

National Preventative Health Taskforce
NPHS@health.gov.au

19 April 2021

Dear National Preventative Health Taskforce

Re: Draft National Preventive Health Strategy Consultation Submission

The Leukaemia Foundation welcomes the opportunity to provide a submission on the Draft National Preventative Health Strategy.

The Leukaemia Foundation is the only national organisation that represents all Australians living with blood cancer. We provide practical and emotional support to Australians diagnosed with a blood cancer at no cost, thanks to the generosity of the community through our fundraising efforts.

Blood cancers are a complex set of diseases that can affect anyone at any stage of life and 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.

Advances in treatments and care are transforming the way some Australians live with a blood cancer; however, incidence rates are increasing and people still face significant challenges accessing the best practice treatment and care they need to improve their chances of survival and quality of life.

Today, blood cancers are the second most diagnosed and the second biggest causes of cancer death in Australia. Australian Institute for Health and Welfare 2020 statistics show that:

- Incidence - breast cancers are the most diagnosed cancer (19,974), followed by blood cancers (17,321) and prostate cancers (16,741).
- Mortality - lung cancer is the leading cause of cancer death (8,641), followed by blood cancers (5,631) and colorectal cancers (5,322).
- Blood cancers are the most diagnosed cancers for Australian children aged 0-14 and the most common cause of cancer death for girls and women aged 15-24.
- Incidence rates of blood cancers are also increasing. The cause for this increase is unknown.

The Leukaemia Foundation's priority is to ensure that all Australians living with blood cancer have access to the best therapies and treatments available, which improve time spent in remission, survival and quality of life.

We appreciate the opportunity to contribute to this this consultation, and previously to the Consultation Paper in December 2020. Many of the comments that were provided by the

Leukaemia Foundation in December remain relevant to the Draft National Preventive Health Strategy (hereafter referred to as the “Draft Strategy”), and bear reiteration.

Overall comments on the Draft Strategy

In broad terms, the adage that an ounce of prevention is worth a pound of cure is an apt one for any health strategy. The Leukaemia Foundation agrees with the intent of the Draft Strategy’s vision, and appreciates that the Draft Strategy is not the singular strategy by which Australia’s health policy direction will take, however we are concerned that it is missing key elements and interactions, particularly for people with blood cancer.

The Leukaemia Foundation’s own vision is “Zero lives lost to blood cancer by 2035”, which was expanded upon in the National Strategic Action Plan for Blood Cancer to a vision supported by the entire blood cancer community: “Zero lives lost to blood cancer by 2035, underpinned by zero preventable deaths regardless of geography or background, through equitable access to best practice treatment and care for all Australians.”¹

These are clearly defined goals, and the National Strategic Action Plan for Blood Cancer provides well defined recommendations towards achieving those goals.

While the vision of the Draft Strategy is admirable and a useful lens to apply to policy, it needs defined and measurable goals both overall and within the focus areas. The Draft Strategy at present lacks real meaning and therefore it is unclear what activities are required from government departments towards achieving the Draft Strategy.

Many of the aims and targets that follow this vision statement are similarly broad and without real measure. For instance, the target that “the proportion of the first 25 years lived in full health will increase by 2% by 2030” is functionally meaningless without an explanation of what ‘full health’ in this context means, and therefore what a 2 per cent increase actually represents.

Similarly, “investment in preventive health will rise to be 5% of total health expenditure by 2030” lacks explanation for how health funding is considered to be split between “preventative” and “non-preventative” and why that needs to be rebalanced. Much of the health spend is unavoidable, and while some may be averted through preventative health expenditure, the expenditure that cannot be avoided through these means is always going to represent the largest slice.

The Leukaemia Foundation believes a whole of government response should explicitly include the need for national leadership and appropriate resourcing to enact the Draft Strategy. It is not addressed in the Draft Strategy how Federal departments and agencies will be tasked and resourced to carry out the strategy, nor how these will translate to state and territory governments, with whom responsibility for health care service delivery lies. The potential for jurisdictional misalignment is high without a clearly defined Federal/state/territory administrative approach.

