine; 1 China; 1 Taiwan; 1 Australia; 1 Norway; 1 Finland)	Parents needed more support from healthcare professionals, teachers and family members	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	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
				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
Psychosocial impact					
21 Children and young people	19 Interviews; 1 focus group (6 USA; 1 Hong Kong; 1 Palestine; 1 Sweden; 1 China; 4 UK; 3 Australia; 1 Taiwan; 1 Ireland; 1 Norway; 1 mixed European countries)	Having a child with ADHD had negative impacts on emotional wellbeing and social functioning	Limitations	moderate limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	minor 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**
High demand					
9 Children and young people	8 interviews; 1 focus group (3 USA; 2 UK; 1 Taiwan; 1 Sweden; mixed European countries;1 Australia)	Bringing up a child with ADHD can be highly demanding and cause high levels of emotional and physical exhaustion	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			Quality assessment		
No of studies contributing to the theme	**Design**	**Themes**	**Criteria**	**Rating**	**Overall assessment of confidence**
Employment/ education					
2 Children and	Interviews (USA;	Parents had to reduce their working hours, stop working entirely, and put educational opportunities on hold to care for their child	Limitations	moderate 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
young people	Mixed European countries)			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
Access to services					
5 Children and young people	Interviews (1 USA; 1 Taiwan; 1 UK; 1 China; 1 Hong Kong)	Parents did not know how to access services Lack of information after diagnosis Treatment options not provided	Limitations	moderate limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns	

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

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**
Information needs					
9 Children and young people	7 interviews; 2 focus groups (5 USA; 2 UK; 1 China; 1 Hong Kong; 1 Australia)	Parents felt they required more information about the causes, mechanisms, and functional implications of ADHD	Limitations	moderate limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

1.5.5.4 Theme 4: Healthcare professionals

Table 29: 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**
Diagnosis					
6	Interviews (2 UK; 1 Belgium and the UK; 1 Netherlands; 1 Norway; 1 Australia)	Healthcare professional's experiences, perspectives and understanding of ADHD impacted whether someone would receive a diagnosis	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate 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**
Recognition					
2	Interviews	GPs had difficulty in recognising ADHD	Limitations	severe	LOW

Study design and sample size			Quality assessment		
No of studies contributing to the theme	Design	Themes	Criteria	Rating	Overall assessment of confidence
		Lack of training		limitations	
	UK	Difference between normal behaviour and ADHD symptoms	Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate 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
Attitudes					
3	Interviews (1 UK; 2 Australia)	GPs had negative attitudes towards ADHD Diagnosis harmful ADHD overused and ill-defined Shortcomings of parenting	Limitations	severe limitations	VERY 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	

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
Management					
3	Interviews (Netherlands; Australia; UK)	GPs had limited understanding of their role in treatment management Online training course	Limitations	moderate limitations	LOW
			Coherence	moderate concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

1.5.5.5 Theme 5: Schools

Table 33: 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**
Challenges for teachers					
3 Children and young people	Interviews (1 Palestine; 1 Korea; 1 USA)	Teachers found it difficult to support children and young people with ADHD Time and resource constraints Lack of training	Limitations	moderate limitations	LOW
			Coherence	minor 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**
Teachers' attitudes					
4 Children and	(3 interviews; 1 focus	Some teachers displayed negative attitudes towards the condition	Limitations	minor limitations	MODERATE
			Coherence	minor	

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

Table 35: 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**
Parents' attitudes					
1 Children and young people	Focus groups USA	Parents felt behavioural problems were a result of poor teaching and were insulted by teachers suggesting visiting a doctor	Limitations	minor limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns	

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

Table 36: 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
Communication					
4 Children and young people	3 interviews; 1 focus group (1 UK; 1 USA; 1 Canada; 1 Australia)	Parents and teacher often conflicted when discussing the child's behavioural difficulties	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 37: 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
Factors influencing the classroom experience					
4 Children and young people	Interviews (2 UK; 1 Canada; 1 USA)	Children benefited from small classes with minimized distractions and good teaching techniques and support	Limitations	minor limitations	MODERATE
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

1.5.5.6 Theme 6: Services

Table 38: 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**
Experiences of service use					
4 2 children and young people	3 interviews; 1 focus group (1 Belgium;	People experienced delayed services with long diagnostic processes and a lack of follow up care	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
Experiences of service use					
	3 UK)		Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 39: 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
Transition to adult services					
2 adults	Interviews UK	People found a delay in referral to adult services	Limitations	minor limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	fully relevant	
			Adequacy	moderate concerns about adequacy	

Table 40: 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**
Improving the treatment pathway					
1	Focus groups UK	Healthcare professionals felt interventions could be improved with initial home visits and addressing parents' own mental health conditions.	Limitations	moderate limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

1.5.5.7 Theme 7: Methods of providing information and support

Table 41: 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**
Support groups					
5 3 children	1 interview; 2 focus groups	People wanted access to support groups to talk to other people in similar situations Emphasised in women with ADHD	Limitations	moderate limitations	MODERATE
			Coherence	minor	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
and young people 2 adults	(3 USA; 1 China; 1 Australia)			concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

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Table 42: 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
Written and oral presentations					
1	Interviews	People felt detailed written information about ADHD or oral summaries would be most useful	Limitations	minor limitations	LOW
Parents of children and young people	USA		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	

Table 43: 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**
The internet					
2 Adults	Interviews (USA; Netherlands)	People felt direction on which internet sources to use would be helpful, and GPs found online training materials to be useful	Limitations	moderate limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

Table 44: 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**
Methods for children					
2	Interviews USA	People felt that care needed to be taken when explaining ADHD to children Avoiding negative words Non-medical narratives Assurances	Limitations	moderate limitations	LOW
			Coherence	minor concerns about coherence	
			Relevance	partially relevant	
			Adequacy	moderate concerns about adequacy	

1.6 Economic evidence

1.6.1 Included studies

No relevant health economic studies were identified.

1.6.2 Excluded studies

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

See also the health economic study selection flow chart in Appendix E:.

1.7 Resource impact

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

1.8 Evidence statements

1.8.1 Clinical evidence statements

- See section 1.5.4.1

1.8.2 Health economic evidence statements

- No relevant economic evaluations were identified.

1.9 Recommendations

B1. Use this guideline with the NICE guidelines on service user experience in adult mental health and patient experience in adult NHS services to improve the experience of care for adults with ADHD. The principles also apply to children and young people and their parents or carers.

B2. Healthcare professionals working with children and young people with ADHD should follow the recommendations on general principles of care in NICE's guideline on antisocial behaviour and conduct disorder in children and young people. This does not mean that all children and young people with ADHD have coexisting antisocial behaviour and conduct disorder but that the same general principles of care apply when working with children and young people.

B3. Provide information and support for people who have an assessment but are not given a diagnosis of ADHD (for example, information about local and national groups and voluntary organisations that offer support for their situation).

Supporting people with ADHD

B4. Following a diagnosis of ADHD, have a structured discussion with people (and their families or carers as appropriate) about how ADHD could affect their life. This could include:

- the positive impacts of receiving a diagnosis, such as:
  - improving their understanding of symptoms
  - identifying and building on individual strengths
  - improving access to services
- the negative impacts of receiving a diagnosis, such as stigma and labelling
- a greater tendency for impulsive behaviour
- the increased risk of substance misuse and self-medication
- the possible effect on driving (for example, some ADHD medication may impact on a person's fitness to drive and people with ADHD must declare their diagnosis to the DVLA if it affects their driving)
- the challenges of managing ADHD when a person has coexisting neurodevelopmental or mental health conditions
- education and employment issues (for example, impact on career choices and rights to reasonable adjustments at school and college, and in the workplace)
- social relationship issues.

This should inform the shared treatment plan.

