

South Australia Cancer Plan: Response to draft plan

Submitted via survey – Questions and answers below.

RESPONSES TO SURVEY QUESTIONS

PRIORITY 1

3. Please provide any comments or feedback on the priority areas 1-6 through the following questions (include where relevant, the specific direction or activity number)

We are particularly interested to know if we need to correct anything, if the intent is correct for a statewide plan or if anything is missing.

Do you have any feedback on 'Priority 1 Enhance Consumer Experience'

Activity 1.6: "Explore opportunities for partnerships between health services and non-government organisations to provide targeted information to cancer patients at critical times throughout the care continuum."

We recommend leveraging disease-specific supportive care organisations such as the Leukaemia Foundation to fast-track the delivery of supportive care.

The Leukaemia Foundation regularly engages in visits and meetings with health services and other NGOs to build and maintain relationships with haematologists and oncology staff to increase awareness of Leukaemia Foundation as an organisation and provides general updates and information regarding our range of services and supports. LF provides disease brochures and other helpful materials for people living with blood cancers to health services. Our community support services can alleviate pressure on the acute health system through the provision of information to patients, emotional support, early identification problems, and appropriate referral to other NGOs.

The Leukaemia Foundation's survey of over 4,600 Australian blood cancer patients found more support is needed across treatment planning, active treatment and post-treatment stages. The top category identified by patients was 'referrals to patient support organisations'.

Referrals to those supportive care services are critical but lacking. In addition to practical supports with bills, accommodation and transport, the Leukaemia Foundation provides a range of resources from booklets and factsheets to seminars and education sessions, and emotional support and assistance with our highly trained support services team. Yet the Leukaemia Foundation's July 2023 "Voice of Customer" service user survey received over 300 responses and shows only one-third were told about our services at diagnosis. This is despite diagnosis being an important time for treatment decisions and a very stressful time for patients.

Activity 1.8: "Explore how to provide simple information to patients on who to contact at various points of a patient's cancer experience (e.g. GP, oncologist)." & **Activity 1.10** "Review and co-design culturally responsive cancer communications resources to enable healthcare providers to communicate respectfully with consumers." & **Activity 1.11** "Develop co-designed cancer resources across the spectrum of care which explain medical terminology and meet the needs of diverse population groups, particularly those with higher cancer incidence, poorer access to care, or worse survival outcomes and in particular, specific resources for Aboriginal and Torres Strait Islander people:"

These activities are important and we would value opportunities to work with Government on their progression. We also recommend these activities note the existing work underway that the Plan could leverage when being implemented.

For example, the Leukaemia Foundation is in the process of developing Guides to best cancer care with 6 guides already published and translated into the 8 most commonly spoken languages in Australia. Five more are being completed. The disease areas are:

- Multiple myeloma
- Chronic myeloid leukaemia
- Chronic lymphocytic leukaemia
- Low grade lymphomas
- Childhood, adolescent, and young adult acute leukaemia
- Myelodysplastic syndromes
- Waldenstrom Macroglobulinaemia
- Acute Lymphoblastic Leukaemia
- AL-Amyloidosis
- Cutaneous T-Cell Lymphoma
- Myeloproliferative Neoplasms

The guides help people with cancer to understand the optimal cancer care that they should be provided throughout their experience and support people with cancer to understand what might happen at each step of their cancer experience and consider what questions to ask. We work with consumers and other relevant disease specific patient groups to develop these guides.

Activity 1.9: "Explore options to help patients understand access to the Patient Assistance Transport Scheme either by incorporating into care navigation systems or as a standalone support or electronic system."

We agree with this activity. However, we recommend Government consider extending the scheme.

Leukaemia Foundation research has demonstrated that around 18 per cent of patients who need transport and accommodation support are unable to access it.

In addition to diagnosis and treatment costs, the financial burden is compounded by ancillary effects of treatment and being away from home – often required for intensive blood cancer treatments.

Patients in metro areas are sometimes not eligible for many of these supports at all, as PATS generally require patients to live further than 100km. This is problematic for those undergoing expensive and arduous blood cancer treatments, such as stem cell treatments, where patients are required to stay within certain time periods from the treatment centre (e.g. within 30 mins during the first 80-100 days after transplantation).

LF provides information on how to access Patient Assisted Travel in each state as well as provides a contact number to help patients access these services. LF also provides our own transport services for people living with blood cancer which include fuel, uber or taxi vouchers, referrals to other transport providers, financial subsidies with other providers, and help completing applications for other providers.

