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Blood Cancers and the Australian Cancer Plan

The Blood Cancer Taskforce bring together Australia's leading blood cancer patient group and all significant blood cancer individuals and organisations into one consortium focused on addressing the incidence and mortality challenges of the diverse set of uncommon and rare cancers in blood. The Leukaemia Foundation is the secretariat for the Taskforce.

We are calling upon Cancer Australia to

1. add specificity to the population health initiatives in the ACP for low survival, non-screenable cancers including blood cancers and
2. add emphasis to supporting additional innovative research and increasing access to new treatments and care.

Blood cancers represent approx. 10% of the cancer burden in Australia. Blood cancers are currently unfortunately, low survival (below 70%), non-screenable and increasing in incidence.

We are supportive of much of the direction of the first national Australian Cancer Plan (ACP) as it will provide tumour-agnostic enabling infrastructure. We applaud its 6 pillars and especially as its continuum of care, performance-based and population health focus are significant step changes. We support the focus on inclusion, equity across all cancers and for all Australians and especially its consideration of hard to reach and/or underserved populations.

We appreciate the comprehensive continuum of care nature of the ACP along with its intent to leverage community, public and private providers in primary, tertiary and supportive care settings.

The draft plan aims to make significant strides in the integration of optimal care (optimal care pathways, clinical guidelines and their embedded standards of care and national performance reporting) with data collection, evaluation and reporting systems. These along with the proposed national network of comprehensive cancer centres and multi-disciplinary navigation models based on individuals' needs will see improvements in patient reported and clinical outcomes.

The Leukaemia Foundation commissioned the *State of the Nation Report Blood Cancer in Australia 2022* and some of its key insights are included in this commentary. The Report is due for public release in early 2023.

Our commentary is aimed to be complementary and additive to the current draft of the ACP and is focused on blood cancer specific patient centred information, models and standards of care along with investment in innovative scientific advances.

We believe equitable and timely access to early diagnosis, treatment, and supportive care is a fundamental linkage between the guiding principles and the strategic objectives of the ACP and, is also a key focus of the Leukaemia Foundation and the Blood Cancer Taskforce as we seek implementation of the National Action Plan (NAP) and alignment with the ACP.

We are concerned, however, that the capacity for the ACP to meet its ten-year ambitions for people living with blood cancer could be hampered if the tumour-agnostic guiding principle is pursued in all instances without any explicit mechanisms or frameworks for addressing disease-specific challenges. We do highlight a major gap in the draft ACP – absence of any emphasis on developing transformative therapies for low survival cancers - and provide rationale for additions to be made to further enhance its relevance and potential for real improvements in cancer control.

We expect the ACP to be iterative over its life, however in this first edition more disease specificity is required to improve outcomes for patients with low survival cancers.

The solutions for low survival cancers are not disease agnostic. The palette of theoretical solutions for such cancers include prevention, earlier detection and transformative new therapies arising from innovative research and enabled by precision diagnostics. For different diseases, one of these is typically more appropriate.

For blood cancers, both as a collective and specifically for rare and uncommon blood cancers as individual diseases, prompt accurate diagnosis, access to best existing treatment and particularly ongoing research for new treatments and care are the priorities to reduce mortality.

To address these concerns, we are seeking consideration of:

1. Initiatives to improve and value the accurate diagnosis of rare, complex-to-treat cancers in primary and community care including rapid adoption of genomics as a standard of care for the diagnosis of blood cancers including investment in diagnostic laboratories and their workforce, and in dedicated pathways for genetically trained pathologists;
2. A research strategy for low survival cancers, including emphasis on development of transformative therapies and a targeted support framework to execute this
3. A national framework to promote equitable and timely access to cellular therapies such as CAR-T
4. Through the ACP or other instruments of government, enhanced efforts to address the access challenges to new treatments and care for rare and low survival cancers;
5. Along with appropriate support to individuals with rare and complex cancers, including the creation of a service directory where specialists in blood cancer subtypes are more easily identified to support appropriate referrals and care;
6. Funding to develop disease-specific models of care, to complement and inform the development of a National Comprehensive Cancer Centre Network;
7. A national approach to the development and sustainable management of OCPs and clinical guidelines;
8. A governance model which allows for national reforms to be implemented in a way that ensures disease-specific clinical and community perspectives should also be addressed;
9. A clear articulation of the Commonwealth, State and Territory governance and oversight of the Plan along with clarity on its ongoing resourcing and implementation approaches.

