## SHPA submission to Inquiry into assessment and support services for people with ADHD, June 2023

### Introduction

The Society of Hospital Pharmacists of Australia (SHPA) is the national, professional organisation for the 6,100+ Hospital Pharmacists, and their Hospital Pharmacist Intern and Hospital Pharmacy Technician colleagues working across Australia's health system, advocating for their pivotal role improving the safety and quality of medicines use. Embedded in multidisciplinary medical teams and equipped with exceptional medicines management expertise, SHPA members are progressive advocates for clinical excellence, committed to evidence-based practice and passionate about patient care.

SHPA convenes a Paediatrics and Neonatology Specialty Practice Group, comprising of a network of SHPA members who work in inpatient, outpatient, ambulatory or primary care settings where infants and children receive pharmacy services, including paediatric intensive care, neonatal intensive care and special care nurseries. Some members work in dedicated children's hospitals, some in maternity hospitals and some in general hospitals that treat paediatric patients.

SHPA also convenes a Mental Health Specialty Practice Group, comprising of a network of SHPA members who work in mental health units and any inpatient, outpatient, ambulatory or primary care settings where patients of any age with mental health conditions, receive pharmacy services. These members see the day-to-day support services for children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), providing specialist advice around ADHD treatment and best practice to wider members of the multidisciplinary team.

Hospital services care for complex patients with ADHD in the context of other comorbidities. These comorbidities can require complex treatment regimes comprising both pharmacological and non-pharmacological treatment, with hospital pharmacists having an essential role in their medication management, treatment selection, evaluation of response to treatment and counselling on how to use their medicines appropriately in the context of psychosocial and environmental factors. Pharmacists also provide advice, education and counselling around ADHD medications to carers, patients and educators.

In Australia, children aged 6-12 years old account for over 40% of Pharmaceutical Benefit Scheme (PBS) ADHD medicines supplied. The number of patients treated with Repatriation Schedule of Pharmaceutical Benefits (RPBS) and PBS items for ADHD has risen at a yearly average growth rate of 9.9%.[1] During a four-year period from 2013 to 2017 alone, the rate of ADHD medicines dispensed per 100,000 people aged 17 years and under, increased by 30% in Australia.[2]

Data shows there is an increasing rate of ADHD medications being prescribed and dispensed to patients, and over 60% of young people with ADHD believing that there should be increased focus on information around ADHD medications including the risks and benefits of treatment[3]. Given this, the role of hospital pharmacists is vital in achieving the quality use of medicines, medicines safety, treatment success and comprehensive counselling and education to patients about the risks and benefits of treatment options to ensure patients are informed of their care.

SHPA welcomes the opportunity to provide recommendations and address the terms of reference to this Inquiry, and wishes to provide evidence at a forthcoming hearing with one of our specialist pharmacist members with expertise in ADHD. If you have any queries or would like to discuss our submission further, please contact Jerry Yik, Head of Policy and Advocacy at jyik@shpa.org.au.

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## Recommendations

Recommendation 1: Investment in the development of specialised training and education to upskill healthcare professionals supporting specialists in the ongoing treatment and management of people with ADHD, including general practitioners (GP), nurses and pharmacists

Recommendation 2: Broadening of the PBS prescribing criteria for medications indicated for the treatment and management of ADHD and associated comorbidities, to be inclusive of late diagnosis of ADHD in adults and reflective of current clinical guidelines

Recommendation 3: New South Wales and the Australian Capital Territory should become signatories of the Pharmaceutical Reform Agreements (PRAs) to achieve equity of access to ADHD medications in hospital settings

Recommendation 4: Enabling sufficient access to clinical pharmacists to support the safe and quality use of medications in hospital settings for people with ADHD by adopting the pharmacist-to-bed ratios in SHPA's Standards of Practice for Clinical Pharmacy Services[4] and ensuring design of every ADHD service includes funding for pharmacy involvement

If you have any queries or would like to discuss our submission further, please do not hesitate to contact Jerry Yik, Head of Policy and Advocacy on jyik@shpa.org.au.