¹ Blood Cancer Taskforce, 2020, *National Strategic Action Plan for Blood Cancer*, p8, available at https://www.leukaemia.org.au/wp-content/uploads/2020/09/National-Strategic-Action-Plan-for-Blood-Cancer_June-2020.pdf

The Draft Strategy does not address how community-led National Action Plans will be supported and used to deliver evidence-based change. Over the past few years, the Government has supported communities of interest to develop more than 20 National Action Plans, including the National Strategic Action Plan for Blood Cancer undertaken by the Blood Cancer Taskforce. The Draft Strategy should articulate how these National Action Plans, which collectively represent decades of intensive and expert community coordination, engagement and policy development, will be used and built upon to help guide health policy and programs.

Prevention in cancer

The Draft Strategy acknowledges that prevention is broader than primordial and primary prevention, however the focus areas articulated later in the document are much more heavily geared towards primary prevention, in particular. It is not articulated how the Draft Strategy or Government will consider greater preventative measures in the secondary, tertiary or quaternary space, and the Leukaemia Foundation considers this to be a concerning gap.

Cancer remains one of the leading causes of premature death, accounting for around 30 per cent of deaths in Australia. The Draft Strategy identifies that one in three cancer cases can be prevented and then focuses only on this third.

While noting that the two thirds of cancers can't be prevented through modification of risk factors, and that "a focus on research, early detection and accurate diagnosis, and equitable access to treatment and supportive care, is required", the Draft Strategy does not articulate any target recommendations or suggested policy achievements by 2030 towards achieving this. This is a significant missed opportunity.

Prevention in blood cancer

Preventative health strategies are critically important in blood cancers, but in this context prevention largely means aspects such as early detection and precise diagnosis to permit fast and accurate treatment, through to subsequent best practice management of the disease – and it is important that the Draft Strategy reflects nuances such as these in its outlook.

While there are currently no screening or early detection programs for blood cancer, there are a number of secondary preventative measures that can be put in place, made more accessible and/or improved. These include:

1. Reducing variation in treatment and care through the development of national standards for quality and safety, including nationally consistent clinical guidelines.
2. Improving the accuracy of diagnosis through the development of guidelines for quality in pathology, reviewing pathology services nationally, and making available genetic and genomic testing part of the standard of care.
3. Improving patient quality of life by making consistent screening for supportive care referrals part of the standard of care, enhancing survivorship support, and increasing the availability of cancer-friendly rehabilitation services.

Preventative health measures of this nature in the blood cancer environment, that focus on the early and accurate detection and best practice management of the disease to reduce deterioration and long-term effects, will make significant inroads in addressing preventable blood cancer deaths. These are inadequately considered in the Draft Strategy.

By way of example as to how nuances in prevention and screening are critically important, we know that people treated for cancers with certain chemotherapy drugs have a higher risk of developing secondary cancers later in life, particularly blood cancers such as myelodysplastic syndrome, acute myeloid leukaemia and acute lymphocytic leukaemia.² People treated for paediatric Hodgkin lymphoma or acute lymphocytic leukaemia also at high risk for developing treatment-related secondary cancers in young adulthood, typically leukaemias and lymphomas if treated with chemotherapy.³

These cancers are not strictly preventable (although altering treatment protocols can reduce incidence), but recognising this risk factor for these patients and following this cohort appropriately can help diagnose these cancers accurately and early, which may improve outcomes for these cancers which are typically difficult to treat.

Exercise and blood cancers

Exercise impacts on all domains of health and wellbeing and has been consistently shown to reduce the risk of mortality. A 2019 study found a 19 per cent reduction in risk of mortality from cancer and 40 per cent all-cause mortality risk reduction for people with high levels of physical activity compared to low levels of physical activity.⁴

Strong evidence is available to show that exercise substantially improves outcomes for blood cancer 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.

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.

This is not considered in either the cancer focus area, or in the physical activity focus area (which largely focuses on for psychosocial issues surrounding exercise and its loose associations to health, rather than directly representing exercise as a preventative health activity).

The Draft Strategy also does not consider how to increase support to patients requiring physical activity and exercise programs as part of their supportive care requirements, and there is a lack of consistent acknowledgement of the linkage between increased physical activity and reduced cancer mortality.

