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## **RACP Submission to The Senate Inquiry into assessment and support services for people with ADHD**

June 2023

## About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 30,000 physicians and trainee physicians, across Australia and Aotearoa New Zealand. The RACP represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, infectious diseases medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients and the community.



*We acknowledge and pay respect to the Traditional Custodians and Elders – past, present and emerging – of the lands and waters on which RACP members and staff live, learn and work. The RACP acknowledges Māori as tangata whenua and Te Tiriti o Waitangi partners in Aotearoa New Zealand.*

## Executive Summary

The Royal Australasian College of Physicians (RACP) warmly welcomes the opportunity to provide feedback to the Senate Inquiry into assessment and support services for people with attention deficit hyperactivity disorder (ADHD).

ADHD affects approximately 281,200 children and adolescents (aged 0-19 years) and 533,300 adults (aged 20+ years) in Australia<sup>1</sup> and is one of the most frequent diagnoses managed by Australian paediatricians.<sup>2</sup> As a lifelong neurological disorder, ADHD can have a deep and profound impact on those who are diagnosed, their families and loved ones.<sup>3</sup> The RACP emphasises diversity and inclusiveness in relation to support for individuals and families living with the challenges of an ADHD diagnosis.

The RACP is committed to supporting enhanced services and support for children, adolescents, and adults with ADHD. In September 2022, the RACP endorsed the Australian ADHD Professionals Association's Australian evidence-based clinical practice ADHD guideline. We view the guideline as a positive and essential step to provide people with ADHD and their families best-practice diagnosis and evidence-based treatments in Australia.

Our RACP submission provides feedback on the specific terms of reference that are relevant to the work of our RACP members, and in particular, focuses on the diagnosis and support experiences of paediatricians treating children and young people with ADHD.

## Key recommendations

The RACP recommends:

1. Improving **facilitated access to mental health services** that is appropriate to the needs of individuals diagnosed with ADHD, particularly at the time of diagnosis.
2. The **development and implementation of innovative models of care** that involve paediatricians working with, and mentoring, primary care health professionals to increase efficiency and reduce waiting times for ADHD assessments, as well as the provision of support services following diagnosis.
3. A **review of regulations for prescribing ADHD stimulant medications** should be undertaken, and for **shared care to be increased** to ensure consistency between the States and Territories in Australia.
4. **Eligibility for disability supports through the NDIS** should be based on the level of functional impairment experienced by the person with ADHD, rather than whether they have a particular diagnosis.
5. Further **research into a range of issues related to ADHD**, particularly epidemiology, modifiable and causative risk factors; prevention; case finding, particularly among women with risk factors; benefits of early treatment; non-pharmacological treatments; and medium to long term outcomes.
6. **Funding for development of community-based research** into the identification and diagnosis of ADHD in **First Nations families** and how to better support their

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<sup>1</sup> The social and economic costs of ADHD in Australia Report prepared for the Australian ADHD Professionals Association July 2019 Deloitte Access Economics <https://aadpa.com.au/wp-content/uploads/2019/07/Economic-Cost-of-ADHD-To-Australia.pdf>

<sup>2</sup> RACP Position Statement: The role of paediatricians in the provision of mental health services to children and young people October 2016 [RACP---the-role-of-paediatricians-in-the-provision-of-mental-health-services-to-children-and-young-people.pdf](https://aadpa.com.au/wp-content/uploads/2016/10/RACP---the-role-of-paediatricians-in-the-provision-of-mental-health-services-to-children-and-young-people.pdf)

<sup>3</sup> Dalsgaard S., Ostergaard S. D., Leckman J. F., Mortensen P. B., Pedersen M. G. (2015). Mortality in children, adolescents, and adults with attention deficit hyperactivity disorder: A nationwide cohort study. *Lancet*, 385(9983), 2190–2196. [https://doi.org/10.1016/s0140-6736\(14\)61684-6](https://doi.org/10.1016/s0140-6736(14)61684-6)

7. **Develop a robust, fully funded strategy for implementation of the Australian Evidence-Based Clinical Practice ADHD Guideline** to ensure that all Australians can receive the best evidenced diagnostic practices, regardless of their age or location, and make informed decisions about next steps.

