



Cancer Care, No Gaps

Protecting Australian cancer patients, and their families, from financial toxicity



Pre Budget Submission

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Foreword

As cancer doctors, we know the hardest words we can say to our patients are: *'you have cancer'*.

As a patient and a family, 'cancer' is the most terrifying of words to hear. If the patient is a child, it is deeply traumatizing for their parents. If the patient is a parent, their first thought goes to their children and how it will affect them, who will look after them?

We know that the cancer care journey starts with those hard-to-hear words but there are also many wonderful innovative treatments now available and a community of connected and experienced specialists and nurses that work together to lessen the blow of this awful disease.

With new advances in immunotherapy, targeted therapies and personalized medicine, many once fatal cancers are now being controlled. Cure rates are increasing and patients are living longer with their disease.

This is to be celebrated but what a cancer patient shouldn't be thinking is *"I can't afford this."*

The Private Cancer Physicians of Australia (PCPA) and Rare Cancers Australia (RCA) welcomes the recognition that Australians, with a diagnosis of cancer, face increasing out of pocket costs. We all applaud the Government for its specialist fee 'transparency' website. But that should be considered the first step of a thorough 'Cancer Care, No Gaps' policy.

As cancer physicians providing high quality, personalised, patient-centred care, we are acutely aware of this issue and we work very hard to control the out of pocket expenses that are within our control. As a lead patient advocacy group, RCA very often steps in to financially assist patients struggling with mounting medical bills.

The problem of financial toxicity experience by cancer patients and their families can, and must, be addressed.

These carefully thought out initiatives have been put together by some of the nation's most experienced and respected oncologists, supported by Australia's lead patient advocacy groups. We are all on the frontline of cancer care every day, and always have the patient's best interests at heart.

We commit this pre-budget submission to the Government for consideration and we look forward to continuing to work with it to ensure the best outcomes for all Australian cancer patients and their families.



Dr Christopher Steer

**Medical Oncologist
PCPA President**



Mr Richard Vines

**Chairman and Founder
Rare Cancers Australia**



Executive Summary

Australia has a world class but complex health system. This rings especially true for the nation's sickest patients facing the fight of their lives, as they are often overwhelmed by the financial toxicity that arrives alongside a devastating cancer diagnosis.

Our collective core mission is the delivery of the best treatment and advocacy for patients with cancer, regardless of where they might live, or what their socioeconomic circumstances. We strive, each day, to rid the scourge of cancer from our patients and provide comfort and support to them and their families.

As a result, PCPA and RCA are acutely aware, and deeply concerned at the overwhelming and often, unexpected financial costs that come with the diagnosis of cancer.

We are all very focused on insulating a patient against "bill shock" and often crippling out-of-pocket expenses gathered along the way. Undergoing treatment for cancer is fraught enough, and financial stress serves only to diverting focus and energy away from treatment.

As cancer physicians providing high quality, personalised, patient-centred care, we work very hard to control the out of pocket expenses that are within our control. As patient advocacy leaders, we see first-hand the often-extreme choices some patient feel they must make. Sell the house or have treatment? Retain childcare services or have treatment? Keep working or take the much-needed time off to recover?

Treatment should never come with a question mark over whether the patient can afford it or not.

The PCPA and Rare Cancers Australia welcomes the recognition by the Morrison Government and Health Minister, the Hon Greg Hunt MP, that Australians, with a diagnosis of cancer, face increasing out of pocket costs. PCPA and Rare Cancers applauds Minister Hunt's commitment to exploring ways to eliminate the worst of out-of-pocket expenses, including the fee transparency website.

The PCPA has delivered to the Government a comprehensive 'Cancer Care, No Gaps' policy paper. In this submission, we focus on the low cost and high impact measures that, if adopted, can and will have an immediate positive effect in the lives of Australian cancer patients and their families.

They are:

- MBS and PBS patient safety nets that allow the benefits of both schemes to flow immediately upon diagnosis of cancer;
- providing support for cancer patient facilitators to help patients to navigate the often-complex system;
- the creation of a technology-driven 'financial concierge' system to ensure all bills (regardless of what, and where, that provider is) can be seen and centred in one place to reduce the 'bill shock'; and
- the development of a National Cancer Plan for a unified, expert-led approach to cancer care.



The size of the problem

An estimated 145,000 new cases of cancer were diagnosed in Australia this year, with that number set to rise to 150,000 by 2020¹

One in two Australian men and women will be diagnosed with cancer by the age of 85. These sobering statistics are equalled only by the pain inflicted by rising out-of-pocket expenses inflicted by cancer.

In some cases, it is estimated patients will be paying up to \$22,000 from their own pocket during their cancer treatment.

