Leukaemia Foundation

The Hon Josh Frydenberg MP
Treasurer
C/O: prebudgetsubs@treasury.gov.au

28 January 2021

Dear Treasurer

Re: 2022-23 Pre-Budget Submission

I am writing you as the co-chair of the Blood Cancer Taskforce to provide input into the Government's priorities for the 2022-23 Federal Budget.

The Blood Cancer Taskforce was established in September 2019 by the Federal Government to deliver Australia's first National Strategic Action Plan for Blood Cancer. The National Action Plan was launched with the Minister for Health in September 2020 and is the basis of the recommendations in this pre-Budget submission.

The Taskforce is supported by the Leukaemia Foundation, as the secretariat, and together we represent and advocate on behalf of the 110,000 Australians of all ages living with a blood cancer in Australia today. We are submitting these recommendations for consideration in the 2022-23 Federal Budget planning process on behalf of the Taskforce and with support from the Leukaemia Foundation.

The Federal Government has already made some early and welcome commitments, which have supported the blood cancer community to come together to develop the National Action Plan and commence work on this ambitious and important agenda to reduce blood cancer deaths. This financial and policy support is very welcome. However, blood cancers are the second most frequently diagnosed cancers in Australia. The National Action Plan was designed to address this burden. So, we urge the Commonwealth to make a multi-year commitment to realise the National Action Plan. Many, although not all, of the recommendations made in the National Action Plan are applicable to other cancers and the health system generally, and are aligned with and interrelated with other reforms currently being considered across the whole cancer care continuum, through the Australian Cancer Plan and for the broader health system, including the National Medicines Policy Review.

If we can provide any further detail please contact Tim Murphy, General Manager Blood Cancer Partnerships at the Leukaemia Foundation, who heads the Taskforce secretariat on tmurphy@leukaemia.org.au or 0435 969 037.

Sincerely,

Chris Tanti
CEO, Leukaemia Foundation
Co-chair of the Blood Cancer Taskforce

Blood Cancer Taskforce & Leukaemia Foundation 2022-23 Pre-Budget Submission

Submission Summary

Blood cancers are one of the most commonly diagnosed cancers in Australia today and one of the leading causes of cancer death, second only to breast cancers and lung cancers respectively.

People with blood cancer can face significant challenges accessing the best treatment and care they need. Substantial differences in treatment and care options exist depending on where a person lives and their personal circumstances, including whether they live in a regional area. This has a determinantal impact on an individual's survival and wellbeing.

Approximately 13 per cent of blood cancer deaths could be prevented through the consistent application of currently available, evidence-based best practice treatment and care – 1,375 deaths could be prevented every year simply by doing what has been proven to work and is already funded in Australia, more consistently across all jurisdictions.

The Blood Cancer Taskforce, through developing the National Strategic Action Plan for Blood Cancer, identified that the implementation of its recommendations would need to be phased. Of the total 21 actions in the National Action Plan, eight are considered a high priority to address achieving best practice, enabling access to treatment and support for new discoveries: 'Phase 1' of the implementation strategy.

The Federal Government has provided funding towards two of the recommendations and also provided funding to extend the Blood Cancer Taskforce until June 2023. The Federal Government has also agreed to support two further items, in partnership with the Leukaemia Foundation.

The Taskforce has identified priority recommendations to consider in the context of the 2022-2023 Federal Budget to fulfill the remainder of 'Phase 1'.

Phase 1 actions that have received Federal funding and partnership support

1. Address gaps in achieving nationally consistent best practice treatment and care, through the development of Australian-specific clinical and diagnostic guidelines for blood cancers. The Federal Government provided funding towards this item in 2021.
2. Develop a suite of Optimal Care Pathways (OCPs) for the main blood cancer sub-types. The Federal Government provided funding in 2020 to develop 6 OCPs, and in 2021 provided funding to undertake a develop a further 5 OCPs.
3. Develop a Research Roadmap for blood cancers, which sets out a clear list of potential research projects extending from basic to clinical research to support high impact research. The Leukaemia Foundation has agreed to fund the development of the Research Roadmap, in partnership with the Federal Government.
4. Commission an epidemiological and health services implementation research study to better understand limitations, improve data collection and statistics on blood cancers in Aboriginal and Torres Strait Islander communities and to enable culturally sensitive care that improves primary health attendance and hospitalisation rates. The Leukaemia Foundation has agreed to fund the development of the epidemiological study, in partnership with the Federal Government.

