



Australian Government

Cancer Australia



REPORT ON THE
NATIONAL
PANCREATIC
CANCER
ROADMAP



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FOREWORD

In March 2020, the Hon Greg Hunt MP, Minister for Health and Ageing, invited Cancer Australia to work with the Department of Health to develop a National Pancreatic Cancer Roadmap (the Roadmap) to improve outcomes and survival for Australians affected by pancreatic cancer.

Over the last 40 years the number of Australians diagnosed with pancreatic cancer has more than tripled and five-year relative survival rates remain very low compared with most other cancer types. Pancreatic cancer is currently the third leading cause of cancer death in Australia and has a disproportionate impact on a range of priority population groups.

Continuing to do more of what we have always done will not be sufficient to make the rapid advances in prevention, diagnosis, treatment and care required to have an impact on one of our deadliest cancers. Novel, bold and strategic initiatives are required.

The Roadmap provides a national focus on priorities for improving outcomes and survival for Australians affected by pancreatic cancer. Thirty-three key priority areas and 60 strategies for collective action over the next five years, across the continuum of care from prevention, early detection, presentation, diagnosis, treatment, supportive care, palliative care, and end-of-life care, set a shared agenda to drive improvements in pancreatic care, experiences and outcomes.

Together with these priorities, major transformational initiatives are outlined to revolutionise the management and care of Australians with pancreatic cancer and deliver the breakthroughs that will fundamentally change long-term outcomes.

The Roadmap is for the Australian community, including people affected by pancreatic cancer, health professionals, clinical colleges, researchers, pancreatic cancer organisations, funders, peak bodies, non-government and government organisations.

The Roadmap provides the opportunity to focus efforts on the issues that will make a significant difference to all Australians impacted by pancreatic cancer and the national collective response to the Roadmap will allow Australia to lead the world in improving outcomes and survival in pancreatic cancer.

I am pleased to present this report on Australia's first National Pancreatic Cancer Roadmap.



Professor Dorothy Keefe PSM MD

Chief Executive Officer

Cancer Australia

1 December 2021

ABBREVIATIONS

Aboriginal Community Controlled Health Organisations (ACCHOs)

Australian Bureau of Statistics (ABS)

Computed tomography (CT)

Culturally and linguistically diverse (CALD)

Endoscopic ultrasound (EUS)

General practitioner (GP)

Key priority areas (KPAs)

Magnetic resonance imaging (MRI)

Medicare Benefits Schedule (MBS)

Multi-Agency Data Integration Project (MADIP)

Multidisciplinary team (MDT)

Multidisciplinary team meeting (MDM)

Optimal care pathway (OCP)

Pancreatic protocol CT (PPCT)

Patient reported experience measures (PREMs)

Patient reported outcome measures (PROMs)

Pharmaceutical Benefits Scheme (PBS)

Positron emission tomography (PET)

Upper Gastrointestinal Cancer Registry (UGICR)

EXECUTIVE SUMMARY

“My grandfather died of pancreatic cancer in 1963. My father died of it in 2009 and the chances of my father surviving the same disease were the same as for my grandfather, even though it was 46 years later.”

Individual respondent, public consultation

Background

Pancreatic cancer incidence has tripled, and survival outcomes have only marginally improved over the last 40 years in Australia. Pancreatic cancer is the third leading cause of cancer death and despite advances in treatment, the five-year survival rate remains low at only 11.5%.

There are no cardinal symptoms for pancreatic cancer, and no population screening test for early detection. Approximately 50% of people are diagnosed with pancreatic cancer at an advanced stage when five-year survival rates are around 3%.

Aboriginal and Torres Strait Islander people are around 50% more likely to be diagnosed with, and 40% more likely to die of, pancreatic cancer. Pancreatic cancer also has a greater impact on people from a range of culturally and linguistically diverse backgrounds and those living in lower socioeconomic areas. Further, the availability, access, and timeliness of treatment and care compound the disadvantage faced by Australians diagnosed with pancreatic cancer in rural and remote areas.

The advanced stage of diagnosis, rapid disease progression, high symptom burden, heightened levels of anxiety and depression, diminished quality of life, and poor outcomes characterise the experience of people diagnosed with pancreatic cancer in Australia today. The National Pancreatic Roadmap is intended to unite, focus and stimulate national action and investment across the continuum of pancreatic care and research.

The Roadmap

The National Pancreatic Cancer Roadmap (the Roadmap) has been developed by Cancer Australia to identify key priority areas (KPAs) for action over the next five years to 2027, across the continuum of pancreatic cancer care.

The Roadmap’s destination is improved outcomes and survival for people affected by pancreatic cancer including reduced incidence, improved equity of access to treatment and care, improved patient and carer experiences, increased participation in clinical trials, reduced mortality, and improved survival, all driven by world leading research and best-practice culturally appropriate care.

The Roadmap structure follows the steps in the *Optimal care pathway for people with pancreatic cancer* (pancreatic cancer OCP)¹ and a multidisciplinary National Pancreatic Cancer Roadmap Steering Group provided high level strategic advice to Cancer Australia to guide development of the Roadmap.

The KPAs were developed following extensive evidence gathering and stakeholder engagement and are underpinned by a set of guiding principles.

Evidence gathering activities examined the national and international literature in pancreatic cancer, reviewed the distribution of investments in pancreatic cancer research, reviewed the clinical trials activity in pancreatic cancer, mapped current pancreatic treatment and care against the pancreatic cancer OCP, and analysed the socio-demographic characteristics of Australians who died of pancreatic cancer.

Further, stakeholder consultation activities engaged around 400 individuals and organisations to understand the most important and urgent issues, challenges and opportunities for different stakeholders and priority population groups.

Key opportunities to improve pancreatic cancer outcomes were distilled from the evidence gathering and consultation activities, and an iterative prioritisation process with stakeholders was undertaken to refine the KPAs before review by the Steering Group and incorporation into the Roadmap.

The Roadmap is comprised of 33 KPAs across 11 domains in the pancreatic cancer OCP, for collective action over the next five years. A total of 60 strategies and associated activities for implementation in the short, medium, and long-term have been identified to achieve the KPAs.

The Roadmap is for the Australian community, and its implementation will be a collective responsibility involving Australian Commonwealth, State and Territory governments, non-government organisations, professional colleges and societies, health services, health professionals, researchers and consumers.

Implementation

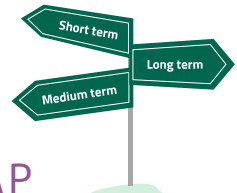
The KPAs and strategies provide a vital starting point for driving change in pancreatic cancer outcomes. However, bold transformational change is required to quickly and fundamentally alter the course of pancreatic cancer outcomes in Australia.

A suite of six high impact, early implementation priorities with the potential to transform and improve pancreatic care, outcomes and survival include:

1. The establishment of **Australia's first National Pancreatic Cancer Centre** to drive and deliver substantial improvements in pancreatic cancer outcomes and survival through leading implementation of the Roadmap, advancing a strategic and coordinated program of research, and enhancing the delivery of best practice care.
2. The creation of a **strategic pioneering pancreatic research scheme** to fund ambitious and ground-breaking research in collaboration with multidisciplinary and cross-industry leaders, and technology enterprises.
3. The development of a **national risk assessment tool** to improve identification of people at high risk of pancreatic cancer for targeted surveillance and strengthen approaches to early detection.
4. The development of **decision support tools to assess signs and symptoms** of pancreatic cancer in primary care and support earlier presentation and diagnosis.
5. The creation of **pathways for access to specialist interventional pain management** to enhance access and improve quality of life.
6. The development of **early referral pathways to palliative care** for people with advanced pancreatic cancer to improve patient experience and quality of life.

Over 20,000 individuals, and their carers, families and communities will directly benefit from the early implementation of these priorities through reduced incidence, improved access to care, improved patient and carer experiences, improved quality of life, and improved survival.

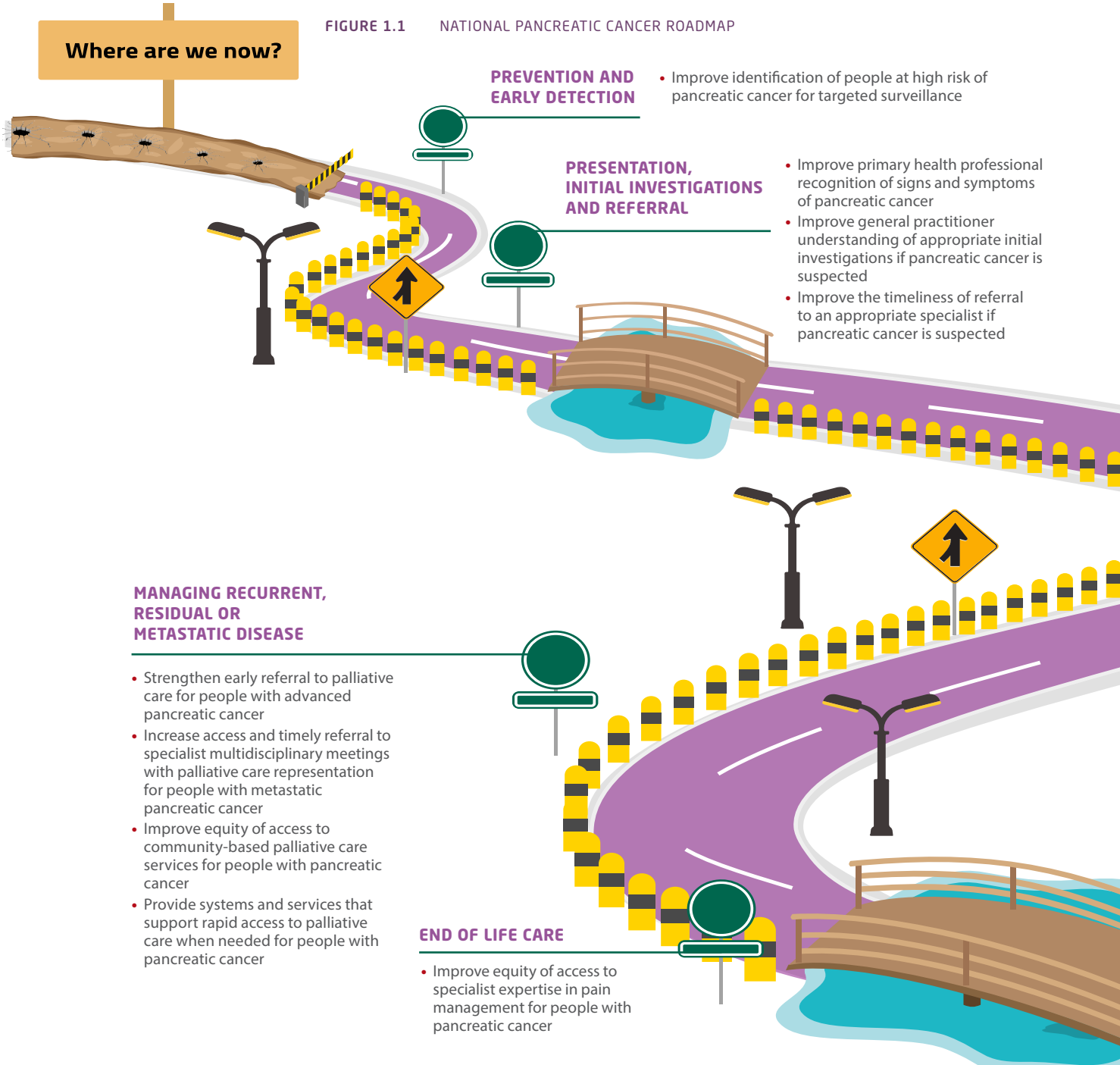
The development of the Roadmap has harnessed the vision and will of stakeholders, and exceptional levels of support and stakeholder commitment provide Australia with a once in a generation opportunity to make a transformational impact on the lives and outcomes of Australians affected by pancreatic cancer.



THE ROADMAP

FIGURE 1.1 NATIONAL PANCREATIC CANCER ROADMAP

Where are we now?



PREVENTION AND EARLY DETECTION

- Improve identification of people at high risk of pancreatic cancer for targeted surveillance

PRESENTATION, INITIAL INVESTIGATIONS AND REFERRAL

- Improve primary health professional recognition of signs and symptoms of pancreatic cancer
- Improve general practitioner understanding of appropriate initial investigations if pancreatic cancer is suspected
- Improve the timeliness of referral to an appropriate specialist if pancreatic cancer is suspected

MANAGING RECURRENT, RESIDUAL OR METASTATIC DISEASE

- Strengthen early referral to palliative care for people with advanced pancreatic cancer
- Increase access and timely referral to specialist multidisciplinary meetings with palliative care representation for people with metastatic pancreatic cancer
- Improve equity of access to community-based palliative care services for people with pancreatic cancer
- Provide systems and services that support rapid access to palliative care when needed for people with pancreatic cancer

END OF LIFE CARE

- Improve equity of access to specialist expertise in pain management for people with pancreatic cancer



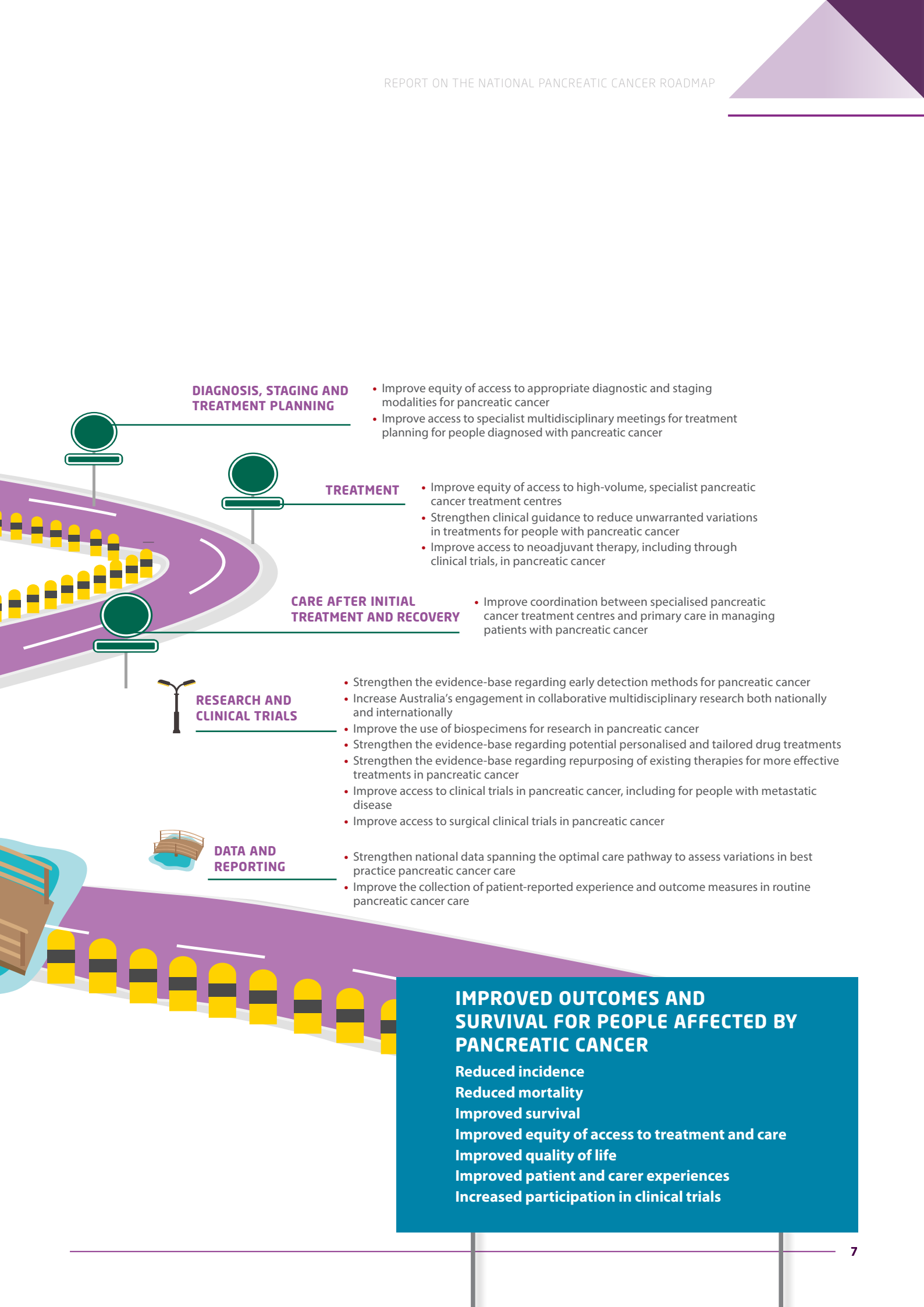
SUPPORTIVE CARE

- Improve equity of access to coordinated supportive care for people with pancreatic cancer
- Improve equity of access to specialist supportive care for pancreatic cancer, including psychosocial support services and networks
- Improve patient navigation and care coordination at point of diagnosis for patient support
- Improve access to symptom management support for people with pancreatic cancer



MODELS OF CARE

- Improve the provision of culturally appropriate models of care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds affected by pancreatic cancer and their carers
- Improve integrated care coordination models, including telehealth, for people from regional and remote areas to minimise delayed treatment
- Improve evidence-based care coordination models for people affected by metastatic pancreatic cancer, including those living in regional and remote areas
- Improve the capacity and capability of the workforce in rural and remote areas to support pancreatic cancer care
- Improve capacity and capability of palliative care nurses and GPs in the provision of pancreatic cancer care particularly in regional areas



DIAGNOSIS, STAGING AND TREATMENT PLANNING

- Improve equity of access to appropriate diagnostic and staging modalities for pancreatic cancer
- Improve access to specialist multidisciplinary meetings for treatment planning for people diagnosed with pancreatic cancer

TREATMENT

- Improve equity of access to high-volume, specialist pancreatic cancer treatment centres
- Strengthen clinical guidance to reduce unwarranted variations in treatments for people with pancreatic cancer
- Improve access to neoadjuvant therapy, including through clinical trials, in pancreatic cancer

CARE AFTER INITIAL TREATMENT AND RECOVERY

- Improve coordination between specialised pancreatic cancer treatment centres and primary care in managing patients with pancreatic cancer

RESEARCH AND CLINICAL TRIALS

- Strengthen the evidence-base regarding early detection methods for pancreatic cancer
- Increase Australia's engagement in collaborative multidisciplinary research both nationally and internationally
- Improve the use of biospecimens for research in pancreatic cancer
- Strengthen the evidence-base regarding potential personalised and tailored drug treatments
- Strengthen the evidence-base regarding repurposing of existing therapies for more effective treatments in pancreatic cancer
- Improve access to clinical trials in pancreatic cancer, including for people with metastatic disease
- Improve access to surgical clinical trials in pancreatic cancer

DATA AND REPORTING

- Strengthen national data spanning the optimal care pathway to assess variations in best practice pancreatic cancer care
- Improve the collection of patient-reported experience and outcome measures in routine pancreatic cancer care

IMPROVED OUTCOMES AND SURVIVAL FOR PEOPLE AFFECTED BY PANCREATIC CANCER

- Reduced incidence
- Reduced mortality
- Improved survival
- Improved equity of access to treatment and care
- Improved quality of life
- Improved patient and carer experiences
- Increased participation in clinical trials

2. INTRODUCTION

In March 2020, the Hon Greg Hunt MP, Minister for Health and Ageing, invited Cancer Australia to work with the Department of Health to develop a National Pancreatic Cancer Roadmap (the Roadmap) that will identify key priority areas (KPAs) for action over the next five years, across the continuum of pancreatic cancer care and pancreatic cancer research, to improve outcomes and survival for Australians affected by pancreatic cancer.