PRIORITY 2

4. Do you have any feedback on 'Priority 2 Maximise cancer prevention and early detection'?

Unlike many solid tumour cancers, blood cancers are neither preventable nor can they be easily identified through population screening.

Instead, reducing mortality relies on public health messaging to alert individuals to the signs and symptoms of blood cancer, access to prompt and accurate diagnosis, access to best practice treatment and care, and further scientific discovery that enhances treatment and care.

This underscores the importance of ensuring Australian blood cancer patients have access to effective diagnostics, treatment options and services.

We recommend the final plan remains cognisant that screening is not possible for blood (and other) cancers and the critical nature of alternative cancer control means to reduce blood cancer mortality

Activity 2.7: "Explore the ethics, access issues and cost-benefits to develop a model of how and when genetic testing should be offered in the context of cancer prevention and screening, in line with national frameworks, guidelines and position statements."

Genomic testing has utility beyond the screening and prevention frame presented in this activity.

The Leukaemia Foundation continues to advocate for genomic testing to be standard of care, because genomic profiling is required for accurate subtype diagnosis and the subsequent treatment of blood cancer patients. Through genomic profiling, clinicians can more precisely match patients to targeted therapies. These efforts are critical to the expansion of precision medicine and the realisation of curative therapies.

In Australia today, however, access to genomic diagnostics is limited and privately funded, creating barriers to equitable access, and slowing the development of data to inform research efforts. To support improvements in clinical practice and blood cancer research

efforts, precision medicine (with genomic testing as required) should be made the standard of care.

We support Government's intent articulated in the Plan to explore how to support genetic testing, but recommend the scope of this work not be limited to screening.

PRIORITY 3

5. Do you have any feedback on 'Priority 3 Enable health systems for optimal care'?

Activity 3.1: *"Integrate Optimal Care Pathways as routine cancer care, including multi-disciplinary approaches. Use a monitoring and evaluation system that links implementation of Optimal Care Pathways to patient outcomes and experience."*

The Leukaemia Foundation strongly supports this activity. The National Strategic Action Plan for Blood Cancers called on governments to reduce unwarranted variation in treatment and care through development, promotion and implementation of individual OCPs for different blood cancer subtypes, clinical guidelines and accreditation, underpinned by patient navigation services, Blood Cancer Information Strategy and a workforce change management strategy.

As noted earlier, the Leukaemia Foundation, through the Blood Cancer Taskforce, is finalising an additional six optimal care pathways for release shortly and would welcome opportunities to work with the state government to identify ways of helping ensure they are embedded as routine cancer care.

Activity 3.13: *"Develop a statewide approach including service provision for high complexity, low volume cancer treatments including extracorporeal photopheresis, CAR T-cells, cellular therapies, and other emerging therapies, as well as strategic direction on equipment needs include PET imaging now and into the future."*

A statewide approach regarding service provision for these therapies is needed and should be prioritised.

Patients in regional/remote areas in particular sometimes struggle to access the novel and specialised therapies that can be so important to treating rare and less common blood cancers. These access gaps may be magnified by new, high-cost cellular therapies such as immunotherapies.

Noting the different funding streams and arrangements for some newer therapies, we recommend the Plan includes exploring how South Australia can take a leadership role in national conversations among governments, such as the national Health Ministers' Meeting, to help progress nationally consistent, sustainable and equitable access to these therapies.

Activity 3.14: *"Increase care as close as possible to home for medical oncology and haematology services in regional SA."*

Consistency of care across the country is a central theme of the 2020 National Strategic Action Plan for Blood Cancer and is supported by the results of the patient survey undertaken for State of the Nation.

Our "State of the Nation" reports have found considerable variation in service delivery depending on where the patient lived. Modelling identified that inconsistent treatment is responsible for 13% variation in survival nationally, 8% between states, and 5% between metro and regional/rural areas.

We recommend this activity include provision of supportive care by organisations such as the Leukaemia Foundation that deliver supportive care services.

Activity 3.16: "Explore the re-establishment of paediatric allogeneic Bone Marrow Transplant availability in South Australia. This may involve pursuing paediatric and adult service partnerships to achieve accreditation."

This activity will also need to consider that not enough suitable Australians are registered as a stem cell donor, and this has been declining over time. As a result, about three in four of all stem cell donations are sourced from overseas donors.

Stem cell (bone marrow) transplants are relatively unique to blood cancer. Patients receiving transplants are required to spend substantial time in hospital and stay nearby post-transplant. Most transplants occur in adults and it is also important to ensure support is provided across all life stages.