B5. Tell people receiving a diagnosis of ADHD (and their families or carers as appropriate) about:

- local and national support groups and voluntary organisations
- sources of more information, including websites
- support for education and employment

B6. Improve communication by providing information to people with ADHD (and their families and carers as appropriate) that:

- takes into account their developmental level, cognitive style, emotional maturity and cognitive capacity, including any learning disabilities, sight or hearing problems, delays in language development or social communication difficulties
- takes into account any coexisting neurodevelopmental and mental health conditions
- is tailored to their individual needs and circumstances, including age, gender, educational level and life stage.

Supporting families and carers

B7. Ask families or carers of people with ADHD how the ADHD affects them, and discuss any concerns they have.

B8. Encourage family members or carers of people with ADHD to seek an assessment of their personal, social and mental health needs, and to join self-help and support groups if appropriate.

B9. Offer advice to parents and carers of children and young people with ADHD about the importance of:

- positive parent– and carer–child contact
- clear and appropriate rules about behaviour
- structure in the child or young person’s day.

B10. Offer advice to families and carers of adults with ADHD about:

- how ADHD may affect relationships
- how ADHD may affect the person’s functioning
- the importance of structure in daily activities.

B11. Explain to parents and carers that any recommendation of parent-training/education does not imply bad parenting, and that the aim is to optimise parenting skills to meet the above-average parenting needs of children and young people with ADHD.

Involving schools and colleges

B12. When ADHD is diagnosed, when symptoms change, and when there is transition between schools or from school to college, obtain consent and then contact the school or college to explain:

- the validity of a diagnosis of ADHD and how symptoms are likely to affect school or college life
- other coexisting conditions (for example, learning disabilities) are distinct from ADHD and may need different adjustments
- the treatment plan and identified special educational needs, including advice for environmental and learning modifications

- the value of feedback from schools and colleges to people with ADHD and their healthcare professionals. .

B13. When a person with ADHD has a coexisting condition contact the relevant healthcare professional, with consent, to explain:

- the validity, scope and implications of a diagnosis of ADHD
- how ADHD symptoms are likely to affect the person's behaviour (for example, organisation, time management) and adherence to specific treatments
- the treatment plan and the value of feedback from healthcare professionals.

1.10 Rationale and impact

1.10.1 Why the committee made the recommendations

Good information and support tailored to need and circumstances are important for all people using NHS services, but some aspects are particularly important for people with ADHD. Evidence identified the need for information tailored to family circumstances, particularly when a child has ADHD, and to highlight the importance of daily structure for adults with ADHD.

Evidence showed the importance of discussing key areas following a diagnosis of ADHD, particularly the positive impacts of receiving a diagnosis, such as improving understanding of symptoms. The committee used the evidence and their experience to agree other areas for discussion, including driving and possible issues with education and employment. They noted that schools, colleges and employers may sometimes question a diagnosis of ADHD and not understand how symptoms can affect daily functioning. In addition, healthcare professionals treating a coexisting condition may not be aware of how ADHD symptoms may affect behaviour (organisation and time management) and adherence to treatment.

There was evidence that parents of children with ADHD often feel a sense of isolation when attending parent-training programmes. The committee agreed that healthcare professionals should explain to parents that an invitation to attend a parent-training programme does not imply bad parenting.

In the committee's experience, people who are assessed for ADHD but not given a formal diagnosis are a neglected group who would benefit from advice on where to get support for troublesome symptoms.

1.10.2 Why we need recommendations on this topic

The NICE guidelines on service user experience in adult mental health and patient experience in adult NHS services outline the key principles of general care. It is also important to identify and address the unique needs of specific conditions. Following a diagnosis of ADHD, children, young people and adults, and their carers and families require up-to-date, relevant information about ADHD provided in formats to suit their individual needs.

Post-diagnostic advice is an invaluable part of the assessment process and these discussions exploring beliefs and perceptions should also be part of forming the shared treatment plan. Support and accurate information is critical in empowering people with ADHD to aid their understanding of their symptoms and reduce self- stigma. Negative and inaccurate beliefs can impact on a person's well- being resulting in poor management and potentially exacerbates behaviours that result in impairment (such as self-medication). Good quality information and support can increase adherence to treatment and help people to develop constructive coping strategies to manage these symptoms and reduce the impact on their everyday lives. Accurate information is helpful for people with ADHD to use when informing people around them about the ways that their ADHD symptoms may affect them and how this should be taken into account. Current practice varies and not everyone diagnosed with ADHD receives this advice and support. There is therefore a need to update and reinforce the previous recommendations on this topic.

1.10.3 Impact of the recommendations on practice

The recommendations should reflect good current practice. Healthcare professionals may spend more time discussing the potential impacts of a diagnosis, but this is likely to mean improved quality of life for the person with ADHD and better management of their symptoms.

1.11 The committee's discussion of the evidence

1.11.1 Interpreting the evidence

1.11.1.1 The quality of the evidence

For many of the subthemes, a large amount of evidence was identified. Most of the evidence was of low to moderate quality, with one review theme of very low quality. There were mainly only minor concerns about the coherence of the themes. Many of the themes had moderate concerns about methodological limitations and the adequacy of the data, which was mainly related to the richness 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 committee were in agreement that the subthemes presented were consistent with their own clinical experiences.

1.11.1.2 Themes identified in the evidence synthesis

Information and support

The committee identified a number of themes that merited recommendations. In studies included in the review, people discussed the impact of ADHD, and of having a diagnosis of ADHD, on their lives as being pervasive and having a mixture of benefits and harms. The committee felt it was important for this to be discussed openly with people at the point of diagnosis.

People noted that they frequently felt they had insufficient support and that this was at least partially due to a lack of awareness of what support was available. The committee chose to recommend that healthcare professionals are aware of and able to direct people to local services (for example charitable organisations, focus groups). The opportunity for parents of children with ADHD to participate in group support was highlighted in the evidence review.

People noted that they wanted more information about ADHD at their diagnosis. While the committee felt that this would be standard practice for any condition, as would referral to the appropriate support group, the committee emphasised the association of ADHD with additional and co existing conditions including risky behaviour, learning difficulties and problems with relationships and the need to specifically elicit concerns in these areas. They felt that it was important for people with ADHD and their families to be aware of the association of ADHD with other conditions and behaviour, based on their experience.

While not identified in the review, the committee also felt that it was important that people with ADHD were made aware of certain legal aspects of their condition, including their rights to reasonable adjustments and, at an appropriate age, their obligations with regards to driving.

The committee also noted that while these recommendations principally pertained to people who received a diagnosis of ADHD, that people who are assessed for but not diagnosed with ADHD may have many of the same needs. It is beyond the scope of this guideline to aim specific recommendations at this group, the committee chose to recommend that healthcare professionals ensure that this group is supported appropriately to their condition, for instance by directing them to other healthcare professionals or for further assessment if required.

The previous guideline included recommendations on the involvement of schools and specific support to be provided to the family and carers. While there was little information specifically on the types of information and support needed for these groups in the evidence review, the review certainly identified schools, families and carers as groups that required support and involvement. The committee made consensus based recommendations informed by the previous guideline and their own experience on the types of support and involvement that would be appropriate for schools, family and carers. The committee discussed that contact with schools and college was good current practice and would usually be delivered by an ADHD nurse specialist, but could be another ADHD specialist within the multidisciplinary team. The specialist works with the schools and colleges to advise on environmental modifications and to liaise with about progress of treatments and impact of ADHD symptoms.

Methods of information and support

The committee noted that the review themes suggested that people generally found information and support most useful if it was available in both oral and written form. People with ADHD also requested direction to appropriate and useful online resources. Finally people said they appreciated the support available from groups in which other people or families dealing with ADHD could discuss their experiences. The committee therefore recommended that healthcare professionals should make people aware of sources of support and additional information. For more information see evidence report G on adherence to treatment.

1.11.2 Cost effectiveness and resource use

No economic evidence was identified for this question.

The committee wanted to outline some general principles of care that would allow appropriate information and support to be provided to people with ADHD, their families, and their teachers (if children). Information can be provided in a variety of formats (written, verbal) and should be tailored to the individual because of the condition. Providing appropriate information and making sure the patient and their families/carers (as well as teachers) are involved in treatment decisions, and understand the impact of the condition, can aid in maximising the benefit from any treatment and allow the patient/families/carers to feel supported.

