



Leukaemia Foundation of Australia

***Pre-Budget submission***  
***2025-26***

## INTRODUCTION

Blood cancer is Australia's **second-leading cause of cancer-related death** and the **third-most common cancer**.

It is the **most expensive** cancer for patients and our health system to treat. And unlike other cancers, cannot be addressed through screening or preventative health programs.

Many of its over 120 sub-types are individually rare, leading to additional challenges like limited treatment options, scarce clinical knowledge, reduced support networks, and delayed diagnoses.

Currently:<sup>1</sup>

- **over 150,000 Australians** live with blood cancer
- **6,324** are expected to die this year
- incidence is projected to **rise 47%** by 2035, to more than 275,000.

Urgent action is required to address these growing challenges.

This pre-Budget submission articulates what measures blood cancer patients want and need from Australia's Federal Budget 2025-26. Further detail is at Appendix A.

### **1. Issue: Patients face systemic and financial challenges in navigating blood cancer care**

Australia's fragmented healthcare system makes it difficult for patients to access support and navigate their care.<sup>2,3,4</sup> This worsens outcomes, particularly for those with complex diseases such as blood cancers and/or who face language and education barriers.<sup>5,6,7</sup>

Supportive care, including navigation services, is critical to improving outcomes,<sup>8</sup> yet only one-third of patients have supportive care discussions.<sup>9</sup>

Blood cancer patients also face some of the highest treatment costs of any cancer, often three times the average. Many of these patients experience significant financial hardship, with 32% taking over three months off work<sup>10</sup> and 43% of patients incurring out-of-pocket expenses.<sup>11</sup>

Restrictive eligibility for the Disability Support Pension (DSP) and NDIS compound this burden. Subsequently, and with rising living costs, the Leukaemia Foundation has received a **37% increase in the number of requests for financial help** over the past year.

### **Solution**

Expanding tailored navigation services through community organisations like the Leukaemia Foundation would ensure patients receive essential guidance, reducing stress and improving care.

Revising eligibility for the Disability Support Pension (DSP) and NDIS to include blood cancer patients will ease financial strain, improve access to care, and enhance outcomes.

### **RECOMMENDATION:**

- 1. Assist patients overcome systemic blood cancer care barriers:**
  - a. Support NGOs providing navigation and supportive care services

- b. Ease the financial hardship through reforms to financial support programs that currently exclude many blood cancer patients, including NDIS and DSP.

## **2. Issue: Australians in non-metro areas have poorer blood cancer outcomes**

Blood cancer outcomes are significantly worse for the 41% of patients living in non-metropolitan areas compared to those in cities.

- Regional patients are 17 times more likely to face locational and financial barriers to care.<sup>12</sup>
- Removing the metro-regional divide could save over 7,000 lives by 2035.<sup>13</sup>

Blood cancers, unlike many solid tumours, cannot be prevented or detected through screening. Early diagnosis and access to best-practice care are critical but challenging due to vague symptoms and the rarity of specific subtypes.<sup>14</sup>

Government policies, including the Australian Cancer Plan, recognise rural and regional populations as a priority, yet gaps in diagnosis and care persist.

### **Solution: Fast-track the creation of a new rural and regional care program**

Fast-track a rural and regional care pilot program to improve diagnosis, treatment, and recovery for patients outside metropolitan areas.

Key program elements include:

- **Community education:** Train primary healthcare workers to recognise blood cancer symptoms.
- **Decision-making support:** Develop tools for GPs, including automated symptom alerts.
- **Specialist advice:** Provide "Phone a Friend" access to haematologists for GPs identifying potential blood cancer cases.
- **Wellness program:** Offer patients evidence-based resources for living well post-diagnosis.

Delivered in partnership with primary care providers, this ready-to-go pilot program is a practical step toward ensuring all Australians have equitable access to lifesaving care.

#### **RECOMMENDATION:**

### **2. Address inequitable blood cancer patient outcomes in rural and regional areas:**

- a. Fund a pilot of the Leukaemia Foundation's new program to enable earlier diagnosis of rural and regional blood cancer patients (\$2.2 million over two financial years).

## **3. Issue: Blood cancer patients are missing out on life-saving treatments**

Blood cancer patients in Australia face unacceptable delays in accessing life-saving treatments, even after regulatory approval.