² Rheingold, S.R., Neugut, A.I., Meadows, A.T. (2003) 'Therapy-Related Secondary Cancers', in Kufe D.W., Pollock R.E., Weichselbaum R.R., et al., (ed) *Holland-Frei Cancer Medicine. 6th edition*. BC Decker.
<https://libguides.ioe.ac.uk/c.php?g=482485&p=3299762>

³ Ibid.

⁴ Friedenreich, C.M., Stone, C.R., Cheung, W.Y., Hayes, S.C., 2020, Physical activity and mortality in cancer survivors: A systematic review and meta-analysis. *JNCI Cancer Spectrum* 4(1) <https://doi.org/10.1093/jncics/pkz080>

Conclusion

The Draft Strategy states, “for those cancers where traditional preventative measures are ineffective or there are currently no screening programs, a focus on research, early detection and accurate diagnosis, and equitable access to treatment and supportive care, is required.”

The Leukaemia Foundation concurs and looks forward to the future articulation of these activities in the next iteration of the Draft Strategy, and its alignment with the forthcoming Australian National Cancer Plan.

We further note that the National Strategic Action Plan for Blood Cancer provides 21 recommendations, many of which are applicable to other cancers. The National Action Plan is provided as an attachment to this submission.

If you require any further information, please contact Emily Forrest, Head of Policy & Advocacy on eforrest@leukaemia.org.au.

Sincerely,



Chris Tanti
Chief Executive Officer

Background

About us and our work

Every year, more than 17,300 Australians will be newly diagnosed with a blood cancer, and more than 5,600 people will lose their life to blood cancer or related blood disorders. This means every day, 47 Australian men, women and children will learn they have blood cancer, and sadly around 15 people will lose their life to the disease each day.

The Leukaemia Foundation's purpose is to help save lives by creating value and impact for people living with blood cancer and their families. We provide support to people living with blood cancer, including accommodation support where patients and their families need to travel for treatment; we fund and facilitate critical blood cancer research; and we advocate on behalf of people living with blood cancer for reforms that will improve diagnosis, treatment and care.

In 2019-20 alone, the Leukaemia Foundation's 37 Blood Cancer Support Coordinators gave personalised support and care to 8,459 people living with blood cancer, and we provided free, safe, self-contained accommodation to 837 families from rural and regional areas.

Demand for our services tripled during the COVID-19 pandemic, and our outreach program connected more than 3,600 families with our support staff, and over 19,000 people accessed 24/7 help and information through our dedicated information hub.

We also invested \$4 million (and leveraged another \$10 million) in 18 new blood cancer research projects, bringing currently funded projects to 32 in 2019/20. Over the past 30 years we have made a \$51.4 million commitment to blood cancer research and built significant collaborations with Cancer Australia, Haematological Society of Australia and New Zealand, Snowdome Foundation and the Leukaemia and Lymphoma Society in the United States.

Our priority is to ensure that all Australians living with blood cancer have access to the best therapies and treatments available, which improve time spent in remission, survival and quality of life.

Changing the paradigm

For over 40 years, the Leukaemia Foundation has supported people living with blood cancer in Australia. Now we are looking forward to leading a new era of change for the Australian blood cancer community by partnering with industry, government, medical professionals and everyday Australians to realise the goal of zero lives lost to blood cancer by 2035.

The Leukaemia Foundation has developed an access strategy, '*Breaking barriers for people living with blood cancer*', which will concentrate our time, talents and resources on three critical areas for every Australian with blood cancer:

- Inform - access to trusted information and education to empower informed choices.
- Treat - access to best practice treatment and the latest trials, tests and diagnostic tools.
- Care - access to essential supportive care to improve quality of life.

That strategy is informed by the evidence-based *State of the Nation: Blood Cancer in Australia* report and the blueprint for reform outlined in Australia's first National Strategic Action Plan for Blood Cancer, and will help unite the blood cancer community in pursuit of the shared goal of zero lives lost to blood cancer by 2035.

Further information about the findings and recommendations from the *State of the Nation* report and the National Action Plan is provided below.

