

SHPA Submission to House Inquiry into Childhood Rheumatic Diseases – March 2022

Introduction

The Society of Hospital Pharmacists of Australia is the national professional organisation representing the 6,300 hospital pharmacists and their intern pharmacist and pharmacy technician colleagues, working across Australia's health system. SHPA is committed to facilitating the safe and effective use of medicines, which is the core business of pharmacists, especially in hospitals. SHPA convenes speciality practice groups in both paediatrics and neonatology, and medical specialities including rheumatology.

SHPA welcomes the opportunity to consult on the Inquiry into Childhood Rheumatic Diseases and will be commenting on terms of reference (TOR) 3 and 4 only.

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 jvik@shpa.org.au. SHPA would welcome an opportunity to provide evidence at an upcoming hearing on this inquiry.

TOR 3. Access to medical services, including diagnosis, treatment and ongoing management and support including patient information, with a focus on rural and remote communities

Access to treatment and pharmacy services in rural and remote communities

Poor access to clinical pharmacy services, especially in rural and remote areas who experience poorer health outcomes, is a risk to safe and quality medicines use and medicines access for children being treated with childhood rheumatic diseases. Current provision of clinical pharmacy services are extremely limited in rural and remote areas and are inadequate to address the complex needs of patients, as evidenced by the 250,000 hospital admissions occurring annually as a result of medication-related problems, costing \$1.4 billion annually¹. In the case of complex paediatric patients with rheumatic disease, the equally complex medication regimens require hospital pharmacist-led medication management.

Paediatric dosing is complex and often calculated according to age or body weight, taking in to account other factors such as renal and hepatic function. This requires the expertise of Hospital Pharmacists, who ensure that patients are not under dosed resulting in treatment failure or overdosed leading to adverse reactions.

This is especially important for Disease Modifying Anti-Rheumatoid Drugs (DMARDs) such as methotrexate, where incorrect dose frequency can lead to hospitalisation and potentially fatal consequences. Over the last decade, there have been seven tragic and preventable deaths due to methotrexate overdose in Australia, with another 28 notifications to regulators on incidents involving methotrexate².

Pharmacists provide counselling to paediatric patients and their carers on how to use methotrexate safely, how to look out for serious side effects of methotrexate relating to immunosuppression and hepatotoxicity to avoid the development of fatal adverse reactions. Discussing different formulation options and easing worries of children and carers by giving reassurance about subcutaneous preparations may help patients feel more involved in their treatment.

Medications such as corticosteroids also form part of the standard treatment for childhood rheumatic diseases. However, significant side effects such as decreased bone density, mood disturbances and weight

gain posed by these agents mean that long-term use must be monitored closely and reduced where possible. Hospital pharmacists have a vital role in the provision of alternative treatments such as DMARDs or alternative formulations, as well as reviewing discontinuation of inappropriate medications. Without hospital pharmacist expertise in this specialised area, paediatric patients have the potential to miss out on medication reviews which can otherwise make a clinical recommendation they can reduce their dose of corticosteroids or cease altogether to avoid long-term adverse effects of these medicines. This disparity in access to hospital pharmacist expertise can be seen in some states more than others.

The poor access to pharmacy services is most evident in rural and regional New South Wales According to the Productivity Commission's annual Report on Government Services, NSW experiences higher rates of medication adverse events than other states such as Victoria and Queensland, who have better resourced hospital pharmacy departments who are better equipped to reduce the medication related errors.

	NSW	VIC	QLD
2011-12	2.4	2.1	2.1
2012-13	2.5	2.3	2.4
2013-14	2.6	2.2	2.4
2014-15	2.8	2.2	2.4
2015-16	2.8	2.1	2.4
2016-17	2.8	2.2	2.4
2017-18	3.1	2.1	2.4

Table 1. Adverse effects of drugs, medicaments and biological substances, events per 100 separations
Source: Productivity Commission, Report on Government Services

SHPA NSW members frequently report that hospital pharmacy departments in NSW public hospitals lack the investment and resources to meet accepted standards of practice for hospital pharmacy services. This means that the full suite of clinical pharmacy services, which reduce the incidence and severity of medication related incidents, cannot be provided to all NSW hospital patients that require it. These issues are exacerbated further in rural and regional NSW health services where there is a shortage of a hospital pharmacist workforce.