- Subsidising treatments under the PBS can be slow, averaging 442 days for oncology medicines, due to high evidence requirements, limited data for rare cancers, and lengthy pricing negotiations.<sup>15</sup>

- These delays are devastating for aggressive blood cancers like acute myeloid leukaemia, where over 50% of patients die within a year.<sup>16</sup>
- High treatment costs (e.g., \$510,000 for Tisagenlecleucel<sup>17</sup>) make new therapies inaccessible for most, creating an inequitable "postcode lottery."

This contradicts Australia's commitment to equitable healthcare and its National Medicines Policy promising "timely and affordable access to medicines." Fragmented funding and assessment processes further delay innovative therapies like CAR T-cell treatments.<sup>18,19,20</sup>

### ***Solution: Enhance access to newer, life-saving blood cancer therapies***

Australia must accelerate access to life-saving blood cancer therapies. Building on the findings of the HTA Review, it needs to:

- **Adopt flexible funding models** using early and varied clinical data to accommodate rare cancers.
- **Streamline evidence requirements** for subsidy approval, following international examples like the UK's flexible approach.
- **Introduce a "Right to Trial" program** to provide early access to unlisted therapies while generating real-world evidence.

#### **RECOMMENDATION:**

#### **3. Make life-saving blood cancer treatments available to patients:**

- a. Support implementation of Health Technology Assessment reforms to accelerate and modernise treatment funding pathways, update evidence requirements, and support the use of real-world evidence

#### ***4. Issue: Challenges in integrating genomics into cancer care remain***

Genomic testing is vital for blood cancer care, enabling accurate diagnosis, targeted treatments, and fewer side effects.<sup>21</sup> This is crucial for blood cancers, which progress rapidly and are the second leading cause of cancer-related deaths in Australia.

Despite its benefits, access to genomic testing remains limited<sup>22</sup> and inequitable.<sup>23</sup> Only 21% of blood cancer patients report having genomic testing to confirm their diagnosis.<sup>24</sup>

Barriers include high costs, incomplete subsidies, and insufficient data on testing uptake and its barriers. Advisory bodies such as MSAC have found that without systemic access, patients risk misdiagnosis and suboptimal treatment, compromising care quality and outcomes.<sup>25</sup>

#### ***Solution***

Recent steps, such as establishing Genomics Australia, Cancer Australia's proposed genomics framework, and new subsidies for some tests, are promising but insufficient.

Australia must:

- Conduct a comprehensive assessment of blood cancer diagnostic services to identify barriers and improve nationwide access to genomic testing.

- Expand MBS funding to include additional genomic tests, ensuring all blood cancer patients can benefit from equitable, timely access.

These actions will integrate genomics into routine blood cancer care, improving accuracy, outcomes, and equity.

#### RECOMMENDATION:

#### 4. Increase uptake of genomics in blood cancer treatment:

- Undertake a wider strategic assessment of blood cancer diagnostics service delivery across Australia
- Support further MBS listings for blood cancer genomics tests.

### 5. **Issue: Australia's pool of stem cell donors is so low that 75% of donations are from overseas**

Australia's low stem cell donor pool means 75% of donations are sourced from overseas, primarily Germany. This reliance creates significant challenges:

- **Limited supply:** Less than 1% of Australians aged 18–35 (the ideal donor age) are registered, leading to a declining domestic donor pool.<sup>26</sup>
- **High costs and delays:** Overseas donations cost more (\$13.2 million in import fees in 2022–23) and face delays that can impact cell viability.<sup>27</sup>
- **Inequity:** Minority groups and First Nations peoples struggle to find matches, as international registries lack diverse representation.

Low awareness, misconceptions about the donation process, and fragmented governance contribute to insufficient donor recruitment and retention.<sup>28</sup>

#### **Solution: Support stem cell donor recruitment**

The government must support targeted recruitment drives and modernise donor enrolment practices to grow the donor pool.

Key actions include:

- Raising awareness through education campaigns in schools and universities.
- Simplifying registration with initiatives like cheek swab-based enrolment, building on the "Strength to Give" program.
- Targeting younger Australians and diverse communities to increase representation.

These steps, alongside improved governance and aligned recruitment efforts, will secure a sustainable, equitable donor pool to meet clinical demand.

#### RECOMMENDATION:

#### 5. Increase the pool of stem cell donors in Australia:

- Support donor recruitment drives
- Commit to reforming stem cell donation governance and funding.

***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:

1. 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
2. Accommodation near major hospitals around Australia and help getting to and from the many appointments that come with a blood cancer diagnosis
3. 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.

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