The median out-of-pocket costs in 2018 [across five cancers studied] were largest for therapeutic procedures (\$670), professional attendances (\$414) and medications (\$288).²

Medical costs for patients with some types of cancer are also high. The consequences can be devastating for patients experiencing financial hardship, including serious impacts such as delays of or non-adherence to therapy and increased morbidity.³

These figures paint a grim picture for the nation's sickest and most vulnerable patients.

The good news is that there are simple and cost-effective practical policy solutions that can make a real and lasting difference.

The solution

Cancer Care Patient Safety Net reforms

The PCPA proposes that cancer patients are granted access to the MBS and PBS patient safety net programs immediately they have a diagnosis of cancer.

Under this proposal, the Medicare item reimbursement would remain the same for all clinicians. Members of the cancer care team would be included in the safety net, which would cover an episode of care that extends across more than a single calendar year.

The cost of cancer care should not be influenced by the month of diagnosis and our proposed measure of a 'Cancer Care' patient safety net, would eliminate the discrimination patients face if diagnosed later in the year. (The current patient safety net resets every January).

¹ Australian Institute of Health and Welfare 2019. Cancer in Australia: In brief 2019. Cancer series no. 122. Cat no. CAN 126. Canberra: AIHW.

² <https://www.hospitalhealth.com.au/content/facility-admin/news/cancer-patients-out-of-pocket-up-to-22-000-1260388335#axzz68VlgZblW>

³ <https://www.hospitalhealth.com.au/content/facility-admin/news/cancer-patients-out-of-pocket-up-to-22-000-1260388335#axzz68VlgZblW>



The cost to Government of this simple but critically important measure is relatively small, compared to the size of the problem that is the financial toxicity and bill shock to our most vulnerable Australians.

If the benefits of the MBS safety net (currently set at a \$2133 threshold⁴) were applied immediately upon diagnosis, the cost to Government would be approximately \$30.9m in 2020 and for each year on (aligned with the number of Australians diagnosed with cancer)

If the benefits of the PBS safety net (currently \$1550.70 for general patients, excluding concessions⁵), were applied immediately upon diagnosis, the cost to Government would be approximately \$22.47m this year and increasingly incrementally with the number of patients diagnosed each year.

The total cost for this practical policy solution, which could be immediately implemented, would be approximately \$53.37m p/a.

We acknowledge there have been past disappointments with a small cohort of obstetric specialists manipulating the system to increase their fees.

We believe we can learn the lessons and avoid any potential 'gaming' by doctors.

If the patient safety net is to be triggered the moment cancer diagnosis is made and the benefits followed the patient (not the providers), there should be no change in fees or any increase in financial benefit to the providers.

The PCPA and RCA stand ready to help model a scheme that brings all of the key stakeholders including patient advocacy groups, leading medical, radiation and surgical oncologists, Specialist Colleges, GPs, private and public hospitals, researchers, private health insurance funds, state governments and insurance companies to the table. There already exists the National Oncology Alliance (NOA) with more than 100 members in four pillars: patients, patient groups, clinicians and the pharmaceutical industry. These committed professionals and patients stand ready to support this scheme.

We have already recommended a working group be established involving all key stakeholders and the Department of Health. It is included in the PCPA's 'Cancer Care, No Gaps' policy position paper. We have attached this paper (Appendix A).

The first priority will be securing an agreement that the benefits of a modified patient safety net must be reaped by the patient and not by the service provider or specialist.

There would also have to be an agreed annual review or audit mechanism to ensure service provider fees are not unduly increased over time.

Indeed, the PCPA has held very positive preliminary discussions with the Department of Health and Chief Medical Officer, Professor Brendan Murphy and his colleagues, to discuss the issue of a 'Cancer Care' patient safety net.

⁴ http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-MSNThresholds_1Jan2019

⁵ <https://www.humanservices.gov.au/individuals/services/medicare/pharmaceutical-benefits-scheme/when-you-spend-lot-pbs-medicines/pbs-safety-net-thresholds>



We have also discussed the formation of a taskforce to address out-of-pocket expenses and understand such a taskforce needs Ministerial direction.

We believe the concept of an immediate safety net for cancer patients was received very favourably received, especially if we could work to eliminate any potential 'gaming' of the system.

Benefit to patients

The benefits to the patient, and their families, of having the Patient Safety Net (for both MBS and PBS) accessible immediately once cancer is diagnosed cannot be underestimated.

It would mark the first important step of taking control over the many financial burdens that are incurred along any cancer journey. We know, as cancer doctors and as patient advocates, the negative impact that concerns over the cost of healthcare can have on the decisions our patients make. Stress is not conducive to early recovery. We need those who are on the cancer journey to focus on their health not their bank balance. We know that this one simple measure will provide enormous positive relief to both patients and their families.

