

Implementation Roadmap

The Implementation Roadmap outlines short- and long-term priorities and actions that will require a whole-of-sector effort, including targeted strategies to address the needs of and actively involve priority populations. 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 horizon (by 2029)	Long-term horizon (by 2033)
A mature performance reporting system	
1.1 Indigenous Data Sovereignty and Governance for improved First Nations community outcomes	
1.1.1 Develop communication strategies for informing First Nations people what data are held relating to their interests, how the data is used and how the data can be accessed	
1.2 Build and maintain public trust in the data system	
<p>1.2.1 Understand the current level of consumer data literacy related to improving health outcomes and the use of data in Australia, with a focus on priority population groups</p> <p>1.2.2 Review best practices for public engagement in data release, open access and public reporting and co-design nationally accessible materials and communication strategies on health and cancer data collection and use</p>	<p>1.2.3 Implement public education and health data 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</p> <p>1.2.4 Develop and publish accessible cancer data reports that present meaningful information to help individuals make informed decisions about their treatment and care and about participation in research, including key performance indicators and benchmarks across jurisdictions</p>
1.3 Establish a robust cancer control monitoring and benchmarking system to drive optimal care	
<p>1.3.1 Establish a National Cancer Control Performance Reporting Framework that:</p> <ul style="list-style-type: none"> • 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, by building on existing agreed definitions and indicators, with a focus on priority populations • tests a national harmonised approach for reporting on two to three priority cancer control indicators across two Optimal Care Pathways 	<p>1.3.2 Report on cancers across the Optimal Care Pathways across all jurisdictions</p>

Implementation priorities and actions	
Short-term horizon (by 2029)	Long-term horizon (by 2033)
A sustainable and fit-for-purpose data system	
2.1 Embed and implement the governance of First Nations data in the cancer data ecosystem	
<p>2.1.1 Enhance First Nations community data capabilities and partnerships throughout the data lifecycle</p> <p>2.1.2 Build towards organisational and cultural change to improve the capability of the sector and support inclusion of Aboriginal and Torres Strait Islander people in data governance</p>	<p>2.1.3 Strengthen First Nations community data capabilities and partnerships throughout the data lifecycle</p> <p>2.1.4 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</p>
2.2 Improve the timeliness of cancer data collection and reporting	
<p>2.2.1 Improve the timeliness of cancer data collection and reporting by:</p> <ul style="list-style-type: none"> • mapping the current state of timeliness of cancer incidence data and other priorities identified and issues impacting data timeliness for each jurisdiction • outlining potential steps and resources required for improvements • prioritising critical data items and exploring options for interoperability 	<p>2.2.2 Implement the necessary changes identified to improve timeliness of national cancer incidence data</p>
2.3 Strengthen existing mechanisms to ensure consistent and valid collection of key cancer data within Australian cancer registries	
<p>2.3.1 Address how the population-based cancer registries and clinical quality registries can support each other's roles and together extend the quality and depth of clinical data at the population level for greater completeness of the cancer data ecosystem</p> <p>2.3.2 Define the role of the Australian Cancer Data Alliance, including representation of the Australasian Association of Cancer Registries, in ensuring consistent cancer data collection across the data ecosystem</p> <p>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</p>	<p>2.3.4 Develop a mechanism to monitor data consistency across the Australian cancer data ecosystem</p>

Implementation priorities and actions	
Short-term horizon (by 2029)	Long-term horizon (by 2033)
2.4 Advance the collection of cancer stage at diagnosis data as a key measure of equity and cancer control	
<p>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</p> <p>2.4.2 Form a demonstration project on the capture and extraction of stage at diagnosis, initially for two to three agreed cancer types, building on investment in breast cancer stage collection</p>	<p>2.4.3 Routine collection of stage at diagnosis for all cancers within electronic information systems</p>
2.5 Agree and prioritise action on national data gaps	
<p>2.5.1 Establish a set of core indicators to assess adherence to the Optimal Care Pathways for inclusion in a National Cancer Control Performance Reporting Framework and define the data items needed to measure these and identify priority data gaps</p> <p>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</p> <p>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</p> <p>2.5.4 Define appropriate collection of nationally consistent patient-reported outcomes and experiences (PROMS and PREMS) for various levels of capture</p> <p>2.5.5 Establish priorities related to the collection and standardisation of genomic data for incorporation in population-based cancer registries</p>	<p>2.5.6 Validate patient-reported outcomes and experiences (PROMS and PREMS) measures and collection approaches for First Nations peoples and for other priority populations</p> <p>2.5.7 Establish a national approach to assessing the effects of early detection (screening programs) on cancer outcomes and experiences and on the long-term outcomes from cancer (mortality and morbidity) that incorporates alignment with the Optimal Care Pathways</p>

