Have your say on the National Pancreatic Cancer Roadmap
Consultation paper: community and individuals

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.

Why is a Roadmap being developed?

The Roadmap is being developed to support improved outcomes experienced by people diagnosed with pancreatic cancer.

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. It will consider all aspects of the cancer pathway, including prevention, early detection, diagnosis, treatment, supportive and palliative care for people with pancreatic cancer, their families and carers.

Who is the Roadmap for?

The Roadmap is expected to be used by governments, funders, researchers, health professionals, pancreatic cancer organisations and people affected by pancreatic cancer.

Pancreatic cancer in Australia

It is estimated that in 2020:

- 3,933 people will be diagnosed with pancreatic cancer in Australia
- 3,300 people will die from pancreatic cancer.

Five-year relative survival is low for pancreatic cancer compared with other cancers. About one in ten people diagnosed with pancreatic cancer are alive five years after diagnosis. In comparison, looking at all cancers together, about seven in ten people are alive five years after diagnosis.

Cancer Australia 2020
How will the Roadmap be developed?

The Roadmap will consider evidence about how to manage pancreatic cancer, research activity and how care is currently being delivered. A set of principles will guide how the Roadmap is developed. This includes the need to build on what we already know, and on work undertaken to date by government and non-government groups. Priorities will consider views and insights from people with a personal and work-related interest in pancreatic cancer. (see Figure 1).

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

<table>
<thead>
<tr>
<th>Review of research activity</th>
<th>Evidence review</th>
<th>Variation in practice</th>
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<tbody>
<tr>
<td>To identify gaps and opportunities in pancreatic cancer research, including clinical trials</td>
<td>To identify the evidence base for best-practice management of pancreatic cancer, including gaps and opportunities, across the continuum of care</td>
<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>
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Stakeholder engagement and consultation

National Pancreatic Cancer Roadmap

Informing the Roadmap: Optimal care pathways

An important part of the Roadmap will be to look at how care is currently provided for people with pancreatic cancer. Current care will be compared with the Optimal care pathway for people with pancreatic cancer and with reference to Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer. Together, these Optimal Care Pathways provide guidance for health services about how to deliver care that meets the needs of people with pancreatic cancer.

The Optimal Care Pathway for people with pancreatic cancer highlights some important issues. These include the fact that symptoms of pancreatic cancer are often quite vague, meaning that pancreatic cancer is often not diagnosed until it is at an advanced stage. 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.
Have your say

Cancer Australia is inviting the public to have their say on the Roadmap through a dedicated Consultation Hub. All interested stakeholders are invited to have their say.

We welcome feedback from members of the public and people with pancreatic cancer, their families and carers. We are keen to hear from Aboriginal and Torres Strait Islander communities, people from all geographic locations, age groups, ethnic and cultural backgrounds. We are also seeking input from people with a work-related interest in pancreatic cancer.

Questions to consider

When answering these questions, think about all aspects of the cancer pathway, including prevention, early detection, diagnosis, treatment, supportive and palliative care for people with pancreatic cancer, their families and carers.

Please highlight any issues related to where people live and / or their cultural or social background that you think may need to be considered in the roadmap.

1. What do you think are the most important issues to be addressed in pancreatic cancer in Australia? Think about all aspects of the cancer pathway including prevention, early detection, diagnosis, treatment, supportive and palliative care for people with pancreatic cancer, their families and carers.

2. What do you think could make the biggest difference to improving outcomes for people with pancreatic cancer in Australia?

3. Are their unique or special challenges and considerations for specific population groups with pancreatic cancer?

4. What do you think are the main challenges and opportunities in the clinical care of pancreatic cancer in Australia?

5. What do you think are the main challenges and opportunities for research into pancreatic cancer (including basic research and clinical trials)?

6. Do you have any other comments and / or insights from your own experience with pancreatic cancer that you think would be helpful to inform the roadmap?

References