# Have your say on the draft National Cancer Data Framework

 Which group do you or your organisation represent or most closely associate with? Please select from the following options.

*
(Maximum selection Limit : 10)

Data custodian

Aboriginal or Torres Strait Islander Health Worker or Health Practitioner

Organisation working with Aboriginal and Torres Strait Islander people

Aboriginal Community Controlled Organisation

Person who has experienced cancer

Family member or carer of a person who has experienced cancer

Consumer advocates

Member of the general public

Health professional

Health service employee / administrator

Peak body employee

Primary Health Network employee

Researcher or academic

Policy maker or government employee

Other (please specify) - Professional Association

 Q.2

**Which state or territory do you reside in, or is your organisation based in?**

*
(Maximum selection Limit : 1)

New South Wales

Victoria

Queensland

Western Australia

South Australia

Tasmania

Northern Territory

Australian Capital Territory

National Organisation

Other (please specify)

⬜ Q.3

**Do you or your organisation represent or identify as any of the following (select all that apply):**

**\***

**(Maximum selection Limit : 12)**

Aboriginal or Torres Strait Islander people

Lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual people

Older Australians

Adolescents or young adults

Children

People from culturally or linguistically diverse backgrounds

People living with disability

People living with a mental health condition

People living in a rural or remote area

People living in a low socioeconomic circumstance

None of the above

Prefer not to answer

⬜ Q.4

**Do you have any comments or feedback on strategic objective 1: A mature performance reporting system? Download the draft National Cancer Data Framework here**

ABNA supports priority 1. Enable Indigenous Data Sovereignty and Governance through the Fair and CARE principals. Cancer incidence data and interoperability (including improvements at a National level) will enhance cancer research capabilities, including biobanking role of provision of biospecimens and related clinical data.


 Regarding goal 1.2.5, include 'informed decisions about their treatment and care and participation in research. We strongly believe that supporting Australians, including First Nations persons to make informed decisions around participating in Research (including clinical trials) is paramount. Australia is expanding research capabilities rapidly, with many care providers

establishing highly integrated research capabilities. As such, many anticipate that within 10 years research will be further embedded into routine clinical care, or be closely adjacent to clinical practice (e.g. personalised medicine; increased access to a range of clinical trials; providing data for research purposes).

**Character Limit : 1500**

⬚ Q.5

**Do you have any comments or feedback on strategic objective 2: A sustainable and fit-for-purpose data system? Download the draft National Cancer Data Framework here**

The Association strongly supports Priority 2, focusing on enhancing cancer incidence data and interoperability, including improvements that support national-level data integration. Cancer incidence data, such as registry and staging data, are essential in shaping both state and national research priorities. These data inform critical strategies, including the development of research biobanking infrastructure, setting recruitment targets, and refining participant recruitment and data collection methods. This encompasses efforts to recruit research participants, provide biospecimens and related clinical data to high-priority research areas, and accelerate the translation of research findings into clinical practice.

**Character Limit : 1500**

⬚ Q.6

**Do you have any comments or feedback on strategic objective 3: User-centred, integrated and accessible data? Download the draft National Cancer Data Framework here**

The Australian Biospecimen Network Association (ABNA) strongly supports the goal to improve mechanisms for dataset interoperability. As a peak body with an extensive network of existing research datasets and deep expertise in cancer research, ABNA recognises the critical importance of enhancing data interoperability to advance scientific progress. It is essential that FAIR (Findable, Accessible, Interoperable, and Reusable) and CARE (Collective Benefit, Authority to Control, Responsibility, Ethics, and) for indigenous data governance principles are applied in a way that respects and upholds the sovereignty and ethical practices of Aboriginal and Torres Strait Islander communities. The enhancement of data through robust data linkage is a key enabler of meaningful research outcomes. The association also believes that standardisation is central to achieving harmonisation across datasets, which minimises resource expenditure and improves the overall quality of research. Given ABNA's broad expertise and network, we are a key stakeholder and are committed to actively participating in these efforts to support better data integration and research outcomes.

**Character Limit : 1500**

⬚ Q.7

**Do you have any comments or feedback on the draft implementation roadmap? Download the draft Implementation Roadmap here**

The roadmap appears to be a carefully developed plan that incorporates SMART goals, making it achievable both in the short term and the long term

**Character Limit : 1500**

Q.8

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

The National Cancer Data Framework, which aims to create a harmonised, fit-for-purpose, and sustainable cancer data ecosystem, is a crucial step forward. This comprehensive approach is essential for driving more equitable and improved cancer outcomes, and it's long overdue. Incorporating the FAIR and CARE principles for Indigenous data governance and sovereignty is a significant and much-needed advancement, and one that will ultimately benefit everyone involved in cancer research and care.

In this context, ABNA advocates for the integration of both research and biobanking—previously identified in the Australian Cancer Plan—into the National Cancer Data Framework. Cancer biobanks play a unique and vital role in supporting clinical care (e.g., hospital-integrated biobanks), facilitating the translation of research into clinical practice (e.g., supporting clinical trials), and enabling or contributing to population-level research (e.g., leading population registries and generating cancer data that enhances existing clinical data). This integration will be key to ensuring that cancer research is effectively translated into better clinical outcomes and improved care for all Australians.

**Character Limit : 1500**

Q.9

**Would you like your contact details to be associated with your comments?**
*
**(Maximum selection Limit : 1)**

Yes

No

**If yes enter preferred email**

(Max Character Limit : 500)

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