

ATTENTION ON ADHD

The value of improving care for people with ADHD

Takeda funded this report. Takeda commissioned MHP Group, a specialist health policy consultancy, to support with the development of this report. This report is intended for policymakers, public affairs & patient advocacy leads & those interested in strengthening the efforts to support ADHD patients. This information is available to the public for information purposes only; it should not be used for diagnosing or treating a health problem or disease. It is not intended to substitute for consultation with a healthcare provider. Please consult your healthcare provider for further advice. Copyright 2023. Takeda Pharmaceutical Company Limited. All rights reserved. Takeda and the Takeda logo are trademarks of Takeda Pharmaceutical Company Limited.

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Foreword



Untreated ADHD can cause many problems in the lives of children, teenagers, adults, which subsequently affects families, colleagues at work in society creating social exclusion, stigma, and discrimination. If ADHD is left untreated, there are many risks of psychiatric disorders which is an extensive list of possibilities that can affect people living with ADHD.

Many adults cope with ADHD alone and without treatment. The symptoms of the disorder can be alleviated in many ways with multi-model treatment and having access to educational evidence-based information.

It is very important that awareness of the symptoms reaches everyone who needs it to have a better quality of life. In general, there is a lack of knowledge with healthcare professionals when patients are looking for a diagnosis and it's imperative to change these misconceptions of proper care for the well-being of society with symptoms of ADHD.

ADHD Europe has 32 non-profit support organisations who represent persons with a lived experience of ADHD in their countries. Together we collaborate with healthcare professional groups and ADHD Experts to agree on strategies to increase diagnosis and treatment rates among society who would benefit from the work we do.

ADHD Europe advocate on behalf of people with ADHD for their rights to have equal access to diagnosis and treatment and serve as a platform for our member organisations to share information and collaborate on research to help the European community. Having said this, **'we need data'** which can have a positive budget impact when engaging with different policymakers and stakeholders. The healthcare systems in each European country have different circumstances for the proper diagnosis and interventions that are possible to access timely treatment for people living with ADHD. It is with great pleasure in my capacity as elected board member of ADHD Europe since 2020, to have been invited to write this foreword to advocate for the 'Value of improving care for people with ADHD'. I am also the Executive Director of ADHD-Liitto ry based in Helsinki, Finland who already benefit from the collaboration of Takeda.

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Executive Summary

ADHD is a neurodevelopmental disorder that has an unrecognised but high burden for individuals^{115,16} and society.^{17,18} ADHD is often under-diagnosed and under-treated.¹²

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Until now, there has been a lack of data to illustrate the cost implication that the under-treatment of ADHD has had on health systems and societies.⁶ As a result, it has been difficult for policymakers to demonstrate the budget impact of investment in interventions to improve access to treatment for people living with ADHD.

To help address this, Takeda has commissioned a budget impact analysis model, based on work from Biederman et al,¹⁶ which uses aggregated data to estimate the impact of untreated ADHD in 12 countries:

- Belgium
- Canada
- Denmark
- Finland
- Germany
- Netherlands
- Norway
- Portugal
- Spain
- Sweden
- Switzerland
- United Kingdom



The key findings of the budget impact analysis model are:²⁰



4,791,270

adults are living with ADHD²⁰



There are currently an estimated **1,796,168**

untreated adult patients who would benefit from treatment²⁰



The cost saving from treating ADHD at the current rate is





70% of adult patients would benefit from treatment⁴⁰



The total cost of untreated ADHD is €6,060,824,499²⁰



The potential cost saving if treatment rates were increased to 70% is



Drawing on the insights from the model, Takeda recommends that policymakers should consider the following actions to reduce the budget impact of untreated ADHD:

Recommendation 1

Design and deliver healthcare services that enable healthcare professionals to implement the Updated European Consensus Statement on diagnosis and treatment of adults with ADHD.

Recommendation 2

Collaborate with non-profit support organisations representing persons with lived experience of ADHD and healthcare professional groups to agree strategies to increase diagnosis and treatment rates among adults who would benefit.

Recommendation 3

Identify opportunities to improve local data collection on ADHD and the positive budget impact of increasing treatment rates.

ADHD is a lifelong, neurodevelopmental disorder

ADHD is a lifelong neurodevelopmental disorder,³² with symptoms of inattention, hyperactivity-impulsivity and emotional dysregulation.²² Once thought to be a childhood disorder, ADHD is now known as a condition that affects a person throughout their life. ADHD affects around 2.5% of adults worldwide – and between 5.9% of children and adolescents.²

People with ADHD are more likely to have comorbid conditions such as depression, bipolar disorder and anxiety disorders,¹³ which can be exacerbated if undiagnosed. Other common comorbid conditions include impulse-control /personality, anxiety, mood, substance use, learning and sleep disorders.²³ These conditions can mask the symptoms of ADHD, which can complicate clinical presentation and diagnosis. One study showed that 58% of adults suffered from misdiagnosis of ADHD, and 69% of respondents with a co-existing disorder felt their ADHD diagnosis was delayed due to the additional disorders.⁴

