

## **National Cancer Data Framework – Public Consultation**

To be submitted via online survey: <https://canceraus.engagementhub.com.au/national-cancer-data-framework-public-consultation>

Cancer Australia is developing the National Cancer Data Framework in partnership with the Australian Institute of Health and Welfare (AIHW) and Cancer Council Australia (CCA), and in consultation with stakeholders across the cancer sector.

The National Cancer Data Framework will set the strategic direction and priorities for the collection, management, use and ongoing development of data to improve cancer outcomes. It will align with existing and planned national health data initiatives, including the ambitions set out in the Australian Cancer Plan. The Data Framework needs to be flexible enough to account for the differing levels of data maturity across jurisdictions. It is about the sector working together to identify and agree where collective effort is needed to improve cancer data.

Cancer data is critical to:

- drive optimal cancer care and a high performing cancer care system
- inform planning, delivery and continuous improvement of cancer care
- inform policy and research priorities across the cancer control continuum to improve cancer outcomes

### **Strategic Objectives and Implementation Priorities**

#### ***"1. A mature performance reporting system***

*Transparent reporting of cancer control indicators will drive improvements in prevention, screening, diagnosis, treatment and care. Australia's capacity to use data to reduce the incidence of cancer and improve survival from cancer is reliant on public trust that data are collected, stored and used safely.*

*1.1 Enable Indigenous Data Sovereignty and Governance for improved Indigenous community outcomes.*

*1.2 Build and maintain public trust in the data system.*

*1.3 Establish a robust cancer control monitoring and benchmarking system to drive optimal care."*

#### ***Q4. Do you have any comments or feedback on strategic objective 1: A mature performance reporting system?***

*Character Limit: 1500*

We support the focus on creating a mature performance reporting system, which is vital for improving prevention, diagnosis, treatment, and care for cancer patients, including those with blood cancers. However, it must address gaps unique to blood cancer patients and care delivery.

**Indigenous Data Sovereignty (1.1):** This is crucial for addressing inequities and improving outcomes for Indigenous communities. Culturally safe data practices are essential to reducing disparities.

**Public Trust in Data Systems (1.2):** Transparent policies on data privacy, use, and security are critical. Clear communication about how data drives better outcomes, alongside robust privacy measures, should be used to enhance trust and participation in data collection.

**Robust Cancer Control Monitoring (1.3):** Establishing a robust monitoring system is vital. It must include blood cancer-specific indicators, including those relevant to genomic testing, timely diagnosis, and equitable treatment. Incorporating real-world evidence (RWE) and patient-reported outcomes (PROs) will enhance understanding of patient experiences and improve long-term care.

Finally, aligning data collection with other state plans and addressing gaps in workforce data, particularly in haematology, will be essential for effective planning and equitable care delivery nationwide. This extends to the need for broader interoperability with whole of health data systems.

## ***"2. Sustainable and fit-for-purpose data system***

*Foster a sustainable and fit-for-purpose data system that enables the timely collection of health and population data inclusive of cancer and non-cancer data, collected across the ecosystem using nationally consistent standards to facilitate system interoperability and greater information exchange across the continuum of care and across jurisdictions.*

*2.1 Embed and implement the governance of Indigenous data into the cancer data ecosystem.*

*2.2 Improve the timeliness of cancer data collection and reporting at the national level.*

*2.3 Strengthen existing mechanisms to ensure consistent and valid collection of key cancer data within Australian Cancer Registries.*

*2.4 Advance the collection of cancer stage at diagnosis data as a key equity measure.*

*2.5 Agree and prioritise national data gaps*

*2.6 Agree on a National Cancer Control Reporting Framework and collect a standardised national cancer data to support reporting on priority needs, including optimal cancer treatment and care, equity and patient outcomes and experiences.*

*2.7 Enhance the capture of structured pathology and radiology reporting, for consistent data capture from source systems.*

*2.8 Explore the potential for structured clinical reporting of key data items within electronic medical records."*

**Q5. Do you have any comments or feedback on strategic objective 2: A sustainable and fit-for-purpose data system?**

*Character Limit: 1500*

A sustainable, "fit-for-purpose" data system is vital for improving outcomes, including for blood cancer patients who face unique challenges due to the rarity and complexity of their diagnoses.