## Adequacy of access to ADHD diagnosis

## Wait times and financial barriers

## Cultural accessibility

## Understanding of ADHD

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Alcohol Syndrome Disorder.<sup>9 10</sup> ADHD also has heightened risk of substance use disorder, obesity, asthma, diabetes, epilepsy, and sleep disorders.<sup>11</sup> Our RACP members commented that poor understanding of comorbidities and contributing factors can lead to poor quality assessment, relevant assessments not being undertaken, no assessment of learning ability, or alternative issues not considered in referrals. This contributes to a high case load for paediatric services and delays in assessment, correct diagnosis, and appropriate treatment/therapy.

Our RACP members provided feedback that there is a lack of easy access to formal cognitive assessments such as the Wechsler Intelligence Scale for Children (WISC) for children where it is unclear whether it is ADHD or intellectual disability (or in some cases, both). These formal cognitive assessments are often done by school psychologists who are in high demand and short supply.

An RACP member noted that as inroads are made to rectify the underdiagnosis of ADHD, this has resulted in people with good coping mechanisms and fewer comorbidities coming forward for assessment. Such people face stigma – often with the implication that they are following a trend rather than genuinely struggling to function to their full capacity because of ADHD. There needs to be better ways of assessing such people, who may have developed elaborate strategies for coping with the impacts of ADHD on their life.

### **Adequacy of access to supports after an ADHD assessment**

Our RACP members noted that more complex cases of ADHD often have several contributing factors and require multimodal care with allied health input. This is rarely available in the public sector and represents a significant cost. Medicare provides a limited number of allied health therapy sessions, but these are generally insufficient and there may be a considerable gap payment. ADHD coaches are not supported by Medicare.

Mental health and developmental comorbidities are common across the lifespan, with about half of those with ADHD also meeting the criteria for at least one other condition.<sup>12</sup> RACP members provided feedback that there is a strong need for improved access to psychology support for people diagnosed with ADHD. In rural Australia there is a well-recognised shortage of mental health professionals.<sup>13</sup> Our RACP members noted that many children and families don't need to be seen by a psychologist on a life-long basis, but they may need psychotherapy at the time of diagnosis and for additional behavioural management, as well as for management of co-morbid anxiety, depression, or trauma. **The RACP strongly recommends improving facilitated access to mental health services that is appropriate to the needs of individuals diagnosed with ADHD.**

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<sup>9</sup> Benjamin R, Haliburn J & King S. Humanising Mental Health Care in Australia: A Guide to Trauma-informed Approaches. 2019.

<sup>10</sup> Van Hulzen KJE et al. Genetic Overlap Between Attention-Deficit/Hyperactivity Disorder and Bipolar Disorder: Evidence From Genome-wide Association Study Meta-analysis. *Biol Psychiatry*. 2017 Nov;82(9):634-641.

<sup>11</sup> The Royal Australian and New Zealand College of Psychiatrists (RANZCP) Position Statement: ADHD Across the Lifespan <https://www.ranzcp.org/clinical-guidelines-publications/clinical-guidelines-publications-library/attention-deficit-hyperactivity-disorder-in-childhood-and-adolescence>

<sup>12</sup> Capusan A. J., Bendtsen P., Marteinsdottir I., Larsson H. (2019). Comorbidity of adult ADHD and its subtypes with substance use disorder in a large population-based epidemiological study. *Journal of Attention Disorders*, 23(12), 1416–1426. <https://doi.org/10.1177/1087054715626511>

<sup>13</sup> RACP Position Statement: The role of paediatricians in the provision of mental health services to children and young people October 2016 <https://www.racp.edu.au/docs/default-source/advocacy-library/racp---the-role-of-paediatricians-in-the-provision-of-mental-health-services-to-children-and-young-people.pdf>

On a broader scale, the National Children's Mental Health and Wellbeing Strategy<sup>14</sup> was developed in response to the limited capacity of mental health services across Australia. The Strategy is designed to implement a preventive, integrated, whole-of-community approach to maintain and support the mental health and wellbeing of children and their families. Ensuring that this Strategy is fully funded and implemented will substantially expand mental health support for children, young people and their families and carers.<sup>15</sup>

Our RACP members emphasised the need for a greater focus on supporting students with ADHD in school and tertiary education settings. In school settings, symptoms of ADHD can result in unsupported or untreated students falling behind academically in comparison to their peers and experiencing adverse social treatment by both peers and teachers.<sup>16</sup> Teachers play an important role in adjusting the school environment to support learning for children and young people with ADHD.

