RACGP
Royal Australian College of General Practitioners

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Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

By email: community.affairs.sen@aph.gov.au

Dear Committee Secretary,

Thank you for the opportunity to provide a submission to the Senate Community Affairs References Committee on this inquiry into the barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD.

The Royal Australian College of General Practitioners (RACGP) is the voice of general practitioners (GPs) in our growing cities and throughout rural and remote Australia. For more than 60 years, we have supported the backbone of Australia's health system by setting the standards for education and practice and advocating for better health and wellbeing for all Australians.

As a national peak body representing over 47,000 members working in or towards a career in general practice, our core commitment is to support GPs address the primary healthcare needs of the Australian population. Patient-centred care is at the heart of every Australian general practice, and at the heart of everything we do.

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. 85% of the population see a GP at least once a year[1]. This holistic, patient-centred, and relationship-based 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[2].

Our submission will provide comment on the relevant Inquiry terms of reference that impact on general practice and patients seeking ADHD assessment and support, highlight the role of general practice in this care, discuss regulatory and cost barriers to patients seeking access, call attention to workforce and training barriers that impact GPs, and outline measures that could be implemented to improve access to ADHD assessment and support.

Our key messages and recommendations, which are expanded on below, are:

- *The current access to ADHD management for many patients is inadequate.*
- *Barriers to adequate access to ADHD management include difficulty in accessing specialists, costs, unclear referral pathways, their environment, and coordination between different services.*
- *GPs with an interest in this area should be supported to take on an expanded role in the diagnosis and treatment of ADHD.*
- *Regulatory barriers need to be addressed, with consistent rules across all states and territories describing the clinicians that are authorised to diagnose and prescribe stimulant medications for patients.*
- *Shared care models show how GPs can work alongside other medical professionals to improve access for patients. These need to be enabled and funded nationally.*

- *Patient rebates are lower per minute for longer consultations, disadvantaging people who require more time with their GP, including patients with ADHD. Increased investment in longer consultations is a simple way to build additional support for these patients.*
- *Funding is needed to support shared care models to be effective.*

### 1. Adequacy of access to ADHD diagnosis

The current access to ADHD management for many patients is inadequate. There are several barriers to patients receiving timely diagnosis, including difficulty in accessing specialists, costs to patients, and unclear referral pathways.

Most public sector mental health services do not provide ADHD services, resulting in an over-reliance on private sector care and services[3]. GPs referring patients for diagnosis report significant delays in appointments to see specialists including paediatricians, psychiatrists, and psychologists, and often several appointments are needed before diagnosis can be confirmed. These delays can be even longer in rural and remote areas where it is more difficult to access these specialists.

Receiving a diagnosis for adult patients with ADHD may be even more difficult as they don't have access to the paediatric services which can support children.

There are financial barriers to receiving a diagnosis, with patients often paying significant out-of-pocket costs, and many patients needing to travel long distances, sometimes interstate, to see a specialist with availability. This cost barrier means that people on low incomes are unable to access care and are disproportionately affected by poor access to care.

Our members shared stories of these barriers and the impact on their patients. It was reported that in South Australia there is one practice that will complete an ADHD assessment at a cost of $500 to the patient, who is then referred back to the GP for management. In Tasmania it was reported that there is a severe lack of face-to-face access to psychiatrists and that GPs need to refer their patients to telepsychiatry. With minimal capacity for patients to be seen publicly one of the GP's patients reported paying over $700 for their diagnosis.

The *Australian Evidence-Based Clinical Practice Guideline For Attention Deficit Hyperactivity Disorder (ADHD) (*referred to throughout this submission as the ADHD Clinical Guideline) identifies that there can also be delays to patient diagnosis due to unclear referral pathways (for example, from GPs to other specialists and back again)[3].

These problems are exacerbated by the substantial increase in ADHD-related presentations in general practice. In a newsGP poll held in March 2023, 78% of the 1453 respondents said they had seen a substantial increase in the number of patient inquiries about referrals for ADHD diagnosis in the previous 12 months. 16% reported seeing a small increase. None of the respondents reported seeing a decrease in the number of referral requests.

These barriers to diagnosis point to a significant need for GPs to be better supported to play a greater role in this area. The recently published ADHD Clinical Guideline have provided a comprehensive, evidence-based resource for GPs to guide the diagnosis and management of ADHD. While guidance was previously available from sources such as DSM-5, this guideline integrates the best available evidence with clinical expertise and input from those with lived experience of ADHD. This guideline is a welcome and essential step in enabling GPs to take on this larger role.

While some GPs have already taken on expanded role in diagnosing and treating ADHD, there is a need for GPs to be supported through appropriate education and training, for regulatory change relating to stimulant

prescribing, and for the development of shared care arrangements. More detail on these suggestions is provided in later sections of this submission.