These recommendations are unlikely to have a large resource impact.

1.11.3 Other factors the committee took into account

The committee noted that many of the themes identified by people with ADHD were not specific to ADHD and were included in generic NICE guidance on communication or in guidelines on similar conditions. The committee chose to cross refer to the following guidelines on communication (Service user experience in adult mental health, Patient experience in adult NHS services and Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence) for further information. The committee also cross referred to the NICE guideline on antisocial behaviour and conduct disorder in children and young people, they endorsed the recommendations on the general principles of care in this guideline and how they applied to people with ADHD. General concepts in the above guidelines that applied to the ADHD population included the need for shared decision making to the level preferred by any individual person, involvement of their family and carers as appropriate and making efforts to understand a person as an individual.

The committee acknowledged the depth and richness of the evidence identified but also considered it was important to supplement the recommendations with examples from their experience that were important to highlight (for example the clear advice on driving). They agreed that these examples were more current and relevant to the UK population.

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Appendices

Appendix A: Review protocols

Table 45: Review protocol: Information and support for people with ADHD

Field	Content
Review question	What are the information and support needs of children, young people and adults with ADHD and their family and carers after diagnosis?
Type of review question	Qualitative
Objective of the review	To identify the information and support needs that of people with ADHD, have to support their wellbeing following diagnosis.
Eligibility criteria – population / disease / condition / issue / domain	• Children, young people and adults with ADHD. • Family, partners and carers of people with ADHD • Teachers/professionals involved in education and employers • Healthcare professionals involved in the care of people with ADHD (primary care, professionals who deliver treatment (pharma or non-pharma) and social care)
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: • What information clinicians should provide to people with ADHD, their families and carers about ADHD • What information should be provided around the possible impacts of ADHD on a person's life • Information for GPs and healthcare professionals (including for professionals treating conditions comorbid to ADHD) • Information for educationalists and employers • The timing/frequency of information and support • Information about managing treatment • Emotional and psychological support, and physical activity and care • Sport and physical activity • Support to engage in education and employment • Support for maintaining relationships • Information around effective coping strategies. Important of personalising information/support • Information/support from expert patient • Information about independent living/financial management, including seeking financial support • The role of written information/support (e.g. leaflets, workbooks) • The role of online information (e.g. factsheets)/support • The role of apps/innovative technology • Individual vs. group sources of support • Proactive support vs. person-led
Eligibility criteria – study	Qualitative interview and focus group studies (including studies using

design	grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data from questionnaires will only be considered if insufficient qualitative evidence is identified
Other inclusion exclusion criteria	Exclusions: ADHD diagnosis made not using DSM-III/ICD-10 or later versions of these (note that studies evaluating treatments for ADHD in a population of people with autistic spectrum disorder will be included if no formal diagnosis of ADHD has been made using these, but evidence of moderate to severe symptoms of hyperactivity, impulsivity, and/or inattention is demonstrated according to validated symptom questionnaires)
Proposed sensitivity / subgroup analysis, or meta-regression	Not applicable
Selection process – 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	For details please see section 4.5 of Developing NICE guidelines: the manual.
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, 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.
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

1

2 **Table 46: 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

Review question	**All questions – health economic evidence**
	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).[144] Inclusion and exclusion criteria If a study is rated as both 'Directly applicable' and with 'Minor limitations' then it will be included in the guideline. A health economic evidence table will be completed and it will 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

Review question	All questions – health economic evidence
	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 47: 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 48: 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.

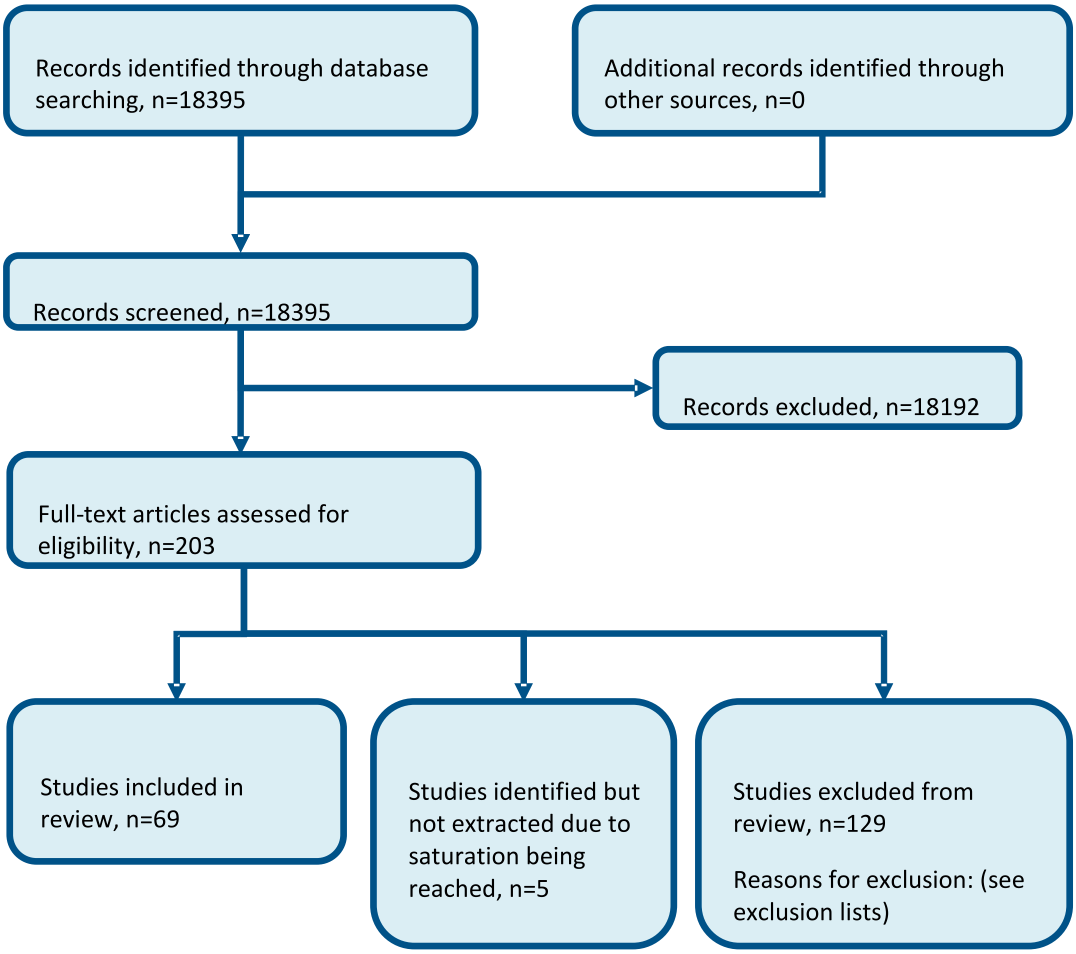
37.	econom* model*.ti,ab.
38.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
39.	or/29-38
40.	*health economics/
41.	exp *economic evaluation/
42.	exp *health care cost/
43.	exp *fee/
44.	budget/
45.	funding/
46.	budget*.ti,ab.
47.	cost*.ti.
48.	(economic* or pharmaco?economic*).ti.
49.	(price* 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 Information and support



1

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	**Bartlett 2010**[8]
Aim	To determine what successful young adults perceive was helpful to them when they had difficulties with their symptoms as children
Population	16 young adult college students (aged 18 – 25)
Setting	USA
Study design and methodology	A semi structured interview was conducted, using an interview guide to direct the discussion. Interviews lasted for 30 minutes to 1 hour and were analysed using content analysis methods. First notes were made in the transcripts, followed by categorisation of the data using concepts that came from participants' words. These categories were used to determine the final themes.
Themes with findings	Support from parents •Participants reported that they found their parents' ability to create a structured environment and teaching strategies of coping to the child to be incredibly useful
Limitations	Minor limitations related to the richness of the data
Applicability of evidence	Partially; conducted in the USA and applicable to the experiences of young college students with ADHD (note: retrospective experiences of young adults' childhoods)

Study	**Bringewatt 2013**[12]
Aim	Explore young adults' experiences of their ADHD
Population	42 young adults with ADHD (aged 18 to 22 years)
Setting	USA
Study design and methodology	Semi-structured interviews analysed using grounded theory

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Study	**Bringewatt 2013**[12]
Themes with findings	Benefit of diagnosis •Young adults reported initially being unhappy with a diagnosis, but found it helpful when further medical information was received
Limitations	Moderate limitations related to data richness, the role of the researcher
Applicability of evidence	Partially; conducted in the USA and limited to young adults with ADHD aged between 18 and 22 years old.

