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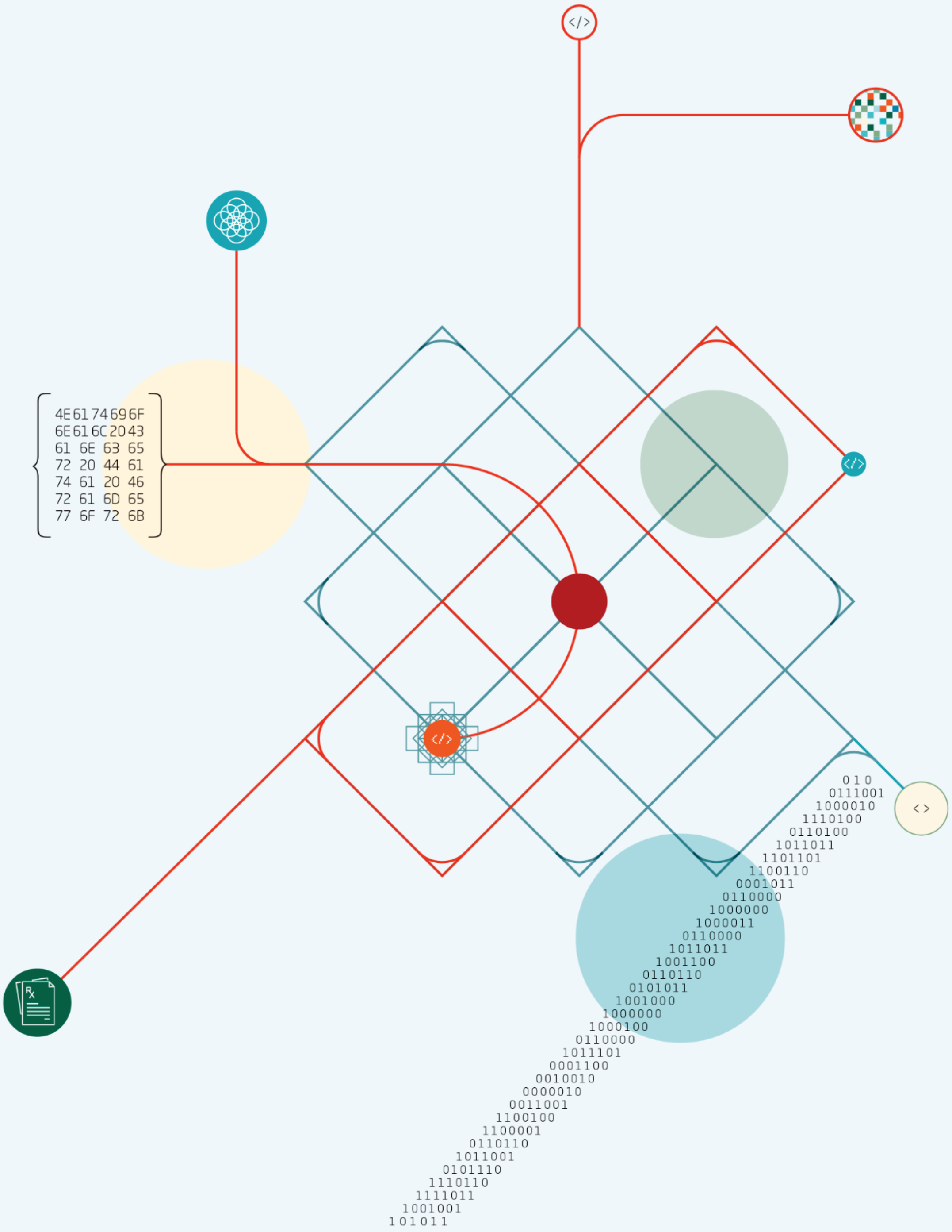
National Cancer Data Framework



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Acknowledgement of Country
Cancer Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of Country throughout Australia. We pay our respects to Elders, past and present.

We celebrate the ongoing connections of Aboriginal and Torres Strait Islander peoples to Country, culture, community, family and tradition and recognise these as integral to health, healing and wellbeing.

Cancer Australia acknowledges great diversity among Aboriginal and Torres Strait Islander peoples, and the contribution of the many voices, knowledge systems and experiences that guide all efforts to create a culturally safe and responsive cancer system that is equitable to all.

Acknowledgements

The Australian Government gratefully acknowledges the support of the many individuals and organisations who have played a role in the development of the National Cancer Data Framework. As a collaborative initiative, led by Cancer Australia, Cancer Council Australia, and the Australian Institute of Health and Welfare, the process was enriched by the advice and support from across the sector.

We thank all state and territory governments, data custodians, healthcare professionals, clinicians, public and private health providers, not for profit organisations, professional colleges, research and clinical trial groups and consumers for their valuable contribution and advice. We also acknowledge and respect the contributions made by the Aboriginal and Torres Strait Islander representatives who participated in the Indigenous-led co-design process and whose perspectives have been vital in the development of the Data Framework. We also thank the National Cancer Data Framework Steering Committee for their advice, which has guided and enhanced the framework's accessibility, consistency, and comprehensiveness.

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Executive Summary

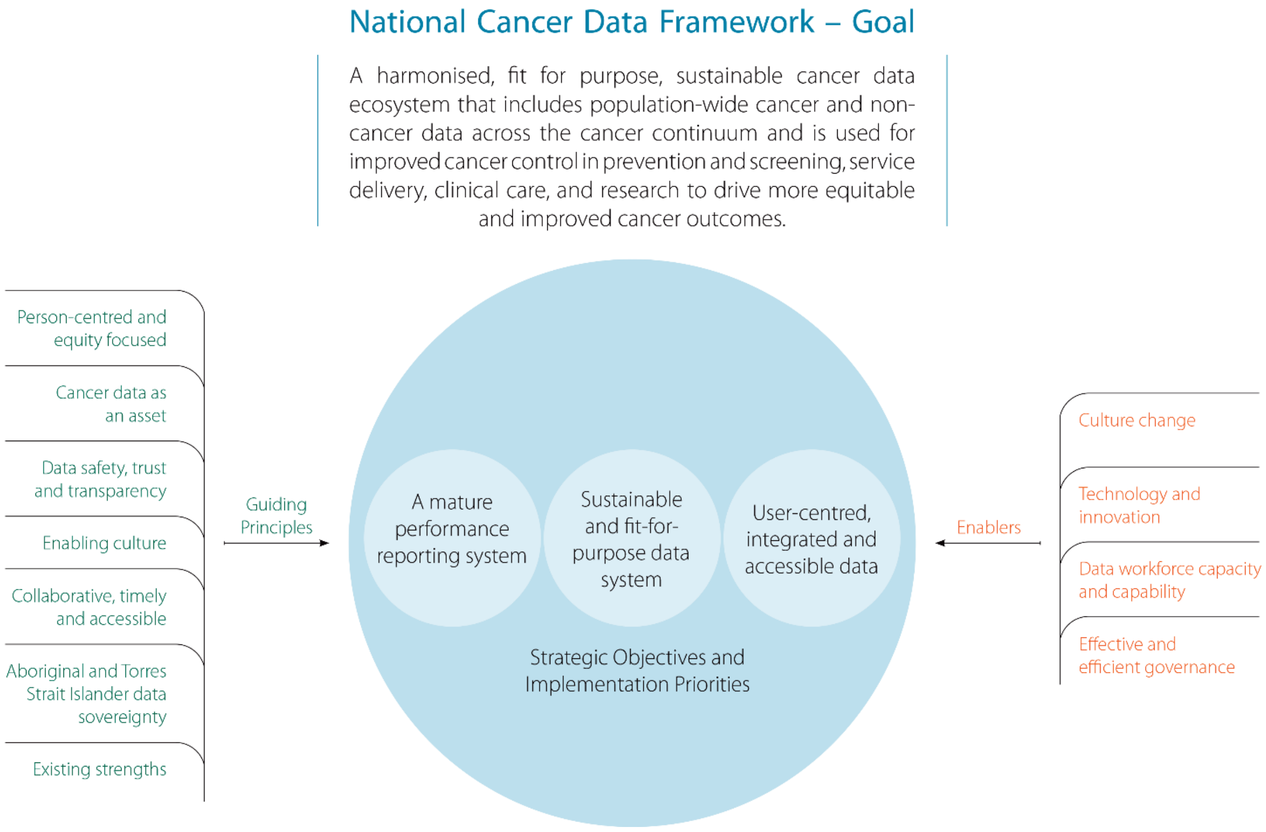
Cancer represents Australia's largest disease burden and is a leading cause of death, with over one million Australians currently living with or having lived with cancer.[3] In response, the Australian Government released the Australian Cancer Plan[4] in 2023, aiming to improve outcomes for all Australians, particularly those facing poorer health outcomes. Achieving equity in cancer outcomes is a fundamental measure of success as we strive for world-class cancer care for all Australians.

The Australian Cancer Plan emphasises that optimal cancer care and a high-performing system rely on access to, use of, and sharing of comprehensive health and cancer data across all care settings. While Australia has rich and diverse cancer data collections, their effective use is hindered by fragmentation, complex governance arrangements, and variation in data collection. The sector needs to work together to improve data availability and better measure how well the healthcare system is performing.

The National Cancer Data Framework will set the strategic direction for the collection, management, use, and ongoing development of comprehensive and consistent health and cancer data. It aligns closely with several key initiatives and priorities in Australia's cancer control and data landscape and complements other strategic objectives of the Australian Cancer Plan.

The Data Framework's development has been informed by extensive sector consultation, reflecting broad national agreement on the current state of cancer data in Australia and priorities for action. It incorporates Indigenous data sovereignty principles to ensure that the unique health needs of First Nations peoples are met.

Figure 1: The guiding principles and enablers of the Data Framework, with three strategic objectives to achieve its overarching vision.



The Data Framework includes three strategic objectives to improve cancer care in Australia:

A mature performance reporting system

The first objective is to create a mature performance reporting framework that measures system performance across the entire cancer care continuum. The framework will address critical questions regarding prevention strategies, screening impacts, equity in access to diagnosis and treatments, and outcomes for priority populations. By leveraging existing frameworks, this objective aims to identify variations in care, to inform interventions and policy decisions, ultimately enhancing patient care.

A sustainable and fit for purpose data system

The second objective is to build a mature and sustainable data system that collects timely and accurate information about cancer care. By standardising the way data is collected, it will make information sharing quicker and easier. This objective will help fill information gaps, like how advanced cancer is when it's first found, to help improve care for patients. Getting this information faster will help with clinical decision making and service and system level planning.

User centred, integrated and accessible data

The third objective is to create a user-centred data system that's easy to access and allows data to be linked between national and local levels. By streamlining approval processes it will be simpler to use this data while keeping it safe and reliable. Connecting information from different parts of a patient's journey will enable a full picture of their cancer care and outcomes.

Achieving these strategic objectives will be key milestones in realising the ten-year vision of the Australian Cancer Plan. The Data Framework aims to provide essential data to address key questions in cancer control. It will improve equity in healthcare access and offer insights into health system performance to enhance cancer outcomes across Australia.