## 2. Adequacy of access to support after an ADHD assessment

People living with ADHD require lifelong, individualised support. The support they need will depend on factors including any co-existing conditions and their external environment. GPs are well placed to provide the holistic care that tackles the biopsychosocial nature of ADHD.

More than two thirds of individuals with ADHD have at least one other co-existing condition[4]. Common co-existing conditions include autism spectrum disorder, anxiety, behaviour disorders, Tourette Syndrome, sleep disorders, and depression. People living with ADHD require individualised care which also diagnoses and treats these conditions alongside the ADHD.

The environment the patient is living in can influence the supports available to that patient. For example, the prevalence of ADHD is much higher in people in custodial settings than in the general population. ADHD is estimated to be five times higher among youth prisoners and 10 times higher among adult prisoners[5]. However, among individuals in the criminal justice system, ADHD is both mis- and under-diagnosed[6]. These patients should receive the same high-quality, integrated care that we would expect any patient to receive. For these patients it is essential that there is close coordination between the prison service and all relevant health agencies, including mental health and disability services.

Given these factors it is essential that people living with ADHD have a comprehensive care plan which is regularly reviewed and has input from a multidisciplinary team.

Higher patient rebates for relevant Medicare-subsidised services would improve access by reducing costs for individual patients. Relevant Medicare Benefits Schedule (MBS) items include: GP Management Plans (items 721 and 732), Team Care Arrangements (items 723 and 732), GP Mental Health Treatment Plans (item 2700-2701, 2712, 2715 and 2717), mental health attendances (item 2713) and multidisciplinary case conferences (items 735-758).

Another way of addressing costs for patients, and therefore improving access for people in low-income groups, would be to address the cost of allied health services. The Grattan Institute reported that in 2021 only 56% of allied health services were bulk billed, and patients paid an average of $55 in out-of-pocket costs per appointment[7].

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

Given the barriers to access described above, and the requirements for coordinated care over the patient's lifetime, patients would benefit from GPs taking on an expanded role in the diagnosis and management of patients with ADHD and acting as care coordinators. To take on this expanded role, GPs need access to appropriate education, training, and funding.

### 3.1 Shared care models

A collaborative approach to managing these cases would help to upskill and support GPs taking on this expanded role. The development of shared care arrangements, for example in the form of clinical protocols and funding

systems, would ensure that GPs can access timely assistance from other specialists and allied health professionals, to support diagnosis and management and mitigate risk of both over and under treatment.

Australian shared care models vary by jurisdiction because regulations on whether GPs can diagnose ADHD or initiate the prescription of stimulant medication, are different in different States and Territories. In Queensland, GPs can provide the diagnosis and can also prescribe stimulant medication if needed for patients aged 4 to 18, while in NSW some GPs can provide a diagnosis and initiate stimulant medication in children aged 6 to 18 if the NSW Ministry of Health grants them the right to do so. In WA GPs cannot provide a diagnosis or prescription of stimulant medication for a patient with ADHD. This inconsistency across the country results in a postcode lottery – where patients living in one region may more easily access diagnosis and treatment than patients living in another region.

Models developed in different states have different protocols and funding arrangements, while all utilising shared care arrangements with GPs working closely with other specialists and a wider team, to provide more timely access to diagnosis and treatment for patients.

An example of one shared care model in WA is the pilot program which has been proposed to the WA Government where four GP practices would work alongside a paediatrician to provide a fast-track diagnostic pathway for children with ADHD, as well as ongoing management. The GP (and their practice team) would take a history, do a full examination including BMI and ECG, and perform an ADHD assessment. The package of information would then be sent to the paediatrician who could provide a formal diagnosis and, if required, prescribe stimulants. The GP would then complete follow up appointments with the patient, checking on their progress and medication use, and referring to the paediatrician if required. This program includes additional training for participating GPs and funding to allow the GPs to carry out the required detailed assessments.

This model seeks to address the issues of access, while being restrained by the regulatory framework in WA which means GPs cannot diagnose and prescribe. While this pilot is of great value in the current framework, we would recommend that the regulatory barriers be lifted to reduce bureaucracy and further increase access for patients.

The situation is similar in Victoria where models have developed to try to increase access for patients while dealing with the regulatory barriers which make the health pathways more complex, and restrictive than they need to be. In Geelong, Victoria there is a project currently being run by Reflect Health Telepsychiatry where a small group of interested GPs have upskilled themselves in the diagnosis and management of ADHD. In collaboration with a psychiatrist, they complete much of the assessment and management of patients. Unfortunately, they can't prescribe without the support of a psychiatrist due to the regulatory restrictions in Victoria.

