

A national framework for the future of genomics in cancer care – Public Consultation

Submitted online via: <https://canceraus.engagementhub.com.au/have-your-say-on-the-draft-national-framework-for-genomics>

The draft *National Framework for Genomics in Cancer Control* has been developed to promote a common understanding of genomics, drive its safe and effective application in practice, foster collaboration and provide future direction for its integration into the cancer care system.

The role of genomics in cancer screening, diagnosis and treatment is expanding rapidly and has broad implications for patient care, workforce, research and data, policy and service delivery.

Genomics has enormous potential to transform cancer screening, diagnosis and treatment. Genomic testing provides information on mutations in genes that drive various cancer behaviours and enables personalised treatments.

The Framework will guide health professionals, researchers, health services and policy makers, as they incorporate the rapidly advancing field of genomics into patient care in a way that is consistent, culturally safe, high-quality, evidence-based and equitable for all Australians.

Objectives

Q.4 Do you have any comments or feedback on strategic objective 1: prevention and early detection?

Character Limit: 1500

Early detection and diagnosis have significantly improved outcomes for solid tumours such as breast and colorectal cancers – however, blood cancers generally lack identifiable precursors or hereditary patterns making population-level screening or prevention using genomics less applicable.

Instead, for blood cancers, genomics serve primarily as a diagnostic tool and a means of personalising treatment. Additionally, and relevant to the Framework's implementation, genomic monitoring may be useful in people who have had previous cancer treatments.

Equitable and effective implementation in personalised genomic approaches requires diverse representation in genomic reference datasets, and this should remain a focus of the Framework. Culturally safe and ethically sound research practices are essential for building trust and fostering meaningful inclusion.

Genomic risk-based screening has the potential to transform cancer detection, however, further research is needed to uncover the biological mechanisms underlying blood cancers and identify actionable genomic markers for risk assessment, prevention, and early detection. Translational research is critical to directing resources toward strategies with proven benefits.

Integrating genomic testing into prevention and early detection approaches is useful, but we request the finalised Framework continues to acknowledge that prevention and screening as early detection mechanisms are less applicable to blood cancers than solid tumour cancers.

Q.5 Do you have any comments or feedback on strategic objective 2: diagnosis, treatment and clinical trials?

Character Limit: 1500

We support this objective to embed genomics in cancer care, which is important for blood cancers. Blood cancers are complex, can progress rapidly, and lack early screening options. Genomic testing is a critical diagnostic and treatment tool, enabling precise subtyping of a patient's blood cancer and identifying specific targeted therapies that improve patient outcomes and reduce side effects.

However, access to genomic testing in Australia remains inequitable, with only 21% of blood cancer patients reporting its use to confirm their diagnosis. Barriers such as high costs, incomplete Medicare Benefits Schedule (MBS) funding, and insufficient data about uptake exacerbate disparities, leaving many patients without access to optimal care.

We recommend the following actions to enhance the framework:

1. Expand MBS funding to include more genomic tests for blood cancers.
2. Conduct a strategic assessment of blood cancer diagnostic services to identify and address barriers to equitable access.
3. Prioritise genomic clinical trials for rare blood cancer subtypes, leveraging real-world data to address challenges in traditional evidence generation.

Q.6 Do you have any comments or feedback on strategic objective 3: supportive care?

Character Limit: 1500

We welcome the focus on supportive care in Strategic Objective 3 and its ambition to improve experiences for people affected by cancer.

Genomics, particularly pharmacogenomics, offers opportunities to personalise supportive care by guiding medication choices for managing side effects like nausea and pain. However, the Framework would benefit from clearer detail on integrating genomic advances into supportive care delivery.

The mention of Patient-Assistance Travel Schemes (PATS) highlights barriers faced by rural and regional patients accessing specialist care. However, it remains unclear how genomics-informed supportive care will address these challenges, especially given the state-based nature of these schemes.

The Leukaemia Foundation's supportive care services provide a strong platform for implementing genomics-informed care. Greater clarity on how genomics will support a structured, sustainable care model, and how the government and Framework will ensure its delivery, would strengthen this objective.

Finally, awareness and referrals for supportive care remain insufficient. Only one in three patients have supportive care discussions [National Strategic Action Plan for Blood Cancers],

and Leukaemia Foundation surveys show only a third of patients were informed about our services at diagnosis. We recommend the Framework explicitly address improving referrals to supportive care services.

Q.7 Do you have any comments or feedback on strategic objective 4: awareness and education?

Character Limit: 1500

We support attempts to build health literacy around genomics, as understanding and informed decision-making are essential for achieving better outcomes in blood cancer care. Genomic testing is critical for accurate diagnosis, personalised treatment, and minimising treatment toxicity in blood cancers.

Education for health professionals is a priority. Only 21% of blood cancer patients report having genomic testing to confirm their diagnosis, indicating gaps in clinician knowledge and referral practices. Further, this needs to be supplemented following MBS listings of genomics-related MBS items, to maximise uptake.

