

ADHD: making the invisible **visible**

**An Expert White Paper on attention-deficit hyperactivity disorder (ADHD):
policy solutions to address the societal impact, costs and long-term
outcomes, in support of affected individuals**

S Young, M Fitzgerald, MJ Postma



This project was initiated, facilitated and funded by Shire AG, and supported by the European Brain Council (EBC) and GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks)

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Foreword: Making the invisible visible

Brussels, 23 April 2013

In today's world, mental health problems are becoming less and less of a priority on the political agenda. This is in part due to the current economic crisis, which has resulted in widespread cutbacks in the resources devoted to health and social care. As a consequence, health systems – and mental health services in particular – are increasingly under strain. At the same time, as a result of the Europe-wide increase in unemployment and poverty, social exclusion and mental health problems are on the rise and reaching alarming proportions in many EU Member States.

Among mental health disorders, attention-deficit hyperactivity disorder (ADHD) is one of the most neglected and misunderstood psychiatric conditions in Europe. While it is estimated to affect approximately 1 in 20 children and adolescents across Europe, with many cases persisting into adulthood, very few people affected by ADHD receive appropriate diagnosis and support. This is largely due to the lack of public awareness and the widespread social stigma surrounding this condition, as well as the lack of appropriate community frameworks to accurately detect and diagnose ADHD.

Due to the lack of public awareness and the widespread social stigma surrounding ADHD, very few people affected by this disorder receive appropriate diagnosis and support. This lack of access to diagnosis and support often results in a worsening of the condition and a deterioration of quality of life. Relationships with other people, school performance and functioning in a work environment can all be affected. The 'socio-emotional' component of the disorder is the most debilitating aspect for many children, adolescents and adults; it can have a negative impact on self-esteem and result in early school leaving problems.

The EU has made and is making efforts to address mental health issues. The 2009 EU Pact on Mental Health, and the recently launched Joint Action on Mental Health and Well-being, both specifically address mental health in children and adolescents; ADHD should be an explicit part of this activity. I therefore believe that this Expert White Paper and its policy recommendations are very timely, concrete and practical. I am convinced it can make a useful contribution to the efforts of European, national and local policy makers to help implement the right of citizens to access high quality mental health care.

In my role as co-Chair of the European Parliament Interest Group on Mental Health, Well-being and Brain Disorders, my colleagues and I will continue to play our part to ensure that mental health issues, including ADHD, remain a solid part of the EU health agenda. This Expert White Paper, with its sensible and practical recommendations, provides a useful tool in our advocacy and policy efforts.

The fact that this Expert White Paper was endorsed by a variety of stakeholders makes the messages it contains even stronger. It is my sincere hope that this document will help to ensure better recognition and better management of ADHD by all stakeholders in the wider healthcare arenas, in schools, in the criminal justice systems and in the workplace in each country across the EU.

Nessa Childers MEP

Co-Chair of the European Parliament Interest Group on Mental Health, Well-being and Brain Disorders



Introduction

Attention-deficit hyperactivity disorder (ADHD) does not feature highly on the current national and EU policy agendas, despite accumulating evidence of its substantial impact on individuals, families and society. This Expert White Paper has been developed to share some facts and figures about this mental health condition and provide EU and national level policy makers with some practical recommendations for action, with the aim of improving timely access to accurate diagnosis and support for people with ADHD.

This Expert White Paper was developed on the basis of a European Expert Roundtable on ADHD held in Brussels on 27 November 2012, with the participation of clinicians, patients' and families' advocacy groups and representatives from the education and criminal justice systems (see Annex 1). The Expert Roundtable addressed specific issues and challenges with regards to the management of ADHD and provided a forum for the discussion of policy recommendations. The three co-authors formulated the outcomes of the Expert Roundtable into this White Paper, which reflects their views based on their clinical and scientific experiences. Additional input was provided by other contributors (see Annex 2). The White Paper has also been endorsed by the European Brain Council (EBC) and GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks).

Chapter 1 provides information on the burden of ADHD on the individual, families and society.

Chapter 2 reports data from recent studies of ADHD, which further highlight the need for timely diagnosis and effective management approaches.

Chapter 3 outlines a number of policy considerations and recommendations for action with regard to raising informed awareness of ADHD, improving access to early and accurate diagnosis, improving access to treatment and care, involving and supporting patient organisations and encouraging a patient-centred research agenda.

Executive summary

This Expert White Paper aims to inform policy makers and other relevant stakeholders of the impact ADHD has on the individual affected by the condition, their family and society as a whole. It provides a framework for action in a number of areas, such as screening, diagnostics and treatment, as well as health systems, schools and the workplace, taking into account the input of a wide range of stakeholders who participated in the European Expert Roundtable on this topic.

Chapter 1: Introduction to ADHD

- ADHD is a multifaceted disorder, which varies widely in terms of the type and severity of its impact.
- Individuals with ADHD may experience:
 - symptoms of inattention
 - symptoms of hyperactivity and impulsivity
 - emotional dysregulation
 - cognitive impairment
 - comorbidities.
- ADHD can have a negative impact on various aspects of an individual's quality of life, including social functioning, academic achievements and psychological wellbeing.
- In adulthood, effects on social functioning may impact on personal relationships with partners, and problems at school may evolve into difficulties in further education, and finding and maintaining employment.
- There are established guidelines for the diagnosis and treatment of ADHD and evidence suggests that effective management can improve quality of life.

Chapter 2: Impact, costs and long-term outcomes of ADHD

- Recent studies have provided data on the impact, costs and long-term outcomes of ADHD:
 - the Lifetime Impairment Survey (LIS): a European survey to establish the degree to which ADHD impacts on children's lives, as well as the areas of life most affected by the disorder
 - cost of illness studies: six published econometric studies on the costs of ADHD in Europe
 - the Long-Term Outcomes (LTO) study: a systematic literature review and analysis to evaluate the long-term outcomes of ADHD and whether they improve with treatment.
- These studies demonstrate that ADHD can have a negative and pervasive impact, with wide-ranging associated costs in terms of healthcare and other services and long-term consequences for multiple aspects of life.
- They also indicate that effective treatment (which may be pharmacological, non-pharmacological, or a combination of both) can help to improve outcomes, highlighting the need to better support individuals with this disorder.
- There is a need for more studies on the costs of ADHD, which will support the development of strategies for devising and implementing cost-effective solutions.



Chapter 3: Opportunities for improved recognition and management of ADHD

- Based on the discussion and outcomes of the European Expert Roundtable organised on 27 November 2012, a set of five recommendations has been developed in this Expert White Paper to provide local, national and European stakeholders with a framework for action on ADHD.
- These recommendations are to:
 1. Increase informed awareness of ADHD
 2. Improve access to early and accurate diagnosis of ADHD, especially via the introduction of early identification and intervention programmes in different policy areas (eg education, mental health-related services, criminal justice services and the workplace)
 3. Improve access to ADHD treatment and develop a multidisciplinary patient-centred approach to ADHD care and support
 4. Involve and support patient organisations
 5. Encourage a patient-centred research agenda on ADHD, through more quantitative and qualitative research and through more involvement of allied stakeholders in developing priorities for future research.
- Each one of these recommendations is accompanied by one or two specific goals, each with a list of suggested specific actions.
 - Most of these actions are targeted towards groups of stakeholders interested in ADHD and active in different sectors of society, with a special focus on education, healthcare and the criminal justice system.
- Overall, these recommendations aim to provide European, national and local stakeholders with a set of indications on which priority actions should be pursued in the short- to medium-term, in order to improve the quality of life of people living with ADHD and to reduce the cost of this disorder on national welfare systems across Europe.

