

# ADHD: Real Action, Real Change



Exploring how to address key challenges and opportunities  
facing the **Attention Deficit Hyperactivity Disorder (ADHD)**  
community in the United Kingdom

#BornToBeADHD

Initiated and Funded by Shire



This manifesto was developed following a workshop attended by the ADHD Foundation, ADHD Solutions, ADD-NI, and Adult ADHD NI. The workshop took place at the offices of ADHD Solutions and was facilitated by Hanover Communications. The project was initiated and funded by Shire. Shire did not attend the workshop or participate in writing the manifesto. Shire has reviewed the manifesto for factual accuracy and compliance with the ABPI Code of Practice for the Pharmaceutical Industry.

Date of Preparation: February 2017

Job No: UK/C-ANPROM/NBU/17/0026

# Challenges



## **The full impact of ADHD is not yet understood by Government**

While the health impact of ADHD is recognised there is less understanding of its wider impact across different government departments, such as Education, Justice and Work and Pensions, or its impact on the wider economy.



## **ADHD is not seen as a condition that spans the whole life cycle**

Often it is believed that ADHD affects children and then “goes away”. Yet for many, ADHD continues into adulthood and can have significant impact on an individual’s wellbeing and life chance.



## **ADHD has a long-standing stigma**

Negative media coverage consistently paints an inaccurate picture of what it means to live with ADHD which undermines how the community at large is seen by the NHS and other public services.



## **There is wide variation in ADHD services across the country**

Despite NICE guidelines, there remains wide variation in service delivery across the country. Too often and in too many places the clinical leadership needed to promote high standards in ADHD care is not strong enough.



## **Short-term and siloed budgets prevent greater emphasis on early intervention and proactive support for people with ADHD**

The financial benefit of investing in ADHD services will not be realised within a one-year budgeting framework. In addition, siloed departmental budgets make it difficult to build a case for ADHD services as the benefits are considerably more impactful across the system rather than taken alone and measured by each department independently.



## **Lack of data combined with poor transparency**

Across the care pathway, including diagnosis, treatment and patient experience, there is insufficient measurement of ADHD care. There is less regular recording of the outcomes that matter to people with ADHD such as school failure, employability and the impact of co-morbidities.

# Opportunities



## ADHD champions in parliament

Having effective champions within the system is necessary to change the perception and minimise the stigma. While support has been patchy, there is an opportunity to engage proactively with target stakeholders. In Northern Ireland Members of the Legislative Assembly (MLAs) act as strong advocates for the ADHD community.

2017

## 2017 is a mission critical year

With continued system change, further devolution and renewed press interest, there is an opportunity for ADHD services to be prioritised. It will be essential for the ADHD community to engage at this time to take full advantage of these changes.

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## The Government is prioritising life chances

Just a week into her leadership, Prime Minister Theresa May acknowledged her desire to prioritise social justice, pledging in her first speech to “fight against the burning injustices” of poverty, race, class and health and give people control of their lives. Improving ADHD care has the potential to make a significant impact on the life chances agenda.



## There is continued interest in mental health

In recent years, mental health has increasingly been acknowledged as a priority area for the Government and NHS, following its inclusion in the Five Year Forward View (5YFV). The Government is also eager to prioritise mental health, particularly improving access to services for young people.



## There is strong anecdotal evidence for early intervention

There is readily available evidence to showcase the cost savings of early intervention in ADHD care and proven models of care that improve long-term outcomes.



## Showcase best practice

There are a number of organisations in the UK doing great work supporting people living with ADHD and their carers. Sharing and scaling up best practice will mean more people living with ADHD receive the best possible care.



## Data and transparency are cross-government priorities

Improving the measurement of quality and outcomes is a key focus of NHS reform and a pillar of the Five Year Forward View.



## Clinical leaders pioneering better care

A leading group of clinicians and providers are tackling stigma and championing more effective interventions at a local level. Harnessing this commitment and expertise will unlock rapid improvements in care across the UK.



# Recommendations

**1 Government should commission a disease impact report for ADHD** - This will highlight the cross-sector impact of ADHD and demonstrate the necessity of greater prioritisation across Government with a focus on early intervention.

**2 There is a need for Public Health England (PHE) to develop a national disease awareness campaign** - ADHD remains overlooked and poorly understood. A national awareness campaign will highlight how undiagnosed and unsupported ADHD affects children, adults and families.

**3 There should be a “responsible reporting deal” to promote accurate reporting of ADHD in both Government publications and in the press** - Accurate statements on ADHD will support better public understanding and undermine the stigma that slows down clinical progress.

**4 Better data on ADHD is required** - Transparent reporting of access to ADHD services and outcomes across different Government departments will deliver recognisable improvement in how people with ADHD are supported and treated by the system.

**5 Multi-year, non-siloed budgets are necessary to support the needs of the ADHD community** - Integrated budgets will unlock investment in new models of care and early intervention that can help people with ADHD better manage their condition and improve their life chances.

**6 The Government should pilot research on cross-departmental funding using ADHD as a case study** - Cross-departmental working has long been an ambition of Government and ADHD has the potential to be an exemplar of delivering this vision in practice. Government should consider funding a local

pilot of joined up ADHD care bringing together NHS, education, criminal justice and welfare services.

**7 Investment should be made into training for clinicians and other public service professionals** - The Government, working with patient groups, should create an easy to use tool kit to be hosted online that can be used by those working within key Departments (particularly the Department for Health, Department for Education and Ministry of Justice) to better understand the signs and symptoms of the condition as well as how best to support those living and working with ADHD.

**8 The system needs to address poor adoption of NICE guidance** - National health authorities need to hold local commissioners to account for delivering recognised standards. If Clinical Commissioning Groups (CCGs) are not adopting NICE guidance they should be

providing an explanation as to why they have not and they should be required to put forward a plan of how they will implement national standards.

**9 Technology should be integrated into the care pathway through the creation of a challenge fund** - Health technology is increasingly an important element of many service pathways for various conditions. ADHD is no exception. Technology is helping people living with ADHD and their carers manage the condition. The Government should set up a targeted challenge fund to encourage the development of apps and products that can support people with ADHD.



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