Plan on a Page

Australian Cancer Plan 10-year ambition

A modern, fit for purpose cancer control infrastructure, advanced by the innovative application of technology, research, and data to improve Australia's cancer outcomes.

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 Aboriginal and Torres Strait Islander people and other priority population groups.

Aboriginal and Torres Strait Islander data sovereignty: Aboriginal and Torres Strait Islander leadership is integral in data collection, management, and use of Indigenous data (Closing the Gap, Priority Reform 4, Shared access to data and information at a regional level)

Cancer data as an asset: Acknowledging 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.

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: Enable collaborative efforts across the whole cancer sector by making cancer data timely and accessible through modern infrastructure and streamlined data governance.

Enabling culture: Enable data access, embrace data-driven decision-making, and promote data collection 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 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.

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.

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.

Enablers

- **Culture change**
- **Technology and innovation**
- **Data workforce capacity and capability**
- **Effective and efficient governance**

Introduction

Cancer represents Australia’s largest disease burden and is a leading cause of death. Over one million Australians are currently living with or have lived with cancer, with projections for 2024 indicating 169,478 new diagnoses and 52,671 cancer-related deaths. [2, 3] These figures exclude non-melanoma skin cancers, which would significantly increase the total.

In response, the Australian Government released the Australian Cancer Plan[4] in 2023, aiming to improve outcomes for all Australians, particularly those with poorer health outcomes. Achieving equity in cancer outcomes is a fundamental measure of success as Australia strives for *World-class cancer outcomes and experiences for all Australians*.

The Australian Cancer Plan emphasises that optimal cancer care and a high-performing system rely on access to, use of, and sharing of comprehensive health and cancer data across all care settings. This data is crucial for informing planning, delivery, and continuous improvement of cancer care, as well as driving policy and research priorities across the cancer control continuum.

Text Box 1: The Australia Cancer Plan

Strong and Dynamic Foundations

Ten-year Ambition: A modern, fit for purpose cancer control infrastructure, advanced by the innovative application of technology, research and data to improve Australia’s cancer outcomes.

Two-year Goal: Nationally agreed frameworks for collection and reporting of comprehensive cancer data, and implementation of new technologies into routine cancer care, with a focus on research priorities that drive innovation and fast-track opening of cancer clinical trials in Australia.

Action: Develop an agreed national cancer data framework to improve accessibility, consistency and comprehensiveness of integrated data assets.

While Australia holds rich and diverse cancer data collections, their effective use is hindered by the segmented structure of the healthcare system (public and private) and other structural and legislative factors. These include multiple data custodians, complex governance arrangements, and a lack of harmonisation across population-based datasets, which prevent compilation of complete national data collections and challenge Australia’s ability to create a nationally consistent view of cancer control.

Addressing these challenges requires a concerted effort to improve data availability, enhance performance measurement and reporting frameworks, and prioritise strength-based, person-centred healthcare metrics nationally. These steps are essential for achieving more consistent and improved cancer care outcomes for all Australians and require whole of sector action.

The development of a National Cancer Data Framework (Data Framework) is a key action towards a two-year goal under the Strong and Dynamic Foundations objective of the Australian Cancer. This Data Framework will set the strategic direction for the collection, management, use and ongoing development of comprehensive and consistent health and cancer data. It aims to ensure Australia has a mature cancer data ecosystem that supports reporting and benchmarking on key cancer control performance indicators, embeds Indigenous data sovereignty, underpins data-driven improvements to patient care, and supports world class research.

The Data Framework complements other Australian Cancer Plan strategic objectives and implementation priorities, including the National Optimal Care Pathways Framework and National Framework for Genomics in Cancer Control. It aligns with national, state, and territory data, digital, and cyber-related policies and reforms, supported by cross-jurisdictional commitments indicated in the *2021 Intergovernmental Agreement on data sharing.*[5]

These reforms will create opportunities to support the implementation of the Data Framework, contributing stronger safeguards, more efficient processes, and fostering innovation to grow the national cancer data asset for the benefit all Australians.

Why cancer data matters

Cancer data plays a vital role in supporting decision-making and improving cancer outcomes across Australia. A comprehensive and integrated cancer data system enables evidence-based decisions, identifies care disparities, and supports targeted interventions. Moreover, it fills gaps and connects data to provide a longitudinal view of patients and priority populations across all interactions with the health system, moving away from episodic care. By understanding risk factors and their relationship with cancer, data informs prevention strategies that can reduce cancer incidence and promote early detection.

Standardised data collection, particularly for priority populations, will facilitate a comprehensive national view of cancer control efforts and work towards a national benchmarking capability that will drive system improvements in cancer care and improve the health systems ability to identify and address inequities.

The Data Framework, when linked to population-level indicators and performance measures, enables the identification of disparities and tracking of progress in reducing them. This approach allows for targeted interventions and resource allocation to areas of greatest need. For instance, variations in cancer screening rates, treatment outcomes, and survival can be monitored across different population groups and geographic regions.

Investing in comprehensive data collection, integration and sharing enhances the health system's effectiveness in meeting the diverse needs of Australians. This data serves various stakeholders (Text Box 2), each with different needs: patients, caregivers and their communities use it for informed decision-making about care options; cancer care teams rely on it for clinical decision-making and quality improvement; researchers use it to identify trends and develop new strategies; health administrators use it for resource allocation and system planning; and policymakers use it to develop evidence-based policies and monitor cancer control efforts

Text Box 2: Cancer data audience

Patients, their cancer care team and communities leverage data for personalised care, leading to improved patient outcomes and experiences. It provides clear information on diagnosis, treatment, follow-up care, and recovery.

Researchers draw on population-based data and sharing their datasets to advance cancer care and make innovative discoveries. This collaborative research, facilitated by integrated data systems, accelerates progress in the field.

Health administrators require data to inform decisions on improving the availability, quality, equity and outcomes of healthcare services.

Policy makers rely on data for evidence-based decision making, resource allocation, equity considerations and monitoring policy impact.

Governance of First Nations Data

The Data Framework is guided by the Maiam nayri Wingara[6] principles on Indigenous Data Sovereignty and Governance, ensuring Aboriginal and Torres Strait Islander peoples' rights are respected and enabled throughout the entire data lifecycle. These principles assert that Indigenous peoples have the right to:

- Exercise control over the data ecosystem, including creation, development, stewardship, analysis, dissemination, and infrastructure.
- Access contextual and disaggregated data at individual, community, and First Nations levels.
- Ensure data relevance that empowers sustainable self-determination and effective self-governance.
- Establish data structures accountable to Indigenous peoples and First Nations.
- Protect and respect individual and collective interests in data.

The Data Framework aligns with and builds upon key national initiatives, including Priority Reform Four of the National Agreement on Closing the Gap[7], the NACCHO Aboriginal and Torres Strait Islander Cancer Plan[8], and the Australian Cancer Plan. It aims to provide implementable actions that deliver on the Aboriginal and Torres Strait Islander Cancer National Control Indicators[9] and Aboriginal and Torres Strait Islander Health Performance Framework[10].

Text Box 3: Priority Reform Four: Shared Access to Data and Information

Priority Reform Four of the Closing the Gap Agreement ensures Aboriginal and Torres Strait Islander peoples can access and use locally relevant data.[1] It empowers Indigenous communities to monitor progress, drive development, and prioritise their needs. By promoting shared access to data at a regional level, Indigenous peoples are enabled to make informed decisions and track progress more effectively.

Indigenous Data Sovereignty in practice

Operationalising Indigenous Data Sovereignty through Indigenous Data Governance requires significant data capability building and governance supports across First Nations Communities. Engaging and supporting First Nations communities and the Aboriginal Community Controlled Health

Sector to be active participants across the data lifecycle with good governance is crucial for ensuring data processes are designed and delivered in partnership and reflective of the aspirations of First Nations communities. It also requires data custodians developing shared understandings, policies and protocols across sectors and jurisdictions to ensure data is repatriated back to communities in a timely and usable way.

The implementation of Indigenous Data Sovereignty principles establishes a framework that addresses the unique health challenges of First Nations communities while setting a benchmark for inclusive, ethical, and effective data utilisation. This approach creates opportunities that benefit all population groups, for more informed, culturally sensitive, and effective health strategies across diverse communities.

Development of the Data Framework

The Data Framework has been developed by Cancer Australia in a collaborative partnership with the Australian Institute of Health and Welfare and Cancer Council Australia.

The Data Framework was informed by advice from the National Cancer Data Framework Steering Committee, state and territory governments, Cancer Australia's advisory groups, a series of national roundtables representing state and territory governments, data custodians, clinicians, public and private health providers, not for profit organisations, professional colleges, research groups, research and clinical trial groups, consumers and through an open public consultation process.

The Data Framework has been developed *in a way that embeds best practice principles for co-design with First Nations Australians.*[23] This was informed by a First Nations led co-design process with First Nations leaders, practitioners, and community members, ensuring the Data Framework and implementation remain culturally appropriate, effective, and aligned with community values.

The Goal of the National Cancer Data Framework

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 im-proved cancer outcomes.

Achieving the goal of this Data Framework will be significant milestone in realising the ten-year Ambition of the Australian Cancer Plan for a *"A modern, fit for purpose cancer control infrastructure, advanced by the innovative application of technology, research and data to improve Australia's cancer outcomes."*. It will make available the data needed to answer Australia's critical cancer control questions, improve equity and provide insights into health system performance that will improve Australia's cancer outcomes.

Current State

Australia holds rich and diverse cancer data collections that offer valuable insights into cancer trends and outcomes. Jurisdiction-based cancer registries provide population-wide data on incidence, mortality, survival, and prevalence, compiled into the Australian Cancer Database (ACD). Clinical quality registries (CQRs) complement this with detailed patient care and outcome data, though their focus and coverage vary. Administrative datasets, hospital and health service data, research data, and surveys further contribute to understanding cancer care and outcomes. The cancer data ecosystem (Figure 2) visually represents this complex network, showcasing the various datasets, their respective custodians, and the connections between them. It illustrates how data flows across different stages of the cancer care continuum, from prevention and screening through to diagnosis, treatment, and outcomes.

Despite these strengths, the current cancer data system faces several key challenges:

- **Fragmentation:** Inconsistent data capture across cancer services, primary care, screening registers, and administrative databases. This fragmentation limits the ability to achieve a nationally consistent, data-driven understanding of cancer control and outcomes.
- **Interoperability:** Limited interoperability between data systems across states, territories, and jurisdictions hinders seamless data exchange. Achieving interoperability would ensure consistent, accurate data across systems, reduce errors and redundancies, and eliminate most manual data entry, while improving the timeliness of information.
- **Data gaps:** Critical gaps exist in national cancer data, particularly in areas like cancer stage at diagnosis, patient-reported outcomes, treatment measures, and service quality indicators. Additionally, integrating genomics data is increasingly important for identifying individual cancer risk, early detection, and personalised treatment options.
- **Data linkages and access:** Linking cancer data with other relevant datasets, such as those covering social determinants of health, is often costly, delayed, and complex. Differing ethics and access requirements from multiple data custodians add to the difficulty. National initiatives like the National Health Data Hub (NHDH)[11] and the Person Level Integrated Data Asset (PLIDA)[12] aim to improve linkages, but more regularly updated and accessible datasets are needed to understand variations in outcomes, especially for priority populations.