Chapter 1: Introduction to ADHD

ADHD affects approximately 1 in 20 children and adolescents across Europe,¹ with many cases persisting into adulthood.² In addition to core symptoms of inattention and/or hyperactivity and impulsivity,³ ADHD can also affect emotional regulation⁴⁻⁷ and cognitive processes,^{5,8,9} with widespread implications for the lives of the affected individuals and their families. There are also clear biological aspects to the disorder, since ADHD has been associated with atypical brain development.¹⁰⁻¹² Nonetheless, timely and effective management of the disorder can improve quality of life,¹³ and, with appropriate support, there is scope for individuals to lead fulfilled and successful lives.¹⁴ Indeed, some adults with ADHD have a positive outlook on some aspects of the disorder.¹⁴



ADHD affects approximately **1 in 20 children and adolescents** across Europe¹

Real-life successes and challenges

Inattentive ADHD: the silent subtype?

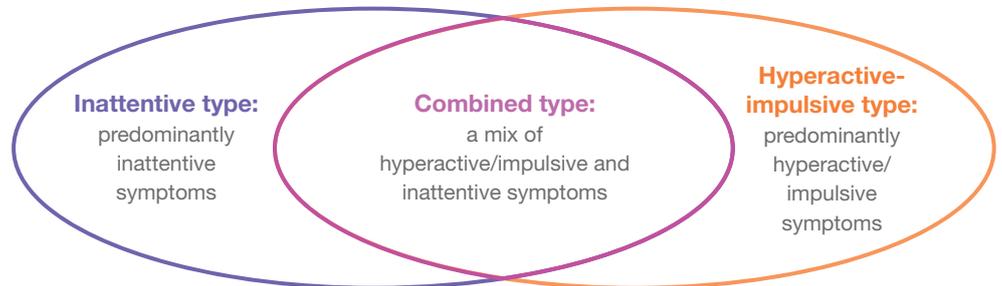
The ratio of girls to boys with ADHD ranges from 1:3 to 1:16 in different countries across Europe.¹⁵ This discrepancy may indicate that, in some countries, more boys than girls with ADHD are referred for clinical evaluation.¹⁵

So, are girls with ADHD overlooked? Compared with boys, girls more frequently present with inattentive symptoms, rather than disruptive behaviours or problems in school.¹⁶ It has been suggested that this presentation may be more difficult to identify and could lead to a gender-based referral bias.¹⁶

The ADHD spectrum

ADHD is a multifaceted, heterogeneous disorder that varies widely in terms of the type and severity of its impact.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) diagnostic tool splits ADHD into three subgroups:³



In addition to the core symptoms of inattention and/or hyperactivity and impulsivity, ADHD can also be associated with other key features in some individuals:

- emotional dysregulation: indicators of emotional lability (eg irritability, hot temper) have been more frequently reported in children and adults with ADHD than in those without⁴⁻⁷
- cognitive impairment: assessments have indicated that some cognitive processes may be affected in children and adults with ADHD^{5,8,9}
- comorbidities: a recent retrospective chart review of 779 children and adolescents with ADHD has indicated that almost half have 1-3 comorbidities at the time of ADHD diagnosis.¹⁷ This supports previous research associating ADHD with an increased risk of developing other distinct mental health conditions, including conduct disorder (CD), oppositional defiant disorder (ODD), depression and anxiety.¹⁶ Such comorbidities can be associated with a further impact on quality of life.^{18,19} In addition, some studies have identified an association between ADHD symptoms and obesity.^{20,21} Comorbid problems are also common in adults with ADHD.²²



Impact on daily life

Research has shown that adolescents with a history of ADHD tend to experience greater peer rejection, have fewer close friendships²³ and are more likely to be bullied than their peers.²⁴ Such effects on social functioning have been found to be greater in girls than in boys, particularly in girls with the inattentive subtype of ADHD.²⁵ Perceived stigmatisation may have negative consequences, potentially contributing to symptoms such as anxiety, social stress and depression.²⁶ In general, ADHD has been associated with low self-esteem and suicidal thoughts in some individuals.^{19,27-29}

Without effective management, ADHD may have a substantial impact on academic and occupational outcomes. Symptoms have been correlated with poor exam performance, grade retention, and failure to graduate from secondary school.^{30,31} In a US study, adolescents with ADHD were more than eight times more likely to drop out of high school completely, compared with adolescents without ADHD.³² In later life, adults with ADHD have expressed feelings that difficulties in school had an important impact on their subsequent lives, and that more effective management of the disorder in these years may have allowed them to achieve greater academic and occupational success.¹⁴

Impact in adulthood

A global survey has indicated that 50% of children and adolescents with ADHD will continue to have ADHD as adults.² In fact, ADHD may persist throughout the lifespan and has been identified in adults aged 55 years and above.³⁴

In adulthood, individuals with ADHD may be faced with different situations and new challenges. For example, effects on social functioning may impact on personal relationships with partners^{35,36} and problems at school may evolve into difficulties in further education and finding and maintaining stable employment.^{35,37-39} Interestingly, recently reported data indicate that adults with ADHD may underestimate the extent of their ADHD-related impairments.⁴⁰

Symptoms of ADHD have also been associated with relatively high rates of arrests and imprisonment in adulthood^{35,41} and relatively high rates of driving offences in a selected young adult population.⁴² Evidence suggests that, in some cases, the increased risk of criminality or risky driving may in fact be attributable to the development of comorbid antisocial or substance use disorders in adolescence, rather than being a direct result of ADHD.^{41,43,44} Nevertheless, it has been reported that criminality may be reduced by one-third if ADHD is treated.⁴⁵

It is important to note that some adults with ADHD lead fulfilled lives and have a positive outlook on some aspects of the disorder.¹⁴ Indeed, the negative impact of ADHD on the quality of life of adults may be lessened through early diagnosis and treatment.^{13,46}

Real-life successes and challenges

Provisions for ADHD in education*

Educational provisions for ADHD vary across Europe, but may include a part-time or full-time special education teacher or special allowances during examinations (eg additional time).³³ In Hungary and Sweden, several private schools offer specific classes and/or services for children with ADHD.

Some countries do not specifically include ADHD on the teaching curriculum, while in a few European countries, ADHD is partially covered in initial teacher training, sometimes as part of general disability education.³³

Real-life successes and challenges

Recognition of adult ADHD

Historically, there has been debate regarding the validity of an ADHD diagnosis in adulthood;⁴⁷ however, advances in science have led to growing recognition and acceptance of ADHD as a disorder present in both childhood and adulthood.

Yet a lack of specific diagnostic services, treatment facilities and workplace provisions for adults have been reported across Europe;^{33,37} perhaps reflecting low rates of referral from adolescent to adult services^{33,48} and premature treatment discontinuation in young adulthood.⁴⁹

In the UK, national guidelines on ADHD make specific recommendations for the care of adult patients.⁵⁰ In addition, efforts are under way to promote effective transition from adolescent to adult services⁴⁸ and raise awareness of ADHD within the criminal justice system.⁵¹

*Based on the findings of an independent survey of ADHD-Europe member organisations conducted in 2011 across 21 European countries. Please refer to the original survey report for further details: Clark S, Carr-Fanning K, Norris J. (2011). Diagnosis and Treatment of ADHD in Europe (2nd eds.). Belgium: ADHD-Europe.

