Australian Government
National Health and Medical Research Council

NHMRC

Community Research Priorities Portal submission template

Important information

Consumers, community and professional groups should only use this template if they are unable to access the Community Research Priorities Portal online submission form. Submissions developed and/or driven by academic researchers or academic/ research institutions will not be considered.

Question 1 - What is the research gap you consider warrants a TCR?

Consider:

- What is the health issue that is not being sufficiently considered by current research efforts or funding?
- Does it relate to diagnosis, treatment or management options?

Maximum 2000 characters

Australia faces a rising problem, with blood cancer incidence increasing by nearly 40% in the past decade.[1] According to the AIHW, when combined, blood cancers rank as the third most commonly diagnosed cancer and the second highest cause of cancer-related death in Australia.[2] In 2025, more than 21,000 Australians will receive a blood cancer diagnosis, projected to escalate beyond 36,000 annually by 2035.[3] With mortality rates rising in tandem, over 6,300 Australians will die from blood cancer in 2024 alone.[4]

While funding for haematological cancer research has increased from $18.5M in 2003-2005 to $125M in 2018-2020, only a small proportion of funds have been allocated to areas such as early detection, diagnosis, and prognosis (12%), aetiology (2%), cancer control, survivorship and outcomes research (2%) and prevention (0%).[5] Funding for biology has decreased from 61% (2009-2011) to 30% (2018-2020), while funding for treatment has increased from 29% to 54% during the same period.[5] When comparing the proportion of funding for all cancer projects vs blood cancer projects in 2018-2020, larger proportions of funding were attributed to early detection, diagnosis and prognosis (21% vs 12%), aetiology (8% vs 2%), cancer control, survivorship and outcomes research (9% vs 2%).[5] This shows that these areas receive less focus in blood cancer research relative to other cancers.

Current funding is insufficient to meet the challenges of high-mortality blood cancers and address the rising incidence.[6] Increased investment in blood cancer research is essential, with a greater proportion specifically focussed on aetiology, prevention, and early detection to help stem the predicted rise in incidence and prevalence. While investment in treatment is critical, especially for high-mortality blood cancers, expanding our understanding of the cause of disease, possible prevention strategies, and earlier detection will ultimately improve outcomes for all patients across the spectrum of blood cancers.

Question 2 – Who and how have you consulted or collaborated with in identifying this research gap?

Name other stakeholder groups you have engaged with and describe how you have collaborated with them in developing this submission. This may include other community groups, health professional organisations and research institutions.

Maximum 8000 characters

In 2022, the Leukaemia Foundation undertook the Survey of People Living with Blood Cancer with 4,600 respondents.[3] The survey delivered a wide-reaching representation of blood cancer subtypes, states, regional status, age, and private health insurance status. Published in the State of the Nation 2023: Blood Cancer in Australia Report, the survey included numerous questions that included time to presentation to a GP, referral time to a haematologist, use of genomic testing, use of bone marrow biopsy, understanding of treatment plans and available resources, supportive care, access to supports, out of pocket costs, financial and productivity impacts, and knowledge of and participation in clinical trials.

In the lead up to the development of the Research Roadmap for Blood Cancers report,[6] comprehensive consultation was undertaken to understand the barriers, limitations, strengths, and recommended improvements for the blood cancer research landscape in Australia. 1:1 interviews were conducted with haematologists, blood cancer researchers, and healthcare professionals, as well as written submissions in response to the consultation paper and surveys which included key stakeholders such as consumers, academic institutions, research institutions, non-profit blood cancer and cancer related organisations, state government health departments, pathology and cancer care centres, and relevant healthcare professional and researcher associations and societies.

Question 3 – How significant an issue is this proposed topic?

Consider:

- Who does this health issue affect (for example, population group, individuals)?
- What percentage of the population is affected by this issue (for example, burden of disease, mortality and morbidity)?
- How does the issue impact on the quality of life of the individual, their family, carers and/or community?
- What is the impact of this issue on the health system?

