



# Draft National Framework for Genomics in Cancer Control Consultation

December 2024

## 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 convenes an Oncology and Haematology Specialty Practice Group, comprising of a network of over 900 AdPha 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. Genomics in cancer control is a growing area, with the role of pharmacists increasingly vital in optimising cancer care.

AdPha also convenes a Research Specialty Practice Group, comprising of over 500 AdPha members with an interest in research. They work in a range of settings including hospitals and other healthcare settings, research organisations and universities. Research may be the major focus of their practice, a smaller part of broader practice, or something they want to add to their practice.

AdPha's *Pharmacy Forecast Australia 2023*<sup>1</sup>, a strategic thought leadership piece on emerging trends and phenomena forecasted to impact pharmacy practice and the health of Australian patients to 2028, under theme 4, focused on emerging aspects of personalised care such as pharmacogenomics and their role in achieving optimal

therapeutic outcomes and patient safety.

In recent years, advancements in health technology and research have seen more complex and high-cost medicines being brought to market to treat diseases requiring acute hospital or outpatient care, such as cancers, autoimmune diseases and genetic diseases. In light of the recent Health Technology Assessment review, future treatments considerations towards assessing the clinical benefits of pharmacogenomic testing, particularly its ability to improve treatment outcomes, reduce adverse drug reactions, and tailor therapies to individual patients based on their genetic profiles will be increasingly vital.

Suitable funding pathways to support the equitable delivery of innovative treatment with pharmacogenomics must be considered to ensure Australia remains at the forefront of this field, providing personalised healthcare and better treatment options for its population.

Pharmacists will continue to play a crucial role in genomics for cancer care, particularly in personalised medicine. As the field of genomics advances, cancer treatment is becoming more individualised, relying on genetic information to guide decisions regarding therapies, medicine selection, and dose adjustments.

Role and responsibilities of pharmacists working in this highly complex area includes interpretation of genomic data, informing personalised treatment plans and identifying adverse reactions. A key role is educating patients on the role of genomic testing and how best to manage their treatment plan based on their individual genomic data.

As the field of cancer genomics continues to evolve, the role of pharmacists will become even more vital members of the multidisciplinary team in optimising cancer care and improving patient outcomes. AdPha therefore welcomes the opportunity to provide feedback to the Draft National Framework for Genomics in Cancer Control.

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](mailto:jyik@adpha.au).

## Response to submission questions

### **Question 4: Do you have any comments or feedback on strategic objective 1: prevention and early detection?**

AdPha supports strategic objective 1 in principle. While equity for all Australians to access preventative measures and early detection is paramount, it is important to note that significant upskilling of healthcare staff will be required in order to accurately utilise genomics.

AdPha supports priority establishment of genomic testing evidence-base in Aboriginal and Torres Strait Islander people as well as other minority populations to reflect the diversity and multicultural landscape of Australia. Development of the testing and educational materials would require co-design with Aboriginal and Torres Strait Islander Peoples and Indigenous Health peak bodies and practitioners, such as AdPha's Aboriginal and Torres Strait Islander Health Leadership Committee and National Aboriginal Community Controlled Health Organisation.

Although recent reforms in legislation to prevent health insurance providers to discriminate on the basis of genetic test results<sup>2</sup>, patients may be hesitant on the uptake of genomic testing if they feel it may impact health or life insurance. Thorough educational campaigns will need to be provided to patients to ensure equity in uptake, as well as to inform them on how their data will be used to gain trust.

### **Question 5: Do you have any comments or feedback on strategic objective 2: diagnosis, treatment and clinical trials?**

#### **Treatment**

Access to chemotherapy services in rural and remote areas varies greatly from that in urban 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 urban 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, for hospital pharmacies in rural and remote areas, a limiting factor is having the requisite hospital pharmacy workforce for chemotherapy services. 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.