Real-life successes and challenges

Training of healthcare professionals*

In many European countries, professional training for healthcare professionals has been reported to lack any special training on ADHD, or only include ADHD as part of a general overview of neuropsychiatric dysfunction.³³

However, specific training on ADHD is now available in some countries, including Germany, Greece and Spain.³³

Impact on carers and society

As well as impacting on the affected individuals themselves, ADHD can also have an important influence on the individual's family: throughout adolescence and even into young adulthood, ADHD has been associated with a substantial burden on carers.⁵² Parents may experience depression, anxiety and stress,^{53,54} and may feel stigmatised by social groups.⁵⁵ Ultimately, ADHD has been associated with high levels of family conflict and poor family cohesion.⁵⁶

Current guidelines for diagnosis and treatment

In addition to international⁵⁷ and pan-European guidelines,⁵⁸ many European countries have developed national guidelines for the diagnosis and management of ADHD, including Germany,⁵⁹⁻⁶¹ Italy,^{62,63} the Netherlands,⁶⁴ Spain⁶⁵ and Sweden.⁶⁶ Notably, the UK National Institute for Health and Clinical Excellence (NICE) guidelines for the diagnosis and treatment of ADHD⁵⁰ are reported to be of high methodological quality⁶⁷ and have come to be regarded as a gold standard in Europe.³³

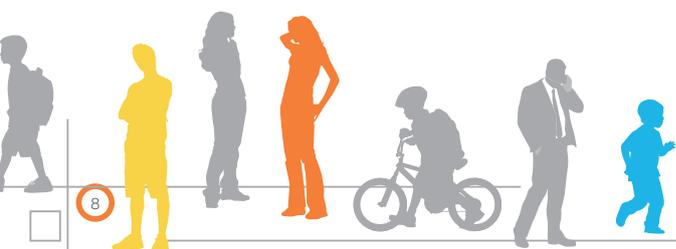
While the recommended treatment approaches outlined in the NICE guidelines will incur costs, it has been noted there may also be substantial associated savings, including:⁶⁸

- reductions in societal costs (eg parental absence from work and related productivity losses)
- reductions in costs of special education and other social services (eg criminal justice system)
- increases in the work productivity and performance of adults with ADHD after starting treatment.

Once diagnosed, the management of ADHD should be carefully tailored to the needs of the individual.^{50,58} Existing guidelines recommend a multimodal approach, which may include a combination of medication and psychosocial therapies.^{50,57,58} Importantly, data suggest that the use of stimulant medications licensed for the treatment of ADHD does not contribute to the subsequent development of substance use disorders.⁶⁹⁻⁷¹

Summary

- ADHD is a multifaceted, heterogeneous disorder that varies widely in terms of the type and severity of its impact.
- ADHD is often associated with widespread effects on social functioning and academic outcomes.
- In many cases, ADHD persists from childhood into adulthood, impacting on the entire lifespan.
- There are established guidelines for the diagnosis and treatment of ADHD, and evidence suggests that effective management can improve quality of life.



*Based on the findings of an independent survey of ADHD-Europe member organisations conducted in 2011 across 21 European countries. Please refer to the original survey report for further details: Clark S, Carr-Fanning K, Norris J. (2011). Diagnosis and Treatment of ADHD in Europe (2nd eds.). Belgium: ADHD-Europe.

Chapter 2: Impact, costs and long-term outcomes of ADHD

ADHD can have far-reaching implications for the lives of affected individuals as well as wider society. Recently, studies have provided data on the impact, costs and long-term outcomes of the disorder:

- the **Lifetime Impairment Survey (LIS)**: a European survey to establish the degree to which ADHD impacts on children's lives, as well as the areas of life most affected by the disorder
- **cost of illness studies**: six published econometric studies on the costs of ADHD in Europe
- the **Long-Term Outcomes (LTO) study**: a systematic literature review and analysis to evaluate the long-term outcomes of ADHD and whether they improve with treatment.

In this chapter we review key findings from these studies that highlight the need for timely diagnosis and effective management approaches, in order to reduce the personal and societal burden and costs of the disorder. As with all research, it is important to note that results represent select patient populations and should be considered within the context of the study designs (please see source references for details of potential limitations).

The impact of ADHD: the Lifetime Impairment Survey (LIS)^{72,73}

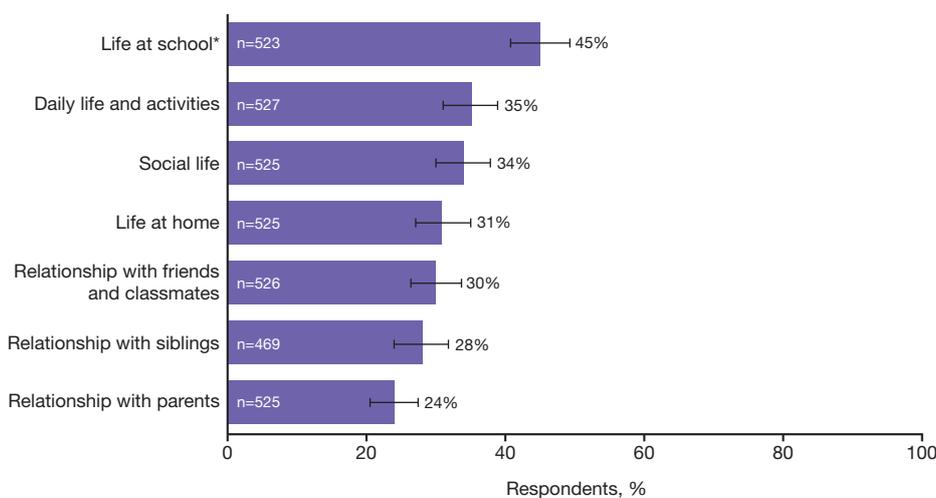
The LIS was a comprehensive online survey, developed by a committee of psychiatrists and psychologists to establish the degree to which ADHD impacts on the lives of children, as well as the areas of life most affected by the disorder. The survey was conducted across six European countries (France, Germany, Italy, the Netherlands, Spain and the United Kingdom), and was based on a similar survey of impairment in adults with ADHD conducted in the USA.³⁵ Questionnaires were completed by parents/carers of children with/without ADHD, as well as adults with/without ADHD.

Survey of parents/carers of children with/without ADHD⁷²

A questionnaire was completed by 535 parents/carers of children with ADHD and 424 parents/carers of children without ADHD, who responded to questions regarding their child's experiences in everyday life (children aged 6-19 years).

When parents/carers of children with ADHD were questioned, it was found that the influence of ADHD was negative and pervasive across multiple domains, including life at school, daily life and activities, and social life (Figure 1). Furthermore, 60% of parents/carers felt that ADHD had a negative impact on their child's self-esteem, and 69% felt that their child would be able to accomplish more if they did not have ADHD.

Figure 1. Percentages of parents/carers reporting a strong or moderate negative impact of ADHD on various aspects of their children's lives



*Life at school reported by parents/carers of children aged ≥ 6 years only

Real-life successes and challenges

Case study 1 – Spain

Spanish Federation of ADHD Supporting Associations (FEAADAH) – getting ADHD care on the education agenda

FEAADAH has worked with different stakeholders to convey the need for a multidimensional approach to the management of ADHD in the education arena.

