



Australian Government
Cancer Australia

National Pancreatic Cancer Roadmap

*Discussion paper to inform
priority setting*

August 2021



Background

Pancreatic cancer is currently the third leading cause of cancer death in Australia. In 2021, it is estimated that 4,261 people will be diagnosed with pancreatic cancer and 3,391 will die from it. The five-year relative survival rate for pancreatic cancer is very low, at just 11.5% in the period 2013-2017.

In the five years from 2014 to 2018, pancreatic cancer was the fifth leading cause of cancer death in Aboriginal and Torres Strait Islander people. From 2011 to 2015, 215 Aboriginal and Torres Strait Islander people were diagnosed with pancreatic cancer each year. From 2014 to 2018, 216 Aboriginal and Torres Strait Islander people died from pancreatic cancer.

Cancer Australia is developing a [National Pancreatic Cancer Roadmap](#) (the 'Roadmap') to identify key priority areas for action over the next five years, across the continuum of pancreatic cancer care and pancreatic cancer research, to improve outcomes and survival for people affected by pancreatic cancer. The Roadmap will be for people affected by pancreatic cancer, health professionals, researchers, pancreatic cancer organisations, non-government and government organisations and funders and, will guide evidence-based research and best practice care to improve experiences and outcomes for people affected by pancreatic cancer.

Roadmap development

Development of the Roadmap has followed a consultative and evidence-based approach, with a comprehensive review of the evidence and multifaceted stakeholder engagement at its core. Consumer consultation has built on the efforts and expertise of the non-government sector. All development activities have been overseen by an expert Steering Group. Evidence gathering activities and stakeholder engagement has included:

- Review of the national and international literature to identify gaps and opportunities in pancreatic cancer, treatment and care, aligned to the *Optimal care pathway for people with pancreatic cancer*
- Review of pancreatic cancer research funding across the continuum of pancreatic cancer
- Review of pancreatic cancer clinical trials across the continuum of pancreatic cancer
- Mapping of treatment and care against the *Optimal care pathway for people with pancreatic cancer*
- Review of Multi-Agency Data Integration Project (MADIP) data to identify socio-demographic characteristics of people with pancreatic cancer
- Public consultation through the Department of Health's Consultation Hub
- Targeted consultations with priority populations including Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people, people from regional and remote areas, and people from lower socio-economic areas.

Development of the Roadmap is aligned with the [Optimal care pathway for people with pancreatic cancer](#). Deciding key priority areas and associated strategies for inclusion in the

Roadmap will be achieved through a consensus-based modified Delphi process with key stakeholders, underpinned by the Roadmap Principles (Table 1) and prioritisation criteria.

Table 1: 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 and 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 *Optimal care pathway for people with pancreatic cancer* with reference to the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*.

Purpose of this discussion paper

The purpose of this discussion paper is to provide context to the 'long list' of key priority areas that key stakeholders will be asked to consider via participation in the Delphi survey Round 1. This Delphi survey is the first step in agreeing priority areas for inclusion.

Key stakeholders invited to participate in the Delphi process and associated stakeholder workshop include 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.

Delphi process

Stakeholders receiving this discussion paper will also receive a link to an online Delphi survey. The aim of the Delphi process is to reach consensus on key priority areas for improving outcomes for people affected by pancreatic cancer. The Delphi technique is a validated approach for establishing consensus on core outcomes and consists of iterative surveys to gain consensus among an expert panel. A two-round modified Delphi survey will be conducted to engage participant experts in setting key priority areas for the Roadmap. Key experts in pancreatic cancer, including consumers who are experts through experience, have been invited to participate in the priority setting exercise directly, or via 'snowballing' where key stakeholders refer on to other relevant stakeholders within their networks.

Delphi survey round 1

The first round Delphi survey design is quantitative and describes a 'long list' of key priority areas for improving outcomes at each step of the *Optimal care pathway for people with pancreatic cancer*, and for supportive care more generally, as well as for research and data. Participants will be invited to answer the below question when considering the long list of key priority areas:

What key priority areas are important to improve outcomes for people affected by pancreatic cancer?

Participants will be invited to rate each key priority area on a 7-point Likert scale where 7 is very important and 1 is not important. Participant responses will be collated and analysed and key priority areas will be subsequently categorised as 'keep', 'consider' or 'remove'.

Delphi survey round 2

A subset of the Delphi survey participants will be invited to a stakeholder workshop to discuss the 'consider' key priority areas to further explore any barriers and enablers realising these priority areas in practice. Following discussion, participants will be invited to complete Delphi survey round 2, where the 'consider' key priority areas will be further refined. The Delphi design, question and analysis will be the same as for Delphi round 1.

The 'keep' key priority areas from Delphi survey round 1 and round 2 will be recommended along with strategies for implementation for the National Pancreatic Cancer Roadmap.