Optimal Care Pathway for Rare and Less Common Cancers (Rare Cancers Australia)

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Introduction

Formerly known as the Society of Hospital Pharmacists of Australia (SHPA), Advanced Pharmacy Australia (AdPha) is the progressive voice of Australian pharmacists and technicians, built on 80 years of hospital innovation that puts people and patients first. AdPha supports all practitioners across hospitals, transitions of care, aged care and general practice clinics to realise their full potential. We are the peak body committed to forging stronger connections in health care by extending advanced pharmacy expertise from hospitals to everywhere medicines are used.

AdPha) welcomes the opportunity to contribute to the development of a new Optimal Care Pathway (OCP) for People with Rare and Less Common Cancers. Our submission focuses on the overarching questions outlined in the consultation and aims to support the delivery of more consistent, high-quality, and person-centred care—regardless of geography or treatment setting.

AdPha convenes an **Oncology and Haematology Specialty Practice Group**, comprising a network of over 900 pharmacists working across inpatient, outpatient, ambulatory, and primary care settings. These members are committed to advancing best practice in cancer care through leadership in education, research, clinical service delivery, and professional collaboration.

Hospital pharmacists are experts in the management of complex and high-risk medicines, particularly for people who are acutely unwell. Those providing oncology and haematology services are **core members of multidisciplinary cancer teams**, applying specialised expertise in cancer therapies to ensure safe, effective, and evidence-based medication use. Their contributions help **reduce serious adverse events** and toxicities, support appropriate treatment decisions, and **strengthen medicines governance** through participation in policy and protocol development. Pharmacists managing the preparation of chemotherapy—

including cytotoxic compounding—also play a critical role in **maintaining safety and quality standards.**

People diagnosed with rare and less common cancers face distinct challenges. These cancers account for **30% of all diagnoses but are responsible for 42% of all cancer-related deaths**.[1] Treatment is often initiated in hospital settings, where pharmacists are key to ensuring safe prescribing, individualised treatment, and access to new or off-label therapies in the absence of national clinical guidelines.

Cancer-related hospitalisations are rising, particularly **same-day admissions involving pharmacotherapy**. Optimising pharmacy services in oncology and haematology settings is essential to improving patient outcomes and addressing the complexity of rare cancer care.

AdPha is pleased to provide this submission on behalf of our members and the broader pharmacy profession. Our insights aim to support the development of an OCP that reflects the full potential of the pharmacy workforce to improve safety, access, and outcomes for people living with rare and less common cancers.

If you have any queries or would like to discuss our submission further, please contact Jerry Yik, Head of Policy and Advocacy at jyik@adpha.au.

Response to survey questions

29.What is the most urgent change needed to improve care for people with rare and less common cancers?

Improve equitable access to timely, specialist-led treatment and novel therapies—especially in regional, rural, and remote areas

This includes addressing funding and workforce barriers that limit the provision of chemotherapy and other specialised treatments outside metropolitan centres, and reforming funding models to better support the viability and sustainability of these services in lower-volume settings.

Australians living in socio-economically disadvantaged and remote areas are disproportionately affected by rare and less common cancers. Once diagnosed, a higher proportion of patients in rural and remote areas experience worse-than-average survival outcomes.[2]

Access to chemotherapy services in these regions remains highly variable compared to metropolitan areas. Many patients are unable to receive treatment locally due to the complex requirements and costs associated with delivering safe, high-quality chemotherapy, compounded by limited economies of scale. This forces patients to travel long distances—often at their own expense—placing additional financial strain through travel, accommodation, and time away from work or family.

A 'postcode lottery' also exists in terms of access to appropriate cancer treatments across the country. Patients are frequently referred back to local hospitals that may lack the specialist clinicians needed to prescribe or administer complex therapies, leading to suboptimal care compared to what's available in tertiary metropolitan centres. This undermines the National Medicines Policy's goal of timely and equitable access to medicines.

Access to treatments is further constrained by the scope of intravenous therapies available on the Pharmaceutical Benefits Scheme (PBS) under the Section 100 Efficient Funding of Chemotherapy (EFC) program. Access to newer therapies—including immunotherapy, targeted agents, and genomic or cell-based treatments—is inconsistent. These are often not yet listed on the PBS, face a delay in PBS listing, or are only available in specialist centres.

The 2017 parliamentary report into Funding and Research into Cancers with Low Survival Rates[3] recommended that the TGA and PBAC adopt more flexible and innovative approaches for approving and funding therapies for these cancers. Despite this, significant access and equity issues remain, particularly with emerging cancer treatments.

Public hospitals and pharmacy departments play a pivotal role in enabling early access to high-cost, off-label, and pre-registration medicines, and in facilitating clinical trial

participation. However, access varies greatly due to:

- Fixed pharmaceutical budgets
- Differences in hospital and jurisdictional policies
- Variable access to compassionate access schemes
- Proximity to major hospitals
- Availability of specialist clinicians
- Local out-of-pocket costs

Hospitals may prioritise treatments for more prevalent conditions, and rural patients may be excluded from trials due to location and logistical challenges. For paediatric patients, clinical trials may be the only treatment pathway—relying on fundraising in some cases, which is neither sustainable nor equitable. Those without private health insurance or means are often left with limited or no options.