PRIORITY 4

6. Do you have any feedback on 'Priority 4 Provide strong and dynamic foundations'?

Activities 4.3: (using Patient Reported Measures for cancer to monitor symptoms including quality of life and toxicity during and after treatment) ***and 4.4:*** (coordinate cancer Patient Reported Measures across the state).

We are supportive of measures to better include and mandate patient reported outcomes and measures. Using PROs allows the lived experience of patients to be better reflected in healthcare decisions, but currently they are not adequately embedded in our healthcare system.

Governments, clinicians, service providers and the broader sector need to ensure PROs continue to be used and collected. This aligns with a raft of policy imperatives, including:

- The National Strategic Action Plan for Blood Cancer called for a national system for patient reported outcomes in blood cancer, and this has been adopted in the draft Australian Cancer Plan.

- The National Health Reform Agreement Roadmap commits governments to striving to "promote the use of Patient Reported Measures to understand what patients value and improve patient experiences and outcomes."ⁱ

In the context of cancers, PROs support engagement during what can be an intense period of diagnosis and treatment. Furthermore, progress in the type and number of therapies available to treat cancer mean that some cancers are becoming long-term chronic conditions, instead of acute, life-threatening ones. This means treatment is required for longer, and the experiences of patients needs to be captured across a longer period.

We support this activity, but recommend it aligns with relevant national activities in the final Australian Cancer Plan when released.

PRIORITY 5

7. Do you have any feedback on 'Priority 5 Enhance the workforce to deliver cancer care into the future'?

***Activity 5.2:** "Develop cancer specific education frameworks to assist guiding novices to advanced nursing practice in oncology and malignant haematology."*

See above for our comments in relation to Optimal Care Pathways. The Leukaemia Foundation is also working with the Blood Cancer Taskforce to develop clinical guidelines, and we recommend this activity is cognisant of this and other work underway.

We also reiterate other cancer workforce recommendations as articulated in the National Strategic Action Plan for Blood Cancers:

2.6.1 Define a service standard, informed by OCPs, clinical and diagnostic guidelines and the research roadmap, to determine workforce needs in primary and specialist settings including supportive care.

- 2.6.2 A skills audit of regional and remote workforce requirements.

- 2.6.4 A training and change management strategy aimed at specialist settings, focussed on advances in telehealth, personalised medicine and implications for clinical practice, the roll-out of hospital training, and the use of supportive care and palliative care for people living with blood cancer.

PRIORITY 6

8. Do you have any feedback on 'Priority 6 Achieve equitable access to cancer healthcare for Aboriginal and Torres Strait Islander South Australians'?

We reiterate key recommendations from the National Strategic Action Plan for Blood Cancers:

- 1.6.2 Work with the Aboriginal and Torres Strait Islander Health Workforce to undertake a gap review of Indigenous Health Workforce expertise in blood cancers to support culturally sensitive care across all healthcare settings (both Indigenous and non-Indigenous).

- 1.6.3 Develop an awareness and education campaign regarding blood cancer signs and symptoms in partnership Community Controlled Health Services.
- 1.6.4 Promote the use of Cancer Australia's OCP for Aboriginal and Torres Strait Islander people with cancer within the blood cancer clinical network, in conjunction with individual OCPs for different blood cancer subtypes.
- 1.6.7 Ensure relevance and use of supportive care assessment tool to support Aboriginal and Torres Strait Islander people living with blood cancers. The supportive care assessment tool should be validated for use with Aboriginal and Torres Strait Islanders, consistent with the advice in the OCP for Aboriginal and Torres Strait Islander people with cancer.

We also recommend alignment with the impending Australian Cancer Plan, as the draft had a strong focus on equitable access.

9. Please include any general feedback or comments on the overall SA Cancer Plan.

This Plan should ensure recommendations align with government-supported strategies being released shortly or identify gaps relating to rare cancers in those strategies.

The first national Australian Cancer Plan (ACP) is an important cancer blueprint. We support the draft Plan's focus on inclusion, equity and hard to reach and/or underserved populations.

Government has also announced [possible changes](#) to national medical research funding arrangements, and is conducting a consultation. Importantly, this will then lead into consultation on a separate national strategy for health and medical research.

The Aboriginal and Torres Strait Islander Cancer Plan developed by the National Aboriginal Community Controlled Health Organisation (NACCHO) is another important plan to be released in late 2023.

ⁱ NHRA Roadmap, <https://www.health.gov.au/sites/default/files/documents/2021/10/national-health-reform-agreement-nhra-long-term-health-reforms-roadmap.pdf>, p.18.