## Terms of Reference

**a) adequacy of access to ADHD diagnosis;**

SHPA is aware of the extended waiting times for children with a potential ADHD diagnosis to be seen by ADHD specialists such as paediatricians and child and adolescent psychiatrists. This issue is further compounded in rural and remote areas, where there is poor access to paediatricians with long wait times for initial assessments. For some, it can mean that children first see an ADHD specialist when first diagnosed, but then are unable to return to the care of specialists, being lost to follow up.

Some children may not be diagnosed with ADHD until later in life due to lack of paediatric services in their locality. In some cases, paediatricians may be able to diagnose ADHD but then are unable to provide responsibility for ongoing management. Due to this lack of access to paediatricians and sub-specialists for ongoing care, GPs are then required to take on care for these complex conditions, without the appropriate skill or support to do so.

**b) adequacy of access to supports after an ADHD assessment;**

In addition to the lack of medical professionals at point of diagnosis, there is also a lack of allied health professionals involved in the holistic care and ongoing support of people diagnosed with ADHD. This can include occupational therapists, psychologists, specialist nurses as well as pharmacists.

If pharmacological treatments are recommended, assessment of existing and appropriate therapy is required, which may include establishing an accurate medical history and potential for interactions with other medications.

Pharmacists have a key role in determining appropriate treatment as well as assessing the capability of the person and their family in managing medications. Pharmacists can also assist in non-pharmacological treatments such as sleep hygiene, diet, lifestyle and interventions could include deprescribing of some medicines that may be unnecessary or causing adverse effects.

Some health services employ specialist ADHD pharmacists who review medicines in public outpatient or private clinics, adjusting medicines where necessary and liaising with primary care services to ensure

continuity of care. Integrating clinical pharmacists into an ADHD specialty clinic has been demonstrated to improve patients' adherence to ADHD treatment.[5]

Ongoing support in the community for children with ADHD is also lacking, especially in school settings. There are barriers due to perceived personal misconceptions by teachers and guidance counsellors and their understanding around ADHD medications, not always founded on professional and scientific sources.[6] This can lead to children not taking medicines as prescribed and having far reaching impacts on learning and education.

Education by pharmacists can help patients to better understand ADHD management, particularly in terms of medication side effects, the onset of action, the instructions on administration, monitoring frequency, and requirements.[7] Parents may also not be aware of how to manage 'medication holidays' (a planned break in treatment sometimes recommended to allow assessment of current treatment regime) and may lack an understanding of how the medications and treatments work most effectively. Further, targeted education is required to help teachers and parents support children with ADHD and preventing interruptions to their prescribed medications.

**c) the availability, training and attitudes of treating practitioners, including workforce development options for increasing access to ADHD assessment and support services;**

Further, targeted education is required for healthcare professionals working in ADHD support services. GPs will require an increased understanding of ADHD and require support to takeover care of complex patients. ADHD may often be diagnosed later in life, so GPs may end up taking over care rather than a specialist.

This role needs to be reflected in GP training, with education around non-pharmacological supports required, without medication being the only treatment considered.

Community pharmacists also require more education in ADHD management as ADHD is more likely to be managed in community if there is an ADHD diagnosis alone, and without other comorbidities such as learning disorder and mental health diagnoses. Those with multiple comorbidities may be managed by specialists in a hospital setting.

Hospital pharmacists especially working in paediatric and mental health settings will be familiar with treatments and management for people with ADHD. Other hospital pharmacists working in other clinical areas also need upskilling in ADHD management. Structured training modules could assist all healthcare professionals in understanding diagnosis, treatment, comorbidities and ongoing support for those with ADHD. Upskilling hospital pharmacists through residency programs for ADHD could be introduced to maximise the existing pharmacy workforce.

Recommendation 1: Investment in the development of specialised training and education to upskill healthcare professionals supporting specialists in the ongoing treatment and management of people with ADHD, including general practitioners (GP), nurses and pharmacists

**d) impact of gender bias in ADHD assessment, support services and research;**

Women are often diagnosed with ADHD later in life as adults, with symptoms being missed in childhood.[8] SHPA believes that this inequity in diagnosis and therefore, access to early intervention and treatment, needs to be addressed by wider educational campaigns.

