

19 July 2023
Dr Dawn Casey PSM FAHA
Deputy CEO
NACCHO

Via email: rebecca.rees@naccho.org.au

Dear Dr Casey,

Re: ABORIGINAL AND TORRES STRAIT ISLANDER CANCER PLAN DRAFT

Thank you for the opportunity to provide a submission to *the Aboriginal and Torres Strait Islander Cancer Plan (the Plan)*.

The Leukaemia Foundation is the only national organisation representing all Australians with blood cancer. For over 45 years we have provided a variety of supports and services, and funded life-changing research. We provide evidence-based policy advice and amplify the voices of those affected by blood cancer.

We share your vision for collective community-led action to address the inequitable and avoidable differences between Aboriginal and Torres Strait Islander Australians and other Australians in cancer prevention, screening, early diagnosis, treatment, and supportive care.

We acknowledge and support the person-focused and the deeply culturally centred approach of the Plan. The five focus areas are to be commended. We celebrate your ambition for the Plan to be different. We encourage you to extend this ambition further to refine the Plan so that its individuals and population level approaches go beyond current norms in cancer control and **overtly** do not leave any person nor disease-type unaddressed.

Specifically, this submission suggests the following refinements to build on the existing extremely comprehensive and holistic vision for cancer care:

1. A more overt focus on developing new cancer control methods for low survival, non-screenable cancers including blood cancers;
2. Integrating community led supportive care organisations into the model of care;
3. Aligning the Plan with the broader strategic objectives of the Australian Cancer Plan esp. workforce, research, application of new therapies and dynamic foundations
4. Creating a network of implementation partners to work with NACCHO and the ACCHOs

Thank you for your consideration of the issues highlighted in this submission. Please contact Mr Tim Murphy, GM Blood Cancer Partnerships (0435 969 037 or tmurphy@leukaemia.org.au) and we will provide further details as needed.

Sincerely,



Chris Tanti
Chief Executive Officer

About the Leukaemia Foundation

The Leukaemia Foundation is the only national organisation that represents all Australians living with blood cancer – including leukaemia, lymphoma, myeloma, myeloproliferative neoplasms (MPN), myelodysplastic syndromes (MDS) and amyloidosis.

We provide the following free services to patients:

- Personalised information and support from highly trained Blood Cancer Support Coordinators for patients and their loved ones alongside a range of health and wellbeing services;
- Accommodation near major hospitals around Australia and help getting to and from the many appointments that come with a blood cancer diagnosis; and
- Trusted information to empower people to navigate the road ahead, including critical education, support groups, booklets, newsletters, and online information.

The Leukaemia Foundation's research program drives rapid advancements in blood cancer treatments, encourages the careers of promising scientists, and helps give Australians access to global clinical trials.

Context: the imperative to improve Blood cancer survival

This year 19,403 Australians will be newly diagnosed with a blood cancer. This is equivalent to 53 people every day or one person every 27 minutes.

Over the past 10 years, the **incidence of blood cancer has increased by 47%**, and 135,000 Australians are now living with a blood cancer. Sixteen Australians will lose their life to blood cancer each day and 1 in 3 people diagnosed with a blood cancer will not survive five years after their diagnosis.

Blood cancers require, in many instances, highly specialised and complex care throughout the treatment period. Many blood cancers can have repeated acute episodes of treatments, remission, and relapse.

Some blood cancers can become refractory to current treatments, leaving patients with very limited options. Treatments are often aggressive, highly toxic and can result in debilitating lifelong side effects.

The health and social imperatives for action are underlined by an economic imperative. By 2035, **blood cancer will cost the economy \$71.9 billion each year**. Myeloma and leukaemia are the first and third most expensive cancers for our health system to treat.¹ Around 43% of individuals report out-of-pocket expenses, and more than one in three of these incur more than \$A5,000 in cost.

¹ Merollini, K.M.D., Gordon L.G., Ho, Y.M., et al., 2022, Cancer Survivors' Long-Term Health Service Costs in Queensland, Australia: Results of a Population-Level Data Linkage Study (Cos-Q), Int J Environ Res Public Health, 19(15), 9473, doi: 10.3390/ijerph19159473.

Using the latest available cancer registry data, the *State of the Nation: Blood Cancers in Australia 2023* report showed that if best practice clinical treatment and care for blood cancers were consistently implemented, potentially up to 29 per cent of blood cancer mortality could be prevented.

However, this on its own will not address blood cancer mortality, especially for blood cancers with the poorest prognosis. Consequently, significant improvements in survival for people living with blood cancer cannot be realised without new investment in research into new therapies and care.

Context: Blood cancers combined are in the Top 3 for incidence and for mortality in Australia

When combined, blood cancers are in the top three for incidence and mortality in Australia along with breast, lung, and bowel cancers. Improved survival outcomes for breast, bowel and lung cancers can be associated with investments in research and major public health interventions, particularly those focussed on early screening and detection. These public health interventions are not applicable for blood cancers as with current knowledge, blood cancers are neither preventable nor can be easily identified through population screening methods.

