

ADHD in children and young people: Prevalence, Care Pathways & Service Provision

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Summary

Attention-Deficit/Hyperactivity Disorder (ADHD) is a common childhood behavioural disorder – systematic reviews indicate that the community prevalence of ADHD globally is between 2% to 7%, with an average of around 5%. In addition, a further 5% of children have significant difficulties with over-activity, inattention and impulsivity that are just sub-threshold to meet full diagnostic criteria for ADHD. Estimates of the administrative (clinically diagnosed and/or recorded) prevalence vary worldwide and although increasing over time, ADHD is still relatively under-recognised and under-diagnosed in most countries, particularly in girls and older children. ADHD often persists into adulthood and is a risk factor for other mental health disorders and negative outcomes including educational under-achievement, difficulties with employment and relationships, and criminality. The timely recognition and treatment of children with ADHD-type difficulties provides an opportunity to improve their long-term outcomes. This review includes a systematic review of the community and administrative prevalence of ADHD in children and adolescents; an overview of the barriers to accessing care for ADHD; a description of costs associated with ADHD; and a broad discussion of evidence-based pathways for the delivery of clinical care, including a focus on key issues for two specific age groups - pre-school children and adolescents requiring transition of care from child to adult services.

Background

Attention-Deficit/Hyperactivity Disorder (ADHD) is a common childhood behavioural disorder, estimated to affect around 3-5% of children.¹ The diagnosis of ADHD is based on pervasive, developmentally excessive and impairing levels of over-activity, inattention and impulsivity. At least a further 5% of children have significant difficulties with these behaviours that are just sub-threshold to meet full diagnostic criteria. ADHD often persists into adulthood and is a risk factor for a wide range of other mental health problems including defiant, disruptive, and antisocial behaviours, emotional problems, self-harm and substance misuse as well as broader negative outcomes such as educational under-achievement and exclusion from school, difficulties with employment and relationships, and criminality.²⁻⁴ For health, education and social care services, the timely and appropriate recognition and treatment of children with ADHD-type difficulties provides an opportunity to enhance their long-term outcomes. This review comprises a systematic review of the community and administrative prevalence of ADHD in children and adolescents; an overview of the barriers to accessing care; a description of costs associated with ADHD; and a discussion of evidence-based pathways and the delivery of clinical care, with consideration of specific issues relating to two age groups (pre-school children and adolescents requiring transition into adult services). Although ADHD treatments are not discussed in detail, key approaches to intervention are outlined as they apply to care pathways.

Prevalence of ADHD

Community prevalence

Community prevalence describes the number of people with ADHD in a representative population sample, according to predefined criteria. A series of searches (see Panel) identified seven systematic review articles reporting on the community prevalence of ADHD.

The first review (Polanczyk) estimated the global prevalence of ADHD as 5.29%.⁵ Based on DSM-IV criteria and using symptoms from parent ratings, teacher ratings or best estimate diagnostic procedures, Willcutt estimated a prevalence of 5.9%-7.1% amongst children and adolescents.⁶ In contrast, Erskine et al's meta-analysis adopted a more conservative approach by applying a greater weight to studies where information was required from more than one

informant and also included a higher proportion of 12-18 years olds than the Polanczyk review.⁷ They estimated the global prevalence of ADHD amongst 5-19 year olds as 2.2%, with a peak prevalence at the age of 9 years. Polanczyk et al. updated their previous review, including 154 studies using either DSM or ICD diagnostic criteria in people aged 18 or under, and concluded that the world-wide community prevalence of ADHD is approximately 5%.⁸ Variation in estimated prevalence was best explained by methodological differences between studies so that when similar methodologies are adopted there was no obvious variation between different geographical locations. Neither were there differences by study year, suggesting that the community prevalence of ADHD has remained stable over the last three decades. Using prevalence data from their previous review (the Global Burden of Disease Study 2010),⁷ Erskine et al conducted a further systematic review to estimate the disability adjusted life years (DALYs) related to ADHD. ADHD was reported to contribute 491,500 DALYs, making it the 98th highest cause for global burden. The number of DALYs for ADHD peaked at ages 10-14 years and was higher for males. As part of a broader meta-analysis of the worldwide prevalence of mental disorders in children and adolescents, Polanczyk et al. estimated the prevalence of ADHD in 6-18 year olds as 3.4% (95% CI 2.6 to 4.5) with heterogeneity in methods between studies cited as a reason for different prevalence estimates.¹⁰ The final review, by Thomas et al., included studies in any language which used DSM-III, DSM-III-R or DSM-IV criteria.¹¹ The overall prevalence was reported as 7.2% (95% CI 6.7 to 7.8) with studies from Europe reporting lower prevalence estimates than those from North America and few studies using random population sampling. Collectively, these systematic reviews suggest that the reported range in the community prevalence of ADHD (between 2.2% and 7.2%) reflects variation in study methodology.

Administrative (clinically recorded) prevalence

This reflects the number of people with clinically diagnosed and/or recorded ADHD as a proportion of the whole population i.e. the prevalence of diagnosis made in practice.¹² These figures, when considered alongside other factors such as community prevalence and the availability and use of services, can inform the planning of service provision to address any significant discrepancies that might emerge. However, many studies have estimated administrative prevalence using only prescription data. These require careful and cautious interpretation as a number of factors can influence both the prescription and uptake of medication treatments for ADHD, after a clinical diagnosis has been made. The balance

between the use of pharmacological and non-pharmacological treatment options for ADHD varies greatly both between and within different countries. In general, however, studies that only report prescription data are likely to reflect an under-estimate of the true administrative prevalence. A series of searches (see Panel) identified 55 papers reporting on the administrative prevalence of ADHD.

In the US, whilst it is difficult to make direct comparisons between studies (Table 1)¹³⁻³⁷ because of differences in how administrative prevalence was defined and estimated, the administrative prevalence based on prescriptions ranged from 0.6% (in under 18 year-olds in 1987)³² to 10% (in 7-11 year-olds in 1995-1996).³¹ The latter figure is higher than other studies from that time and may reflect a regional variation. The administrative prevalence based on diagnosis ranged from 0.93% (in 2-5 year-olds in 2002)²⁰ to 11.0% (in 4-17 year olds in 2003 to 2011).¹⁸ The pattern of an increase in the prevalence of ADHD over time was reported across studies with a peak involving the 10-14 year age group.