**e) access to and cost of ADHD medication, including Medicare and Pharmaceutical Benefits Scheme coverage and options to improve access to ADHD medications;**

Limited access to specialist care can create unnecessary barriers to timely and adequate treatment, as ADHD medicines have certain restrictions with respect to their prescribing as they are Schedule 8 Controlled Drugs , and also additional regulatory requirements for PBS Authority required prescriptions. Responsibility for the ongoing care and management then falls with the person's GP. PBS listings for ADHD treatments and their associated prescribing requirements may need to be reconsidered to reflect role of GPs in management of ongoing ADHD for those diagnosed later in life. Being Schedule 8 Controlled Drugs, there are also legal hurdles to consider when GPs are prescribing specialist ADHD medications, such as the requirement for obtaining prescribing permits. Only one prescriber can hold a permit for any given patient.

SHPA welcomes news of methylphenidate's (Ritalin) PBS listing criteria being expanded to include access for adults with a retrospective diagnosis of ADHD. However, a retrospective diagnosis may be difficult to ascertain, hindering access to ADHD medication for some adults with ADHD.

Some hospitals may not stock all ADHD medications as hospitals are not funded to do so. Some larger hospitals may be able to provide these non-formulary treatments and incur costs of inpatient supply, with smaller regional hospitals unable to do so, creating further inequities of access to ADHD medications. In addition to this there are variations on policies in hospitals around utilising a patient's own medicines when they are admitted as an inpatient.

Some specialist ADHD medicines such as atomoxetine (Strattera) are not subsidised on the PBS. As outlined in the Therapeutic Guidelines and Australian Evidence-Based Clinical Practice Guideline For Attention Deficit Hyperactivity Disorder, Atomoxetine is recommended for use where a stimulant medicines cannot be used or tolerated either due to Tourette syndrome, severe anxiety disorder or risk of stimulant misuse.[9,10] Some medicines such as risperidone or melatonin, although not outlined as treatments for ADHD in clinical guidelines, are used in practice for the treatment of comorbidities, which are also not subsidised for these indications. This results in some hospitals bearing the cost of these treatments, with other hospitals unable to, widening the gap in inequity in treatment. This is more pronounced outside of metropolitan areas where smaller hospitals are unable to fund these treatments. In the community, these treatments would have to funded privately by the patient. SHPA understands that some medicines, like melatonin, are being sourced by parents overseas as compounding formulations for children would be otherwise be too expensive for ongoing supply if sourced in Australia.

SHPA recommends broadening of the PBS prescribing criteria for medications indicated for the treatment and management of ADHD and associated comorbidities, to be inclusive of late diagnosis of ADHD in adults and reflective of current clinical guidelines.

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A further contributor to access of ADHD treatment is the variation in access to medication in different jurisdictions owing to differing formularies across hospitals. This is further compounded by jurisdictions such as NSW and ACT being non-signatories to the Pharmaceutical Reforms Agreements (PRA). The PRAs enable hospital prescribers and pharmacists to prescribe and dispense PBS subsidised medicines to hospital patients upon discharge from hospital, outpatients and patients receiving care from day-treatment services. They support the transitions of care for patients discharging from hospital back into the community and allow for people to be supplied the standard PBS quantity of one-months' supply of discharge medicines. One of the main pillars of the National Medicines Policy (NMP) includes equitable, timely, safe and reliable access to medicines and medicines-related services, at a cost that individuals and the community can afford – becoming signatory to the PRAs are one part in achieving this.

Recommendation 3: New South Wales and the Australian Capital Territory should become signatories of the Pharmaceutical Reform Agreements (PRAs) to achieve equity of access to ADHD medications in hospital settings

### Other ADHD medicine access issues

In Australia, a nationwide paediatric service has recently announced that it is unable to recruit enough specialist paediatricians to keep up with the increased demand in ADHD services, further compounding access to ongoing management of their treatment.[11] Medication shortages can also be challenging, especially when access to a specialist for alternative treatment is not viable.

Last year, the U.S Food and Drug Administration reported a shortage of the immediate release formulation of amphetamine mixed salts (Adderall) due to increased demand and shortage of the active ingredient.[12] In Australia, the medicine shortage reports database lists atomoxetine as currently being in shortage.[13] In addition, 40.3% of people with ADHD already have difficulties in finding the right medication and therapy[14] with shortages heightening limitations to accessing treatment. If access to treatment is not available, some parents may present to emergency departments to get the care and treatment they require for their children.