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

Study	**Brinkman 2008**[14]
	Factors supporting initiation of treatment •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 were developed by all investigators and informed by the literature. Inductive coding of transcripts was used, followed by focused coding
Themes with	Driving skills

Study (ref id)	**Brinkman 2012[15]**
findings	•Many participants were unaware of the increased risk for automobile accidents with ADHD, and the impact of medication on this 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

Study (ref id)	**Charach 2006[27]**
	•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	**Cheung 2015[30]**
Aim	Explore young adults experiences in accessing treatment and services
Population	40 young adults (aged 16 to 23 years (20 patients 16-17 and 20 18+))
Setting	Hong Kong
Study design and methodology	Face to face semi-structured interviews using an interview guide from an earlier study, carried out by a team of pharmacists and paediatricians. Interviews lasted for approximately 30 minutes to an hour. Analysis by grounded theory principles
Themes with findings	Accessing services •Experiences with accessing treatment varied across patients, with some having no difficulty and some having to wait a long time. Transition to adult services •Patients reported staying within child and adolescent services due to doctors deciding this was more appropriate Transition to adult services •Patients reported their care being terminated until they were referred to an adult psychiatry centre Challenges of ADHD

Study	Cheung 2015[30]
	•Academic impairment was reported to be due to inability to listen in class and failure to complete homework Challenges of ADHD •Patients relationships with classmates and teachers were negatively impacted by ADHD, due to teachers disciplining and classmates subsequent judgements and bullying
	Challenges of ADHD •Patients reported difficulties in employment, particularly around carrying out repetitive tasks, having poor attention, being careless and having poor time management Emotional aspects of ADHD •Patients felt sad due to feeling inferior to others due to their ADHD Worrying about medication •Patients felt worried that the medication was damaging their health, even though they were accepting doctors' clinical decisions Accessing services •Some participants reported not being offered non pharmacological treatment options Decision making •Patients felt unqualified to make decisions around their treatment and trusted their decision making Decision making •Patients took on more responsibility of decision making as they got older
	Emotional support •Patients felt they required more emotional support from doctors Explaining the condition •Patients felt that doctors needed to explain ADHD better, particularly during childhood, to help patients understand their condition and therefore manage it Transition to adult services •Patients felt that staying in child and adolescent services was more appropriate than transitioning to adult services
Limitations	Minor limitations related to the richness of the data
Applicability of evidence	

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Limitations	Minor limitations related to the richness of the data
Applicability of evidence	

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
Themes with findings	Harm of diagnosis •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
Themes with findings	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.
	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[41]**
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 evidence	Partial applicability

Study	**dosReis 2010[44] (dosReis 2007[46])**
Aim	To explore the experiences of parents with a child with ADHD
Population	26 African-American parents of children with ADHD (aged 6 to 18 years)
Setting	USA
Study design and methodology	Telephone interviews were conducted with 46 participants and face to face interviews with 2 participants. Interviews were semi-structured, and a field guide developed by the principal investigator was used. The analysis utilised a grounded theory approach. Transcripts were coded line-by-line, followed by discussions of the defining characteristics of each code. A coding manual was developed and the whole data set was recoded using this. Codes were refined, collapsed, or eliminated as needed, until 100% agreement was achieved.
Themes with	Difficulties for parents

Study	**dosReis 2010[44] (dosReis 2007[46])**
findings	•Parents reported social isolation for both themselves and their children
	Lack of support for parents •Parents felt that their concerns were being dismissed by HCPs and educational professionals.
Limitations	Minor limitations related to the richness of the data
Applicability of evidence	Partial applicability

Study	**Einarsdottir 2008[49]**
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[54]**

Study	**Fiks 2010**[54]
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	**Flannagan 2002**[56]
Aim	
Population	40 mothers and their children with ADHD (aged 8 to 11 years)
Setting	USA
Methods and analysis	Open-ended one-on-one interviews of each mother and child were completed, using an interview schedule. Each interview lasted approximately 2 hours. Analysis method unclear; coding used
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Providing information •Mothers reported receiving little functional information about ADHD

Study	**Gallichan 2008**[60]
Aim	Explore young peoples' perspectives of ADHD

Study	**Gallichan 2008**[60]
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 •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**[65]
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

Study	**Ghosh 2016**[65]
	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	**Goodwillie 2014**[67]
Aim	Explore parental views of the impact of having a child with ADHD
Population	6 parents with children diagnosed with ADHD (aged children' not specified)
Setting	UK
Methods and analysis	Interviews were analysed using interpretative phenomenological analysis
Limitations	Moderate limitations related to data richness, the role of the researcher and the data analysis
Themes	Difficulties for parents •Parents did not feel other people were equipped to look after their children safely, including close relatives, because they didn't understand the extent of behavioural issues the child exhibited

Study	**Hallberg 2008**[71]
Aim	To explore the experiences of parents with teenage daughters with ADHD
Population	12 parents of adolescents with ADHD (aged Adolescent)
Setting	Sweden
Methods and analysis	Open-ended interviews lasted for approximately 60 to 90 minutes. An interview guide was used which mainly focused on the experiences and feelings of the parents. Grounded theory was used to analyse transcripts. Initially open coding was carried, and the substance of the data was captured and segmented into codes, which were labelled concretely. Similar codes were grouped to form

Study	**Hallberg 2008[71]**
	abstract themes.
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Burden for parent’s •Parents reported severe distress and living at the edge of ones' capability due to having a child with ADHD. Parents said they had no private lives at all and their lives were completely taken over by their daughter

Study	**Hallerod 2015[73]**
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[72]
Aim	Explore parents' experiences of medicating their child with ADHD
Population	10 parents of children with ADHD (aged 8 to 22 years)
Setting	Canada
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 phenomenological 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[74]
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

Study	**Harazni 2016[74]**
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
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[77]**
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

Study	**Hassink-Franke 2016**[77]
	•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 •GPs felt more confident in managing patients with ADHD after taking part in an online training course

Study	**Henry** [80] **(#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	**Ho 2011**[192]
Aim	To explore parents' perceptions of their child with ADHD
Population	12 parents of children with ADHD (aged Children (not specified))
Setting	China
Methods and analysis	Semi-structured interviews using open ended questions that focused on parents' understanding of the illness and their perception of ADHD, their care-giving experiences, perceived barriers and the implications for their family. Data was analysed by content analysis
Limitations	Moderate limitations related to data richness, the role of the researcher and the context of the study

Study	**Ho 2011[192]**
Themes	Understanding of ADHD •Parents had a limited understanding of ADHD and perceived it to be mainly concerned with difficult behaviours
	Sources of information •Parents reported seeking other parents when they had questions about the illness
	Barriers to child care •Parents reported finding it difficult to provide normal care for their children, due to their behaviour, time constraints and financial constraints
	Accessing services •Parents reported not knowing how to obtain a better understanding of the condition or how to receive academic assistance.
	Parental support •Parents reported that care-giving demands negatively impacted their psychological state
	Lack of support •Parents reported a lack of support from loved ones and healthcare professionals. Many felt other parents in the primary schools were stigmatizing them.