Remaining Phase 1 actions to be funded

1. Continue to work with the blood cancer community to implement the actions in the National Strategic Action Plan for Blood Cancer – particularly priority actions that address the issue of preventable deaths.
2. Ensure a nationally consistent, minimum standard approach to written communications to patients about treatment and care, through development of minimum standards or a template for written treatment and survivorship care plans for blood cancers.

3. Ensure a nationally consistent approach to implementing Patient Reported Outcomes (PRO) for blood cancer, by forming a clinical advisory working group of clinicians and patients to undertake a PRO scoping study.
4. Develop a national information strategy for cancer as recommended by the Cancer Council of Australia, including a blood cancer specific stream.
5. Establish a multidisciplinary Enabling Access Working Group to deliver a plan for improving national, equitable access to clinically important technologies that are not publicly funded and a plan for reducing inequities to standard of care diagnostics and therapies as defined by the clinical guidelines across jurisdictions and public-private settings.
6. Fund a clinical trial program to develop evidence for MBS item number listing for cancer-patient friendly exercise and lifestyle services.

About the Blood Cancer Taskforce

The Blood Cancer Taskforce was established by the Federal Government in 2019 to deliver Australia's first National Strategic Action Plan for Blood Cancer (the National Action Plan).

The National Action Plan was commissioned by Government to improve diagnosis, treatment and the understanding of blood cancer, with the ultimate goal of saving lives.

The Taskforce unites a group of more than 30 leaders in the blood cancer community, from haematologists, clinicians, researchers, patients, patient advocates and cancer charities.

Supported by the Leukaemia Foundation, as the Taskforce secretariat, together we represent and advocate on behalf of the 110,000 Australians of all ages living with a blood cancer in Australia today.

The National Strategic Action Plan for Blood Cancer

The National Strategic Action Plan for Blood Cancer, developed by the Blood Cancer Taskforce, is an evidence-based blueprint to coordinate national efforts to improve survival and quality of life for people diagnosed with blood cancer. It makes 21 recommendations for change, including setting national quality standards for treatment and care.

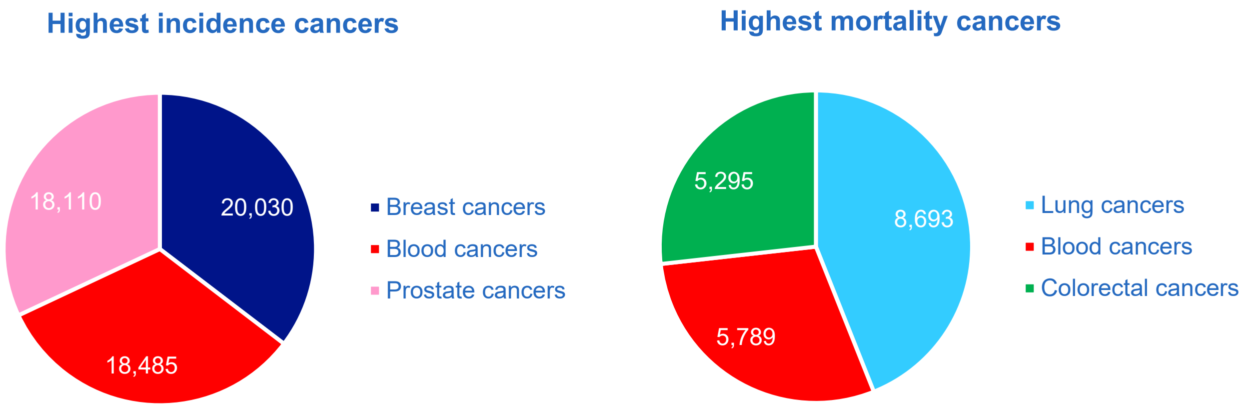
The recommendations build on the strength of our health systems in Australia, which are achieving remarkable results in improving blood cancer survival rates and treatment, and importantly redoubles focus on addressing the survival gaps which still exist for Australians dealing with a blood cancer.

Blood cancer in Australia

Blood cancers are a complex group of diseases that can affect anyone, at any stage of their life. They are one of the most common, costly and fatal cancers in Australia today. Blood cancers arise from abnormalities that affect normal blood cell production and function. Typically, blood cancers are grouped into one of three major sub-type classifications: leukaemia, lymphoma or myeloma.

