A Framework for Optimal Cancer Care Pathways in Practice

SUPPORTING CONTINUOUS IMPROVEMENT IN CANCER CARE

Developed by the National Cancer Expert Reference Group to support the early adoption of the Optimal Cancer Care Pathways.
FORWARD

Dear colleagues,

We are united in our efforts to improve cancer outcomes across our nation. This message is to inform you of developments that I expect will have a real impact on patient outcomes. Currently, the pathway for patients who are undergoing diagnosis and treatment for cancer is complex and poorly comprehended by many of those involved. It usually involves multiple healthcare providers and covers a range of institutions, both public and private.

Optimal Cancer Care Pathways are national guides to promote best practice cancer care for specific cancer types. They describe the key stages in a patient’s cancer journey and expected standards of care at each step. They aim to improve patient outcomes by promoting quality cancer care and ensuring that all people diagnosed with cancer receive the best care, regardless of where they live or receive cancer treatment.

Optimal Cancer Care Pathways have been developed for 15 cancer types. Each is grounded in the best available evidence and informed by extensive consultation with expert multidisciplinary teams, peak health organisations, consumers and carers. The pathways are nationally endorsed by the National Cancer Expert Reference Group (NCERG), the Australian Health Ministers’ Advisory Council (AHMAC), Cancer Australia and Cancer Council Australia.

This Framework aims to support Australian health jurisdictions in their journeys towards adoption of Optimal Cancer Care Pathways, particularly in the first 12 months (2016–17). Adoption of Optimal Cancer Care Pathways will be an ongoing process that needs to align with each jurisdiction’s priorities, context and capabilities. In the first 12 months, most jurisdictions are likely to focus on a few aspects of the pathway for one or two cancer types.

The Framework combines essential information about the pathways with guidance and practical tools to assist the early adoption process. While the focus is on the early stages, we hope the Framework will also help strengthen continuous improvement in cancer care and cancer control in the longer term.

We look forward to hearing about each jurisdiction’s journey towards adopting the Optimal Cancer Care Pathways locally, and being able to share lessons learned along the way.

Professor Robert Thomas OAM,
Chair, National Cancer Expert Reference Group
A NATIONAL APPROACH TO OPTIMAL CANCER CARE

A NATIONAL WORK PLAN

The purpose of Optimal Cancer Care Pathways
Optimal Cancer Care Pathways aim to improve patient outcomes by facilitating consistent, safe, high quality and evidence-based care across Australia.

A national consensus to provide optimal cancer care is anticipated to improve outcomes for patients. Through the Australian Health Ministers’ Advisory Council (AHMAC), all Australian states and territories have committed to improve cancer care by working towards the adoption of Optimal Cancer Care Pathways, starting in 2016–17.

Optimal Cancer Care Pathways are cancer-specific guides to the best cancer care, developed for 15 different cancer types. All 15 pathways are based on the best available evidence and have been developed through consultation with a wide range of expert multidisciplinary teams, peak health organisations, consumers and carers. They are nationally endorsed by the National Cancer Expert Reference Group (includes representation from each jurisdiction and nationally), Cancer Australia and Cancer Council Australia. The Australian Health Ministers’ Advisory Council and COAG Health Council have endorsed 11 of the Optimal Cancer Care Pathways in 2015 and will consider the remaining four for endorsement later in 2016.

The development of Optimal Cancer Care Pathways
The Optimal Cancer Care Pathways were developed as part of a national cancer work plan, led by the National Cancer Expert Reference Group. The National Cancer Expert Reference Group is a panel of experts and jurisdictional and consumer representatives that was established by the Council of Australian Governments in 2010. In developing a national cancer work plan for improving cancer care in Australia, the National Cancer Expert Reference Group identified the value of a national approach to delivering consistent and optimal cancer care. This group is committed to supporting ongoing work towards national adoption of the Optimal Cancer Care Pathways.
FRAMEWORK OVERVIEW

FRAMEWORK PURPOSE

This Framework aims to guide Australian health jurisdictions in the early stages of adopting Optimal Cancer Care Pathways (2016–17). It is intended to guide aspects of the overall adoption process and provide key background information and practical tools to support stakeholder engagement, communications, data capture and reporting.