Study	**Hong 2008[83]**
Aim	Explore teachers' experiences and perspectives of children with ADHD
Population	8 kindergarten teachers, 2 day care teachers, 1 occupational therapist, and 12 schoolteachers. (Aged N/A)
Setting	Korea
Methods and analysis	Some participants were interviewed and some took part in a focus group. 10 teachers only participated in the survey. Each interview/focus group took between 30 to 60 minutes. Analysis not specified
Limitations	Severe limitations related to data richness, the role of the researcher and the design of the study
Themes	Difficulties for teachers •Teachers felt helpless and frustrated when unsuccessful in helping or controlling a child with ADHD
	Social impact of ADHD •Teachers reported that children with ADHD often did not have any friends due to their behavioural characteristics
	Difficulties for teachers •Teachers did not feel they had the resources to fully support children with ADHD
	Harm of medication •Teachers found that the effects of medication wore off very quickly throughout the day
	Relationship with parents/ drug holidays

Study	**Hong 2008**[83]
	•Teachers did not feel it was right that parents did not strictly follow doctors' prescriptions, but medicated them based on their own subjective judgement

Study	**Honkasilta 2016**[85]
Aim	To explore teachers' classroom management strategies for ADHD
Population	Teachers
Setting	Finland
Methods and analysis	Interviews lasted on average around 90 minutes and were conducted with an interview guide. Functional methods were also used, such as using feeling cards. A narrative approach was applied to analyse the data. By this approach the authors assumed participants' experiences could be captured and constructed in the form of stories. Initial phases of analysis dealt with coding the data, followed by distinguishing between 'real' narrative and merely reported opinions. The next stage focused on identifying similarities and differences between them, thus grouping the narratives together
Limitations	Minor limitations
Themes	Lack of support from teachers •Students described many situations in which students needed help and guidance from teachers, but there was a lack of available support
Study	Honkasilta 2014[84]
Aim	To explore parental involvement in their child's schooling
Population	18 mothers of children with ADHD (aged Not specified)
Setting	Finland
Methods and analysis	Critical discourse analysis was used to analyse interview data. No further details
Limitations	Minor limitations related to the richness of the data
Themes	Support from schools •Parents reported a difficulty in communication and support from schools

Study	**Hughes 2009**[87]
Aim	How to support children with ADHD in their learning environment
Population	

Study	**Hughes 2009[87]**
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[86]**
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	**Jones 2014[91]**
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.

Study	Jones 2014[91]
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[94]
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.
	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,

Study	**Kendall 2003[94]**
	in terms of being uninterested in fun activities and feeling 'depressed'.

Study	**Kildea 2011[96]**
Aim	Explore stakeholders' thoughts concerning ADHD in the context of CAMHS
Population	28 stakeholders consisting of 7 mental health professionals, 2 teachers, 7 parents/carers, and 5 children referred for an ADHD assessment (aged -)
Setting	UK
Methods and analysis	Individual semi structured interviews ranging from 30 to 95 minutes (adults) and 20 to 55 minutes (children). The adults' interviews involved an interview schedule. The children's' interviews involved techniques tailored for junior aged children. Thematic analysis used. Each group was initially treated as a separate data set, followed by across group analysis.
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Consultation difficulties •HCPs reported finding it different to interpret the family and child difficulties in each consultation. They reported attempting to separate cases out into 'real' ADHD and 'pseudo' ADHD
	Challenges for parent's •Parents reported distress involved in raising a child with challenging behaviour.
	Benefit of diagnosis •Parents reported short term relief of gaining a diagnosis
	Improvement to services •Parents reported wanting a holistic service that looks at all the needs of their child, rather than focusing on some factors and not appreciating the impact this could have on the whole family system

Study	**Klasen 2000[99]**
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

Study	**Klasen 2000**[99]
Themes	Understanding of ADHD •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	**Kovshoff 2012**[105]
Aim	Explore clinicians experiences and attitudes to the diagnosis and management of ADHD
Population	50 clinicians (28 from Belgium and 22 from UK, consisting of psychiatrists and paediatricians) (aged N/)
Setting	UK and Belgium
Methods and analysis	Semi-structured interview with a schedule developed by senior consultant psychiatrists. Questions were open-ended and interviews lasted typically for one hour. Thematic analysis was used, enhanced by the principles of grounded theory, to identify broad themes and sub themes.
Limitations	Minor limitations related to the richness of the data

Study	**Kovshoff 2012[105]**
Themes	Factors leading to diagnosis •Clinician's personal perspectives was a clear factor in whether or not a child would receive a diagnosis, with some feeling ADHD is over diagnosed, and some not feeling comfortable making the diagnosis
	Factors leading to diagnosis •Clinicians took into account the wishes of the family, and the impact a diagnostic label could have, when they decide to make the diagnosis
	Role of the family •Clinicians reported that some families were reluctant to work on the wider psychological factors, instead just wanting the medical intervention

Study	**Larson [108] 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.
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[111]**
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	Interviews were conducted by a graduate assistant and took about 1 hour. Data was analysed by searching for emergent themes and

Study	Lee 2008[111]
analysis	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[112]
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

Study	Lefler 2016[112]
	•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	Leslie 2007[114]
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	**Lin 2009**[119]
Aim	To understand the experiences of primary caregivers who are bringing up children with ADHD
Population	10 mothers of children diagnosed with ADHD (aged 8 to 13 years)
Setting	Taiwan
Methods and analysis	In depth face-to-face interviews were conducted and lasted between 1-2 hours. An unstructured interview guide was used to allow caregivers to talk about their experiences. Colaizzi's approach was used to analyse the data. Significant themes were extracted, meaning was formulated, clusters of themes were identified and organised based on these meanings, descriptions of the experiences were written as exhaustively as possible and these were then identified and summarised.
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Burden of care •Parents reported severe parenting, emotional, and family burdens caused by their children's condition. They felt that the condition completely took over their lives due to the level of care their child needed
	Lack of support •Parents reported that when their child was initially diagnosed, it was hard for them to understand what they should do or where they should get assistance.
	Lack of support •Parents reported a lack of support mainly from spouses and other family members, and from professionals. They felt professionals had a poor understanding of the nature of ADHD and a lack of skills to deal with children, or to use resources

Study	**Loe 2008**[121]
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).
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	**Ma 2016**[123]
Aim	To learn about the lived experiences surrounding maltreatment in parent-child relationships
Population	Families with children with ADHD. 15 of 44 families that took part in a family intervention with a child with ADHD (31 fathers, 42 mothers, one grandmother, 44 children with ADHD, 18 siblings). All had been recommended for the study by social workers
Setting	China
Methods and analysis	Families took part in sessions which involved an group family intervention that involved role play and addressing issues of maltreatment. Families were interviewed before and after these sessions. Qualitative data were collected in the form of video and audio tapes of the 8 groups, from all 3 phases of the study. All families were additionally invited to attend family therapy conducted by the principal author after the study. Topics discussed in interviews included stories of maltreatment, with the aid of drawing on a whiteboard. Data were analysed using systemic theory.
Limitations	Moderate methodological limitations
Themes	Children and parents reported incidences of child maltreatment, in the form of parents harming their children, as a result of their child’s behaviour and the conflict that arose from this. Conflict often arose as a result of homework supervision, parents demands when the child was playing, parents misunderstanding their child's behaviour, and parents threatening to remove their child from their home Parents reported serious incidences of being physically abused by their children, during times of aggressive and disruptive behaviour. They specified being hit and having their hair pulled out, along with verbal abuse. Conflict often arose as a result of homework supervision, parents demands when the child was playing, parents misunderstanding their child's behaviour, and parents threatening to remove their child from their home

Study	**Matheson 2013**[127]
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

Study	Matheson 2013[127]
	•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
	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

Study	**Matheson 2013[127]**
	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	McIntrye 2012[131]
Aim	Explore parents' experiences of ADHD
Population	18 parents of children diagnosed with ADHD (aged 7 to 12 years)
Setting	UK
Methods and analysis	Open-ended interviews were carried out in the homes of participants. Interviewers prompted discussions around the experiences of the parent. Interviews lasted between 40 minutes to 1 hour 30 minutes. Data were analysed using thematic analysis. Initial codes were combined into themes, which were reviewed to ensure they made sense in relation to the coded extracts of the entire data set.
Limitations	Severe limitations related to data richness, the role of the researcher and the context of the study
Themes	Difficulties for parents •Parents reported the demanding nature of their child with ADHD, which caused feelings of guilt as they had less time to care for their other children, and marital/family friction. Parents reported the exhausting nature of their role, and many sacrifices they had made in order to care for their child
	Lack of support •Parents felt that they were being blamed for their child’s ADHD and had a lack of support from the school system, or even when schools were trying to be supportive, they did not consider the child’s needs properly
	Problems with healthcare support •Parents reported a long and arduous process to receive a diagnosis of ADHD. They reported that often, the services referred to be far away, didn't provide conclusive treatment plans, offered a lack of follow up care, and elicited too many administrative duties to stay on top of.
	Support for parents •Parents wanted to have more behavioural therapy alongside of practical advice on dealing with their child’s ADHD.