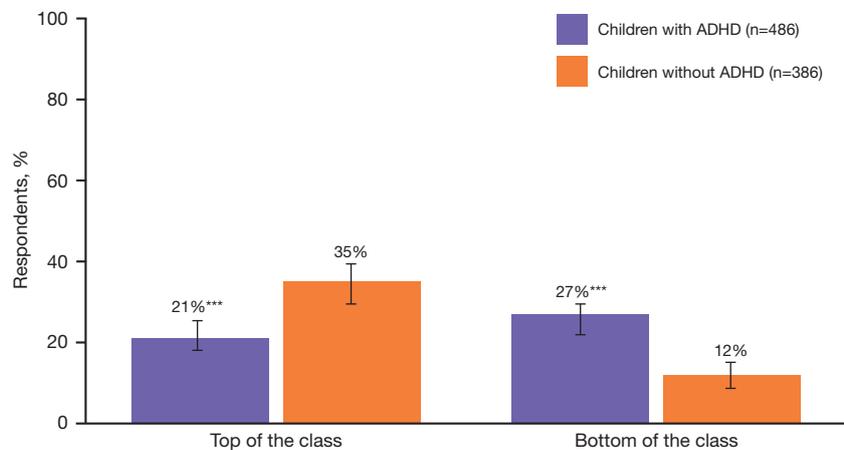
- Since 2010, Spanish state law has recognised that children with ADHD need specific educational support; financial support is granted to families when the school is unable to provide this support.
- Some regional laws recognise the right of children with ADHD to have provisions in schools, eg for exams and homework. Provisions are also in place in university entrance exams.
- Several regions have established protocols for coordination between education, health and social services to facilitate timely diagnosis and management of ADHD.
- FEAADAH has submitted a proposal to explicitly include ADHD in national education law. In 2012, this proposal was presented to the Congress of Deputies and the Ministers of Education of all Spanish regions.

Case study provided by
Prof Dr Fulgencio Madrid Conesa,
President of FEAADAH.

In the home, significantly fewer children with ADHD than those without ADHD were considered to have a good relationship with their siblings (54% vs 74%, respectively), or were considered to get along with their parents (74% vs 83%, respectively). However, some areas of home life did not differ significantly between study groups, including the likelihood of spending time with family, playing organised sports or participating in volunteer work.

There were also significant differences in academic performance between children with and without ADHD. Compared to children without ADHD, more with ADHD were reported to feel frustrated at school (25% vs 68%, respectively), fewer were reported to be able to concentrate easily on schoolwork (53% vs 21%, respectively), and more were reported as being in the bottom of their class at school (Figure 2).

Figure 2. Percentages of parents/carers, of children with or without ADHD, reporting that their children are in the top or bottom of their class



***p<0.001 vs children without ADHD

In terms of behavioural and conduct problems, significantly more children aged ≥ 13 years with ADHD than those without ADHD were reported to participate in fights (22% vs 4%, respectively) or consume excessive amounts of alcohol (11% vs 5%, respectively).

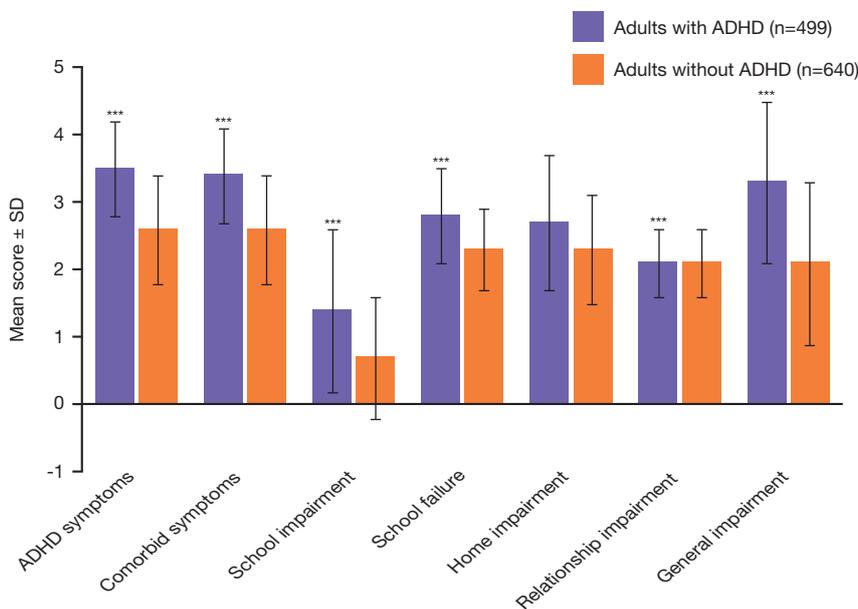


Survey of adults with/without ADHD⁷³

A separate questionnaire was completed by 588 adults with ADHD (average age: 36 years) and 736 adults without ADHD (average age: 46 years), who responded to questions regarding their childhood experiences at home, at school and in relationships.

When individual questionnaire items were grouped and converted to scales, mean scores for impairment and symptom domains were generally significantly higher in adults with ADHD than in those without ADHD, indicating poorer outcomes (Figure 3).

Figure 3. Mean symptoms and impairment scores derived from the recollection of childhood experiences by adults with or without ADHD.



***p<0.001 vs adults without ADHD
SD, standard deviation

Individual survey items were grouped into symptom and impairment scales (mostly 5-point scales, except for home impairment, which was a 3-point scale; higher scores indicate a greater degree of impairment)

School impairment included the following items: got along with teachers, able to handle a large workload, popular in school, thought highly of by teachers, fitted in with peers, liked by adults, and had a good relationship with parents

School failure covered the following items: in 'bottom' of class, had a tutor or special classes to help with school work, repeated a grade, and got expelled or suspended

Home impairment covered the following items: spending time with family and friends, exercising or playing sports, participating in volunteer work, participating in cultural or educational activities outside of school, going on dates, and participating in school clubs or other extracurricular activities

Mean scores were calculated for respondents who answered at least half of the questions for each particular scale; only respondents with scores on all applicable scales were included in this analysis

Real-life successes and challenges

Case study 2 – Germany

MindMatters

MindMatters is an innovative programme that provides a framework to promote mental health in primary and secondary schools. Originally developed in Australia, the programme is based on the concept of a 'good and healthy' school system to promote the mental wellbeing of young people through the collaborative efforts of schools, parents and community support agencies. Different issues are addressed, including developing friendships, dealing with stress, bullying, grief, and psychiatric disorders.

Key aims include:

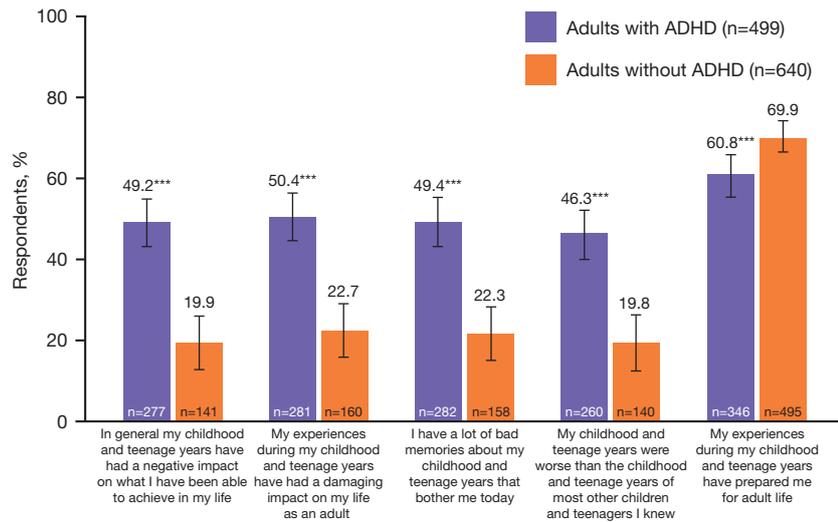
- the development of a school culture in which all students feel safe, valued and included
- the improvement of the quality of relationships within schools, supporting an ethos of respect and tolerance
- the improvement of student health and learning conditions by encouraging the development of life skills and resilience.

