



SHPA submission to Inquiry into Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer, August 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 an Oncology and Haematology Specialty Practice stream, comprising of a network of SHPA members who work to optimise best practice cancer care for oncology and haematology patients in inpatient, outpatient, ambulatory care or primary care settings where patients of any age receive pharmacy services. They promote and foster education, research and communication in cancer pharmacy related issues. The treatment of patients with rare cancers is usually initiated in hospital settings, with these pharmacists playing a vital role in managing their medications.

Hospital pharmacists are experts in complex medication management for people who are acutely unwell. Pharmacists providing oncology and haematology clinical pharmacy services are clinical pharmacists with expertise in cancer therapies, practicing within a hospital's multidisciplinary team with a key focus on promoting safe and effective use of cancer medications, reducing the incidence of serious adverse events and toxicities, and improving patient care. Depending upon the capacity and preferences of the hospital, Oncology and Haematology pharmacists work with multidisciplinary committees to support effective governance including policies and procedures to drive improved patient care. Pharmacists managing the manufacturing of these cancer therapies are also clinical pharmacists with expertise in the compounding of cytotoxic medications.

Rare cancers represent a disproportionate number of deaths compared to more common cancers. While 30% of all cancers diagnosed are classified as rare or less common cancers, these are responsible for 42% of all cancer deaths.¹ The cancer-related hospitalisation rate has been rising steadily in Australia, largely due to an increasing number of same day hospitalisations where a pharmacotherapy treatment was recorded.¹

The treatment of rare cancers presents a further challenge - being harder to diagnose, the lack of available treatments and research into rare cancers, as well as the lack of evidence-based guidelines specific to the management of rare cancers. Hospital pharmacists provide evidence-based medication related interventions in this cohort of patients and have a vital role in optimising rare cancer treatment, ultimately aiming to reduce mortality rates.

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



List of Recommendations to Inquiry into Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer

Recommendation 1: For smaller hospitals, particularly in regional, rural and remote settings, funding models should recognise that the overheads and ongoing costs uniquely associated with the provision of Section 100 Efficient Funding of Chemotherapy (EFC) medicines separate to other PBS medicines, are much more pronounced and less affordable, negatively impacting the viability of rare cancer services.

Recommendation 2: Chemotherapy pharmacy services should be delivered by appropriately experienced and trained pharmacists in cancer services, with health services provided dedicated support for recruitment, retention and training of this specialised workforce, such as training pharmacists through SHPA's Cancer Services Advanced Training Residency Program.

Recommendation 3: The provision of cancer medicines should be delivered alongside best-practice clinical pharmacy services for oncology and haematology services with the following ratios according to SHPA's Standard of practice in oncology and haematology for pharmacy services:

- 1 full-time equivalent (FTE) pharmacist to 20 medical oncology inpatients
- 1 FTE pharmacist to 15 haematology inpatients
- 1 FTE pharmacist to 20 same-day admitted or home-based care patients

Recommendation 4: Improve chemotherapy service delivery and access to Aboriginal and Torres Strait Islander People by addressing health literacy and developing culturally appropriate resources on chemotherapy medicines and cancer care in hospitals, through co-design and consultation with Aboriginal and Torres Strait Islander Peoples and Indigenous Health peak bodies and practitioners.

Recommendation 5: New South Wales and Australian Capital Territory should become signatories to the Pharmaceutical Reform Agreements, allowing public hospitals to directly supply Section 100 EFC medicines and chemotherapy services more efficiently and improve access.

Recommendation 6: Digital health infrastructure investment into electronic medical records design and implementation should consider the safety and workflow requirements of chemotherapy services and support the enabling and delivery of TeleChemotherapy services to increase access in rural and remote areas.



Terms of Reference

Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer, with particular reference to:

- a. barriers to screening and diagnosis, including the impact of factors such as:**
 - i. geographic location,**
 - ii. cost,**
 - iii. cultural and language barriers,**
 - iv. type of cancer, and**
 - v. availability of treating practitioners;**

The majority of medical oncology specialists work in metropolitan areas.² The lack of specialists familiar with rare cancers can mean that detection rates can be lower in areas without specialists or referral centres that can adequately screen and diagnose rare cancers. Patients may therefore present to hospitals at advanced stages of disease, with the incidence rate for all cancer for very remote areas influenced by lower population screening participation rates and later detection of a cancer³ – for rare cancers, it would be anticipated that these rates would be even lower. The impact of the COVID-19 pandemic and reduced access to screening services or regular medical appointments, also is another factor impacting detection rates and higher incidence of advanced disease upon diagnosis.