ADHD also increases the likelihood of obesity, smoking, and alcohol and drug misuse, and is associated with autoimmune diseases and other poor long term health outcomes. People with ADHD have been shown to be three times more likely to be obese and experience twice the prevalence of certain autoimmune diseases including ankylosing spondylitis, ulcerative colitis, and autoimmune thyroid disease, and over 50% greater likelihood of asthma, allergic rhinitis, and atopic dermatitis compared with the general population.^{2,24} Effective treatment for people with ADHD involves early intervention and diagnosis paired with individualised treatment and care. To prevent the development of comorbid psychiatric disorders like anxiety, depression or substance use, a skill-based educational programme that teaches individuals coping strategies is preferred.²⁵

ADHD is under-diagnosed and under-treated

There are often barriers to obtaining an ADHD diagnosis, accessing care and getting the right treatment.²⁶

In Europe, an adult patient has on average 2.7 visits to a specialist to receive a diagnosis over a period of 20.4 months.¹⁴ In some European countries, such as France and Italy, services for adults with ADHD are limited to those who have been diagnosed as children before turning 18.²⁷

In Canada, surveys of adults with ADHD suggest that 85% of respondents were not diagnosed as children. One survey found that a third of respondents found it difficult to obtain a diagnosis as an adult, with 69% of those saying this was due to the lack of access to a physician.⁴

ADHD is likely to be under-diagnosed and under-treated in specific populations such as women within the prison population. Girls are considered to display fewer symptoms of hyperactivity than boys, which can explain the diagnostic discrepancy.²⁸ Women are also more likely to internalise their features and suffer from anxiety and depression, which can lead to a misdiagnosis.²⁹ Many people with undiagnosed ADHD will likely be in the health system already but are being treated for a different comorbidity. It is estimated that 80% of adults with ADHD have at least one comorbid psychiatric disorder.¹

Their ADHD may or may not be identified at a crisis point, by which stage their mental well-being could have significantly worsened. In addition to psychiatric comorbidities, people with ADHD are more likely to present with health issues such as asthma, diabetes, hypertension, obesity, psoriasis, and immune and metabolic disorders.²



The societal impact associated with undiagnosed ADHD are widespread, affecting almost every facet of society from schools, workplaces, the criminal justice system and healthcare system. ADHD can have a serious impact on educational attainment and professional life, leading to low levels of educational attainment, frequent school drop-outs, sub-optimal outcomes in the workplace, difficulties in finding stable employment and regular unemployment.² In Europe, adolescents with ADHD are more than eight times more likely to drop out of school than those without ADHD.⁶ Those lacking treatment are also susceptible to transport accidents, unemployment, repeat criminal offences and high rates of suicide.²

Some research has also been conducted on the economic impact of ADHD. For example:

- A Dutch study showed the annual costs of ADHD to the state could range from €10.41 million to €15.29 million, of which 42-62% was in education and 8-25% in healthcare.¹⁷
- Criminal justice systems also face additional costs as many incarcerated individuals have an ADHD diagnosis.³¹
- A UK study from 2018 demonstrating an increment of at least £590 extra spend per year for a prisoner with ADHD compared to one without, amounting to an estimated £11.7 million per annum in costs³²
- Untreated ADHD also has wide-ranging, serious economic implications through loss of earnings and productivity, for both the individual and the state. People with ADHD are likely to have lower salaries, lower tax contributions and greater reliance on social assistance. An estimate on the cost of ADHD in Europe cited the annual cost in productivity loss as €762-€1,798 per patient.⁶

Best practice recommendations on ADHD are not always fully implemented

Best practice recommendations on ADHD include the Updated European Consensus Statement on diagnosis and treatment of adults with ADHD.²³ The consensus statement includes recommendations on screening and diagnostic assessment, and recommends that treatment should follow a multi-modal and multidisciplinary approach including psychoeducation, pharmacotherapy, cognitive behaviour therapy, and coaching.²³

The benefits of timely diagnosis and treatment of ADHD are well understood. For example:

- Timely detection and treatment is likely to moderate risks and improve outcomes in people with ADHD.³³ Additional research from a systematic review showed that 72% of people with ADHD indicated a significant benefit of treatment on long-term outcomes.³⁴
- Effective management of ADHD through a comprehensive treatment approach that includes medication reduces core symptoms, improves functioning and enhances self-esteem, academic /professional achievement and social behaviour which have the potential to bring wider societal benefits such as lower criminality and risk-taking behaviours, reduced accidents and substance addiction/disorders (such as smoking and drug-taking).^{5,16,17,33,34,35,36}
- One study showed a 20% decreased risk of depression during periods of medical adherence, with a further study indicating a 72% drop in suicide attempt risk among treated children and young people (CYP) ADHD patients.¹⁶

 One study showed improvements in 33-100% of outcomes in individuals treated for ADHD, with the largest improvements seen in driving, self-esteem and social function.³⁴ Medication for ADHD has been shown to reduce criminality rates among men by 32%, and 41% among women, as well as a 58% risk reduction in serious traffic accidents in males, 31% reduction in substance abuse and 31% lower risk of suicide attempts.^{5,32,37}

However, the provision of ADHD services is inconsistent and not often easily accessible, resulting in long waiting times,¹⁴ missed diagnoses and a lack of treatment provision.^{27,38,39} 36% of European services do not have a national guideline for ADHD diagnosis, medication and treatment for children and adults²⁷ and waiting lists for adult ADHD have been shown to range between 1 and 3 years in the national health services of different European countries.²⁷

The design of Takeda's budget impact analysis model

Until now, there has little data available on the impact of untreated ADHD on health and societal budgets. As a result, it has been difficult for policymakers to demonstrate the positive budget impact of investment in interventions to improve diagnosis and access to treatment for people living with ADHD.