More details are available at:
<http://www.mindmatters-schule.de/>

MindMatters is supported by
BARMER GEK, Unfallkasse North Rhine-Westphalia and Gemeinde-Unfallversicherungsverband Hannover.

In addition, significantly more adults with ADHD than those without ADHD strongly or somewhat agreed that their childhood and teenage years were worse than those of most of their peers or had a negative impact on what they have been able to achieve in life (Figure 4).

Figure 4. Percentages of adults with or without ADHD who strongly or somewhat agreed with statements regarding their childhood and teenage years.



*** $p < 0.001$ vs adults without ADHD
Only respondents answering each specific item/question were included in this analysis

Conclusions

- ADHD can have a negative impact on a range of aspects of children's everyday lives, with life at school being the most frequently affected area.
- Children with ADHD may have a higher frequency of behavioural and conduct problems than children without ADHD, which indicates the wider societal implications of the disorder.
- Many adults with ADHD feel that their childhood experiences continue to have a negative impact in adult life.

The costs of ADHD: cost of illness studies

Six econometric studies of the incremental costs of childhood and adolescent ADHD in Europe were identified in a literature search of peer-reviewed, original research articles published between 1999 and 2012.⁷⁴⁻⁷⁹

The costs reported in the six studies were grouped into cost categories according to whether they were attributable to the patients or their family members, and whether they were associated with healthcare, education, social services or productivity losses (Table 1).



Table 1. Number of studies reporting cost data by cost category (total number of studies = 6)

Cost category	Number of studies reporting cost data, n	
	Patient	Family members
Healthcare	6	1
Education	2	0
Social services	1	0
Productivity loss	0	2

The reported annual costs for each of these cost categories were converted to euros where necessary and adjusted for inflation to give estimates for the year 2012 (Table 2). Annual healthcare costs per patient were reported for all six studies, and adjusted values ranged from €716 to €2134. There were additional costs associated with educational support and social services for the patient, and healthcare and productivity loss for family members, although data for these categories were sparse.

Table 2. Annual costs for each cost category by study

Study	Country	Costs per patient			Costs per family member	
		Healthcare	Education	Social services	Healthcare	Productivity loss
de Ridder A, De Graeve D, 2006 ⁷⁴	Belgium	€1289	€50	-	-	-
Hakkaart-van Rooijen L et al, 2007 ⁷⁵	The Netherlands	€2134	-	-	€658	€1798
Schöffski O et al, 2008 ⁷⁶	Germany	€716	-	-	-	-
Wehmeier PM et al, 2009 ⁷⁷	Germany	€812	-	-	-	-
Myrén KJ et al, 2010 ⁷⁸	Sweden	€1960	-	-	-	€762
Telford C et al, 2012 ⁷⁹	UK	€1753	€5559	€37	-	-

Currency conversion was computed using GDP per capita Purchasing Power Parity (PPP) according to the year of the study; the Harmonized Index for Consumer Prices (HICP) for the Netherlands was used to adjust for inflation to provide cost estimates for the year 2012.

By comparison, other studies across Europe have estimated mean annual costs per patient (direct and indirect costs, including productivity loss) of:

- €285 for headache⁸⁰
- €1583 for persistent asthma in adults⁸¹
- €5221 for epilepsy.⁸⁰

Conclusions

- There are considerable costs associated with ADHD, attributable both to the patient and their family members.
- Costs associated with healthcare have been consistently reported across studies. Data on costs associated with education, productivity loss and social services are sparse, highlighting a need for more research in these areas.
- It is important to note that costs relating to the criminal justice system or road traffic accidents could not be considered due to a lack of data.

Real-life successes and challenges

Costs of ADHD in the USA

Systematic reviews have analysed published data to estimate annual national costs associated with childhood and adolescent ADHD in the USA.^{82,83}

The most recent of these reviews estimated annual costs per patient of \$621-2720 for healthcare and \$2222-4690 for education, while costs per family member were estimated to be \$1088-1658 for healthcare and \$142-339 for productivity loss.⁸² In addition, annual costs to the justice system were also estimated as \$267 for adolescents with ADHD. The estimated healthcare costs appear to be of a similar order of magnitude to those reported in Europe, although there are limited European data to support a comparison of the other types of costs.

Studies in the USA have also indicated substantial costs associated with ADHD in adulthood, including those resulting from lost work performance and health benefit costs.^{84,85}

Real-life successes and challenges

Direct medical costs of ADHD in Nordbaden, 2003

The extent of the costs associated with ADHD in Europe have been supported by a study of healthcare utilisation in Nordbaden, Germany.⁸⁶ Based on analyses of administrative data from 2003, direct medical costs for children and adolescents with ADHD, from the perspective of statutory health insurance, exceeded those for children and adolescents without ADHD by a factor of >2.5.

The long-term outcomes of ADHD: the Long-Term Outcomes (LTO) study^{46,87}

The LTO study was a systematic review and analysis of 351 published studies, designed to evaluate the long-term outcomes of ADHD and whether they improve with treatment.

Designs of the analysed studies

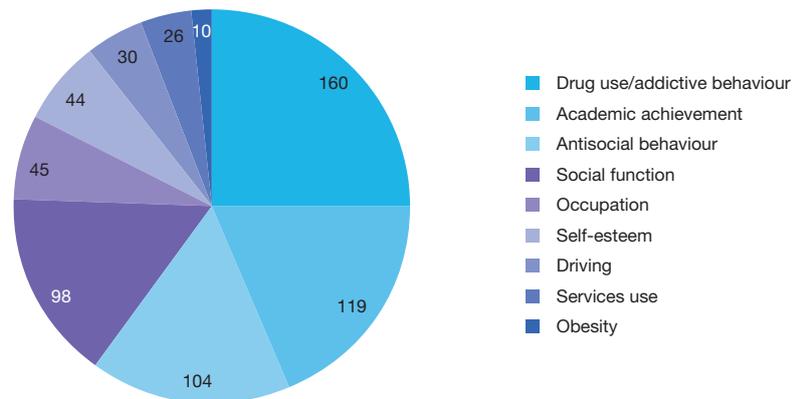
Studies included longitudinal studies with prospective or retrospective follow up of 2-40 years, cross-sectional studies comparing two age groups differing by ≥ 2 years, and single cross-sectional studies of participants aged ≥ 10 years.

Outcomes were reported for patients who had untreated ADHD or had received pharmacological treatment (eg stimulant or non-stimulant medications), non-pharmacological treatment (eg behavioural therapy, family therapy) or multimodal treatment (a combination of at least one pharmacological and one non-pharmacological treatment).

Types of outcomes reported in the analysed studies

Overall, the studies reported 636 outcome results, which were grouped into nine outcome categories, as shown in Figure 5. The most frequently reported outcomes were within the categories of drug use/addictive behaviour, academic achievement and antisocial behaviour.

Figure 5. Number of outcome results by outcome category (all age groups)



Note that the number of outcomes exceeds the number of studies included, because some studies examined more than one outcome.

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Outcome categories were also examined according to the ages of the participants. When examined in this way, the most commonly reported outcome categories were social function and academic outcomes in children (53%), while drug use/addictive behaviour and antisocial behaviour comprised the largest proportion of adult and adolescent outcomes (43% and 46%, respectively).