Patients would also need to be referred to tertiary hospitals that have the necessary diagnostic imaging services required for diagnosis which could potentially be a barrier to screening for those unable to fund transport and accommodation required.



b. barriers to accessing appropriate treatment;

Equity of access to treatment irrespective of geographical location

Recommendation 1: For smaller hospitals, particularly in regional, rural and remote settings, funding models should recognise that the overheads and ongoing costs uniquely associated with the provision of Section 100 Efficient Funding of Chemotherapy (EFC) medicines separate to other PBS medicines, are much more pronounced and less affordable, negatively impacting the viability of rare cancer services.

The impact of rare cancer types is greatest for Australians living in more socio-economically disadvantaged and remote areas. Once diagnosed with a rare cancer, a greater proportion of rural and remote patients have worse than average survival rates.⁴

Access to chemotherapy services in rural and remote areas varies greatly from that in metropolitan areas of Australia. Patients requiring chemotherapy in rural and remote areas are often unable to receive treatment near their residence due to the challenges and costs associated with safe and high-quality chemotherapy services and the lack of economies of scale. This results in a reliance on patients to travel and receive treatment at metropolitan centres, often at their own cost. This has downstream effects on increased out-of-pocket costs associated with travel and accommodation if necessary.

In addition to this, a postcode lottery exists for patients across Australia in regard to accessing appropriate cancer treatments, which does not support the National Medicines Policy central pillar of timely access to medicines. Tertiary hospitals that have specialised cancer services often do not treat patients who are outside of their catchment, instead referring them back to their local hospital which often doesn't have the most appropriately qualified health professional to prescribe and/or administer some of these highly specialised medicines. Without access to specialists, sub optimal cancer care is provided to patients compared to their metro counterparts.

Access also depends on which treatments for rare cancers are included on the Pharmaceutical Benefits Scheme (PBS) under the Efficient Funding of Chemotherapy (EFC) initiative, such as immunotherapy, targeted therapies (monoclonal antibodies, small molecule inhibitors) as well as new and emerging therapies involving genomics, cell and gene therapies.

In 2017, the report following the *Inquiry into the Funding and Research into Cancers with Low Survival Rates*⁵, included Recommendation 15 (5.102) suggesting that the Therapeutic Goods Administration (TGA) and Pharmaceutical Benefits Advisory Committee (PBAC) examine their assessment processes and the appropriateness of those processes for innovative treatments for low survival rate (LSR) cancers, such as immunotherapies and consider adopting more flexible and innovative approaches to approving innovative treatments for LSR cancers and assessing them for listing on the PBS. However, these rapidly evolving cancer treatment options which have changed the profile of new medicines being brought to market, have continued to highlight issues around access and equity.

Public hospitals and hospital pharmacy departments play a crucial role in facilitating 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 these medicines, 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 clinicians
- proximity to large hospitals
- varying out-of-pocket expenses determined by local and jurisdictional policies.

Hospitals may opt to allocate budgets to the treatment for other conditions that affect a greater number of patients. Accessing clinical trials may require the patient to make repeated hospital visits to access the medicines and to complete any required monitoring which may not be practical for those outside of metropolitan hospitals, where clinical trials typically operate from. For paediatric patients, clinical trials may be the only viable option to receive treatment and some hospitals may rely on fund raising to provide these treatments which is neither sustainable or guaranteed. Some patients may opt for cancer treatment through private health services, with those of lower socioeconomic backgrounds unable to afford this option.

In addition, for hospital pharmacies in rural and remote areas, a limiting factor is having the requisite specialist hospital pharmacy workforce to successfully operate chemotherapy services. As the National Rural Health Alliance outlines in their 'Cancer in Australia' factsheet⁶, comprehensive cancer care requires adequate funding of pharmacists in order for patients benefit from this level of service. Recruitment and retention of specialised and experienced hospital pharmacy staff is significantly more challenging than in urban settings, due to a smaller pool of available pharmacists with the requisite skills.