Table 1 about here

Table 2 summarises studies conducted in the UK.³⁸⁻⁴⁴ None of these studies estimated the administrative prevalence of ADHD based only on diagnosis. Based on prescriptions, the prevalence ranged from 0.003% (in under 19 year-olds in 1992)⁴³ to 0.92% (in 6-12 year-olds in 2008).⁴⁰ The administrative prevalence based on prescriptions with/without diagnosis ranged from 0.19% (in 6-17 year-olds in 1998)³⁹ to 0.76% (in 5-15 year-olds in 2011-2012).³⁸ Using the Health Improvement Network (THIN) primary care database, the prevalence of ADHD between 2003 to 2008 was estimated as 0.73% in 6-12 year-olds, 0.57% in 13-17 year-olds and 0.06% in 18-24 year-olds.⁴⁰ This trend for decreasing prescriptions has been noted after the age of 15 years.⁴¹ Although the administrative prevalence of ADHD has increased over time, there is some suggestion that this has now levelled off, for example a UK study using the Clinical Practice Research Datalink (CPRD) suggested that the prevalence of diagnosed ADHD has decreased since 2007.³⁹

Table 2 about here

Table 3 summarises studies conducted globally outside the US or UK.⁴⁵⁻⁶⁷ In all countries except Israel the administrative prevalence estimates were lower than in the US. The administrative prevalence based on prescriptions ranged from 0.06 (in 5-17 year olds in 2010-2011)⁴⁷ to 2.5% (in under 18 year-olds in 2004).⁶⁵ The administrative prevalence based on

diagnosis ranged from 0.06% (under 18 year-olds in 1996)⁶² to 12.6% (in 6-13 year-olds in 2003 to 2009).⁵⁶ Two studies using Israeli health insurance data reported relatively high prevalence estimates in Kibbutzim areas - 5.99% based on prescriptions;⁶⁶ 12.6% based on diagnosis.⁵⁶ It is possible that these high estimates reflect a selected population of people with access to health insurance that are not reflective of the wider population, especially since the reported prevalence of ADHD based on prescriptions was 0.20% in Arab areas.⁶⁶

Table 3 about here

Differences by sex

Although ADHD is more common in males than females with a ratio of 2-3:1 reported in community prevalence studies, the sex ratio is consistently greater in administrative prevalence studies. This suggests a relative under-recognition of ADHD in females.^{6,7} For example, a UK study conducted using THIN data (2010-2012) concluded that males are five times more likely to be diagnosed with ADHD than females and a study based on diagnosis and prescription data from Germany estimated a 3-4 times greater administrative prevalence in males than females.^{38,61} A study from the Netherlands estimated that 3-8 times more boys than girls received prescriptions for ADHD and suggested that the administrative prevalence of ADHD has been rising faster in boys.⁶⁸ In the UK, a study using prescriptions data from the CPRD estimated that, amongst under 19 year-olds, the male to female ratio of the prevalence of ADHD increased over time between 1992 and 2001.⁴³ In contrast, other studies from the US, Switzerland, the Netherlands and Sweden have suggested a more rapid increase in females than males.^{24,62,58,69} Similarly, a study of 6-17 year olds using CPRD diagnoses and prescriptions data showed that the male to female ratio has reduced over time, ranging from 8.4 in 1999 to 5.8 in 2009.³⁹ In another study, using THIN data, the male to female ratio also reduced from 6.6 in 2003 to 5.5 in 2008 in people aged 6-12 years and from 9.8 (2003) to 6.3 (2008) in people aged 13-17 years.⁴⁰ Collectively, these studies suggest that the initial increase in prescribing prevalence was mainly in males but that, in more recent years, prescribing has also increased for females.

Differences by socio-economic deprivation

A few studies have stratified estimates of community prevalence of ADHD according to socio-economic deprivation.⁶ These studies indicate that individuals from families defined as more

deprived were between 1.5-4 times more likely to have ADHD than individuals from less deprived families. In contrast, there are mixed findings, particularly from the US, on the association between the administrative prevalence of ADHD and deprivation. For example, a nationwide survey reported that areas with greater levels of deprivation have a higher administrative prevalence of ADHD (based on parent report of clinical diagnosis) compared to areas with lower levels of deprivation.⁷⁰ Similarly, a study of primary school children found that children from the lowest income quintile had the greatest probability of being reported to have a clinical diagnosis of ADHD compared to the middle income quintile.⁷¹ However, some US-based studies have suggested a greater prevalence of childhood ADHD amongst families with a higher income.^{72,73} Although this association was not explained by the availability of health insurance,⁷³ it is less clear how the administrative prevalence of ADHD varies according to private and public health insurance status. For example, a household survey with pharmacy data on 2.8 million children and adolescents found a drug-treated prevalence of ADHD of 1.3% amongst those without insurance, 3.4% with private insurance and 4.3% with public insurance.²² Studies from countries where access to healthcare is more universally available have generally confirmed an association between the administrative prevalence of ADHD and deprivation.⁷⁴⁻⁷⁶

Barriers to care

As noted above, the community prevalence of ADHD globally is estimated to be between 2-7%, with an average of around 5%, and a suggestion that most of the variation reflects methodological differences across studies rather than a true variation between different regions. Estimates of the administrative prevalence also vary worldwide, with the highest estimates coming from the US and Israel. Although the community prevalence of ADHD has remained stable over time, its administrative prevalence has been increasing. This is likely to reflect better identification and awareness of the condition and improved access to treatment in countries where under-diagnosis has been an issue but may, in some instances, reflect over-diagnosis. These overall figures also mask regional variations within countries. There are particular concerns about rates of prescribing in some parts of the US as these far exceed what would be expected from epidemiological data.^{77,78} This may reflect sub-threshold difficulties being diagnosed and treated as ADHD. Data from other countries mainly indicate that ADHD is still relatively under-recognised and under-diagnosed, particularly in girls and older children.

For example, two reviews of ADHD care across Scotland reported low rates of diagnosis with minimal increases over time (0.6% of school-aged children in 2007 and 0.7% in 2012) and ten-fold variations between regions.^{79,80} Patterns of prescribing of ADHD medications also show significant regional variations across the US,²¹ Scotland⁸¹ and Australia⁸² amongst others.

