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