In SHPA's submission for the Review of the Section 100 Efficient Funding of Chemotherapy (EFC)⁷, the range of recommendations include a funding model that properly recognises the overheads, ongoing costs uniquely associated with the provision of Section 100 EFC medicines separate to other PBS medicines to support sustainability and access to chemotherapy, particularly in smaller hospitals in regional and rural settings.

Given the importance of economies of scale on the viability of chemotherapy services, funding models and/or remuneration fee structures for provision of Section 100 EFC medicines should be tiered to recognise this and the marginal costs of chemotherapy services provided in hospitals of different sizes and capacities, to facilitate improved patient access in regional and rural settings. This would aim to reflect and cost-recover for increased workload relating to logistics of ordering, transportation, receiving, storing and dispensing of chemotherapy in rural and remote settings.

This increased funding will also support the recruitment of appropriately skilled and trained pharmacists that have experience in or specialise in chemotherapy services. This could come in the form of targeted service fees for regional, rural and remote specialised chemotherapy services to improve viability and access of these services.

Specialist workforce: Cancer services pharmacists

Recommendation 2: Chemotherapy pharmacy services should be delivered by appropriately experienced and trained pharmacists in cancer services, with health services provided dedicated support for recruitment, retention and training of this specialised workforce, such as training pharmacists through SHPA's Cancer Services Advanced Training Residency Program.

SHPA supports both pharmacists and pharmacy technicians to operate at their full scope of practice in order to achieve optimal patient and pharmacy outcomes. Utilising the existing skilled workforce of hospital



pharmacists to deliver excellent cancer care services is essential. National funding is required in order to develop and sustain this workforce through funded hospital pharmacy internship programs in cancer hospitals and workforce development and training programs.

SHPA has established a Cancer Services Advanced Training Residency (ATR) which launched in the middle of 2021, to provide a structured two-year training program for Hospital Pharmacists who want to specialise in cancer services. At present, there is no dedicated funding at a federal or state level for Cancer Services ATRs to develop the Cancer Services pharmacist workforce, and there are only four hospitals across three states who have been able to fund these positions from existing resources.

Cancer services pharmacists are essential interdisciplinary team members, who have specialised knowledge of cancer therapy and help to maximise the benefits of therapy and minimise toxicities.⁸ As integral members of interdisciplinary teams, oncology and haematology pharmacists offer a variety of services that have both a direct and indirect impact on patient care. These include contributing to the selection of therapy, prescribing, dosing, monitoring, evaluation, education, procurement and storage.⁹

Various reports stemming from both the 2016 Inquiry into Off-protocol prescribing of chemotherapy in New South Wales¹⁰ and Independent Review into the Incorrect Dosing of Cytarabine to ten patients with Acute Myeloid Leukaemia at Royal Adelaide Hospital and Flinders Medical Centre¹¹ in South Australia, demonstrate the critical nature of hospital pharmacists acting as a safeguard for the quality and safety of cancer care.

Given the highly specialised nature of rare diseases, the importance of utilising a cancer services pharmacist's evidenced based approach is paramount in treatment selection where national guidelines may not exist. Pharmacists may also be involved in counselling patients on side effects of treatment, their management as well as safe handling of cytotoxic medicine.

Recommendation 3: The provision of cancer medicines should be delivered alongside best-practice clinical pharmacy services for oncology and haematology services with the following ratios according to SHPA's Standard of practice in oncology and haematology for pharmacy services:

- 1 full-time equivalent (FTE) pharmacist to 20 medical oncology inpatients
- 1 FTE pharmacist to 15 haematology inpatients
- 1 FTE pharmacist to 20 same-day admitted or home-based care patients

The integration of clinical pharmacy services into an oncology and haematology service results in increased interventions relating to prescriptions for hospitalised adult cancer patients¹², with the majority of the interventions accepted and implemented by the medical team. Australian research has highlighted that oncology and haematology pharmacists can improve the continuum of care during clinical handover by providing accurate information in relation to cancer therapies.¹³ Integration of an oncology and haematology pharmacist into the outpatient clinic setting has been demonstrated to:

- improve the management of supportive care
- enhance the education of patients receiving complicated chemotherapy regimens as those that may be seen in the treatment of rare cancers
- improve the efficiency of chemotherapy infusion units
- lead to better patient-centred interactions¹⁴
- contribute positively towards the assessment of medicines adherence, understanding of medicines, improving symptom control, patient satisfaction, and improvement in the quality of life.¹⁵



SHPA's *Standard of practice in oncology and haematology for pharmacy services*¹⁶ describes current best practice for the provision of oncology and haematology pharmacy services, by oncology and haematology pharmacists and the pharmacy department or employer. The roles of oncology and haematology pharmacists are varied, dependent on the model of care and size of the health service, and recommended staffing is, therefore a reflection of this.

SHPA's Standard of practice in oncology and haematology for pharmacy services recommends 1 pharmacist to 20 medical oncology inpatient beds, with a higher ratio of pharmacists 1:15 needed for haematology inpatients, and SHPA supports for these ratios to be mandated and enforced in hospitals to ensure safe and quality pharmacy care is provided to cancer patients.

Aboriginal and Torres Strait Islander access to Cancer Services

Recommendation 4: Improve chemotherapy service delivery and access to Aboriginal and Torres Strait Islander People by addressing health literacy and developing culturally appropriate resources on chemotherapy medicines and cancer care in hospitals, through co-design and consultation with Aboriginal and Torres Strait Islander Peoples and Indigenous Health peak bodies and practitioners

Between 2015–2019, the cancer mortality rate for Indigenous Australians was 45% higher than the rate for non-Indigenous Australians.¹ SHPA members have reported several challenges with the current access arrangements to chemotherapy for Aboriginal and Torres Strait Islander People across Australia. Hospitals are often considered culturally unsafe institutions and places to go and associated with morbidity in Aboriginal and Torres Strait Islander communities. Better messaging is required to improve health literacy around the role of hospitals in healing, and of chemotherapy in the treatment of cancer.

Culturally and linguistically diverse medication information resources are not currently available for chemotherapy and supportive non-chemotherapy medications. These resources would support these important conversations and help improve cultural perspectives on hospitals and cancer treatment options. SHPA supports development of these resources through co-design and consultation with Aboriginal and Torres Strait Islander Peoples and Indigenous Health peak bodies and practitioners, such as SHPA's Aboriginal and Torres Strait Islander Health Leadership Committee and National Aboriginal Community Controlled Health Organisation.

Additionally, there is limited access to supportive non-chemotherapy medications (i.e., pain medicines, anti-nausea medicines) in Remote Area Aboriginal Health Services (RAAHS) and the PBS co-payment for supportive medications is also a barrier to receiving these medicines. SHPA members also note that referral of complex and often marginalised Aboriginal and Torres Strait Islander patients from urban centres to rural and remote centres, to better place them closer to home and their support networks, has cost implications on rural and remote centres to provide a level of complex care usually only reserved for urban centres.

Pharmaceutical Reform Agreements

Recommendation 5: New South Wales and Australian Capital Territory should become signatories to the Pharmaceutical Reform Agreements, allowing public hospitals to directly supply Section 100 Efficient Funding of Chemotherapy (EFC) medicines and chemotherapy services more efficiently and improve access.



Patients living in jurisdictions which are non-signatories to the Pharmaceutical Reform Agreements (PRAs) are unable to benefit from the same access to PBS listed medicines as their counterparts in other jurisdictions. The impact of this on chemotherapy services in New South Wales public hospitals is that it hinges on workarounds where the dispensing and manufacturing of Section 100 EFC medicines is undertaken by a community pharmacy – who likely outsources the compounding – and delivers the prepared product to the public hospital for administration. This model of care to deliver chemotherapy, involves three different stakeholders to co-ordinate the supply and administration of a high-risk chemotherapy medicine safely and efficiently.

The clinical review process of chemotherapy orders is also devolved in the absence of a singular chemotherapy clinical software system that all parties have access to, thus increasing the risk of error caused by transcription of chemotherapy order details, patient details and particulars regarding their chemotherapy protocol and cycle.