2.1. Context

Pancreatic cancer is currently the eighth leading cause of cancer incidence but the third leading cause of cancer mortality in Australia.² In 2021, over 4,000 Australians are expected to be diagnosed with, and over 3,000 Australians are expected to die from, pancreatic cancer.²

There are currently no data available on stage at diagnosis for pancreatic cancer in Australia. However, international data suggest that the majority of pancreatic cancers are diagnosed at an advanced stage. For example, around half (49.5%) of all pancreatic cancers in 2009–2018 in the United States were diagnosed at the distant stage, 29% at the regional stage, and only 12% at the localised stage.³

Data from the United States also show that five-year relative survival rates are higher for patients diagnosed with localised tumours (41.6%), compared with those diagnosed with tumours with regional spread (14.4%) and tumours with distant spread (3.0%).⁴

In Australia, the five-year relative survival rate for pancreatic cancer has increased marginally over the last 30 years from 3.4% (1988–1992) to 11.5% (2013–2017) but remains low compared with a survival rate of 69.7% for all cancers combined.²

FIGURE 2.1 ESTIMATED NUMBER OF CANCER DEATHS, AUSTRALIA (2021)

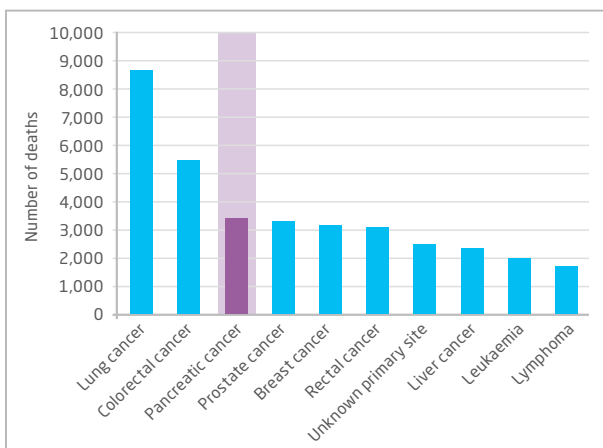
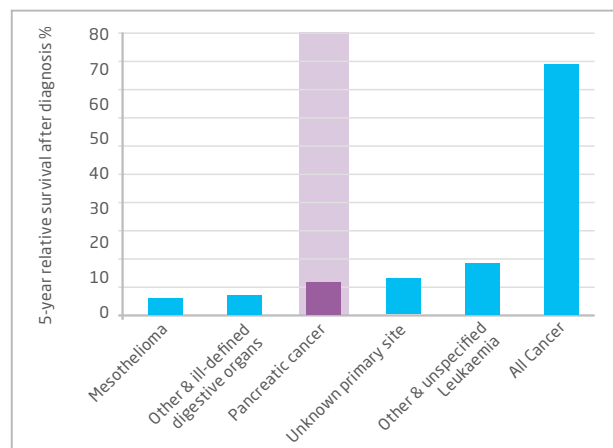


FIGURE 2.2 5-YEAR RELATIVE CANCER SURVIVAL RATE, AUSTRALIA (2013-2017)



INTRODUCTION

Pancreatic cancer has a greater impact on people among lower socioeconomic groups with higher incidence and mortality rates seen with decreasing socioeconomic status.⁵ The incidence of pancreatic cancer, however, is higher in major cities compared with remote areas.⁵

FIGURE 2.3 AGE-STANDARDISED PANCREATIC CANCER INCIDENCE RATE (2010-2014) AND MORTALITY RATE (2013-2017) BY SOCIOECONOMIC STATUS, AUSTRALIA

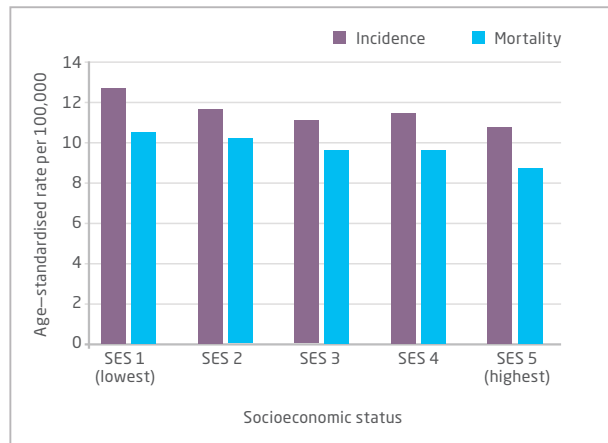
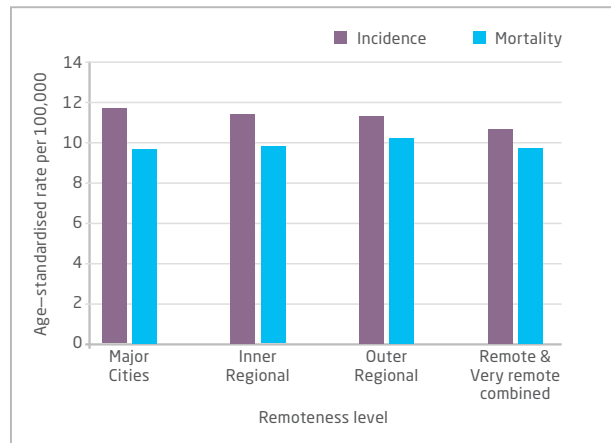


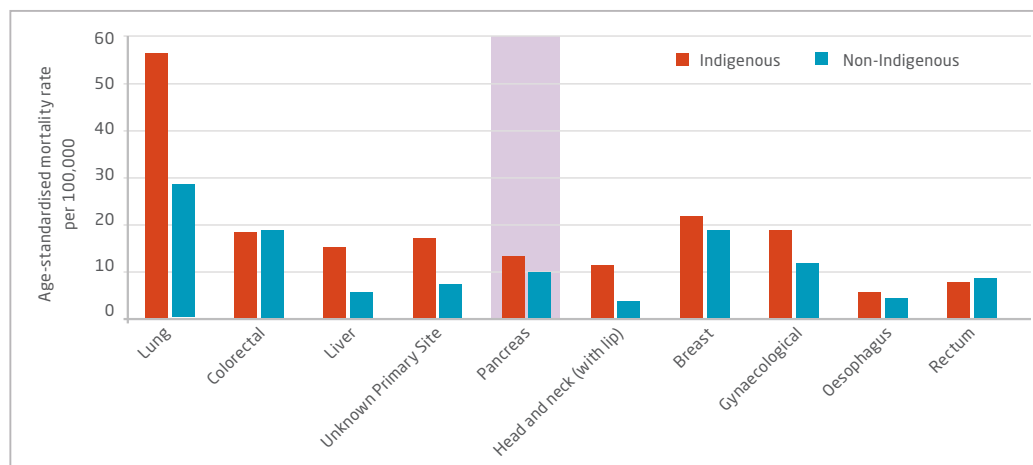
FIGURE 2.4 AGE-STANDARDISED PANCREATIC CANCER INCIDENCE RATE (2010-2014) AND MORTALITY RATE (2013-2017) BY REMOTENESS, AUSTRALIA



Pancreatic cancer is currently the 13th leading cause of cancer incidence but the 5th leading cause of cancer death among Aboriginal and Torres Strait Islander people.⁶

Aboriginal and Torres Strait Islanders are around 50% more likely to be diagnosed with pancreatic cancer, and 40% more likely to die from pancreatic cancer compared with non-Indigenous Australians.⁶

FIGURE 2.5 AGE-STANDARDISED CANCER MORTALITY RATES IN INDIGENOUS AND NON-INDIGENOUS AUSTRALIANS (2014-2018)



Pancreatic cancer incidence increases with age for both Aboriginal and Torres Strait Islander people and non-Indigenous Australians. While Aboriginal and Torres Strait Islander people have higher pancreatic cancer incidence and mortality rates across all age groups, the difference in incidence and mortality rates is largest for the 65-74 years age group.⁶

FIGURE 2.6 AGE-SPECIFIC PANCREATIC CANCER INCIDENCE RATE IN INDIGENOUS AND NON-INDIGENOUS AUSTRALIANS (2011-2015)

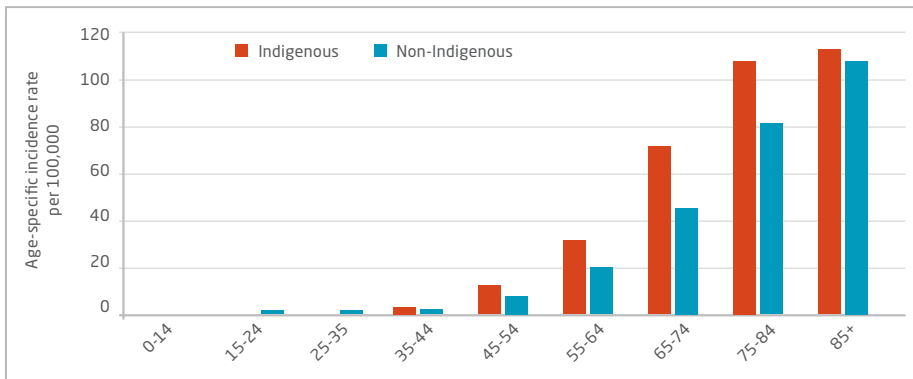
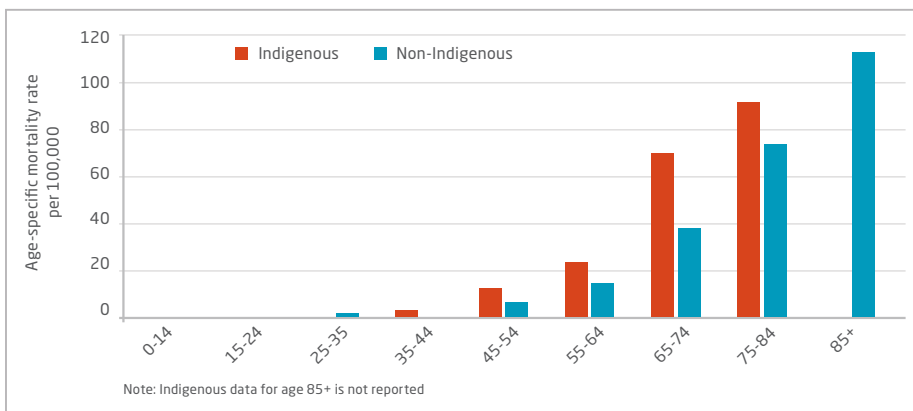


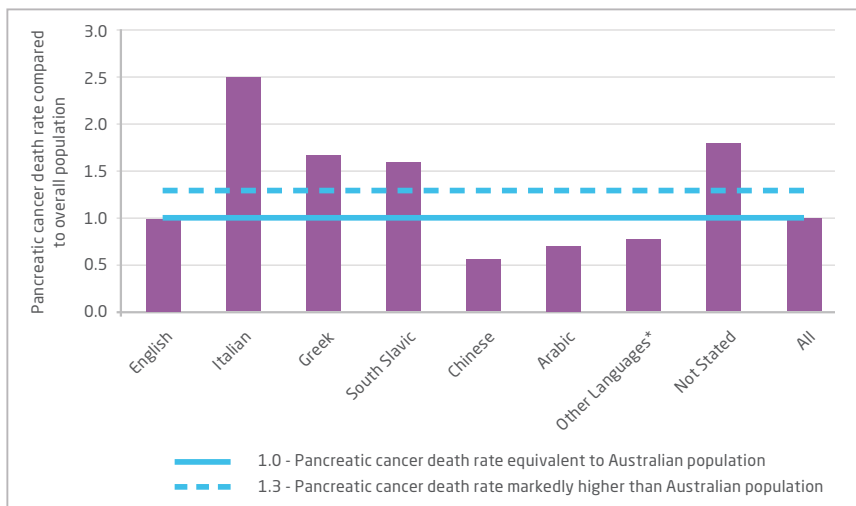
FIGURE 2.7 AGE-SPECIFIC PANCREATIC CANCER MORTALITY RATE IN INDIGENOUS AND NON-INDIGENOUS AUSTRALIANS (2014-2018)



INTRODUCTION

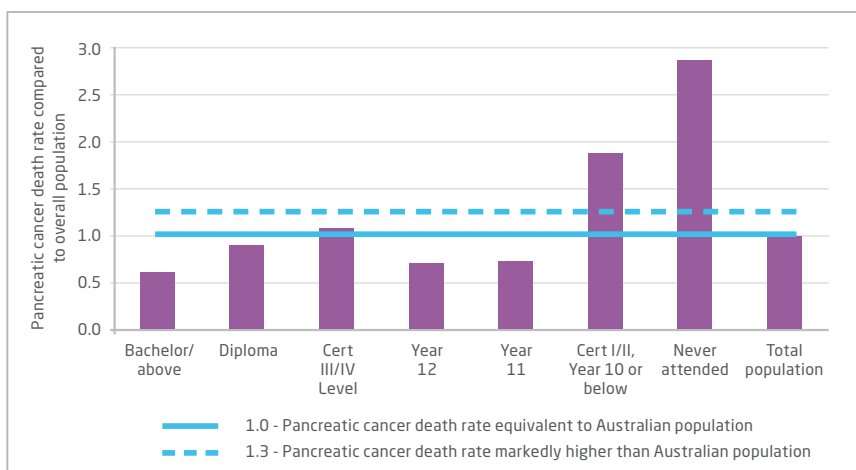
Pancreatic cancer also disproportionately impacts on a range of culturally and linguistically diverse (CALD) groups. An analysis of the Australian Bureau of Statistics' (ABS) Multi-Agency Data Integration Project (MADIP) dataset on the sociodemographic characteristics of people who have died from pancreatic cancer in Australia between 2011 and 2018 identified a higher rate of death from pancreatic cancer for people born in Southern or Eastern Europe, or of Southern or Eastern European descent, people born in North-West Europe, and people not born in Australia who arrived before 1986. Similarly, for persons speaking another language at home, those speaking mainly Italian, Greek, or South Slavic languages (Figure 2.8) and those who had a lower proficiency of spoken English had a higher death rate from pancreatic cancer.

FIGURE 2.8 SOCIODEMOGRAPHIC PROFILE AT THE 2011 CENSUS OF THE MADIP PANCREATIC CANCER COHORT, BY MAIN LANGUAGE SPOKEN AT HOME



Associations between pancreatic cancer mortality and education, employment and income have also been observed. A higher rate of death from pancreatic cancer has been observed for people with lower educational attainment (i.e. persons whose highest educational attainment was Year 10 or below including Certificate I/II) and those who never attended school or had no non-school qualification (Figure 2.9), people aged under 65 years who were not in the labour force, and those with a personal or household weekly income at or below the median.

FIGURE 2.9 SOCIODEMOGRAPHIC PROFILE AT THE 2011 CENSUS OF THE MADIP PANCREATIC CANCER COHORT, BY HIGHEST EDUCATIONAL ATTAINMENT



2.2. Approach

The Roadmap identifies KPAs for collective action over the next five years to 2027, across the continuum of pancreatic cancer care and pancreatic cancer research, to improve outcomes and survival for people affected by pancreatic cancer. The Roadmap structure follows the steps in the pancreatic cancer OCP. The KPAs were developed following extensive evidence gathering and stakeholder engagement activities. For each of the KPAs included in the Roadmap, a set of short, medium and long-term strategies was identified. The strategies were derived from the evidence activities and the input from stakeholders.

Governance

The development of the Roadmap was overseen by a National Pancreatic Cancer Steering Group (the Steering Group) (Table 2.1). The multidisciplinary membership of the Steering Group included representation from people affected by pancreatic cancer, consumers, clinical experts, researchers, representatives from Aboriginal and Torres Strait Islander peak bodies and the non-government and government sector. The Steering Group first met in October 2020 and members participated in four meetings during the 21-month Roadmap development period. The Steering Group provided high level strategic and expert advice to Cancer Australia to guide the development of the Roadmap. The outcome of all the evidence gathering activities, public consultation hub findings, and targeted consultations with Aboriginal and Torres Strait Islander stakeholders and health professionals, including those that provided care to CALD population groups, was presented to the Steering Group.

TABLE 2.1 NATIONAL PANCREATIC CANCER STEERING GROUP

Dr Lorraine Chantrill (Chair)	Head of Department Medical Oncology, Illawarra Cancer Care Centre, NSW Chair, Australasian Gastro-Intestinal Trials Group, NSW
Professor Meera Agar	Chair, Palliative Care Australia Palliative Medicine Specialist, Liverpool Hospital, NSW IMPACCT Director at University of Technology Sydney
Professor Chris Baggoley AO	Consumer, SA Board Member, PanKind, The Australian Pancreatic Cancer Foundation
Dr Dawn Casey	Deputy Chief Executive Officer, National Aboriginal Community Controlled Health Organisation
Mr Daniel Goulburn OAM	Chair, Australian Pancreatic Cancer Alliance Co-founder, Purple Our World
Mr Doug Hawkins	Chief Executive Officer, Pancare Foundation
Ms Claire Howlett	Assistant Secretary, Cancer Policy and Services, Department of Health
Mr Gino Iori	Consumer representative, Cancer Voices Australia, NSW
Professor James Kench	Head of Tissue Pathology and Diagnostic Oncology, Royal Prince Alfred Hospital, NSW
Professor Mei Krishnasamy	Chair, Cancer Nursing, University of Melbourne Professor/Director, Academic Nursing Unit, Peter MacCallum Cancer Centre, VIC

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Dr Dominique Lee	Radiation Oncology Consultant, Princess Alexandra Hospital, QLD Royal Australian and New Zealand College of Radiologists representative
Ms Bryce McCarthy	Upper Gastrointestinal Clinical Nurse Specialist, WA Cancer and Palliative Care Network, WA
Professor Geoff Mitchell	Emeritus Professor, General Practice and Palliative Care, University of Queensland, QLD Royal Australian College of General Practitioners representative
A/Professor Mehrdad Nikfarjam	Liver, Pancreas and Biliary Surgeon Senior Lecturer, Department of Surgery, University of Melbourne, Austin Health, VIC
A/Professor Phoebe Phillips	Head Pancreatic Translational Research Group, Adult Cancer Program, Lowy Cancer Research Centre, NSW
Ms Perry Sperling PSM	Consumer, VIC Former member of Cancer Australia's Advisory Council
Ms Michelle Stewart	Chief Executive Officer, PanKind, The Australian Pancreatic Cancer Foundation

Guiding principles

The identification of KPAs for inclusion in the Roadmap was evidence-informed, consensus-based and underpinned by the Roadmap Principles (Table 2.2)

TABLE 2.2 PRINCIPLES FOR IDENTIFYING KEY PRIORITY AREAS FOR ACTION

Person-centred	Informed by and for people affected by pancreatic cancer. Respectful of, and responsive to, the preferences, needs and values of the individual, family and carer. Considerate of culture, age, co-morbidities, stage at diagnosis, location and socioeconomic circumstance.
Focus on priority populations	Focus on the needs of priority populations including: Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, and people living in regional and remote and lower socioeconomic areas.
Accessible	All people affected by pancreatic cancer should have access to quality pancreatic cancer care irrespective of demographic, geographical, socioeconomic, cultural and other factors.
Collaborative engagement	Collaborative and deep engagement with people affected by pancreatic cancer, health professionals, clinical colleges, researchers and research institutes, pancreatic cancer organisations, peak bodies, health services, government and non-government organisations, to improve pancreatic cancer outcomes.
Innovative and responsive	Fast track innovation and be responsive to existing evidence-based pancreatic cancer treatment and care, clinical trials and research.
Evidence-based	Key priority areas for action will be based on the best evidence, assessed on scientific rigour, and informed by the best available national and international guidance in pancreatic cancer treatment, care and research.
Optimal pancreatic cancer treatment and care	Provide holistic, best practice treatment and care throughout the care continuum, aligned with the <i>Optimal care pathway for people with pancreatic cancer</i> and with reference to the <i>Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer</i> .

Process

Development of the Roadmap adopted an evidence-based, consultative and consensus approach, with a comprehensive review of the evidence and multifaceted stakeholder engagement at its core. Consumer consultation has been undertaken with, and built on the efforts and expertise of, the non-government sector.

Key activities undertaken to inform development of the Roadmap have included:

1. A review of the national and international literature to identify gaps and opportunities in pancreatic cancer, treatment and care;
2. A review of pancreatic cancer research funding in Australia;
3. A review of pancreatic cancer clinical trials in Australia;
4. The mapping of pancreatic treatment and care against the pancreatic cancer OCP;
5. A MADIP data analysis of socio-demographic characteristics of Australians who died of pancreatic cancer;
6. Public consultation through the Department of Health's Consultation Hub;
7. Targeted stakeholder consultations;
8. Consultations with health professionals who care for people with pancreatic cancer from CALD backgrounds;
9. An examination of the experiences of Aboriginal and Torres Strait Islander people affected by pancreatic cancer; and
10. Consultation with Cancer Australia's Advisory Groups and the National Pancreatic Cancer Roadmap Steering Group.

The outputs of these evidence gathering and stakeholder engagement activities were reviewed to identify key opportunities to improve pancreatic cancer outcomes. Over 680 evidence statements were extracted spanning the 10 evidence and consultation activities. A thematic analysis was then undertaken to identify the KPAs and associated strategies.

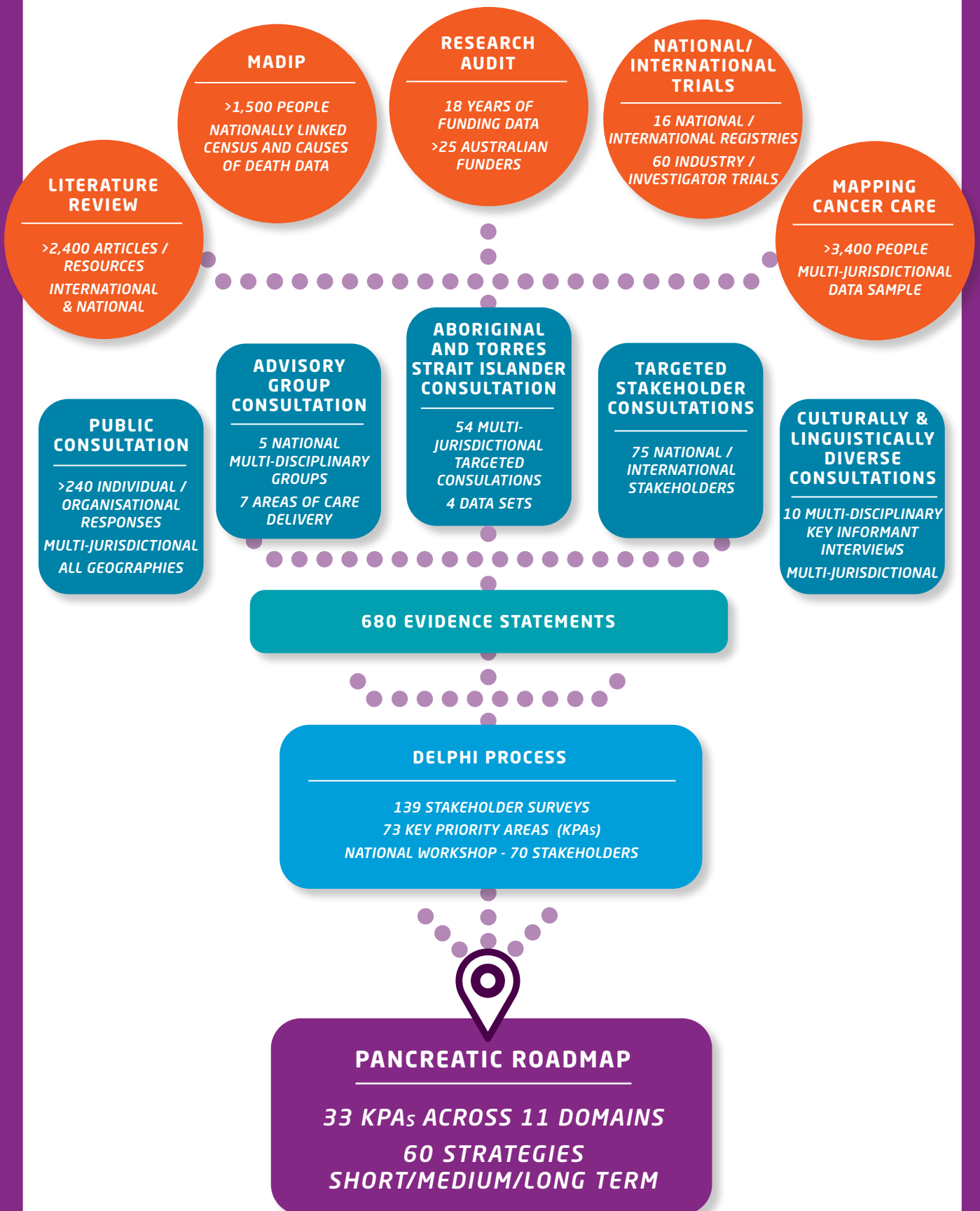
Key stakeholders including people affected by pancreatic cancer, members of pancreatic cancer organisations, other cancer organisations and peak bodies, representatives from research institutes and researchers, clinical colleges, health professionals, non-government organisations and government entities, were invited to participate in a two-stage modified consensus Delphi priority-setting process.

