Have your say on the National Pancreatic Cancer Roadmap

Consultation paper: technical

On 23 March 2020, the Minister for Health, the Hon. Greg Hunt MP, invited Cancer Australia to work with the Department of Health to develop a National Pancreatic Cancer Roadmap (the Roadmap) to support improved outcomes for people with pancreatic cancer.

Cancer Australia is seeking input and submissions from all Australians with an interest in pancreatic cancer to help inform development of the Roadmap.

Consultation paper

This consultation paper is for stakeholders who wish to provide input on the Roadmap through the National Pancreatic Cancer Roadmap Consultation Hub. It includes information about why the Roadmap is being developed, provides a brief overview of known issues across the continuum of care for pancreatic cancer, and outlines the proposed approach to developing the Roadmap.

Why is the Roadmap being developed?

The Roadmap is being developed to support improved outcomes experienced by people diagnosed with pancreatic cancer, including the impact of the disease.

Pancreatic cancer is expected to be the third leading cause of cancer death in Australia in 2020. Five-year relative survival is low, with little improvement seen over the last 30 years. Currently, there are no early detection tests for pancreatic cancer.

What will the Roadmap include?

The Roadmap will identify priority areas for action over the next five years to improve outcomes for people with pancreatic cancer. This will include priorities across the continuum of care for pancreatic cancer as well as research opportunities.

Pancreatic cancer in Australia

It is estimated that in 2020:
- 3,933 people will be diagnosed with pancreatic cancer in Australia (2.7% of all new cancer cases)
- 3,300 people are estimated to will die from pancreatic cancer (6.9% of all cancer-related deaths).

Five-year relative survival for pancreatic cancer is low compared with all cancers combined (2012–2016 data: 10.7% vs 69.2%).

Cancer Australia 2020
Who is the Roadmap for?

The Roadmap is expected to be relevant to, and used by, a range of pancreatic cancer stakeholders including governments, funders, researchers, health professionals, pancreatic cancer organisations and people affected by pancreatic cancer.

Approach to developing the Roadmap

Development of the Roadmap will involve three key components, supported by a set of guiding principles and informed by stakeholder consultation and engagement (see Figure 1).

Figure 1: Overview of the approach to the development of the National Pancreatic Cancer Roadmap

<table>
<thead>
<tr>
<th>Principles underpinning the development of the Roadmap</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Review of research activity</strong></td>
</tr>
<tr>
<td>To identify gaps and opportunities in pancreatic cancer research, including clinical trials</td>
</tr>
<tr>
<td><strong>Evidence review</strong></td>
</tr>
<tr>
<td>To identify the evidence base for management of pancreatic cancer, including gaps and opportunities, across the continuum of care</td>
</tr>
<tr>
<td><strong>Variation in practice</strong></td>
</tr>
<tr>
<td>To identify variations in care compared with the Optimal care pathway for people with pancreatic cancer and with reference to the Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer</td>
</tr>
</tbody>
</table>

Stakeholder engagement and consultation

National Pancreatic Cancer Roadmap

Principles

A set of guiding principles will underpin the development of the Roadmap and the approach to identifying priority areas for action.

A key principle is the importance of building on existing knowledge and experience, including work undertaken to date through the non-government sector.
What will the Roadmap consider?

The evidence-based approach to developing the Roadmap will consider:

- **evidence**, applicable to Australia, about pancreatic cancer across the [Optimal care pathway for people with pancreatic cancer](#), including:
  - contextual information about pancreatic cancer in Australia and burden of disease
  - evidence about best practice care for pancreatic cancer across the Optimal care pathway
  - evidence for best practice strategies for different population groups, including Aboriginal and Torres Strait Islander peoples, people living in rural and remote locations, people from culturally and linguistically diverse communities and those from lower socioeconomic backgrounds
- a **review of research funding and clinical trials activity** in pancreatic cancer in Australia and internationally to identify gaps and opportunities
- a **review of current practice** in pancreatic cancer care compared with the [Optimal care pathway for people with pancreatic cancer](#), to identify gaps and opportunities.

Informing the Roadmap: Optimal care pathways

The [Optimal care pathway for people with pancreatic cancer](#) maps the cancer pathway for pancreatic cancer with a view to promoting quality cancer care and patient experience. The optimal care pathway is underpinned by a set of principles that highlight the importance of:

- patient-centred care
- safe and quality care
- multidisciplinary care
- supportive care
- care coordination
- communication
- research and clinical trials.

In addition to the [Optimal care pathway for people with pancreatic cancer](#), the [Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer](#) highlights the importance of a holistic and coordinated approach to the delivery of cancer care that recognises and is responsive to the needs of Aboriginal and Torres Strait Islander people.
The Optimal care pathway for people with pancreatic cancer highlights a number of issues and considerations across the continuum of care for pancreatic cancer, including:

- information about the aetiology of pancreatic cancer is limited
- symptoms are often non-specific or asymptomatic until advanced stages of the disease process
- there is no recommended population-based screening program for pancreatic cancer
- referral to a gastroenterologist, oncologist or hepatopancreatobiliary (HPB) surgeon with professional expertise in pancreatic cancer management and access to a multidisciplinary team are important
- even if initial treatment outcomes are good, the rate of recurrence is high
- treatment is often given with palliative rather than curative intent, and early specialist palliative care is important
- individualised supportive care should be provided for the individual, their family and carers.

Stakeholder engagement and consultation

Stakeholder engagement is critical to the development of the Roadmap to gain insights and expert advice from people with an interest in pancreatic cancer. This includes people affected by pancreatic cancer (patients, carers, family and friends), health professionals, professional colleges, consumer organisations, cancer organisations, funders, peak bodies, cancer services, Aboriginal and Torres Strait Islander health services and organisations, government and non-government organisations.

Cancer Australia is committed to ensuring an inclusive and consultative process throughout all activities for development of the Roadmap. Stakeholder engagement will include public and targeted consultation processes.

We will engage collaboratively with a range of population groups, including Aboriginal and Torres Strait Islander Peoples, rural and remote communities, and culturally and linguistically diverse groups.

References