In the UK, national data from 2004 suggested that less than half of children with ADHD have been diagnosed and receive treatment.⁸³ However, this picture of under-diagnosis co-exists alongside some societal and media concerns about increases in methylphenidate prescribing in the UK.⁸⁴ A closer look at prescribing trends in the UK suggests that whilst prescription rates have increased considerably over the past 20 years, the actual rates of prescribing remain much lower than one would predict from the epidemiological data.^{40,41} Furthermore, the rate of increase in prescribing has slowed considerably in recent years.³⁹ Under-recognition of ADHD in many countries may reflect particular barriers to care for these children and young people. A systematic review of the international literature highlighted that barriers operate at multiple levels, including identification of need and entry into care.⁸⁵ Socio-demographic factors identified as barriers to accessing care included female gender, older age, non-white ethnicity, rural residence and lower family socio-economic status. The importance of enhancing knowledge about ADHD amongst parents, teachers and primary care clinicians and the need to reduce ADHD-related stigma were noted. The review recommended that interventions that enhance the knowledge of and communication between these key adults may improve access to care. Streamlining care pathways (e.g. liaison and consultation models between primary healthcare professionals, specialist education professionals and specialist children's health services) may also help to overcome barriers to access.⁸⁵

Costs of ADHD

ADHD has a huge impact on the lives of affected children and their families. As well as direct use of health, specialist education, social care, and criminal justice services, the wider costs to society also reflect impacts on parental employment and mental health, family-borne expenses, and crime and offending.

A review of the US literature on the cost of illness related to ADHD has emphasised the considerable and persistent costs incurred at both the individual and societal level.⁸⁶ In the US,

the total annual costs have been estimated at between \$143billion-\$266billion. The majority of these costs were attributable to family members of people with ADHD or to adults with ADHD; the economic impact being approximately three times greater for affected adults compared to children and adolescents. The cost burden mainly related to healthcare and educational services for children and loss of income and productivity for adults.

In the UK, the impact on educational services has been confirmed in longitudinal studies. Data from the nationally representative British Child and Adolescent Mental Health survey were assessed for resource use and estimated costings over a three year follow-up period.⁸⁷ Children with hyperkinetic disorder (using ICD-10) incurred greater costs than children with emotional disorders, mainly relating to the use of frontline and special educational services. In England and Wales, in 2006, basic NHS costs for ADHD (excluding medication) were estimated at £23 million for initial specialist assessment and £14 million annually for follow-up care.⁸⁸ For 2012, drug costs for ADHD in England were estimated to exceed £78 million.⁸⁹ A study conducted using the CPRD estimated that the mean annual total healthcare costs for people with ADHD were higher than for people without (£1,327 vs. £328 per year, in the first year of the study).³⁹ Another UK study estimated resource use costs in relation to a sample of 12-18 year olds who were referred to specialist healthcare services and received a clinical diagnosis of ADHD five years earlier.⁹⁰ Based on 2010 prices, the estimated annual total costs to the NHS, social care, and education services were estimated at £670 million. The majority (76%) of the mental health-related costs fell to the education sector.

Evidence is also emerging from longitudinal studies about the long-term cost impacts of childhood attention and hyperactivity problems, even if sub-threshold to meet full ADHD diagnostic criteria. Over an 11-22 year follow-up period, when compared with controls, a community sample of pre-school children at risk of ADHD had 17.6 times higher average costs per annum across most domains (apart from non-mental health costs).⁹¹ Attention and hyperactivity problems at the age of 10 are associated with lower levels of employment and earnings at age 30.⁹² Another community-based 20 year follow-up study highlighted the importance of comorbid conduct problems in childhood in terms of incurring recent costs related to receipt of state benefits and use of general health and social care services.⁹³ Delays in receiving a clinical diagnosis of ADHD also result in greater long-term costs - individuals with ADHD who were not diagnosed until adulthood cost 13,608 euros more per year than their same-sex sibling.⁹⁴

Evidence-based Care Pathways

Diagnostic controversies and difficulties

Even in countries where ADHD is now more generally accepted, ADHD remains a controversial diagnosis in society and also amongst some professionals who work with children e.g. clinicians, teachers, and social care professionals. This is in contrast to other neurodevelopmental conditions such as autism where the diagnosis is often less contentious. Whilst these concerns are often lumped together they actually reflect a range of quite distinct issues. These include the lack of any specific objective tests to diagnose ADHD, the fact that ADHD symptoms reflect the extreme end of a spectrum that spans the entire population, the perception of a somewhat arbitrary cut-off for symptoms and impairment that itself requires a degree of individual judgement, the broadening of the diagnostic criteria over time, variation amongst clinicians and services in rates of diagnosis and the use of medication (in particular, stimulant medications) for ADHD. The absence of a diagnostic test for ADHD does not, however, invalidate the diagnosis. This issue applies to all psychiatric disorders and many physical conditions such as hypertension.⁹⁵ Compared to other psychiatric disorders in the DSM5 field trials, the assessment of ADHD was one of the most reliable diagnoses with a pooled test-retest reliability (intra-class kappa) across sites of 0.61. This was only exceeded by major neurocognitive disorder (0.78) and autism (0.69) and was much higher than the figures for disorders such as schizophrenia (0.46), bipolar disorder (0.56), major depressive disorder (0.28) and generalized anxiety disorder (0.20). Data from routine clinical practice (involving a clinical sample of 502 cases) in the UK indicated that, although some ADHD cases are missed (false negatives), the only 'false positive' case was one that had become sub-threshold following appropriate treatment.⁹⁶ Based on the evidence outlined above, although there appears to be an issue with over-diagnosis in some parts of the US with the risk of misdiagnosis (false positives) if clinicians take short-cuts during assessment, the diagnosis of ADHD can be made both accurately and reliably if the assessment is conducted carefully using standardised approaches.¹

Whilst the recommendations of published ADHD guidelines are on one level very clear and consistent,^{1,97-101} clinicians often complain that guidelines are still somewhat vague, particularly in relation to assessment and diagnosis.¹⁰² Many clinicians perceive the assessment and diagnostic decision-making processes to be inherently complicated as it requires both time

and experience to piece together information gathered.¹⁰² From an applied health research perspective, there is a need to understand whether interventions that assist clinicians in optimising the assessment and diagnostic decision-making process also improve the clinical outcomes of children and adolescents with ADHD.

Within child psychology and psychiatry there is also an ongoing debate about whether some of those cases currently diagnosed as having ADHD would actually be better understood using an attachment or trauma paradigm and vice versa.¹⁰³ However, this is not an either/or debate and there are strong theoretical reasons why these disorders may often co-exist. However, it is a question that has been relatively neglected by researchers and merits further attention.

Service Organisation

In addition to the variability in administrative prevalence noted above, there are also considerable global differences in the way that clinical care for ADHD is organised.¹⁰⁴ Although this partly reflects general differences between healthcare systems (e.g. the balance between public and privately funded systems), there are also historical and cultural differences in the acceptance of ADHD as a valid disorder and of pharmacological and non-pharmacological treatments for child and adolescent mental health problems in general and ADHD more specifically.