One hundred and thirty-nine multi-disciplinary stakeholders from around Australia contributed to Round 1 of the Delphi process. A quantitative survey approach prioritised the KPAs identified from the evidence and stakeholder activities.

A representative subset of 70 stakeholders from Round 1 was then invited to a stakeholder workshop - Round 2 of the Delphi process - to further refine the KPAs and discuss associated strategies. The final KPAs and strategies were reviewed by the National Pancreatic Cancer Roadmap Steering Group prior to incorporation into the Roadmap.

FIGURE 2.10 APPROACH TO IDENTIFICATION OF KEY PRIORITY AREAS AND STRATEGIES FOR THE NATIONAL PANCREATIC CANCER ROADMAP

DEVELOPMENT OF THE ROADMAP



3. FINDINGS

The following sections summarise the findings from the ten-evidence gathering and stakeholder consultations. The sections are based on the seven steps in the pancreatic cancer OCP plus four additional domains that cross the whole continuum of cancer care - supportive care, research and clinical trials, data and reporting, and models of care.

In each section, the related goal to improve outcomes and survival in pancreatic cancer is identified and key information and collective issues raised in the evidence and stakeholder activities are distilled and described. The opportunities to improve pancreatic cancer care and outcomes are presented in a right-hand panel and reflect the common opportunities identified in the evidence gathering initiatives and highlighted across a range of stakeholder forums. At the end of each section, the 'way forward' outlines the KPAs prioritised by stakeholders.

Priority population groups

A number of priority population groups are disproportionately impacted by pancreatic cancer, including Aboriginal and Torres Strait Islander people, people who live in lower socioeconomic status areas and people from some CALD backgrounds. In addition, issues of equity of access to treatment and care affect individuals from these groups as well as those from regional and rural areas.

The issues and opportunities raised by priority population groups span all steps in the pancreatic cancer OCP and are incorporated in each chapter summary. The identified opportunities and KPAs for action apply to all priority population groups and particular consideration will be given to the specific or unique needs of these population groups during implementation of the Roadmap priorities.

3.1 Prevention and Early detection

Goal 1 - Reduce risk, and find pancreatic cancer early

Risk factors

Evidence summary

Primary prevention provides a cost-effective long-term strategy to reduce the risk of cancer.

While the aetiology of pancreatic cancer is unknown, smoking, diabetes mellitus, alcohol, obesity, and somatic and germline mutations have been shown to increase the risk of developing pancreatic cancer.⁷⁻¹⁰ Other studies have shown some association between factors such as chronic pancreatitis, periodontal disease, and edentulism (or severe teeth loss) and the development of pancreatic cancer.^{11, 12}

Several modifiable risk factors for pancreatic cancer, such as smoking and obesity, have health benefits that extend beyond the prevention of pancreatic cancer and into other cancers and chronic diseases.

Stakeholder input

Over a third of all individual and organisational public consultation responses referenced risk factors and prevention as important issues that could make the biggest difference to pancreatic cancer outcomes.

Stakeholders supported continuing to promote and invest in implementation of existing preventive health strategies to reduce the prevalence of risk factors.

A lack of knowledge and awareness among the public and health professionals about causes of pancreatic cancer was highlighted, and education and campaigns to raise awareness, and framing information without blame, were supported.

A holistic approach to addressing risk factors including preventive health checks, management of associated chronic conditions, education and awareness campaigns, and lifestyle promotion and risk-behaviour programs, including programs developed and delivered by Aboriginal and Torres Strait Islander people to suit local preferences and contexts are required.

Stakeholders also raised fear about the familial or genetic risk and identified strategies including genetic testing and counselling as well as the storage of biospecimens to study familial risk.

Opportunities

Raise awareness of risk factors

Reduce risk factor prevalence

Enhance community-led programs/ communications

Identify individuals at high risk

Establish targeted surveillance

Enhance clinical guidance

Early detection

Evidence summary

The early detection of pancreatic cancer can support the diagnosis of early-stage disease when treatments may result in better survival outcomes.

While there is no current evidence to support population-level screening for pancreatic cancer, targeted surveillance programs present an opportunity to strengthen the early detection of pancreatic cancer among high-risk individuals. However, there is conflicting evidence on psychosocial impact of surveillance for first-degree relatives at risk of pancreatic cancer.^{13, 14}

The lack of validated biomarkers and imaging approaches suitable for long-term surveillance of at-risk cohorts presently limits the implementation of targeted surveillance

For those with a strong family history of pancreatic cancer or related hereditary conditions, referral to a familial cancer service, geneticist or oncologist for genetic testing is recommended.¹⁵ Opportunities to increase clinicians' knowledge about genetic testing are valuable to the management of an individual with pancreatic cancer as well as broadening the reach of genetic testing as a cancer risk reduction and early detection tool.¹⁶

Clinician guidance on prevention and early detection, including the identification and screening of individuals at high risk of pancreatic cancer, can support the prevention and early detection of pancreatic cancer.

Stakeholder input

The lack of early detection and screening tests for pancreatic cancer together with the lack of validated biomarkers to support early detection and diagnosis was also raised by stakeholders.

While routine inclusion of cancer screening in the annual general health check for Aboriginal and Torres Strait Islander people and opportunistic cancer surveillance of individuals with risk factors such as diabetes, was raised, the large-scale separation of Aboriginal and Torres Strait Islander families in earlier generations means that many Indigenous people do not know the medical history of their biological family. Taken together with uncertainty, individual reluctance and mistrust of institutions, Aboriginal and Torres Strait Islander people may be deterred from taking up options for early detection. A range of contextual and logistical barriers for Aboriginal and Torres Strait Islander people, and other priority population groups, will need to be considered when providing access to future surveillance programs.



THE WAY FORWARD

IMPROVE IDENTIFICATION OF PEOPLE AT HIGH RISK OF PANCREATIC CANCER FOR TARGETED SURVEILLANCE

Identify current evidence for risk assessment.

Design/ adapt, test and implement risk assessment tools in primary care.

Design/ adapt, test and implement targeted surveillance of people at high risk of pancreatic cancer.

3.2 Presentation, initial investigations and referral

Goal 2 - Facilitate early presentation, streamline appropriate investigations, and support timely referral

Opportunities

Improve community and health professional awareness of signs and symptoms

Improve general practitioner understanding of appropriate initial investigations

Improve timeliness of appropriate referral to a specialist linked to a multidisciplinary team

Support presentation, initial investigations and referral for priority population groups

Signs, symptoms and presentation

Evidence summary

The signs and symptoms associated with pancreatic cancer can be non-specific and common to a range of benign and malignant conditions, and include jaundice, back or upper abdominal pain, weight loss, loss of appetite, nausea and vomiting, fatigue and new onset diabetes. However, few distinctive signs or symptoms appear until the cancer is well advanced, making early detection difficult. As a result, 80-85% of people presenting with signs and symptoms of pancreatic cancer have locally advanced or metastatic disease.¹⁷

Stakeholder input

Limited community and health professional awareness about pancreatic cancer signs and symptoms was raised across stakeholder engagement initiatives, and the importance of raising public awareness and increasing knowledge and education for health professionals was highlighted.

The generic nature of symptoms, the masking of symptoms by other co-morbidities, language barriers, and low levels of health literacy can all contribute to a reluctance of some consumers to present to their general practitioner (GP) even when symptoms are acute.

This potential reluctance needs to be addressed through more effective community education and engagement. Tailored community-led campaigns developed and delivered in partnership with community organisations, can support the provision of culturally appropriate information to increase awareness of signs and symptoms among CALD and Aboriginal and Torres Strait Islander population groups, support self-determination, and increase confidence and capacity to engage with health services, leading to the earlier presentation and detection of pancreatic cancer.

Strong partnerships between community members and culturally safe health services can also create a safe environment for people to present in a more timely manner, and models of community-based care navigation were also raised as enablers to presentation, investigations and referral.

In addition, developing and trialling awareness messages and education activities with GPs including those working in Aboriginal Community Controlled Health Organisations (ACCHOs) and using tools to help GPs consider symptoms of pancreatic cancer can also support early detection.

Assessment and initial referral

Evidence summary

While a range of guidance exists around managing initial investigations and referral, strengthening this guidance and providing GPs with streamlined processes to support timely investigation and referral can assist to address potential diagnostic delays.

Data from the Upper Gastrointestinal Cancer Registry (UGICR) indicate that 97% of patients are referred to a specialist, however age-related variations were observed, with only 11.2% aged 85 or over referred to a specialist (surgeon, medical oncologist, or radiation oncologist). Data on timeframes for referral were not available.

Opportunities exist to ensure that GPs facilitate timely referral to high-volume pancreatic cancer centres, for further assessment and treatment planning if pancreatic cancer is suspected.

Stakeholder input

Limited health professional awareness about appropriate investigation and referral pathways for pancreatic cancer was raised. Disparities in availability of diagnostic tests and specialist referral, and the importance of equity of access to diagnostic tests, referral pathways and subsequent treatment, especially for those in rural and regional areas, were highlighted.

Implementation of decision support tools to prompt timely referral for diagnostic tests based on specific symptoms and combinations of symptoms, was supported.

To assist with culturally competent and effective care, it was also considered beneficial for referring GPs to provide more comprehensive information in the referral process, such as information on the cultural background of the patient, the social context specific to cancer management, as well as other background information such as duration of residence in Australia.



THE WAY FORWARD

IMPROVE PRIMARY HEALTH PROFESSIONAL RECOGNITION OF SIGNS AND SYMPTOMS OF PANCREATIC CANCER

Promote and communicate signs and symptoms through existing channels.

Identify, design/ adapt, test and implement decision support tools for assessment of signs and symptoms of pancreatic cancer.

Develop and implement education modules on signs and symptoms.

IMPROVE GENERAL PRACTITIONER UNDERSTANDING OF APPROPRIATE INITIAL INVESTIGATIONS IF PANCREATIC CANCER IS SUSPECTED

Design/ adapt, test and implement standardised clinical pathway for initial investigations (diagnostics) and referrals.

Develop and implement education modules on appropriate initial investigations.

IMPROVE THE TIMELINESS OF REFERRAL TO AN APPROPRIATE SPECIALIST IF PANCREATIC CANCER IS SUSPECTED

Identify barriers and enablers to timely referrals.

Develop, test and implement systems of rapid and seamless referral.

3.3 Diagnosis, staging and treatment planning

Goal 3 - Standardise diagnostic investigations, improve staging, and enhance access to multidisciplinary meetings

Diagnosis and Staging

Evidence summary

The diagnosis of pancreatic cancer is primarily imaging-based, although there is significant variation in the modality of imaging performed.

The pancreatic cancer OCP suggests that diagnosis should include contrast-enhanced computed tomography (CT) and, if diagnostic uncertainly remains, endoscopic ultrasound (EUS) with or without biopsy, magnetic resonance imaging (MRI) and/or laparoscopy, with or without ultrasound. Staging involves CT of the chest/abdomen/ and pelvis and positron emission tomography (PET), MRI and laparoscopy, with or without ultrasound.

The pancreatic cancer OCP specifies the importance of staging in treatment planning and prognosis, with synoptic reporting (the process of reporting specific data elements in a specified format in surgical pathology reports) encouraged where operative resection has occurred, and pathological staging is available. The use of protocols and algorithms for investigation and staging can assist to ensure uniformity and equity of access to high quality care.¹⁸⁻²⁰ Specifically, increased pancreatic protocol-based imaging can play an important role in identifying patients who would most benefit from surgery or neoadjuvant treatment.

An analysis of the UGICR indicated that CT chest/ abdomen/and pelvis was not performed in all patients. Despite the critical role of pancreatic protocol CT (PPCT) for assessing localised disease, only 37% of patients within the UGICR received imaging according to this protocol. Of those CT images taken, 90% were undertaken as per protocol. There were no observable differences in the characteristics of patients who received diagnostic imaging by different imaging modalities.

Further, EUS was performed in approximately half of cases, and biopsy in 80% of patients who underwent EUS. There were no differences in the demographic characteristics of patients who received EUS or tissue biopsy.

A higher proportion of patients from regional (28%) or remote (32%) areas received imaging including an MRI scan, when compared with those from major cities (23%). The difference in for these variations needs to be explored. Consistent with the pancreatic cancer OCP recommendations, a greater proportion of patients with metastatic disease underwent less scanning compared with those with no metastases identified. Multidisciplinary care is an integral component of cancer care and can improve

Opportunities

Improve equity of access to, and unwarranted variations in, diagnostic investigations and staging

Standardise approach to synoptic reporting for diagnostic investigations and staging

Improve access to multidisciplinary meetings

Tailor diagnostic information for Aboriginal and Torres Strait Islander people and people from CALD backgrounds

Improve the provision of culturally safe cancer care

patient outcomes.¹ Multidisciplinary team meetings (MDM) are meetings that involve all relevant health professionals (a multidisciplinary team (MDT)) discussing all appropriate treatment options and making joint recommendations about treatment and supportive care plans, taking into account the personal preferences of patients.¹ The pancreatic cancer OCP recommends that most diagnostic procedures should be completed prior to the MDM. Around 42% of patients on the UGICR had clinical stage documented at diagnosis. However, there did not appear to be any demographic differences in whether clinical stage was known. Full staging of patients with localised disease also appeared to be lacking and this lack of diagnostic workup/staging limits treatment options for patients.

Adherence to imaging protocols could be increased through improved education and the introduction of a synoptic reporting template. In addition, opportunities exist to improve diagnostic accuracy, safety, sample adequacy and quality, needle technical performance and cost of EUS-guided biopsy.²¹

Detailed population level data on timeframes from diagnostic investigations to treatment are lacking. Standardising diagnostic tests and staging, and reducing the time from referral to imaging, presentation at the MDM, and definitive treatment would support more patients to receive treatment according to the pancreatic cancer OCP.

Stakeholder input

Stakeholders identified variable access to key diagnostic tests and lack of Medicare Benefits Schedule (MBS) funding for PET scans for staging. They supported the mapping of diagnostic infrastructure to identify gaps, the use of imaging protocols, standardised reporting for radiology, MBS rebates for key staging procedures, and implementation of strategies to ensure faster access to diagnostic tests and treatment for people in rural areas.

The importance of timely diagnosis in initiating an effective treatment plan for people from CALD backgrounds was also raised, noting that the point of diagnosis was when the requirement for cultural competence and responsiveness in dealing with CALD consumers and their families was most critical. Indigenous stakeholders also identified the need for better communication in the pre-diagnosis and diagnosis phases, and novel and culturally safe ways to describe diagnosis and treatment options were proposed.

Travelling for diagnostic tests, staging and treatment and being away from family and country take a toll on Aboriginal and Torres Strait Islander people. In addition to displacement from family and country, the costs of travel, accommodation, living expenses and diagnostic tests were highlighted. Increasing affordable access to diagnostic investigations and specialist consultation, and opportunities for initial work-up and some subsequent treatments to be provided closer to home using telemedicine, were also supported by Indigenous stakeholders.

Treatment planning

Evidence summary

The pancreatic cancer OCP recommends that all newly diagnosed patients should be discussed in an MDM before beginning treatment. Overall, around 59% of patients in the UGICR were reviewed by an MDM prior to treatment. Less than half (41%) of patients in the UGICR with metastatic disease were presented to an MDM compared with 84% of those with non-metastatic disease. In addition, higher proportions of patients aged less than 85 years were referred to an MDM, with only 23% of patients aged 85 years or older presented to an MDM.

FINDINGS

A number of barriers to presentation at MDMs have been identified, including lack of awareness of the benefits and/or disagreement that pancreatic cancer patients should be presented at an MDM, and burden of attendance, particularly for radiologists.²⁰ Strengthening referral pathways to MDMs and education about the benefits of presentation at an MDM, support for radiologists by providing streamlined reporting procedures including through teleradiology, and increasing the capacity of MDMs to allow discussion of larger volumes of patients, would increase the proportion of patients reviewed at an MDM.

A Queensland sample of Aboriginal and Torres Strait Islander people diagnosed with pancreatic cancer showed that only 28% were referred to an MDT for treatment planning between 2001 and 2020. Aboriginal and Torres Strait Islander people seen by an MDT tended to be younger, and those diagnosed were more likely to be referred to an MDT following the publication of the pancreatic cancer OCP in 2015, (44% in 2015-2020 compared with 11% before release of the pancreatic cancer OCP). Access to MDTs improved across all remoteness categories following the introduction of the pancreatic cancer OCP.

Stakeholder input

Stakeholders raised the need for increased, rapid and timely access to expert MDTs for treatment planning and to centres of excellence for treatment. In addition, the need for the composition of the MDT to include radiation oncologists, palliative care specialists and experts in culturally appropriate care for Aboriginal and Torres Strait Islander people was highlighted. Stakeholders also raised consideration of separate palliative care MDTs for patients with metastatic pancreatic cancer.

Stakeholders supported developing and publishing current referral pathways to ensure referral of all people diagnosed with pancreatic cancer to an MDT with expertise in the management of pancreatic cancer. The need to capture the proportion and characteristics of patients presented at an MDM was also raised.



THE WAY FORWARD

IMPROVE EQUITY OF ACCESS TO APPROPRIATE DIAGNOSTIC AND STAGING MODALITIES FOR PANCREATIC CANCER

Identify barriers and enablers for diagnostic and staging investigations.

Develop a framework for use of teleradiology/ telehealth.

Develop and implement educational modules on appropriate diagnostic and staging investigations.

Develop and implement referral pathways for diagnostic and staging investigations.

IMPROVE ACCESS TO SPECIALIST MULTIDISCIPLINARY MEETINGS FOR TREATMENT PLANNING FOR PEOPLE DIAGNOSED WITH PANCREATIC CANCER

Promotion and communication of the OCP through existing channels.

Develop and implement directories of specialists linked to a multidisciplinary team.

Implement reporting of clinical quality indicators to measure access to specialist multidisciplinary meetings.

3.4 Treatment

Goal 4 - Strengthen best-practice treatment

Evidence summary

There is strong evidence to suggest that high-volume hospitals have better clinical outcomes for complex cancer surgery such as pancreatic resections.²² While there is disagreement about the exact number of cases needed to be treated in a given period to be considered a high-volume centre, it is clear that the very small number of pancreatic resections done within many Australian centres makes it harder for them to achieve optimal outcomes. Centres that do not have sufficient caseloads should establish processes to routinely refer surgical cases to high-volume centres.¹

Recommended treatment options differ depending on the stage at diagnosis, and the performance status of the patient. Those with localised disease are offered surgery followed by adjuvant chemotherapy. Those with borderline resectable or locally advanced disease undergo neoadjuvant chemotherapy first and then may proceed to surgery, while those with unresectable or metastatic disease undergo chemotherapy alone. Patients with poor performance status are provided with the best supportive care.²³

Localised, borderline, locally advanced disease

Forty five percent of patients in the UGICR were diagnosed with non-metastatic disease. Of those patients, 29% received neoadjuvant chemotherapy, 78% underwent surgery, and 46% received adjuvant chemotherapy.

Metastatic disease

The remaining 55% of patients were diagnosed with metastatic disease. Of those patients 3% received neoadjuvant chemotherapy, 2% underwent surgery, 1% received adjuvant chemotherapy, 47% received chemotherapy, and 11% received radiation therapy

Specialist review

While the majority (92%) of patients in the UGICR were reviewed by a medical or radiation oncologist, only two thirds of patients aged 85 years of age or over were seen by a medical or radiation oncologist.

Of the patients reviewed by an oncologist, 65% went on to have treatment, and of those treated, less than two thirds received treatment within the pancreatic cancer OCP recommended timeframe of four weeks of initial diagnosis.

Opportunities

Strengthen clinical guidance to reduce unwarranted variations and support optimal care

Enhance utilisation of stereotactic radiation therapy

Improve access to neoadjuvant therapy

Improve equity of access to high-volume centres

Therapy

Treatment rates were lower in those with unresectable disease (locally advanced or metastatic disease) compared with those with resectable or borderline resectable disease (53% vs. 93%).

For those with unresectable disease, treatment was received less commonly. Where treatment was given, chemotherapy was the most common form of therapy, however, it was rarely provided to those aged 85 years or over. Around 90% of patients with locally advanced disease did not receive chemotherapy due to comorbidities, performance status, or patient choice.