Implementation priorities and actions	
Short-term horizon (by 2029)	Long-term horizon (by 2033)
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	
<p>2.6.1 Build on the National Cancer Control Indicators (NCCI) and national leadership by the Australian Institute of Health and Welfare and the Australian Bureau of Statistics, in collaboration with the Australasian Association of Cancer Registries, to develop and implement standardised nationally consistent, comparable and timely data to the extent feasible, collected across the cancer continuum, that can inform the NCCI. This data will be linkable to other health and health-relevant data (e.g. Person Level Integrated Data Asset) to provide a comprehensive sociodemographic picture of cancer in Australia and drive improved health system performance</p> <p>2.6.2 Standardise national datasets with agreed data definitions and formats, where feasible, to minimise discrepancies in data capture across platforms, jurisdictions and health sectors (e.g. primary care, public or private)</p> <p>2.6.3 Establish a process engaging all stakeholders across the cancer sector to prioritise data gaps, focusing on their importance and utility in addressing key questions and identifying specific data needs of end users across the cancer continuum. This should include a mechanism for identifying new gaps as new technologies arise</p> <p>2.6.4 Define a set of core indicators to assess adherence to the Optimal Care Pathways. Conduct a demonstration project with a small number of priority indicators for Optimal Care Pathways that can then be used to progress the next set of indicators</p>	

Implementation priorities and actions	
Short-term horizon (by 2029)	Long-term horizon (by 2033)
2.7 Enhance the capture of structured pathology and radiology reporting for consistent data capture from source systems	
<p>2.7.1 Support the implementation of a standardised approach to electronic pathology data flow into cancer registries</p> <p>2.7.2 Work with the Royal College of Pathologists of Australasia and the Royal Australian and New Zealand College of Radiologists to build on work underway to address the barriers and enablers of structured pathology and radiology reporting for cancer. Develop an action plan for the implementation of level 6 structured pathology reporting and explore the utility of radiology data flow into cancer registries</p>	<p>2.7.3 Identify leading pathologists who are adopting level 6 structured pathology reporting and leading radiologists who are adopting structured radiology reporting. Expand structured reporting training in educational programs to support the highest level of adoption</p> <p>2.7.4 Plan for the capture of recurrence and disease progression from radiology and pathology reports, and establish a national approach to incorporating radiology data into cancer registries, particularly for monitoring recurrence/progression, while considering legislative differences across jurisdictions</p> <p>2.7.5 Implement level 6 structured pathology reporting for agreed priority cancers</p>
2.8 Explore the potential for structured clinical reporting of key data items within digital health systems	
<p>2.8.1 Examine current initiatives in extracting treatment data from oncology medical information systems (systemic therapy 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 consumer and workforce health literacy as barriers to implementation</p> <p>2.8.2 Form a working group comprising digital health system 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</p>	<p>2.8.3 Pilot the collection of agreed structured clinical reporting data for a range of cancers (including haematologic and paediatric)</p>

Implementation priorities and actions	
Short-term horizon (by 2029)	Long-term horizon (by 2033)
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	
<p>3.1.1 Apply the CARE and FAIR principles to First Nations cancer research and data linkage</p> <p>3.1.2 Develop communication strategies for informing First Nations people what data are held relating to their interests, how the data is used and how it can be accessed.</p>	<p>3.1.3 Apply the CARE and FAIR principles to First Nations cancer research and data linkage</p> <p>3.1.4 Shift from dominant deficit discourses (e.g. BADDR data – blaming, aggregate, decontextualised, deficit, restricted) in data collection and reporting, to position First Nations communities to develop strength-based and culturally appropriate datasets</p>
3.2 Enhance data access through effective and efficient data governance and streamlined ethics approvals	
<p>3.2.1 Align with ongoing efforts to harmonise data access and approval approaches and processes across jurisdictions, including for linked data assets, and monitor progress (potentially overseen by a jurisdictional/national committee)</p>	<p>3.2.2 Expand harmonised and simplified data access systems across all jurisdictions</p>
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	
<p>3.3.1 Create a comprehensive data blueprint for cancer data assets in Australia that leverage the Australian Core Data for Interoperability (AUCDI) Sparked program and National Health Data Hub models</p> <p>3.3.2 Develop a collaboration of national data custodians to define a harmonised approach to data flow 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</p> <p>3.3.3 Develop a nationally agreed accredited user model and mechanisms to monitor its impact on data use and data security</p> <p>3.3.4 Work with the Australian Government to establish a mechanism to trial a model for data subsets incorporating key research, clinical trials and biobank datasets</p>	<p>3.3.5 Implement a nationally agreed accredited user data access approach with transparent public reporting about its effectiveness</p>