The Framework aims to help jurisdictions achieve the following objectives as they progress Optimal Cancer Care Pathway adoption.

**Objectives**

1. **Engage and communicate**
   - Facilitate awareness, understanding and commitment to Optimal Cancer Care Pathways

2. **Collaborate**
   - Facilitate reflection, sharing of knowledge and key lessons

3. **Drive best practice care**
   - Drive continuous improvement of best practice cancer care using data where possible

4. **Monitor and act**
   - Create opportunities to identify and address local variation in cancer care, while developing data collection
FRAMEWORK OVERVIEW

USE OF FRAMEWORK

Who the Framework is for

This Framework is intended to be used by those within jurisdictions who are responsible for facilitating adoption of Optimal Cancer Care Pathways during the period 2016–17. The settings, roles and pre-existing knowledge of the pathways are likely to vary between readers.

The Framework provides a consistent approach to the adoption of Optimal Cancer Care Pathways and will be tailored to the priorities and initiatives of cancer control within each jurisdiction. The Framework is not a mechanism for national benchmarking: it is intended to guide adoption at a jurisdictional level and within each jurisdiction at a service delivery level.

In the early stages of adopting the Optimal Cancer Care Pathways (2016–17), each jurisdiction will tailor their approach, based on the local context. For example, each jurisdiction will vary in:

- chosen cancer type(s) for early focus
- selection of stage(s) of the pathway for early focus
- the nature of established stakeholder networks and communication channels
- current capacity to collect data to assess gaps or improvements in line with Optimal Cancer Care Pathway adoption.

When to use the Framework

All sections of the Framework may inform planning for the early adoption of Optimal Cancer Care Pathways. Planning for stakeholder engagement, communications and monitoring will all be important considerations in the first few months.

Each jurisdiction has committed to providing a report on the first 12 months of adoption of Optimal Cancer Care Pathways to the National Cancer Expert Reference Group by mid-2017.

The Framework is a living document that can be adapted or added to in response to user feedback. Contact National Cancer Expert Reference Group Secretariat for more information NCERGSecretariat@health.gov.au
OPTIMAL CANCER CARE PATHWAYS

IMPROVING PATIENT OUTCOMES

Optimal Cancer Care Pathways aim to improve patient outcomes by facilitating consistent, safe, high quality and evidence-based care across Australia.

Click on the icons below to access the Optimal Cancer Care Pathways for the following 15 cancer types:

- Acute myeloid leukaemia
- Basal and squamous cell carcinoma
- Bowel cancer
- Breast cancer
- Endometrial cancer
- Head and neck cancer
- High grade glioma
- Liver cancer
- Lung cancer
- Lymphoma
- Melanoma
- Oesophageal cancer
- Ovarian cancer
- Pancreatic cancer
- Prostate cancer
STAGES OF THE PATHWAY

Each pathway maps the key stages in a cancer patient’s journey, from prevention and early detection to survivorship or end-of-life care. They detail principles and recommendations for optimal care at critical points in the cancer continuum.

Importantly, Optimal Cancer Care Pathways are not detailed clinical practice guidelines. They are not intended to constitute medical advice or replace clinical judgement.

Each pathway is presented using the following structure:

**SUPPORT:** access to supportive care needs, including survivorship, at every step of the pathway with referrals to appropriate health professionals or organisations

1. **PREVENTION AND EARLY DETECTION**
   - Prevention, risk factors, early detection, screening

2. **PRESENTATION, INITIAL INVESTIGATIONS AND REFERRAL**
   - Signs and symptoms, investigations, referral
   - Lead clinician communication

3. **DIAGNOSIS, STAGING AND TREATMENT PLANNING**
   - Diagnosis, treatment planning, research and clinical trials
   - Lead clinician communication

4. **TREATMENT**
   - Treatment options, palliative care referral
   - Lead clinician communication

5. **CARE AFTER INITIAL TREATMENT AND RECOVERY**
   - Treatment summary
   - Follow-up care plan
   - Survivorship
   - Lead clinician communication

6. **MANAGING RECURRENT, RESIDUAL AND METASTATIC DISEASE**
   - Detection, treatment, palliative care
   - Lead clinician communication

7. **END-OF-LIFE CARE**
   - Palliative care, advance care plan
   - Lead clinician communication
OPTIMAL CANCER CARE PATHWAYS

UNDERPINNING PRINCIPLES

PATIENT-CENTRED CARE: is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and carers.