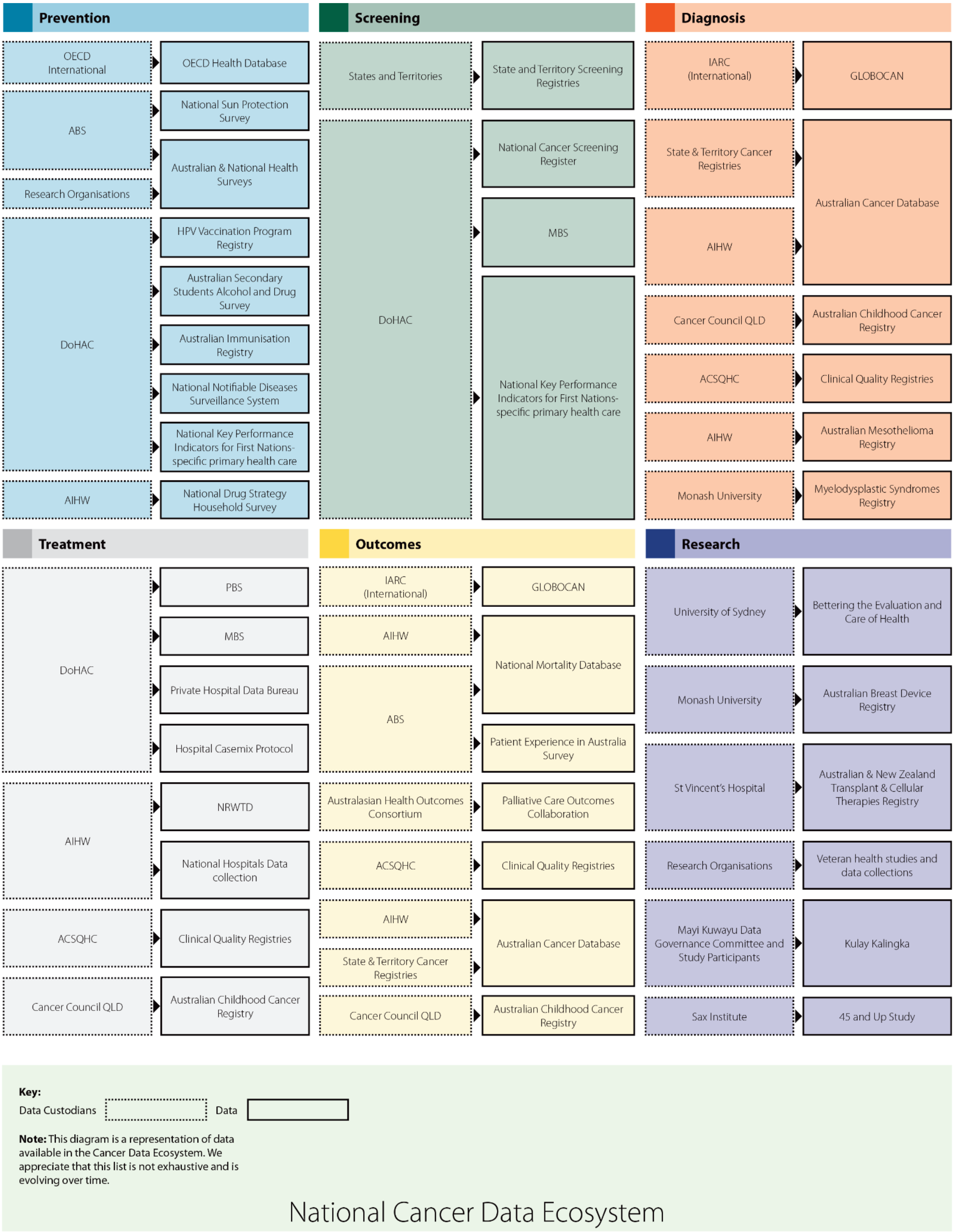
- **Underutilisation of research data:** A significant amount of valuable data is generated from cancer research and clinical trials, including genomics information. However, this data is often underutilised, limiting its potential to inform clinical practice, guide future research, and generate further insights.
- **Limited reporting:** Despite the extensive cancer data collected in Australia, there is no standardised or mandatory system for performance measurement and reporting. This hinders benchmarking and the identification of improvement opportunities. Much of the data remains unreported and uncollated, reducing its potential to drive better healthcare and outcomes.

Efforts to standardise data collection across the cancer care continuum are essential to improving data quality, timeliness, completeness, and interoperability. Standardisation will help identify variations in diagnosis, treatment, and outcomes and improve equity in cancer care.

Achieving full interoperability across systems would not only facilitate seamless data exchange but also ensure consistent and accurate data across all platforms, enhancing the potential for improving patient care, service planning, and system performance, reducing errors, and strengthening national cancer control efforts.

Figure 2: Australia's Cancer Data Ecosystem

The cancer data ecosystem demonstrates the various data sources and custodians involved in cancer care, highlighting the need to integrate diverse datasets for a unified view of cancer control.



Note: This diagram is a representation of data available in the Cancer Data Ecosystem. We appreciate that this list is not exhaustive and is evolving over time.

Guiding Principles

These guiding principles shape the development and ongoing implementation of the Data Framework, ensuring it remains adaptable as Australia's cancer data system matures.

- **Leverage existing strengths:** Strategic objectives and priority actions align with, build on and add to existing initiatives and innovations in policy approaches to data capture and sharing that can be harnessed and scaled.
- **Indigenous Data Sovereignty:** First Nations peoples have the right to exercise ownership over Indigenous Data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous Data.
- **Cancer data as an asset:** Acknowledging 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.
- **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 people, priority population groups and their communities.
- **Data safety, trust, 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:** Enable collaborative efforts across the whole cancer sector by making cancer data timely and accessible through modern infrastructure and streamlined data governance.
- **Integrated and relevant data use:** Enable data access, embrace data-driven decision-making, and promote data collections as part of patient care through seamless integration into clinician workflows.

Strategic Objectives

This Framework outlines three strategic objectives to support improvements to cancer data nationally and ensure Australia has a mature data ecosystem that support data driven improvements to cancer control across the length of the cancer care continuum, including improving system performance. They provide the foundation for delivering on the goal of this framework.

Implementation priorities sit underneath each of our strategic objectives to guide where action is required to achieve the goal of the Framework.

Strategic Objective 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.*

This objective aims to develop a mature, trusted performance reporting system that measures cancer control system performance across the entire continuum while addressing the needs of priority populations.

This will be achieved through a mature national cancer control performance reporting framework, measuring key indicators assessable against the cancer control continuum and optimal care pathways. The Data Framework will address critical cancer control questions, such as the effectiveness of prevention strategies, the reach and impact of screening programs, equity in access to diagnosis and treatment, outcomes of cancer care, support for survivors and palliative care patients, and disparities among priority populations.

Leveraging existing frameworks like the National Cancer Control Indicators (NCCI) (and associated Aboriginal and Torres Strait Islander Indicators) and Australian Health Performance Framework (AHPF) is crucial. The national and Indigenous NCCI tracks indicators across the cancer care continuum and supports international benchmarking, while the AHPF provides data for evaluating health system performance and intervention effectiveness.

The comprehensive framework will enable population-level cancer surveillance and support improvement efforts at various levels through enhanced data use. The goal is a transparent, trusted system that improves patient care by answering these critical questions and informing targeted interventions and policy decisions.

Importance

Monitoring and reporting on cancer control system performance enhances our understanding of its effectiveness against optimal cancer pathways, guiding future efforts. Population-level cancer surveillance and performance reporting are critical for identifying gaps leading to unwarranted variations in incidence, diagnosis, and outcomes, informing improvement efforts.

This is particularly crucial for Aboriginal and Torres Strait Islander people, who face higher cancer diagnosis and mortality rates, and lower 5-year relative survival compared to non-Indigenous Australians. For First Nations communities, aligning data practices with self-determination is essential to accurately capture and address their unique health challenges and outcomes. Internationally, cancer care system performance reporting is well-developed in some countries, as highlighted by the International Cancer Benchmarking Partnership (ICBP).[13] The ICBP measures variations in cancer survival, incidence, and mortality across countries to identify best practices and inform policy changes. Australia can benefit from adopting ICBP practices that contribute to improved cancer outcomes.

Current challenge

Achieving robust performance reporting is challenging, requiring consideration of system-level factors (e.g., service access), person/community-level factors (e.g., social determinants, health behaviours), and disease/treatment-level factors (e.g., stage at diagnosis, treatment appropriateness). Accounting for this complexity is crucial to understanding cancer outcome variations across populations and informing improvement efforts. For First Nations communities, embedding Indigenous data governance to support local service improvement is essential, considering tailored needs and interests.

In Australia, national cancer surveillance and performance reporting are hampered by:

- Lack of a comprehensive national performance monitoring framework including service quality indicators
- Unstandardised data collection, analysis, and reporting approaches
- Complex, unconnected data holdings across public and private systems, including clinical cancer registries, trial, and research datasets
- Complex data custodian arrangements, particularly for cross-custodian linkage

Building on strengths

Several jurisdictions are advancing cancer surveillance and system performance reporting. Highly developed approaches are *NSW and ACT's Reporting for Better Cancer Outcomes*[14] program and *Queensland's Cancer Alliance Cancer Control Quality and Safety Partnership*[15], with various strengths also evident in other jurisdictions. Both emphasise clinician leadership and collaboration but differ in focus: NSW covers prevention, screening, treatment, and research, while Queensland concentrates on specific cancer types.

To build on these strengths, Australia's cancer care system needs increased cross-jurisdictional collaboration to assess real-world impacts of investments across the cancer care continuum.

Implementation priorities and actions

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

It is essential for First Nations communities to have a clear understanding of the available cancer data in the cancer data ecosystem, including data types, custodians, and reporting options. This understanding extends to knowing and comprehending existing cancer control indicators, as well as being actively engaged in the development of new indicators that are relevant and meaningful to their communities.

Aligning data use with Indigenous data sovereignty principles enables First Nations communities to determine the reporting that is important to them, which can then be leveraged to support decision-making and influence health outcomes. This process involves building data-related capabilities and enhancing knowledge of data assets, supporting self-determination and informed choices.

1.2 Build and maintain public trust in the data system.

Public trust is essential for the Data Framework's success. Given concerns about data breaches and cyber security, earning trust requires demonstrating ethical practices, respecting privacy, and highlighting the benefits of transparent reporting.

A key outcome is improved health literacy about the value of aggregated data and performance reporting for public benefit. Ensuring responsible data use, particularly for priority groups, will build confidence in data initiatives. Meaningful engagement with the public and stakeholders will foster collaboration. Harmonised approaches to data use and reporting will further enhance public trust.

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

Harmonised national reporting will address diverse end-user needs by answering priority questions and supporting cancer control research. To drive optimal care and ensure accurate national benchmarking, a consistent analysis and reporting process will be established across all states and territories, involving agreed methodology and indicators for core outcomes comparison.

