



Rural Care Travel Project

Rare Cancers Australia

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Introduction

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 cancers. Founded in 2012 by Kate and Richard Vines, RCA has supported cancer patients with rare and less common cancers for the last decade. Through this shared journey, RCA have come to learn what matters most to patients, their families, and carers. We have also been made acutely aware of the health system's failure to meet the needs of cancer patients consistently, particularly those with rare and less common cancers on non-curative pathways. Patients frequently approach RCA looking for help to access treatment options. In more recent years, our patient support navigators have started to receive a growing number of calls from patients with complex cancers that were historically considered 'common' and who have exhausted standard treatments. There is growing demand to support these patients – to pay for diagnostic screening tests, to find and access clinical trial treatments, to participate in special access programs or to find ways to pay for therapies that are not reimbursed.

Now more than ever it is important that we look for new ways to support all Australians – not just the wealthy – to have affordable and timely access to the best treatment and medical technologies. RCA maintains that no patient, family, or carer should be significantly out of pocket in the pursuit of treating their disease. It is the fundamental right of every Australian to have access to the best health care at an affordable cost.



Proposal

Rural Care Travel Project

Rare Cancers Australia is seeking Commonwealth support to undertake a pilot program to support people living with cancer in rural and regional Australia to access investigator-led clinical trials away from home.

It is proposed that the Rural Care Travel Project will operate as a two-year pilot in conjunction with some of the Australian Centers of Excellence such as the Peter MacCallum Cancer Centre in Melbourne (Peter Mac Centre).

The pilot would involve supporting up to 200 patients in the first year to travel to a treatment centre such as the Peter Mac Centre to participate in clinical trials. Once the pilot is established, the second year sees the Rural Care Travel Project extended to other treatment centres and an increase to 500 patients will be assisted. To be eligible, patients would need to live in rural, regional or remote Australia and meet the criteria of the patient transport/travel assistance scheme in their home state or territory, noting that, currently, the schemes do not cover clinical trial participation.

The pilot would include funding of \$3,800 per patient – this constitutes funding for the costs of the patient’s travel and accommodation, and additionally, funding of \$600,000 per year to support infrastructure and staff within RCA. The pilot will be led by RCA and supported by multi-channel support service including a website and telephone hotline.

Conversations with the Peter Mac Centre have been promising as the potential initial location for the pilot and it has indicated an in-principle willingness to participate. The Peter Mac Centre have provided data which supports the clear and urgent need for this type of program; Peter Mac conducts many of the cancer clinical trials patients are regularly required to travel long distances to. We understand the important work being undertaken in tele trials, and highlight that for many clinical trials, traveling to treatment centres will remain a reality. Once the first year of the pilot is complete, it would be broadened to include other major cancer treatment centres across Australia in year two.

Why is this needed?

AIHW data shows that almost a third of Australians live in rural, regional and remote areas. People living in these areas face unique challenges due to their geographic location and often have significantly poorer health outcomes, including poorer cancer survival rates and shorter life expectancies, than people living in metropolitan areas.