SAFE AND QUALITY CARE: is provided by appropriately trained and credentialed clinicians and by hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care.

MULTIDISCIPLINARY CARE: is an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient.

SUPPORTIVE CARE: is an umbrella term used to refer to services, both generalist and specialist, that may be required by people affected by cancer.

CARE COORDINATION: is a comprehensive approach to achieving continuity of care for patients.

COMMUNICATION: is the responsibility of the healthcare system and all people within its employ, in order to ensure the communication needs of patients and carers are met.

RESEARCH AND CLINICAL TRIALS: participation opportunities should be offered to patients where practical, at any stage of the care pathway.
OPTIMAL CANCER CARE PATHWAYS

ACCESSING THE PATHWAYS

There are three versions for each Optimal Cancer Care Pathway:

1. **Detailed clinical pathways** for cancer specialists, health professionals and health service administrators.
2. **Quick reference guides for GPs** to familiarise GPs and other primary care providers with the cancer care pathway.
3. **Patient ‘what to expect’ guides** to help patients and their carers understand the cancer care pathway and what to expect at each stage.

The Optimal Cancer Care Pathways can be accessed electronically via the link below.

[Optimal Cancer Care Pathways](#)
ADOPTION OF OPTIMAL CANCER CARE PATHWAYS

DEFINING ADOPTION

Optimal Cancer Care Pathways can be considered a tool to support state-wide cancer control initiatives and continuous improvement in cancer care towards best practice. The pathways support health systems, health professionals and services, and patients and carers to improve patient outcomes by encouraging consistent, optimal treatment and supportive care at each stage of a patient’s journey.

- Patients and carers
  - align with key national health service improvement priorities
  
- Health professionals & services
  - enable identification of gaps in current cancer services
  
- applicable across all cancer service settings, regardless of location, or whether public or private
  
- double as an educational and/or audit tool to improve clinical outcomes and patient experience
  
- provide information to patients, carers and GPs about how to optimally navigate the cancer care journey
Ultimately, adoption of Optimal Cancer Care Pathways is about aligning all aspects of cancer control and cancer care with the pathways to ensure all patients have access to optimal care. This is likely to include identifying areas of focus in which there are gaps in optimal cancer care and implementing initiatives to address variation.

Adoption of Optimal Cancer Care Pathways will be an ongoing process that needs to align with a jurisdiction’s existing context including:

- methodologies used for continuous improvement in the health sector
- cancer control initiatives, plans and policies
- cancer service delivery approach
- current gaps in cancer care and inequalities in cancer outcomes
- current priorities for service improvement
- current stakeholder engagement methodologies
- data capture and monitoring capabilities.

### Victorian example
There are plans to use new and existing Melbourne Health Pathways (primarily GP referral pathways into and out of acute care) as a mechanism for Optimal Cancer Care Pathway adoption. Potential examples include:

- using Optimal Cancer Care Pathways as the key reference point for localising relevant Melbourne Health Pathways
- using the localisation process to mandate and monitor appropriate referral pathways to secondary care
- incorporating Optimal Cancer Care Pathways as key resources for the Melbourne Health Pathways
- providing education and support to primary care practices around the Pathways
- developing and integrating follow-up pathways, including shared care and referral to community palliative care, into localised Melbourne Health Pathways.

### South Australian example
There are plans to embed the Optimal Cancer Care Pathway for people with colorectal cancer into existing colorectal cancer initiatives in the state.