Less than one-third of all patients underwent surgical resection and of those with resectable tumours, the majority (90%) of patients underwent pancreaticoduodenal resection (Whipple procedure).

Adjuvant therapy was administered in 55% of people with resectable disease and 31% of those with borderline resectable disease. Adjuvant chemotherapy was used in 70% of patients but only 0.5% of patients aged 85 years or over. One third of patients with resectable and borderline resectable disease did not receive chemotherapy due to poor performance status.

Neoadjuvant chemotherapy was rarely used in those with resectable cancers (22%) but was more common (79%) in those with borderline resectable disease.

Radiotherapy use in the context of surgical resection was uncommon (<15%).

Two-thirds (66%) of patients in the UGICR received treatment within 30 days of presentation at an MDM, but almost 14% of patients waited 60 days or more.

Overall, 50% of a sample of Aboriginal and Torres Strait Island people diagnosed between 2001 and 2020 received some form of cancer treatment. Of these 15% received surgery, 43% received chemotherapy and 10% radiotherapy. Being seen by an MDT, being of a younger age, and having diabetes were associated with receiving treatment. Significantly more patients received treatment after the introduction of the pancreatic cancer OCP in 2015 than before (57% compared with 43% respectively) and receipt of treatment was associated with a 12-month survival advantage.

Guidelines

While extensive guidance exists for the treatment of pancreatic cancer, opportunities exist to ensure that all pancreatic treatment is provided in accordance with recommended evidence-based Australian guidelines and protocols. Where there are gaps in available local guidelines, existing international guidelines should be adapted for the Australian context.

There are opportunities to improve surgical outcomes through the implementation of protocolised pre- and post-operative pancreatic cancer care and further opportunities to improve patient outcomes by ensuring that all pancreatic cancer chemotherapy and chemoradiation therapy reflects the best evidence-based care. Increasing uptake of chemotherapy in both the neoadjuvant and adjuvant setting could be achieved by better education of clinicians on the benefits of treatment in the surgical setting.

Stakeholder input

Stakeholders identified a range of treatment issues in pancreatic cancer including the lack of effective treatments and the burden of existing treatments.

A large variability in care delivered to and received by Aboriginal and Torres Strait Islander people with pancreatic cancer was raised. This care variability was associated with rurality and having to travel for investigations, treatment and follow-up.

The proximity of available treatment, the availability of specialists in regional sites, and travel burden, in particular for Aboriginal and Torres Strait Islander patients and their families were identified as barriers to treatment by a range of stakeholders.

Suggested opportunities for improvements in treatment included utilisation of stereotactic radiation therapy, chemotherapy delivered closer to home, centralisation of surgical services in accredited high-volume centres of excellence, networks of excellence, and broadening the concept of centralisation beyond centres of high-volume surgical expertise to multidisciplinary centres combining diagnostic, treatment, supportive care and research expertise. Increasing availability of specialists in regional areas, chemotherapy delivered in the home, and the use of telehealth were opportunities identified to improve access to treatment.

Information for patients and families about available treatments, potential side effects and likelihood of success, together with clear communication from health professionals on all treatment options, was also highlighted. In addition, recognition and respect for the individual and family identity, and consideration of personal circumstances in scheduling appointments, treatment and follow up was raised by Aboriginal and Torres Strait Islander stakeholders.

Guidelines and referral pathways for health professionals were identified as important enablers for improving the quality and consistency of pancreatic cancer care.

Guidelines on surgical volume and development of optimal care guidance for surgical interventions, as well as the importance of access and equity of access to high volume centres was highlighted.

Stakeholders noted that awareness of the OCPs was limited at the service level and supported improving awareness and uptake of the pancreatic cancer OCP and the *Optimal Cancer Pathway for Aboriginal and Torres Strait Islander people with cancer*.



THE WAY FORWARD

IMPROVE EQUITY OF ACCESS TO HIGH-VOLUME, SPECIALIST PANCREATIC CANCER TREATMENT CENTRES

Establish a working definition of 'high-volume centre'.

Create a registry of treatment centres that are high-volume/ specialised in pancreatic cancer treatment.

Develop national standards of clinical capability for high-volume, specialist centres.

Develop and implement a nationally agreed minimum dataset and framework for data collection, collation and reporting of clinical quality indicators.

Identify existing technologies to leverage access to high-volume specialist centres.

Design and implement hybrid models of treatment/ care delivery linking high-volume, specialist pancreatic cancer treatment centres and regional cancer services.

STRENGTHEN CLINICAL GUIDANCE TO REDUCE UNWARRANTED VARIATIONS IN TREATMENTS FOR PEOPLE WITH PANCREATIC CANCER

Identify unwarranted variations and gaps in clinical practice.

Develop, test and implement strategies to address variations.

Identify gaps in clinical guidance.

Develop/ adapt and implement strengthened clinical guidance. Promote awareness of existing best-practice guidance.

IMPROVE ACCESS TO NEOADJUVANT THERAPY, INCLUDING THROUGH CLINICAL TRIALS, IN PANCREATIC CANCER

Promote awareness of the benefits of chemotherapy treatment options.

Design and implement standardised approaches for routine access to neoadjuvant therapy including through clinical trials and leveraging technology and innovation.

3.5 Care after initial treatment and recovery

Goal 5 - Define and improve follow-up care

Opportunities

Improve coordination between specialised pancreatic cancer treatment centres and primary care

Evidence summary

The pancreatic cancer OCP notes the importance of the transition from active treatment to post-treatment care. Depending on the stage of cancer, some people will need ongoing, hospital-based care, and in other cases a shared follow-up care arrangement with their GP may be appropriate.¹

However, there is currently no established protocol for post-operative surveillance, although for patients at high-risk of a new pancreatic cancer, three to six-monthly tumour markers and radiological imaging is recommended.¹

Opportunities exist to improve long-term follow-up and supportive care for people after pancreatic surgery with a specific focus on diabetes management, diabetes-related morbidity and gastrointestinal effects, as well as addressing supportive and palliative care needs.²⁴⁻²⁷

There are also opportunities to extend telehealth as part of highly sub-specialised care to ensure the timely follow-up, assessment and provision of information to patients, including those living in rural and remote Australia.²⁸

The proportion of patients receiving shared care or coordinated care, the details of communication with the patient and their family, and whether patient preferences are included in their care plan are not readily available in current national population data sets.

Stakeholder input

Aboriginal and Torres Strait Islander stakeholders raised the lack of coordination between cancer treatment centres and primary care, and opportunities for continued engagement between local and specialist medical teams and provision of ongoing care. Continuity of care and care coordination, incorporating financial and psychosocial support, and cancer survivors becoming advocates to normalise discussions about cancer, reducing its stigma and increasing awareness of available cancer services, were also raised as enablers of supporting care after initial treatment and recovery.



THE WAY FORWARD

IMPROVE COORDINATION BETWEEN SPECIALISED PANCREATIC CANCER TREATMENT CENTRES AND PRIMARY CARE IN MANAGING PATIENTS WITH PANCREATIC CANCER

Identify barriers and enablers to coordination of shared-care between specialists and primary care.

Identify existing electronic tools to support information sharing.

Develop, test and implement strategies for coordination of shared-care in alignment with the Primary Health Care 10 Year Plan.

3.6 Managing recurrent, residual or metastatic disease

Goal 6 - Improve management of recurrent, residual or metastatic disease

Evidence summary

People with pancreatic cancer who present with recurrent, residual or metastatic disease should be managed by an MDT and offered timely referral to appropriate physical, practical and emotional support.

An analysis of the UGICR found that over half of all people with pancreatic cancer were diagnosed with metastatic disease. Only 41% of these people were presented to an MDM and very few received treatment.

Palliative care input is associated with better supportive care and quality of life in people with advanced cancer including pancreatic cancer.²⁹ Early integration of specialist palliative care is acceptable, feasible, and results in better quality of life for people with pancreatic cancer.^{30, 31} Early integration of palliative care needs to focus on the specific needs of patients and their carers, and opportunities exist to use validated needs assessment tools to identify unmet palliative care needs³² and provide concurrent cancer care and palliative care close to a person's place of residence.^{33, 34}

Data from the UGICR identified that 94% of people with metastatic disease were referred to palliative care. Those that were referred to palliative care were younger, of higher socioeconomic status, and were more likely from regional or remote areas. Current UGICR registry data were unable to identify the proportion of patients with metastatic disease being palliated, the therapies received for recurrent or residual disease, or the timing of referral for palliative care.

Inclusion of palliative care physicians and supportive care staff in MDTs/MDMs, and improving referral pathways to these services, have also been identified as important aspects of pancreatic cancer care.

Stakeholder input

Remoteness and limited access to oncology specialists were raised by Indigenous stakeholders noting that access to treatment for managing recurrent, residual or metastatic disease may be governed by availability, not best-practice care.

The need for palliative care specialists to be part of the multidisciplinary pancreatic care team was also raised by stakeholders.

Stakeholders highlighted the importance of timely discussion of goals of care with patients across the care continuum, and early referral to palliative care, noting the variation in availability and timing of palliative

Opportunities

Strengthen early referral to palliative care and initiation of conversations about preferred goals of care

Increase access and referral to MDMs with palliative care representation

Support active treatment with integrated models of specialist palliative care and supportive care

Strengthen models of palliative care including rapid access

Strengthen culturally appropriate models of palliative care

care, gaps in available palliative care workforce, and the need to strengthen the involvement of palliative care trained nurses and GPs in the provision of palliative care, particularly in rural areas.

Early involvement of palliative care concurrent with active treatment was also supported by stakeholders, along with the provision of culturally appropriate palliative care delivered as close to home as possible, and consideration of unique end-of-life needs for Aboriginal and Torres Strait Islander people and other priority population groups.

The development of palliative care options that are able to accommodate the cultural, linguistic, and spiritual requirements of CALD communities and individuals was raised by stakeholders.

A limited understanding among Indigenous communities and health professionals about the role of palliative care was highlighted. Opportunities to enhance understanding by Aboriginal and Torres Strait Islander people of the benefits of palliative care, and the engagement and education of CALD communities about the value of palliative care beyond its application at the very end-of-life were raised.

The importance of patient management and place of care whilst awaiting palliative care was also raised along with the importance of provision of information to patients and families to help plan for what to expect at end-of-life. Dedicated palliative care spaces for Aboriginal and Torres Strait Islander people in mainstream hospital and cancer care settings, and the importance of palliative care being extended beyond a patient's death, to provide support for grieving Aboriginal and Torres Strait Islander families and carers was also highlighted.

The need to develop better support frameworks for palliative and end-of-life care and integration of palliative care services as a standard part of the care pathway was raised, with stakeholders supporting the development of an agreed national palliative care pathway for pancreatic cancer. The national pathway should outline and drive strategies to facilitate processes and outcomes that are critical for pancreatic cancer.



THE WAY FORWARD

STRENGTHEN EARLY REFERRAL TO PALLIATIVE CARE FOR PEOPLE WITH ADVANCED PANCREATIC CANCER

Identify current status and gaps in access to palliative care.

Design/ adapt and implement standardised supportive care pathway incorporating rapid access to palliative care in alignment with the National Palliative Care Strategy.

Develop accessible information for patients, carers, families and communities on local support services.

INCREASE ACCESS AND TIMELY REFERRAL TO SPECIALIST MULTIDISCIPLINARY MEETINGS WITH PALLIATIVE CARE REPRESENTATION FOR PEOPLE WITH METASTATIC PANCREATIC CANCER

Promotion and communication of OCP through existing channels.

Develop directories of specialists linked to a multidisciplinary team with palliative care representation.

Increase access to multidisciplinary meetings with palliative care representation.

Implement reporting of clinical quality indicators to measure and support access to specialist multidisciplinary meetings for people with metastatic pancreatic cancer.

IMPROVE EQUITY OF ACCESS TO COMMUNITY-BASED PALLIATIVE CARE SERVICES FOR PEOPLE WITH PANCREATIC CANCER

Identify current status and gaps in access to community-based palliative care support and services.

Develop and implement a culturally appropriate consumer accessible guide(s) on community-based palliative care.

PROVIDE SYSTEMS AND SERVICES THAT SUPPORT RAPID ACCESS TO PALLIATIVE CARE WHEN NEEDED FOR PEOPLE WITH PANCREATIC CANCER

Identify current status and gaps in access to palliative care support.

Design/ adapt and implement standardised care pathways incorporating rapid access to palliative care in alignment with the National Palliative Care Strategy.

3.7 End-of-life care

Goal 7 - Enhance end-of-life care

Opportunities

Improve access to pain management

Strengthen knowledge and awareness of end-of-life for patients and families

Evidence summary

The primary aim of end-of-life care is to maintain the patient's quality of life, addressing health and supportive care needs, as well as the needs of their family.¹ If the treatment team does not include a palliative care member, the lead clinician should consider referring the patient to palliative care services, with GP engagement.¹ Patients may require additional support for home and community-based care, including community nursing and specialist palliative care workers.

However, life-prolonging medical treatments can dominate over supportive care near the end-of-life^{35, 36} and potentially inappropriate end-of-life care can have a negative impact on a patient's quality of care at the end-of-life.^{37, 38}

Most patients with cancer prefer to remain at home as much as possible towards the end-of-life, and a high level of hospital care in the last months of life may, therefore, not be associated with improved quality of life.³⁹⁻⁴⁴

An analysis of the UGICR indicated that over one-quarter of individuals with pancreatic cancer had spent more than 14 days in an acute hospital in the 30 days prior to their death, and around 10% had presented two or more times to an emergency department in the 30 days prior to their death. In addition, of those that died of pancreatic cancer 20% had died within 30 days of chemotherapy and 4% died within 30 days of surgery.

People with pancreatic cancer experience a significant symptom burden. While 53 guidelines for the treatment and care of people with pancreatic cancer were identified through evidence gathering activities, a notable gap is the lack of pancreatic cancer-specific end-of-life care guidelines. The development of comprehensive multidisciplinary guidelines specifically focused on a range of symptoms associated with the disease and end-of-life care, can enhance support and care for people diagnosed with pancreatic cancer.

Stakeholder input

Given that end-of-life is steeped in cultural protocol and religious observance, a high degree of cultural sensitivity is required to manage end-of-life care. The unique end-of-life needs for Aboriginal and Torres Strait Islander people and other priority population groups were raised.

A lack of appropriate time and space to allow Aboriginal and Torres Strait Islander families and communities to conduct cultural practices, including ceremony leading up to and at the time of death, a balance between male and female Aboriginal and Torres Strait Islander palliative care workers, and limited resources (staff, equipment, medications) to facilitate comfortable dying on country were highlighted.

Improved access to supportive and palliative care, and resources to help palliative care professionals understand the priorities and contexts of Aboriginal and Torres Strait Islander people were noted, together with the need to increase funding for repatriation to country at end-of-life.

While stakeholders highlighted a range of symptoms that are challenging for patients to manage, including the debilitating side effects of chemotherapy and surgery, the most common symptom referenced was pain. Stakeholders raised the importance of health professional training and education in pain management protocols and ensuring all pancreatic cancer patients have access to expert, effective, pancreatic cancer-specific pain management advice and support.

The importance of provision of information to patients and families to help plan for what to expect at end-of-life and the need to develop better support frameworks for palliative and end-of-life care were highlighted.

Stakeholders supported an increased role for primary care in planning for and delivering end-of-life care, in collaboration with community-based support and inpatient palliative care expertise, noting however, that establishing appropriate care plans and making end-of-life considerations was made more challenging due to the poor health literacy and language barriers experienced by some CALD patients.



THE WAY FORWARD

IMPROVE EQUITY OF ACCESS TO SPECIALIST EXPERTISE IN PAIN MANAGEMENT FOR PEOPLE WITH PANCREATIC CANCER

Identify current status and gaps in access to pain management.

Design/ adapt and implement standardised supportive care pathway incorporating rapid access models to pain management expertise.

Promote awareness of interventional pain management procedures.

Develop and implement educational modules on interventional pain management.

3.8 Supportive care

Goal 8 - Improve access to supportive care

Evidence summary

Throughout the patient journey, patients with pancreatic cancer will require supportive care for their physical, psychological, social, information and spiritual needs.

Access to timely and evidence-based supportive care is critical, and regular and comprehensive assessment of patient and carers' needs is required so that tailored supportive care interventions are implemented to improve care experiences.

Supportive care interventions such as care coordination, counselling, exercise programs, and nutritional support have shown improvements in levels of disease-related symptoms, overall physical function and mental health in people living with pancreatic cancer.^{45, 46}

However, around 96% of Australians with pancreatic cancer have unmet needs, including unmet physical (54%) and/or psychological needs (52%), information (32%), care (21%) and/or sexuality (16%) needs.^{47, 48} In addition, over 70% of people reported one or more moderate-to-high-level needs, and needs were highest in the physical/daily living and psychological domains.⁴⁷ Carers also describe feelings of lacking knowledge and competence to support their family member post pancreatic cancer surgery.⁴⁹

Assessing a patient's performance status is an indicator that a person may require supportive care or is not fit for definitive anti-cancer therapy. At least one-third of patients on the UGICR had no documented measure of performance status recorded.

There is limited national information on type of supportive care provided for people with pancreatic cancer. However, prioritising assessment and support for carers from point of diagnosis, embedding home-based exercise programs, providing equity of access to interventional procedures for pain management, routine screening for depression and anxiety using validated tools triggering a comprehensive assessment and referral as required, and improving access to nutritional support could assist to improve supportive care for people affected by pancreatic cancer.

While there is limited evidence of the effectiveness of designated cancer care coordinators, data from a large Australian cohort study indicates that people living with pancreatic cancer want to know who is coordinating their care and want to receive care from health professionals who provide medical and psychosocial support.⁴⁵

Opportunities

Enable routine screening for supportive care needs, with referral to support services, as needed

Improve access to supportive care

Improve access to psychosocial support and symptom management

Strengthen access to information for patients and carers

Provide culturally appropriate supportive care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds

Improve patient navigation and care coordination from point of diagnosis

Stakeholder input

The fear, anxiety and distress associated with a diagnosis of pancreatic cancer along with the sense of hopelessness experienced by patients, their families and their carers, and the impact of symptoms and side effects were highlighted by stakeholders.

Stakeholders raised the importance of assessing supportive care needs for patients and carers from the point of diagnosis and throughout the care continuum with referral to appropriate health professionals and organisations based on their needs.

Regular assessment of a patient's unmet needs using a validated supportive care needs assessment tool for Aboriginal and Torres Strait Islander people together with raising awareness of culturally appropriate tools to assess supportive care needs were highlighted.

Aboriginal and Torres Strait Islander stakeholders raised the lack of awareness of supportive care services and the importance of initiating culturally safe supportive care across the continuum of care from the point of diagnosis together with the importance of carers having an equal focus in relation to supportive care needs.

Stakeholders supported strengthened access to allied health support, improving the availability and access to specialist and allied health services during treatment including dietetics, and strengthening the role of the GP in symptom management.

Information and communication

Stakeholder input

Stakeholders identified that access to support and information is critical and should be proactively and comprehensively provided to patients, carers and families.

The development and provision to patients and families of clear and transparent information on all aspects of diagnosis and care, including treatment options and side effects was highlighted, together with assessment of patient and carer information needs throughout the pancreatic cancer journey, and increasing the availability and access to support networks and forums to assist in addressing information needs.

The opportunity to map the availability of digital resources for patients and carers was raised together with support for strengthening the skills of health professionals in provision of open, sensitive and hopeful communication.

The gap in information availability to CALD communities, the resultant lack of knowledge about pancreatic cancer, and the subsequent effect on communication and engagement with consumers, their families and carers to support full participation in complex decision-making and selection of care pathways was raised. Providing information and education to CALD communities and individuals can support understanding and awareness of pancreatic cancer and provide important community knowledge. This information needs to be provided with a high degree of sensitivity and any health literacy communications need to be developed with the involvement of CALD communities and relevant health professionals.

Resources developed in multilingual formats were identified as important to build the level of knowledge and understanding of pancreatic cancer, and the availability of community infrastructure such as in-language media that could be used to deliver information about pancreatic cancer in a format and

a language that would be preferred by CALD consumers and their families was highlighted. However, when developing information and education resources, consideration should be given to developing resources in the languages of long-term migrant communities who are currently overrepresented in the 65+ age cohort.

Challenges faced by CALD Australians when engaging with the health system include language and communication. Stakeholders raised the importance of developing communication skills to interact with patients with limited English proficiency and the need for language support guidance for health professionals including the importance of using plain or simple English, avoiding complex medical terminology, and engaging with interpreters to ensure understanding of the message.

The development or referral to resources to support cultural competence of health professionals, provision of guidance for health professionals in how to work with interpreters, and development of a resource for interpreters explaining key concepts and terminology related to pancreatic cancer were highlighted.

Appropriate information resources and supportive care for Aboriginal and Torres Strait Islander patients, family members and carers were identified as a notable gap together with issues of poor communication in relation to diagnosis, prognosis, treatment and supportive care options, the language and style of interpersonal communications or written materials, and the wide variety in standards of information and communication. Novel and culturally safe ways to describe diagnosis and treatment options were raised by Aboriginal and Torres Strait Islander stakeholders as well as system supports to address communication barriers including, the availability of highly skilled Aboriginal liaison officers and social workers, supportive care services provided through ACCHOs, and health care systems and health professionals that provide culturally-responsive and person-centred care.

Increased use of communication technologies and telemedicine to facilitate planning and treatment closer to home together with improved supportive services that make it less onerous for patients who have to travel away from home were also supported by Aboriginal and Torres Strait Islander stakeholders.

Care coordination

Stakeholder input

Stakeholders highlighted the challenge for patients, families and carers of navigating through the process of diagnosis, treatment and care and the role and importance of care coordinators/ coordination/ patient navigation for all patients from the point of diagnosis. The critical importance of care coordination for those with late-stage disease and those in regional and remote areas was specifically highlighted.