Maximum 8000 characters

Blood cancer has over 120 different subtypes and can affect anyone at any age. According to the AIHW, when combined, blood cancers are the third most commonly diagnosed cancer, with over 20,000 cases in 2024 (age standardised rate 73.8 cases per 100,000 persons)[1] and the second highest cause of cancer-related mortality, with over 6,000 deaths in 2024 (age standardised rate 23.3 deaths per 100,000 persons).[4] Leukaemia is also the most commonly diagnosed cancer in children and adolescents in Australia.[7]

Blood cancers, both acute and chronic, have a significant impact on people's lives. People living with blood cancer face intense, multi-month treatment regimens that can require patients to relocate from their homes to specialist centres. This is especially evident with those who reside outside of metropolitan areas and face intensive treatment or transplantation.

Alongside the heavy treatment burden, it can place families at higher risk of financial strain, depression and anxiety compared to other cancers.[6] Side effects – both short-term and long-term – can significantly affect quality of life, such as persistent fatigue, nausea, sleep disturbances. More severe effects, such as graft versus host disease after a stem cell transplant, can be life threatening.

Blood cancer survivors are also at an increased risk of developing secondary malignancies later in life.[8,9] Psychological impacts are also profound as fear of recurrence and progression of disease are common given the unpredictable nature of many blood cancers.

High mortality blood cancers such as acute myeloid leukaemia, myelodysplastic syndromes, and chronic myelomonocytic leukaemia have poor prognoses. Reasons for this include limited treatment options especially for older patients, high rates of relapse and drug resistance, delays in genomic testing, lack of targeted treatment options, and lack of knowledge from healthcare professionals and standard treatment approaches for rare cancers. [10,11,12,13]

Blood cancers are among the costliest cancers to treat, with myeloma and leukaemia in the top five.[3] Costs escalate further if blood cancers recur and additional rounds of treatments are required after initial therapy. Direct health costs for all blood cancers are predicted to triple to $10.9 billion by 2035.[6] In addition to the health system costs, individual patients bear significant costs too—more than one in three report out-of-pocket costs of more than $5,000.[3]

Loss of productivity also majorly affects blood cancer patients and their carers. Results from the Survey of People Living with Blood Cancer 2022 shows that only 22% of patients returned to work after their diagnosis, with 28% returning with reduced hours, and 50% not having returned to work.[3] Similarly for carers, only 27% were able to continue working with the same hours while supporting a person living with blood cancer during their treatment phase.[3]

A patient perspective on the physical and emotional impacts of blood cancer:

"My illness is chronic and doesn't get much understanding because most people ache and get tired. But it never stops. I struggle daily but I'm not sick enough for any financial assistance so I have to work. There is not much understanding of blood cancers when compared to breast cancer. I have bad symptoms (as bad as fibromyalgia), however, someone with fibromyalgia can get government assistance. It's really unfair. I don't want sympathy, I want understanding." – a person living with blood cancer.[3]

Overall, blood cancer remains a significant and growing health and economic burden in Australia, with over 120 subtypes affecting individuals across all age groups and contributing to high mortality rates and substantial personal, social, and economic costs. The impact extends far beyond treatment, with many patients facing long, intensive care regimens, serious side effects, and lasting psychological and financial strain. Poor outcomes in high mortality blood cancers such as acute myeloid leukaemia and myelodysplastic syndromes highlight the urgent need for new approaches.

Question 4 – How would research on this topic benefit the health of Australians?

Consider how research would:

- change health outcomes for the community generally, affected groups within the community and people living with a specific health condition
- influence health policy development or health service delivery including diagnosis, treatment or management.

Maximum 8000 characters

To date, blood cancers cannot be prevented and cannot be screened for, unlike many other solid tumour cancers.

Central to addressing this challenge is a greater focus on research into the aetiology of blood cancers. A deeper understanding of the biological, genetic, and environmental drivers of disease is critical for identifying individuals at risk, which then leads to developing more precise diagnostic tools, and creating targeted, less toxic therapies.