A further barrier in rural and remote hospitals is the availability of skilled pharmacy staff required to safely manage chemotherapy services. As the National Rural Health Alliance outlines in their 'Cancer in Australia' factsheet , comprehensive cancer care requires adequate funding of pharmacists in order for patients benefit from this level of service.[4] Recruiting and retaining experienced hospital pharmacists in these areas is difficult due to workforce shortages and competition from urban centres.

In its submission to the Review of the Efficient Funding of Chemotherapy (EFC) program[5], AdPha called for a revised funding model that recognises the unique, ongoing costs of providing intravenous chemotherapy—separate from other PBS medicines—and better supports smaller hospitals in regional and rural areas.

Given the impact of economies of scale on the viability of services, funding should be tiered to reflect the higher marginal costs in lower-volume settings. This would help cost-recover for the additional workload related to ordering, transport, storage, and preparation of chemotherapy in rural and remote hospitals.

Additional targeted funding would also enable recruitment of skilled pharmacists with chemotherapy expertise, supporting the viability and sustainability of specialised services and improving access for patients outside metropolitan areas.

Ensure national consistency in access to chemotherapy and PBS-listed medicines across all jurisdictions—particularly by addressing systemic inequities faced by patients in non-PRA (Pharmaceutical Reform Agreement) jurisdictions like New South Wales and the ACT.

This reform would enable safer, timelier, and more efficient chemotherapy services for rare and less common cancers, reducing treatment delays, medication errors, and unnecessary waste.

Patients living in jurisdictions that are not signatories to the Pharmaceutical Reform Agreements (PRAs)—notably New South Wales and the Australian Capital Territory—do not have the same access to PBS-listed medicines as patients in other states. This

directly affects the provision of chemotherapy services in public hospitals.

In these jurisdictions, the supply of Section 100 Efficient Funding of Chemotherapy (EFC) medicines depends on a workaround model involving three separate stakeholders:

- A community pharmacy (that may outsource compounding),
- The public hospital for administration, and
- External logistics to coordinate delivery of the prepared chemotherapy.

This fragmented model introduces risks and inefficiencies, especially in the delivery of high-risk, high-cost chemotherapy medicines. It can lead to:

- Delayed treatment if last-minute dose modifications are needed,
- Wastage of expensive compounded drugs, and
- Increased clinical risk due to reliance on manual transcription of orders between providers using different systems, without shared access to the patient's full clinical record.

By contrast, in PRA-signatory states and territories, chemotherapy can be compounded in-house within public hospitals. This allows for:

- Real-time dose adjustments with minimal delay or wastage,
- Direct clinical oversight and review of chemotherapy orders by the hospital team using integrated electronic health records, and
- Safer, more responsive and cost-efficient cancer care—particularly important for rare and less common cancers, where treatments are more individualised and complex.

While this issue sits outside the direct scope of the OCP, AdPha supports ongoing discussions to enable New South Wales and the ACT to establish Pharmaceutical Reform Agreements. Aligning these jurisdictions with the national framework would allow public hospitals to directly supply and manage Section 100 EFC medicines and chemotherapy services, leading to safer, more coordinated, and equitable cancer care.

30.What are we currently not doing well enough for people with rare and less common cancers?

There remain significant gaps in how we support and embed specialised oncology and haematology pharmacy services as a standard component of cancer care—despite clear evidence that these services improve patient safety, treatment outcomes, and overall quality of care, particularly for people with rare and less common cancers.

Cancer services pharmacists are integral members of interdisciplinary care teams. They provide critical expertise in areas such as therapy selection, dosing, monitoring, patient counselling, managing toxicities, and ensuring safe handling of complex chemotherapy and biologic agents. This is especially important for rare and less common cancers, where national treatment guidelines may not exist and therapy decisions require a tailored,

evidence-based approach.

Yet, at present:

- There is no dedicated federal or state funding to support cancer pharmacy workforce development.
- AdPha's Cancer Services Registrar Training Program—a structured two-year pathway for pharmacists to specialise in oncology—has only been implemented in a handful of hospitals across three states, relying on internal resources.
- Hospitals are not consistently resourced or mandated to meet best-practice staffing levels for pharmacy services.