**Indigenous Data Governance (2.1):** Embedding Indigenous data governance is essential to addressing inequities. Co-designed frameworks should ensure cultural safety and reflect community priorities.

**Timeliness and Consistency (2.2, 2.3):** Timely, consistent cancer data collection is critical. For blood cancers, data on genomic testing, treatment, and outcomes should be included to inform research and care.

**Cancer Stage Data (2.4):** Capturing stage-at-diagnosis data will improve equity measures. Blood cancers often present late, so this will highlight gaps in early diagnosis.

**Addressing Data Gaps (2.5):** Workforce planning for haematologists is a priority. Understanding their geographic distribution and trends will improve access to specialised care.

**Reporting and Standards (2.6, 2.7, 2.8):** Standardised data collection, including pathology and radiology reporting, will improve interoperability and support real-world evidence (RWE) generation. For blood cancers, integrating RWE and patient-reported outcomes into frameworks is essential.

A coordinated, patient-centred data approach will maximise benefits and improve outcomes for all cancer patients. Embedding patient access to performance reporting is critical – this will empower individuals in their healthcare seeking and compel health care providers to address service gaps.

**3. "User-centred, integrated and accessible data"**

*Deliver a user-centred, integrated and accessible data system through the timely, streamlined and safe promotion of trusted, transparent, and advanced data-sharing arrangements with systems at national and jurisdictional levels.*

*3.1 Ensure enduring data linkages and associated access as well as research is overseen with appropriate Aboriginal and Torres Strait Islander ethical practices*

*3.2 Enhance data access through effective and efficient data governance and streamlined ethics approvals.*

*3.3 Adopt a harmonised approach to enduring integrated data assets that safely enable rapid access by accredited end users, while ensuring data safety, quality and reliability"*

***Q6. Do you have any comments or feedback on strategic objective 3: User-centred, integrated and accessible data?***

We are supportive of the draft Framework's focus on user-centred, integrated, and accessible data systems, which are important for improving outcomes for all cancer patients, including those with blood cancers.

**Data Linkages (3.1):** Ensuring enduring data linkages and ethical oversight for Aboriginal and Torres Strait Islander data is critical to addressing inequities in cancer outcomes. This approach should be considered for all other priority populations. Co-designed systems will enhance their relevance and impact.

**Data Governance (3.2):** Streamlined governance and ethics approvals are essential to improving timely access to data for research and policy development. Simplifying processes will also reduce burdens on health services and researchers.

**Integrated Assets (3.3):** A harmonised approach to integrating data assets must prioritise safety, quality, and reliability. For blood cancer patients, this should include real-world evidence and genomic data, which are vital for advancing precision medicine and equitable care, and for keeping patients at the centre.

Finally, accessibility, user-centredness and integration also must align with other state/territory initiatives, to avoid duplication and maximise impact. Robust privacy measures and clear communication will build trust and ensure data systems are patient-centred and effective.

***Q7. Do you have any comments or feedback on the draft implementation roadmap?***

*Character Limit: 1500*

Clear implementation objectives, timelines and resources are essential to realise this Framework in a timely manner. We encourage reconsideration of the broad "short term" goal timeframes, including bringing them forward.

***Q8. Are there any other comments you would like to make regarding the National Cancer Data Framework?***

*Character Limit : 1500*

The draft National Cancer Data Framework is a vital step toward improving outcomes for all cancer patients, including those with blood cancers. Its focus on transparent reporting, sustainable systems, and accessible data is commendable. However, specific priorities must address gaps unique to blood cancers.

**Performance Reporting (1):** Include blood cancer-specific indicators, such as access to genomic testing, timeliness of diagnosis, and equitable treatment. Integrating patient-reported outcomes (PROs) and real-world evidence (RWE) is essential for understanding patient needs and improving care. Use of agreed standards of care in Optimal Care Pathways will provide consumers with clear and measurable performance expectations.

**Sustainable Data Systems (2):** Address gaps in workforce data, particularly for haematologists, to enable effective planning and equitable access to specialised care. Prioritise the integration of cancer stage-at-diagnosis data to reduce inequities in outcomes.

**Accessible Data (3):** Streamline data-sharing arrangements to avoid duplication and ensure consistent national standards. Strengthen privacy measures and communication to maintain public trust while supporting timely research access.

Finally, alignment with other federal/state/territory-level initiatives will maximise the framework's impact and ensure coordinated, patient-centred care across Australia.