### **The availability, training and attitudes of treating practitioners, including workforce development options for increasing access to ADHD assessment and support services**

The RACP strongly supports integrated, cross-profession, team-based approaches to care, albeit with varying roles in relation to screening, diagnosis, co-management, and prescribing. Assessment and diagnosis of ADHD should remain the role primarily of paediatricians (or other trained specialists such as psychiatrists) with specialised training, and who have models of care set up to facilitate the kinds of assessments that are needed.

The RACP acknowledges that children and their families are currently experiencing extended wait times for ADHD assessments and there are insufficient medical physician specialists to meet the need for assessment and diagnosis of ADHD. The RACP has been liaising with the Federal Government and advocating to increase the number of training positions across the country, which has a longer-term impact. In the 2023 Federal budget, the Government announced it will boost incentives to expand multidisciplinary team care in primary care settings. The RACP strongly recommends that physician specialist care, including paediatric care, is included in these reforms so that patients, including children, young people and their families, can access the services they need.

General practitioners (GPs) are the first point of contact and provide care for patients of all ages, genders, and cultures across all disease categories through all stages of life. Our RACP members agree that this holistic, patient-centred approach places GPs in an excellent position to aid in the diagnosis and management of patients with ADHD and connect patients and their families with other specialists and support as necessary. As summarised in the Royal Australian College of General Practitioners (RACGP) feedback on the Australian Evidence-Based Clinical Practice ADHD Guideline "shared care arrangements should be supported, in the form of clinical protocols and funding systems, so GPs can access timely assistance from paediatricians and psychiatrists to support diagnosis and management and mitigate risk of both over and under treatment."<sup>17</sup>

<sup>14</sup> National Children's Mental health and Wel being Strategy (2021) National Mental Health Commission Australian Government <https://www.mentalhealthcommission.gov.au/projects/childrens-strategy>

<sup>15</sup> RACP Kids Catch Up Campaign <https://kidscatchup.org.au/wp-content/uploads/2022/08/KCCU-website-additional-info-formatted-into-web-2022-Ask-3.pdf>

<sup>16</sup> Jangmo A, Ståhlhandske A, Chang Z, Chen Q, Almqvist C, Feldman I, Bul k CM, Lichtenstein P, D'Onofrio B, Kuja-Halkola R, Larsson H. Attention-Deficit/Hyperactivity Disorder, School Performance, and Effect of Medication. J Am Acad Child Adolesc Psychiatry. 2019 Apr;58(4):423-432. doi: 10.1016/j.jaac.2018.11.014. Epub 2019 Feb 2. PMID: 30768391; PMCID: PMC6541488.

<sup>17</sup> RACGP Submission to the Australian ADHD Professionals Association [RACGP-submission-to-AADPA-ADHD-guidelines-7-April-2022.pdf.aspx](https://www.racgp.org.au/clinical-resources/position-statements-and-guidelines/ADHD-guidelines-7-April-2022.pdf.aspx)



An RACP member provided an example of a pilot model for integrated care to address the shortage of ADHD assessments within the public sector. At the Lifespan Community ADHD Clinic at Cranebrook Community Health Centre<sup>18</sup> in Nepean Blue Mountains Local Health District (LHD), NSW, GPs train with experienced clinicians in ADHD identification and are given the same prescribing rights as psychiatrists and paediatricians. These GPs have privileged access to the ADHD Clinic for more complex patients, peer support and ongoing education. Suitable clinic patients are referred back to an increasingly experienced cohort of GPs, who can provide continuity of care into adulthood.