State of the Nation: Blood Cancer in Australia

In September 2019, the Leukaemia Foundation released the *State of the Nation: Blood Cancer in Australia*⁵ report, a first of its kind analysis to quantify and articulate the challenges and opportunities that influence survival and quality of life for people living with all blood cancers.

As part of this research, we also undertook a survey of people living with blood cancer and their families and received over 3,200 people responses. Respondents were widely distributed across sub-types, states and territories, regional vs metropolitan, age and private health insurance status, providing a representative and statistically powerful sample.

Modelling using AIHW and State Cancer Registry data developed for the *State of the Nation* found that blood cancers are amongst the most prevalent and deadly cancers affecting Australians today. Over 110,000 Australians of all ages are living with a blood cancer in Australia today, and by the year 2035, modelling predicts that number will increase to around 275,000 people. Over 186,000 people will die as a result of blood cancer between 2018 and 2035, and the annual cost to the health system of treating and caring for people with a blood cancer in 2035 is expected to reach \$10.9 billion.

People with blood cancer can face significant challenges accessing the best treatment and care they need – from the moment they walk into their doctor's office, right through to the type of tests, treatment and supportive care they are offered.

The patient survey of more than 3,200 people living with a blood cancer in Australia⁶ found that less than 30 per cent of respondents reported having access to genetic testing to inform their diagnosis and treatment; less than 40 per cent were given a written care plan or referred to patient support; and less than 20 per cent participated in a clinical trial.

In addition, people with blood cancer living in regional and remote areas report longer delays to see a haematologist (almost a third of patients report that it took more than a month to see a haematologist after first presenting to their GP, and for almost one in five patients it took more than two months); reduced access to genetic or genomic testing to inform both their diagnosis and treatment; and are 10 per cent less likely to report having access to oral over IV chemotherapy and 10 per cent less likely to report receiving a drug therapy.

More than a third of patients living in non-metropolitan areas are more likely to report that they felt completely uncertain about their treatment plan and are 25 per cent more likely to report that they did not know where to go if they had questions about their diagnosis, treatment or supportive care.

Substantial differences in treatments and care options available for people depending on their home state or whether they live in a regional/remote area are of significant concern and have a determinantal impact on an individual's survival and wellbeing.

Survival outcomes data collected as part of the *State of the Nation* report indicates that 13 per cent of blood cancer deaths could be prevented through the consistent application of currently

⁵ Leukaemia Foundation, 2019, *State of the Nation: Blood Cancer in Australia*, available at <https://www.leukaemia.org.au/how-we-can-help/advocacy-and-policy/state-of-the-nation/>

⁶ Ibid.

available, evidence-based best practice. Specifically, if best practice survival rates achieved in Australia today were realised nationally:

- Approximately 5 per cent of deaths could be prevented through reforms to reduce variation in survival outcomes for people living in regional and remote areas
- Consistent application of best practice treatment and care across all jurisdictions has the potential to reduce the number of deaths expected by a further 8 per cent, yielding a cumulative 13 per cent improvement.

Collectively, that means that 22,000 deaths could be prevented by 2035 simply by doing what has been proven to work and is already funded in Australia, more consistently across all jurisdictions. Addressing these differences, and the 13 per cent disparity in survival outcomes, is therefore our first priority for action.

The National Strategic Action Plan for Blood Cancer

Following the release of *State of the Nation*, the Leukaemia Foundation was commissioned by the Federal Government in 2019 to establish the Blood Cancer Taskforce⁷ and develop Australia's first National Strategic Action Plan for Blood Cancer⁸ ('National Action Plan') with the blood cancer community. The National Action Plan was launched by The Hon Greg Hunt MP, Minister for Health, on 27 September 2020.

The National Action Plan provides an evidence-based blueprint to coordinate and accelerate national efforts to improve survival and quality of life for people diagnosed with blood cancer and to support their carers and families. It sets out the necessary priority areas, objectives and actions for addressing the challenges of blood cancer to achieve the vision of zero lives lost to blood cancer by 2035, underpinned by zero preventable deaths regardless of geography or background, through equitable access to best practice treatment and care for all Australians.