Care coordination across stages of the pancreatic cancer OCP and across service providers was identified as key to improving outcomes for Aboriginal and Torres Strait Islander people with pancreatic cancer. Poor coordination of information about supportive care services was raised, and greater collaboration and coordination of care between cancer care services and ACCHOs or other Aboriginal and Torres Strait Islander community services was raised as helping patients navigate their care journey and supporting patients' needs.



THE WAY FORWARD

IMPROVE EQUITY OF ACCESS TO COORDINATED SUPPORTIVE CARE FOR PEOPLE WITH PANCREATIC CANCER

Identify current status and gaps in access to coordinated supportive care.

Design/ adapt and implement a standardised supportive care pathway, incorporating rapid access models.

Strengthen linkages between primary health professionals and specialist multidisciplinary teams to support provision of coordinated supportive care in alignment with the Primary Health Care 10 Year Plan.

Promote awareness of supportive care services.

Develop and implement educational modules on best-practice supportive care.

IMPROVE EQUITY OF ACCESS TO SPECIALIST SUPPORTIVE CARE FOR PANCREATIC CANCER, INCLUDING PSYCHOSOCIAL SUPPORT SERVICES AND NETWORKS

Identify current status and gaps in access to psychosocial support services.

Design or adapt a standardised supportive care pathway, incorporating rapid access models to psychosocial support.

Strengthen linkages between primary health professionals and specialist multidisciplinary teams in alignment with the Primary Health Care 10 Year Plan.

Promote awareness of supportive care services, including psychosocial services.

Develop and implement educational modules on best-practice supportive care including psychosocial support.

IMPROVE PATIENT NAVIGATION AND CARE COORDINATION AT POINT OF DIAGNOSIS FOR PATIENT SUPPORT

Design/ adapt and implement models of care coordination, including virtual care.

IMPROVE ACCESS TO SYMPTOM MANAGEMENT SUPPORT FOR PEOPLE WITH PANCREATIC CANCER

Identify current status and gaps in access to symptom management.

Design/ adapt and implement standardised pathway, incorporating rapid access models.

Design/ adapt, test and implement needs assessment tools.

3.9 Research and clinical trials

Goal 9 - Undertake collaborative research, and increase clinical trial participation

Research

Evidence summary

Research that spans the continuum of pancreatic cancer prevention, treatment, and care is essential to drive improvements in pancreatic cancer outcomes.

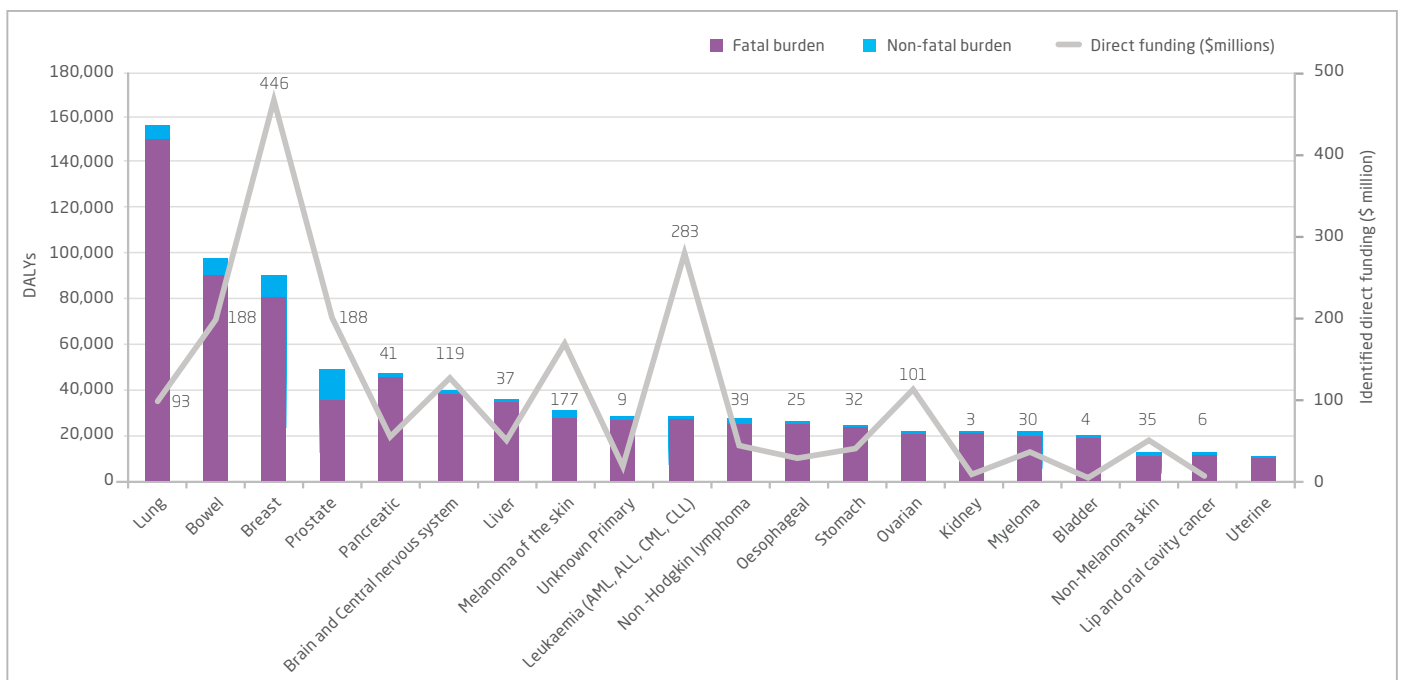
During the period 2003-2005 to 2018-2020 \$40 million was provided to 145 pancreatic cancer research projects and research programs in Australia. While this represented a 20-fold increase in funding and more than a 9-fold increase in the number of research projects over this timeframe, funding to pancreatic cancer research was proportionally low compared with its burden on the Australian population (Figure 3.1).

The Australian Government provided more than half (56%; \$22.3m) of all pancreatic cancer research funding and 90% of pancreatic cancer research projects were funded by a single funding source.

Opportunities

- Increase national and international collaborative multidisciplinary research
- Undertake research across the continuum of care
- Strengthen the evidence base regarding early detection of pancreatic cancer, personalised and tailored drug treatments, and repurposing of existing therapies
- Improve access to biospecimens
- Improve access to surgical clinical trials and clinical trials including for people with metastatic disease

FIGURE 3.1 DIRECT FUNDING TO SPECIFIC TUMOUR SITES 2003-2020 VERSUS BURDEN OF DISEASE DISABILITY-ADJUSTED LIFE YEARS (DALYs)⁵⁰



In the period 2003-2020, no research investment was identified in the areas of presentation, initial investigations and referral, care after initial treatment and recovery, managing recurrent, residual, or metastatic disease, or end-of-life care (Figure 3.2). While there were proportional changes in funding, the total amount of funding for pancreatic cancer research in Australia increased in the areas of prevention and early detection, diagnosis, staging and treatment planning, and treatment.

More than half (53%; 81) of all research projects involved one or more named co-investigators, but only 9% of research projects had a named international co-investigator.

FIGURE 3.2 THE PATTERN AND PROPORTIONAL RESEARCH FUNDING AT EACH STEP OF THE OPTIMAL CARE PATHWAY, 2003 TO 2020



	Total Funding	1 Prevention and early detection	2 Presentation, initial investigations and referral	3 Diagnosis staging and treatment planning	4 Treatment	5 Care after initial treatment and recovery	6 Managing recurrent, residual or metastatic disease	7 End-of-life care
Triennium	\$M	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7
2003-2005	0.8	46%	0%	0%	54%	0%	0%	0%
2006-2008	1.9	66%	0%	0%	34%	0%	0%	0%
2009-2011	5.3	55%	0%	0%	45%	0%	0%	0%
2012-2014	5.8	50%	0%	23%	27%	0%	0%	0%
2015-2017	9.8	34%	0%	19%	47%	0%	0%	0%
2018-2020	17.0	24%	0%	14%	63%	0%	0%	0%

Stakeholder input

Stakeholders highlighted the need for increased, focused and continued funding for pancreatic research and clinical trials and the importance of having a balanced portfolio of research funding across the continuum. The collaboration of funders and exploring international funding opportunities were strongly supported.

To realise significant improvements in survival, stakeholders highlighted the importance of research to understand disease aetiology, to identify better methods for early detection and treatment, and to understand mechanisms of treatment response, resistance and disease recurrence. Survivorship and palliative care research together with research into the needs of families, carers and priority population groups was highlighted. Health-services research and translational/implementation science to optimise survival and quality-of-life outcomes were also raised.

The importance of a research focus on understanding the link between pancreatic cancer and diabetes, screening, early detection, and surveillance, the prevalence of recurrent, residual and metastatic disease and its management were also raised by Aboriginal and Torres Strait Islander stakeholders. The inclusion and participation of people from culturally, ethnically and linguistically diverse backgrounds in primary health care research, and sharing specific stories and experiences of Aboriginal and Torres Strait Islander people with pancreatic cancer were highlighted.

Increased public awareness of the importance of tissue banking and biopsies for research, funding for tissue sampling, expansion of available infrastructure, and mechanisms to support access and use of technologies such as biobanks, organoids and patient-derived xenografts were raised by stakeholders.

Pancreatic stakeholders noted that existing national and international networks can be leveraged and built upon to address critical questions and areas of unmet need in pancreatic cancer, and a strengthened coordination of the research effort, including collaboration across research groups, government, industry and philanthropic sectors, was strongly supported. Facilitating national forums with scientific and clinical researchers to share progress and accelerate idea generation was also raised.

A key priority for pancreatic stakeholders is the targeted and sustained funding for a strategic national program of pancreatic cancer research that fosters a collaborative program of preclinical and clinical research to drive improvements in outcomes, facilitates meaningful consumer engagement to ensure that research is responsive to the needs of patients and carers, incorporates industry engagement, leverages technology, and requires and rewards national and international collaboration.

The evidence gathering and stakeholder engagement activities surfaced a substantial number of research opportunities across all stages of the continuum of care. The significant emphasis on research underscores the paucity of existing evidence and critical need for research to drive improvements in pancreatic cancer outcomes. The key areas of research focus across the continuum of care are summarised in Table 3.1. and for each area a number of specific research opportunities were raised.

TABLE 3.1 KEY PANCREATIC RESEARCH OPPORTUNITIES ACROSS THE CONTINUUM OF CARE

Phase of care continuum	Recommended areas of research focus
Prevention and early detection	<ul style="list-style-type: none"> - Aetiology - Risk factors and behavioural interventions - Epidemiology - Early detection - Identification and surveillance of high-risk populations
Presentation, initial investigations and referral	<ul style="list-style-type: none"> - Health service research to expedite time between the onset of symptoms and the final diagnosis - Symptom cluster assessment
Diagnosis, staging and treatment planning	<ul style="list-style-type: none"> - Classification of staging in borderline resectable disease - Detection of distant metastasis
Treatment	<ul style="list-style-type: none"> - Quantify high-volume centres/ clinician procedures/ impact on resourcing, outcomes, and cost in Australian context - Treatment sequencing - Improved patient selection for, and role of neoadjuvant treatment - Role of radiotherapy in neoadjuvant treatment - New radiation techniques - Adoption of new systemic regimens - Optimal dose and de-escalation regimens - Role of immunotherapies and targeted therapies - Personalised treatment - Novel therapeutic strategies - Response and treatment resistance - Optimal management of advanced/ metastatic disease - Clinical trial access and participation
Care after initial treatment and recovery	<ul style="list-style-type: none"> - Optimal models of care coordination, information and support - Optimal frequency of imaging and follow up
Managing recurrent, residual or metastatic disease	<ul style="list-style-type: none"> - Optimal models of integrated palliative care
Supportive care	<ul style="list-style-type: none"> - Management of treatment-related side effects - Physical, psychological, social, information supportive care needs of patients and carers - Needs assessment tools - Quality of life - Patient experience
Models of care	<ul style="list-style-type: none"> - Variations in outcomes in priority population groups - New models of care - Models of culturally safe care - Longitudinal research on models of care - Health professional's roles - Economic evaluation

Clinical trials

Evidence summary

Clinical trials benefit the community by improving the survival of people affected by cancer and contribute to a reduction in premature death and disability. Clinical trials help generate evidence for best-practice cancer care and are fundamental to establishing whether new cancer treatments, diagnostic tests or preventive interventions are effective.

The pancreatic cancer OCP recommends that all patients be given the opportunity to participate in relevant clinical trials where available. Data from the UGICR indicates only 8% of patients with pancreatic cancer participated in a clinical trial and less than 1% of patients aged over 85 were involved in a clinical trial. A higher proportion of patients participated in a clinical trial if they had been presented to an MDM (11% vs. 4% not presented). Those who did participate in clinical trials tended to be younger, from higher socioeconomic advantage, born in Australia, located in major cities and had non-metastatic disease.

Between 2012 and 2020 in Australia, 148 pancreatic clinical trials were identified, 60 of which focused exclusively on pancreatic cancer. Of these, 31 were investigator-driven and 29 were industry-driven trials.

The majority of investigator-initiated trials were intervention trials, phase 2, conducted in a single, Australian investigational site. These trials focused on diagnosis, staging and treatment planning, and first-line chemotherapy and/or radiotherapy-related interventions. The trials were inclusive of participants with all stages of pancreatic cancer and the main outcomes of interest were survival, intervention feasibility and tumour progression.

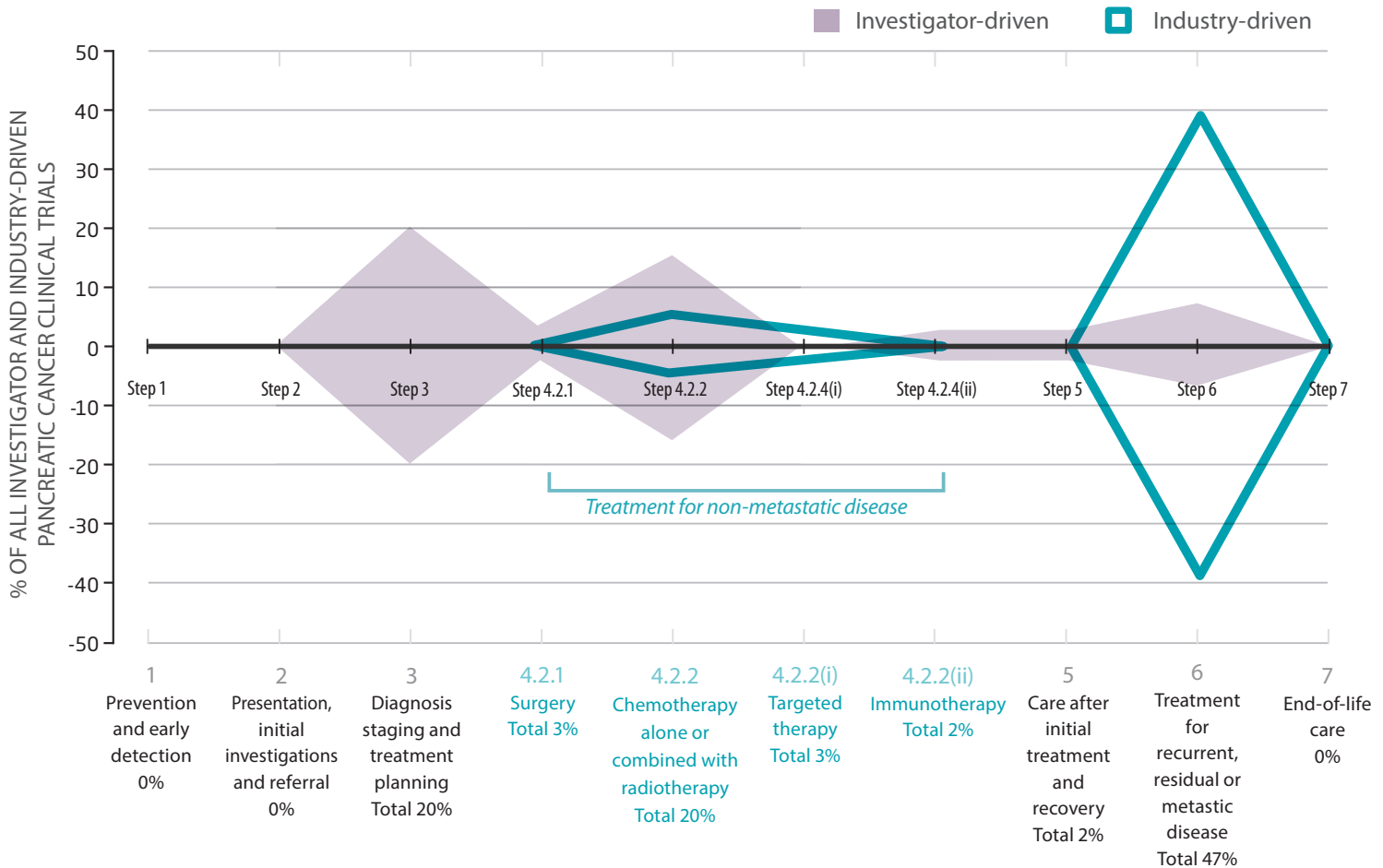
In contrast the majority of industry-driven trials while also intervention trials, were phase 3, conducted both in Australia and internationally. These trials focused on treatment for recurrent, residual or metastatic disease and principally included patients with metastatic disease. The main outcomes of interest were survival and adverse effects.

A larger proportion of industry trials compared with investigator-initiated (79% vs. 6%) recruited participants from across multiple Australian states, however, the majority of pancreatic cancer trials were conducted in metropolitan Australia alone. Only a small proportion of investigator-initiated and industry trials, 6% vs. 38% respectively, recruited participants from regional areas.

Investigator-driven clinical trials predominantly focused on interventions in the earlier steps of the optimal care pathway while industry-driven trials had a greater focus on the treatment of recurrent, residual or metastatic disease (Figure 3.3).

The measurement of patient-reported outcomes, such as quality of life and symptom burden in the trials assessed was limited, and the active inclusion of priority populations such as Aboriginal and Torres Strait Islander people, CALD people and people living in lower socioeconomic areas was not specified in the registered inclusion criteria of the identified trials. Consequently, it is difficult to ascertain if the clinical trials included and represented the wider pancreatic cancer population across Australia.

FIGURE 3.3 INTERVENTION FOCUS OF INVESTIGATOR AND INDUSTRY-DRIVEN TRIALS, FOCUSED EXCLUSIVELY IN PANCREATIC CANCER (60 TRIALS), ALONG THE OPTIMAL CARE PATHWAY



Stakeholder feedback

Stakeholders raised the importance of increased awareness, promotion and participation in clinical trials, including active promotion, inclusion and participation of people from culturally, ethnically and linguistically diverse backgrounds in pancreatic cancer clinical trials. Barriers to Aboriginal and Torres Strait Islander participation in clinical trials included lack of awareness, understanding of clinical trial information, consent processes, location and number of visits, cultural safety and support.

Stakeholders supported equitable access to clinical trials, improved access to trials in rural and remote areas, and the use of technology and teletrials to improve geographic access.

The development of a standardised approach for streamlined recruitment into clinical trials, the education of health professionals about access to, and the benefits of, clinical trials for pancreatic cancer, national and international collaborative opportunities to conduct larger investigator-driven trials and facilitate higher participation rates, and the requirement for international collaboration and engagement with industry to ensure that Australians can access novel therapeutics and benefit from trial participation were also highlighted.



THE WAY FORWARD

STRENGTHEN THE EVIDENCE-BASE REGARDING EARLY DETECTION METHODS FOR PANCREATIC CANCER

Design a national pancreatic cancer research strategy.

Implement approaches within the strategy that encourage research in early detection of pancreatic cancer.

STRENGTHEN THE EVIDENCE-BASE REGARDING POTENTIAL PERSONALISED AND TAILORED DRUG TREATMENTS

Design and implement research and clinical trials in personalised and tailored drug treatments for pancreatic cancer.

IMPROVE ACCESS TO SURGICAL CLINICAL TRIALS IN PANCREATIC CANCER

Promote patient and clinician awareness of the benefits of participation in surgical clinical trials.

Identify barriers to patient participation in surgical trials.

Design and implement standardised approaches for routine access to treatment trials, leveraging technology and innovation.

INCREASE AUSTRALIA'S ENGAGEMENT IN COLLABORATIVE MULTIDISCIPLINARY RESEARCH BOTH NATIONALLY AND INTERNATIONALLY

Formation of a Pancreatic Cancer Network to strengthen collaboration across pancreatic cancer research groups and between academia/research, government, industry and philanthropic sectors.

Establishment of a national/ international peer reviewed program of research excellence in pancreatic cancer.

STRENGTHEN THE EVIDENCE-BASE REGARDING REPURPOSING OF EXISTING THERAPIES FOR MORE EFFECTIVE TREATMENTS IN PANCREATIC CANCER

Design and implement research and clinical trials in repurposing of existing therapies for pancreatic cancer.

IMPROVE THE USE OF BIOSPECIMENS FOR RESEARCH IN PANCREATIC CANCER

Design and establish a national pancreatic biospecimen registry.

IMPROVE ACCESS TO CLINICAL TRIALS IN PANCREATIC CANCER, INCLUDING FOR PEOPLE WITH METASTATIC DISEASE

Promote patient and clinician awareness of the benefits of participation in clinical trials.

Identify barriers to patient participation.

Design and implement standardised approaches for routine access to clinical trials, leveraging technology and innovation.

3.10 Data and reporting

Goal 10 - Strengthen and increase the use of data to improve pancreatic cancer outcomes

Evidence summary

The benefits of research will take time to be realised. In the meantime, outcomes for people with pancreatic cancer and their families can be improved through the enhanced collection, access, linkage, analysis and reporting of real-world data to understand causes of variation, and drive service delivery and care.