Australian Institute of Health and Welfare (AIHW) data shows that blood cancers collectively are the second most commonly diagnosed cancers in Australia today and second highest cause of cancer death.[1]

Figure 1: AIHW projected top three cancers by incidence and mortality in Australia in 2021



Blood cancers, like other cancers, can also have a significant adverse financial impact on patients and their families, arising from out-of-pocket costs from diagnostics and services, travel, accommodation,

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[1] Australian Institute of Health and Welfare, *Cancer data in Australia*, updated 14 January 2022, accessed at: https://aihw.gov.au/reports/cancer/cancer-in-australia-2021/data.

and long-term impacts on employment and household savings. Survivors face ongoing and often a lifetime of health and financial side effects as a result of their treatments.

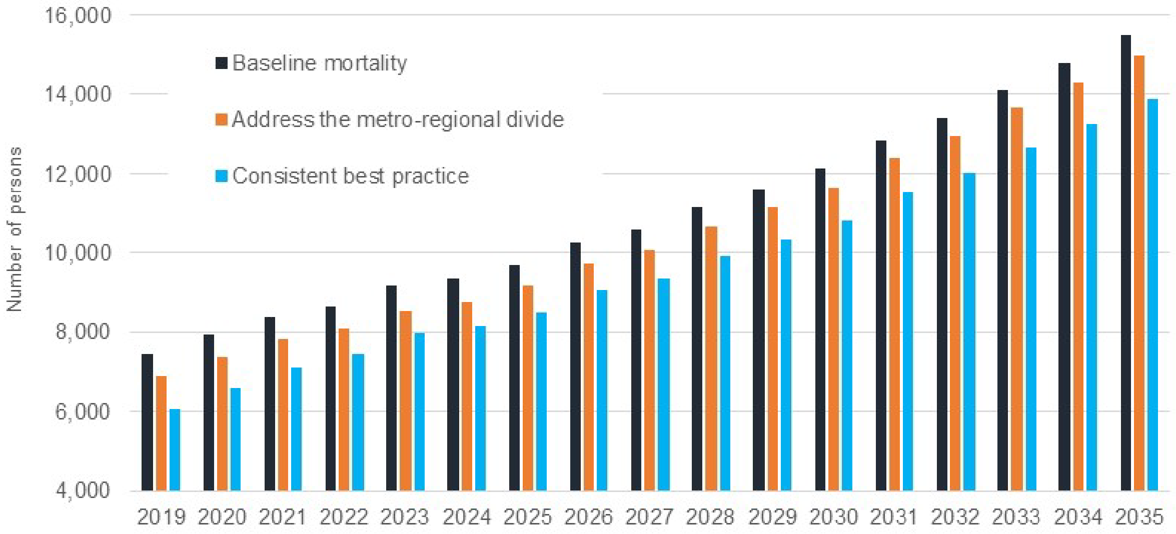
Every year, 1,375 Australians die unnecessarily from blood cancer because they don't get the best treatment available.[2] Getting the best blood cancer treatment can be challenging, depending on where a person lives and, in some instances, whether they can afford to pay for tests and treatments. They need to be diagnosed quickly and correctly and work with their treating team to know exactly what sort of treatment will work best. They also need the right care plan and support in place to live well during and after treatment.

Across Australia there is substantial variation in clinical practice in treating blood cancers:

- On average, there is a 13 per cent disparity in survival outcomes for blood cancer based on where a person lives[3] - an 8 per cent difference between states and territories, and a 5% difference between metro and rural/regional areas.
- While adherence to clinical best practice is associated with a 40 per cent reduction in the risk of death for some blood cancers, like diffuse large B-cell lymphoma, people who received their treatment outside metropolitan areas are 37 per cent less likely to receive treatment that complies with current guidelines[4].

Collectively, that means that 22,000 deaths could be prevented simply by doing what has been proven to work and is already funded in Australia, more consistently across all jurisdictions (see Figure 2). Addressing these differences, and the 13 per cent disparity in survival outcomes, is therefore our first priority for action.