As outlined in AdPha's Standard of Practice in Oncology and Haematology for Pharmacy Services[6], best-practice pharmacist-to-patient ratios are:

- 1 FTE pharmacist per 20 medical oncology inpatients
- 1 FTE per 15 haematology inpatients
- 1 FTE per 20 same-day or home-based care patients

These ratios are designed to ensure that pharmacists can operate at full scope and deliver high-quality clinical pharmacy services alongside the provision of cancer medicines. Research shows that embedding pharmacists in oncology and haematology services:

- Improves prescription safety and reduces medication errors
- Enhances continuity of care during transitions (e.g. hospital discharge)[7]
- Improves patient education, particularly for complex chemotherapy regimens seen in rare cancers
- Increases adherence, symptom control, and patient satisfaction[8]
- Boosts efficiency in chemotherapy infusion units

Despite these benefits, many services lack the resources to meet these ratios, resulting in gaps in care quality, preventable risks, and inequitable outcomes for patients with rare and less common cancers.

To address this, we must:

- Mandate and fund nationally consistent pharmacist staffing ratios in oncology and haematology services
- Invest in workforce training programs, including funded internships and registrar training for cancer pharmacists
- Ensure the inclusion of pharmacy services as a core element in the design and delivery of care within the Optimal Care Pathway for Rare and Less Common Cancers

Taking timely action will enhance the safety, effectiveness, and person-centred nature of cancer care for this vulnerable patient group.

31.Are there specific principles or approaches to care that you feel should be emphasised for rare and less common cancers?

For rare and less common cancers, several key principles and approaches to care should be emphasised to improve equity, access, and quality of care:

1. Person-centred care that minimises the burden of travel and cost

Due to the centralisation of specialist services in tertiary hospitals, many patients—particularly those in rural or regional areas—are required to travel long distances for diagnosis, treatment, and follow-up. This creates significant emotional, physical, and financial burdens.

- Care models must prioritise decentralised support, including:
- Funded travel and accommodation assistance
- Telehealth consultations where clinically appropriate
- Shared-care models between tertiary and regional hospitals to reduce the need for repeated travel

2. Equitable access to genetic and genomic testing

Rare and less common cancers often have unique genetic profiles. Timely access to funded genetic testing is essential for accurate diagnosis, targeted treatment selection, and eligibility for clinical trials.

This should be a core component of any optimal care pathway and embedded in national funding arrangements to avoid postcode-based inequities.

3. Workforce capacity-building through education and training

Healthcare professionals in regional and smaller hospitals need access to ongoing professional development in rare cancers—not just those based in major centres.

Approaches could include:

- Government-funded education programs and rare cancer-specific conferences
- Inter-hospital learning networks and case-sharing platforms
- Collaborative care protocols between tertiary and regional teams

Building this knowledge base will enable care to be delivered closer to home while ensuring safe and evidence-based practice.

4. Formalised care pathways and service collaboration

Rare cancers require clear, nationally recognised pathways for diagnosis, treatment, and referral. These should be underpinned by strong collaboration across institutions to ensure continuity of care and consistent clinical decision-making, regardless of where a patient lives.

32. Is there anything else that you think should be considered in developing the Optimal Care Pathway for people with rare and less common cancers?

To strengthen the Optimal Care Pathway (OCP) for people with rare and less common cancers, the following additional considerations should be included:

1. Investment in digital health infrastructure to support safe and accessible cancer care

Chemotherapy services have highly specialised workflow and safety requirements. Electronic Medical Record (EMR) systems must be designed with the specific needs of chemotherapy prescribing, preparation, and administration in mind.

Further, to expand access in rural and remote areas, digital systems should be leveraged to support TeleChemotherapy models of care, where patients receive chemotherapy locally under remote specialist oversight. This model improves equity and reduces travel burdens while maintaining safety.

2. Support for telehealth-enabled clinical trials

Telehealth should be better utilised in the delivery of clinical trials, particularly for oral therapies, which are common in rare cancers. However, current governance frameworks, especially around Investigational Product (IP) access and ethics approvals, limit the feasibility of remote trial participation.

The OCP should advocate for:

- National consistency in ethics and trial governance to enable decentralised models
- Broader definitions of trial delivery to include telehealth and remote monitoring
- Funding to support infrastructure for trial access in rural settings

3. Addressing inequities in access to unfunded treatments

For many rare cancer patients, Compassionate Access Programs (CAPs) are a lifeline when PBS-listed options do not exist. However, access to these programs is inconsistent, resource-intensive for hospitals, and varies by jurisdiction.

Some barriers include:

- Lack of statistical evidence to justify access due to the rarity of the condition
- Inability to charge patient co-payments in some states (e.g., Queensland)
- Hospitals often funding CAPs from internal budgets, which is unsustainable

The OCP should include recommendations for:

- National coordination and transparency around CAP access

- Policy changes to allow equitable and ethical co-payment models
- Support for rare cancers to be included in PBS/EFC trials and data collection pathways

4. Patient travel support for trial participation

Patients with rare cancers are often self-funding travel and accommodation to participate in clinical trials, further exacerbating inequity.

Subsidy schemes should be expanded or created to specifically support participation in clinical trials for rare cancers—recognising this as both a treatment option and a vital contribution to evidence generation.

In summary, the OCP should address digital health, trial access, unfunded treatment equity, and patient support as key enablers of high-quality, equitable care for rare and less common cancers.

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