These challenges are exacerbated where last minute dose modification is required due to changing patient status, causing potential delays to treatment and/or wastage of high-cost chemotherapy medicines. This contrasts with public hospitals in all other states that are signatories to the Pharmaceutical Reform Agreements, where they have the option to have in-house compounding services for chemotherapy medicines, as larger public hospitals with higher volumes of chemotherapy patients are able to make these compounding services more viable. The benefits from this include:

- More timely responsiveness and capacity to undertake any dose changes or modifications for chemotherapy orders, thus limiting risk of wastage of a high-cost medicine
- Increased safety and quality of chemotherapy services through access to patient file and notes within the hospital to undertake clinical review of chemotherapy orders to ensure it is accurate, safe and appropriate for the patient

Thus, SHPA recommends that New South Wales and the Australian Capital Territory become signatories to the Pharmaceutical Reform Agreements, allowing public hospitals to directly supply Section 100 EFC medicines and chemotherapy services.



c. the adequacy of support services after diagnosis;

Maximise potential of electronic medical records and innovative models of care

Recommendation 6: Digital health infrastructure investment into electronic medical records design and implementation should consider the safety and workflow requirements of chemotherapy services and support the enabling and delivery of TeleChemotherapy services to increase access in rural and remote areas.

Australian hospitals are currently on an electronic medical records journey, with different hospitals, states and territories at varying levels of design, scoping and implementation, with varying state-wide versus local approaches to this. As electronic prescribing rollout in primary care settings has mostly concluded, the Commonwealth is now ramping up electronic prescribing implementation in hospital settings. It is imperative that implementation of these systems is safe, fully integrated with existing systems and complex workflows, as well as end users being educated on its use.

Investment in electronic medication management systems that are integrated with procurement, scheduling and dispensing systems and processes would reduce the risk of errors, administrative burden, and promote safe and quality use of medications and cancer services.

Electronic medication management systems can also possibly aid the establishment of innovations such as TeleChemotherapy that would improve patient access to specialised cancer care, especially in rural and remote areas where it is difficult to or not feasible to recruit dedicated pharmacist resources for very small patient cohorts.

Once diagnosed, funding and enabling of TeleChemotherapy could allow for patients based in regional, rural and remote areas to receive their chemotherapy without travelling to an urban area, whilst still receiving comprehensive pharmacy care by suitably trained and experienced pharmacists. One such example is the Western Australia Country Health Service TeleChemotherapy Pharmacy Service, which has received national recognition for its innovation in delivering chemotherapy treatment to regional, rural and remote patients. Thus far, this service has allowed dozens of patients in these regions receive lower-risk chemotherapy locally with the support of specialist metropolitan-based clinicians via telehealth services.



d. the adequacy of Commonwealth funding for research into rare, less common and neuroendocrine cancer;

SHPA welcomes news of the federally funded Clinical Trials Activity initiative which addresses rare cancers, rare diseases and unmet needs will provide \$750 million over 10 years from 2022-23.¹⁷ In addition, welcome improvements to new treatment pathways through funding for genomic and precision medicine profiling via the Precision Oncology Screening Platform enabled Clinical Trial (ProSPeCT) program importantly includes recruitment of rural, regional, and remote patients.

As the majority of clinical trials occur in hospital settings, SHPA anticipates that role of clinical trial pharmacists is adequately considered as part of these initiatives and programs. This includes adequate funding and staffing criteria to be built into the overall cost of clinical trial. Roles of clinical trial pharmacists go beyond the provision of the investigational product, and includes:

- co-ordinating, collaborating and providing support for the clinical trials pharmacy service
- delivery of pharmacy services that improve participant medication outcomes and add value to health care systems, while encouraging the financial sustainability of healthcare
- development of and input into policies, procedures, guidelines and resources
- commentary on clinical trials protocols
- provision of education and training for healthcare professionals and students
- provision of education and counselling to clinical trial participants, carers, medical and nursing staff and other pharmacists
- pharmacy research related to clinical trials.¹⁸

Funding needs to incorporate the full breadth of these services in order for research into treatment for rare cancers to continue.



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