A key challenge in national benchmarking of diagnosis, treatment, and care indicators is ensuring high clinician engagement and trust in the analysis and reporting. This has been crucial to the success of work in NSW, Queensland and other jurisdictions, and remains a requirement for broader implementation.

Short term actions

- **1.1.1** Develop communication strategies for informing First Nations people what data are held relating to their interests, its use, and how it can be accessed. This may include:
    - Partnering with First Nations communities to ensure data are described in a culturally relevant way (easy to use, interpret and digest).
    - Engaging with Aboriginal and Torres Strait Islander organisations and community in how they would like the data reported.
- **1.2.1** Understand the current level of data health literacy in Australia, with a focus on priority population groups.
- **1.2.2** Review best practice approaches to public engagement in data release, open access and public reporting.
- **1.2.3** Co-design the development of nationally accessible materials on health and cancer data collection and use for public engagement.
- **1.3.1** Establish a National Cancer Control Performance Reporting Framework that:
    - Leverages existing frameworks and identifies new key indicators for cancer control, including adherence to Optimal Care Pathways
    - Establishes a technical and clinical working group to define core indicators and data requirements
    - Implements cross-jurisdictional benchmarking and develops a process for transitioning from confidential to public reporting
    - Standardises data definitions and reporting indicators, with a focus on priority populations
    - Tests a national harmonised approach for reporting on 2-3 priority cancer control indicators across two Optimal Care Pathways

Long term actions

- **1.2.4** Implement public education and health literacy measures to enhance trust and engagement in cancer data usage, explaining how data is collected, analysed, safeguarded, and reported while empowering consumers to interpret and utilise this information effectively.
- **1.2.5** Develop and publish accessible cancer data reports that present meaningful information to help individuals make informed decisions about their treatment and care, including key performance indicators and benchmarks across jurisdictions.
- **1.3.2** Report on cancers across the Optimal Care Pathway across all jurisdictions

Strategic Objective 2: A sustainable and fit-for-purpose data system

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Foster a sustainable and fit-for-purpose data system that enables the timely collection of our 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.

This objective aims to create a robust, cohesive data system ensuring timely, accurate, and standardised data collection across the cancer continuum, fostering interoperability and enhancing health and population data utility. Enable analysis of outcomes for priority groups, service benchmarking, and broader population.

Importance

Adopting best practices in data collection will reduce fragmentation and duplication, improve quality, and enhance timeliness of data capture, release, and reporting, aligning with national policies and agreements. For First Nations communities, these practices must align with Indigenous data sovereignty principles to meet unique health data needs and community priorities.

A harmonised approach to data capture, storage, and access will increase the cancer control sector's capacity to use emerging technologies and improve data interoperability across holdings.

Advancing cancer data collection and integration will enhance Australia's ability to answer crucial questions about cancer incidence, mortality, practice variations, outcome disparities, and resource use. Incorporating Indigenous data sovereignty will ensure data reflects First Nations health experiences and needs. Addressing data gaps for priority populations will improve understanding of cancer prevalence and mortality rates across different locations and support CQI and service design efforts.

Integrating cancer data within the broader health landscape will leverage existing clinical and non-clinical assets to examine performance at multiple levels. Establishing population data as the foundation will mirror successful approaches like AIHW's National Health Data Hub. Over time, enhanced data availability will provide more precise insights into national health trends, benefiting from patient perspectives and addressing equity considerations for priority populations.

Current challenge

The cancer data ecosystem is fragmented, with important data scattered across various public and private holdings using inconsistent data definitions. This lack of a unified data system, combined with poorly defined roles, leads to duplication and data gaps, particularly affecting First Nations communities and other priority groups. The absence of common infrastructure and system interoperability further compounds these challenges.

Developing a mature data system that enables appropriate linkage or federated approaches across these holdings is critical. Incorporating Indigenous data sovereignty principles in this process will enhance trust and data utility for First Nations communities.

Overcoming barriers such as the lack of structured clinical reporting and inadequate data management support is essential for effective data access. This will provide a more comprehensive view of the cancer continuum and enable better-targeted improvements in patient outcomes. While challenging, implementing structured clinical reporting at the point of service delivery is essential for capturing currently unavailable data such as stage, treatment, and prognostic factors including genomic data. A structured reporting approach will significantly enhance data integrity and utility.

Building on strengths

Population based cancer registries exist in all jurisdictions and form the core of the cancer data ecosystem. Some registries have innovated with enhanced e-path extraction, radiology data capture, and stage and treatment data collection from medical systems. Integrating these innovations with appropriate governance of Indigenous data can ensure culturally appropriate practices beneficial to First Nations communities.

Australia's growing network of clinical quality cancer registries has engaged clinicians in improving diagnosis and treatment quality for several cancers. Several innovative large data assets have also been developed as research initiatives that demonstrate safe integration of data from multiple sources.[22]

These innovations demonstrate the potential for a harmonised approach to creating a sustainable, fit-for-purpose data ecosystem. This would provide a comprehensive view of patient, clinical, population, and health service data, alongside broader health determinants, research insights, clinical trials, and emerging data streams like ambulatory care and genomics.

Addressing key data gaps and improving data quality, particularly for Indigenous communities, is crucial for effective monitoring of population-level changes, identifying disparities in cancer outcomes, and guiding targeted cancer-control strategies.

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

Embedding strong governance of Indigenous data within the cancer data ecosystem is crucial for upholding Indigenous data sovereignty and improving cancer outcomes for First Nations communities. This approach requires partnering with Indigenous people throughout the entire data lifecycle and ensuring their perspectives guide data governance decisions.

Establishing Indigenous data champions and enhancing data literacy within these communities are essential steps. Additionally, the cancer care sector must focus on cultural and organisational changes to prioritise Indigenous involvement in decision-making. By providing accessible cancer data and fostering local accountability, we can create a more inclusive system that empowers Indigenous communities. This approach not only respects Indigenous data sovereignty but also contributes to more effective and culturally appropriate cancer care strategies.

2.2 Improve the timeliness of cancer data collection and reporting.

Australia's cancer data in the ACD is typically available several years after diagnosis, which is insufficient for timely national surveillance of early outcomes of services. It also limits broader service performance monitoring. Despite advancements in electronic health records (EHR), automated reporting systems, and AI technologies, many health facilities still rely on manual processes for data management.

Improving timeliness requires streamlining data entry, enhancing EHR systems, training healthcare staff, allocating sufficient resources, establishing clear guidelines, and developing efficient validation infrastructure. The aim is to provide data that supports timely clinical decision-making and health service evaluation for improving outcomes at both local and national levels. This is crucial for responsive and efficient cancer care management across Australia.

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

Population-based cancer registries (PBCRs) are a critical component of Australia's data ecosystem. Initially established under jurisdictional public health legislation to report cancer incidence, their role has evolved to become a key foundation for integrated data assets. This evolution has led some registries to expand their data collection to include stage at diagnosis, broader pathology data, radiology information, and treatment details.

However, this development has resulted in variability across registries in terms of data capture and definitions. There is now significant diversity in the roles, resources, and capacities of both PBCRs and clinical quality registries (CQRs) in Australia.

As Australia moves towards a harmonised national approach to creating integrated data assets, it is essential to clearly define and adequately resource the role of cancer PBCRs and CQRs to ensure their important contribution to the data ecosystem. Additionally, exploring how PBCRs and CQRs can support each other's functions and enhance the understanding of cancer across Australia will be important. This collaboration will improve efficiency across registries, facilitating that data is collected once but utilised for multiple purposes.

2.4 Advance the collection of cancer stage at diagnosis data as key measures of equity and cancer control.

Cancer stage is a key variable for understanding variations in cancer outcomes. It plays an integral role in assessing the success of screening and early diagnosis initiatives, evaluating treatment appropriateness, and exploring outcome variations across populations. Assessing cancer stage at diagnosis is particularly important for initiatives aimed at improving outcomes for Aboriginal and Torres Strait Islander people and other priority population groups.

At population-based registry level, collecting stage data is resource intensive. While suitable for analysing whole-population trends, registry staging is not intended for assessment of treatment appropriateness at individual person level. A key limitation is the potential risk of missing metastatic disease information when radiology reports are not included in registry data.

A report on national stage at diagnosis collection by Australasian Association of Cancer Registries, commissioned by Cancer Australia, recommended prioritising stage data collection within health service data systems.[16] This approach would allow for easier extraction into cancer registries and other data systems. Several jurisdictions are currently exploring barriers and enablers of stage collection and extraction to inform future work. There are also ongoing efforts to collect cancer stage data within clinical quality registries.

2.5 Agree and prioritise national data gaps

Comprehensive reporting on national cancer indicators is hindered by existing data gaps, variations in availability, and incomplete information along the cancer care continuum. This issue is particularly pronounced for certain tumour types, including rare and less common cancers.

In addition to the gaps in data regarding cancer stage at diagnosis, several other critical areas lack consistent or systematic collection across the country. These areas include metrics that support optimal and equitable care, patient experience data, quality of care indicators, Indigenous identification, and equity determinants for priority population groups, and non stage prognostic indicators. Furthermore, there is insufficient data on genomics and longer-term outcomes such as disease progression and recurrence by treatment type, treatment plans, received treatments, treatment locations, and co-morbidities.

Identifying and prioritising these data gaps is a crucial step toward enhancing existing data and generating new insights. This process is essential for improving health service utilisation and ultimately achieving better cancer outcomes across Australia.

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.

Consistent national reporting of key cancer data is fundamental to achieving the 10-year ambition of a modern, fit-for-purpose cancer control infrastructure, advanced by innovative application of technology, research, and data.

Leveraging existing initiatives such as the NCCI and AHPF into a comprehensive national reporting framework represents a significant step towards achieving this goal. The NCCI currently provides a valuable foundation for reporting indicators and measures across the cancer care continuum, sourcing data from numerous collections. However, to fully realise its potential as the primary national reporting framework, several enhancements are necessary.

Efforts must be made to address existing data gaps within the NCCI. By identifying and filling these gaps, we can ensure a more comprehensive view of cancer control across Australia. This process will involve standardising data collections where relevant and expanding the scope of data sources.

The reporting framework should be expanded to incorporate additional quality indicators that measure the implementation of optimal care pathways into services. These indicators will provide crucial insights into the effectiveness of cancer care delivery and help identify areas for improvement.

The development of nationally agreed core data specifications will be essential to support the NCCI's evolution. These specifications will provide foundational data for improving accessibility, consistency, and comprehensiveness of cancer data for national reporting.

To ensure a comprehensive view of cancer across Australia, agreeing on and prioritising national questions is fundamental. The Australian Cancer Plan emphasises the necessity to address data gaps that impact the ability to assess optimal care provision at a population level and implications for improving cancer outcomes, as well as identifying specific data needs of end users across the complete cancer continuum. The prioritisation of data gaps would enable a focus on their respective importance and utility in addressing key questions. When data is collected across more than one asset, it is essential to ensure standardisation of data definitions, collection protocols, and quality control measures to maintain consistency and comparability in national reporting.

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

Obtaining ready-to-use source data from electronic systems will significantly benefit cancer databases. Structured reporting enables automated data extraction, particularly from pathology and radiology which are key cancer data sources. This approach aligns with a growing global consensus.