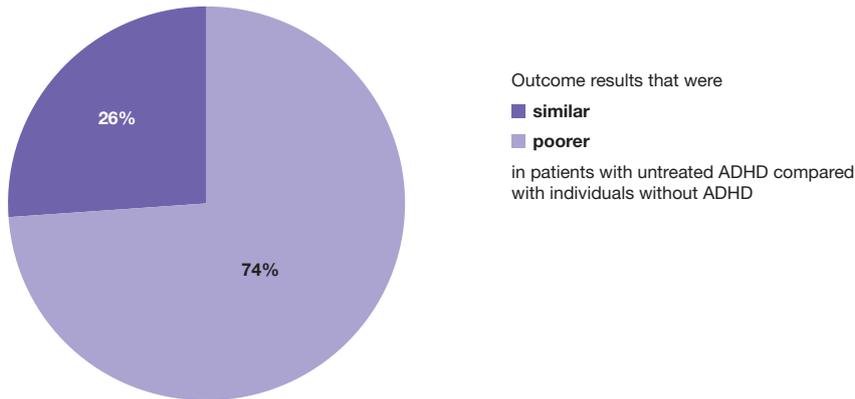
Geographical variation was observed: studies based in the USA or Canada most commonly reported drug use/addictive behaviour outcomes (27%), studies based in Europe most commonly reported antisocial behaviour outcomes (28%), while studies based in East Asia predominantly focused on both of these outcomes as well as self-esteem (21% for each).



What the outcomes showed

For the majority (74%) of outcome results, patients with untreated ADHD experienced significantly poorer long-term outcomes than individuals without ADHD (Figure 6).

Figure 6. Comparison of long-term outcome results in patients with untreated ADHD and individuals without ADHD



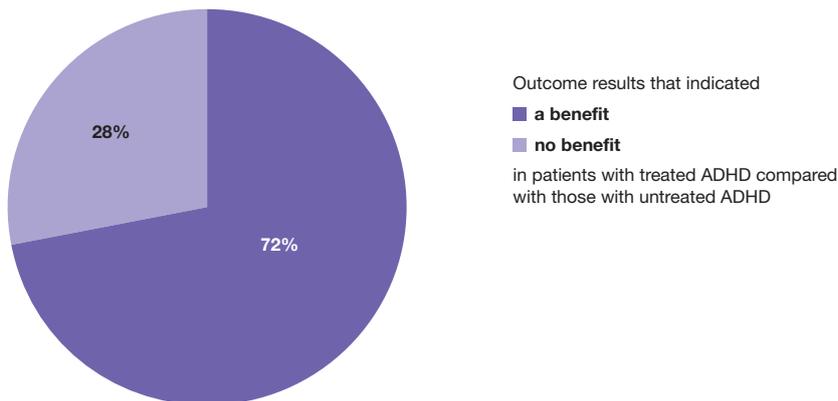
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“I went to four different colleges. I dropped out three different times. I don’t know how I made it through. It was just sheer will that I did it, but just the emotional turmoil I went through was just horrendous. [. . .] I think if I had known earlier, people would’ve been nurturing about it and my parents would’ve advocated for me at school. I think I would’ve had better outcomes.”
Individual with ADHD, UK¹⁴

Originally published in Brod M et al. Health Qual Life Outcomes 2012; 10: 47. Quote reproduced with kind permission from the publishers.

In addition, when patients with untreated ADHD were compared with those who had received pharmacological, non-pharmacological or multimodal treatment, the majority (72%) of outcome results indicated a significant benefit of treatment on long-term outcomes (Figure 7). These benefits were clear, although treatment was generally not associated with normalisation of outcomes to an equivalent level to those reported in individuals without ADHD.

Figure 7. Comparison of long-term outcome results in patients with treated ADHD and patients with untreated ADHD



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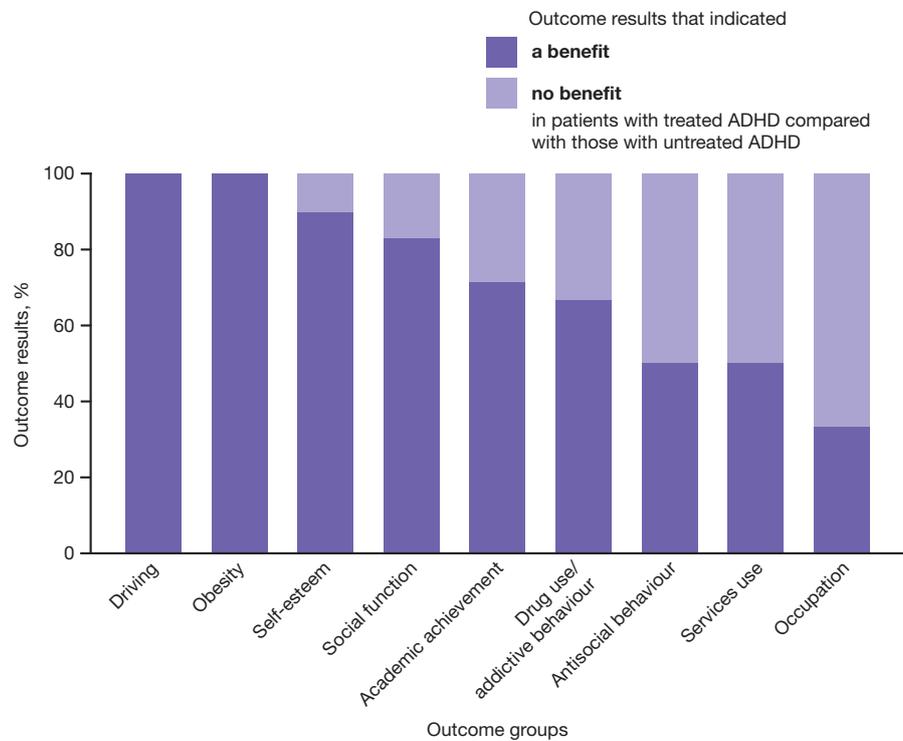
Treatment was more often beneficial for some outcome categories, compared with others. Treatment was reported to be beneficial for 100% of both driving and obesity outcomes, 90% of self-esteem outcomes, 83% of social function outcomes, 71% of academic outcomes, 67% of drug use/addictive outcomes, and 50% of both antisocial behaviour and services use outcomes. Only 33% of occupational outcomes were reported to benefit following treatment (Figure 8).

“One aspect I’d like to mention that is the self-esteem problem. It is a great handicap I think. Although I’ve really made great inroads and I don’t see everything negative anymore but you sometimes get feedback from others that something isn’t as it should be and then you start to interpret and you start to over emphasise and you start to read too much into it.”

Individual with ADHD, Germany¹⁴

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Figure 8. Comparison of long-term outcome results in patients with treated ADHD and patients with untreated ADHD, by outcome category



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Conclusions

- Long-term outcomes of patients with untreated ADHD are typically much poorer than those of individuals without ADHD.
- In many cases, long-term outcomes can be improved with treatment for ADHD.
- Some specific outcome types may respond particularly well to treatment (eg those relating to driving, obesity, self-esteem, social function, academic achievement and drug use/addictive behaviour).

Summary

- ADHD can have a negative and pervasive impact, with wide-ranging associated costs in terms of healthcare and other services and long-term consequences for multiple aspects of life.
- Effective treatment (which may be pharmacological, non-pharmacological, or a combination of both) can help to improve outcomes, highlighting the need to better support individuals with this disorder.
- There is a need for more studies on the costs of ADHD, which will support the development of strategies for devising and implementing cost-effective solutions.