In the UK, diagnosis is normally made by paediatric or child and adolescent psychiatry specialists within secondary healthcare, depending on locally agreed care pathways. Although these physicians usually work within the context of a multi-disciplinary team, the involvement of non-medical professionals in the assessment process varies considerably according to local service organisation and structures. Ongoing care and treatment is supervised by secondary care with shared care arrangements for medication prescribing, in some places, with primary care. In the US, where much healthcare provision is delivered privately, ADHD is generally managed by primary care paediatricians or child and adolescent psychiatrists working in relative isolation with few cases managed within a multi-disciplinary team. ADHD is now generally recognised as a valid and important disorder in some parts of the world including North America, northern Europe and several other regions. However, there are still many countries including much of Africa, Asia, Central and South America and parts of Southern Europe where ADHD is less well accepted, rates of recognition remain low and the scant

resources available for treatment tend to be mainly focused on teaching hospital or tertiary centres rather than in community settings. Where service access is limited, telehealth service delivery models for managing ADHD can be effective and merit further investigation around their acceptability and cost-effectiveness.¹⁰⁵

Clinical Guidelines and Treatment Recommendations

There are now a broad range of evidence-based guidelines, mainly from North America and Europe, addressing both the assessment and management of ADHD.^{1,97-101} The most notable aspect about these guidelines is that, despite the different international traditions and perspectives on ADHD noted above and different approaches to their development, they are very similar in their recommendations for assessment and many aspects of treatment. They all agree that assessment should be relatively structured and comprehensive, including assessment of general functioning and comorbid disorders in addition to the core ADHD assessment. Although they all recognise the potential importance of both pharmacological and non-pharmacological treatment approaches for ADHD, the main area of divergence relates to the order in which treatments should be offered to those with a new diagnosis. North American guidelines generally recommend that medication should be considered as a first-line treatment in most cases whereas guidelines from Europe suggest that, whilst medication is appropriate as an initial treatment for more severe cases, behavioural management approaches should be offered first for less severe cases. These recommendations reflect a more conservative approach towards medication in Europe as well as data from the Multimodal Treatment of ADHD (MTA) randomised controlled trial (RCT) which suggested that, for symptom reduction, medication was superior to behavioural treatment for those with more severe ADHD but that the differences were less striking for less severe cases.¹⁰⁶

However, it is likely that these decisions will need to be re-assessed on the basis of a series of carefully conducted meta-analyses.^{107,108} These analyses suggest that, when considering outcomes from the perspective of a probably blinded informant, behavioural treatments appear to improve parenting and conduct problems but are relatively ineffective at reducing ADHD symptoms. In contrast to these analyses, even the most conservative approaches to assessing the effectiveness of pharmacological treatments for children and adolescents with ADHD suggest moderate to large effect sizes with respect to ADHD symptoms in school-age children. Although this has been replicated across a number of systematic reviews, a Cochrane review

that also reported moderate to high effect sizes for methylphenidate urged caution in its use.¹⁰⁹ This conclusion was based on the authors' interpretation of the risk of bias in the included studies which, in their view, resulted in a very low quality of evidence. This is in direct contrast to the conclusions of NICE which rated the evidence to be of moderate to high quality.¹ Several aspects of the methodology and authors' interpretation of this Cochrane review have been challenged.¹¹⁰⁻¹¹² These reviews also highlight that whilst ADHD medications are associated with a range of non-serious adverse effects there is as yet little evidence for serious adverse events. Whilst these data are encouraging, they refer in general to relatively short-term effects from highly structured RCTs that are unlikely to accurately reflect usual clinical practice. There are, however, encouraging data which support the positive effects of ADHD medications on more naturalistic measures of outcome.^{4,113,114} There remains a poverty of data regarding the longer-term benefits and risks associated with drug treatments for ADHD. In part, this reflects the inherent difficulties associated with collecting such data, particularly in terms of running long-term RCTs of ADHD medications, and with interpreting data from long-term observational studies that lack a comparison group. Looked at collectively, the evidence suggests that whilst behavioural treatments are likely to benefit many children with ADHD, they are less likely to reduce ADHD symptoms. It would therefore seem appropriate, at least for school-aged children, to consider medication as a first-line treatment as part of a comprehensive treatment package that will often include non-pharmacological interventions.

Implementing guidelines into practice

Relatively little is known about how well ADHD guidelines are implemented into routine clinical practice. However, in Scotland, there have been two national reviews of adherence to the SIGN guidelines for ADHD. The first review highlighted that, whilst adherence to guidelines was generally fairly good, there were significant variations in practice across the country, particularly with respect to the administrative prevalence that ranged between 0.2-1.0%.⁷⁹ The second review noted improvements in service developments and recommended further work particularly around recognition, capacity building, outcome measurement, partnership with other agencies and transition services into adulthood.⁸⁰ Many published guidelines lack the detail and organisational structure required to make them readily implementable in day-to-day practice. In an attempt to address this, the European ADHD guidelines have been operationalised into a format that describes the steps required at each stage of the process.^{115,116}

Data from the MTA study suggested that, for children with combined type ADHD, a well-organised medication package of care resulted in enhanced clinical outcomes at 14 months compared to a comprehensive package of behavioural treatment or community care and that the combination of the medication and behavioural treatments was similar in most respect to medication alone.¹¹⁷ Longer term naturalistic follow-up of these children highlighted continued effects for all groups but that the additional benefits seen in the medication groups were not sustained over time.¹¹⁸ Whilst some authorities have argued that these findings suggest that medications do not work in the long term, an alternative explanation is that the added effect of more intensive medication management diminishes once the intensive control of treatment is relaxed.¹¹⁹ Supporting this notion, Coghill and Seth have demonstrated continued benefits up to ten years after titration using a carefully crafted clinical care pathway that aimed to optimise symptom control within a routine clinical setting.¹²⁰ Unfortunately, such strong outcomes are not typical of the literature.¹²¹ Recent work assessing UK clinicians' attitudes towards implementing medication management strategies in routine practice suggests that although key recommendations from guidelines are seen as important and feasible to implement, others present considerable implementation challenges in practice.¹²² Collectively, these findings suggest that there needs to be greater use of implementation science approaches to ensure that clinicians work towards implementing evidence-based protocols and that these efforts achieve the desired clinical outcomes.