Both the Section 100 Efficient Funding of Chemotherapy (EFC) and Pharmaceutical Reform Agreements are essential for attempts by hospitals and hospital pharmacists to facilitate equitable, timely and affordable access to medicines subsidised on the PBS for

cancer patients, and hospital patients receiving medicines upon discharge or from outpatient clinics. Since Section 100 EFC and PRAs have been enabled throughout most jurisdictions, hospital pharmacists have never been provided appropriate or equitable remuneration compared to community pharmacists for supplying the same PBS medicines, providing a barrier for equity of access in rural and remote hospitals with smaller budgets than their metropolitan counterparts.

This is further compounded with the specialist skills required in interpreting and implementing results from genomic testing. Bioinformaticians and cancer services pharmacists are crucial members of the multidisciplinary teams which will be critical for the delivery of quality diagnostics and therapeutics.

In addition, consideration of timeframes involved in ordering tests, interpreting results, then implementing them through a treatment plan are a limiting factor that could potentially delay treatment.

### **Clinical Trials**

AdPha supports action 2.2 of the Framework to enable timely access to genomics-informed cancer treatments through Health Technology Assessment (HTA) processes and clinical trials.

AdPha is represented on the Stakeholder Advisory Group of the Inter-Governmental Policy Reform Group that has been tasked with driving Australia's clinical trials reform agenda among other reform items within health and medical research and is also committed to the Australian Teletrial Program to support comprehensive, consistent and equitable access to clinical trials. These groups are highly relevant to this national framework and we encourage collaboration with this group to inform the national framework.

Recruitment for clinical trials should be more easily facilitated and targeted towards populations less represented in current studies as prioritised in this Framework, in addition to ensuring enrolment criteria enable recruitment diverse populations. The cost-effectiveness of genomics would ultimately be improved through further research into effective chemotherapy agents in sub-population groups.

Inclusion and engagement with Community Controlled Health Services (CCHS) would enable expanded access to clinical trials for this population group. In addition, Telehealth and virtual services could be utilised to increase access to services in rural and remote areas, as mentioned in the Framework.

### **Question 6: Do you have any comments or feedback on strategic objective 3: supportive care?**

Whilst we support the proposed goals and actions outlined in Strategic Objective 3, we acknowledge that cancer care is highly complex for patients and/or their carers to navigate and note a need for each patient to have a cancer care co-ordinator as a

central point to refer to for all matters related to their cancer care. This will alleviate patients and/or their carers of the pressure to be across multiple aspects of their care and separately communicate with a large number of care providers whilst also managing the mental and emotional challenges that come with a cancer diagnosis.

In many hospitals and health services, pharmacists have taken on the role of de-facto care co-ordinators due to their important role in managing transitions of care, managing side effects and adverse impacts from cancer treatment in the home, and supporting patients to obtain medicines and other treatments when in the community.

As outlined under Action 3.1, psychosocial support, access to mental health clinicians must also be available for patients and their carers given the highly sensitive nature and implications of genomic testing.

For Aboriginal and Torres Strait Islander people and other priority populations it is vital to ensure local, culturally appropriate co-ordinators to ensure that people are able engage fully.

**Question 7: Do you have any comments or feedback on strategic objective 4: awareness and education?**

The historical misuse of genetic information has led to a certain level of mistrust among special populations, including Aboriginal and Torres Strait Islander communities. To build trust, it is essential to focus on community education and ensure the ethical use of data. Including real-life examples or success stories of genomic testing can help demonstrate its benefits in practical terms.

Low health literacy in some communities may hinder the effectiveness of genomics education campaigns, making it crucial to develop culturally relevant language and visually engaging materials.

Social media, short videos and infographics can be effective tools for explaining genomic concepts, while integrating basic genomic knowledge into school curricula or youth programs can foster foundational understanding and awareness of genomics.

**Question 8: Do you have any comments or feedback on foundational objective 1: research and data?**

It is crucial to learn from actual prevalence data, as it can help refine economic calculations when genomic variants are more or less common than in study or reference populations.

Involving patients and communities in decisions about data governance ensures that policies align with patients' values and concerns. The ethical challenges associated with working with genomic data, such as the risks of bias, discrimination, and misuse, cannot be overstated. This highlights the importance of establishing robust frameworks and seeking input from the community.