Study	**McIntyre 2012[131]**
Aim	Explore the experiences of parents of children with ADHD
Population	18 care givers/parents of children with ADHD (aged 7 to 10 years)

Study	**McIntyre 2012[131]**
Setting	Ireland
Methods and analysis	Open-ended interviews were carried out with prompts of relevant topics that could be used. Interviews ranged from 40 minutes to 1.5 hours. Data were analysed using thematic analysis
Limitations	Severe limitations related to data richness, the role of the researcher and the context of the study
Themes	Emotional distress •Parents emphasised the emotional impact of having a child with ADHD
	Stigma •Parents felt that their children were discriminated against and stigmatized by other children, teachers, family members and parents.
	Coping mechanisms •Parents reported coping with stigma by not telling people about the diagnosis and avoiding situations where they would likely meet other parents. Others opted to explain their child's behaviour to those around them.
	Support from healthcare professionals •Parents expressed extreme dissatisfaction with the quality of services their child had received. This was particularly due to the long process of diagnosis and waiting times and a lack of treatment plans
	Improving services •Parents felt that they needed more behavioural therapy alongside practical advice on dealing with their children's' behaviour

Study	**Meaux 2009[134]**
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 •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

Study	**Meaux 2009[134]**
	•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[137]**
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 •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.

Study	**Mills 2011**[137]
	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**[138]
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
	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

Study	**Moen 2011[138]**
	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	**Mychailyszyn 2008[142]**
Aim	Explore parents views of ADHD and mental health care services
Population	34 parents whose children were diagnosed with ADHD (aged 6 to 18 (mean age 8.5 years))
Setting	USA
Methods and analysis	Semi structured telephone interviews were scheduled with parents whose child had recently been diagnosed with ADHD. A field guide was developed to focus on parents' understanding of their child's behaviours; their perceptions of services, and their own responsibility. Interviews lasted from 31 to 62 minutes. Grounded theory methods were used to analyse the data. Each member of the research team identified initial topics and researchers coded transcripts line-by-line.
Limitations	Minor limitations related to the richness of the data
Themes	Understanding of ADHD •Parents struggled to identify or explain the origin of their child's behaviour and symptoms. Many offered explanations of prenatal exposure to substance use.
	Understanding of ADHD •Many parents felt their parenting skills were to blame for their children's' diagnosis
	Understanding of ADHD •How parents make sense of their children's behaviour and how they interpret the diagnosis has potentially important implications for the delivery of interventions

Study	**Nehlin 2015[180]**
Aim	To investigate how adults with ADHD perceive the role of substance abuse and drugs in their lives
Population	14 adults with ADHD, under the age of 30 with self-defined problematic alcohol/drug use (aged >18 years)
Setting	Sweden
Methods and analysis	Semi-structured interviews with pre-defined areas of interest, carried out by two psychologists, mostly at subjects homes. Narrative psychological analysis was used to extract themes.
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Substance abuse to feel normal

Study	Nehlin 2015[180]
	Participants noted that they often used alcohol or drugs to minimise symptoms and feel normal , principally through bringing a feeling of calm Missed diagnosis Participants noted that they felt if they had been diagnosed with ADHD sooner, they may have been able to avoid some of their problems with substance abuse

Study	O'Callaghan 2014[146]
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
	Stopping medication •Participants stopped medication when the costs outweighed the benefits of the treatment.

Study	**O'Callaghan 2014[146]**
	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[147]**
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[149]**
Aim	To explore Latino families' experiences with ADHD

Study	**Perry 2005**[149]
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	**Reid 1996**[153]
Aim	To explore parents' experiences of support from school systems
Population	20 parents of children with ADHD (aged 5 to 18 years)
Setting	USA
Methods and analysis	Interviews lasted approximately 20 to 40 minutes and followed an interview schedule, which was revised following the initial 15 interviews. Data were analysed using a grounded theory approach. 3 initial transcripts were coded 'openly' to break down the data and attach conceptual labels to the experiences of participants. These concepts were grouped into categories, which formed a smaller set of codes. Axial coding was then used to categorise the themes further and to arrange the remaining data under
Limitations	Minor
Themes	Support from teachers

Study	**Reid 1996**[153]
	•Parents reported a range of ways teachers/schools did not having enough understanding of ADHD or did not offer enough support. This included disagreements around medication and behaviour, poor communication, and lack of understanding for the parents' difficult situation.

Study	**Russell 2016**[156]
Aim	Explore educational practitioners views of ADHD
Population	41 educational practitioners that work with young people with ADHD, recruited from primary and secondary schools, and pupil referral units. (Aged 11 to 18)
Setting	UK
Methods and analysis	Interviews/focus groups lasted between 40 minutes and 1 hour. Both followed the same topic guide, which covered various areas of experiences working with children with ADHD. Thematic analysis used to identify codes and organise into patterns. There were 6 focus groups and 3 individual interviews
Limitations	Minor limitations related to the methodology
Themes	Blaming parents •Some education practitioners felt that parenting skills and home environment were the cause of many behaviours seen in children with ADHD, which this attribution often framed negatively
	True' ADHD •Many educational practitioners felt that many were diagnosed with ADHD that they felt only had these symptoms due to their environment. They felt that a diagnosis should not be given in these cases

Study	**Salt 2005**[157]
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 •GPs did not feel that they had adequate training in the recognition of ADHD, and felt specialist involvement was crucial
	Understanding of side effects

Study	**Salt 2005**[157]
	•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	**Schrevel 2014**[161]
Aim	To assess the perspectives, problems and needs of adults with ADHD
Population	52 adults with ADHD (aged 21+)
Setting	The Netherlands
Methods and analysis	5 focus groups explored the daily experiences of adults with ADHDs, including a brainstorm session and discussion phase. The final 3 focus groups consisted of a reflection phase of the findings of the previous focus groups, a creative phase in which participants were asked to visualize their current situation and their desired situation, and how they could achieve this, and an exercise to identify real world solutions for reaching this situation.
Limitations	Moderate limitations related to data richness
Themes	Impact of ADHD •Patients felt that their symptoms greatly impacted their ability to undertake everyday tasks

Study	**Segal 1998**[164]
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**[163]
Aim	Explore mothers' experiences raising children with ADHD

Study	**Segal 2001**[163]
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 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	**Shaw 2003**[166]
Aim	Explore GPs attitudes towards ADHD
Population	28 GPs caring for people with ADHD (aged N/A)
Setting	Australia
Methods and analysis	Focus groups were conducted which lasted up to 2 hours and contained 4-5 GPs per group. A moderator guide was developed and used thematically to guide and facilitate the unstructured group discussion. Type of analysis not specified
Limitations	Moderate limitations related to data richness, the role of the researcher and the context of the study

Study	**Shaw 2003[166]**
Themes	GP understanding of ADHD •Many GPs felt that ADHD was a result of difficult family situations and poor parenting, often feeling that labels were not helpful
	GP understanding of ADHD •Many felt that ADHD was over diagnosed
	GP involvement in support •GPs showed little interest in being the primary care provider for children with ADHD
	GP involvement in support •GPs reported that they would be more willing to be involved in the care of these children if they received more training to do so

Study	**Sikirica 2014[167]**
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
	Reasons for discontinuing •Participants reported the main reasons for discontinuing being due to side effects and decreased efficacy.