Figure 2: Reduction in deaths from blood cancer if best practice in Australia is consistently implemented[5]



Priorities for action for the blood cancer community

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[2] Analysis of state cancer registry data in the *State of the Nation: Blood Cancer in Australia* report (2019) shows 13% of blood cancer deaths could be prevented through consistent application of currently available and funded best practice treatment and care (22,000 deaths between 2019-2035), utilising therapies and technologies already funded in Australia more effectively across all jurisdictions.

[3] Leukaemia Foundation, 2019, *State of the Nation: Blood Cancer in Australia*, prepared by Insight Economics, https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf p85

[4] Wong Doo N et al, 2019, 'The use of optimal treatment for DLBCL is improving in all age groups and is a key factor in overall survival, but non-clinical factors influence treatment', *Cancers* 11(7) 928; https://doi.org/10.3390/cancers11070928

[5] Source: Leukaemia Foundation, 2019, *State of the Nation: Blood Cancer in Australia*, prepared by Insight Economics, accessed at: https://www.leukaemia.org.au/about-us/mylifecounts/stateofthenation/. Note the "Baseline" projections, "Address the Metro-Regional Divide" projections and "Consistent Best Practice" projections are based on AIHW and registry data using technologies currently in use in Australia.

As the Blood Cancer Taskforce has previously advocated, the recommendations in the National Action Plan should be taken holistically and work together to reduce mortality from blood cancer. We recognise that the first step in addressing differences in survival outcomes must be through reforms and recommendations aimed at improving the consistent implementation of best practice nationally – which is also relevant to other cancers where application of best practice can be inconsistent.

This will require ongoing coordination and commitments from across the blood cancer community over many years. Within this multi-year reform agenda, there are recommendations that must be enacted first in order to set the standard for best practice diagnosis, treatment and care.

In 2020, the Federal Government provided funding to support the first project from Phase One of implementation, which allowed for the capture of clinical best practice from the Blood Cancer Taskforce and its broader network of experts to create the first tranche of six Optimal Care Pathways for blood cancers.

In 2021, the Federal Government provided further funding to support the development of clinical guidelines and an additional five Optimal Care Pathways. The Leukaemia Foundation and the Department of Health further entered into a formal partnership agreement, which will see the Leukaemia Foundation fund the development of two recommendations with endorsement of the Commonwealth:

- Scoping work to develop the Blood Cancer Research Roadmap, and
- Undertake an epidemiological study in Indigenous people.

In 2022, the Blood Cancer Taskforce seeks commitments from the Federal Government to support the remainder of the Phase One recommendations. Many of these reforms and specific recommendations either rely on or will benefit from Federal Government leadership and/or funding, as recommended in this pre-Budget submission.

The development of the Australian Cancer Plan by Cancer Australia, which is now underway, provides an opportunity to streamline policies and activities across the cancer space. The development of the Australia Cancer Plan must include close consideration of these recommendations, and recommendations made by other cancer organisations in the development of other National Action Plans.

The Blood Cancer Taskforce is closely engaged with Cancer Australia in the development of the Australian Cancer Plan.

Priority actions in the National Action Plan

Recognising that this is a multi-year strategy, with some actions requiring considerable change in the health system, the Blood Cancer Taskforce has phased the implementation of the National Action Plan. Of the total 21 actions in the National Action Plan, eight are considered a high priority to begin reducing preventable blood cancer deaths: ‘Phase 1’ of the implementation strategy.

These actions are scalable, may be piloted in a blood cancer setting and may also be applicable to other cancer groups. Appropriate funding sources include the Federal Government, public-private partnership arrangements, a mix of Federal, state and/or philanthropic funding and funding from existing programs (such as the Medical Research Future Fund).

We are pleased that work has begun on implementing Phase 1, including Optimal Care Pathways, clinical and diagnostic guidelines, funded by the Federal Government, and the Research Roadmap and Indigenous epidemiological study which the Leukaemia Foundation has funded to undertake in partnership with the Federal Government.

Recommendation 1: Continue to work with the blood cancer community to implement the actions in the National Strategic Action Plan for Blood Cancer – particularly priority actions that address the issue of preventable deaths.

The People Living with Blood Cancer Survey found that less than half of patients reported receiving a written care plan, which is inconsistent with clinical best practice and current Optimal Care Pathways endorsed by all jurisdictions through the then-Council of Australian Governments.

This contributes to poor understanding of diagnosis and treatment options and may compound the multi-factorial issues face by blood cancer patients, such as immunosuppression, infections, vaccination, diet and exercise, which can lead to poor survivorship outcomes and low adherence to recommended follow-up care.