Current limitations that exist with repeat prescription intervals for PBS prescription dispensing of Schedule 8 medications like ADHD medications until 20 days has passed since the last date they were dispensed to a patient, does not take into consideration individuals with ADHD who may have difficulties with accessing medication and need to have adequate supplies on hand at all times for holidays or from losing medication.

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

No comment.

**g) the adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people with ADHD at all life stages;**

Different jurisdictions have varying regulations in regard to prescriptions and medication supply, creating inequities in meeting the needs of people with ADHD. Please refer to Recommendation 3 described above.

**h) the adequacy of Commonwealth funding allocated to ADHD research;**

No comment.

**i) the social and economic cost of failing to provide adequate and appropriate ADHD services;**

A systematic review looking at the long-term outcomes for people with ADHD and the effects of treatment and non-treatment found that, without treatment, people with ADHD had poorer long-term outcomes in educational

and occupational outcomes compared with people without ADHD. The same study also found treatment for ADHD improved long-term health outcomes compared with untreated ADHD.[15]

An economic study looking at the social and economic cost to the Australian community found that the financial and non-financial costs of ADHD in Australia reached $12.76 billion during the 2018/2019 financial year.[16] Identifying areas where services are lacking and addressing them, can help reduce these costs to the individual, society, the economy, and government.

This does not include the burden on carers and teachers in caring for those with ADHD. For teachers, ongoing professional learning through seminars, webinars are preferred to build teacher capabilities related to educating students with ADHD.[17] Hospital pharmacists, especially those working in medicines information could assist in providing further education and support to carers and teachers alike, similar to the role of speech pathologists and psychologists in school environments.

**j) the viability of recommendations from the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD;**

SHPA believes that while an excellent resource, the Australian evidence-based clinical practice guideline for ADHD[11] recommendations can only be effective if they are put into practice in all settings. The recommendations around pharmacological treatments centre around providing adequate information around medicines for ADHD for clinicians and consumers alike. Hospital pharmacists are ideally placed to support shared decision making in ADHD treatment and ongoing monitoring. However, these pharmacists are not present in all services that care for those with ADHD and as a result are unable to provide advice on treatment decisions, quality use of medicines, medicines management as well as counselling patients and carers on best use of their ADHD medications. Many healthcare services are missing out on these essential clinical pharmacy services.

In order to achieve the recommendations, SHPA believes that adopting the pharmacist-to-bed ratios as outlined in SHPA's Standards of Practice for Clinical Pharmacy Services[4] is essential. This is of particular importance in areas where pharmacists make interventions around ADHD treatments in the practice settings of paediatrics and mental health.

Recommendation 4: Enabling sufficient access to clinical pharmacists to support the safe and quality use of medications in hospital settings for people with ADHD, by adopting the pharmacist-to-bed ratios as outlined in SHPA's Standards of Practice for Clinical Pharmacy Services[4] and ensuring design of every ADHD service includes funding for pharmacy involvement

**k) international best practice for ADHD diagnosis, support services, practitioner education and cost; and**

Availability of alternative medication delivery forms, such as methylphenidate patches, are available in the USA[18], which are not available in Australia. Providing an alternative formulation could improve adherence to ADHD medicines, ensure correct dosing, as well as improve outcomes for those with ADHD. As Australian guidelines are updated with novel treatments, these treatments must be made accessible to people with ADHD.

**l) any other related matters..**

As many ADHD medicines are commenced in hospital settings, usually in outpatient clinics, SHPA believes that hospital pharmacists can play a greater role in medication counselling, and ongoing management of ADHD medications. SHPA acknowledges that this could be more challenging outside of metropolitan area due to lack of hospital pharmacists let alone paediatric pharmacists. Hospital Initiated Medication Reviews

(HIMR) could allow access to these specialised pharmacist services, including the hospital-initiated referral pathways of the federally funded Home Medicines Review program for patients with multiple comorbidities and meet the eligibility criteria for a Home Medicines Review referral.

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