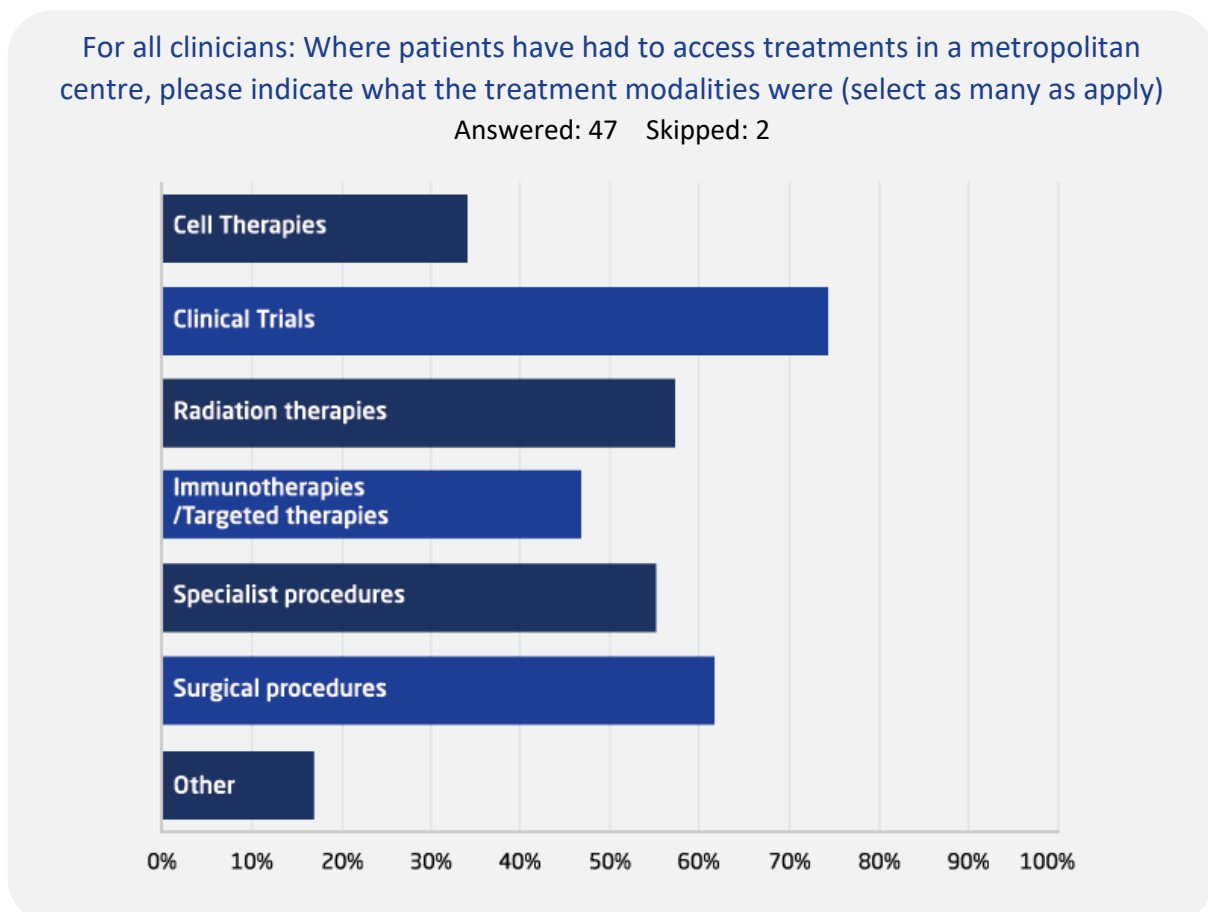
Anecdotally, we know that approximately 1,500 – 2,000 Australians are participating in cancer clinical trials at any one time. About one third of these people are estimated to be from rural, regional, or remote Australia. The Peter Mac Centre alone is currently running 500 cancer clinical trials.

The Minister for Health has stated that people in rural, regional and remote Australia should not be disadvantaged when it comes to accessing clinical trials, purely because of where they live. Yet we know that these patients currently don’t receive the same level of support or have access to the same clinical trial options as those living in metropolitan areas, and they frequently pay for that inequity with their lives.

While travel and accommodation schemes are available in each state and territory to assist patients with accessing treatment, the schemes do not cover costs associated with participating in Government funded investigator-led cancer clinical trials. This differs from a pharmaceutical company-led trial, where costs to the patient are usually covered by the company. This is a critical issue, as many complex clinical trials are undertaken in metropolitan centers, requiring rural and regional people with cancer to travel away from home and even interstate in order to participate in potentially life extending opportunities.

Data from the Peter Mac Centre shows that between 2016 and 2021, there were more than 277,000 visits to Peter Mac from people who were not from metropolitan Melbourne. This included more than 3,000 visits from South Australians, almost 6,000 visits from Queenslanders, and 1,500 visits from people from the Northern Territory.

Critically, a clinician survey of regional, rural and metropolitan patient travel undertaken by RCA in September 2021 showed that the most common reason provided by a clinician for referring a rural/regional patient to a metropolitan centre was to participate in a clinical trial. (see figure below)



The current situation for rural and regional people with cancer is that at a time when they are dealing with a cancer diagnosis, significant physical and emotional distress, loss of income and substantial expense, they are also investigating their eligibility for clinical trials, many of which are interstate and away from home, and funding and booking their own airfares, travel, and accommodation in order to participate.

This is a significant burden for people with cancer and their families and carers and in RCA's experience, the complexity of the process, as well as inadequate or non-existent levels of assistance, is prohibiting access to clinical trials for some patients.