Future inclusion or linkage of data on modifiable risk factors and family history could assist to inform, drive and benchmark a range of prevention and early detection activities.

Health services research relevant to the Australian healthcare setting must be underpinned by access to robust data. Improving the collection and linkage of clinical data to biospecimen and administrative datasets, such as hospital admissions, MBS and Pharmaceutical Benefits Scheme (PBS), will facilitate research and care. Barriers and enablers to collection and linkage need to be addressed, and periodic and contemporary linkage is required to maximise data use and relevance.

In addition to the routine collection of clinical and administrative data, standardising reporting within clinical trials to support meta-analysis and attainment of higher levels of evidence to drive models of care and treatment provision is indicated.

Developing and implementing appropriate indicators to measure care across the pancreatic cancer OCP will drive national benchmarking to optimise care.

There are also opportunities to improve patient experience and pancreatic cancer outcomes by embedding routine patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) into clinical practice as part of local quality improvement processes. However, consumer input is required to better understand how to meaningfully embed experience measures into the healthcare system.

Stakeholder input

Pancreatic stakeholders supported the need for a comprehensive approach to the collection of real-world clinical and patient-reported outcome data to identify unwarranted variations in optimal care for pancreatic cancer. As such, the need for clear service level indicators to assess the provision of optimal care and access to clinical data that allows measurement of patterns and timeliness of care with respect to the OCPs was supported.

Embedding core elements of quality care into health service key performance indicators and funding agreements, the role of credentialing and accreditation to strengthen alignment with optimal care and importance of health services and clinician access to data for benchmarking were highlighted.

Opportunities

Improve access to, and linkage of, key data sets

Strengthen national data spanning the optimal care pathway

Standardise national clinical data collection

Enhance standardisation of reporting of information within clinical trials

Improve the collection of patient reported experience and outcome measures

Stakeholders supported the longitudinal collection, storage and use of pancreatic cancer biospecimens to understand drivers of treatment response and resistance over time, and a national data strategy, linking key datasets including MBS, PBS, hospital separations data, cancer registry, staging and biospecimens to enable long-term tracking of patient outcomes was also supported.

Better recording of stage at diagnosis and the benefits of building consistency around data definitions were specifically noted. Stakeholders also raised the importance of Aboriginal and Torres Strait Islander status to be recorded for all newly diagnosed patients with pancreatic cancer and the need for the inclusion of appropriate measures of CALD in data sets.



THE WAY FORWARD

STRENGTHEN NATIONAL DATA SPANNING THE OPTIMAL CARE PATHWAY TO ASSESS VARIATIONS IN BEST PRACTICE PANCREATIC CANCER CARE

Develop and implement a nationally agreed minimum dataset for reporting of clinical quality indicators.

Establish/ enhance a national clinical data registry spanning the optimal care pathway.

Design an approach to increase the scope of and access to existing clinical data.

IMPROVE THE COLLECTION OF PATIENT-REPORTED EXPERIENCE AND OUTCOME MEASURES IN ROUTINE PANCREATIC CANCER CARE

Identify existing approaches to collection of patient-reported experience and outcome measures (PREMs and PROMs).

Develop, test and implement nationally standardised PREMs and PROMs for inclusion in the agreed minimum dataset for reporting of clinical quality indicators.

3.11 Models of care

Goal 11 - Develop evidence-based, culturally competent models of care

Evidence summary

The pancreatic cancer OCP describes the standard of care that should be available to all patients with pancreatic cancer treated in Australia. The pathway supports patients and carers, health systems, health professionals and services, and encourages consistent optimal treatment and supportive care at each stage of a patient's journey.¹

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*⁵¹ was developed with the aim of reducing disparities and improving outcomes and experiences for Aboriginal and Torres Strait Islander people with cancer. This optimal care pathway is relevant to all cancers and complements the pancreatic cancer OCP.

The pancreatic cancer OCP was the only identified model of care for people with pancreatic cancer and their carers. There are no specific models of care for the various stages of a person's pancreatic cancer journey and only limited levels of evidence for various elements of care within each stage.

Having surgery in a high-volume pancreatic surgical centre undertaken by a trained surgeon who performs a minimum number of procedures has been associated with better short and long-term outcomes.^{52, 53}

There is low to moderate evidence that regional cancer networks improve pancreatic cancer outcomes. However, international studies have demonstrated that the integration of telehealth with specialist pancreatic care enhanced access and led to better integration of family and carers into pancreatic cancer clinical decision making.²⁸

Opportunities exist to test hybrid models of pancreatic care that include reciprocal arrangements between low-volume centres in regional areas and high-volume centres in metropolitan areas, to extend telehealth as part of highly sub-specialised care to ensure the timely follow-up, assessment and provision of information to patients, and to improve the patient experience by developing optimal models of care coordination, information and support.

The development and testing of new models of care are required to deliver the care experience in an appropriate, responsive and coordinated manner and drive improved quality of life and survival outcomes. The models of care should meet the needs of priority population groups and strengthen access to, and integrate provision of, culturally safe care for patients, their families and carers.

Opportunities

Strengthen evidence-based models of coordinated care

Strengthen culturally appropriate models of care

Improve the capacity and capability of the workforce in rural and remote areas

Stakeholder input

Models of care

Stakeholders noted that the best pancreatic cancer outcomes occur when an experienced team is involved in treatment and management, and treatment is usually undertaken at specialist services located in metropolitan areas.

Stakeholders highlighted issues of access to best-practice treatment and care, equity of outcomes of a range of population and patient groups, challenges in access to specialist treatment and care for rural patients, precedents in other cancer types to establish networked models of centres of excellence, and the importance of agile multidisciplinary models of culturally competent care.

Stakeholders also supported the development of new models of care and service delivery, including telehealth, virtual support services, and innovative models for delivery of supportive and palliative care. The need to define essential and desirable components of excellent pancreatic cancer care with a view to ensuring complex care is delivered safely in services with appropriate resources and expertise, while facilitating delivery of less complex components of treatment and care closer to home where it is safe to do so was also highlighted.

Stakeholders identified that models of care must be effective in public and private settings and be accessible regardless of location or sociodemographic of the population serviced. Greater collaboration between local Indigenous organisations and cancer care services to develop new models of culturally safe care, and provision of culturally appropriate support services were highlighted. The use of funding models and rebates to support and incentivise the delivery of optimal models of care was identified.

Culture influences beliefs, values and practices in relation to health and cancer care. CALD consumers were not seen as involved in decision-making to the level that is expected for both person-centred models of care and social models of service delivery. Stakeholders identified that CALD consumers should be offered patient-centred care models and be able to participate in discussions about their care. The need for a cultural framework to provide culturally appropriate and person-centred care was raised and establishing an optimal care pathway for CALD people was highlighted.

The role of informal carers is enhanced in situations involving CALD consumers and their families and there is a strong perception that this role is neither identified nor supported. Collective decision-making often forms part of how families from CALD backgrounds deal with important decisions and support is often provided by community structures including religious organisations and other individuals. In addition, given the generally late diagnosis and rapid progression of pancreatic cancer, and potential linguistic and cultural issues faced by CALD consumers, there is a greater likelihood that substitute decision-makers need to be identified for CALD patients.

Capacity building for substitute decision-makers to support their role and offering a more community-oriented model of care, in which decision-making is facilitated for the CALD patient and their family, were seen as assisting to deliver more culturally relevant care and acceptable decision-making.

People, health, and connection to land, community and identity are intrinsically linked for Aboriginal and Torres Strait Islander people.⁵¹ The impact of pancreatic cancer and its treatment is greatly compounded for Aboriginal and Torres Strait Islander people as it dramatically ruptures connections between people, health, land, community and identity.

The importance of access to good quality care that is culturally, as well as medically, appropriate across the continuum of care was highlighted by Aboriginal and Torres Strait Islander stakeholders, together with the importance of patients and their families being informed of the treatment options and prognosis, so that they are empowered to make informed choices.

Workforce

A suitably trained and capable workforce is required to support new or enhanced delivery of high-quality models of culturally safe cancer care. Workforce considerations include the need for recruitment and retention of health professionals in rural areas, consideration of innovative models of outreach care, optimising cancer workforce capability across the care continuum, and the development of health professional cultural competence.

Low levels of cultural competence among health professionals were raised by stakeholders along with the need for a cultural framework to increase cultural responsiveness through training and human resources. Stakeholders raised the importance of culturally appropriate communication skills for health professionals. The education of the cancer care workforce in cultural communication skills was seen as an enabler to strengthen access to, and integrate provision of, culturally safe cancer care.

The ability to practice with a cultural lens was also seen to facilitate positive impacts on a CALD consumer's cancer journey and involving bicultural health professionals provides a conduit to achieving high levels of understanding, treatment compliance and advance care planning.

The role of bilingual/ bicultural health workers to provide linguistic skills as well as a cultural lens and insights, was seen to be invaluable in the care of CALD people. However, the availability of interpreters, interpreter experience in health settings, additional time and complexity of interpreted communications, and concerns over confidentiality were raised as barriers to providing culturally competent care.

Investing in the Aboriginal health workforce to ensure the provision of culturally safe and responsive care was also identified as a priority. Specifically, strengthening and expanding the Aboriginal and Torres Strait Islander workforce in cancer services, ACCHOs and other primary health care settings, and increasing the number of Aboriginal liaison officers, and patient navigators in communities or hospitals were identified.



THE WAY FORWARD

IMPROVE THE PROVISION OF CULTURALLY APPROPRIATE MODELS OF CARE FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE AND PEOPLE FROM CALD BACKGROUNDS AFFECTED BY PANCREATIC CANCER AND THEIR CARERS

Codesign/ adapt and implement models of culturally appropriate care.

Strengthen inclusion of cultural experts in multidisciplinary teams.

Promote awareness of *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*.

Develop and implement in-language resources for patients, carers, families and communities.

IMPROVE INTEGRATED CARE COORDINATION MODELS, INCLUDING TELEHEALTH, FOR PEOPLE FROM REGIONAL AND REMOTE AREAS TO MINIMISE DELAYED TREATMENT

Design/ adapt, test and implement models of care coordination including virtual care.

Develop and implement education modules on models of care coordination.

IMPROVE THE CAPACITY AND CAPABILITY OF THE WORKFORCE IN RURAL AND REMOTE AREAS TO SUPPORT PANCREATIC CANCER CARE

Develop and implement education modules on follow-up and supportive care.

Leverage technology to build virtual capacity of workforce.

Strengthen linkages between primary health professionals and specialist multidisciplinary teams in alignment with the *Primary Health Care 10 Year Plan* and the *National Aboriginal and Torres Strait Islander Health Plan*.

Implement recruitment and retention initiatives in alignment with the *National Medical Workforce Strategy*, *National Nursing Strategy*, *Nurse Practitioner 10 Year Plan*, and the *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework*.

IMPROVE EVIDENCE-BASED CARE COORDINATION MODELS FOR PEOPLE AFFECTED BY METASTATIC PANCREATIC CANCER, INCLUDING THOSE LIVING IN REGIONAL AND REMOTE AREAS

Design/ adapt, test and implement existing models of care coordination for metastatic disease.

Develop and implement education modules about models of care coordination for metastatic disease.

IMPROVE CAPACITY AND CAPABILITY OF PALLIATIVE CARE NURSES AND GPs IN THE PROVISION OF PANCREATIC CANCER CARE PARTICULARLY IN REGIONAL AREAS

Develop and implement education modules on best-practice care.

Promote awareness of existing tools and resources. Leverage technology to build virtual capacity of workforce.

Strengthen linkages between primary health professionals and specialist multidisciplinary teams in alignment with the *Primary Health Care 10 Year Plan* and the *National Aboriginal and Torres Strait Islander Health Plan*.

Implement recruitment and retention initiatives in alignment with the *National Medical Workforce Strategy*, *National Nursing Strategy*, *Nurse Practitioner 10 Year Plan*, and the *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework*.

4. THE NATIONAL PANCREATIC CANCER ROADMAP

The Roadmap covers 11 domains - the seven steps in the pancreatic cancer OCP plus four additional domains that cross the whole continuum of cancer care - supportive care, research and clinical trials, data and reporting, and models of care. The content of the Roadmap has been informed by evidence gathering and stakeholder engagement activities, with collective prioritisation of areas for action undertaken by pancreatic cancer stakeholders.

The Roadmap's destination is improved outcomes and survival for people affected by pancreatic cancer including reduced incidence, improved equity of access to treatment and care, improved patient and carer experiences, improved quality of life, increased participation in clinical trials, reduced mortality, and improved survival, all driven by world leading research and best-practice culturally appropriate care.

4.1 Key priority areas for action

The National Pancreatic Cancer Roadmap consists of 33 KPAs for collective action over the next five years to 2027 (Figure 4.1). These KPAs have been identified by stakeholders from a total of 73 priority areas drawn from the evidence gathering and stakeholder engagement activities (Appendix 1).

A total of 60 strategies and associated activities for implementation in the short (one to two years), medium (three to four years), and long-term (five years) have been identified to achieve the priority KPAs (Figure 4.2 and Appendix 2).

The KPAs and strategies apply to all high-risk population groups including Aboriginal and Torres Strait Islander people, people of CALD backgrounds, people from rural and remote areas, and people who live in lower socioeconomic status areas. Particular consideration will be given to the specific or unique needs of these population groups when implementing the Roadmap.

THE NATIONAL PANCREATIC CANCER ROADMAP

FIGURE 4.1 NATIONAL PANCREATIC CANCER ROADMAP - KEY PRIORITY AREAS FOR COLLECTIVE ACTION

THE WAY FORWARD

PREVENTION AND EARLY DETECTION



1. Improve identification of people at high risk of pancreatic cancer for targeted surveillance

PRESENTATION, INITIAL INVESTIGATIONS AND REFERRAL



2. Improve primary health professional recognition of signs and symptoms of pancreatic cancer
3. Improve general practitioner understanding of appropriate initial investigations if pancreatic cancer is suspected
4. Improve the timeliness of referral to an appropriate specialist if pancreatic cancer is suspected

DIAGNOSIS, STAGING AND TREATMENT PLANNING



5. Improve equity of access to appropriate diagnostic and staging modalities for pancreatic cancer
6. Improve access to specialist multidisciplinary meetings for treatment planning for people diagnosed with pancreatic cancer

TREATMENT



7. Improve equity of access to high-volume, specialist pancreatic cancer treatment centres
8. Strengthen clinical guidance to reduce unwarranted variations in treatments for people with pancreatic cancer
9. Improve access to neoadjuvant therapy, including through clinical trials, in pancreatic cancer

CARE AFTER INITIAL TREATMENT AND RECOVERY



10. Improve coordination between specialised pancreatic cancer treatment centres and primary care in managing patients with pancreatic cancer

MANAGING RECURRENT, RESIDUAL OR METASTATIC DISEASE



11. Strengthen early referral to palliative care for people with advanced pancreatic cancer
12. Increase access and timely referral to specialist multidisciplinary meetings with palliative care representation for people with metastatic pancreatic cancer
13. Improve equity of access to community-based palliative care services for people with pancreatic cancer
14. Provide systems and services that support rapid access to palliative care when needed for people with pancreatic cancer

END OF LIFE CARE



15. Improve equity of access to specialist expertise in pain management for people with pancreatic cancer

SUPPORTIVE CARE



16. Improve equity of access to coordinated supportive care for people with pancreatic cancer
17. Improve equity of access to specialist supportive care for pancreatic cancer, including psychosocial support services and networks
18. Improve patient navigation and care coordination at point of diagnosis for patient support
19. Improve access to symptom management support for people with pancreatic cancer

RESEARCH AND CLINICAL TRIALS



20. Strengthen the evidence-base regarding early detection methods for pancreatic cancer
21. Increase Australia's engagement in collaborative multidisciplinary research both nationally and internationally
22. Improve the use of biospecimens for research in pancreatic cancer
23. Strengthen the evidence-base regarding potential personalised and tailored drug treatments
24. Strengthen the evidence-base regarding repurposing of existing therapies for more effective treatments in pancreatic cancer
25. Improve access to clinical trials in pancreatic cancer, including for people with metastatic disease
26. Improve access to surgical clinical trials in pancreatic cancer

DATA AND REPORTING



27. Strengthen national data spanning the optimal care pathway to assess variations in best practice pancreatic cancer care
28. Improve the collection of patient-reported experience and outcome measures in routine pancreatic cancer care

MODELS OF CARE



29. Improve the provision of culturally appropriate models of care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds affected by pancreatic cancer and their carers
30. Improve integrated care coordination models, including telehealth, for people from regional and remote areas to minimise delayed treatment
31. Improve evidence-based care coordination models for people affected by metastatic pancreatic cancer, including those living in regional and remote areas
32. Improve the capacity and capability of the workforce in rural and remote areas to support pancreatic cancer care
33. Improve capacity and capability of palliative care nurses and GPs in the provision of pancreatic cancer care particularly in regional areas

THE NATIONAL PANCREATIC CANCER ROADMAP

FIGURE 4.2 KEY PRIORITY AREAS, STRATEGIES AND ASSOCIATED TIMEFRAMES

	SHORT	MEDIUM	LONG
KPA 1. Improve identification of people at high risk of pancreatic cancer for targeted surveillance			
Strategy 1. Integrate a pancreatic cancer risk assessment tool			
Strategy 2. Establish a pancreatic cancer targeted surveillance program			
KPA 2. Improve primary health professional recognition of signs and symptoms of pancreatic cancer			
Strategy 3. Promote primary health professional awareness of signs and symptoms of pancreatic cancer			
Strategy 4. Educate primary health professionals on the signs and symptoms of pancreatic cancer			
Strategy 5. Integrate a decision support tool for assessment of signs and symptoms of pancreatic cancer into primary care			
KPA 3. Improve general practitioner understanding of appropriate initial investigations if pancreatic cancer is suspected			
Strategy 6. Establish a standardised clinical pathway for initial investigations			
Strategy 7. Educate GPs on appropriate initial investigations			
KPA 4. Improve the timeliness of referral to an appropriate specialist if pancreatic cancer is suspected			
Strategy 8. Establish systems of rapid and seamless specialist referral			
KPA 5. Improve equity of access to appropriate diagnostic and staging modalities for pancreatic cancer			
Strategy 9. Establish referral pathways to appropriate diagnostic and staging investigations			
Strategy 10. Educate health professionals on appropriate diagnostic and staging investigations			
KPA 6. Improve access to specialist multidisciplinary meetings for treatment planning for people diagnosed with pancreatic cancer			
Strategy 11. Promote clinician awareness of OCP and importance of prompt referral to a multidisciplinary team			
Strategy 12. Establish directories of specialists in pancreatic cancer management linked to a multidisciplinary team			
Strategy 13. Establish reporting of clinical quality indicators to measure access to multidisciplinary meetings			
KPA 7. Improve equity of access to high-volume, specialist pancreatic cancer treatment centres			
Strategy 14. Establish parameters for high-volume pancreatic cancer treatment centres			
Strategy 15. Establish hybrid models of treatment/care delivery			
KPA 8. Strengthen clinical guidance to reduce unwarranted variations in treatments for people with pancreatic cancer			
Strategy 16. Establish strategies to address unwarranted variations in treatments			
Strategy 17. Update clinical guidance to address gaps			
Strategy 18. Promote patient and clinician awareness of existing clinical guidance			

THE NATIONAL PANCREATIC CANCER ROADMAP

	SHORT	MEDIUM	LONG
KPA 9. Improve access to neoadjuvant therapy, including through clinical trials, in pancreatic cancer			
Strategy 19. Establish routine access to neoadjuvant therapy			
KPA 10. Improve coordination between specialised pancreatic cancer treatment centres and primary care in managing patients with pancreatic cancer			
Strategy 20. Establish strategies for coordination of shared-care between specialists and primary care			
KPA 11. Strengthen early referral to palliative care for people with advanced pancreatic cancer			
Strategy 21. Establish standardised palliative care pathway			
Strategy 22. Promote awareness of local support services			
KPA 12. Increase access and timely referral to specialist multidisciplinary meetings with palliative care representation for people with metastatic pancreatic cancer			
Strategy 23. Promote clinician awareness of OCP and importance of prompt referral to a multidisciplinary team			
Strategy 24. Establish directories of specialists linked to a multidisciplinary team with palliative care representation			
Strategy 25. Establish reporting of clinical quality indicators to measure timely referral to multidisciplinary meetings			
KPA 13. Improve equity of access to community-based palliative care services for people with pancreatic cancer			
Strategy 26. Promote patient and clinician awareness of community-based palliative care support services			
KPA 14. Provide systems and services that support rapid access to palliative care when needed for people with pancreatic cancer			
Strategy 27. Establish standardised care pathway for rapid access to palliative care			
KPA 15. Improve equity of access to specialist expertise in pain management for people with pancreatic cancer			
Strategy 28. Establish standardised pathway for access to pain management			
Strategy 29. Promote patient and clinician awareness of interventional pain management			
Strategy 30. Educate health professionals on interventional pain management			
KPA 16. Improve equity of access to coordinated supportive care for people with pancreatic cancer			
Strategy 31. Establish standardised pathway for coordinated supportive care			
Strategy 32. Promote patient and clinician awareness of supportive care services			
Strategy 33. Educate health professionals on best-practice supportive care			

