

Queensland Cancer Strategy Draft Implementation Plan and Horizon 1 Action Plan Consultation

To be submitted via online survey

Which section/s of the Draft Implementation Plan and Horizon 1 Action Plan would you like to provide feedback on? The next question will give you the option to return here if you'd like to provide feedback on multiple sections.
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○ Governance (Page 6)
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O Monitoring, reporting and evaluation (Page 9)
O Focus Area 1: Coordinated care (Page 10)
O Focus Area 2: Achieving health equity in cancer care with Aboriginal and Torres Strait Islander Queenslanders (Pages 11-12)
O Focus Area 3: Prevention, screening and early detection (Pages 13-14)
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O General feedback

What is your feedback on the Implementation Plan for Focus Area 1?

Relevant Strategies:

- **1.03 -** Enhance partnerships with cancer care providers in the private and non-government sectors, community organisations, support services and advocacy groups to enhance cancer coordination efforts and improve access to services.
- **1.07** Increase access to cancer care information for consumers, families and communities in multiple formats including digital platforms, phone and text-based communication and support for those who need it. Ensure these resources complement the Australian Cancer Navigation Service being developed under the Australian Cancer Plan.
- **1.08** Partner with non-government organisations to provide customised and accessible information about cancer care at all stages to individuals affected by cancer, their families and support networks. Recognise differences in messaging across the lifespan



Strategies 1.03, 1.07 & 1.08: We recommend partnerships with disease-specific supportive care organisations such as the Leukaemia Foundation for enhancing cancer coordination care, improving access to specific cancer services, and increasing access to cancer information and support for patients and families.

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 the Leukaemia Foundation as an organisation and provide general updates and information regarding our range of services and supports. Leukaemia Foundation provides disease brochures, information guides, 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 of problems, and appropriate referral to other NGOs.

In addition to practical supports with bills, accommodation and transport, the Leukaemia Foundation provides a range of resources including booklets, factsheets, seminars and education sessions, and emotional support and assistance from 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. Therefore, by enhancing partnerships with organisations such as the Leukaemia Foundation, cancer coordination can be further improved by increased awareness of the supports and services available for patients with specific cancers earlier on in their cancer journey.

What is your feedback on the Implementation Plan for Focus Area 3?

Relevant strategies:

- **3.01** Empower consumers by building awareness and knowledge of their individual risk factors, the signs and symptoms of cancer and how to self-check for cancers like skin cancer and breast cancer
- **3.04** Develop and enhance partnerships with organisations and providers already delivering care to specific populations (for example primary care, multicultural health organisations, disability support organisations) at risk of greater incidence, later diagnoses or poorer outcomes to achieve better cancer prevention, screening rates and outcomes.
- **3.16** Educate health professionals in all settings about the signs and symptoms of different cancers across the lifespan (for example in children, in adolescents and young adults, or post-partum) and how to ensure appropriate follow up, especially in community and primary health settings.
- **Strategies 3.01 & 3.16:** Blood cancers collectively rank as the 3rd most commonly diagnosed cancer in Australia, with over 150,000 Australians currently living with the disease. However, according to the recent YouGov Consumer Intelligence Report (2024), 78% of respondents didn't know any symptoms associated with blood cancer. Blood cancer



symptoms can vary depending on the subtype and can include some non-specific/vague symptoms such as fatigue, and bone and joint pain.

Many blood cancer subtypes are uncommon, spontaneous, and challenging to diagnose in primary care settings. They are also not preventable and not able to be screened for often making early detection difficult. 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. Many healthcare providers also have limited experience with blood cancers, especially the rarer subtypes.

The Leukaemia Foundation offers different resources for patients including disease specific booklets and guides which are often circulated through health services, online educational content including written information, webinars and podcasts, and 1:1 support over the phone with trained blood cancer support coordinators.

The Blood Cancer Taskforce, supported by the Leukaemia Foundation, has developed a total of 11 disease-specific Optimal Care Pathways (OCPs) for blood cancers to increase awareness among GPs and primary healthcare workers and to provide recommendations on what optimal care looks like from initial diagnosis through to end-of-life care and survivorship for the specific diseases. The OCPs also include a Guide to Best Cancer Care targeted towards patients that helps to explain what optimal care to expect, how the care journey will look like, and potential questions to raise with their doctor.

These resources can be leveraged along with wider awareness and education campaigns such as Blood Cancer Awareness Month to increase knowledge of the signs and symptoms of blood cancers among patients and healthcare professionals.

Strategy 3.04: The Leukaemia Foundation is working towards bridging the significant rural-metro divide in blood cancer outcomes with regional, rural, and remote patients, a priority population as identified in the Australian Cancer Plan. Blood cancer outcomes are significantly worse for regional, rural, and remote patients, and 41% of blood cancer patients reside in non-metro areas. Leukaemia Foundation's State of the Nation 2023 Report found that 29% of blood cancer deaths can be avoided through consistent adherence to national standards of timely and accurate diagnosis, treatment, and care. The Leukaemia Foundation will be launching a rural and regional care pilot program to improve symptom awareness and cancer recovery support leading to increased proactive health engagement, prompt diagnosis, referral to appropriate care, and better quality of life post-diagnosis. Leukaemia Foundation are currently engaging with regional public health networks to pilot this program and are open to extending this to Queensland.