Consideration of specific age-groups

Pre-schoolers with ADHD

Although initially considered a disorder of childhood there is now convincing evidence and wider acceptance that ADHD is a lifespan disorder with early onset and is associated with considerable burden and costs.¹²³ Chorozoglou et al highlighted the long-term costs associated with pre-school ADHD; higher costs were consistently predicted by male gender and, for some cost codes, conduct problems.⁹¹ Identification of ADHD during the pre-school years is often complicated by the fact that ADHD symptoms are typical behaviours that are developmentally inappropriate for the child's age.¹²⁴ Maniadaki et al explored parents' understanding of child behaviour problems and their likelihood of help-seeking.¹²⁵ Parents whose pre-school child displayed very high levels of ADHD behaviours tended to perceive these as normal

developmental behaviours and were not planning on seeking professional help. This study highlights the challenges of identifying young children at risk of ADHD and encouraging and ensuring early access to care.⁸⁵

From a treatment perspective, research evidence shows that pre-school pharmacological treatment for ADHD is associated with lower efficacy and higher levels of side effects than for school-aged children¹²⁶ and longer-term follow-up studies suggest high levels of medication discontinuation (25%) in pre-school children.¹²⁷ Although many parents have a preference for individual-based treatment,¹²⁸ guidelines for pre-school ADHD recommend group-based behavioural interventions based on social learning theory for ADHD.¹

Within a systematic review examining the efficacy of behavioural interventions for children with ADHD,¹⁰⁸ results of meta-regression indicated larger effect sizes in trials involving younger children for outcomes related to positive parenting, ADHD symptoms and conduct problems, (as reported by the most proximal informant). In addition, a sensitivity analysis exploring trials with no or low medication use (nearly all involved pre-school children) showed higher effect sizes. However, when considering the role of behavioural interventions for ADHD, clinicians should be aware that very little is known about the impact of mediators and moderators on treatment outcomes. Few treatment moderators have been identified although parental ADHD strongly influences treatment outcomes, with parents with higher ADHD symptoms having children with poorer outcomes.¹²⁹ In addition, a study with mothers and children with ADHD found that treatment of parental ADHD did not influence the outcome of behavioural parent training on child ADHD symptomatology.¹³⁰ Therefore, given the lack of evidence to help clinicians identify for whom behavioural interventions might be most effective, it would seem prudent to continue to offer these to all parents of pre-school children with ADHD.

Transitions between child and adult services

Regardless of the precise service organisation, which varies between countries, optimum transition from child to adult services involves planning, information transfer and joint working between teams and should lead to continuity of care during and following the transfer of clinical responsibility.¹³¹ Successful transition requires resources as well as the acquisition of additional skills and knowledge to enable the receiving team to provide continuity of care that meets the

young person's needs, but has been relatively neglected in relation to ADHD.¹³² In the UK, NICE guidelines recommend that, for young people with ADHD who require treatment transition to adult mental health services, ongoing review of pharmacological treatment should be shared between specialist mental health and primary health care services.¹ However, many adult mental health practitioners lack experience and training in the management of ADHD, and may have negative and sceptical attitudes towards it as a condition that warrants intervention.¹³³⁻¹³⁵ Similarly, few practitioners in primary/ambulatory care have direct experience of child and adolescent psychiatry and may be unfamiliar with the management of ADHD without support from specialist services.¹³⁶

The transition from child to adult mental health services poses particular challenges due to differences in training, thresholds and focus between child and adult mental health services, leaving a proportion of young people without a clear pathway. Young people often face multiple other transitions around the time that children's healthcare services withdraw, and given the nature of ADHD, some young adults with the condition struggle to organise themselves to attend appointments and continue treatment. Choices about education, occupation and residence during the teenage years can have profound impacts on subsequent life chances. Poor transition may result in young people with ongoing needs disengaging from services and consequently having worse outcomes.^{137,138} Studies from European case registers suggest that the discontinuation of pharmacological treatment for ADHD among young men is associated with an increased risk of serious road traffic accidents and criminal convictions;^{112,139} and with increased accidents, injuries and emergency department attendance among children and young people.¹⁴⁰

Two multi-methods studies of transition of mental health care have demonstrated that transition is often poorly planned, lacks co-ordination and frequently results in discontinuity of care, particularly for children with neurodevelopmental disorders.^{131,141} However, insufficient numbers of young people with neurodevelopmental disorders meant that neither study could explore transition for young people with ADHD in depth. The limited literature on transition in ADHD suggests that policy recommendations are not often translated into practice.^{142,143} Findings from the CPRD in the UK have shown a 95% drop in ADHD drug prescriptions for young people between the age of 15 and 21 years, with the reduction being most marked between the ages of 16 and 17.⁴¹ This fall in prescribing is far greater than the expected age-related decrease in symptoms and suggests the possibility of premature discontinuation of

medication among some young people.¹⁴⁴ While the management of ADHD is relatively common within children's services, clinicians describe high levels of attrition in attendance at school-leaving age, so that relatively few young people with ongoing service needs are referred onto adult services. Two of the review authors are currently involved in a multi-method study that is gathering prospective data from across the British Isles on the number of young adults who require transition, mapping the available services for young adults with ADHD and exploring the experience of transition with young people who have ADHD, their parents and the practitioners who work with them (<http://medicine.exeter.ac.uk/catchus/>).

Summary

In this article focusing on children and adolescents with ADHD, we have reviewed and highlighted key findings from the international literature relating to the community and administrative prevalence of ADHD with an exploration of possible reasons for discrepancies between these two sets of figures, barriers and facilitators to care and the cost burden of ADHD. We have also discussed a range of aspects that influence the development and implementation of evidence-based care pathways for ADHD, with consideration of specific issues relating to pre-schoolers and older teenagers who require transition into adult services.

Authors' contributions

KS conceptualised the review, wrote or co-wrote the first draft of sections of the review and critically reviewed and revised the manuscript. VP carried out the literature search and wrote the first draft of the related section. DD, TF & DC wrote the first drafts of sections of the review. All authors contributed to the writing of the review, reviewed and revised the manuscript and approved the final manuscript as submitted.