Blood cancer mortality rates are increasing compared with concurrent reductions in the other major high incidence cancers.

By 2035, blood cancer diagnoses per year are predicted to double (projected to be 36,000) and an estimated 275,000 Australians will be living with a blood cancer. Between 2022 and 2035 it is predicted that over 155,000 Australians will die from blood cancer. The social and economic burden of these increases have been articulated in the *State of the Nation Report: Blood Cancer in Australia 2019*.

Blood cancers are complex group of individually rare or uncommon diseases, each with a host of genetically distinct subtypes requiring bespoke treatment and care. Blood cancer treatments are complex, often requiring many lines of treatments, involving combination chemotherapies, immunotherapies and cell-based therapies and transplants. The treatment pathway for a patient may not be streamlined or time-limited, with many people needing to be under active treatment for very long periods of time, and in some instances for the remainder of their life.

Precision medicine is rapidly becoming a key component of cancer therapy. Blood cancer has been at the forefront of precision medicine discoveries and treatments, but these therapies can come at a significant cost and with regulatory and reimbursal complexity. Access to appropriate precision medicine necessitates access to precision diagnostics, and while access to subsidised tests has improved in recent years, there are still significant barriers to access for many people living with blood cancer.

Treatments in blood cancer are complex and many are prolonged. Treatments may range from well understood multi-agent chemotherapy to stem cell transplant to more innovative oral immunotherapies and/or CAR-T therapies. Recent scientific advances are significantly altering standard of care and keeping abreast of these across all treating centres is complex.

Context: Blood cancer in First Nations Australians

Current health data show that cancer is contributing to the gap in health outcomes for Aboriginal and Torres Strait Islander people and that survival rates across all cancers are lower for Indigenous Australians compared to other Australians.

The *National Strategic Action Plan for Blood Cancer (NAP)* developed by the Blood Cancer Taskforce identified that:

- there is under-diagnosis and under-reporting of blood cancers in all jurisdictions across Australia;
- this is likely to be exacerbated for Aboriginal and Torres Strait Islander people; and
- the incidence and prevalence of blood cancers in Aboriginal and Torres Strait Islander communities is likely significantly under-diagnosed and under-reported.

Publicly reported data from the AIHW on the incidence and survival rates of blood cancers in Aboriginal and Torres Strait Islander communities is largely limited to lymphoma with no data currently reported for leukemia, myeloma, or other blood cancers.

What data are available, however, suggests that Aboriginal and Torres Strait Islander people experience poorer health outcomes for blood cancer than other Australians. Multiple intersecting factors contribute to lower rates of presentation, later diagnoses, lower rates of service utilisation and poorer outcomes. Aboriginal and Torres Strait Islanders are also less likely to be able to find a matched donor if they require an allogenic stem cell transplant, due to a lack of Aboriginal representation on the Australian Bone Marrow Donor Registry.

The potential for under-reporting and the absence of consistent, reliable data on incidence and outcomes across all blood cancer sub-types in the Aboriginal and Torres Strait Islander population are challenges to ensuring high-quality, equitable care and informing policy development.

The *National Strategic Action Plan for Blood Cancer* is a blueprint for change in the lives of people living with blood cancer. It reimagines the way treatment and care of blood cancer patients is planned and administered and is underpinned by the fundamental principle that every Australian with a blood cancer should have equitable access to the best information, treatment, and care wherever they live and whatever their background.

The *National Strategic Action Plan for Blood Cancer* is being incorporated into the soon to be released Australian Cancer Plan. Both Plans recognise the challenges for Aboriginal and Torres Strait Islander people living with cancer.

A key recommendation of *National Strategic Action Plan for Blood Cancer* was to commission an epidemiological study of blood cancer in Aboriginal and Torres Strait Islander populations to better understand limitations, improve data collection and statistic on blood cancers.

Action 1.6 Address challenges for Aboriginal and Torres Strait Islander people with blood cancer

- 1.6.1 In consultation with organisations managing current data collection systems (e.g., hospitals, state cancer registries, AIHW), commission an epidemiological and health services implementation research study to better understand limitations, improve data

collection and statistics on blood cancers and to enable culturally sensitive care that improves primary health attendance and hospitalisation rates.

In 2022 the Leukaemia Foundation and the Federal Government entered a public-private partnership to continue to fund actions outlined in the National Action Plan. As part of that partnership the Leukaemia Foundation has committed \$730,000 to funding the first stage of the epidemiological study of blood cancer in Aboriginal and Torres Strait Islander populations. This initiative is fully supported by the Commonwealth with representatives from Cancer Australia taking part in the delivery. The project is currently in development.

Specific Response: Maximising early detection and diagnosis: developing new cancer control methods for low survival, non-screenable cancers including blood cancers.