	METRO Hospital Pharmacist to Population	REGIONAL Hospital Pharmacist to Population	METRO Hospital Pharmacist to Hospital Beds	REGIONAL Hospital Pharmacist to Hospital Beds
NSW	1:5517	1:8516	1:13	1:27
VIC	1:3741	1:6706	1:8	1:18
QLD	1:3367	1:5436	1:8	1:14

Table 2. Ratio of hospital pharmacist to population & hospital beds along comparable Eastern seaboard states *This data records all pharmacists reporting working in hospitals not only those providing ward-based services Data source: National Health Workforce Data Set, Australian Bureau of Statistics

TOR 4. Best practice quality of care and availability of treatments, including emerging treatments with a focus on equitable access to effective drugs

Inefficient and variable access to emerging Treatments

In recent years, the majority of Pharmaceutical Benefits Scheme (PBS) expenditure and listings are for high-cost complex medicines, biologics, and DMARDs used to treat autoimmune diseases, which are often initiated and supplied in hospital settings.

After the role of cytokines interleukin-1 (IL-1) and interleukin-6 (IL-6) in the pathogenesis of Systemic-onset Juvenile Idiopathic Arthritis (SJIA) were identified, rapidly evolving treatments in biological have changed the profile of new medicines being brought to market for autoimmune diseases, increasingly highlighting issues around access and equity.

Public hospitals and hospital pharmacy departments play a crucial role in access to novel, usually high-cost and/or off-label medicines to treat complex and uncommon diseases before these medicines are registered on the Australian Register of Therapeutic Goods (ARTG) and well before they are listed on the PBS. They are also integral to patient access to clinical trials.

Due to the complex and specialised nature of biologic DMARDs, as well as their cost, patient access to these medicines differs greatly between hospital networks and between jurisdictions. They are subject to various factors including:

- fixed hospital pharmaceutical budget constraints
- varying access to compassionate access schemes
- local Drug and Therapeutic Committee policies and decisions
- access to specialist rheumatologists
- proximity to large hospitals (required for infusions)
- varying out-of-pocket expenses determined by local and jurisdictional policies

The majority of biologics approved for adult Rheumatoid Arthritis (RA) on the PBS are not approved for paediatric use in Juvenile Idiopathic Arthritis (JIA) and other childhood rheumatic diseases such as Cryopyrin-Associated Autoinflammatory Syndromes (CAPS). In addition, the IL-1 antagonist, anakinra, was approved by the Therapeutic Goods Administration (TGA) for treatment of JIA; however, it is not available on the PBS for treatment of JIA, resulting in hospital Drug and Therapeutics Committees having to decide individually on granting access and supply of these high cost medicines. This further contributes to the inequitable access to treatment for children, with some public hospitals absorbing these costs and other hospitals without the resources to fund supply and having to deny treatment or ask patients and families to self-fund treatment.

Medicines access inequities for Aboriginal and Torres Strait Islander patients

Another inequity is the exclusion of public hospitals from participating in the Closing the Gap (CTG) PBS Copayment Measure (the Measure). Whilst the Measure provides co-payment relief for concessional patients in the community, indigenous patients discharging from hospital are not eligible for co-payment relief and are often discharged without any medicines. Given that the Indigenous Australian population has a higher prevalence of arthritis than non-Indigenous Australians, makes this a key priority.³

Without access to the Measure, individual hospital policies (which require a co-payment as specified by PBS procedures) often prevent Indigenous patients from receiving their medicines at discharge to avoid incurring operational cost. If parents are unable or unwilling to pay the co-payment, they must attend a community pharmacy to receive discharge medicines for their children. Research shows that these patients have lower medicines adherence compared to other population groups⁴, and that over a quarter of patients fail to make it to a local pharmacy until days later to have their discharge prescription dispensed. ⁵ This is further

compounded by some rural and remote communities having limited access to a community pharmacy within a reasonable distance.

SHPA is advocating for hospital pharmacies to be eligible to participate and supply medications under this Measure, to improve equity of access of medications for Aboriginal and Torres Strait Islander People being discharged from hospital. Furthermore, gaps in health literacy need to be addressed by utilising patient-centred medication counselling provided by hospital pharmacists. Investing in this workforce can ensure that Indigenous patients have access to healthcare that takes into account culturally safe practices that is holistic in nature.

References

¹ Pharmaceutical Society of Australia. (2019). Medicine Safety: Take Care. Canberra: PSA

² Pharmacy Board of Australia. (2021). Analysis of notifications involving oral methotrexate – summary report. Available at: https://www.pharmacyboard.gov.au/News/2021-03-24-summary-report-published.aspx

³ Australian Institute of Health and Welfare. (2020) Data Table: Arthritis Web Report. Available at: https://www.aihw.gov.au/reports/chronic-musculoskeletal-conditions/arthritis-snapshot/contents/arthritis

⁴ Cass A, Lowell A, Christie M, Snelling PL, Flack M, Marrnganyin B et al. (2002) Sharing the true stories: improving communication between Aboriginal patients and health care workers. Med J Aust, 176(10):466-470.

⁵ Fallis B.A, Dhalla I.A, Klemensberg J., Bell C.M. (2013). Primary Medication Non-Adherence after Discharge from a General Internal Medicine Service. PLoS ONE 8(5): e61735.