Understanding blood cancers in Australia

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, incidence of blood cancer has increased by 47%, and it is now estimated that 135,000 Australians are living with a blood cancer. 16 Australians will lose their life to blood cancer each day and 1 in 3 people diagnosed with a blood cancer will not survive 5 years after their diagnosis.

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 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 since the development of the NAP, there are still significant barriers to access for many people living with blood cancer.

Blood cancers require, in many instances, highly specialised and complex care for the duration of the treatment period. Many blood cancers can have repeated acute episodes of treatments, remission and relapse. Some blood cancers can become refractory to treatment leaving patients with very limited options. Treatments can be highly invasive and can have extreme toxicity. 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.

Blood cancer in Australia today: Maximising Early Detection

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 ACP 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.

As a result, traditional population health cancer control mechanisms such as screening are not appropriate as early detection methods for blood cancers. This, too, is the case for many other cancers, therefore the ACP should focus on innovative strategies to engage with the general public while minimising undue anxiety, and educate primary care staff and General Practitioner (GP), but not limited to education geared towards the General Practitioner (GP).

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 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 to a timely and accurate diagnosis and 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.

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

- Initiatives including public and GP education aimed at improving prompt and accurate diagnosis and appropriate referral of low survival, non-screenable cancers, including blood cancers.
- the creation of 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 an/ or a blood cancer with complex care needs

Complex care needs: World class health systems for Optimal Care

Unwarranted variation in care is beginning to be addressed by the recent introduction of blood cancer specific Optimal Care Pathways (OCPs). The Blood Cancer Taskforce has also been separately supported to develop a pilot clinical guideline for a single blood cancer sub-type.

We support the approach to evidence-based optimal care as the basis of the integrated National Comprehensive Cancer Centre Network. We are supportive of the introduction of a National Cancer Data Framework by 2025 with performance monitoring by 2028 against OCP key metrics of quality and safety.

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

- funding to develop disease-specific models of care, to complement and inform the development of a National Comprehensive Cancer Centre Network and a ‘tumour agnostic’ model of care; and
- a national approach to the development and sustainable management (the cycle of commissioning, governance, development, dissemination, update, review of clinical guidelines) to reduce preventable mortality, and consideration of initiatives to improve the more rapid adoption of genomics as a standard of care for the diagnosis of blood cancers.

Access to Innovative therapies and Blood cancer research: Strong and Dynamic Foundations

We currently know there are over 120 discrete blood cancers. As our understanding of the genetic basis of blood cancer improves through research, the number of identified blood cancer subtypes is increasing. This “splitting” into smaller and smaller subtypes can challenge traditional approaches to research, to the cost-effective assessment of new therapies and creates a new imperative for strategic research collaboration for impact. Scientific advances are accelerating the development of targeted and curative therapies.

With regards to the importance of research, the 2017 report by the **Select Committee into Funding for Research into Cancers with Low Survival Rates** made a series of recommendations to address the issues relating to low survival cancers. It stated, “The impact of effective research investment is clearly demonstrated by the increased survival rates for people with certain cancers, such as breast and prostate cancer.” It is clear that this also applies to blood cancers, indeed the major barriers to addressing mortality from blood cancer include inadequate understanding of disease biology and a consequent lack of curative therapies for many specific subtypes. Investments in research have led to significant advances in the past 15 years. Improved therapies for paediatric cancers have delivered cures for many children, tyrosine kinase inhibitor therapies have enabled people with chronic myeloid leukaemia (CML) to live effectively normal lifespans and more recently, the development of novel cellular therapies is offering the promise of curative treatment for a range of historically low-survival subtypes. Australian discoveries brought now standard therapies – G-CSF, peripheral blood stem cell transplants, venetoclax - that have changed outcomes for patients with low survival leukaemias and lymphomas.

Arising from these recent examples where individuals’ survival outcomes have been transformed through their access to new, innovative, research-based therapies, including from Australian cancer research, we support the Senate Committee’s recommendations for a National Low Survival Cancer Research strategy and its incorporation into the ACP

While many of the Select Committee’s recommendations are pertinent to the ACP, we wish to point out the Report’s overall identification of the real challenges associated with the mortality differential between low survival and high survival cancers. We particularly emphasise the targeted recommendations to address this disparity.