Structured pathology reports can provide several advantages by supporting automated cancer extraction and use in enhancing treatment planning, and research. The Royal College of Pathologists of Australia publishes structured pathology reporting protocols for various cancers; however, there is much variability in their uptake and use in automated flow of data into cancer registries.

In radiology, the Royal Australian and New Zealand College of Radiologists is promoting structured reporting and exploring AI solutions. Notably, structured radiology reporting is less commonly utilised, and radiology reports do not routinely flow to cancer registries due to both policy and implementation challenges. The Queensland Cancer Registry is currently exploring the automated flow of radiology reports to support stage capture and, perhaps more importantly, to monitor recurrence and disease progression. The large volume of images presents a challenge, highlighting the need for AI solutions to facilitate the flow and interpretation of the most relevant images.

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

In addition to stage at diagnosis, various treatment and clinical variables are relevant for assessing prognosis, adherence to optimal care pathways, and evaluating treatment appropriateness. As Australia shifts to electronic medical records (EMRs), there is an opportunity to implement structured collection of key variables that can be extracted into broader data holdings.

Exploring the potential for structured clinical reporting of key data items within EMRs requires leveraging existing successful models and frameworks but also significant cultural change and clinical engagement for success.

Short term actions

- **2.1.1** Enhance First Nations community data capabilities and partnerships throughout the data lifecycle. This may include:
    - Leveraging relevant guidance from state and territory data governance groups.
    - Aligning with existing First Nations communities' data groups, acknowledging that Indigenous data governance is not prescriptive.
    - Identifying data-ready communities to collaborate and engage in every aspect of data governance.
    - Applying the OCCAARS (ownership, control, custodianship, accessibility, accountability, amplifying First Nations, relevant, sustainability) framework, focusing on accountability and amplifying community voices.
    - Developing and using a culturally relevant and accurate data dictionary specific to First Nations communities to standardise data collection to the extent feasible and reporting, ensuring it is culturally relevant and accurate and reflects Indigenous knowledges.
    - Establishing First Nations communities' data champions across the cancer control sector to drive implementation of this Data Framework.
    - Ensuring protective data practices that safeguard individual and collective interests, prioritising ethics and active community engagement.
    - Partnering with First Nations communities at all stages of the data lifecycle to reflect their priorities in community data.

Short term actions

- **2.1.2** Improve the capabilities of staff involved in the cancer care sector relating to Indigenous data across the data lifecycle. This may include:
    - Creating internal information resources to increase understanding of Indigenous Data Sovereignty within each individual organisation.
    - Convening communities of practice related to data which should incorporate consideration of this Data Framework into their terms of reference to embed a culture of best practice and knowledge sharing for governance of Indigenous data amongst staff.
- **2.1.3** Build towards organisational and cultural change within the cancer care sector to support the inclusion of Aboriginal and Torres Strait Islander people in data governance. This may include:
    - Enacting Priority Reform 3 under Closing the Gap: Transforming Governments
- **2.2.1** Map the current state for timeliness of cancer incidence data and other data priorities identified, and the issues impacting on the timeliness of data for each jurisdiction, and outlining the potential steps required to achieve timeliness improvements.
- **2.2.2** Prioritise the data items that are most critical for improving the timeliness of cancer incidence data and understand options for interoperability.
- **2.3.1** Address how the population-based cancer registries and clinical quality registries can support each other's roles, and together extend the clinical quality registries representation of the population for greater completeness of the cancer data ecosystem.
- **2.3.2** Define the role of the Australian Cancer Data Alliance, including representation of the Australian Association of Cancer Registries, in ensuring consistent cancer data collection across the data ecosystem.
- **2.3.3** Explore any potential for establishing a common cancer registry software platform that would enable greater levels of technical cooperation across all jurisdictions in Australia and support linkage of integrated data for people affected by cancer who cross borders for treatment.
- **2.4.1** Establish a cross-jurisdictional working group incorporating representation from population- based registries and clinical quality registries and clinical informatics, to explore the barriers and enablers of standardised stage collection in clinical workflows.
- **2.4.2** Form a demonstration project on the capture and extraction of stage at diagnosis, initially for 2-3 agreed cancer types, building on investment in breast cancer stage collection.
- **2.5.1** Establish a set of core indicators to assess adherence to the optimal care pathways (cancer type agnostic) for inclusion in a National Cancer Control Performance Reporting Framework and define the data items needed to measure these and identify priority data gaps. This may include:
    - Undertaking a stocktake of existing projects measuring adherence to optimal care pathways
    - Establishing a technical and clinical working group to define core indicators, and expanding on the National Cancer Control Indicators (NCCI), to assess adherence to optimal care pathways (tumour stream agnostic) for a National Cancer Control Performance Reporting Framework.
    - Defining the data items needed to measure these indicators and identify the priority data gaps. This work will build on and link to work already underway on the Optimal Care Pathway Framework Development.
- **2.5.2** Develop an agreed definition of key non-cancer variables linked to variations in cancer outcomes and a plan for their routine collection and integration in data assets.
    - Patient level (e.g., performance status and comorbidities)
    - Service level (e.g. service volume)
- **2.5.3** Develop an agreed priority list of non-stage related prognostic factors and test their collection within clinical and population-level information systems to support data extraction for analysis.
- **2.5.4** Define appropriate collection of nationally consistent Patient Reported Outcomes and Experiences (PROMS and PREMS) for various levels of capture.
    - Point of care measures to guide clinical encounters
    - PROMS AND PREMS for Aboriginal and Torres Strait Islanders and other priority populations.
    - Service level measures to inform resourcing.
    - Population level measures to inform understanding of factors influencing treatment completion, hospitalisations and morbidity and mortality outcomes.
- **2.6.1** Build on the National Cancer Control Indicators (NCCI) and national leadership by the Australian Institute of Health and Welfare (AIHW) and Australian Bureau of Statistics (ABS) in collaboration with the Australasian Association of Cancer Registries (AACR), develop and implement standardised nationally consistent,

Short term actions

comparable, and timely data to the extent feasible, collected across the cancer continuum that can inform NCCI.

- **2.6.2** This data will be linkable to other health and health-relevant data (e.g. PLIDA) to provide a comprehensive sociodemographic picture of cancer in Australia and drive improved health system performance. Defining national datasets with standardisation and agreed information formats for data capture, where feasible, will alleviate discrepancies in data capture across platforms, jurisdictions, and health sectors (e.g., primary care, public or private).
- **2.6.3** Establish a process engaging all stakeholders across the cancer sector to prioritise data gaps to focus on their importance and utility in addressing key questions and identifying specific data needs of end users across the cancer continuum.
- **2.6.4** Define a set of core indicators to assess adherence to optimal care pathways. Conduct a demonstration project of a small number of priority indicators for optimal care pathways that can then be used to progress the next set of indicators.
- **2.7.1** Support the implementation of a standardised approach to electronic pathology data flow into cancer registries.
- **2.7.2** Work with the Royal College of Pathologists of Australasia to build on work underway to address the barriers and enablers of level 6 structured pathology reporting for cancer and develop an action plan for implementation.
- **2.7.3** Work with the Royal Australian and New Zealand College of Radiologists to build on work underway to address barriers and enablers of structured radiology reporting of cancer and to explore the utility of radiology data flow into cancer registries
- **2.8.1** Examine current initiatives in extracting treatment data from oncology medical information systems (chemotherapy and radiotherapy) and develop a national action plan for implementation of national treatment data capture in all jurisdictions. This may include investigation the policy, regulation, legislation, funding and health literacy/workforce health literacy as barriers for implementation.
- **2.8.2** Form a working group comprising EMR implementation leads, clinicians, technical experts, and other stakeholders. This group will identify and agree on the key data items to be recorded in a structured way, starting with cancer stage. The group will also determine the best model to achieve this, define the barriers and enablers for implementation, and develop a pilot proof of concept approach as an initial step.

Long term actions

- **2.1.4** Strengthen First Nations community data capabilities and partnerships throughout the data lifecycle. This may include:
    - Building data literacy, supported by tools specifically developed by Lowitja.
    - Supporting the development of data infrastructure for First Nations peoples.
    - Supporting data training for First Nations peoples in the cancer sector.
    - Developing partnership arrangements between First Nations community stakeholders and government agencies to facilitate agreed regular systematic data sharing.
- **2.1.5** Build towards organisational and cultural change within the cancer care sector to support the inclusion of Aboriginal and Torres Strait Islander people in data governance. This may include:
    - Ensuring the control of data ecosystems overseen by First Nations communities, grounded in traditional governance, practices, and knowledge.
    - Ensuring contextual and disaggregated data is accessible at individual and community levels.
    - Ensuring data sets are co-created with First Nations peoples and communities.
    - Engaging with or developing First Nations data governance groups.
- **2.2.3** Implement the necessary changes identified to improve timeliness of national cancer incidence data.
- **2.3.4** Develop a mechanism to monitor data consistency across the Australian cancer data ecosystem.
    - Implementing unified standards to the extent feasible and regular audits will ensure accurate and consistent cancer data across Australia's ecosystem.
- **2.4.3** Routine collection of stage at diagnosis for all cancers within electronic information systems.

Long term actions

- **2.5.5** Validate PROMS and PREMS measures and collection approaches in First Nations peoples and for other priority populations.
- **2.5.6** Establish a national approach to assessing long term outcomes from cancer (mortality and morbidity) that incorporates alignment with the OCPs.
- **2.5.7** Establish priorities related to the collection and standardisation of genomic data for incorporation in population-based cancer registries.
- **2.5.8** Establish a national approach to assess the impact of population screening programs on cancer outcomes and experiences.
- **2.7.4** Implement level 6 structured pathology reporting for agreed priority cancers.
- **2.7.5** Plan for the capture of recurrence and disease progression from radiology and pathology reports.
- **2.7.6** Establish a national approach to incorporating radiology data, particularly for the monitoring of recurrence/progression, into cancer registries, considering legislative differences across jurisdictions.
- **2.7.7** Identify leading pathologists and radiologists who are adopting Level 6 structured reporting and embedding structured reporting training in educational programs to support general adoption.
- **2.8.3** Pilot the collection of an agreed structured clinical reporting dataset for a range of cancers (including haematologic and paediatric).

Strategic Objective 3: User-centred, integrated and accessible data

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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.

Importance

Effective data integration and interoperability across systems and datasets are crucial for achieving the Data Framework's goals. Linking cancer data with other health and routinely collected person-level data, including quality clinical registries and research datasets, and relevant routinely collected administrative data will provide comprehensive patient outcome insights to inform improvements.

For priority populations, this integration must be undertaken in an ethical way to ensure key benefits are focused on First Nations peoples, culturally and linguistically diverse communities, people with disabilities, and those in rural and remote areas.

Simplifying data access and improving data timeliness will encourage greater data utilisation, leading to improved assessment of cancer care and outcomes and increased opportunities for system enhancements. Prioritising collaboration and openness across government, as inherent values of public data custodianship, is key to reducing integration barriers and simplifying access for all end-users. This includes establishing formal data-sharing agreements and traditional knowledge labels to protect and explain Indigenous data.