To help address this, Takeda has commissioned a budget impact analysis model, based on work from Biederman et al,¹⁶ which uses aggregated data to estimate the impact of untreated ADHD in 12 countries:

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The number of people living with ADHD is estimated using population data for each of the 12 countries included in the model, combined with ADHD prevalence estimates (2.5% for adults aged 18 to 65) from Faraone et al.² The model uses country-level estimates for the number of people currently being treated for ADHD to estimate the percentage of people that are undiagnosed and therefore going untreated. The model assumes that only 70% of patients treated with medication would benefit from treatment, in accordance with Massuti et al,⁴⁰ who estimates that 26% to 30% of patients had mild ADHD and would not benefit from treatment. Treatment rates above 70% of the estimated ADHD population is considered as over-treatment in the model.

The model uses number needed to treat (NNT) figures from Biederman et al¹⁶ for ADHD stimulant medication to prevent the occurrence of a given outcome. NNTs relating to lifetime psychiatric outcomes (mood disorders, anxiety disorders and addictive disorders) were included in the model. A full list of the NNTs reported in this publication is shown in Table 1. **Table 1:** Number needed to treat (NNT) figures from Biederman et al.

Disruptive behaviour disorders	NNT	95% CI	Sex-by-Treatment Status Interaction P-value
Oppositional defiant disorder	3	1.85 - 3.48	0.26
Conduct disorder	3	2.04 - 4.20	0.42
Mood disorders			
Major depressive disorder	4	2.30 - 5.64	0.24
Bipolar disorder	5	3.03 - 12.11	0.31
Anxiety disorders			
Multiple (>2) anxiety disorders	3	1.78 - 3.10	0.85
Addictive disorders			
Cigarette smoking	6	3.24 - 21.94	0.15
Any substance use disorder (alcohol or drugs)	10	4.07 - 25.64	0.27
Educational outcomes			
Repeating a grade in school	3	2.01 - 3.71	0.46
Driving outcomes			
Motor vehicle collisions	4	1.97 - 16.19	0.25

The model includes adults aged 18 to 65, and uses the NNTs associated with mood disorder, anxiety disorder, and addictive disorder.

The findings from Takeda's budget impact analysis model[®]

In total the budget impact analysis mode indicates that across the 12 countries included:

- There are 4,791,270 adults living with ADHD²⁰
- 1,556,921 (32.5%) adults living with ADHD are receiving treatment, while 3,234,349 (67.5%) are untreated²⁰
- To achieve a treatment rate of 70%, the estimated rate at which all patients would benefit, **an additional 1,796,968 people living with ADHD would need to be treated**²⁰

Figure 1: The number of adults living with ADHD who are currently untreated but who would benefit from treatment

70% of adult patients would benefit from treatment⁴⁰







The model indicates that the current treatment rate – 32.5% of adults living with ADHD – the 12 countries are collectively realising €3.69 billion combined healthcare and social savings (made up of €1.57 billion of healthcare savings and €2.12 billion of social savings) compared to not treating anyone. These savings are as a result of a reduced impact of the comorbidities associated with ADHD (Figure 3).²⁰



Figure 3: The healthcare and social savings from adults living with ADHD who are currently treated

If the treatment rate were increased to 70% of people living with ADHD across the 12 countries included in the model, a total of \notin 9.75 billion healthcare and social savings (made up of \notin 3.32 billion of healthcare savings and \notin 6.43 billion of social savings) could be achieved (Figure 4).²⁰





Recommendations for policymakers

The budget impact analysis model demonstrates that increasing the diagnosis and treatment rate for people living with ADHD would realise healthcare and social savings by reducing the impact of the comorbidities associated with the condition. This would benefit people living with ADHD and their families, as well as the healthcare systems and societies in which they live.

To achieve these benefits, Takeda recommends that policymakers should:

Recommendation 1

Recommendation 2

Design and deliver healthcare services that enable healthcare professionals to implement the Updated European Consensus Statement on diagnosis and treatment of adults with ADHD. In some countries this may require investment to increase capacity in ADHD services and updates to local treatment protocols. Collaborate with non-profit support organisations representing persons with lived experience of ADHD and healthcare professional groups to agree strategies to increase diagnosis and treatment rates among adults who would benefit. These should include ambitious but achievable targets and a clear implementation plan.

Recommendation 3

Identify opportunities to improve local data collection on ADHD and the positive budget impact of increasing treatment rates. These data should be reported on a regular basis and should include healthcare and wider social metrics to demonstrate the value of investment in increasing ADHD treatment rates.

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