Chapter 3: Opportunities for improved recognition and management of ADHD

ADHD has received little attention from policy makers, healthcare and education stakeholders to date. Although more health economic research is needed on the economic consequences and the increased costs to society, the LIS, the cost of illness studies and the LTO study clearly demonstrate that ADHD constitutes a considerable burden to individuals, their families and society as a whole. Importantly, the LTO study confirms the benefits of ADHD treatment for a wide range of outcomes.

In order to better address the negative long-term consequences of ADHD and its impact on society, a strong commitment from policy makers and relevant stakeholders will be required. Based on the discussion and outcomes of the European Expert Roundtable (27 November 2012), a set of recommendations has been developed to provide a framework for action on ADHD.

Recommendation 1: increase informed awareness of ADHD

The studies outlined in Chapter 2 show that ADHD can impact on many areas of an individual's life with potentially far-reaching and disabling consequences. These may result in an individual failing to participate in their community and wider society in a meaningful way, and being unable to achieve success and their 'full potential' in life. Recognition of ADHD in the wider health, education, occupation, criminal justice system and public arenas is needed, particularly for children with predominantly inattentive symptoms, and more generally in order to raise awareness that ADHD often persists into adulthood. Too often ADHD is associated with child hyperactivity only, with not enough consideration given to inattentiveness, cognitive impairment and emotional dysregulation. For many people with ADHD, recognition and understanding of the disorder may help to alleviate some of their burden and that of society. In order to accomplish this, we recommend the following:

Goal

Increase informed awareness and recognition of ADHD, particularly in schools, the workplace, the criminal justice system and the broader society

Actions

In schools:

- integrate ADHD into mental health promotion in schools and further education
- prioritise and organise specific ADHD training and education programmes for education professionals
- facilitate access to appropriate interventions, including exam provisions and individual support/tutoring as needed.

In the workplace:

- prioritise and organise specific ADHD training and education programmes for employment and occupational health professionals.

In the criminal justice system:

- prioritise and organise specific training programmes to educate criminal justice professionals to recognise the symptoms of ADHD and apply appropriate service-relevant management programmes.

In the broader society:

- initiate awareness campaigns to inform and educate the wider public and policy makers about the impact, long-term outcomes and cost of ADHD
- inform all stakeholders about the potential savings in societal costs that are expected to be generated by effective action on ADHD
- identify celebrities with ADHD to provide testimonials on the successful management of their disorder.

Real-life successes and challenges

Case study 3 – Spain

Spanish Federation of ADHD Supporting Associations (FEAADAH) – getting ADHD on the agenda beyond the education arena

In addition to its work in the education arena (see Case study 1), FEAADAH has also worked towards addressing the needs of ADHD in other sectors.

- In 2010, at the request of FEAADAH, the Spanish Senate passed a motion urging the national government to take action on ADHD. Subsequently, FEAADAH appeared in the Senate to explain the needs of those affected by ADHD.
- FEAADAH succeeded in having many regional parliaments approve motions to put in place actions to support the diagnosis, treatment and care of those affected by ADHD, as well as their families.
- In 2012, FEAADAH worked with the Spanish Congress of Deputies to call on the national government to declare an ADHD Day. In addition, FEAADAH has launched a worldwide campaign requesting that the World Health Organization declare a Day of Awareness about ADHD.
- In 2012 the President of FEAADAH and a psychiatrist representing another Spanish ADHD initiative (the Pandah Project) appeared before the Chairs of the Committees of Health, Education and Justice of the Senate and the Spanish Congress of Deputies to call for joint action of public administrations regarding ADHD in these sectors.

Case study provided by
Prof Dr Fulgencio Madrid Conesa,
President of FEAADAH.

“When I was diagnosed with ADHD, it gave me the feeling that I had a user manual, a road map. Now I know more about what’s the matter with me. I feel more serene. Now I know where my problems come from. I don’t control it yet. I’m hoping the diagnosis will give me better control over myself.”
Individual with ADHD, France¹⁴

Originally published in Brod M et al. Health Qual Life Outcomes 2012; 10: 47. Quote reproduced with kind permission from the publishers.

Real-life successes and challenges

Case study 4 – UK

Programme for Early Detection and Intervention for ADHD (PEDIA)

The aim of PEDIA is to develop an early detection and intervention model that can be implemented for preschoolers with high levels of ADHD symptoms to help improve long-term outcomes.

PEDIA will include the development of an ADHD risk index and profile that could be used to identify children most in need of early treatment. It will also include an enhanced version of the New Forest Parenting Programme, which has been designed to tackle the core symptoms of ADHD.

More details are available at:

http://www.southampton.ac.uk/psychology/research/projects/programme_for_early_detection_and_intervention_for_adhd_pedia.page

PEDIA is co-ordinated from the University of Southampton, UK, is funded by the National Institute of Health Research (NIHR) under its Grants for Applied Research Programme (RP-PG-0108-10061), and is being carried out in collaboration with NHS Solent Healthcare.

Recommendation 2: improve access to early and accurate diagnosis of ADHD

The diagnosis of ADHD requires a comprehensive assessment of symptoms by healthcare professionals with training in the diagnosis and management of ADHD. The observations of third parties should be taken into account, which for children may include parents/carers and education professionals, and for adults may include partners, parents/carers, further education and/or occupational professionals.

Given the apparent lack of comprehensive and specific training across many services, we strongly recommend the development and implementation of educational programmes for healthcare and allied professionals in order to ensure that people with ADHD receive an early and accurate diagnosis. Specific recommendations include:

Goal

Promote the introduction of early identification and intervention programmes for ADHD in schools, the workplace, mental health-related and criminal justice services

Actions

In schools (including preschool setting):

- introduce the use of second fixed-term exclusion from school to trigger screening assessment and, if positive, referral to healthcare services
- encourage the use of standardised and available screening tools for use in pre-school, primary and secondary school services by education professionals
- develop ‘conduct protocols’ to guide education professionals in the (referral for) assessment of children with suspected ADHD
- ensure that young people with ADHD are supported, via the provision of special tutoring and career advisory services in schools and further education establishments, especially for children with inattentive type of ADHD, who are at higher risk of leaving school early.

In the workplace:

- develop ADHD-specific employment policies and referral protocols for employment agencies and occupational health services
- facilitate access to appropriate interventions, including reasonable adjustments to working premises or practices to support job applicants and employees with ADHD
- ensure occupational safeguards to enhance productivity for adults with ADHD (eg mentoring systems, workplans with clear written targets and deadlines, desk location that minimises distraction).

In mental health-related services:

- consistently include specific training on ADHD as an essential component in the academic and training curricula for mental health professionals
- encourage ADHD screening in children, adolescents and adults who present with other mental health problems (eg anxiety disorders, bipolar disorder, depression, personality disorder).

In criminal justice services:

- establish protocols for routine screening for ADHD in criminal justice services (prison, probation, police and forensic mental health institutions) with referral for assessment and management of ADHD as needed.



Recommendation 3: improve access to ADHD treatment, care and support

As illustrated by the data presented in Chapter 2, ADHD can result in substantial costs to Europe's healthcare, social and education services and the long-term outcomes of ADHD are significantly poorer without treatment.

The management of ADHD should be carefully tailored to the needs of the individual, taking into account any response or lack of response to previous treatments. In general terms, a multimodal approach to ADHD treatment is most appropriate, and treatment options may include a combination of medication and psychological treatment (eg behavioural therapy, cognitive-behavioural therapy, parent training programmes). In terms of ADHD care and support in schools, classroom support and special allowances during examinations are generally considered useful arrangements to help children with ADHD manage their condition.

In terms of care and support for adults with ADHD, a large gap still remains, as specific provisions for managing ADHD in the workplace are generally not in place across Europe.