Ongoing communication between data users and custodians regarding data use, analysis outputs, and project governance is essential. These communications, underpinned by strong governance principles, will serve as a risk management tool and help identify additional barriers to addressing common data requests and needs.

Current challenge

The current data governance system is complex, with multiple custodians, multi-layer ethics approvals, and duplicative access processes leading to high costs and delays for linked data. This complexity particularly hinders First Nations communities' data access and utilisation.

Without effective data linkage, there is insufficient information on priority populations, limiting our understanding of their specific cancer experiences and outcomes. This gap hinders the development of targeted interventions and policies to address health disparities. Furthermore, establishing linkage and associated business rules requires significant resources, including skilled personnel to perform the complex work of data integration and management.

Ensuring enduring data linkages and research overseen by appropriate Aboriginal and Torres Strait Islander ethical practices is crucial to overcoming these barriers. A robust solution is needed to streamline and expedite data access while upholding standards.

An improved system should establish enduring linked data collections with streamlined governance, simplifying access for users while ensuring data safety, transparency, accountability, and ethical standards. This necessitates fit-for-purpose models, potentially including a federated data infrastructure facilitating a 'link once, use many times' approach.

Building on strengths

National initiatives like the National Health Data Hub (NHDH) can serve as blueprints for enduring data linkage assets. Attaching a cancer module to the NHDH will create a usable asset for exploring cancer outcomes, potentially including jurisdictional collections. The NHDH's strength lies in its integration with datasets like the Australian Cancer Database and PLIDA, allowing examination of unwarranted variations and better understanding of cancer care and outcomes for priority groups.

Nationally, the DATA scheme, managed by the Office of the National Data Commissioner under the Data Availability and Transparency Act 2022, aims to streamline accreditation and sharing of national datasets across government bodies and universities.

At the jurisdictional level, initiatives like NSW's CanDle program feature overarching ethics approval for system performance reporting, researcher accreditation processes, and a community of practice to build capacity and reduce duplication. Integrating governance of Indigenous data principles into these initiatives can ensure culturally appropriate practices beneficial to First Nations communities.

These approaches reduce burden on data users, increase work volume and quality, and shift focus from process to outcomes in performance monitoring and improvement efforts.

3.1 Ensure enduring data linkages and associated access as well as research is overseen with appropriate Aboriginal and Torres Strait Islander ethical practices.
Enduring data linkages and open data access must adhere to Aboriginal and Torres Strait Islander ethical practices, ensuring research aligns with First Nations communities' aspirations and respects their data sovereignty.

Formal data-sharing agreements, traditional knowledge labels, and clear identifier parameters protect Indigenous data. Implementing Indigenous Data Governance within linked datasets and robust linkage protocols ensures comprehensive and respectful data collection.

Ethical practices must prioritise Indigenous rights at all stages, including developing accessible methods for communities to understand and access relevant data. Reviewing policies hindering data sharing aligns with Closing the Gap goals, empowering Indigenous-driven development.

Organisational and cultural change in the public sector is essential to include Indigenous people in data governance. Ethical research conduct and accountable data structures are paramount. Cancer Australia-funded projects should have appropriate controls over secondary data use, aligning with MRFF and NHMRC ethical requirements.

Applying CARE (Collective benefit, Authority to Control, Responsibility and Ethics) and FAIR (Findable, Accessible, Interoperable, Reusable) principles ensures open and accessible cancer datasets with appropriate cultural governance. While FAIR principles facilitate data sharing and reuse, CARE principles complement them by ensuring ethical data use and advancing Indigenous innovation and self-determination.

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

Streamlining and harmonising data governance across states and territories is essential to enhance data access while maintaining security. This will ensure timely, secure data sharing among healthcare providers, researchers, and policymakers, improving care provision, research capabilities, and informed decision-making.

Data governance will cover policies promoting data availability, accessibility, quality, and security. Data custodians will be responsible for dataset management.

Prioritising streamlined data custodian approvals over ethics alone is crucial. Standardising these processes will simplify and expedite data access. Simplifying legal, ethical, and compliance processes will remove current system constraints.

Developing a nationally consistent approach to consent waivers, in collaboration with consumers, is necessary. Implementing a carefully managed opt-out consent process is crucial for public trust. Clinicians play a key role in informing patients about data usage, with clear guidance on when opt-in and opt-out consent is required.

Implementation of these actions will be considered, noting some initiatives are already in place.

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.

Data access approaches are evolving from project-specific approvals to enduring linked data assets with multiple users. These assets will enhance data access and return on investment while ensuring data safety. National adherence to FHIR (Fast Healthcare Interoperability Resources) standards will enable interoperability across the data ecosystem.

Models like the National Health Data Hub can serve as a blueprint for enduring data linkage assets. Attaching a cancer spine to the NHDH will create a usable asset for exploring cancer outcomes, potentially including jurisdictional collections.

Integrating clinical trial and research data into these assets is crucial, where possible supporting the 'collect once, share and use multiple times' model. This will enhance collaboration, promote data reuse, and accelerate research innovation.

Monitoring data quality and performance is fundamental for reliability. Involving consumers in quality assessment can build public trust. Robust security and privacy measures are crucial for maintaining data integrity. Linking cancer data with other datasets will provide a comprehensive view of outcomes for patient groups, requiring quality analytic tools.

Once established, the focus will shift from asset creation to enabling access, with successful use approaches already demonstrated in various jurisdictions.

Short term actions

- **3.1.1** Apply the CARE and FAIR principles to Indigenous cancer research and data linkage. This may include:
    - Ensuring Indigenous Data Sovereignty (IDS) principles are integrated into the development of linked data sets, respecting the rights and interests of Indigenous communities.
    - Establishing clear parameters around identifiers, particularly for Aboriginal people, to ensure their data are accurately represented and protected.
    - Implementing robust data linkage protocols that respect IDS principles, providing a comprehensive and respectful view of patient information
    - Ensure strong First Nations governance and leadership of linked data assets
- **3.1.2** Develop communication strategies for informing First Nations people what data are held relating to their interests, its use, and how it can be accessed: This may include:
    - Reviewing and updating existing data governance policies and frameworks to align with this Data Framework.
    - Developing an Aboriginal and Torres Strait Islander data catalogue which would provide data requesters with an easier path to locate the relevant data assets and request access.
    - Publishing data access protocols, ensuring they are promoted to Aboriginal and Torres Strait Islander people and communities.
    - Reviewing policies and legislation that are barriers to data sharing at a disaggregated level.
    - Facilitating a culture of data sharing to achieve aims of Priority Reform 4 of Closing the Gap.
- **3.2.1** Align with ongoing efforts across Governments, to establish consistent data access approval approaches and other data processes at jurisdictional and national levels across Government assets.
- **3.2.2** Develop a plan to harmonise data access approval approaches across jurisdictions and national levels for cancer data linkage and monitor progress, potentially overseen by a jurisdictional/national committee.
- **3.3.1** Create a comprehensive data blueprint for cancer data assets in Australia that leverage the AUCDI SPARKED program and NHDH models.
- **3.3.2** Develop a collaboration of national data custodians to define a harmonised approach to dataflow into the jurisdictional and national data assets and processes to maintain currency. This will include streamlined legal, ethical, and compliance processes through mutual recognition and other means to facilitate timely data access.
- **3.3.3** Develop a nationally agreed accredited user model and mechanisms to monitor its impact on data use and data security.
- **3.3.4** Work with the Australian Government to establish a mechanism to trial a model for data subsets incorporating key research and clinical trials datasets

Long term actions

- **3.1.3** Apply the CARE and FAIR principles to Indigenous cancer research and data linkage. This may include:
    - Ensuring data ecosystems are designed and function in ways that enable First Nations peoples to derive collective benefit from the data.
    - Support First Nations governance structures to develop data governance policies and practices.
    - Ensure potential data risks are mitigated for First Nations communities.

Long term actions

    - Ensure ethical access and use of cancer data.
    - Ensure accountable data structures exist, ensuring data practices are transparent, responsible and accountable.
    - Develop formal data sharing agreements where appropriate.
- **3.1.4** Shift from dominant deficit discourses, e.g. BADDR data (Blaming, Aggregate, Decontextualised, Deficit, and Restricted) in data collection and reporting to position First Nations communities to develop strength-based and culturally appropriate data sets.
- **3.2.3** Expand harmonised and simplified data access systems across all jurisdictions.
- **3.3.5** Implement a nationally agreed accredited user data access approach with transparent public reporting about its effectiveness.

Enablers

The enablers are the building blocks underpinning the Framework's success and are essential to achieving its goal. These enablers will be shaped by the collective efforts of the sector, integrating with the broader national context and complemented by collaboration between jurisdictions and the cancer sector.

Achieving the strategic objectives requires whole-of-sector resourcing commitments and responsibility to take and enable action.

Culture change

A shift in the culture surrounding data use and management is essential to success.

Viewing cancer data as an asset to leverage for improved cancer control requires transparent communication and public trust. Clinicians and stakeholders across public and private sectors need to understand and adopt efficient governance practices and structured reporting. Education and training programs empower effective data use, promoting a culture of data sharing and collaboration. This cultural shift ensures high-quality data collection and utilisation.

Technology and innovation

Technology and innovation are critical to enhancing how data is captured, stored, analysed, reported and shared across the system.

There are opportunities to capitalise on the evolving nature of AI and natural processing technologies, while also considering the associated risks. A harmonised approach leverages expanding technologies to align system processes across jurisdictions and the cancer control continuum. This enables timely data monitoring and automation, driving more efficient service delivery, clinical care, and research. Technology has the potential to transform cancer data, but ensuing data security is maintained will be critical for ongoing use.

Data workforce capacity and capability

A skilled and capable data workforce is necessary to maximise the use of cancer data.

This includes roles in data collection (including at point of care), governance, and analysis. Encouraging skill pooling across content areas overcomes the current siloing of data skills across teams, fostering an integrated workforce. Enhanced capacity ensures high-quality data management and analysis, providing the insights needed to inform practice and policy, thereby improving diagnosis, treatment, health service delivery and care.

Effective and efficient governance

Effective data governance and management ensures efficient, safe, and appropriate data use.

An overarching governance framework standardises principles for data management, accreditation, and use across jurisdictions. Embedding accountability and monitoring the system's effectiveness enhances access. This drives improvements, supporting the creation of a sustainable data ecosystem that informs service delivery and clinical care, leading to better cancer outcomes. Incorporation of IDS principles ensures Aboriginal and Torres Strait Islander people control the collection, use and storage of data about their communities.

