

Richard Vines  
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Dear Richard

## **Re: Realising the rights and roles of Australian cancer patients**

The Leukaemia Foundation is pleased for the opportunity to provide insights towards the National Oncology Alliance's upcoming report, "Realising the rights and roles of Australian cancer patients".

As you know, the Leukaemia Foundation is the only national organisation that represents all Australians living with blood cancer. We provide practical and emotional support to Australians with a blood cancer, thanks to the generosity of the community through our fundraising efforts.

We provide support to people living with blood cancer, including accommodation when patients and their families need to travel for treatment; we fund and facilitate critical blood cancer research; and we advocate for reforms that will improve diagnosis, access to treatment and care.

In performing our role as advocates for the 110,000 Australians living with a blood cancer, we have developed two important reports over the last four years. At the very heart of these reports is the patient as a recipient of care, as a taxpayer, and as a citizen. You will see the central organising principle of "An Empowered Patient" upon which the health care system is reformed to provide equitable access to the best possible treatment and supportive care across our vast country. Please take these two reports into consideration as the NoA team develops its upcoming report.

### **State of the Nation: Blood Cancer in Australia**

In September 2019, the Leukaemia Foundation released the *State of the Nation: Blood Cancer in Australia* 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.

To understand real experiences, we undertook a survey of people living with blood cancer and their families, with over 3,200 respondents from across the blood cancer spectrum. 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.

The survey 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.

As you know, this important body of work led to the creation of the Blood Cancer Taskforce, charged by Health Minister the Hon Greg Hunt MP with the creation of a blood cancer community-led strategy. We welcome your continued involvement with the Blood Cancer Taskforce.

### **The National Strategic Action Plan for Blood Cancer**

In September 2020, the Blood Cancer Taskforce released the National Strategic Action Plan for Blood Cancer (the National Action Plan), which sets out the priority areas and actions to address the challenges of blood cancer and to achieve the shared 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 community, we have identified four major priorities for people living with blood cancer and their families: Empower patients and their families; Achieve best practice; Accelerate research; and Enable access to novel and specialised therapies. These priorities are supported by 21 recommendations, from research, clinical trials, precision medicines, treatment access and reimbursement, through to achieving best practice in diagnosis, treatment and supportive care.

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

The Leukaemia Foundation and Blood Cancer Taskforce remain committed to carrying forward the recommendations of the National Action Plan, to honour the voices of people living with blood cancer, their families and carers who were represented in the work in *State of the Nation*. These documents are attached and we ask that they be considered in development of NOA's report.

If you require any further information, please contact Emily Forrest, Head of Policy & Advocacy on [eforrest@leukaemia.org.au](mailto:eforrest@leukaemia.org.au).

Sincerely,



Chris Tanti  
Chief Executive Officer