In particular, we recommend the following:

Goal 1

Provide people with ADHD – both children and adults – with timely access to appropriate, integrated and cost-effective treatment and care

Actions

- Raise awareness of, and promote and assess the use of, published treatment guidelines

Goal 2

Develop and support a multidisciplinary patient-centred approach to ADHD care, fostering collaborative practices between home, school, clinic, criminal justice and community services

Actions

- Organise workshops, conferences and public-private partnerships between relevant stakeholders to foster collaborative and integrated care pathways
- Ensure that healthcare professionals collaborate with parents/carers (and other allied professionals as appropriate) in providing monitoring, review and follow-up

Real-life successes and challenges

Case study 5 – UK

UK ADHD Partnership (UKAP): The Better Futures Campaign

UKAP is a group of medical and educational specialists with expertise in working with young people with ADHD. It has engaged in a political campaign to raise the profile of ADHD on the healthcare and political agenda with a 'Call to Action' to build better futures for children with the condition and drive better access to identification, diagnosis, support and management.

In 2011, the Better Futures Campaign gained parliamentary support in a launch event at the UK House of Lords, hosted by Lord Keith Bradley. The government was called upon to work with experts in mental health, child psychology and special educational needs to ensure that children with ADHD are taken into consideration independently from children with other special educational needs in future legislation or guidelines. The campaign specifically asked for a 'Call to Action':

- Use of second fixed-term exclusion from school as an opportunity to assess children with possible ADHD
- Recognition of the importance of tackling ADHD more effectively in future education legislation and guidelines.

More details are available at: www.UKADHD.com*

The Better Futures Campaign was initiated and funded by Shire Pharmaceuticals Ltd. Case study provided by Dr Susan Young, President of UKAP.

**Website currently under construction*

Recommendation 4: involve and support patient organisations

Patient organisations provide invaluable support, information and education to patients with ADHD and their families. They are often the first to initiate activities that raise the awareness of ADHD and promote best practices for ADHD management and care. In addition, ADHD patient organisations can provide relevant information and advice to policy makers and regulators. It is of key importance that the perspectives of people with ADHD are at the centre of the development and implementation of ADHD policy measures and guidelines, in close collaboration with policy makers and healthcare professionals.

The involvement and support of individuals with ADHD and their representative organisations is instrumental in developing ADHD patient-centred strategies that ensure early intervention, equity of access to appropriate treatment and adequate therapy and support. Therefore, we recommend the following:

Goal 1

Facilitate the exchange of information and cooperation between ADHD patient organisations, policy makers and other allied stakeholders

Actions

- Include ADHD patient organisations in policy debates and decision-making procedures relevant to their members
- Establish semi-permanent/permanent joint working groups and policy dialogue forums to create alliances between patient organisations and other civil society organisations

Goal 2

Enhance the capacity of ADHD patient organisations to support their individual members

Actions

- Develop patient-friendly versions of relevant guidelines and other documents by including contributions and/or approvals from patient organisations
- Ensure European Union and national government funding for ADHD patient organisations



Recommendation 5: encourage a patient-centred research agenda on ADHD

Further research is needed to help improve the understanding of ADHD in young people, together with the progression and impairment associated with the disorder in later life. Moreover, research is needed to guide cost-effective and evidence-based practice in the treatment and management of ADHD across the lifespan. In particular, we recommend the following:

Goal 1

Support better understanding and management of ADHD through more quantitative and qualitative research

Actions

- Ensure adequate levels of public funding for fundamental research on ADHD, with a focus on the following priority areas:
 - the impact of ADHD on daily life, including research on:
 - measures to reduce social stigma associated with ADHD
 - patient needs and the psychosocial/socio-emotional impact of the disorder
 - the costs of untreated ADHD for different sectors of society and estimated savings generated by timely intervention
 - the long-term outcomes for different patient subgroups and the potential benefits of the following care and support measures:
 - early identification, intervention and continued support throughout the transition from child to adult services
 - pharmacological and non-pharmacological treatments
 - provisions in schools and the workplace
 - training of healthcare and allied professionals on the management of ADHD.

Goal 2

Ensure the active participation of allied stakeholders in developing priorities for future research on ADHD

Actions

- Give priority to collaborative research projects where academics and patient organisations can collaborate with each other
- Establish permanent channels of communication between patient organisations, research centres and policymakers to ensure dissemination and practical implementation of research results



Annex 1: Participants in the European Expert Roundtable

Name	Title	Organisation
Moderator		
Tony Elliot	Clinical Director for Older People (Mental Health)	Shelton Hospital, Shrewsbury, UK
Participants		
Phil Anderton	Management Consultant and Director	Justice in Mind Ltd
Alistair Benbow	Executive Director	European Brain Council (EBC)
Kate Carr-Fanning	Vice Chairperson	Hyperactivity Attention Deficit Disorder (HADD), Ireland
	PhD candidate	School of Education, Trinity College, Dublin, Ireland
Stephanie Clark	Core group	Aandacht Adult ADHD Support Groups, Belgium
Marina Dankaerts	Professor	Research Group Psychiatry, University of Leuven, Belgium
Manfred Döpfner	Director	Centre for Neurology and Psychiatry (AKiP), University of Cologne, Germany
Ton Duif	President	European School Heads Association (ESHA)
Michael Fitzgerald	Henry Marsh Professor of Child and Adolescent Psychiatry	Trinity College, Dublin, Ireland
Dolores Gauci	Immediate Past President	GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks)
Franziska Koch	Youth Policy Unit Representative	Directorate General for Education and Culture, European Commission
Fiona McNicholas	Professor, Consultant Child and Adolescent Psychiatrist	Lucena Clinic, Dublin, Ireland
Fulgencio Madrid Conesa	President	Spanish Federation of ADHD Supporting Associations (FEAADAH)
Myriam Menter	Chief Executive Officer	ADHS Deutschland, Germany
Pedro Montellano	President	GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks)
Joanne Norris	President and Education Chair	ADHD-ASC-LD Family Resources, Belgium
Maarten J Postma	Professor in Pharmacoeconomics	University of Groningen, the Netherlands
Javier Quintero	Director	Department of Child Psychiatry, Hospital Infanta Leonor, Madrid, Spain
Silvia de Ruiter	Representative	School for Health Europe (SHE), Dutch Institute for Healthcare Improvement (CBO), Utrecht, the Netherlands
Agnes Uherezky	Director	Confederation of Family Organisations in the European Union (COFACE)
Susan Young	Clinical Senior Lecturer in Forensic Clinical Psychology	King's College London, Institute of Psychiatry, UK
Gil Zalsman	Chair of Child and Adolescent Psychiatry	European Psychiatric Association (EPA)

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Gil Zalsman	Chair of Child and Adolescent Psychiatry	European Psychiatric Association (EPA)



Co-author disclosures

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In addition, S Young has received research funding, speaker or consulting fees, and/or conference attendance support, from Eli-Lilly, Flynn-Pharma, Janssen-Cilag, Novartis and Shire AG. She was a member of the UK NICE Guideline Development Group for ADHD and is a consultant at the Cognitive Centre of Canada. She is President of the UK ADHD Partnership (UKAP) and Vice-President of the UK Adult ADHD Network (UKAAN).

M Fitzgerald has received consulting fees from Eli-Lilly and Shire in the past two years.

MJ Postma has received grants, honoraria and travel stipends from Abbott, Amgen, Boehringer Ingelheim, Gilead, GlaxoSmithKline, MSD, Novo Nordisk, Pfizer, Roche, Shire, Sanofi Pasteur and Sanofi Pasteur MSD.

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