Strategic Policy Context

All governments across Australia recognise the value of data for evidence informed decision making and have committed to long-term reforms to improve national data sharing across Australia, including through:

- The 2021 Intergovernmental Agreement on Data Sharing Agreement[5] (IGA). This commits all governments to share public sector data by default, where it can be done securely, safely, lawfully and ethically. The agreement promotes a shared understanding and uplifts confidence that there will not be adverse consequence for jurisdictions or data entities who share data. The IGA was reviewed in 2023 and will next be reviewed in 2026.
- The *Data and Digital Government Strategy*[17] released in 2023. This combined strategy builds on the initial *Australian Data Strategy* and sets the Australian Government's ambition and expectations for Australian Public Service's data and digital transformation. The associated Implementation Plan identifies actions under 5 missions that guide how the Australian Public Service will to keep up with technology, invest well, proactively leverage technology and adopt leading data practices.
- The *2023-2030 Australian Cyber Security Strategy*[18] aims to improve Australia's national resilience to cyber threats as well as responses to cyber incidents.
- The *Review of the Privacy Act 1988*[19] released in 2023 has prompted actions to strengthen the Act's principles-based approach to protecting personal information. The Commonwealth is working with the states and territory governments to harmonise elements across respective privacy laws.
- The National Agreement on Closing the Gap[7] Priority Reform 4 aims to ensure that data and information is shared and made available to Aboriginal and Torres Strait Islander people, to enable communities to access and use locally-relevant data and information to set and monitor implementation efforts to close the gap.
- The Data Framework aligns with the leadership and ethical direction being set by the government and the Office of the National Data Commissioner (ONDC)[20] to ensure that government contributions are increasingly being linked to the broader public-sector data reform agenda. The ONDC *Foundational Four* minimum data governance standards focus on leadership, strategy, governance and asset discovery, providing clear steps for data entities wanting to improve organisational capability, maturity and data culture.

- The ONDC as a regulator of the DATA Scheme supported by the *Data Availability and Transparency Act 2022* delivers new assurances to build trust and transparency when sharing data. This new, best practice scheme for sharing Australian Government data is underpinned by strong safeguards and efficient processes. The ONDC's new Dataplace platform helps to manage data sharing requests for the Australian Government. The Dataplace platform also hosts the Australian Government Data Catalogue, which enhances the transparency of data held by Australian Government agencies and supports the increased reuse of existing Australian Government data assets.

Beyond the Australian Government, states and territory governments are each individually and collectively enhancing their own data specific policies and assets. A shared responsibility and commitment to actions exist to enhance national health data outlined under national agreements such as the *National Health Reform Agreement*, the *National Health Reform Agreement Long Term Reforms Roadmap*[21], and the Intergovernmental Agreement on National Digital Health 2023-2027.[22]

The Data Framework fits into this whole-of-government movement towards more proactive and engaged approaches to enhance data use and sharing. Integrated national data will support better decisions and improves cancer outcomes and save lives.

Implementation Roadmap

The Implementation Roadmap outlines short- and long-term priorities and actions that will require a whole of sector effort. This roadmap is aligned with the 10-year timeframe of the Australian Cancer Plan, published in November 2023. Implementation priorities were determined through targeted consultation with stakeholders.

Implementation priorities and actions	
Short term (By 2029)	**Long term (By 2033)**
A mature performance reporting system	
1.1 Indigenous Data Sovereignty and Governance for improved Indigenous community outcomes	
1.1.1 Develop communication strategies for informing First Nations people what data are held relating to their interests, its use, and how it can be accessed	
1.2 Build and maintain public trust in the data system	
1.2.1 Understand the current level of data health literacy in Australia, with a focus on priority population groups **1.2.2** Review best practice approaches to public engagement in data release, open access and public reporting **1.2.3** Co-design the development of nationally accessible materials on health and cancer data collection and use for public engagement	**1.2.4** Implement public education and health literacy measures to enhance trust and engagement in cancer data usage, explaining how data is collected, analysed, safeguarded, and reported while empowering consumers to interpret and utilise this information effectively **1.2.5** Develop and publish accessible cancer data reports that present meaningful information to help individuals make informed decisions about their treatment and care, including key performance indicators and benchmarks across jurisdictions
1.3 Establish a robust cancer control monitoring and benchmarking system to drive optimal care	
1.3.1 Establish a National Cancer Control Performance Reporting Framework that: • Leverages existing frameworks and identifies new key indicators for cancer control, including adherence to Optimal Care Pathways • Establishes a technical and clinical working group to define core indicators and data requirements • Implements cross-jurisdictional benchmarking and develops a process for transitioning from confidential to public reporting • Standardises data definitions and reporting indicators, with a focus on priority populations • Tests a national harmonised approach for reporting on 2-3 priority cancer control indicators across two Optimal Care Pathways	**1.3.2** Report on cancers across the Optimal Care Pathway across all jurisdictions

Implementation priorities and actions	
Short term (By 2029)	**Long term (By 2033)**
A sustainable and fit-for-purpose data system	
2.1 Embed and implement the governance of Indigenous data into the cancer data ecosystem	
2.1.1 Enhance First Nations community data capabilities and partnerships throughout the data lifecycle **2.1.2** Improve the capabilities of staff involved in the cancer care sector relating to Indigenous data across the data lifecycle **2.1.3** Build towards organisational and cultural change within the cancer care sector to support the inclusion of Aboriginal and Torres Strait Islander people in data governance	**2.1.4** Strengthen First Nations community data capabilities and partnerships throughout the data lifecycle **2.1.5** Build towards organisational and cultural change within the cancer care sector to support the inclusion of Aboriginal and Torres Strait Islander people in data governance
2.2 Improve the timeliness of cancer data collection and reporting	
2.2.1 Map the current state for timeliness of cancer incidence data and other priorities identified, and the issues impacting on the timeliness of data for each jurisdiction, and outlining the potential steps required to achieve timeliness improvements **2.2.2** Prioritise the data items that are most critical for improving the timeliness of cancer incidence data and understand options for interoperability	**2.2.3** Implement the necessary changes identified to improve timeliness of national cancer incidence data
2.3 Strengthen existing mechanisms to ensure consistent and valid collection of key cancer data within Australian Cancer Registries	
2.3.1 Address how the population-based cancer registries and clinical quality registries can support each other's roles, and together extend the clinical quality registries representation of the population for more thorough completeness of the cancer data ecosystem **2.3.2** Define the role of the Australian Cancer Data Alliance, including representation of the Australian Association of Cancer Registries, in ensuring consistent cancer data collection across the data ecosystem **2.3.3** Explore any potential for establishing a common cancer registry software platform that would enable greater levels of technical cooperation across all jurisdictions in Australia and support linkage of integrated data for people affected by cancer who cross borders for treatment	**2.3.4** Develop a mechanism to monitor data consistency across the Australian cancer data ecosystem
2.4 Advance the collection of cancer stage at diagnosis data as key measures of equity and cancer control	
2.4.1 Establish a cross-jurisdictional working group incorporating representation from population- based registries and clinical quality registries and clinical informatics, to explore the barriers and enablers of standardised stage collection in clinical workflows **2.4.2** Form a demonstration project on the capture and extraction of stage at diagnosis, initially for 2-3 agreed cancer types, building on investment in breast cancer stage collection	**2.4.3** Routine collection of stage at diagnosis for all cancers within electronic information systems

Implementation priorities and actions	
Short term (By 2029)	**Long term (By 2033)**
2.5 Agree and prioritise national data gaps	
2.5.1 Establish a set of core indicators to assess adherence to the optimal care pathways (cancer type agnostic) for inclusion in a National Cancer Control Performance Reporting Framework and define the data items needed to measure these and identify priority data gaps **2.5.2** Develop an agreed definition of key non-cancer variables linked to variations in cancer outcomes and a plan for their routine collection and integration in data assets **2.5.3** Develop an agreed priority list of non-stage related prognostic factors and test their collection within clinical information systems to support data extraction for analysis **2.5.4** Define appropriate collection of nationally consistent Patient Reported Outcomes and Experiences (PROMS and PREMS) for various levels of capture	**2.5.5** Validate PROMS and PREMS measures and collection approaches in First Nations peoples and for other priority populations **2.5.6** Establish a national approach to assessing long term outcomes from cancer (mortality and morbidity) that incorporates alignment with the OCPs **2.5.7** Establish priorities related to the collection and standardisation of genomic data for incorporation in population-based cancer registries **2.5.8** Establish a national approach to assess the impact of population screening programs on cancer outcomes and experiences
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	
2.6.1 Build on the National Cancer Control Indicators (NCCI) and national leadership by the Australian Institute of Health and Welfare (AIHW) and Australian Bureau of Statistics (ABS) in collaboration with the Australasian Association of Cancer Registries (AACR), develop and implement standardised nationally consistent, comparable, and timely data to the extent feasible, collected across the cancer continuum that can inform NCCI **2.6.2** This data will be linkable to other health and health-relevant data (e.g. PLIDA) to provide a comprehensive sociodemographic picture of cancer in Australia and drive improved health system performance. Defining national datasets with standardisation and agreed information formats for data capture, where feasible, will alleviate discrepancies in data capture across platforms, jurisdictions, and health sectors (e.g., primary care, public or private) **2.6.3** Establish a process engaging all stakeholders across the cancer sector to prioritise data gaps to focus on their importance and utility in addressing key questions and identifying specific data needs of end users across the cancer continuum **2.6.4** Define a set of core indicators to assess adherence to the optimal care pathways. Conduct a demonstration project of a small number of priority indicators for optimal care pathways that can then be used to progress the next set of indicators	
2.7 Enhance the capture of structured pathology and radiology reporting for consistent data capture from source systems	
2.7.1 Support the implementation of a standardised approach to electronic pathology data flow into cancer registries **2.7.2** Work with the Royal College of Pathologists of Australasia to build on work underway to address the barriers and enablers of level 6 structured pathology reporting for cancer and develop an action plan for implementation **2.7.3** Work with the Royal Australian and New Zealand College of Radiologists to build on work underway to address barriers and enablers of structured radiology reporting of cancer and to explore the utility of radiology data flow into cancer registries	**2.7.4** Implement level 6 structured pathology reporting for agreed priority cancers **2.7.5** Plan for the capture of recurrence and disease progression from radiology and pathology reports **2.7.6** Establish a national approach to incorporating radiology data, particularly for the monitoring of recurrence/progression, into cancer registries, considering legislative differences across jurisdictions **2.7.7** Identify leading pathologists and radiologists who are adopting Level 6 structured reporting and embedding structured reporting training in educational programs to support general adoption