The development of minimum standards or a template for written treatment and survivorship care plans is considered a critical recommendation.

Recommendation 2: Ensure a nationally consistent, minimum standard approach to written communications to patients about treatment and care, through development of minimum standards or a template for written treatment and survivorship care plans for blood cancers.

As the treatment of cancer is transforming many cancers from acute, life-threatening disease to long-term chronic conditions, patient reported outcomes (PROs) are increasingly recognised as important tools for symptom management and adverse event monitoring to enable better patient care, as well as tools to guide investment in research and regulatory decision making.

There is considerable evidence that PROs in an oncology setting can improve patient satisfaction, symptom detection, therapy adherence, clinician-patient communication and patient involvement in care, as well as management of side-effects and utilisation of supportive care. PRO systems have also been shown to reduce presentation to Emergency Departments and frequency of hospitalisation, and improve overall survival and health-related quality of life. In one recent study, overall survival was extended and health-related quality of life improved.[6]

Given the compelling evidence of benefit, and the need for a nationally coordinated approach, a scoping study for PROs in the blood cancer setting is considered a critical recommendation.

Recommendation 3: Ensure a nationally consistent approach to implementing Patient Reported Outcomes (PRO) for blood cancer, by forming a clinical advisory working group of clinicians and patients to undertake a PRO scoping study.

A significant barrier to empowering any person dealing with a cancer diagnosis is the complexity of the healthcare system and accessing reliable, evidence-based information to help them understand their diagnosis, manage their disease and make decisions about their care.

The People Living with Blood Cancer Survey of more than 3,200 people with blood cancer identified that access to evidence-based and trusted sources of information was one of their top priorities. More than one in five people reported feeling “completely uncertain” or “having lots of questions” about their diagnosis, and one in ten about their treatment plan.

Some patients may be able to access patient support services and information through specific patient organisations. Others may be dealing with a rare or less common cancer where there is no dedicated patient organisation that can offer any assistance. This situation is not unique to blood cancers. For people facing cancer more broadly, there are complicated issues involved in diagnosis, treatment, choosing a doctor, living with their cancer, maintaining quality of life, palliative and end of life care, for which an information pathway that guides patients through their journey is a high priority.

The Cancer Council has supported a need to develop a broader national information strategy for all cancers, which is needed now to improve the provision of information to people affected by cancer.

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[6] *Review of Evidence for Action: Summary of key literature and data (June 2020)*, prepared by Insight Economics as a supporting document for the *National Strategic Action Plan for Blood Cancer*, accessed at: https://www.leukaemia.org.au/wp-content/uploads/2020/09/National-Strategic-Action-Plan-for-Blood-Cancer_Review-of-Evidence-for-Action-1.pdf. Note section 2.3 Enable patient-centred care through system for Patient Reported Outcomes (pp. 37-53).

This is consistent with the evidence of the People Living with Blood Cancer Survey and with the National Action Plan, which recommends forming an inclusive, patient-focussed and cross-organisational working group to develop a Blood Cancer Information Strategy as part of a broader digital health and information strategy for cancer.

Recommendation 4: Develop a national information strategy for cancer as recommended by the Cancer Council of Australia.

As evidenced in *The New Frontier - Delivering better health for all Australians*, the final report of the Health, Aged Care and Sport Committee's *Inquiry into approval processes for new drugs and novel medical technologies in Australia* in late 2021, the landscape for the registration and subsidisation of new medicines, diagnostics and services in Australia is and not fit for purpose, especially for people living with blood cancers and especially rare blood cancers where speed of approvals and subsidy is critical for survival.

The currently rapidly-evolving technology landscape for blood cancer presents challenges for patients, governments, service providers, researchers, clinicians and industry – in what is an already complex regulatory, funding and research landscape. The Blood Cancer Taskforce presented evidence to the Inquiry on these matters as relevant to the blood cancer context, and are pleased to see that the final report addresses these issues in detail.

The National Action Plan recommended that a multidisciplinary working group should be established to address challenges for patient access to novel and specialised therapies – and develop plans to improve access to clinically important technologies that are not publicly funded and reduce inequities to access to standard of care diagnostics and therapies.

