

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

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1. About the RACGP

The Royal Australian College of General Practitioners (RACGP) is the voice of general practitioners (GPs) in our growing cities and throughout rural and remote Australia. For more than 60 years, we have supported the backbone of Australia's health system by setting the standards for education and practice and advocating for better health and wellbeing for all Australians.

As a national peak body representing over 46,000 members working in or towards a career in general practice, our core commitment is to support GPs from across the entirety of general practice address the primary healthcare needs of the Australian population.

We cultivate a stronger profession by helping the GPs of today and tomorrow continue their professional development throughout their careers, from medical students and GPs in training to experienced GPs. We develop resources and guidelines to support GPs in providing their patients with world-class healthcare and help with the unique issues that affect their practices. We are a point of connection for GPs serving communities in every corner of the country.

Patient-centred care is at the heart of every Australian general practice, and at the heart of everything we do.

2. Summary of RACGP recommendations

Recommendation 1 – GPs are supported and funded to deliver evidence-based and coordinated care to patients with complex health issues and shared-care models are supported

Recommendation 2 – Increased funding for HealthPathways to include guidance on rare and less common cancers, with point-of-care information on assessment, diagnosis and local referral pathways.

Recommendation 3 – Increase funding for clinical research into the symptoms and diagnosis of rare and less common cancers.

Recommendation 4 – Funding to scope and research into the feasibility of an urgent cancer referral system in Australia that includes people with suspected rare and less common cancers.

Recommendation 5 – Work in consultation with specific population groups to develop strategies that most effectively address discrimination and access barriers for rare cancer diagnosis.

Recommendation 6 – Provide further incentives for pharmaceutical companies to bring treatments for rare cancers to market more quickly.

Recommendation 7 – Bolster support for the Optimal Care Pathways to include rare and uncommon cancers.

Recommendation 8 – Work in consultation with specific population groups to develop appropriate support services that meet the needs of specific populations diagnosed with rare cancer.

Recommendation 9 – Develop a national cancer data ecosystem.

3. Introduction

The RACGP thanks the Senate Standing Committees on Community Affairs for the opportunity to provide a submission for the *Inquiry into Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer*. Our submission strongly advocates for the important role of the GP in the diagnosis, screening, treatment and care coordination of people with a rare cancer.

Rare conditions, combined, are relatively common in Australia, with an estimated 8% of the population having a rare condition. Rare cancer types collectively comprise around a fifth of all cancer diagnoses in Australia, with a quarter of cancer-related deaths between 2007 and 2016 attributed to a rare cancer¹. As GPs see 90% of the Australian population in a year^{2,3}, they will often care for and manage patients who have rare conditions, including rare cancers.

As expert generalists in the Australian health system, GPs provide a vital role in the diagnosis, holistic management and care coordination of patients diagnosed with a rare cancer. As indicated in the [National Strategic Action Plan for Rare Diseases](#), GPs are one of the key initial points of contact for people with rare diseases, and the active involvement and inclusion of the patient's GP in the care of people with cancer ultimately improves the quality of care that patients receive.

3.1 GP scope of practice

GPs are highly trained generalist specialists who work with patients at every stage of their healthcare. The holistic, patient-centred, and relationship-based approach of general practice ensures the effective delivery of care and treatment. GPs are often the anchor within a multi-disciplinary team of health professionals delivering high-quality healthcare for patients. As expert generalists, GPs work across a broad scope of practice and seek relevant education to gain the knowledge and skills they need to serve the needs of their patient populations⁴.

The role of the GP in cancer care encompasses:

- Screening, testing and diagnosis – GPs are usually the first port of call for patients for any health conditions, new symptoms, or when patients are due for a routine screening test. Diagnosing rare conditions is often complex and requires significant time investment.
- Active treatment and management of cancer and other chronic conditions – GPs are a key member of shared care teams. They provide a coordinated approach to whole-person care, including ensuring that other preventive and chronic health issues are managed alongside the patient's cancer treatment. This also includes providing care, support and information for the patient's family.
- Survivorship - GPs continue to provide support for cancer survivors through the coordination of cancer survivorship care, chronic disease management, and secondary prevention.
- End-of-life care - GPs support their patients through end-of-life care. Patients in rural areas of Australia are particularly reliant on their GP for end-of-life care.