Through collaboration with patients and leaders in the blood cancer community, the National Action Plan identifies four major priorities to improve outcomes for people living with blood cancer and their families:

- Empower patients and their families
- Achieve best practice
- Accelerate research
- Enable access to novel and specialised therapies.

These priority areas are supported by 21 recommendations across the entire blood cancer ecosystem: from research, clinical trials, precision medicines, treatment access and reimbursement, through to achieving best practice in diagnosis, treatment and supportive care. It builds upon a long history of hard work and success in the blood cancer community and redoubles focus on addressing the survival gaps which still exist for Australians dealing with a blood cancer.

The 21 recommendations in the National Action Plan work together to reduce overall blood cancer mortality and will require ongoing coordination and commitments from across the blood cancer

⁷ Leukaemia Foundation, 2021, *Blood Cancer Taskforce*, available at <https://www.leukaemia.org.au/how-we-can-help/advocacy-and-policy/blood-cancer-taskforce-2/>

⁸ Leukaemia Foundation, 2020, *National Strategic Action Plan for Blood Cancer*, available at <https://www.leukaemia.org.au/national-action-plan/>

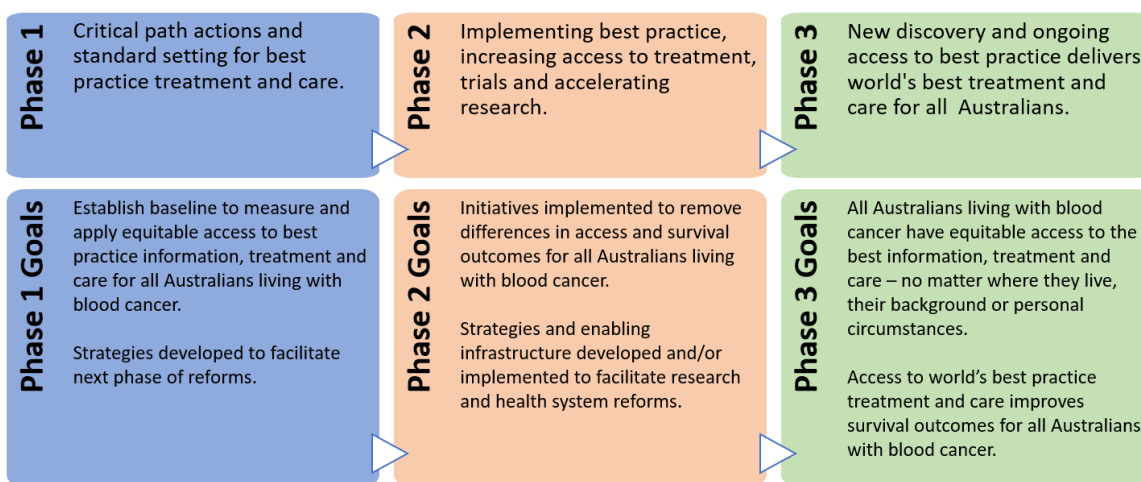
community over many years. Within this multi-year reform agenda, there are some recommendations that should be enacted first as the necessary scaffolds for future work.

The Blood Cancer Taskforce has endorsed a phased approach to implementation (see Figure 1) with Phase 1 focusing on recommendations that seek to set the standard and establish a baseline for achieving best practice information, treatment and care. This is the first step towards addressing differences in survival outcomes between jurisdictions, and between people living in metropolitan compared to regional areas.

This will also help address challenges for patients from other high-risk groups (including Indigenous Australians and people from Culturally and Linguistically Diverse backgrounds with blood cancer) because these actions seek to remove variations in survival outcomes by setting the standard for best practice for all Australians with blood cancer – no matter where they live, their background or personal circumstances.

Subsequent phases of implementation (Phase 2 and 3) seek to implement agreed best practice, increase access to new treatments, trials and accelerate research efforts for technologies with curative potential.

Figure 1: National Action Plan recommendations -phases and goals of implementation



While the recommendations seek to achieve lasting change for people living with blood cancer, many of these challenges and potential solutions are not unique to blood cancer and could also be applicable to other cancers.

Many of these reforms and specific recommendations either rely on or will benefit from Federal Government leadership.