It will also have a significant flow on effect to organisations, such as Rare Cancers Australia, who step in to financially 'plug the gaps' for thousands of Australians each year who simply can't afford their treatment and ongoing monitoring.

Knowing these important grassroot organisations can focus on supporting the cancer patient and their families with other practical and logistical support measures, rather than with money, will remove an immense cost pressure from these overwhelmed not-for-profit services.

Patient navigators

As cancer physicians we work closely with our medical and allied health colleagues to ensure our patients receive world class treatments at the right time, as close to their homes as possible.

We also appreciate that our most vulnerable patients often need practical, as well as medical advice, throughout their journey and we see the benefits of targeted care coordination.

This is why we recommend the policy measures in this submission to soften the worst of the blows delivered by cancer, by delivering support for patient-focused facilitators.

Crucially, support for facilitators of patient-centred cancer care for those patients being treated outside public hospitals is needed.

The cost to provide patient navigators across the spectrum of cancer care has not been intimately modelled, the PCPA and RCA believes similar funding to the \$8.6 million provided to support and facilitate patient navigators in palliative care is an appropriate guide.

Already, RCA undertakes this role in small way through its patient care team. The challenge with rare and less common cancers (RLC) is that navigators need to more flexible and knowledgeable of hurdles than those dealing with cancers that have accessible established standards of care. To meet these challenges, funding for specific training and education of patient navigators is required.



Benefit to patients

The provision of cancer care coordinators, patient navigators, palliative care providers and nurses for all patients with cancer will help patients to navigate the often-complex system. The great work done by the McGrath Foundation for patients with breast cancer and the Prostate Cancer Foundation for men with this diagnosis should be applied to all patients regardless of the site of origin of their cancer. Indeed, RLC cancers are a bigger and more complex problem than both prostate and breast cancers.

Given that the majority of cancer occurs in older adults, the provision of cancer care coordinators for older Australians with cancer is a huge unmet need that will help the most vulnerable of patients – and their families – navigate the system.

It will also provide new career opportunities for nurses and create other employment opportunities within the healthcare system.

Benefit to Government and taxpayers`

Having very unwell patients in the wrong parts of the health system or being seen multiple times by GPs just to ask questions about what the next steps are in their cancer care journey – are both unnecessarily costly to the Government and ineffective for the patient and those who are there to care for them medically.

Ensuring that our most vulnerable patients and their families are being escorted efficiently, and with compassion, through the complexities of our public and private health care systems, marks a significant return on investment.

The Government has recognised this and provided funding for a ‘navigator’ for Australians requiring palliative care, breast cancer or prostate treatment.

The Government knows this application of funding is both a sound investment and the cost benefit returns to the nation are demonstrable.

Removing ‘bill shock’

We know how bills can mount quickly for all patients but ‘bill shock’ can be particularly distressing for those with cancer.

Significant out of pocket costs can hit without warning or with our patients having little, if any say in what, and how, their money is spent or prioritised. Often, patients, and their families, are blindsided by significant out of pocket costs and have had little time to prepare for, or accommodate, those expenses.

We believe this ‘bill shock’ can be negated with a form of ‘clinician-controlled bundling’ of fees and the creation of technology-driven ‘financial concierge’ system to ensure all bills (regardless of what, and where, that provider is) can be seen and centred in one account.

The PCPA and RCA applauds Prime Minister Scott Morrison’s recent statement that innovation and technology should be utilised in far greater capacity and circumstance, to provide solutions to existing health problems.



We believe that using Artificial Intelligence technology to assist in reducing financial toxicity on Australian cancer patients is indeed in line with the Government's innovative health agenda.

We would look to partner with Sydney Health Partners Education Research and Enterprise (SPHERE) and/or Monash Partners who are already developing data-driven health care improvements and clinical trial platforms to help develop this Australian-first initiative.

Benefit to patients

The benefits are immense and demonstrable. Tourists in resorts can expect their expenses to be consolidated in one transparent account and yet those with mounting, and often unexpected, costs whilst also dealing with a potentially fatal health diagnosis have no visibility of the costs they will incur on their cancer journey.

As medical oncologists, we can control our cost impact but our patients should be able to know and pre-empt *all* costs incurred by other specialists and GPs. We believe this certainty will allow our patients to focus on the one thing that is most important to them and their families – to get better.

Benefit to taxpayers and government

Allowing cancer patients to know beforehand, or as they are undertaking treatment, will also ensure efficiency in an often-inefficient system.

With privacy rules firmly in place, data harnessed from the AI-driven 'concierging' of the out of pocket expenses, will allow governments (Federal and State) to plan and fund appropriate services and to ensure that excessive charging and unnecessary over-servicing by health providers can be reigned-in. It will ensure a fully accountable health system.

The data can also be leveraged to further streamline Australia public and private health services and ensure the patient and the taxpayer receive the best value for their tax dollar as well as an informed blueprint for future health care innovations and policy development.