3.2 GPs ensure routine preventive activities and chronic disease management is not overlooked.

It is essential that other common health conditions and preventive screens are not overlooked when the treatment and management of cancer is the main focus. GPs are best placed to undertake this work, and it is important that patients with cancer are encouraged to continue to see their GP during their treatment, so that they don't miss out on other important health activities, such as:

- management of chronic disease and/or comorbidities (such as diabetes, asthma)
- routine screening and preventive activities
- management and support for the patient's mental health (particularly if the patient has been diagnosed with a rare cancer where local support groups may not be available).

3.3 GP funding for cancer care

General practice is the cornerstone of the Australian health system because it is accessible and affordable for patients, but the complex and important GP role is often not well-supported. While the Medicare Benefits Schedule (MBS) fee-for-service structures work well for an individual patient's face-to-face care, current MBS funding levels reward short, episodic care, rather than long-term management of complex and chronic diseases.

The MBS also does not effectively support collaborative team-based approaches to care. Current MBS arrangements fail to adequately support direct communication between members of the healthcare team leading to an over reliance on periodic letters or waiting for MBS-funded consultation visits⁴.

Patient care coordination is also not funded under this system. For example, when GPs receive test results from pathology providers, time is required to review reports, to compare and update screening records. For rare cancers, this coordination work requires further research, analysis and liaison with other health professionals involved in the patient's care.

The RACGP advocates for investment in the MBS and the introduction of blended payment models to better support longer complex consultations and collaborative shared care models⁵.

3.4 Shared care models

A Shared Care Model is where there is joint responsibility for planned care that is agreed between healthcare providers, the patient and any carers. Benefits of the Shared Care Model include improved quality and continuity between services, reductions in hospital admissions, cost savings to the health system, improved patient health outcomes, higher levels of follow-up care and patient adherence to treatment⁴.

Patients do not do well in fragmented systems, characterised by a siloed sub-specialised workforce. Investment in shared care models, which enable GPs and other health professionals in the team to work collaboratively at the top of their existing scopes of practice, have proven to be effective. GPs, with their existing training in differential diagnoses and care coordination, work well in supported shared care models. Furthermore, local and international evidence shows that better support for, and use of, general practice is associated with lower emergency department presentations and hospital use⁶⁻¹⁰, decreased hospital re-admission rates¹¹, health benefits for Aboriginal and Torres Strait Islander communities^{12,13} and significant savings for the healthcare system¹⁴⁻¹⁶.

Existing barriers in shared care need to be addressed so people with rare cancers can benefit from GPs working in coordination with non-GP specialist teams to manage their condition⁴. The importance of shared care pathways cannot be more highly emphasised, good communication and information exchange will ensure improved care coordination and continuity between services. Health professionals alone cannot bring about sustainable change without health system improvements to support them. Appropriate funding and adequate support for shared multidisciplinary care will deliver better quality and cost-effective care to patients⁴.

Recommendation 1 – GPs are supported and funded to deliver evidence-based and coordinated care to patients with complex health issues and shared-care models are supported.

4. Response to the Inquiry terms of reference

4.1 Barriers to screening and diagnosis of rare and less common cancers

4.1.1 The lack of point-of-care, accessible clinical information for GPs with local pathways for rare and less common cancers.

GPs are the first point-of-contact for initial investigations and referrals for most people with rare and less common cancers. There is currently a lack of supportive and easily accessible clinical information and local pathways for rare and less common cancers available for GPs at the point-of-care. The process to diagnose a rare and less common cancer can be time-consuming and complex, therefore, it is essential that the existing systems in primary care are boosted to support GPs in this process.