A pilot has been developed in the Nepean Blue Mountains Local Health District, NSW, where an ADHD clinic has been established, led by a paediatrician. GPs train at the clinic, gaining skills so they can diagnose and treat children with ADHD in their own practices[8]. The GPs have access to the clinic for peer support and ongoing education. This model relies on those GPs being granted prescribing rights by the NSW Ministry of Health.

A similar model has been established in Queensland at the Hype ADHD centre. GPs are trained to work at the clinic, providing diagnosis and treatment to patients, in collaboration with a psychiatrist. They gain skills and experience which can then be used in their own practice.

Another example of a collaborative approach already in use is the Project ECHO Networks in Queensland. ECHO networks are interactive, conversational communities of practice, enabling GPs and hospital-based specialists to share ideas, discuss cases and learn from each other[9].

**3.2 Training**

It is common for GPs to develop specific areas of interest throughout their career, to support the needs of their local community. Examples of other areas of interest include dermatology, psychological medicine, addiction medicine, and sexual health. The RACGP supports GPs to develop these areas of interest, to find education and training opportunities, and to network among peers with the same interests through our 37 Specific Interest groups. The ADHD, ASD, and Neurodiversity Specific Interest group has around 800 members, and earlier this year produced two educational webinars for GPs with attendance on the night of over 500 RACGP members per webinar. There is significant interest from GPs in opportunities to upskill and develop in this area.

Support for GPs to develop their expertise in this area through shared care models as described above, or through more formal training pathways, is needed.

**3.3 Funding**

The current MBS rebate schedule is an impediment to comprehensive ADHD care in primary care. ADHD medicine involves taking a careful history, getting collateral histories, screening for other commonly occurring conditions, physical examinations, psychoeducation, and shared decision making. All of these are vital but time consuming. Patient rebates are lower per minute for longer consultations, disadvantaging people who require more time with their GP. The RACGP recommends increased investment in longer consultations as a simple way to build additional support for these patients.

Funding is also needed to support the time spent by GPs and other specialists in discussing the diagnosis and treatment of patients with complex care needs, including those with ADHD, with the aim of improved, more efficient and effective care. Best practice in ADHD care includes collaboration, liaison and further upskilling.

It should be noted that the above funding should be delivered without the creation of a specific MBS item number for ADHD. The RACGP does not support the introduction of single disease focused MBS items[10].

There are a variety of opportunities available in terms of the models for training, education and support to enable GPs to help tackle the bottleneck of diagnosis and treatment, and to provide more timely, coordinated care for patients. A combination of local, state, and Commonwealth funding is likely to be needed to enable this approach.

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

Medications are often more costly for adults as there are fewer medication options listed on the Pharmaceutical Benefits Scheme (PBS) for those who are diagnosed with ADHD in adulthood. There are only two long-acting medications listed on the PBS for adults, meaning if that medication doesn't work for a patient, they need to pay much more to find one that works for them. This cost barrier is hardest for those on low-incomes and often people go without needed medications if they are from low-income groups.

It is essential that there is affordable access to these medications for patients across the country.

Non-stimulant medications such as Guanfacine and Atomoxetine are only available on the PBS if commenced by a paediatrician or psychiatrist. And, as mentioned above, access to stimulant medication depends on your

postcode. Given the major barriers to access, GPs in all states and territories should be enabled to prescribe these medications.

### 5. The adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people with ADHD at all life stages

The regulatory issues described in section three above should be addressed, with consistent rules across all states and territories describing the clinicians that are authorised to diagnose and prescribe stimulant medications for patients. This should include general practitioners. We support the recommendation in the ADHD Clinical Guideline that these regulations should 'reflect scientific evidence and best practice, and not restrict the availability of medication or treatment where it is required'.

We also support coordination between Commonwealth, state and local governments in funding models of care which support shared care models and clear health pathways for patients.

### 6. The adequacy of Commonwealth funding allocated to ADHD research

More research into ADHD is needed, with potential areas for further research including screening tools, shared care models, effective non-pharmacological therapies, and development of culturally appropriate assessment tools for Aboriginal and Torres Strait Islander peoples, and those from culturally and linguistically diverse groups. A detailed summary of areas for future research is included in the ADHD Clinical Guideline.

The RACGP supports the recommendations in the ADHD Clinical Guideline which state that:

- A process for setting research priorities should be established, involving all key stakeholders, including people with lived experience of ADHD, and following established participatory research methods.
- Research prioritisation should include individual and health service research and should consider cost-effectiveness and new models of shared care.

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

We support the recommendations contained in the ADHD Clinical Guideline and have referred to them heavily in this submission. We would encourage decision makers to implement the recommendations within the guideline.

Thank you again for the opportunity to provide a submission to the Senate Community Affairs References Committee on this inquiry into the barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD. For any queries regarding this submission please contact Gillian Elliott, Manager, RACGP Specific

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