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Declarations of Interest

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Table 1: The administrative prevalence of ADHD reported in studies conducted in the US

First author	Year published	Year start	Year end	Ages	Prevalence % (Year, if applicable) and case definition
Wolraich	2014	Not stated	Not stated	5-13Y	10.1% and 7.4% in two separate states (South Carolina (SC) and Oklahoma (OK)) according to medication use. However, this study also estimated community prevalence as 8.7% and 10.6% respectively in the same two states. Of those medicated, 39.5% (SC) and 28.3% (OK) met the criteria for cases of ADHD.
MMWR	2015	2011	2014	5-17Y	10% by parents reporting their child has been diagnosed with ADHD in a national telephone interview survey.
Mayne	2016	2009	2014	4-18Y	8.6% by diagnosis recorded in primary care medical record and 9.2% by stimulant prescription.
Fulton	2015	2003	2012	6-13Y	8.6% in 2003, 10.4% in 2007, 11.8% in 2011 by diagnosis reported in the National Survey of Children's Health.
McCabe	2013	2010	2011	18Y	Lifetime medical use of stimulants 9.5% in high school students in a national questionnaire survey.
Visser	2014	2003	2011	4-17Y	11.0% had 'ever' received a diagnosis of ADHD in 2011 compared to 8.8% with a 'current' diagnosis of ADHD in 2011. 4.8% in 2007 and 6.1% in 2011 had 'current' medication and diagnosis of ADHD using data from the National Survey of Children's Health.
Tian	2013	2008	2010	4-40Y	1.9% (2008); 2.5% (2010) by diagnosis. 2.4% (2008); 3.5% (2010) by prescription.
Fontanella	2014	2002	2008	2-5Y	0.93% (2002); 1.31% (2008) based on diagnosis
McDonald	2013	2008	2008	0-17Y	2.5% (2008) based on prescription
Zuvekas	2012	2008	2008	0-18Y	2.4% (1996); 3.5% (2008) based on prescriptions

First author	Year published	Year start	Year end	Ages	Prevalence % (Year, if applicable) and case definition
Centers for Disease Control	2010	2003	2007	4-17Y	Increase in parent-reported diagnosis from 7.8% to 9.5% during 2003-2007 in results from National Survey of Children's Health.
Castle	2007	2000	2005	0-19Y	4.4% based on prescriptions
Brinker	2007	2004	2004	1-20Y	3.7% based on prescriptions
Centers for Disease Control	2005	2003	2004	4-17Y	In 2003 7.8% had ever had a diagnosis of ADHD. 4.3% ever had a diagnosis of ADHD and were taking medication for ADHD.
Castle	2007	2000	2005	0-19Y	4.4% based on prescriptions
Brinker	2007	2004	2004	1-20Y	3.7% based on prescriptions
Centers for Disease Control	2005	2003	2004	4-17Y	In 2003 7.8% had ever had a diagnosis of ADHD. 4.3% ever had a diagnosis of ADHD and were taking medication for ADHD.
Olfson	2013	2002	2004	13-18Y	2.8% of respondents used a stimulant medicine in the previous year in this national survey. Nearly half of the users of stimulants met ADHD criteria in the previous 12 months and an additional 13.1% met ADHD criteria in their lifetime.
Habel	2005	1996	2000	2-18Y	1.86% (1996); 1.93%(2000) based on prescriptions
Goldstein	2001	1999	1999	5-11Y	1.39% based on prescriptions
Lin	2005	1990	1997	All ages	3.8% (1997) based on prescription of amphetamines (not methylphenidate) in 10-14Y olds
LeFever	1999	1995	1996	7-11Y	8% and 10% based on prescriptions in two separate cities.

First author	Year published	Year start	Year end	Ages	Prevalence % (Year, if applicable) and case definition
Olfson	2002	1987	1996	0-18Y	0.6% (1987); 2.4% (1996) based on prescriptions
Robison	1999	1990	1995	5-18Y	2.8% (1995) based on prescriptions; 4.5% (1995) based on diagnosis; 3.4% based on diagnosis and prescription (1995)
Zito	2000	1991	1995	2-19Y	Increasing prevalence of prescribing over time in all age groups e.g. in one programme stimulant prevalence in preschoolers was 1.2% in 1995.
Wolraich	1996	1993	1994	5-11Y	11.4% in this study had ADHD by DSM-III-R criteria of whom 26% were known to the teacher to have had an ADHD diagnosis received stimulant treatment.
Safer	1994	1971	1993	5-18Y	2.1% (1975); 3.6% (1993) in elementary pupils. 0.22% (1983); 0.70% (1993) in senior pupils. Based on prescriptions
Rappley	1995	1992	1992	0-19Y	1.1% based on prescriptions

Table 2: The administrative prevalence of ADHD reported in studies conducted in the UK

First author	Year published	Country	Year start	Year end	Ages	Prevalence % (Year, if applicable) and case definition
O'Leary	2014	UK	2010	2012	5-15Y	0.75% (2010-11); 0.76% (2011-12) based on diagnosis and prescription
Holden	2013	UK	1998	2010	6-17Y	0.19% (1998); 0.55% (2006); 0.51% (2009) based on diagnosis and/or prescription
McCarthy	2012	UK	2003	2008	6-12Y	0.48% (2003); 0.92% (2008) based on prescriptions
McCarthy	2009	UK	1999	2006	15-21Y	0.09% (1999); 0.51% (2006) based on prescriptions in males
Wong	2009	UK	2001	2004	15-21Y	0.03% (1999); 0.2% (2006) based on prescriptions
Hsia	2009	UK	1992	2001	<19Y	0.003% (1992); 0.29% (2001) based on prescriptions
Jick	2004	UK	1999	1999	5-14Y	0.53% (1999) based on prescriptions in males

Table 3: The administrative prevalence of ADHD reported in studies conducted outside the US and UK

First author	Year published	Country	Year start	Year end	Ages	Prevalence % (Year, if applicable) and case definition
Geirs	2014	Iceland	2003	2012	>19Y	0.29% in 2003 and 1.2% in 2012 by prescriptions in a national database.
Pottegard	2014	Denmark	2000	2012	7-12Y	1.2% by prescription in Danish prescription registry.
Wallach-Kildemoes	2015	Denmark	2010	2011	5-17Y	0.06% are prescribed a stimulant medication in national electronic health registers.
Norum	2014	Norway	2004	2011	<19Y	Peak of 0.65% aged 0-9 years in Northern region in 2010 and low of 0.25% aged 0-9 years in Western region by prescriptions. Peak of 2.9% in Northern region in 2011 and low of 0.9% aged 10-19 years in Western region by prescriptions in national database.
Boland	2015	Ireland	2002	2011	<15Y	0.38% in 2002 and 0.86% in 2011 by prescription in Irish prescription claims register.
Pottegard	2012	Denmark	1995	2011	All ages	Increasing prevalence with calendar year based on prescriptions. Peak prevalence 2.4% in 13-17Y old males in 2011
Dalsgaard	2014	Denmark	1990	2011	7-20Y	2.08% by prescription in a national database.
Prosser	2015	Australia	2010	2010	5-17Y	1.24% were diagnosed and medicated in the state of New South Wales.
Okumura	2014	Japan	2002	2010	6-18Y	Article in Japanese but personal correspondence with author revealed: 0.15% aged 6-12 years and 0.05% aged 13-18 years by prescriptions in a nationwide claims database.
Dalsgaard	2013	Denmark	1990	2010	0-20Y	1.56% based on prescriptions
Zetterqvist	2013	Sweden	2006	2009	8-14Y	0.66% (2006); 1.26% (2009) based on prescriptions
Cohen	2013	Israel	2003	2009	6-13Y	12.6% based on diagnosis