While identifying prevention strategies remains a long-term goal, it is through advancing aetiological research that early detection and more effective interventions can be realised. Strengthening this research area is essential to shifting outcomes, improving survival, and reducing the devastating impact of blood cancer on patients, families, and the healthcare system.

Earlier diagnosis of blood cancer allows for earlier intervention and often better survival outcomes. By healthcare professionals being able to identify and diagnose blood cancer earlier, especially in cases of rarer blood cancers, treatments begin sooner before severe complications have occurred due to the volume of cancerous cells in the blood and bone marrow. Identifying blood cancer in early stages can also sometimes prevent highly toxic treatments from being required as first-line therapy. In consultation with our consumers, we have heard multiple accounts of delays to diagnosis and misdiagnoses occurring which has led to suboptimal health outcomes.

Patient perspectives on delay to diagnosis and misdiagnosis include the following:

“I had been to many GP appointments (3-4 different GPs), they all failed. Young people – and especially women – often feel dismissed. GPs often dismiss symptoms suggesting it’s okay and that there are other causes, and are often hesitant to over-test. My GP just kept telling me that it was probably just hormones, and I was, at the time, hesitant to push back. However, there were red flags – I had every symptom in the book, but they were all being treated as individual issues to be dealt with. I hear time and time again that people are misdiagnosed for extremely long periods of time…” – a person living with blood cancer[3]

“My GP misdiagnosed me and I could have died as a result. I have heard many similar stories. There seems to be poor recognition of blood cancer symptoms in general practice. At best, the GP cause me to lose my fertility without being able to take preservation steps. At worst, I will still die of this disease. I blame him hugely. I presented to him for 4 months with symptoms that were dismissed as asthma and eczema. I think this is the biggest issue facing blood cancer patients”. – A person living with blood cancer[3]

This also greatly affects patients who reside in regional and rural areas and Indigenous populations who are less connected with specialists, integrated cancer networks, GPs, and supportive care. Additionally, due to the rarity of many subtypes of blood cancer, many GPs will not come across a single case in their careers.

“Aboriginal patients present with multiple co-morbidities which complicates diagnosis. Aboriginal patients are often misdiagnosed or have their symptoms dismissed, I know a patient who presented to the GP four times before they got referred onwards; unfortunately it’s a common story. I want GPs to first rule out cancer and then look at other things.

There needs to be GP education, and more comprehensive investigation around early signs and symptoms. Our mob has to be aware of signs and symptoms." – stakeholder perspective (State of the Nation for Blood Cancer Report 2023)[3]

In regard to health policy development, in the long-term, if causes of disease are able to be identified (e.g. specific genetic mutations, occupational or environmental exposure) it can inform targeted screening programs similar to those currently being undertaken with breast and bowel cancer which in turn has positively affected earlier detection of disease and ultimately improved survival.[14,15] More evidence of cause of disease can also positively impact earlier diagnosis of patients which can ultimately result in earlier intervention, reduced treatment costs, reduced treatment toxicity and improved survival. This in turn could support increased investment in necessary infrastructure such as diagnostics, broader genomic testing, and further support for regional and rural patients with blood cancer.

Question 5 – Would a TCR on this topic build on existing research or government initiatives?

Consider providing details on:

- current or previous research, initiatives, action plans or strategies
- international research or initiatives that a TCR would build on to address the proposed issue.

Maximum 8000 characters

Current initiatives that are relevant to blood cancer research include the following:

- MRFF Low Survival Cancer Mission
- MRFF Genomics Health Futures Mission
- MRFF Stem Cell Therapies Mission

While these missions address key issues related to blood cancer such as improving survival of blood cancers with poor prognoses and the importance of new targeted interventions and genomic testing, early detection and aetiological research is not directly captured. This remains a significant gap in the funding of blood cancer research.

Further funding or re-balancing of existing funding is strongly supported by the recommendations made in the Research Roadmap for Blood Cancer report.[6] The report states that the current pattern of government funding will not match the estimated doubling of blood cancer cases by 2035 and a further increase in government funding beyond the next triennium will be required to curb the predicted growth in cases and deliver the actions outlined in the Research Roadmap.[6]

There is an opportunity to continue to develop targeted funding programs to address the looming healthcare burden posed by blood cancers. It is important for funding bodies to understand that the research priorities for blood cancers that are non-preventable and with no national population screening programs in place are different from those for other cancers such as breast, prostate, lung and bowel cancers.