Enabling GPs to have easy access to accurate, locally relevant information will assist them in making an early diagnosis, providing optimal management and support, and advocating for patient and their families living with a rare and less common cancer¹⁷. HealthPathways is a system developed through [Primary Health Networks](#) (PHNs) to be used during consultations, with links to clinical guidance for assessing and managing a patient with a particular symptom or condition. HealthPathways also provides locally relevant information on referrals to existing services and specialists.

Given the impracticability of providing comprehensive education and keeping up to date on changing guidance of all the rare and less common cancers, a cost-effective option is to expand these existing systems to include current clinical guidance on rare and less common cancers, with local referral information to GPs and primary care teams when required.

Recommendation 2 – HealthPathways to include guidance on rare and less common cancers, with point-of-care information on assessment, diagnosis and local referral pathways.

4.1.2 Education and research funding for rare and less common cancers.

Patients who present to general practice early in their illness usually have ambiguous symptoms that will typically have more common benign explanations, with the connections between the symptoms not yet clear¹⁸. Rare and less common cancers do not have clear symptom signatures and individual symptoms have low positive predictive values. Consequently, many patients will visit their GP multiple times as their symptoms evolve, before the diagnosis is made. Additionally, there is currently a lack of sufficiently sensitive and specific screening tests suitable for use in the general population. As such, it will be difficult to identify individuals who are at high risk of many rare cancers to institute regular surveillance and asymptomatic detection.

Further research into rare and less common cancers will assist in providing further information that will help with the identifying risk factors, enabling faster diagnosis of these conditions, and possibly over time, leading to the development of targeted and accurate screening and testing.

The United Kingdom has a two-week urgent referral system for suspected cancer, along with overall diagnostics, management plan and treatment (if required) within 16 weeks. Further scoping and research should be undertaken to ascertain as to whether this would be successful in an Australian context, and if so, ensuring that adequate resources and investment are provided.

Recommendation 3 – Increase funding for clinical research into the symptoms and diagnosis of rare and less common cancers.

Recommendation 4 – Provide funding to scope and research into the feasibility of an urgent cancer referral system in Australia that includes people with suspected rare and less common cancers.

4.1.3 Specific populations face discrimination and lack of local access to screening and diagnosis services.

As highlighted in the Terms of Reference, specific Australian populations face discrimination and accessibility issues for screening and diagnosis services. This provides additional barriers to the screening and diagnosis of rare cancers. These groups include:

- Aboriginal and Torres Strait Islander people
- LGBTIQ+ people
- People living in rural and regional areas
- People with disability
- People of a lower-socioeconomic background
- People from culturally and linguistically diverse backgrounds

For example, for LGBTIQ+ people, access to screening is reduced due to the gendered nature of services. Additionally, in trans and gender-diverse people, there are 'common' cancers that are rarely seen or suspected, for example, ovarian cancer in trans men, prostate cancer in trans women¹⁹.

Similarly, systemic and institutional racism can create conditions in which Aboriginal and Torres Strait Islander patients do not receive appropriate, timely and respectful care. Previous discrimination may also impact willingness to seek out healthcare²⁰.

Recommendation 5 – Work in consultation with specific population groups to develop strategies that most effectively address discrimination and access barriers for rare cancer diagnosis.

4.2 Barriers to accessing appropriate treatment.

4.2.1 The availability and expense of medication for rare cancers.

The five-year survival for rare cancer cases between 2007 and 2016 was 53.2%, which is much lower than for common cancers (79.3%)¹, and is partly the result of lack of treatment options.

Pharmaceutical companies are often reluctant to invest in the development and trialling medication that will likely only benefit a small market¹⁷. As a result, drugs development does not occur, and when they are developed, are often expensive and can be cost-prohibitive for the patient¹⁷, particularly for patients of lower socioeconomic status.

While Australia has adopted an [orphan drug designation](#) to provide incentives for pharmaceutical companies to bring these drugs to market more quickly, few such drugs have been registered in Australia¹⁷.