Embedding genomics education in curricula and professional development, as proposed, is crucial for equipping healthcare providers with the skills needed to integrate genomics into routine care.

Public awareness campaigns must emphasise the practical benefits of genomics in blood cancer treatment. Co-designing resources with consumer groups and priority populations, including Aboriginal and Torres Strait Islander communities, will ensure culturally appropriate messaging and equitable access to information.

The Leukaemia Foundation provides extensive support to blood cancer patients and families, and we recognise the potential for genomics to enhance shared decision-making. However, clear guidance is needed on how proposed tools for primary care and education campaigns will bridge the current knowledge gaps and translate into increased uptake of genomics in practice.

Q.8 Do you have any comments or feedback on foundational objective 1: research and data?

Character Limit: 1500

We support the focus on evidence-based and data-driven cancer genomics in Foundational Objective 1. Robust genomic research and data systems are crucial to addressing the unique challenges of blood cancers, including rapid progression, high mortality rates, and disease complexity.

Equitable, culturally safe access to genomics in clinical trials is vital, particularly for rural and Aboriginal and Torres Strait Islander communities who often face barriers to participation. Inclusivity ensures genomic advancements benefit all patients. A diverse pool of genetic data and disease characteristics will enable the development of precision therapies to minimise toxicity and improve outcomes.

Nationally consistent processes for collecting, storing, and sharing genomic data are essential. These systems must prioritise privacy, security, and Indigenous Data Sovereignty while integrating with broader research networks.

The Leukaemia Foundation advocates for embedding genomics into routine care, supported by initiatives like the National Clinical Quality Registry Strategy. Streamlining access and standardising data will enhance collaboration, reduce disparities, and accelerate personalised treatment development. Linking real-world genomic data with clinical outcomes can drive innovation, improve equity, and deliver significant health and economic benefits for patients and the healthcare system.

Q.9 Do you have any comments or feedback on foundational objective 2: workforce and models of care?

Character Limit: 1500

We commend the focus on workforce capability and culturally safe care in genomics. For blood cancer patients, timely access to genomics-informed diagnosis and treatment is crucial. However, key gaps must be addressed for equitable and sustainable delivery.

Currently, only 21% of blood cancer patients receive genomic testing despite its potential to improve precision and reduce side effects. Upskilling clinicians in primary care and regional services is needed to bridge this gap. Mainstreaming genomic education in outreach programs is essential.

Expanding access to genetic counselling is vital for informed decision-making, addressing emotional and practical challenges for patients and families. Integrating counselling into multidisciplinary teams will enhance support and outcomes.

The framework must prioritise data transparency and security, ensuring patient ownership of genomic data. Systems must protect privacy, address misuse concerns, and align with Indigenous Data Sovereignty for culturally appropriate care.

Aligning the Framework with Australia's Primary Health Care 10-Year Plan, is key with particular reference to the action "Scale up mechanisms for specialist support to general practice on genomics and precision medicine".

Finally, addressing structural barriers, such as cost and geographic access, particularly for regional and Indigenous communities, is critical. Sustainable funding for outreach services will ensure equitable genomics-informed care.

Q.10 Do you have any comments or feedback on foundational objective 3: Funding, quality, and safety?

Character Limit: 1500

We support the ambition to integrate genomics safely and cost-effectively across the cancer care continuum. For blood cancer patients, genomic testing is essential for improving diagnosis, guiding targeted treatments, and reducing care burdens. However, key areas must be addressed to ensure equitable and ethical implementation.

Evolving Health Technology Assessment (HTA) processes is critical to streamline access to subsidised genomic testing and therapies. Inconsistent funding for genomic diagnostics creates inequities. Expanding Medicare Benefits Schedule (MBS) funding is necessary to ensure all patients can access life-saving technologies.

Data privacy and ownership are central to this framework. Patients should have control over their genomic data, with safeguards against misuse. Applying Indigenous Data Sovereignty principles is vital to respecting and protecting the rights of Aboriginal and Torres Strait Islander communities.

Innovative care models should prioritise culturally safe, high-value care while addressing geographic and financial barriers for regional and rural patients. Sustainable funding for oncology and genetics outreach services can bring the benefits of genomics to underserved communities.

Clear protocols, dedicated funding, and strong ethical oversight are essential to embedding genomics into routine care while maintaining equity and trust.

Q.12 Are there any other comments you would like to make regarding the National Framework for Genomics in Cancer Control?

Character Limit: 1500

We recommend that the framework acknowledge the differing applications of genomics across cancer types. For blood cancers, emphasis should be placed on its diagnostic, treatment-guiding, and post-treatment monitoring roles rather than on prevention and screening. This distinction ensures the framework's guidance aligns with the evidence base and clinical utility across cancer subtypes.

Of the two 'Future State' objectives, the second – *"Equitable access to genomics-guided treatment"* – is particularly relevant to blood cancers. While preventive screening does not apply to blood cancers, we welcome the explicit recognition of the importance of genomics in treatment. This dual focus ensures that the proven value of genomics in treatment is not overshadowed by its role in screening. We ask that the final Framework continues to acknowledge this.