A TCR for further research into early detection of blood cancer and blood cancer aetiology can complement and build on current international initiatives including:

- National Cancer Institute (US) – Leukemia Specialized Programs of Research Excellence (SPORE) which supports the efficient movement of basic scientific findings into clinical settings, as well as studies to determine the biological basis for observations made in individuals with cancer or in populations at risk for cancer.[16]
- National Cancer Institute (US) – Division of Cancer Epidemiology and Genetics run studies investigating novel biomarkers for leukaemia, clarify relationships of established risk factors, environmental and workplace exposure risks, familial cases and inherited bone marrow failure syndromes.[17]
- Genomics England (UK) – Cancer 2.0 project – analyses genomic and long-term clinical data to gain insight into the nature of genetic changes that drive cancer evolution.[18]
- The International Alliance for Cancer Early Detection (UK) - funds research to drive innovation and change in how and when cancer is detected (pan cancer initiative)[19]

Question 6 – Research keyword/phrases

To enable NHMRC to retrieve relevant funding data, provide up to 10 research keywords and consider the keywords and phrases developed by the Australian Bureau of Statistics – also available on the NHMRC website.

Aetiology
Early detection
Early diagnosis
Haematological malignancy
Cancer prevention
Cancer genetics
Epigenetics
Genetic risk factors
Environmental risk factors
Gene mutations

Supporting material

You can provide additional material such as letters of support, references, graphs, images (maximum of 3 documents). Provide these in PDF format and attach them to the submission email, addressed to: targeted.research@nhmrc.gov.au

[1] Australian Institute of Health and Welfare. (2024). *Cancer data in Australia, Cancer incidence by age visualisation*. https://pp.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/cancer-incidence-by-age-visualisation
[2] Australian Institute of Health and Welfare. (2024). *Cancer data in Australia, Cancer rankings data visualisation*. https://pp.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/rankings
[3] Leukaemia Foundation. (2023). *State of the Nation: Blood cancers in Australia Report 2023*. https://www.leukaemia.org.au/wp-content/uploads/2023/02/Leukaemia-Foundation_Final-Report_State-of-the-Nation-Blood-Cancers-in-Australia-Report-2023.pdf
[4] Australian Institute of Health and Welfare. *(2024). Cancer data in Australia, Cancer mortality by age visualisation*. https://pp.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/cancer-mortality-by-age-visualisation
[5] Cancer Australia. (2023). *Cancer Research in Australia: An overview of funding for cancer research projects and programs in Australia, 2021 to 2020, Cancer Australia, Surry Hills, NSW*
[6] Australian Academy of Science (2024). *Research Roadmap for blood cancer.* https://www.leukaemia.org.au/wp-content/uploads/2024/10/5-August-AAS-Research-Roadmap-for-Blood-Cancer.pdf
[7] Australian Institute of Health and Welfare, (2024). *Overview of Cancer in Australia, 2024*. https://pp.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/overview
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[10] Kropp, E. M., & Li, Q. (2022). Mechanisms of resistance to targeted therapies for relapsed or refractory acute myeloid leukemia. *Experimental Hematology*, *111*, 13–24. https://doi.org/10.1016/j.exphem.2022.04.001
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[13] Turell, W., Ackbarali, T., Del Nido, E. L., Pucci, K., O'Hara, R., Kowalski, K., Hopper, J., & Palma, J. (2021). Addressing gaps in care for patients with rare cancers and blood disorders: The impact of a collaborative digital education initiative. *Journal of Clinical Oncology*, *39*(15_suppl), e23005. https://doi.org/10.1200/jco.2021.39.15_suppl.e23005
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[15] Australian Institute of Health and Welfare. (2025). *Cancer Screening.* https://www.aihw.gov.au/reports/australias-health/cancer-screening-and-treatment
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