In light of the release of the report of the Committee, we propose that this Working Group be formed to work closely with the Department of Health and Cancer Australia to deliver a plan that complements the realisation of the recommendations of the Committee in *The New Frontier*.

Recommendation 5: Establish a multidisciplinary Enabling Access Working Group to deliver a plan for improving national, equitable access to clinically important technologies that are not publicly funded and a plan for reducing inequities to standard of care diagnostics and therapies as defined by the clinical guidelines across jurisdictions and public-private settings.

Strong evidence is available to show that exercise substantially improves outcomes for patients across a range of dimensions including fatigue, pain, distress, anxiety, depression, declines in bone health, cognitive and cardiovascular function, as well as increased health related quality of life.

Exercise improves survival outcomes for people living with blood cancer and is safe, even after undergoing a transplant, but current strategies to engage people with cancer in exercise are not working. As a result, very few people with cancer are realising the widespread benefits exercise provides to restoring health and wellbeing during and after treatment.

In addition to exercise, there is a wide range of evidence that supports health and wellness benefits of other lifestyle services, such as dietetics and wellness programs (including smoking and alcohol cessation) for cancer patients.

The benefits of such programs are not specific to blood cancers however could be trialled in the blood cancer setting to generate the required evidence of benefit for greater public subsidy to access such programs. Depending on the outcomes of the patient engagement and understanding of patient goals, clinicians should refer people to a program for cancer patient-friendly exercise and lifestyle services, depending on their individual support requirements. The program should trial referrals to a range of supervised and self-directed programs in both healthcare provider and community settings, activity levels and in turn quality of life and survival.

The Leukaemia Foundation sought to include this project in the partnership agreement with the Commonwealth in December 2021, and in the future, we will be seeking further partnership arrangements with the Commonwealth to progress this action. We look forward to working with the Commonwealth on integrating this work with the findings of the related Inquiry into approval processes for new drugs and novel medical technologies in Australia, and the upcoming 2022 Health Technology Assessment Review.

Recommendation 6: Fund a clinical trial program to develop evidence for MBS item number listing for cancer-patient friendly exercise and lifestyle services.

Budget implications

Costs have been developed independently by Insight Economics for the Blood Cancer Taskforce and are provided below (Table 1). Additional background and cost assumptions can be provided on request.

Table 1: Budget implications

	Total	2020-21	2021-22	2022-23	2023-24	2024-25	2025-26	2026-27
Current Phase 1 projects (Funded by Government)	**$1,597,500**	**$602,500**	**$995,000**	**$0**	**$0**	**$0**	**$0**	**$0**
Blood Cancer Taskforce, implementation work and LF support	$427,500	$302,500	$125,000	-	-	-	-	-
Action 2.1.1 & 2.2.1 Clinical and diagnostic guidelines	$700,000	-	$700,000	-	-	-	-	-
Action 2.1.1 OCPs	$470,000	$300,000	$170,000	-	-	-	-	-
Current Phase 1 projects (Funded by Leukaemia Foundation)	**$913,343**	**$0**	**$0**	**$669,436**	**$243,907**	**$0**	**$0**	**$0**
Action 3.1.1 Blood Cancer Research Roadmap	*$181,623*	-	-	$181,623	-	-	-	
Action 1.6.1 Epidemiological study in Indigenous people	*$731,720*	-	-	$487,813	$243,907	-	-	-

Total for Phase 1 projects funded by Government and Leukaemia Foundation	**$4,108,343**

Remaining Phase 1 projects to be funded	**$12,857,041**	**$0**	**$0**	**$1,273,378**	**$2,444,424**	**$520,425**	**$0**	**$0**
Blood Cancer Taskforce and secretariat funding	$176,789	-	-	$58,930	$58,930	$58,930	-	-
Action 1.3.1 Written care plan templates	$282,862	-	-	$282,862	-	-	-	-
Action 4.3.1 Improve access to therapies	$1,107,588	-	-	$184,598	$461,495	$461,495	-	-
Action 1.5.1 Patient Reported Outcomes	$1,120,227	-	-	$505,707	$614,519	-	-	-
Action 2.5.2 Exercise Oncology in Blood Cancer clinical trial	$9,929,576	-	-	$241,281	$1,189,481	$2,593,952	$3,283,146	$2,621,717
Leukaemia Foundation personnel support	$240,000	-	-	-	$120,000	$120,000	-	-

Total of current funding proposal	**$12,857,041**