We recommend the ACP explicitly build on the nation’s cancer research expertise to reinvigorate hypothesis-driven basic, translational and clinical trials research to not just improve how we deliver existing care but to transform it through new diagnostics and therapeutics. This is an essential complement to the investment in early detection and prevention goals that are appropriate for other cancers.

We believe that the ACP should include goals to:

1. Define new investment in such areas as genomics, microbiota, diagnostics, immunotherapies, targeted therapies and cellular therapies which hold the potential to address the unmet needs of blood cancer subtypes for which there is currently no cure and where five-year survival is poor.

Australia has unique strengths and capabilities from fundamental science through to translational and clinical practice. These should be strengthened in the ACP.

Australia has unique access challenges in realising the full benefits of novel therapies and precision medicine, as we have a small population i.e. small market for an OECD country. The November 2021 House of Representatives report: *The New Frontier Delivering better health for all Australians* describes how new innovations reflect the new frontier of medicine which is giving hope for better treatments and technologies for conditions ranging from cancers to rare diseases. At its forefront is the development of personalised or precision medicine which is being delivered as our understanding of fields like genomics grows. This report again makes specific recommendations relating to uncommon and rare cancers, especially relating to evidentiary requirements for health technology assessment for cell and gene therapies. We support implementation of these specific recommendations and their incorporation in the ACP.

We are calling for continued development in Australia of globally leading research and through the ACP or other instruments of government, enhanced efforts to address the access challenges to new treatments and care for rare and low survival cancers will enable Australian patients to gain access to life-saving therapies sooner.

The National Action Plan for Blood Cancer: Governance National collaboration and investment

The National Action Plan (NAP) is an evidence-based blueprint to coordinate and accelerate national efforts to improve survival and quality of life outcomes for people diagnosed with blood cancer and to support their carers and families.

The National Action Plan includes 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 for patients – wherever they live.

The Blood Cancer Taskforce is a volunteer network of the leading haematological clinicians, researchers, policy makers and patient groups and individual patient voices in blood cancer in Australia. This leadership forum is a unique collaboration and focused on the governance and oversight of the Plan. The Taskforce is also a resource for the understanding of new advances, challenges and developments in blood cancer.

The Blood Cancer Taskforce has made a major achievement in the national cancer policy environment through the development, and oversight of the first *National Strategic Action Plan for Blood Cancer*. We believe a grouping of blood cancer experts can continue to provide the Federal Government and its agencies with expert disease specific advice on blood cancer issues as a key implementation partner in the delivery of the ACP.

The ACP could be strengthened with a clear articulation of the Commonwealth, State and Territory governance and oversight of the Plan along with clarity on its ongoing resourcing and implementation

approaches. We appreciate the implementation plan is proposed to be launched at the time of the ACP's launch however clarity on its government, health system and community governance should be addressed now. The role of disease specific expert advice and oversight from clinical and community perspectives should also be addressed.

As secretariat for the Blood Cancer Taskforce, the Leukaemia Foundation is keen to see the collective expertise of this leadership forum having a clear advisory role in the ACP's governance to help guide implementation and to incorporate blood cancer specificity to the ongoing oversight of the plan. We anticipate that other cancers would be seeking similar governance representation.

It is critical to the success of ACP that its goals across the 10-year period, and the projects behind them, are specific and measurable, potentially utilising a KPI framework for monitoring and evaluation. We look forward to examining the detail of these projects when they are developed.

Conclusion

We would like to particularly highlight the issue of disease agnosticism as one of the ACP's guiding principle: we appreciate the plan is for all Australian however blood cancers are not like other cancers, and typical coordinated approaches for screening and prevention, which have been shown to work well for many other types of cancer, simply do not apply to blood cancers. We hope Cancer Australia is adopting an agile approach to this principle, to ensure that the specific needs of cancers such as blood cancers can be acknowledged and addressed.

Noting the alignment of the principles of the Australian Cancer Plan with the four pillars of the National Action Plan for Blood Cancer – empowering people living with blood cancer, accelerating research, enabling access to novel and specialised therapies, and achieving best practice - the Taskforce looks forward to seeing these issues reflected, with appropriate measurable goals and accountabilities, in the Australian Cancer Plan and its implementation tools.

Sincerely,



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