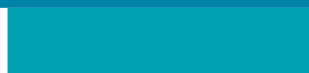
THE NATIONAL PANCREATIC CANCER ROADMAP

	SHORT	MEDIUM	LONG
KPA 17. Improve equity of access to specialist supportive care for pancreatic cancer, including psychosocial support services and networks			
Strategy 34. Establish standardised supportive care pathway for equitable access to specialist supportive care			
Strategy 35. Promote patient and clinician awareness of supportive care services, including psychosocial support services			
Strategy 36. Educate health professionals on best-practice supportive care including psychosocial support			
KPA 18. Improve patient navigation and care coordination at point of diagnosis for patient support			
Strategy 37. Establish models of care coordination			
KPA 19. Improve access to symptom management support for people with pancreatic cancer			
Strategy 38. Establish standardised pathway and needs assessment tool for symptom management support			
Strategy 39. Integrate a needs assessment tool for symptom management support			
KPA 20. Strengthen the evidence-base regarding early detection methods for pancreatic cancer			
Strategy 40. Establish a national pancreatic cancer research strategy			
KPA 21. Increase Australia's engagement in collaborative multidisciplinary research both nationally and internationally			
Strategy 41. Form a National Pancreatic Cancer Network			
Strategy 42. Establish a program of research excellence in pancreatic cancer			
KPA 22. Improve the use of biospecimens for research in pancreatic cancer			
Strategy 43. Establish a national pancreatic biospecimen registry			
KPA 23. Strengthen the evidence-base regarding potential personalised and tailored drug treatments			
Strategy 44. Facilitate research and clinical trials in personalised and tailored drug treatments for pancreatic cancer			
KPA 24. Strengthen the evidence-base regarding repurposing of existing therapies for more effective treatments in pancreatic cancer			
Strategy 45. Facilitate research and clinical trials in repurposing of existing therapies for pancreatic cancer			
KPA 25. Improve access to clinical trials in pancreatic cancer, including for people with metastatic disease			
Strategy 46. Promote participation in clinical trials for pancreatic cancer			
KPA 26. Improve access to surgical clinical trials in pancreatic cancer			
Strategy 47. Promote participation in surgical clinical trials for pancreatic cancer			
KPA 27. Strengthen national data spanning the optimal care pathway to assess variations in best practice pancreatic cancer care			
Strategy 48. Establish national reporting on clinical quality indicators			

SHORT | MEDIUM | LONG

KPA 28. Improve the collection of patient-reported experience and outcome measures in routine pancreatic cancer care

Strategy 49. Establish national reporting on standardised PREMs and PROMs

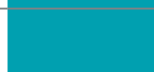


KPA 29. Improve the provision of culturally appropriate models of care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds affected by pancreatic cancer and their carers

Strategy 50. Establish culturally appropriate care models



Strategy 51. Promote patient and carer awareness of pancreatic cancer treatment and care

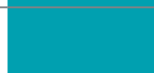


KPA 30. Improve integrated care coordination models, including telehealth, for people from regional and remote areas to minimise delayed treatment

Strategy 52. Establish integrated care coordination models

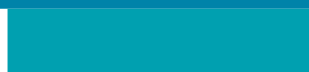


Strategy 53. Educate health professionals about models of care coordination

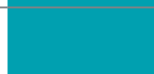


KPA 31. Improve evidence-based care coordination models for people affected by metastatic pancreatic cancer, including those living in regional and remote areas

Strategy 54. Establish care coordination models for people with metastatic pancreatic cancer



Strategy 55. Educate health professionals about models of care coordination for people with metastatic pancreatic cancer



KPA 32. Improve the capacity and capability of the workforce in rural and remote areas to support pancreatic cancer care

Strategy 56. Educate health professionals on best-practice care in rural and remote areas



Strategy 57. Establish linkages between primary health professionals and specialists



KPA 33. Improve capacity and capability of palliative care nurses and GPs in the provision of pancreatic cancer care particularly in regional areas

Strategy 58. Promote patient and clinician awareness of palliative care tools and resources for pancreatic cancer



Strategy 59. Educate health professionals on best-practice care



Strategy 60. Establish linkages between primary health professionals and specialists



4.2 Implementation

Implementation of the Roadmap will be a collective responsibility involving Australian Commonwealth, State and Territory governments, non-government organisations, professional colleges and societies, health services, health professionals, researchers and consumers. Stakeholder involvement in implementing the Roadmap will leverage cross-sector skills and expertise and facilitate the collaboration and partnerships required to improve pancreatic cancer outcomes.

The Roadmap KPAs and strategies set the course over the next five years to drive positive incremental change across the continuum of pancreatic cancer care. However, transformational initiatives are also required to realise rapid and significant improvements in pancreatic outcomes and survival.

Early implementation efforts concentrating on a strategic set of impactful initiatives can unite stakeholders and stimulate implementation of the Roadmap. Early detection, palliative care, end-of-life care, and research have been identified as critical areas for immediate action in the Roadmap. The following proposed suite of six early implementation initiatives will benefit over 20,000 individuals, and their carers, families and communities, through reduced incidence, improved access to care, improved patient and carer experiences, improved quality of life, and improved survival.

Early implementation initiatives to transform and improve pancreatic outcomes and survival

1. Establish Australia's first National Pancreatic Cancer Centre

A national collaborative approach is required to realise the vision of the Roadmap and deliver improvements in pancreatic cancer outcomes and survival in Australia.

Co-located in an existing research institute or university, the National Pancreatic Cancer Centre (the Centre) will drive the pancreatic cancer change agenda by bringing together stakeholders to implement the Roadmap, advance a strategic and coordinated program of research, and enhance and monitor the delivery of best-practice care to improve pancreatic cancer outcomes.

Implementing the Roadmap

Coordinated and ongoing implementation of the Roadmap is essential to achieve continuous improvements across the continuum of pancreatic cancer care.

The Centre will lead and coordinate implementation of the Roadmap in partnership with stakeholders. This model of central governance and oversight of the Roadmap reduces the risk of fragmentation or duplication of effort, supports the effective and cost-efficient delivery of initiatives, and is vital to ensuring that implementation of the Roadmap maintains momentum over the five-year duration.

Collaborative research and best-practice care

Although physically located at an institute or university, the Centre will play a key role in the establishment of an International Pancreatic Network creating an alliance of international and Australian organisations, researchers, consumers and health professionals. Building on existing partnerships, the Network will unite groups and sectors to identify, develop and support collaborative initiatives in research and clinical trials, and facilitate international and national collaboration in data and clinical care to accelerate discoveries beyond borders.

At a national level, the Centre will bring together researchers, consumers, clinicians, health service providers, and policy makers in a prioritised collaborative program of preclinical, clinical, and health service research. The Centre will also build future capacity by training the next generation of researchers, and capture and report on clinical care and outcomes to hasten improvements in survival and quality of life for all Australians affected by pancreatic cancer.

Early investment would support the establishment of the Centre and the Network.

Implementation of this priority will require a range of partnerships. A collaboration of funding partners including governments, research institutes/ universities and pancreatic cancer organisations could support the establishment of the Centre. The design, conduct and translation of research and best-practice care would engage all stakeholders including researchers, health professionals, professional colleges, policy makers, and cancer and consumer organisations.

2. Create a strategic pioneering pancreatic research scheme

A significant shift in survival and quality of life for Australians affected by pancreatic cancer requires strategic investment in ambitious and ground-breaking research.

Investment would support a dedicated pancreatic cancer grant initiative, over the five-year duration of the Roadmap, that funds exceptional and pioneering research in priority areas to make a significant and measurable contribution to changing pancreatic cancer outcomes. The innovative grant scheme will bring together diverse, multidisciplinary, and cross-industry leaders with expertise both within and outside pancreatic cancer, incorporate partnership with medtech/ biotech/ digital technology enterprises, foster and reward national/ international collaboration, facilitate meaningful consumer engagement, and support implementation of findings into the health care system.

In addition to accelerating changes in pancreatic cancer outcomes, the scheme will leverage Australia's position as leader in the medical technologies and pharmaceutical sector, enhance collaboration and commercialisation, improve skills and capability, and stimulate health technology job development and economic growth.

Implementation of this priority would be underpinned by a national pancreatic cancer research strategy. The research strategy would identify research priority areas for funding and would be developed by National Pancreatic Cancer Centre in collaboration with national and international stakeholders. The grants may also be co-funded, and a funding partnership approach would bring together national and international pancreatic cancer organisations and philanthropy, to leverage, coordinate and maximise investment.

3. Develop a national risk assessment tool to improve identification of people at high risk of pancreatic cancer for targeted surveillance

Most people are diagnosed with pancreatic cancer once the disease has spread and this late stage at diagnosis contributes to the poor survival outcomes.

While the evidence doesn't support population screening for pancreatic cancer, targeted surveillance programs present an opportunity to strengthen the early detection of pancreatic cancer among high-risk individuals to assist improve survival outcomes.

To improve the identification of people at high risk of pancreatic cancer, early investment would support the development of a national risk assessment tool that could be used in a primary care setting. The tool would be designed/ adapted and validated for the Australian population for implementation across primary care. The early investment would also support identifying efficient and cost-effective approaches to targeted surveillance for those at high risk.

Implementation would engage health research groups, professional colleges including the Royal Australian College of General Practitioners (RACGP) and Australian College of Rural and Remote Medicine (ACRRM), ACCHOs, primary care practitioners, pancreatic cancer organisations, and consumers.

4. Develop a decision support tool to improve primary health professional recognition of signs and symptoms of pancreatic cancer

Currently, there is limited health professional awareness about pancreatic cancer signs and symptoms. Increasing awareness, knowledge and education could support earlier presentation and diagnosis, with a consequent long-term improvement in patient outcomes.

Early investment in this initiative would support the identification, development and testing of decision support tools for assessment of signs and symptoms of pancreatic cancer in primary care, promotion and communication of a symptom guide, and the development of educational activities for primary health professionals.

Implementation would engage professional colleges including RACGP, ACRRM, Aboriginal Health Services, Aboriginal health workers, primary care practitioners and consumers.

Increasing recognition of the signs and symptoms of pancreatic cancer in the community could be undertaken in parallel and be led by pancreatic consumer organisations leveraging the information and resources developed through the early investment activities.

5. Create pathways to improve equity of access to specialist expertise in pain management for people with pancreatic cancer

While stakeholders highlighted a range of symptoms that are challenging for patients to manage, the most common symptom referenced was pain. Early intervention in pain management can improve the quality of life of people diagnosed with pancreatic cancer.

Early investment would support scoping current status and gaps in access to pain management, subsequent development and testing of care pathways, development of education modules on interventional pain management, and engagement with health professionals through clinical colleges and professional associations to increase awareness of interventional pain management procedures.

Implementation of this priority would engage professional colleges including the Australian and New Zealand College of Anaesthetists - Faculty of Pain Medicine, Royal Australasian College of Surgeons, Royal Australian and New Zealand College of Radiologists, Royal Australasian College of Physicians, RACGP, ACRRM, ACCHOs, and consumers.

6. Develop pathways to strengthen early referral to palliative care for people with advanced pancreatic cancer

Palliative care input is associated with better supportive care and quality of life in people with advanced pancreatic cancer and early integration of specialist palliative care is acceptable, and feasible for people

with pancreatic cancer. Given the majority of people are diagnosed with pancreatic cancer at an advanced stage, timely referral to palliative care is essential to support improved quality of life outcomes.

Early investment would support scoping the current status and gaps in access to palliative care, plus the development or adaptation and testing of standardised supportive care pathways incorporating rapid access to palliative care.

Implementation of this priority would engage professional societies and colleges including Palliative Care Australia, RACGP, ACRRM, ACCHOs, and consumers.

CONCLUSION

Australia has some of the best cancer outcomes in the world, but those outcomes are not universally enjoyed.

The need for a National Pancreatic Cancer Roadmap has never been greater, and the Roadmap provides an unprecedented opportunity for a focused national response to address the significantly poorer outcomes experienced by Australians affected by pancreatic cancer.

The Roadmap was developed in, and will be implemented in, true partnership with governments, non-government organisations, health professionals, researchers, policy makers, consumers, carers, families and communities.

The opportunities to drive change are numerous and bold, and this reflects the significant journey we must undertake to make a transformational impact on the lives of Australians affected by pancreatic cancer.

ACKNOWLEDGEMENTS

Cancer Australia gratefully acknowledges the support of the many individuals and organisations that contributed to the National Pancreatic Cancer Roadmap.

We appreciate the submissions received throughout the public consultation process, including input from people with lived experience of pancreatic cancer and their families and carers, Aboriginal and Torres Strait Islander people, health professionals working in primary, secondary and tertiary care, the general public, researchers, jurisdictional health departments and organisations representing diverse stakeholder groups, including those representing clinical and consumer perspectives and interests.

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All Cancer data has been sourced from the Australian Bureau of Statistics (<https://www.abs.gov.au/>), Australian Institute of Health and Welfare (<https://www.aihw.gov.au/>) or Cancer Australia (<https://www.canceraustralia.gov.au/>; <https://ncci.canceraustralia.gov.au/>).

NATIONAL PANCREATIC CANCER ROADMAP

73 PRIORITY AREAS

PREVENTION AND EARLY DETECTION (N=9)

- Reduce the prevalence of modifiable risk factors associated with pancreatic cancer e.g. smoking, obesity
- Raise health professional awareness and understanding of known modifiable risk factors for pancreatic cancer
- Raise health professional awareness and understanding of known non-modifiable risk factors for pancreatic cancer e.g. familial, genetic links
- Raise public awareness of the known modifiable risk factors for pancreatic cancer
- Raise public awareness of known non-modifiable risk factors for pancreatic cancer e.g. familial, genetic links
- Tailor health promotion and education messaging about pancreatic cancer risk factors for Aboriginal and Torres Strait Islander people and people from CALD backgrounds
- Improve identification of people at high risk of pancreatic cancer for targeted surveillance
- Improve evidence-based guidance and protocols for the surveillance of people at high risk of pancreatic cancer
- Improve access to targeted surveillance for people at high risk of pancreatic cancer

PRESENTATION, INITIAL INVESTIGATIONS AND REFERRAL (N=5)

- Improve primary health professional recognition of signs and symptoms of pancreatic cancer
- Raise public awareness of the signs and symptoms of pancreatic cancer to support early detection
- Improve general practitioner understanding of appropriate initial investigations if pancreatic cancer is suspected
- Improve the timeliness of referrals to an appropriate specialist if pancreatic cancer is suspected
- Strengthen culturally appropriate primary care services to support presentation, initial investigations and referral for Aboriginal and Torres Strait Islander people and people from CALD backgrounds if pancreatic cancer is suspected

DIAGNOSIS, STAGING AND TREATMENT PLANNING (N=6)

- Improve equity of access to appropriate diagnostic and staging modalities for pancreatic cancer
- Reduce unwarranted variation in use of diagnostic and staging modalities
- Standardise approach to synoptic reporting for diagnosis and staging of pancreatic cancer
- Improve access to specialist multidisciplinary meetings for treatment planning for people diagnosed with pancreatic cancer
- Tailor information about diagnostic and treatment planning for Aboriginal and Torres Strait Islander people and people from CALD backgrounds affected by pancreatic cancer
- Improve the provision of culturally safe cancer care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds

TREATMENT (N=6)

- Strengthen clinical guidance to reduce unwarranted variations in treatments for people with pancreatic cancer
- Strengthen clinical guidance regarding the optimal application of chemotherapy regimens to enhance outcomes and minimise toxicities
- Enhance utilisation of stereotactic radiation therapy to minimise toxicity and assist surgery for curative treatment
- Improve access to neoadjuvant therapy, including through clinical trials, in pancreatic cancer
- Tailor information about treatment for Aboriginal and Torres Strait Islander people and people from CALD backgrounds affected by pancreatic cancer
- Improve equity of access to high-volume, specialist pancreatic cancer treatment centres

APPENDIX 1 - EXPANDED LIST OF PRIORITIES

CARE AFTER INITIAL TREATMENT AND RECOVERY (N=1)

- Improve coordination between specialised pancreatic cancer treatment centres and primary care in managing patients with pancreatic cancer

MANAGING RECURRENT, RESIDUAL OR METASTATIC DISEASE (N=5)

- Strengthen early referral to palliative care for people with advanced pancreatic cancer
- Strengthen the early initiation of preferred goals of care conversations and revisit as the person's clinical status changes
- Increase access and timely referral to specialist multidisciplinary meetings with palliative care representation for people with metastatic pancreatic cancer
- Improve equity of access to community-based palliative care services for people with pancreatic cancer
- Provide systems and services that support rapid access to palliative care when needed for people with pancreatic cancer

END-OF-LIFE CARE (N=2)

- Improve equity of access to specialist expertise in pain management for people with pancreatic cancer
- Strengthen knowledge and awareness of patients and family on what to expect in end-of-life for people with pancreatic cancer

SUPPORTIVE CARE (N=8)

- Improve equity of access to coordinated supportive care for people with pancreatic cancer
- Improve equity of access to specialist supportive care for pancreatic cancer, including psychosocial support services and networks
- Enable routine screening for supportive care needs, with referral to support services, as needed
- Strengthen access to information to address patient and carer key information needs e.g. prognosis, treatment, side effects, support services
- Provide culturally appropriate supportive care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds affected by pancreatic cancer and their carers
- Improve patient navigation and care coordination at point of diagnosis for patient support
- Improve access to psychosocial support for patients and carers following a diagnosis of pancreatic cancer
- Improve access to symptom management support for people with pancreatic cancer

RESEARCH AND CLINICAL TRIALS (N=17)

- Increase Australia's engagement in collaborative multidisciplinary research both nationally and internationally
- Strengthen the evidence-base regarding modifiable and non-modifiable risk factors that increase the risk of developing pancreatic cancer
- Strengthen the evidence-base regarding the presenting symptoms of pancreatic cancer
- Strengthen the evidence-base regarding early detection methods for pancreatic cancer
- Strengthen the evidence-base regarding the best diagnostic and staging methods for pancreatic cancer
- Improve the use of biospecimens for research in pancreatic cancer
- Strengthen the evidence-base regarding potential personalised and tailored drug treatments
- Strengthen the evidence-base regarding novel gene-therapies for more effective treatments in pancreatic cancer
- Strengthen the evidence-base regarding repurposing of existing therapies for more effective treatments in pancreatic cancer
- Strengthen the evidence-base regarding the optimal application of newer radiation therapy options e.g. Stereotactic Body Radiation Therapy, OncoSilTM
- Strengthen the evidence-base regarding optimal surgical techniques
- Improve access to clinical trials in pancreatic cancer, including for people with metastatic disease
- Improve access to surgical clinical trials in pancreatic cancer
- Strengthen the evidence-base regarding supportive care interventions that improve patient outcomes and experiences
- Strengthen the evidence-base regarding optimal models of follow-up care
- Strengthen the evidence-base regarding the supportive care needs of carers
- Strengthen the evidence-base regarding the supportive and survivorship care needs of survivors

DATA AND REPORTING (N=6)

- Improve data linkages and access to key data sets to understand variations in practice
- Standardise national clinical data collection to ascertain the sequence and timing of investigation, referral, diagnosis and treatment for pancreatic cancer
- Strengthen national data spanning the optimal care pathway to assess variations in best practice pancreatic cancer care
- Improve the collection of patient-reported experience and outcome measures in routine pancreatic cancer care
- Enhance standardisation of reporting of information within clinical trials for comparability of data across pancreatic cancer clinical trials
- Improve the collection and reporting of data related to care processes and clinical outcomes

MODELS OF CARE (N=8)

- Improve integrated care coordination models, including telehealth, for people from rural and remote areas to minimise delayed treatment
- Improve the capacity and capability of the workforce in rural and remote areas to support pancreatic cancer care
- Improve capacity and capability of palliative care nurses and general practitioners in the provision of pancreatic cancer care particularly in regional areas
- Improve evidence-based care coordination models for people affected by metastatic pancreatic cancer, including those living in regional and remote areas
- Improve the provision of culturally appropriate models of care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds affected by pancreatic cancer and their carers
- Tailor the provision of culturally appropriate, timely palliative care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds
- Strengthen culturally appropriate models of care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds affected by metastatic pancreatic cancer
- Support active treatment with integrated models of specialist palliative care and supportive care

KEY PRIORITY AREAS AND STRATEGIES

STRATEGIES FOR COLLECTIVE ACTION		
SHORT-TERM	MEDIUM-TERM	LONG-TERM
OCP STEP 1: PREVENTION AND EARLY DETECTION		
KPA 1. Improve identification of people at high risk of pancreatic cancer for targeted surveillance		
<i>Strategy 1. Integrate a pancreatic cancer risk assessment tool</i>		
<ul style="list-style-type: none"> Identify current evidence for pancreatic cancer risk assessment and existing risk assessment tool(s) Design or adapt and test a pancreatic cancer specific risk assessment tool 	<ul style="list-style-type: none"> Implement pancreatic cancer specific risk assessment tool in primary care 	
<i>Strategy 2. Establish a pancreatic cancer targeted surveillance program</i>		
<ul style="list-style-type: none"> Design or adapt and test existing approaches to targeted surveillance 	<ul style="list-style-type: none"> Implement a targeted surveillance program 	
OCP STEP 2: PRESENTATION, INITIAL INVESTIGATIONS AND REFERRAL		
KPA 2. Improve primary health professional recognition of signs and symptoms of pancreatic cancer		
<i>Strategy 3. Promote primary health professional awareness of signs and symptoms of pancreatic cancer</i>		
<ul style="list-style-type: none"> Promotion and communication of signs and symptoms of pancreatic cancer through existing channels 		
<i>Strategy 4. Educate primary health professionals on the signs and symptoms of pancreatic cancer</i>		
<ul style="list-style-type: none"> Develop and implement educational modules on signs and symptoms of pancreatic cancer 		
<i>Strategy 5. Integrate a decision support tool for assessment of signs and symptoms of pancreatic cancer into primary care</i>		
<ul style="list-style-type: none"> Identify existing decision support tool(s) for assessment of signs and symptoms of pancreatic cancer Design or adapt and test a pancreatic cancer decision support tools 	<ul style="list-style-type: none"> Implement pancreatic cancer decision support tool(s) 	
KPA 3. Improve general practitioner understanding of appropriate initial investigations if pancreatic cancer is suspected		
<i>Strategy 6. Establish a standardised clinical pathway for initial investigations</i>		
<ul style="list-style-type: none"> Design or adapt and test standardised clinical pathway for initial investigations (and diagnostics) and referrals for suspected pancreatic cancer based on OCP guidance 	<ul style="list-style-type: none"> Implement standardised clinical pathway for initial investigations (and diagnostics) and referrals 	
<i>Strategy 7. Educate GPs on appropriate initial investigations</i>		
<ul style="list-style-type: none"> Develop and implement educational modules on appropriate initial investigations 		
KPA 4. Improve the timeliness of referrals to an appropriate specialist if pancreatic cancer is suspected		
<i>Strategy 8. Establish systems of rapid and seamless specialist referral</i>		
<ul style="list-style-type: none"> Identify barriers and enablers to timely referrals into specialist care Develop and test approaches to rapid referral 	<ul style="list-style-type: none"> Implement systems of rapid and seamless referral into specialist care 	
OCP STEP 3: DIAGNOSIS, STAGING AND TREATMENT PLANNING		
KPA 5. Improve equity of access to appropriate diagnostic and staging modalities for pancreatic cancer		
<i>Strategy 9. Establish referral pathways to appropriate diagnostic and staging investigations</i>		
<ul style="list-style-type: none"> Identify barriers and enablers for diagnostic and staging investigations for pancreatic cancer Develop a framework for use of teleradiology/ telehealth 	<ul style="list-style-type: none"> Develop referral pathways for diagnostic and staging investigations 	<ul style="list-style-type: none"> Implement referral pathways for diagnostic and staging investigations