In addition, the Optimal Cancer Care Pathways will feature in the SA Cancer Control Plan 2016–21.
Focus for early stage adoption

Initial jurisdictional efforts to facilitate adoption of Optimal Cancer Care Pathways are likely to:

- align with existing cancer control and improvement plans, priorities and initiatives
- focus on pathways for one or two cancer types
- focus on one or two aspects of the pathway and/or in one or two settings
- integrate into current systems (e.g. data, referral and treatment systems), workflows and initiatives
- work within current jurisdictional capabilities for data collection.

What to consider in early stage adoption

In the early stages of working towards adoption of Optimal Cancer Care Pathways, the following will be critical:

- Stakeholder engagement and communication:
  - Effective and sustained stakeholder engagement will be essential for the successful adoption of Optimal Cancer Care Pathways and continuous improvement in best practice cancer care.
  - Refer to the Communications Strategy for information, tools and resources to plan stakeholder engagement and communication.
  - Jurisdictions can engage directly with state-level organisations (e.g. cancer councils, state branches etc.); the National Cancer Expert Reference Group will be engaging with relevant national level stakeholder groups.

Northern Territory example

In the first 12 months, the Northern Territory intends to focus on the time frame and steps from initial referral to definitive treatment in one or two pathways. Final selection of pathway(s) was in progress when this Framework was developed, but is likely to include the Optimal Cancer Care Pathway for people with lung cancer and/or breast cancer.
MONITORING PROGRESS

WHY MONITOR

The underpinning principle is to facilitate collection of data that is useful for future service planning and supporting continuous improvement and best practice cancer care.

Jurisdictional representatives indicated a strong interest in guidance in data collection and monitoring progress.

Monitoring the adoption of Optimal Cancer Care Pathways will enable jurisdictions to identify where there are gaps in cancer care and may provide leverage to embed the Optimal Cancer Care Pathways into future policy and strategy.

In the first 12 months, data collection may involve establishing measurement and data systems to support continuous improvement and best practice cancer care.

A national approach to the early adoption of Optimal Cancer Care Pathways and monitoring progress may enable sharing of experiences, lessons and expertise between jurisdictions.
MONITORING PROGRESS

PRIORITY MONITORING QUESTIONS

There are three priority questions identified (by the National Cancer Expert Reference Group) as being the most important focus for monitoring, reflection and reporting in the first year of adoption of the Optimal Cancer Care Pathways. They provide guidance for data collection and reporting, recognising variations in the context and data capabilities within each jurisdiction.

1) To what extent are Optimal Cancer Care Pathways embedded into policy and strategy?

This is likely to include a description of initiatives to engage key stakeholders and may be defined by proxy measures. Embedding Optimal Cancer Care Pathways into policy and strategy will be limited by jurisdictional planning cycles for state-wide cancer plans and work plans. Options include:

- Describe initiatives to engage key stakeholders.
- Report on formal agreements and plans to implement Optimal Cancer Care Pathways.
- Measure awareness of Optimal Cancer Care Pathways across jurisdictions or reach of communications activities as a proxy measure of awareness.
- Describe incorporation of (or commitment to) Optimal Cancer Care Pathways into jurisdictional cancer plans or clinical pathways.

2) How do Optimal Cancer Care Pathways influence patient experience?

This is likely to be defined by current approaches to measure patient experience and/or by proxy measures. Options include:

- Measure patient awareness of Optimal Cancer Care Pathways (consumer versions) or reach of communications activities as a proxy measure of awareness.
- Measure core indicators of patient experience.

3) To what extent does current practice align with Optimal Cancer Care Pathways?

This is likely to be defined by current practice and data capabilities (rather than expecting to document change), areas of focus for Optimal Cancer Care Pathway adoption, and proxy outcome measures. Options include:

- Map current practice against Optimal Cancer Care Pathways.
- Measure core indicators at key points on pathway (depending on data capabilities).
- Process measures, including resource implications, enablers, challenges and barriers, sustainability and transferability (of strategies to other cancer streams or settings) associated with adopting Optimal Cancer Care Pathways.
MONITORING PROGRESS

DATA COLLECTION GUIDANCE

The following data guidance is for optional and includes more options than are likely to be relevant, or possible, and may provide aspirational goals for the future.