First author	Year published	Country	Year start	Year end	Ages	Prevalence % (Year, if applicable) and case definition
Zoega	2011	Denmark, Finland, Iceland, Norway, Sweden	2007	2007	7-15Y	1.1% based on prescriptions
Hodgkins	2011	Netherlands	2000	2007	6-17Y	1.1% (2000); 2.1% (2007) based on prescriptions
Schubert	2010	Germany	2000	2007	<18Y	1.06% (2007) based on prescriptions
Kraut	2013	Germany	2004	2006	3-17Y	1.5% (2005) based on prescriptions
Lindemann	2012	Germany	2004	2006	3-17Y	2.5% (2005) based on diagnosis and prescriptions
Chien	2012	Taiwan	1996	2005	<18Y	0.06% (1996); 1.64% (2005) based on diagnosis
Gumy	2010	Switzerland	2002	2005	5-14Y	0.74% (2002); 1.02% (2005) based on prescriptions
Preen	2007	Australia	2004	2004	3-17Y	2.4% based on prescriptions
Vinker	2006	Israel	1998	2004	0-18Y	0.7% (1998); 2.5% (2004) based on prescriptions
Fogelman	2003	Israel	1999	2001	0-18Y	5.99% in Kibbutzim; 0.20% in Arab areas based on prescriptions
Miller	2001	Canada	1990	1996	0-19Y	0.19% (1990); 1.1% (1996) based on prescriptions

Search strategies for literature searches

Table 1 Using Medline (1948 to 22nd June 2016)

Search terms used	
Aim: To ascertain the published community prevalence of ADHD	
1	Meta-analysis as Topic/
2	meta analy\$.tw.
3	metaanaly\$.tw.
4	Meta-Analysis/
5	(systematic adj (review\$1 or overview\$1)).tw.
6	exp Review Literature as Topic/
7	or/1-6
8	cochrane.ab.
9	embase.ab.
10	(psychlit or psyclit).ab.
11	(cinahl or cinhal).ab.
12	science citation index.ab.
13	bids.ab.
14	(psychinfo or psycinfo).ab.
15	or/8-14
16	reference list\$.ab.
17	bibliograph\$.ab.
18	hand-search\$.ab.
19	relevant journals.ab.
20	manual search\$.ab.
21	or/16-20
22	selection criteria.ab.
23	data extraction.ab.
24	22 or 23
25	Review/
26	24 or 25
27	Comment/
28	Letter/
29	Editorial/
30	animal/
31	human/
32	30 not (30 and 31)
33	or/27-29,32
34	7 or 15 or 21 or 26
35	34 not 33
36	*Attention Deficit Disorder with Hyperactivity/
37	ADHD.mp.
38	attention-deficit.mp.
39	(hyperkinetic adj disorder\$1).tw.
40	or/36-39
41	*Prevalence/
42	prevalence.mp.
43	*Epidemiology/
44	occurrence.mp.
45	rate.mp.
46	or/41-45
47	46 and 40
48	47 and 35

Search strategies for literature searches

Table 2 Using Embase (1974 to 22nd June 2016)

Search terms used	
Aim: To ascertain the published community prevalence of ADHD	
1	exp Meta Analysis/
2	((meta adj analys\$) or metaanalys\$).tw.
3	(systematic adj (review\$1 or overview\$1)).tw.
4	or/1-3
5	cochrane.ab.
6	embase.ab.
7	(psychlit or psyclit).ab.
8	(psychinfo or psycinfo).ab.
9	(cinahl or cinhal).ab.
10	science citation index.ab.
11	bids.ab.
12	or/5-11
13	reference lists.ab.
14	bibliograph\$.ab.
15	hand-search\$.ab.
16	manual search\$.ab.
17	relevant journals.ab.
18	or/13-17
19	data extraction.ab.
20	selection criteria.ab.
21	19 or 20
22	review.pt.
23	21 and 22
24	letter.pt.
25	editorial.pt.
26	animal/
27	human/
28	26 not (26 and 27)
29	or/24-25,28
30	4 or 12 or 18 or 23
31	30 not 29
32	*attention deficit disorder/
33	ADHD.mp.
34	attention-deficit.mp.
35	(hyperkinetic adj disorder\$1).tw.
36	or/32-35
37	*prevalence/
38	prevalence.mp.
39	*epidemiology/
40	occurrence.mp.
41	rate.mp.
42	or/37-41
43	42 and 36
44	43 and 31

Search strategies for literature searches

Table 3 Using PsycINFO (1806 to 22nd June 2016)

Search terms used	
Aim: To ascertain the published community prevalence of ADHD	
1	exp Meta Analysis/
2	((meta adj analy\$) or metaanalys\$).tw.
3	(systematic adj (review\$1 or overview\$1)).tw.
4	or/1-3
5	exp Attention Deficit Disorder with Hyperactivity/
6	ADHD.mp.
7	or/5-6
8	exp Epidemiology/
9	prevalence.mp.
10	occurrence.mp.
11	rate.mp.
12	or/8-11
13	12 and 7
14	13 and 4

Search strategies for literature searches

Table 4 Using CINAHL (1982 to 22nd June 2016)

Search terms used	
Aim: To ascertain the published community prevalence of ADHD	
1	(MH "Meta Analysis") OR Meta analys\$.tw. OR Metaanaly\$.tw. OR exp Literature review/ OR (systematic adj (review or overview)).tw.)
2	(MH "Animals+")
3	Commentary.pt. OR Letter.pt. OR Editorial.pt.
4	2 or 3
5	1 not 4
6	(MH "Attention Deficit Hyperactivity Disorder")
7	"ADHD"
8	6 or 7
9	(MH "Epidemiology+")
10	(MH "Prevalence")
11	prevalence
12	occurrence
13	rate
14	9 or 10 or 11 or 12 or 13
15	14 and 8
16	15 and 5