**The RACP strongly recommends the development and implementation of innovative models of care that involve paediatricians working with, and mentoring, primary care health professionals to increase efficiency and reduce waiting times for ADHD assessments, as well as the provision of support services following diagnosis.**

### **Impact of gender bias in ADHD assessment, support services and research**

Gender differences among children with ADHD are not well understood. Females are a largely under-diagnosed and under-treated cohort.<sup>19</sup> Young people suspected of having ADHD should have their self-perceptions, social behaviours and treatment by others in school and peer groups in childhood explored.<sup>19</sup> Masking and internalisation of symptoms and behaviours is common in females and social perceptions lead to the under-recognition of the disorder.<sup>19</sup>

Our RACP members provided feedback that current questionnaires do not account for masking strategies. For example, they may not pick up on girls with inattention as teacher reports may describe them as 'model students'. Awareness of bias in practice is important and needs to be always addressed in diagnosis and treatment.

Our RACP members have observed that the underdiagnosis of young females means that there is a backlog of adult women who were undiagnosed in childhood. This is an area that requires further research.

### **Access to and cost of ADHD medication, including Medicare and Pharmaceutical Benefits Scheme coverage and options to improve access to ADHD medications**

Currently, all States and Territories have different laws about stimulant prescribing which poses a problem for patients moving between jurisdictions and for medical professionals engaging in telehealth across jurisdictions. In addition, some States/Territories do not honour prescriptions from other jurisdictions.<sup>20</sup>

Generally, only specialist clinicians are authorised to prescribe stimulant medications. To receive regular medication, those diagnosed with ADHD must see a medical specialist on an ongoing basis. Only in limited circumstances are GPs authorised to prescribe medication. For example, our RACP members commented that the NSW Pharmaceutical Regulatory Unit (PRU) recognise only a small number of GPs who are given 'other designated prescriber' (ODP) status and allowed to treat children and young people up to the age of 18 years.

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<sup>18</sup> Lifespan Community ADHD Clinic at Cranebrook Community Health Centre  
<https://www.nsw.gov.au/health/nbmlhd/locations/adhd-clinic-nepean>

<sup>19</sup> Carboneau M et al. Meta-Analysis of Sex Differences in ADHD Symptoms and Associated Cognitive Deficits. J Atten Disord. 2021 Oct;25(12):1640-1656.

<sup>20</sup> [ADHD Stimulant Prescribing Regulations & Authorities in Australia & New Zealand \(aadpa.com.au\)](https://aadpa.com.au)

The Pharmaceutical Benefits Scheme (PBS) subsidises ADHD medications but has limitations based on both age and dosage. These restrictions on subsidies for ADHD medications specifically target people with ADHD. Our RACP members provided the following examples of medication regimes which some people require for optimal function, but that are not supported by the PBS:

- People who respond best to modified release stimulants given twice daily: current regulations require the total dose to be given together in the morning.
- People who require doses of long-acting stimulant above the formulary maximum, which is now the ceiling for Medicare subsidy.
- Non stimulants (atomoxetine or guanfacine) when initiated by GPs.
- Adults who cannot provide evidence to confirm that they had ADHD in childhood and require certain long-acting formulations. This would exclude 100% of older adults.

**The RACP would like to see a review of regulations for prescribing ADHD stimulant medications, and for shared care to ensure consistency between the States and Territories in Australia.** These regulations should reflect scientific evidence and best practice, and not restrict the availability of medication or treatment where it is required.

### **The role of the National Disability Insurance Scheme (NDIS) in supporting people with ADHD, with particular emphasis on the scheme's responsibility to recognise ADHD as a primary disability**

The RACP supports the NDIS, its underlying values and principles, including individual autonomy, non-discrimination, and full and effective participation and inclusion in society.<sup>21</sup>

Our RACP members noted those with complex ADHD should be eligible for the NDIS. A functional assessment should consider comorbidities with ADHD; for example, anxiety, learning difficulties and trauma, that require NDIS funding to support sufficient psychology, tutors/learning support and parenting support. People with ADHD may benefit from the support of a life coach to teach strategies to help them to function more efficiently.

**The RACP is supportive of the recognition of ADHD within the NDIS, but strongly recommends that eligibility for disability supports through the NDIS should be based on the level of functional impairment the person experiences, rather than whether they have a particular diagnosis.**

Feedback from our RACP members emphasised the need to provide local, accessible psychology, occupational therapy, and speech therapy support without having to gain access through the NDIS. Our RACP members noted that this is particularly important at the time of diagnosis. There should be publicly funded ADHD psychology services to assist with psycho education, management of behavioural difficulties, and management of co-morbid anxiety/depression.