We commend the Plan for Identifying focus Area 3: Timely Screening and Early Diagnosis and specifically 3.3 Prompt diagnosis in a supportive patient-led clinical environment of any sign and symptom suspicious of cancer.

Rare and less common cancers comprise approximately a third of all cancer diagnoses, and approximately 40% of all cancer deaths. Many of these cancers are non-screenable. Most blood cancers are either rare or very uncommon cancers.

While overall cancer survival in Australia has steadily increased for all cancers combined, improvements in cancer survival vary by cancer type and for a few cancers there has been a decrease in survival outcomes over time. Many rare and uncommon cancers have low survival rates.

Traditional tools for reducing preventable mortality in cancer have included screening and public health promotion campaigns. This is evident, for example, with the success of the multi-pronged approach to cervical cancer, which involved long-term screening plus HPV vaccination programs. The Plan has a strong focus on improving the prevention and early detection of cancer through improved population screening.

By their very nature, blood cancers are not screenable. Blood cancers can affect anyone at any stage of life, anytime and anywhere. Blood cancers are uncommon or rare, many have survival rates lower than 70% and by their very nature are spontaneous, so they are therefore challenging to readily diagnosis in primary care settings.

Traditional population health cancer control mechanisms such as screening are not appropriate as early detection methods.

This, too, is the case for many other cancers, therefore the Plan should focus on innovative strategies to engage with the diverse range of Aboriginal and Torres Strait Islander communities while minimising undue anxiety as well as to develop symptom decision support tools to assist General Practitioner (GP), along with education for primary care staff and GPs.

We understand that up to 1/3 of blood cancer deaths can be avoided through the consistent adherence to agreed national standards of timely and accurate diagnosis, treatments, and care.

Further implementation of the standard setting work which is currently underway in the blood cancer community will assist in this regard. Minimising discrepancy between the primary and tertiary care systems will also assist in embedding current best practice at Optimal Care Pathway (OCP) levels across all levels of care.

But getting a timely and accurate diagnosis and a referral to the right specialist can be a major challenge for people diagnosed with a blood cancer. Delays in an accurate diagnosis can result in improper or delayed treatment, potentially limiting treatment choices and impacting a patient's quality of life and can ultimately cost the patient their life.

RECOMMENDATIONS

We believe the Plan would be enhanced through the adoption of new goals relating to:

- Integrating alternative early detection methods for blood cancers and other non-screenable cancers into the narrative of the Plan
 - e.g page 14: What are the Determinants of Health

*This Aboriginal and Torres Strait Islander Cancer Plan acknowledges the cultural and social determinants of health as essential to improving cancer outcomes for Aboriginal and Torres Strait Islander peoples through more responsive and targeted cancer prevention, **alternative early detection methods**, treatment, and care.*
 - Page 16 Add new focus area: A focus on non-screenable cancers and subsequent articulation through the Plan esp in Area of Focus 3 Timely Screening and Early Diagnosis
 - Page 21 Enablers for change 1.4 Awareness, communication, and coordination universal across the cancer continuum.
- Developing initiatives such as community engagement and education and symptom support tools for GPs aimed at improving prompt and accurate diagnosis and appropriate referral to specialists of low survival, non-screenable cancers, including blood cancers.
- Utilising the Aboriginal and Torres Strait Islander Optimal Care Pathways and the suite of eleven (11) blood cancer OCPs to guide service planning and delivery.
- Creating a service directory where specialists in blood cancer subtypes are more easily identified to empower and support an individual's cancer care planning, this will empower patients and their families and improve transparency of health care delivery and expectations; especially for those dealing with rare and/ or a blood cancer with complex care needs

Specific Response: Integrating community-led supportive care organisations into the model of care.

We commend the Plan for Identifying Focus Area 4: Improving the health system at all stage of individual cancer journeys.

There have been several recent studies investigating models of care and the role of community based supportive care organisations and cancer navigators. They found there are a variety of unmet needs in the current health system and the more effort is required to ensure all people with cancer have access to the specialised care and support required to improve outcomes for them, their family, and carers.

The unmet needs cover the following domains:

- Financial
- Health system and unmet information needs
- Psychological
- Physical and daily living
- Patient care and support
- Relationships/social

Existing initiatives covering specialist cancer nurses, palliative care teams, hospital based multi-disciplinary care teams and community based and primary care services provide discrete yet non-networked care.

There is an opportunity to efficiently integrate these services to the continuum of care for Aboriginal and Torres Strait Islander Australians.

RECOMMENDATION

We believe the Plan would be enhanced through the adoption of new goals relating to enhancing the continuity of care model by:

- Integrating community-led disease specific supportive care organisations such as the Leukaemia Foundation for blood cancer into the model of care
- Leveraging the educational, navigation and supportive care resources of disease specific supportive care organisations such as the Leukaemia Foundation to fast-track the delivery of supportive