

National Cancer Data Framework – Goal

A harmonised, fit-for-purpose, sustainable cancer data ecosystem that includes population-wide cancer and non-cancer data across the cancer continuum and is used for improved cancer control in prevention and screening, service delivery, clinical care and research, to drive more equitable and improved cancer outcomes.

Guiding principles

Person centred and equity focused: Data are used to provide person-centred treatment and care, delivering the best outcomes and improved equity for all Australians, focusing on First Nations peoples, priority population groups and their communities.

Indigenous Data Sovereignty: First Nations peoples have the right to exercise ownership over First Nations data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, governance, dissemination and reuse of First Nations data.

Cancer data as an asset: Acknowledging that Australia requires a cancer data ecosystem that is accessible through modern infrastructure, enables collaboration to inform policy and health service delivery, drives economic value, supports innovation and improves cancer outcomes for all Australians.

Leverage existing strengths: Strategic objectives and priority actions align with, build on and add to initiatives and innovations in policy approaches to data capture and sharing that can be harnessed and scaled.

Data safety, trust and transparency: Personal data are protected, and public reporting is transparent, helping to build community trust in reporting on progress in cancer outcomes and effectively addressing inequities.

Collaborative, timely and accessible: Making cancer data timely and accessible through modern infrastructure and streamlined data governance enables collaborative efforts across the whole cancer sector.

Integrated and relevant data use: Data access is enabled, data-driven decision-making is embraced and data collection is promoted as part of patient care through seamless integration into clinician workflows.

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 palliative 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 Indigenous Data Sovereignty and Governance for improved First Nations 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.

2. A 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 First Nations data in the cancer data ecosystem.
- 2.2 Improve the timeliness of cancer data collection and reporting.
- 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 measure of equity and cancer control.
- 2.5 Agree and prioritise national data gaps.

- 2.6 Collect 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 digital health systems.

3. User-centred, integrated and accessible data

Deliver a user-centred, integrated and accessible data system that incorporates longitudinal data to track changes over time, through the timely, streamlined and safe promotion of trusted, transparent and advanced data-sharing arrangements using integrated data assets 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.

Enablers

Culture change

Technology and innovation

Data workforce capacity and capability

Effective governance and standards