It is vital that we ensure that regardless of their financial position, location, and personal situation, rural and regional Australians with cancer can participate in investigator-led clinical trials. These trials represent the best and last chance for many Australians living with cancer.



Case study: Hosam

Hosam, a young father of two little young children has lived with a super-rare brain malignancy for four years. Much of this time has been spent enrolled in clinical trials and the initial expected prognosis for this young dentist has well-expired due to the rapid evolution of opportunities for patients like Hosam in Australia. Unfortunately, Hosam and his family live in Western Australia and costs in the order of 100s of thousands of dollars

have been paid out of pocket to allow him to travel the country, from coast to coast, chasing the gold standard Australia has to offer to extend his young life. An example of this is his extended family being forced to sell their homes and having to crowd-fund, both of which strike at the heart of dignity for Australian families already in emotional peril, like Hosam's. Having been devastated by Case his cancer diagnosis, his family continue to fundraise to fulfill his dream of seeing his children grow up, whilst clinical trials represent his standard of care and his best hope.



Case study: Madonna

Madonna was a much-loved mother who was diagnosed with a rare sarcoma that led her down a path to Rare Cancers Australia (RCA), specialists in cancer navigation. The journey for Madonna, diagnosed with a poor-prognosis cancer was compounded by living in a regional area of Queensland. Having worked all her life as a police officer, Madonna was fortunate enough to have had financial resources to access treatments

and specialists in metropolitan centers. For two years, she and her carer, husband Greg, relied on clinical trials and emerging therapies. When Madonna contacted RCA, she was enrolled in a clinical trial and was receiving a targeted therapy for her particular molecular profile, cutting edge personalised medicine. She had picked up the phone to tell the trials coordinator that she would no longer be able to travel to Sydney as her finances were depleted - she was dropping out of the trial. When advised to call RCA we enrolled her to our Patient Support Program and helped provide finances to keep Madonna on that life extending study. She remained on it for a further nine months, a clinically confirmed extension of her life, precious time with her family and a priceless contribution to study data. Many people we support rely on clinical trials to stay alive, and there is currently no financial mechanism to support them to do so.

What are the benefits of this proposal?

The Federal Government has invested significant funding in recent years to increase the number of Australian-led clinical trials and improve patient access, including for people with rare and less common cancers.

However, we know that many regional and rural Australians are struggling to afford and organise their travel and accommodation to take advantage of these life-saving and life-extending treatments.

There is, therefore, a growing gap between the clinical trials offered in Australia and the ability of rural and regional patients to access them. This situation will only become more common as new cutting-edge treatments like the Federal Government funded Australian Bragg Centre for Proton Therapy in South Australia become operational and a plethora of clinical trials instigated (expected in 2024).

The Rural Care Travel Project will magnify the impact of the Federal Government's significant investments in clinical trials by ensuring patients from rural and regional Australia are physically and financially supported to participate.

The Rural Care Travel Project will therefore:

- Boost opportunities for patients across Australia to participate in investigator-led clinical trials of new treatments.
- Improve recruitment to clinical trials, a well-documented challenge.
- Allow patients from all over Australia to access potentially lifesaving and life-extending treatments.
- Reduce the burden and costs for patients and their families.

It is important to note that the initiative will not fund patient participation in pharmaceutical company-led cancer clinical trials. The costs of participating in these trials are typically already fully covered by the company undertaking the trial.

How much will it cost?

RCA estimates the total cost of the pilot would be \$3.86 million over two years.

2022-23	2023-24
\$1.36 m	\$2.5 m

This cost estimate takes into account the following:

- \$760,000 to support up to 200 patients in the first year and \$1.9m to support 500 patients in the second year (a cost of \$3,800 per patient)
- \$600,000 per year to establish the pilot and support a small team of staff within RCA who will lead the pilot and support patients to book their travel and accommodation.

Note that these costs are based on RCA's demonstrated experience in supporting patients to access treatments including CAR-T cell therapy for regional and rural patients.

As part of the initiative, RCA will:

- Coordinate with trial site to book and coordinate travel and accommodation for the patient
- Provide a multi-platform navigation hub for coordination and data collection
- Continue to maintain a dedicated evidence-based 360-degree support service to cancer patients on clinical trials

RCA has demonstrated experience in successfully undertaking these activities and the pilot would leverage our existing knowledge base, skill sets, processes, infrastructure, and relationships to deliver better outcomes for rural and regional Australians living with cancer.

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