4.2.2 Care pathways

The Optimal Care Pathways provide clear referral pathways for common cancers, to ensure that all Australians receive consistent and high-quality care. These Pathways should also include rare and uncommon cancers. The Pathways are particularly effective for people in lower socioeconomic groups and/or those at higher risk. The ability to provide electronic referrals into cancer care services should underpin quick and efficient referral processes.

Recommendation 6 – Provide further incentives for pharmaceutical companies to bring treatments for rare cancers to market more quickly.

Recommendation 7 – Bolster support for the Optimal Care Pathways to include rare and uncommon cancers.

4.3 Adequacy of support services after diagnosis.

4.3.1 The provision of cancer care coordination is unfunded in general practice.

Cancer care and care coordination requires complex discussions and a shared decision-making approach with patients of varying levels of health literacy. This is particularly the case if patients have a rare cancer where there may be a lack of support available. The work undertaken by GPs in these consultations includes:

- discussing the potential benefits and harms of treatments,
- managing other complex chronic conditions for people with a rare cancer diagnosis,
- managing the mental health of the patient, family and carers,
- discussing Advance Care Directives with the patient, family and carers.

This complex work involves a multidisciplinary team including the GP, nurses, Aboriginal Health Practitioners and pharmacists, alongside hospital treating teams and other specialists. This complex coordination of care is currently unfunded for GPs.

4.3.2 Specific populations in Australia face additional barriers to treatment for rare cancers.

Similarly, as per the section on barriers to screening and diagnosis of rare cancers, specific populations in Australia also face additional barriers for treatment. This includes:

- Geographic barriers¹ – particularly for patients in rural and remote areas where access to treatment for any type of cancer requires prolonged stays away from home, family, friends and other support systems¹.
- Financial barriers – such as the cost of treatment and needing to take time off work (particularly for people with insecure work with little to no sick leave)
- Discrimination due to race²⁰
- Discrimination due to sexuality and/or gender identity¹⁹ – LGBTIQ+ people report that their partners are not included as part of their treatment, leaving them without access to their most important support.
- Discrimination due to disability²¹ – may result in unequal outcomes.

Recommendation 8 – Work in consultation with specific population groups to develop appropriate support services that meet the needs of specific populations diagnosed with rare cancer.

4.4 The adequacy of Commonwealth funding for research into rare, less common and neuroendocrine cancer.

In our submission to the Australian Cancer Plan 2023-2033²², RACGP supported the proposal for a national cancer data ecosystem. Most patients are currently unlikely to have knowledge of specific clinical trials, so this may help identify and increase participation in relevant trials. Participation in such trials ensures a similar standard of care is accessible for all

people with cancer. It is important that research needs to include and be accessible to Aboriginal and Torres Strait Islanders, LGBTIQ+ people, rural and remote people, low socioeconomic people and people with disability.

Recommendation 9 – Develop a national cancer data ecosystem.

4.5 Other related matters.

RACGP's Guideline for preventive activities in general practice (the Red book)

The RACGP is currently updating the [Guidelines for preventive activities in general practice 9th edition](#) (the Red book). This guideline includes evidence-based recommendations on cancer prevention and cancer screening activities for Australians across all ages of the lifecycle.

These guidelines do not receive any public funding but are critical source of advice to GPs and other health professionals. Public funding would enable the RACGP to invest greater resources in the development and implementation of the guidelines recommendations.

Coordinated public health campaigns can also be valuable in raising public awareness of the importance of preventive activities. This could be done alongside policy development and economic modelling for

- providing incentives for agriculture and retail to promote fruit and vegetables;
- promoting the reduction of alcohol consumption;
- A taxation on sugar

5. Conclusion

The RACGP looks forward to crucial and much needed systemic changes to improve the health and wellbeing of people diagnosed with rare cancers and less common cancers. The RACGP once again thanks the Australian Government for the opportunity to provide this submission.

For any enquiries regarding this submission, please contact _____, National Manager, Practice Management, Standards & Quality Care on _____ or _____.

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