What is your feedback on the Implementation Plan for Focus Area 4?

Relevant Strategies:

4.06 - Develop networked service models for high complexity, low volume cancer treatments and therapies including CAR T-cells, apheresis stem cells, and theranostics. These networked service models will be linked to statewide services for production and supply of therapeutic agents.



- **4.07** Consider the options for localised networked service arrangements to expand access to subspecialty services focused on haematology and palliative care.
- **4.10** Align service key performance indicators with published Optimal Care Pathways and support continued implementation of existing and new Optimal Care Pathways for children and adults as outlined in the Australian Cancer Plan.
- **4.17** As the role of genomics and precision oncology continues to evolve, increase coordinated access to genomic testing to guide effective cancer treatment.

Strategies 4.06 & 4.17: Genomic testing is a critical tool in blood cancer treatment that can help significantly improve health outcomes including a more accurate diagnosis leading to more targeted treatment choices and less side effects stemming from the more targeted treatment options. Blood cancers are difficult to treat, can progress rapidly, and have high mortality rates making them the second leading cause of cancer-related deaths in Australia. Access to genomic diagnostics in Australia is limited and inequitable. Usage is inconsistent across the population with only 21% of blood cancer patients reporting the use of genomic testing to confirm their diagnosis. The State of the Nation 2023 Report also shows that 31% of patients who underwent genomic testing had their diagnosis and treatment plans altered, highlighting its critical role in patient care.

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 vitally important in treating rare and less common blood cancers. These access gaps may be magnified by new, high-cost cellular therapies such as immunotherapies.

"Genomic testing is critical. There's no comprehensive coordinated testing process, which needs to be addressed as it underpins everything we do. An accurate diagnosis is absolutely necessary for provision of best quality care." - A quote from a blood cancer clinician.

Strategy 4.07: Expanding access to subspeciality services focussed on haematology is critical for blood cancer patients, especially to those who live regionally and rurally and already have limited access to such services. Many blood cancer subtypes are rare and difficult to diagnose with some patients having to wait years for an accurate diagnosis. Increasing access to speciality services, especially for those in underserved populations, together with resources such as Optimal Care Pathways, work to improve the delivery of best-practice care and decrease the variation in care. It will also work towards decreasing locational and financial barriers faced by patients who need to travel long distances to access speciality haematology services.

Strategy 4.10: Optimal Care Pathways are one of the key recommendations in Australia's National Strategic Action Plan for Blood Cancer. Optimal Care Pathways help health professionals provide nationally consistent, high-quality, evidence-based information and care at each stage of the blood cancer pathway, from diagnosis and treatment to ongoing care. Aligning service key performance indicators with these pathways will improve delivery of best-practice care and ultimately improve variation in care and patient health outcomes.



What is your feedback on the Implementation Plan for Focus Area 5?

Relevant Strategy:

5.10 - Partner with non-government organisations and cancer support groups to ensure all consumers with metastatic cancer receive psychosocial and peer support.

Strategy 5.10: Blood cancers are not metastatic as they are not solid tumours and are already widespread due to their presence in the blood and lymphatic system. Blood cancers can also be acute or chronic whereby patients require different supports and services to manage their blood cancer journey. The Leukaemia Foundation provide a range of psychosocial and emotional support including 1:1 support with trained blood cancer coordinators who help patients to adjust to their diagnosis, changes in their lives and the impact on family and friends, refer to psychologists, counsellors and other allied health professionals such as occupational therapists, exercise physiologists and nutritionists, and offer grief and bereavement support. Leukaemia Foundation also run support groups including peer support groups and support groups lead by trained staff, with topics including but not limited to fear of cancer recurrence, exploring mental health and blood cancer, watch and wait, speaking up for yourself, and surviving and thriving with blood cancer.

Knowledge of and referrals to these supports can be further improved among health service staff to ensure patients are aware of their existence as early as possible in their cancer journey to support their wellbeing.

What is your feedback on the Implementation Plan for Focus Area 6?

Relevant Strategy:

6.03 - Continue to expand opportunities for all consumers and clinicians to participate in clinical trials and research activities

Strategy 6.03: Increasing access to clinical trials is a key objective of the National Strategic Action Plan for Blood Cancer with recommendations to commission a pilot study to implement a KPI for clinician-led discussion regarding enrolment in clinical trials where available and appropriate to the patient (Action 4.1), and increase trial access in regional and remote areas, including a national approach to prioritising tele-trials (Action 4.2).

Increasing patient knowledge and understanding of clinical trials needs to be improved. The 2022 Survey of People Living with Blood Cancer found that only 21% of patients participated in a clinical trial, and among those who did not participate, the primary reason was that it was not discussed (74%) and 10% indicated that their specialist had looked for a trial, but no relevant clinical trial was available. Other barriers exist for regional and rural patients as access to these trials are often limited due to costs involved to travel to recruitment and treating sites and like many other States, the Queensland Patient Travel Subsidy Scheme does not support financial assistance for travel to receive treatment from a clinical trial.