STRATEGIES FOR COLLECTIVE ACTION		
SHORT-TERM	MEDIUM-TERM	LONG-TERM
Strategy 10. Educate health professionals on appropriate diagnostic and staging investigations		
<ul style="list-style-type: none"> Develop and implement educational modules on appropriate diagnostic and staging investigations for pancreatic cancer 		
KPA 6. Improve access to specialist multidisciplinary meetings for treatment planning for people diagnosed with pancreatic cancer		
Strategy 11. Promote clinician awareness of OCP and importance of prompt referral to a multidisciplinary team		
<ul style="list-style-type: none"> Promotion and communication of OCP through existing channels 		
Strategy 12. Establish directories of specialists in pancreatic cancer management linked to a multidisciplinary team		
<ul style="list-style-type: none"> Develop and implement directories of specialists linked to a multidisciplinary team¹ 		
Strategy 13. Establish reporting of clinical quality indicators to measure access to multidisciplinary meetings		
		<ul style="list-style-type: none"> Implement reporting of clinical quality indicators to measure access to specialist multidisciplinary meetings
OCP STEP 4: TREATMENT		
KPA 7. Improve equity of access to high-volume, specialist pancreatic cancer treatment centres		
Strategy 14. Establish parameters for high-volume pancreatic cancer treatment centres		
<ul style="list-style-type: none"> Establish working definition of 'high-volume centre' in order to map and categorise existing centres Create a registry of treatment centres that are considered high-volume/specialised in pancreatic cancer treatment across each state and region 	<ul style="list-style-type: none"> Develop national standards of clinical capability for high-volume, specialist centres in pancreatic cancer Develop a nationally agreed minimum dataset and framework for data collection, collation and reporting on clinical quality indicators and national benchmarking 	<ul style="list-style-type: none"> Implement standardised data collection within high-volume specialist pancreatic cancer treatment centres
Strategy 15. Establish hybrid models of treatment/ care delivery		
<ul style="list-style-type: none"> Identify existing technologies (i.e. telehealth) which may be leveraged to facilitate equitable access to high-volume specialist pancreatic cancer treatment centres 	<ul style="list-style-type: none"> Design hybrid models of treatment/ care delivery linking high-volume, specialist pancreatic cancer treatment centres and regional cancer services 	<ul style="list-style-type: none"> Implement hybrid models of care through strengthening linkages with high-volume specialist pancreatic cancer treatment centres and lower volume centres including regional cancer services
KPA 8. Strengthen clinical guidance to reduce unwarranted variations in treatments for people with pancreatic cancer		
Strategy 16. Establish strategies to address unwarranted variations in treatments		
<ul style="list-style-type: none"> Identify unwarranted variations in treatments including gaps in clinical practice 	<ul style="list-style-type: none"> Develop and test strategies to address variations in treatment 	<ul style="list-style-type: none"> Implement strategies to address unwarranted variations in treatment
Strategy 17. Update clinical guidance to address gaps		
<ul style="list-style-type: none"> Identify gaps in clinical guidance 	<ul style="list-style-type: none"> Develop or adapt new clinical guidance to address gaps 	<ul style="list-style-type: none"> Implement strategies to address unwarranted variations in treatment
Strategy 18. Promote patient and clinician awareness of existing clinical guidance		
		<ul style="list-style-type: none"> Promote awareness of existing best-practice pancreatic cancer treatment guidance
KPA 9. Improve access to neoadjuvant therapy, including through clinical trials, in pancreatic cancer		
Strategy 19. Establish routine access to neoadjuvant therapy		
<ul style="list-style-type: none"> Promote awareness of the benefits of chemotherapy treatment options, including neoadjuvant therapy 	<ul style="list-style-type: none"> Design and implement standardised approaches for routine access to neoadjuvant therapy including through clinical trials, leveraging technology and innovation 	

APPENDIX 2 - KEY PRIORITY AREAS, STRATEGIES AND ACTION AREAS

STRATEGIES FOR COLLECTIVE ACTION		
SHORT-TERM	MEDIUM-TERM	LONG-TERM
OCP STEP 5: CARE AFTER INITIAL TREATMENT AND RECOVERY		
KPA 10. Improve coordination between specialised pancreatic cancer treatment centres and primary care in managing patients with pancreatic cancer		
<i>Strategy 20. Establish strategies for coordination of shared-care between specialists and primary care</i>		
<ul style="list-style-type: none"> Identify barriers and enablers to coordination of shared-care between specialists and primary care Identify existing electronic cancer care plans for information sharing between specialists and primary care 	<ul style="list-style-type: none"> Develop and test strategies to address identified barriers to coordination of shared-care between specialists and primary care Implement strategies for coordination of shared-care between specialists and primary care in alignment with the <i>Primary Health Care 10 Year Plan</i> 	
OCP STEP 6: MANAGING RECURRENT, RESIDUAL OR METASTATIC DISEASE		
KPA 11. Strengthen early referral to palliative care for people with advanced pancreatic cancer		
<i>Strategy 21. Establish standardised palliative care pathway</i>		
<ul style="list-style-type: none"> Identify current status and gaps in access to palliative care Design or adapt and test standardised supportive care pathway, incorporating rapid access models to palliative care 	<ul style="list-style-type: none"> Implement standardised palliative care pathway in alignment with the <i>National Palliative Care Strategy</i> 	
<i>Strategy 22. Promote awareness of local support services</i>		
<ul style="list-style-type: none"> Develop accessible information for patients, carers, families and communities on local support services 		
KPA 12. Increase access and timely referral to specialist multidisciplinary meetings with palliative care representation for people with metastatic pancreatic cancer		
<i>Strategy 23. Promote clinician awareness of OCP and importance of prompt referral to a multidisciplinary team</i>		
<ul style="list-style-type: none"> Promotion and communication of OCP through existing channels 		
<i>Strategy 24. Establish directories of specialists linked to a multidisciplinary team with palliative care representation</i>		
<ul style="list-style-type: none"> Develop and implement directories of specialists linked to a multidisciplinary team with palliative care representation 		
<i>Strategy 25. Establish reporting of clinical quality indicators to measure timely referral to multidisciplinary meetings</i>		
		<ul style="list-style-type: none"> Implement reporting of clinical quality indicators that measure timely referral of people with metastatic pancreatic cancer to specialist multidisciplinary meetings with palliative care representation
KPA 13. Improve equity of access to community-based palliative care services for people with pancreatic cancer		
<i>Strategy 26. Promote patient and clinician awareness of community-based palliative care support services</i>		
<ul style="list-style-type: none"> Identify current status and gaps in access to community-based palliative care support and services 	<ul style="list-style-type: none"> Develop and implement a culturally appropriate, consumer-accessible guide(s) on community-based palliative care services 	
KPA 14. Provide systems and services that support rapid access to palliative care when needed for people with pancreatic cancer		
<i>Strategy 27. Establish standardised care pathway for rapid access to palliative care</i>		
<ul style="list-style-type: none"> Identify current status and gaps in access to palliative care support Design or adapt and test standardised care pathway incorporating rapid access models to palliative care 	<ul style="list-style-type: none"> Implement standardised care pathway in alignment with the <i>National Palliative Care Strategy</i> 	

STRATEGIES FOR COLLECTIVE ACTION		
SHORT-TERM	MEDIUM-TERM	LONG-TERM
OCP STEP 7: END-OF-LIFE CARE		
KPA 15. Improve equity of access to specialist expertise in pain management for people with pancreatic cancer		
Strategy 28. Establish standardised pathway for access to pain management		
<ul style="list-style-type: none"> Identify current status and gaps in access to pain management Design or adapt and test standardised supportive care pathway incorporating rapid access models to pain management expertise 	<ul style="list-style-type: none"> Implement standardised supportive care pathway 	
Strategy 29. Promote patient and clinician awareness of interventional pain management		
<ul style="list-style-type: none"> Promote awareness of interventional pain management 		
Strategy 30. Educate health professionals on interventional pain management		
<ul style="list-style-type: none"> Develop and implement educational modules on interventional pain management in pancreatic cancer 		
ACROSS OCP: SUPPORTIVE CARE		
KPA 16. Improve equity of access to coordinated supportive care for people with pancreatic cancer		
Strategy 31. Establish standardised pathway for coordinated supportive care		
<ul style="list-style-type: none"> Identify current status and gaps in access to coordinated supportive care Design or adapt and test standardised supportive care pathway, incorporating rapid access models, for access to supportive care 	<ul style="list-style-type: none"> Strengthen linkages between primary health professionals and specialist multidisciplinary teams in alignment with the <i>Primary Health Care 10 Year Plan</i> Implement standardised supportive care pathway 	
Strategy 32. Promote patient and clinician awareness of supportive care services		
<ul style="list-style-type: none"> Promote awareness of supportive care services 		
Strategy 33. Educate health professionals on best-practice supportive care		
<ul style="list-style-type: none"> Develop and implement educational modules on best-practice supportive care for pancreatic cancer 		
KPA 17. Improve equity of access to specialist supportive care for pancreatic cancer, including psychosocial support services and networks		
Strategy 34. Establish standardised supportive care pathway for equitable access to specialist supportive care		
<ul style="list-style-type: none"> Identify current status and gaps in access to psychosocial support services Design or adapt and test standardised supportive care pathway, incorporating rapid access models to psychosocial support 	<ul style="list-style-type: none"> Strengthen linkages between primary health professionals and specialist multidisciplinary teams in alignment with the <i>Primary Health Care 10 Year Plan</i> Implement standardised supportive care pathway 	
Strategy 35. Promote patient and clinician awareness of supportive care services, including psychosocial support services		
<ul style="list-style-type: none"> Promote awareness of supportive care services, including psychosocial support services 		
Strategy 36. Educate health professionals on best-practice supportive care including psychosocial support		
<ul style="list-style-type: none"> Develop and implement educational modules on best-practice supportive care including psychosocial support 		
KPA 18. Improve patient navigation and care coordination at point of diagnosis for patient support		
Strategy 37. Establish models of care coordination		
<ul style="list-style-type: none"> Design or adapt and test existing models of cancer care coordination, including virtual care models 	<ul style="list-style-type: none"> Implement models of care coordination from the point of diagnosis 	

APPENDIX 2 - KEY PRIORITY AREAS, STRATEGIES AND ACTION AREAS

STRATEGIES FOR COLLECTIVE ACTION		
SHORT-TERM	MEDIUM-TERM	LONG-TERM
KPA 19. Improve access to symptom management support for people with pancreatic cancer		
Strategy 38. Establish standardised pathway and needs assessment tool for symptom management support		
<ul style="list-style-type: none"> Identify current status and gaps in access to symptom management support Design or adapt and test standardised pathway incorporating rapid access models for symptom management support 	<ul style="list-style-type: none"> Implement standardised pathway for symptom management support 	
Strategy 39. Integrate a needs assessment tool for symptom management support		
<ul style="list-style-type: none"> Identify existing needs assessment tools for symptom management Design or adapt and test a needs assessment tool for symptom management 	<ul style="list-style-type: none"> Implement needs assessment tool for symptom management support 	
ACROSS OCP: RESEARCH AND CLINICAL TRIALS		
KPA 20. Strengthen the evidence-base regarding early detection methods for pancreatic cancer		
Strategy 40. Establish a national pancreatic cancer research strategy		
<ul style="list-style-type: none"> Design a national pancreatic cancer research strategy to incentivise a coordinated approach, including early detection methods for pancreatic cancer 	<ul style="list-style-type: none"> Implement mechanisms within the pancreatic cancer research strategy that encourage research in early detection methods for pancreatic cancer 	
KPA 21. Increase Australia's engagement in collaborative multidisciplinary research both nationally and internationally		
Strategy 41. Form a National Pancreatic Cancer Network		
<ul style="list-style-type: none"> Formation of a National Pancreatic Cancer Network to strengthen national and international collaboration across pancreatic cancer research groups and between academia/research, government, industry and philanthropic sectors 		
Strategy 42. Establish a program of research excellence in pancreatic cancer		
	<ul style="list-style-type: none"> Establish a national/ international peer reviewed program of research excellence in pancreatic cancer 	
KPA 22. Improve the use of biospecimens for research in pancreatic cancer		
Strategy 43. Establish a national pancreatic biospecimen registry		
<ul style="list-style-type: none"> Design a national pancreatic biospecimen registry including governance structure, infrastructure, quality standards and linkage with the national clinical data registry as part of the national research strategy 	<ul style="list-style-type: none"> Establish a national pancreatic biospecimen registry with linkage to the national clinical data registry 	
KPA 23. Strengthen the evidence-base regarding potential personalised and tailored drug treatments		
Strategy 44. Facilitate research and clinical trials in personalised and tailored drug treatments for pancreatic cancer		
<ul style="list-style-type: none"> Design research and clinical trials in personalised and tailored drug treatments for pancreatic cancer as part of the National Pancreatic Cancer Network and national research strategy 	<ul style="list-style-type: none"> Implement research and clinical trials in personalised and tailored drug treatments for pancreatic cancer 	
KPA 24. Strengthen the evidence-base regarding repurposing of existing therapies for more effective treatments in pancreatic cancer		
Strategy 45. Facilitate research and clinical trials in repurposing of existing therapies for pancreatic cancer		
<ul style="list-style-type: none"> Design research and clinical trials in repurposing of existing therapies for pancreatic cancer as part of the National Pancreatic Cancer Network and national research strategy 	<ul style="list-style-type: none"> Implement research and clinical trials in repurposing of existing therapies for more effective treatments in pancreatic cancer 	

STRATEGIES FOR COLLECTIVE ACTION		
SHORT-TERM	MEDIUM-TERM	LONG-TERM
KPA 25. Improve access to clinical trials in pancreatic cancer, including for people with metastatic disease		
<i>Strategy 46. Promote participation in clinical trials for pancreatic cancer</i>		
<ul style="list-style-type: none"> Promote patient and clinician awareness of the benefits of participation in clinical trials for, people with metastatic disease Identify barriers to patient participation in a clinical trial 	<ul style="list-style-type: none"> Design and implement standardised approach for routine access to clinical trials, leveraging technology and innovation 	
KPA 26. Improve access to surgical clinical trials in pancreatic cancer		
<i>Strategy 47. Promote participation in surgical clinical trials for pancreatic cancer</i>		
<ul style="list-style-type: none"> Promote patient and clinician awareness of the benefits of patient participation in surgical clinical trials Identify barriers to patient participation in surgical clinical trials 	<ul style="list-style-type: none"> Design and implement standardised approach for routine access to surgery and treatment clinical trials, leveraging technology and innovation 	
ACROSS OCP: DATA AND REPORTING		
KPA 27. Strengthen national data spanning the optimal care pathway to assess variations in best practice pancreatic cancer care		
<i>Strategy 48. Establish national reporting on clinical quality indicators</i>		
<ul style="list-style-type: none"> Develop a nationally agreed minimum dataset for reporting of clinical quality indicators and national benchmarking Establish/ enhance a national clinical data registry spanning the optimal care pathway 	<ul style="list-style-type: none"> Design the approach to increase the scope of and access to existing clinical data 	<ul style="list-style-type: none"> Implement nationally agreed minimum dataset for reporting on clinical quality indicators and national benchmarking
KPA 28. Improve the collection of patient-reported experience and outcome measures in routine pancreatic cancer care		
<i>Strategy 49. Establish national reporting on standardised PREMs and PROMs</i>		
<ul style="list-style-type: none"> Identify existing approaches to collection of patient-reported experience and outcome measures (PREMs and PROMs) in pancreatic cancer care Develop or adapt and test nationally standardised PREMs and PROMs for inclusion in the agreed minimum dataset for reporting of clinical quality indicators and national benchmarking 	<ul style="list-style-type: none"> Implement national standardised PREMs and PROMs for reporting on patient outcomes across the pancreatic cancer care pathway 	
ACROSS OCP: MODELS OF CARE		
KPA 29. Improve the provision of culturally appropriate models of care for Aboriginal and Torres Strait Islander people and people from CALD backgrounds affected by pancreatic cancer and their carers		
<i>Strategy 50. Establish culturally appropriate care models</i>		
<ul style="list-style-type: none"> Codesign or adapt and test models of culturally appropriate care 	<ul style="list-style-type: none"> Implement models of culturally appropriate care Strengthen inclusion of cultural experts in specialist multidisciplinary teams 	
<i>Strategy 51. Promote patient and carer awareness of pancreatic cancer treatment and care</i>		
<ul style="list-style-type: none"> Promote awareness of the <i>Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer</i> (OCPs) Develop and implement in-language resources for patients, carers, families and communities, on pancreatic cancer treatment and care 		
KPA 30. Improve integrated care coordination models, including telehealth, for people from regional and remote areas to minimise delayed treatment		
<i>Strategy 52. Establish integrated care coordination models</i>		
<ul style="list-style-type: none"> Design or adapt and test existing models of care coordination, including virtual care models, for people from regional and remote areas 	<ul style="list-style-type: none"> Implement integrated care coordination models, including virtual care for people from regional and remote areas 	

APPENDIX 2 - KEY PRIORITY AREAS, STRATEGIES AND ACTION AREAS

STRATEGIES FOR COLLECTIVE ACTION		
SHORT-TERM	MEDIUM-TERM	LONG-TERM
Strategy 53. Educate health professionals about models of care coordination		
<ul style="list-style-type: none"> Develop and implement education modules on models of care coordination in pancreatic cancer 		
KPA 31. Improve evidence-based care coordination models for people affected by metastatic pancreatic cancer, including those living in regional and remote areas		
Strategy 54. Establish care coordination models for people with metastatic pancreatic cancer		
<ul style="list-style-type: none"> Design or adapt and test existing models of care coordination for metastatic disease, including virtual care 	<ul style="list-style-type: none"> Implement evidence-based care coordination models for metastatic disease, including virtual care 	
Strategy 55. Educate health professionals about models of care coordination for people with metastatic pancreatic cancer		
<ul style="list-style-type: none"> Develop and implement education modules on models of care coordination for metastatic disease 		
KPA 32. Improve the capacity and capability of the workforce in rural and remote areas to support pancreatic cancer care		
Strategy 56. Educate health professionals on best-practice care in rural and remote areas		
<ul style="list-style-type: none"> Develop and implement education modules on follow-up and supportive care in rural and remote areas 		
Strategy 57. Establish linkages between primary health professionals and specialists		
	<ul style="list-style-type: none"> Leverage technology to build virtual capacity of workforce in rural and remote areas Strengthen linkages between primary health professionals and specialist multidisciplinary teams in alignment with the <i>Primary Health Care 10 Year Plan</i> and the <i>National Aboriginal and Torres Strait Islander Health Plan</i>. 	<ul style="list-style-type: none"> Implement recruitment and retention initiatives in alignment with the <i>National Medical Workforce Strategy</i>, <i>National Nursing Strategy</i>, <i>Nurse Practitioner 10 Year Plan</i>, and the <i>National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework</i>.
KPA 33. Improve capacity and capability of palliative care nurses and GPs in the provision of pancreatic cancer care particularly in regional areas		
Strategy 58. Promote patient and clinician awareness of palliative care tools and resources for pancreatic cancer		
<ul style="list-style-type: none"> Promote awareness of existing tools and resources 		
Strategy 59. Educate health professionals on best-practice care		
<ul style="list-style-type: none"> Develop and implement education modules on best-practice care with an emphasis on regional and remote settings 		
Strategy 60. Establish linkages between primary health professionals and specialists		
	<ul style="list-style-type: none"> Leverage technology to build virtual capacity of workforce in regional and remote areas Strengthen linkages between primary health professionals and specialist multidisciplinary teams in alignment with the <i>Primary Health Care 10 Year Plan</i> and the <i>National Aboriginal and Torres Strait Islander Health Plan</i>. 	<ul style="list-style-type: none"> Implement recruitment and retention initiatives in alignment with the <i>National Medical Workforce Strategy</i>, <i>National Nursing Strategy</i>, <i>Nurse Practitioner 10 Year Plan</i>, and the <i>National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework</i>.

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