### **Question 9: Do you have any comments or feedback on foundational objective 2: workforce and models of care?**

At present, there is no dedicated funding at a federal or state level to develop a 'well-supported' Cancer Services pharmacist workforce. 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.

AdPha's *Standard of practice in oncology and haematology for pharmacy services*<sup>3</sup> recommends 1 pharmacist to 20 medical oncology inpatient beds, with a higher ratio of pharmacists 1:15 needed for haematology inpatients. AdPha supports for these ratios to be mandated and enforced in hospitals to ensure a well-supported workforce that can provide safe and quality pharmacy cancer care to patients.

AdPha's Cancer Services Resident and Registrar Training Programs (previously known as the Foundation Residency and Advanced Training Residency Program) are Australia's premier structured, formalised, supported and accredited national pharmacy training program for hospital pharmacists who want to specialise in cancer services. However, there are only eight hospitals across five states who have been able to fund these positions from existing resources.

By providing a structured and supported training environment, the Resident Training Program equips early career pharmacists with foundation clinical skills whilst the Registrar Training Program offers a pathway for speciality development for pharmacists with three to five years of foundation hospital experience, seeking to advance their practice towards the [Australian and New Zealand College of Pharmacy \(ANZCAP\) Registrar](#) status.

AdPha supports both pharmacists and pharmacy technicians to operate at their full scope of practice as outlined in AdPha's *Standard of practice in oncology and haematology for pharmacy services*<sup>3</sup> and in evolving scope activities, such as pharmacist-led clinics, and pharmacist prescribing, in order to achieve optimal patient and pharmacy outcomes.

Although the pharmacy workforce will play a crucial role in delivering genomic-based care, substantial training for oncologists and cancer care nurses will be essential to enhance the adoption and effective use of available information.

To improve the retention of genomics-trained professionals, strategies such as clear career pathways, mentorship programs, or incentives for working in rural and remote areas could be beneficial. Including cancer pharmacists and other specialists in care teams can enhance the delivery of genomics-informed care.

Establishing national competency standards in genomics for various roles, including oncologists, primary care providers, and nurses, is essential to ensure consistency in training and practice.



**Question 10: Do you have any comments or feedback on foundational objective 3: Funding, quality, and safety?**

Funding genomics is challenging in the current financial climate. It is important to consider potential cost savings and reductions, such as avoiding unnecessary treatments for low-risk patients or providing better treatment for high-risk patients to reduce progression or recurrence.

Adopting international protocols and best practices for quality and safety, while considering the unique conditions of Australia and its diverse population, is crucial.

A clear and transparent approach for the allocation of funds to genomic programs is recommended, with involvement from stakeholders across various fields. Additionally, policies should be developed to minimise the financial burden on patients, such as regulating the costs of genomic testing or supporting expensive therapies through public-private partnerships.

**Question 11: Do you have any comments or feedback on the draft Framework at a Glance graphic?**

No comment.

**Question 12: Are there any other comments you would like to make regarding the National Framework for Genomics in Cancer Control?**

No comment.

## References

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<sup>1</sup> AdPha (previously known as SHPA). Pharmacy Forecast Australia 2023. Available at: <https://adpha.au/publicassets/5297d615-345b-ee11-912d-00505696223b/Pharmacy-Forecast-Australia-2023.pdf>

<sup>2</sup> Monash University. (2024). News article: Australian Government bans genetic discrimination in life insurance: A big win for preventive health. Available at: <https://www.monash.edu/medicine/news/latest/2024-articles/australian-government-bans-genetic-discrimination-in-life-insurance-a-big-win-for-preventive-health#:~:text=Following%20the%20recommendations%20of%20a%20report%20led,genetic%20test%20results%20in%20life%20insurance%20underwriting>

<sup>3</sup> Advanced Pharmacy Australia. (2020). Standard of practice in oncology and haematology for pharmacy services. Journal of Pharmacy Practice and Research. 50, 528–545.