Study	**Sikirica 2014**[167]
	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**[168]
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**[169]

Study	**Singh 2003**[169]
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	**Smith 2014**[174]
Aim	Understanding the reasons of low uptake and completion of parent interventions for ADHD
Population	19 practitioners running services for preschool children with ADHD, and 13 parents of children with ADHD (aged Pre-schoolers)
Setting	UK
Methods and analysis	Semi-structured focus groups using an interview schedule based on themes for a qualitative literature synthesis. Analysed using thematic analysis
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Psychological barriers to parenting interventions •Parents reported feeling ashamed and embarrassed, and were fearful of being judged as a bad parent
	Situational barriers to parenting interventions •Parents reported being unable to access interventions due to time constraints
	Difficulties in changing parenting behaviour •Both parents and practitioners reported great difficulties in changing parenting approaches
	Improving interventions

Study	**Smith 2014**[174]
	•HCPs suggested parenting programmes would be better implemented if an initial home visit were carried out, to build trust with the parent and explain the programme.
	Improving interventions •HCPs felt that parents' own mental health problems, domestic violence, and low confidence should be recognised and supported by the HCP before referral to parental interventions. HCPs felt it was particularly important to identify and treat depression and ADHD when present
	Negative impact of non-pharmacological interventions •Parents reported feeling isolated due to group interventions, where they could not relate to the behaviour or experiences of other parents
	Intervention drop out •Parents were more likely to drop out if they did not see improvement they expected quickly enough.

Study	**Swift 2013**[181]
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**[184]
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

Study	**Taylor 2006[184]**
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

Study	**Taylor 2006**[184]
	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	**Waite 2010**[188]
Aim	To explore the experiences of women with ADHD
Population	16 women with ADHD (aged 18+)
Setting	USA
Methods and analysis	Face to face interviews took place, with each participant being interviewed twice. The first interview lasted for about 60 minutes and the second 30 minutes. Data were assigned conceptual codes to aid analysis Any codes or themes that were not linked to at least 2 participants were eliminated from the analysis and were not used within the themes.
Limitations	Minor limitations
Themes	Benefit of diagnosis (for women) •Women reported relief and elation from gaining a diagnosis and having an opportunity to understand their daily struggles.
	Harm of diagnosis (for women) •Many women, having being diagnosed as an adult, was highly frustrated at having not been diagnosed earlier in life.
	Support for women •Women highlighted a strong desire for support groups to help them to learn about other women's experiences of having ADHD

Study	**Wallace 2005**[189]
Aim	Explore the perception of mothers of sons with ADHD
Population	10 parents of children with ADHD (aged NC)
Setting	Australia
Methods and analysis	Semi structured interviews using topic guide, informed by grounded theory, lasting from 1 to 1.5 hours.

Study	**Wallace 2005**[189]
Limitations	Minor
Themes	Emotional difficulties for parents •Some parents struggled with their child's behaviour and reported feelings of guilt and grief towards the condition
	Social impact for parents •Parents reported a lack of understanding from friends and a reduction in their social network
	Role of teacher's •Parents reported communication difficulties with schools and teachers, which resulted in them feeling angry, sad and shameful. Those who did receive support from teachers did not feel that this greatly impacted the child's behaviour, but did improve the parents' peace of mind
	Bullying •Parents reported their children were often bullied, and felt that this was due to their symptoms such as poor social skills, low self-esteem and aggression.

Study	**Wiener 2015**[191]
Aim	Explore school experiences of adolescents with ADHD
Population	12 adolescents with ADHD (aged 14 to 16 years)
Setting	Canada
Methods and analysis	Clinical interviews were used using an interview guide covering various aspects of student life. Participants were also asked to bring with them binders or notebooks, recent essays or projects, a sample of an exam and other items used in school in order to examine how he/she learns. Interviews were semi structured and ranged from 2 hours to 3 hours 15 minutes. Grounded theory was used to analyse the data, with initial steps of open coding, followed by grouping into abstract categories.
Limitations	Minor limitations related to the richness of the data
Themes	Inadequate study skills •Participants did not have clear techniques of how to organize and carry out their schoolwork.
	The ideal classroom •Participants felt that classes should be a quiet environment that minimized distractions such as sitting away from the window, having separate desks, having smaller class sizes
	The ideal teacher •Participants described an ideal teacher, as being open minded, strict when necessary, engaging, flexible with deadlines, and approachable.
	Challenges with social relationships

Study	**Wiener 2015**[191]
	•Participants reported having been bullied due to their behaviour. They felt this was not helped by having a low tolerance for others' behaviour
	Challenges with social relationships •Participants had clear social instability, with friendships not lasting for long. They reported that time spent with friends was limited to the school setting

Study	**Williams 2014** [194]
Aim	To explore parent's perspectives of parenting a child with ADHD
Population	16 parents of children with ADHD
Setting	Australia
Methods and analysis	Interviews and grounded theory
Limitations	Minor limitations
Themes	Parents experienced challenging situations with their children daily, which caused emotional and physical exhaustion

Study	**Wolpert 2004**[75]
Aim	To investigate how parents make sense of the different aetiological models
Population	10 parents of children with ADHD (aged 8 to 11)
Setting	UK
Methods and analysis	Semi structured interviews were conducted ranging from 30 to 90 minutes. Interviews followed an open format using an interview schedule. Analysis was conducted with a grounded theory approach. Categories were developed and linked together to form a coherent model
Limitations	Moderate limitations related to data richness, the role of the researcher
Themes	Stigma •Parents reported feeling stigmatisation from teachers, their own families, people they didn't know in public places, and other parents

Study	**Wolpert 2004[75]**
	Difficulties in gaining support •Parents reported having to battle with professionals to gain support, particularly with teachers that could not manage the child's behaviour
	Emotional distress •Parents emphasised the profound impact of their family situation on their emotional wellbeing

Study	**Wright 1997[198]**
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[201]**
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.