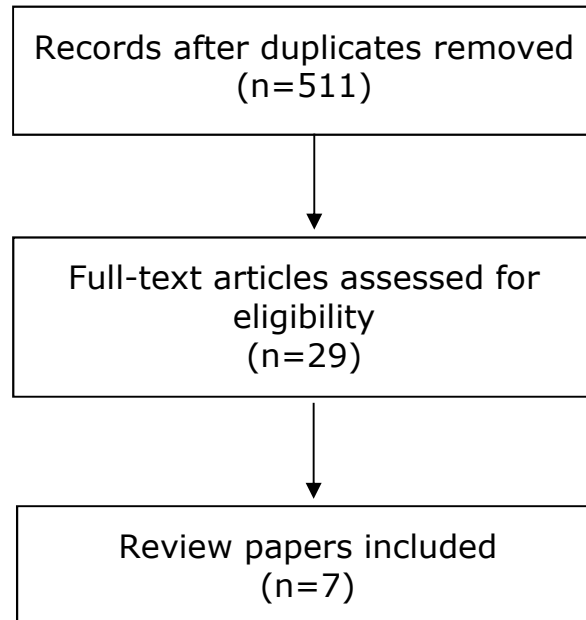
Search strategies for literature searches

Table 5 Using ASSIA (1987 to 22nd June 2016)

Search terms used	
Aim: To ascertain the published community prevalence of ADHD	
1	("Meta analysis" OR "literature review" OR "systematic review" OR "systematic overview") AND ((ADHD OR "Attention-deficit hyperactivity disorder") AND (prevalence OR epidemiology OR occurrence OR rate))

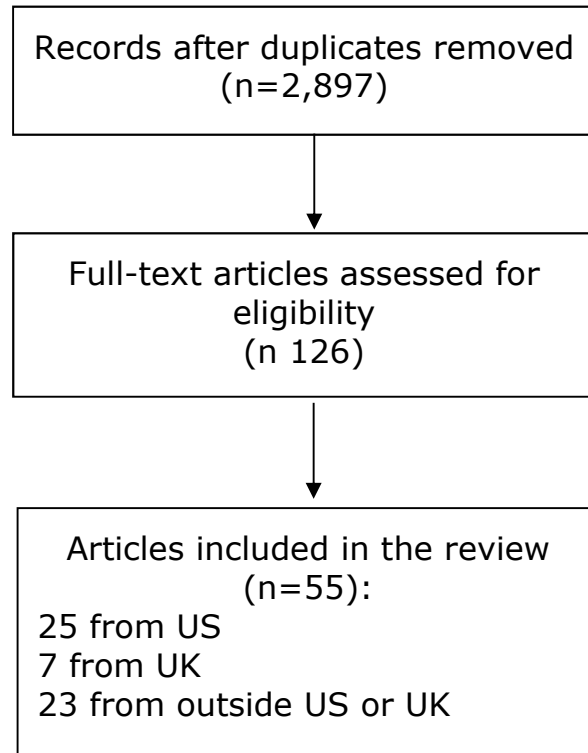
PRISMA flow chart

Published systematic reviews describing community prevalence of ADHD



PRISMA flow chart

Published studies describing administrative prevalence of ADHD



Appendix – Search strategies for literature searches

Table 6 Using Medline (1946 to 22nd June 2016)

Search terms used	
Aim: To ascertain the published administrative prevalence of ADHD	
1	*Drug Utilization/
2	Office Visits/td [Trends]
3	prescribing.mp.
4	*Diagnosis/ec, sn, td [Economics, Statistics & Numerical Data, Trends]
5	exp Primary Health Care/
6	or/1-5
7	Meta-Analysis as Topic/
8	meta analy\$.tw.
9	metaanaly\$.tw.
10	Meta-Analysis/
11	(systematic adj (review\$1 or overview\$1)).tw.
12	exp Review Literature as Topic/
13	or/7-12
14	reference list\$.ab.
15	bibliograph\$.ab.
16	hand-search\$.ab.
17	relevant journals.ab.
18	manual search\$.ab.
19	or/14-18
20	selection criteria.ab.
21	data extraction.ab.
22	20 or 21
23	Review/
24	22 and 23
25	Comment/
26	Letter/
27	Editorial/
28	animal/
29	human/
30	28 not (28 and 29)
31	or/25-27,30
32	*Attention Deficit Disorder with Hyperactivity/
33	ADHD.mp.
34	attention-deficit.mp.
35	(hyperkinetic adj disorder\$1).tw.
36	or/32-35
37	*Prevalence/
38	prevalence.mp.
39	*Epidemiology/
40	occurrence.mp.
41	rate.mp.
42	or/37-41
43	42 and 36
44	43 and 6
45	44 not 31
46	or/13,19,24
47	45 not 46

Search Strategy and Selection Criteria

Community prevalence: To identify published systematic reviews describing the community prevalence of ADHD, a series of searches were conducted using the following databases (from the date of inception to 22nd June 2016): Medline; Embase; PsycINFO; CINAHL and ASSIA using (*terms describing systematic reviews*) and (*terms describing ADHD*) and (*terms describing prevalence*). The full search strategies used in each database are described in the Appendix (See Appendix Tables 1-5). After duplicate records were removed, 511 titles remained. The titles and abstracts were reviewed to identify systematic reviews summarising the prevalence of ADHD. Twenty-nine full papers were obtained from which seven review papers (published between 2007 and 2015) reported on the prevalence of ADHD in the community.

Administrative (clinically recorded) prevalence: We conducted a separate search (from the date of inception to 22nd June 2016) in Medline; Embase; PsycINFO; CINAHL; and ASSIA using a search strategy reflecting: (*terms describing diagnosis or prescribing*) and (*terms describing ADHD*) and (*terms describing prevalence*). The full search strategy used in Medline is described in the Appendix - Table 6. To address the possibility that restricting papers with terms describing diagnosis or prescribing might be too specific, a further hand search was performed in Medline from 1996 to 2016 using a search strategy reflecting: (*terms describing ADHD*) for the following three journals: 'Journal of Attention Disorders'; 'Journal of the American Academy of Child and Adolescent Psychiatry' and 'Morbidity and Mortality Weekly Report' (MMWR). After duplicate records were removed, 2897 titles and abstracts were reviewed, 126 full papers were obtained and 55 studies reporting on the administrative prevalence of ADHD were identified: 25 studies from the US, 7 from the UK and 23 conducted outside the US and UK.