We believe that partnering with Monash Partners and SPHERE, will allow this initiative to be developed quickly and effectively, upscaled and potentially exported as an Australian-owned healthcare initiative.

National Cancer Plan

RCA together with the PCPA, are asking the Federal Government to recognise the need for a unified approach to cancer care by supporting the development of a National Cancer Plan.

In recent years, the global investment for research and development in cancer, has far surpassed the investment in any other therapeutic area. The nature of cancer care, therapeutics and technology are changing remarkably and at a rapid pace for the better as a result.

Globally, we are embarking on a golden era of personalized therapy for cancer, that promises targeted and more reliable approaches to prevention, diagnosis, treatment and maybe even cure. The Australian Government is to be congratulated for its investment in new cancer treatments, facilities and medical research, via the Medical Research Future Fund. All of these initiatives are deeply appreciated but a clear blue print for the future of cancer care is now required.



The profound changes in the nature of new technology and the models of care required will challenge multiple aspects of the Australian health care system in its current form. The system will not only be challenged at the fiscal and evidentiary levels but it may also struggle with developing infrastructure and the ability to deliver a raft of personalized treatments while maintaining quality standards and consistency.

The National Oncology Alliance - an initiative led by PCPA and RCA - has engaged the best minds across the cancer care continuum to develop a vision of what cancer care could look like in Australia by 2030. This will be delivered in Parliament House on the 25th of June this year.

The opportunities, gaps and challenges posed by a changing cancer landscape identified within the Vision 2030 report will provide an obvious pathway for the development of a National Cancer Plan.

Australia needs a National Cancer Plan that is progressive and provides unified actions to address the complicated challenges of tackling cancer as technology and science progress.

Benefits to government, taxpayers and patients

There is an opportunity for the Federal Government to invest now to secure the best possible survivorship for Australian cancer patients into the future. By unifying an approach, expensive and redundant duplication in bureaucratic systems and treatments within the health system will be streamlined, targeted and more effective.

Australia can get ahead of the challenges associated with rapid advances in technology, Artificial Intelligence, genomic screening and big data development by developing unified and thoughtful approaches to cancer – all of which will add to the collective improvement in health outcomes for patients.



Recommendations

1. That the Australian Government supports cancer patients by creating a special MBS and PBS “cancer patient” safety net category

Estimated cost: \$45.6million p/a

2. That the Government supports the cancer patient journey with patient-focused navigators

Estimated cost: \$10 million p/a

3. That the Australian Government support the creation of a technology-driven ‘financial concierge’ system to ensure all cancer treatment bills are centred in one place to reduce the ‘bill shock’.

Estimated cost: \$5m initially to scope and develop a prototype software platform that can then be scaled up and exported internationally

4. That the Federal Government supports the development of a National Cancer Plan which seeks to deliver the best survivorship opportunities to Australian patients equally across all cancers, demographics and geographies

Estimated cost: \$4m initial investment



Who we are

The Private Cancer Physicians of Australia (PCPA)

The Private Cancer Physicians of Australia (PCPA) Limited is a not-for-profit organisation dedicated to the improvement of the health system for all cancer patients, but particularly for private cancer patients in Australia.

Although the majority of cancer patients are treated in the private system, there are many anomalies in funding and regulation that disadvantage private patients. Private cancer physicians also face issues in accessing drugs for their patients and sometimes beds. Barriers also exist to the participation of private physicians in research and training. The PCPA has been established to address these issues.

Established in 2007 the PCPA is a membership organisation for medical oncologists and clinical haematologists in private practice in Australia. The PCPA has a pivotal role in the Australian community for the implementation, delivery and planning of improved cancer services in the Private Health Sector. The PCPA welcomes the interest of politicians, policy makers, funding bodies, health providers, other professionals, professional organisations and, of course, patients themselves.

Our Mission

To promote and work towards a health system that provides high quality, fair, integrated cancer treatment that benefits patients and supports medical practitioners.

Our Vision

All cancer patients in Australia will receive a high quality, timely and personal care from a physician of their choice.

Our Values

- Quality care for patients
- Personal, patient centred care
- Well educated professionals
- Evidence based medicine
- Collegiality and peer support

Rare Cancers of Australia

Rare Cancers Australia Ltd (RCA) is a charity whose purpose is to improve the lives and health outcomes of Australians living with rare and less common (RLC) cancers. In Australia in 2017, an estimated 52,000 people were diagnosed with RLC cancers, and 25,000 died from them, according to Cancer in Australia 2017 estimates.

As distinct from common cancers (breast, prostate, bowel, lung and melanoma) there is very little patient support offered to RLC cancer patients. RCA works tirelessly to ensure that this cancer group will never be forgotten or ignored again.



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