



Cancer Care, No Gaps

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



**Pre Budget Submission
2021-2022**



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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 one of 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?

These words are even harder to digest when compounded with the worry and stress triggered by this terrible pandemic. During 2020, thousands of sick Australians were so fearful of contracting COVID-19 or so worried of the cost, at a time of deep economic uncertainty, that they ignored their cancer symptoms and delayed seeing a doctor.

7000 Australians may have gone undiagnosed or had a late diagnosis during 2020¹. We know as Australia wins the fight against this terrible pandemic and the fear factor eases; there will be a surge of patients into our clinics and, for that, we are grateful as cancer does not wait.

And whilst a delayed diagnosis can make the start of the cancer journey even more stressful than usual, we know there are 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) are collaborating on this vitally important challenge because we know that more now than ever, Australian cancer patients, and their families are doing it very tough indeed.

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. Sadly, COVID-19 has ruthlessly stripped that cupboard bare for all patient support groups.

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

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.

¹ <https://www.canceraustralia.gov.au/about-us/news/cancer-wont-wait-during-covid-19-pandemic>



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.



A handwritten signature in black ink, appearing to read "C Steer".

Dr Christopher Steer

**Medical Oncologist
PCPA President**

A handwritten signature in black ink, appearing to read "Richard Vines".



Mr Richard Vines

**Chairman and Founder
Rare Cancers Australia**



Executive Summary

Australia has a world class health system. The Australian Government must be applauded for the cautious and evidence-based approach it has taken to mitigating the worst of the health and economic impacts of this global pandemic.

But our health system is very complex – sometimes overwhelmingly so.

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?

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

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.

NO more is this important than now when we know more than 7000 cancer patients in 2020 have deferred confirming (or otherwise) their cancer symptoms and when many sick Australians, and their families, are struggling with more financial hardship than ever.

We know our recommendations will go a long way to help cancer patients and their families right now and for the longer future. These include:

- Introducing an MBS and PBS ‘Cancer Patient Safety Net’ that allows the benefit of both schemes to flow immediately to the patient, upon the clear diagnosis of cancer;
- 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
- a taskforce to ensure all key stakeholders can collaborate on a delivery model that prevents any ‘gaming’ of the new system by health providers.



The size of the problem

An estimated 145,000 new cases of cancer were diagnosed in Australia in 2019, with that number predicted to rise to 150,000 in 2020²

However, according to a recent [report](#) by Cancer Australia, there were 150,000 fewer cancer-related medical services and procedures for breast, colorectal, lung and prostate cancers undertaken in Australia, in January to September 2020, during the COVID-19 pandemic.

This is deeply troubling and we hope those patients listen to their symptoms and seek the treatment they need now, if they haven't already. Delayed diagnosis too often leads to poor outcomes for cancer sufferers and we applaud the Government for launching its [Cancer Won't Wait](#) video campaign to encourage cancer sufferers to see their doctor.

With or without a pandemic, 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. Delayed diagnosis may mean even more financial hardship as many patients would have already been doing it tough, as our economy crashed under the weight of the global health crisis.

Their worry about out-of-pocket costs may have added to their decision to delay treatment or, indeed, to continue with it.

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).³

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.⁴

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.

² Australian Institute of Health and Welfare 2019. Cancer in Australia: In brief 2019. Cancer series no. 122. Cat no. CAN 126. Canberra: AIHW.

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

⁴ <https://www.hospitalhealth.com.au/content/facility-admin/news/cancer-patients-out-of-pocket-up-to-22-000-1260388335#axzz68VlgZblW>



The solution

Cancer Care Patient Safety Net reforms

The PCPA and RCA 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).

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 (the extended MBS is currently set at a \$2133 threshold⁵) were applied immediately upon diagnosis, the cost to Government would be approximately \$30.9m in 2021 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 concessions⁶), 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. This issue is being addressed and a resolution may require further independent economic modelling. We support the Government on its determination that all specialists are demonstrably fiscally responsible.

The PCPA and RCA stand ready to help model a scheme that brings all of the key stakeholders including the Government, 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.

⁵ http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-MSNThresholds_1Jan2019

⁶ <https://www.humanservices.gov.au/individuals/services/medicare/pharmaceutical-benefits-scheme/when-you-spend-lot-pbs-medicines/pbs-safety-net-thresholds>



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.

The first priority will be engaging an independent health economist to work with the taskforce. The end game is 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.

This taskforce would be supported by a secretariat (within the Department of Health or within PCPA) that would coordinate the ongoing liaison between stakeholders and fully develop and roll out the new cancer safety net model. There would also have to be an agreed annual review or audit mechanism to ensure service provider fees are not unduly increased over time.

We are exploring with the Department of Health, other options to lock in any guarantees that the specialist or GP won't seek to exploit the situation. We know it is a situation we can absolutely resolve to the benefit of Government, patients and taxpayers.

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

We have also discussed the formation of a taskforce to address all other 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, especially if we could demonstrably 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. This is particularly so during and as we emerge out from under this pandemic. Cancer patients need all the help (financially and otherwise) that we, as a society, can offer them.

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. Never has this been more in demand than now during this shocking global health and economic crisis.

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.



These patient groups have been hit hard financially by the pandemic in terms of managing additional demand from financially stressed cancer patients and a dramatic reduction in private sponsorship and philanthropic support.

Benefit to Government and taxpayers`

Right now, too many sick Australians are not seeing their doctor for a timely diagnosis of cancer. The hesitancy is out of fear of COVID-9 or worry about the financial costs or both.

The cost of this delayed treatment will be significant to patients and to taxpayers. Cancer doesn't go away just because a patient can't afford the treatment or out of pocket expenses but the more delayed the treatment, the more challenging it can become.

With the right levers in place, taxpayers can be assured that the cancer patient safety net works and is audited and its participating health professionals can, and will, be held accountable.

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.

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.



Recommendations

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

Estimated cost: \$53.37m p/a.

2. Establish a healthcare working group, with a professional support secretariat, that can consult widely and collaborate on an evidence-based model that negates, and removes, the risk of specialist ‘gaming’ of the reforms. Engagement of a health economist to work with the Government on the new model.

Annual auditing and benchmark review of the cancer patient safety net to ensure, its integrity is maintained and action can be taken if not.

Estimated cost: \$1 million initiative investment.

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

Conclusion

As the World Economic Forum observes⁷, since early 2020, health systems around the globe have marshalled a response to the nearly unrelenting demands of the COVID-19 pandemic.

Cancer has not stopped, but patients’ access to services for these has been paused or delayed, likely leading to further loss of life among people with conditions like cancer, where time to treatment is critical. The financial toxicity of the cancer journey is also likely to worsen as many sick Australians are already struggling to recover from the economic blow the pandemic has dealt this country.

We need to help cancer patients start their cancer journey, knowing that the out of pocket expenses with medicines (PBS) and health services (MBS) will be significantly reduced for them and their families. This cancer net safety net initiatives is a low cost, high impact policy that is needed more now than ever.

RCA and PCPA, commits this “No Gaps Cancer Care” pre budget submission for adoption on behalf of the one in two Australians – and their families - who will be diagnosed with cancer before the age of 85⁸.

⁷ <https://www.weforum.org/agenda/2021/01/covid19-impact-lung-cancer/>

⁸

<https://www.cancer.org.au/about-cancer/what-is-cancer/facts-and-figures.html>



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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