Implementation priorities and actions	
Short term (By 2029)	**Long term (By 2033)**
2.8 Explore the potential for structured clinical reporting of key data items within electronic medical records	
2.8.1 Examine current initiatives in extracting treatment data from oncology medical information systems (chemotherapy and radiotherapy) and develop a national action plan for implementation of national treatment data capture in all jurisdictions. This may include investigation of policy, regulation, legislation, funding and health literacy/workforce health literacy as barriers for implementation. **2.8.2** Form a working group comprising EMR implementation leads, clinicians, technical experts, and other stakeholders. This group will identify and agree on the key data items to be recorded in a structured way, starting with cancer stage. The group will also determine the best model to achieve this, define the barriers and enablers for implementation, and develop a pilot proof of concept approach as an initial step	**2.8.3** Pilot the collection of an agreed structured clinical reporting dataset for a range of cancers (including haematologic and paediatric)
User-centred, integrated and accessible data	
3.1 Ensure enduring data linkages and associated access as well as research is overseen with appropriate Aboriginal and Torres Strait Islander ethical practices	
3.1.1 Apply the CARE and FAIR principles to Indigenous cancer research and data linkage **3.1.2** Develop communication strategies for informing First Nations people what data are held relating to their interests, its use, and how it can be accessed	**3.1.3** Apply the CARE and FAIR principles to Indigenous cancer research and data linkage **3.1.4** Shift from dominant deficit discourses, e.g. BADDR data (Blaming, Aggregate, Decontextualised, Deficit, and Restricted) in data collection and reporting to position First Nations communities to develop strength-based and culturally appropriate data sets
3.2 Enhance data access through effective and efficient data governance and streamlined ethics approvals	
3.2.1 Align with ongoing efforts across Governments, to establish consistent data access approval approaches and processes at jurisdictional and national levels across Government assets **3.2.2** Develop a plan to harmonise data access approval approaches across jurisdictions and national levels for cancer data linkage and monitor progress, potentially overseen by a jurisdictional/national committee	**3.2.3** Expand harmonised and simplified data access systems across all jurisdictions
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	
3.3.1 Create a comprehensive data blueprint for cancer data assets in Australia that leverage the AUCDI SPARKED program and NHDH models **3.3.2** Develop a collaboration of national data custodians to define a harmonised approach to dataflow into the jurisdictional and national data assets and processes to maintain currency. This will include streamlined legal, ethical, and compliance processes through mutual recognition and other means to facilitate timely data access **3.3.3** Develop a nationally agreed accredited user model and mechanisms to monitor its impact on data use and data security **3.3.4** Work with the Australian Government to establish a mechanism to trial a model for data subsets incorporating key research and clinical trials datasets	**3.3.5** Implement a nationally agreed accredited user data access approach with transparent public reporting about its effectiveness

Glossary

Term	Definition
Ambulatory Care	Ambulatory care refers to medical services performed on an outpatient basis, without admission to a hospital or other facility.
Cancer care continuum	A person's cancer experience and interactions with the health system, from prevention and early detection, initial presentation, diagnosis, treatment, survivorship, and/or end-of-life care and long-term follow-up.
Cancer care sector	All parts of health and other systems relevant to cancer control including people, services and organisations that contribute to cancer control, along the continuum from prevention to survivorship and/or end-of-life care and long-term follow-up. Cancer care is delivered through both public and private health systems by government and non-government providers.
Cancer control	Cancer control aims to reduce the incidence, morbidity, and mortality of cancer and to improve the quality of life of cancer patients in a defined population, through the systematic implementation of evidence-based interventions for prevention, early detection, diagnosis, treatment, and palliative care. Comprehensive cancer control addresses the whole population, while seeking to respond to the needs of the different subgroups at greater risk.
Cancer incidence	The number of new cases diagnosed each year per 100,000 population.
Clinical informatics	Technology and data analytics used to improve patient care outcomes, treatment and care.
Clinical Quality Registries	Clinical quality registries are structured systems that collect and analyse clinical data to monitor and improve the quality of care, facilitating benchmarking and evidence-based practice across the cancer care continuum.
Co-design	Co-design brings professionals and end-users together to design new services, resources, and policies. Applied to policy, this can include empowering people affected by a policy issue to contribute to its solution. Co-design with Aboriginal and Torres Strait Islander people is fundamental to achieving change across the health system and to achieve better outcomes. *Key Principles and Best Practices for co-design in health with First Nations Australians* include First Nations leadership, Culturally grounded approach, Respect, Benefit to community, Inclusive partnerships and Transparency and evaluation.
Comprehensive Care	Comprehensive cancer care integrates cancer research, clinical trials, education and treatment, providing optimal care and support for people affected by cancer in all locations across the entire cancer continuum, and subsequent care monitoring in the longer term.
Consumer	Consumer is used to refer to *a person affected by cancer* as a patient, survivor, carer, or family member; or a consumer organisation representing the views of consumers.
Data custodian	A data custodian is a person or entity responsible for managing and protecting an organisation's data. Data custodians work closely with data owners, users, IT staff, and compliance teams to ensure that data is managed, protected, and used properly.
Data-driven	Utilising analysis and interpretation of comprehensive data to inform strategic decision-making.

Term	Definition
Data governance	Data governance means setting internal standards and data policies that apply to how data is gathered, stored, processed, and disposed of. It governs who can access different kinds of data and what kinds of data are under governance.
Diagnosis, stage at diagnosis and treatment planning	This step outlines the process for confirming (or eliminating) a cancer diagnosis, stage of cancer, relevant biomarkers and subsequent treatment plan. The guiding principle is that an appropriate multidisciplinary team should determine the treatment plan.
Ecosystem	A complex network or interconnected system, in this case referring to the interconnectedness of health and cancer data.
Equity	Health equity means all Australians are supported by our national systems in the ways most suited to their cultural, socioeconomic, geographic, environmental, and personal situation to achieve the best possible cancer outcomes. The Australian Cancer Plan acknowledges that to achieve equity, some priority population groups need an additional and targeted focus and support. Equitable access to services is a further objective.
Genomics	Genomics is the study of genes and other genetic information, their functions, how they interact with each other and with the environment, and how certain diseases, such as cancer, form. This may lead to new ways to prevent, diagnose, and treat cancer.
Indigenous Data Sovereignty	The right of Aboriginal and Torres Strait Islander peoples to govern the collection, ownership, and application of information and knowledge about Indigenous communities, peoples, lands, and resources.
Health outcome	A health-related change due to a preventive or clinical or health service intervention. The intervention may be single or multiple, and the outcome may relate to a person, group, or population, or be partly or wholly due to the intervention.
Health professionals	The health workforce in Australia is large and diverse, covering many occupations. These include health practitioners registered with the Australian Health Practitioner Regulation Agency as well as other health professionals and health support workers.
Health service	Services that provide health care, treatment, and support. This includes public, private and non-government services.
Hospital administration datasets	Hospital administration datasets encompass comprehensive data on treatment given in hospitals, and related patient demographics, patient care activities and other clinical interventions. This is crucial for administrative purposes such as resource management, policy development and compliance.
Metrics	Standards of measurements used for assessing and evaluating performance or outcomes.
Mortality	The death rate or the number of deaths in a certain group of people in a certain period of time.
Oncology	A branch of medicine that is focused on the prevention, diagnosis, and treatment of cancer.
Optimal Care Pathways	The Optimal Care Pathways (OCPs) outline consistent, safe, high-quality, and evidence-based care for people with cancer. They aim to improve patient outcomes by promoting quality cancer care and ensuring that all people diagnosed with cancer receive the best care, irrespective of where they live or receive cancer treatment. There are cancer specific OCPs and population-specific OCPs.

Term	Definition
	Seven key principles underpin the guidance provided in the OCPs: patient-centred care, safe and quality care, multidisciplinary care, supportive care, care coordination, communication, and research, clinical trials and service monitoring. These principles remain central to the delivery of quality care throughout the cancer continuum and always put patients at the centre of care. OCPs define seven steps in the cancer continuum. Each step outlines nationally agreed best practice to achieve high-quality cancer care: 1. Prevention and early detection 2. Presentation, initial investigations and referral 3. Diagnosis, staging and assessment of other prognostic indicators, and treatment planning 4. Treatment 5. Care after initial treatment and recovery 6. Managing recurrent, residual or metastatic disease 7. End-of-life care.
Population-based Cancer registries	Population-based cancer registries systematically collect and maintain data on cancer incidence, types, and outcomes within a defined population to support epidemiological research, healthcare planning and treatment.
Primary Care	Primary care usually refers to the first contact an individual with a health condition has with the health system. Primary health care covers hospital care and health care that is not related to a hospital visit, including health promotion, prevention, early intervention, treatment of acute conditions, and chronic condition management. Primary health care services are delivered in settings such as general practices, community health centres, allied health practices, Aboriginal Community Controlled Health Services and via technologies such as telehealth and video consultations. Primary health care professionals include general practitioners, nurses, nurse practitioners, allied health professionals, midwives, pharmacists, dentists, and Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners.
Priority population groups	The Australian Cancer Plan identifies the following population groups as priority for the delivery of nationally equitable outcomes in cancer control. • Aboriginal and Torres Strait Islander people • Adolescents and young adults • Children • People from culturally and linguistically diverse (CALD) backgrounds • People living with disability • Lesbian, gay, bisexual, transgender, intersex, queer, and asexual, and other gender diverse people. (LGBTIQA+) • People in lower socioeconomic groups, people living with a mental illness • Older Australians • People living in rural and remote areas.
Screening	An organised program (using tests, examinations, or other procedures) to identify diseases such as cancer, or changes which may later develop into disease such as cancer, before symptoms appear.
Social determinants of health	Determinants of health are non-medical sociodemographic factors that positively or negatively influence health outcomes. Social determinants of health are part of the wider determinants of health, which include the conditions in which people are born, grow, work, live, and age.

Term	Definition
	Social determinants of health include family, housing, employment, working conditions, and social support and participation.
Stakeholder	Any person, group, or organisation that has a vital interest in cancer care or services.
Structured reporting	Structured reporting is the creation of a standardised reports usually based on templates, which provide essential criteria and classifications that are relevant for the report and therefore for the documentation of the diagnosis and the therapy initiated by the referring physician. i.e. medical reports.
Treatment	This step includes the use of tailored therapies and medical interventions for managing and treating specific cancer types. This step also may encompass provision of training experiences and facilities required of treating clinicians and health services for providing optimal cancer care.

Acronyms

Acronym	Phrase
AACR	Australasian Association of Cancer Registries
ABS	Australian Bureau of Statistics
ACP	Australian Cancer Plan
AI	Artificial Intelligence
AIHW	Australian Institute of Health and Welfare
APS	Australian Public Service
AIR	Australian Immunisation Register
BADDR	Blaming, Aggregate, Decontextualised, Deficit, and Restricted
CanDLe	The Enduring Cancer Data Linkage, Community of Practice
CARE	Collective Benefit, Authority to Control, Responsibility, Ethics
CCQ	Cancer Council Queensland
CCA	Cancer Council Australia
CSIRO	Commonwealth Scientific and Industrial Research Organisation
CTG	Closing The Gap
EMR	Electronic Medical Records
FAIR	Findable, Accessible, Interoperable, and Reusable
FHIR	Fast Healthcare Interoperability Resources
IDS	Indigenous Data Sovereignty
LGBTIQA+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, and Asexual
MBS	Medicare Benefit Schedule
MDS	Minimum Dataset
MRFF	Medical Research Future Fund
NCCI	National Cancer Control Indicators
NDDA	National Disability Data Asset
NHDH	National Health Data Hub
NDI	National Death Index
NHMRC	National Health and Medical Research Council
NIAA	National Indigenous Australians Agency
NSW	New South Wales
NT	Northern Territory
OCCAAARS	Ownership, Control, Custodianship, Accessibility, Accountability, Amplifying First Nations, Relevant, Sustainability
OCP	Optimal Care Pathways
PBCR	Population-Based Cancer Registries
PBS	Pharmaceutical Benefits Scheme
PHRN	Population Health Research Network
PLIDA	Person Level Integrated Data Asset

Acronym	Phrase
PREMS	Patient Reported Experience Measures
PROMS	Patient Reported Outcome Measures
QLD	Queensland
RCPA	The Royal College of Pathologist of Australasia
RPBS	Repatriation Pharmaceutical Benefits Scheme

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