Capabilities for health data collection are in various stages of development across the Australian jurisdictions. However, consistent data collection, and monitoring across the cancer control continuum, is an ongoing priority at the national level.

Cancer Australia has developed a framework of key National Cancer Control Indicators to target policy or modify activities to achieve best-practice care, reduce inequalities in cancer control, and ultimately improve cancer outcomes across the population. Wherever possible, the data guidance tables provided in this Framework are consistent with the current status of this national work.

The focus and depth of data collection will vary, depending on jurisdictions’ existing initiatives, data capabilities, systems, priorities, and foci for Optimal Cancer Care Pathway adoption. In many cases, proxy measures may be appropriate or available in the absence of established jurisdiction-wide core data systems.

Data guidance tables

There are four data guidance tables that propose a range of options for jurisdictions to consider for data collection. Many more options are proposed than are likely to be relevant or possible.

New South Wales example

Data collection for patient experience is currently being piloted at three cancer services in NSW. Patients will complete a quality of life assessment at each clinic visit, during the various stages of the pathway. NSW is continuing to progress towards collecting patient reported outcomes over the next five years. This information is intended to be used to understand patient experience and outcomes aligned to various stages of the pathway.

Queensland example

Queensland’s primary focus for data collection will be on whether patients receive appropriate treatment based on key decisions made in a multidisciplinary team meeting (sourced through multidisciplinary team records) and data that capture the time period between referral, diagnoses and treatment. Existing electronic medical records (capturing referral, multi-disciplinary team meeting and treatment data) will be used to monitor the progress of early stage adoption of Optimal Cancer Care Pathways.

The data guidance tables list indicators that are high-level and not cancer type specific, so that they can be applied across all 15 Optimal Cancer Care Pathways. Some jurisdictions with the data capabilities may choose to collect and report on cancer type-specific data at much greater depth than suggested in this guidance.
MONITORING PROGRESS

REPORTING

Each jurisdiction is asked to complete a report on the first 12 months of Optimal Cancer Care Pathway adoption.

It is not expected that all data collection options are relevant or even possible for jurisdictions to report on; jurisdictions can adapt the report template, based on feasible data collection activities.

A significant achievement within the first year would be a report that indicates the level of relevant current data capabilities within the jurisdiction and any possible data or proxy measures that may provide a baseline for measuring future changes associated with adoption of the Optimal Cancer Care Pathways.

The National Cancer Expert Reference Group (NCERG) Secretariat will synthesise findings from all jurisdictional reports into a national update, to be submitted to AHMAC. The national report will summarise progress across jurisdictions, and nationally, in supporting the adoption of the Optimal Cancer Care Pathways. It may highlight barriers and enablers to the adoption of the Optimal Cancer Care Pathways.

Monitoring and reporting on the progress of Optimal Cancer Care Pathways can provide leverage for future service delivery planning and identify the necessary systems required to support continuous improvement and best practice cancer care.
COMMUNICATIONS STRATEGY

Effective ongoing stakeholder engagement and communication will be essential for successful national adoption of Optimal Cancer Care Pathways. Successful engagement of stakeholders requires clarity of purpose and required levels of engagement.

The Communications Strategy will facilitate awareness, understanding and commitment to early stage (2016–17) adoption of Optimal Cancer Care Pathways in jurisdictions across Australia.

The strategy is designed for jurisdictions to tailor stakeholder engagement and communications based on areas of focus. Using the strategy and the accompanying tools and resources will help jurisdictions consider and plan the most effective and efficient approaches to stakeholder engagement and communications.
TOOLS AND RESOURCES

Download tools and resources to support the early adoption of Optimal Cancer Care Pathways (2016-2017).

- Framework (print version)
- Data Guidance Tables
- Communications Strategy
- Jurisdictional Report Template
- Stakeholder Mapping & Analysis Tool
- Sample Communication Briefs
- Key Messages
- Factsheet
- Communications Planning Tool
- Frequently Asked Questions
- Optimal Cancer Care Pathways Presentation