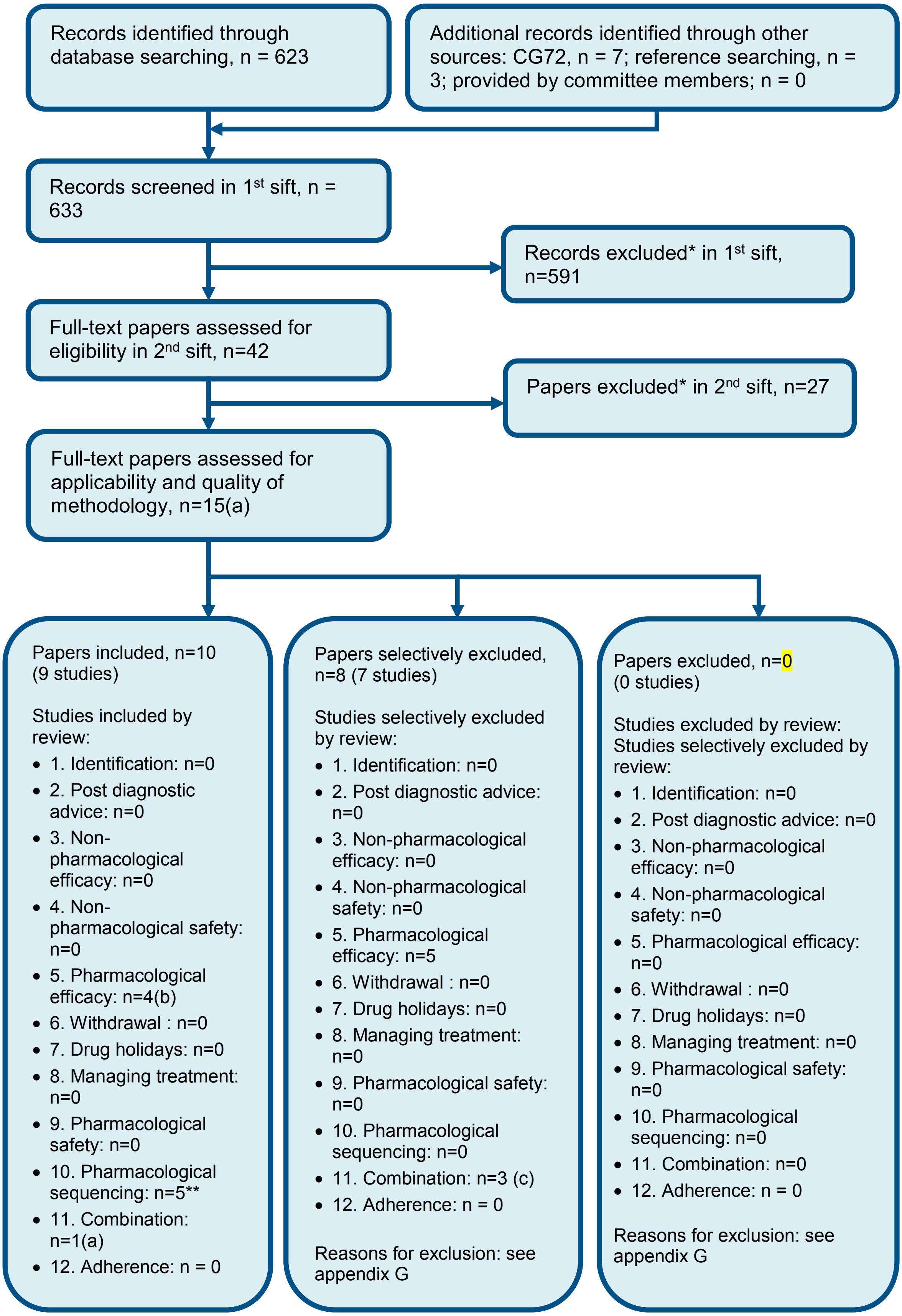
Study	**Young 2009[201]**
Limitations	Moderate limitations related to data richness, the context of the study and the findings
Themes	Benefits of diagnosis •Partners felt that the diagnosis of ADHD gave people an explanation for some of their difficulties and alleviated some guilt
	Benefits of drug treatment •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[199]**
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 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

Study	**Young 2008**[199]
	it wore off

Study	**Young 2009**[200]
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 have only been included here under Q11. One paper here was selectively excluded in Q11 but included in Q5 and so is double counted in this flowchart.

Appendix F: **Health economic evidence tables**

None.

Appendix G: **Excluded studies**

G.1 Excluded qualitative studies

Table 49: Studies excluded from the qualitative review

Reference	Reason for exclusion
Ahmed 2013[3]	Systematic review
Ahmed 2013[1]	No relevant themes
Andrews 2015[195]	Incorrect study design
Ansari 2016[4]	Survey
Arango 2013[5]	Article
Bachman 2000[6]	Survey
Ball 2001[7]	Survey
Bekle 2004[9]	Survey
Berger 2008[10]	Survey
Berger 2015[11]	No relevant themes
Brinkman 2012[15]	No relevant themes
Brinkman 2011[13]	Literature review
Brodin 2008[16]	No relevant themes
Brook 2005[17]	Incorrect study design
Brook 2000[18]	Survey
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 2014[29]	No relevant themes
Charach 2008[28]	Incorrect study design
Clarke 2013[31]	Incorrect population
Clarke 2012[32]	Incorrect study design
Clay 2008[33]	Wrong population
Corcoran 2016[36]	Systematic review
Couture 2003[38]	Questionnaire
Darredeau 2007[39]	Survey
Davis-Berman 2010[40]	No relevant themes
Deane 2012[42]	Incorrect population
Dennis 2008[43]	Literature review
Dosreis 2008[47]	Incorrect study design
dosReis 2007[46]	No relevant themes
dosReis 2009[45]	No relevant themes
Edwards 2013[48]	Wrong population
Eisenberg 2007[50]	Survey
Elias 2017[51]	Incorrect population

Reference	Reason for exclusion
Emilsson 2016[52]	Survey
Faber 2006[53]	Incorrect study design
Fiks 2010[54]	No relevant themes
Firmin 2009[55]	No relevant themes
Fleishcmann 2013[57]	Survey
Frank 2015[58]	Incorrect study design
Friars 2009[59]	No relevant themes
Garro 2009[61]	Article
Gau 2009[62]	Incorrect study design
Gerdes 2014[63]	Incorrect study design - questionnaire
Ghanizadeh 2010[64]	Questionnaire
Ginsberg 2008[66]	Incorrect study design
Gwernan-Jones 2015[69]	Literature review
Gwernan-Jones 2016[68]	Systematic review
Hack 2001[70]	Incorrect study design
Harvey 2009[76]	Wrong population, incorrect study design
Hazell 2004[78]	No qualitative results reported
Hebert 2013[79]	Survey
Hill 2016[81]	Survey
Ibrahim 2016[88]	No relevant themes
Ide-Okochi 1016 [89]	Article
Jackson 2008[90]	No relevant themes
Kean 2005[92]	Incorrect study design
Kendall 1997[93]	Incorrect study design
King 2016[97]	Wrong population
Kisely [98]	Survey
Knipp [100]	No relevant themes
Ko [101]	Questionnaire
Koerting [102]	Review
Kollins [103]	Review
Kronenberg [106]	Incorrect population
Kutuk 2016[107]	Survey
Laugesen [109]	Unable to access
Laugesen [109]	Systematic review
Lee [110]	No relevant themes
Leggett [113]	No relevant themes
Lewis 2016[116]	No relevant themes
Lewis 2016[117]	Erratum
Lewis-Morton [115]	No relevant themes
Liebrenz 2016[118]	No relevant themes
Ljusberg [120]	No relevant themes
Loe [121]	No relevant themes
Lopes [122]	Incorrect population
Maassen [124]	No relevant themes
Marcer [125]	Questionnaire

Reference	Reason for exclusion
Mathers [126]	Incorrect study design
Matthys [128]	No relevant themes
McCarthy [129]	Survey
McGoron [130]	Questionnaire
McKay [132]	Wrong population
McMenamy [133]	Wrong population
Meaux [135]	No relevant themes
Michielsen [136]	Wrong population
Mills [104]	Abstract
Morsink 2017[139]	No relevant themes
Muhlbacher [140]	Abstract
Muhlbacher [140]	Abstract
Murrell [141]	Incorrect study design
Myers [143]	Incorrect study design
Oruche [148]	Wrong population
Ramsay [150]	Incorrect study design
Raskind [151]	Survey
Reale [152]	Survey
Richardson[154]	Systematic review
Rogalin [155]	No relevant themes
Sandler [158]	No relevant themes
Schatz [159]	Systematic review
Schubert [162]	No relevant themes
Segal [164]	No relevant themes
Shattell [165]	No relevant themes
Singh [170]	Article
Singh [171]	Article
Singh [172]	Article
Sleath 2016[173]	Survey
Solberg [176]	Incorrect study design - questionnaire
Sox [177]	Incorrect study design
Srignanasoundari 2017[178]	No relevant themes
Stroh [179]	Survey
Surman [180]	Incorrect study design
Tatlow-Golden 2016[182]	Systematic review
Taylor 2015[183]	No relevant themes
Thiruchelvam [185]	Incorrect study design
Travell [186]	Analysis
Varley [187]	Article
Wilkes-Gillan [82]	No relevant themes (parental intervention)
Wilkinson [193]	No relevant themes
Williamson [196]	Incorrect study design
Winter [197]	Incorrect study design
Young [200]	No relevant themes
Zhang 1017[202]	No relevant themese

Table 50: Studies identified but not included in the qualitative review due to saturation being reached

Reference
Canela 2017[24]
Kendall 2016[95]
Schreuer 2017[160]
Soderqvist 2017[175]
Wan 2016[190]

G.2 Excluded health economic studies

None.