### **The adequacy of Commonwealth funding allocated to ADHD research**

The RACP strongly supports research to better understand certain aspects of ADHD. Research has the potential to improve knowledge about the factors that increase the risk

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<sup>21</sup> RACP Submission to the RACP Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability [racp-submission-to-the-royal-commission-into-violence-abuse-neglect-and-exploitation-of-people-with-disability.pdf](#)



for ADHD, as well as the causes, and best treatments, and will aid the development of resources to help people living with ADHD. Our RACP members suggested in particular research funding should be allocated to:

- Long term studies on the outcomes of ADHD medication especially stimulants.
- Research into understanding of the genetics of ADHD.
- Effective strategies to teach children with ADHD to avoid cognitive overload and disengagement with the education system.
- Evidence on the association of ADHD with other comorbidities.

**The RACP recommends further research into a range of issues related to ADHD, particularly epidemiology, modifiable and causative risk factors; prevention; case finding, particularly among women with risk factors; benefits of early treatment; non-pharmacological treatments; and medium to long term outcomes.**

A specific area which warrants further investment as a priority is the lack of research on understanding, identifying, assessing, and treating ADHD in First Nations people. There may be a lack of knowledge and awareness about ADHD in some First Nations communities. This may result in overdiagnosis or underdiagnosis of ADHD, resulting in stigma or a lack of treatment. The lack of statistical data on the extent of ADHD in First Nations communities is another concern, a situation similar to many mental health issues in First Nations populations.<sup>22 23</sup>

**The RACP recommends funding should be allocated for development of community-based research into the identification and diagnosis of ADHD in First Nations families with exploration of how to better support their needs and aspirations.** It is critical that the voices of First Nations families are heard in ADHD research.

### **The viability of recommendations from the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD**

The RACP endorsed the Australian ADHD Professionals Association's Australian evidence-based clinical practice ADHD guideline <sup>24</sup> in September 2022, and views the guideline as a positive and essential step to improve diagnosis and support for people with ADHD in Australia.

The RACP also provided feedback to the Australian ADHD Professionals Association for consideration when the guideline is next revised, including the need for greater emphasis on culturally safe diagnosis and treatment and capacity building within the Aboriginal Community Controlled Health Sector to provide First Nations led services. The RACP recommends that targeted consultation is undertaken with peak First Nations health groups such as the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Australian Indigenous Doctors Association (AIDA) when the guideline is revised.

Our RACP members raised concerns that the guideline cannot be implemented due to lack of resources for ADHD assessment and treatment, and that it has small outreach. Our RACP members commented that many medical specialists are not aware of the

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<sup>22</sup> Loh, P., Hayden, G., Vicary, D., Mancini, V., Martin, N., & Piek, J. (2017). Attention Deficit Hyperactivity Disorder: An Aboriginal perspective on diagnosis and intervention. *Journal of Tropical Psychology*, 7, E2. doi:10.1017/jtp.2017.1

<sup>23</sup> Australian Evidence-Based Clinical Practice Guideline For ADHD FACTSHEET: ADHD and Aboriginal & Torres Strait Islander Peoples [ADHD-Factsheet-ADHD-in-Aboriginal-and-Torres-Strait-Islander-Peoples.pdf \(aadpa.com.au\)](https://aadpa.com.au/adhd-factsheet-adhd-in-aboriginal-and-torres-strait-islander-peoples.pdf)

<sup>24</sup> Australian Evidence-Based Clinical Practice ADHD Guideline (aadpa.com.au) <https://adhdguideline.aadpa.com.au/>

guideline. **The RACP recommends the development of a robust, fully funded strategy for implementation of the Guideline to ensure that all Australians can receive the best evidenced diagnostic practices, regardless of their age or location, and make informed decisions about next steps.**

The RACP and our members would welcome the opportunity to discuss the information in this submission further with the Committee, and believe that engagement with our experts, such as our paediatrician members, would be of significant benefit. Please contact Policy and Advocacy via [policy@racp.edu.au](mailto:policy@racp.edu.au) for further engagement.