



Inquiry: The Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer.

Date: 31 August 2023

Subject: Addressing Disparities in Pancreatic Cancer Care in Australia

We represent PanKind, The Australian Pancreatic Cancer Foundation, dedicated to advocating for improved health outcomes, well-being, and care of pancreatic cancer patients and their families in Australia. Our involvement with patients and their families provides firsthand insight into the profound challenges and heartbreak that pancreatic cancer brings. We understand the devastating impact of a pancreatic cancer diagnosis, especially when that cancer offers so little hope.

A Decade in Retrospect: The Stark Reality of Pancreatic Cancer:

Human Loss:

Over the last ten years, pancreatic cancer has taken away 34,000 Australians, leaving gaping holes in families, friendships, and communities.ⁱ

Its mortality rate, stagnant for decades, is chilling: only 12.2% of patients live beyond five years post-diagnosisⁱⁱ, a grave contrast to survival rates for cancers like breast and prostate.

The rapid progression of this cancer is deeply troubling: 50% of deaths occurring within five months of diagnosisⁱⁱⁱ.

Community Engagement and the Quest for Information:

In the last four years, our website has been visited by 340,000 individuals, indicating an urgent and large-scale quest for information, support, and understanding.

Patient stories, which often serve as rays of hope and vital sources of information for many, have been accessed 82,000 times. These narratives underscore the human dimension of the medical statistics and policy debates.

PanKind's Involvement and Investment:

Research Funding:

Since 2010, we've invested \$12 million into pancreatic cancer research.

Notably, \$1.5 million has been allocated to the PanKind Early Detection Initiative, reflecting our commitment to early diagnosis, and enhancing survival rates and quality of life.

Patient Support:

Beyond research, our Foundation directly offers supportive care resources to pancreatic cancer patients.

In a bid to ensure comprehensive outreach, these crucial resources are also disseminated to nearly 400 clinical centres across Australia for distribution to their patients.



Core Challenges:

Time: Difficult early diagnosis due to non-specific symptoms often results in late-stage detection.

Traction: The deadly efficiency of pancreatic cancer results in limited visibility, reduced public awareness, and consequently, decreased research funding.

Treatment: Lack of effective treatments, compounded by the absence of early detection methods, makes this disease especially ruthless.

Underfunding Amidst Immense Need:

Despite its grievous impact, pancreatic cancer research is disproportionally funded in Australia, even as it stands as the 3rd most common cancer killer in our nation.

Recommendations for Urgent Implementation:

- **Boost Funding for the National Pancreatic Cancer Roadmap:** Recognise and provide additional funding for the essential work of the National Pancreatic Cancer Roadmap, managed by Cancer Australia, in identifying and quantifying equity challenges in this space and coordinating a national effort to address patient outcomes.
- **Bolster coordination of care for patients:** The aggressive progression of pancreatic cancer demands a coordinated plan to ensure that patients receive swift, effective, and compassionate care at every stage of their journey.
- **Immediate Access to Patient Support Resources Post-Diagnosis:** Assist us in promptly identifying and reaching out to patients immediately after diagnosis. This timely intervention can be crucial in offering them vital supportive care, addressing their unique needs, and ensuring they are not navigating this journey in isolation.
- **Amplify Research Funding:** It's essential to boost funding for research until pancreatic cancer survival rates rise to at least the level of other major cancers. As survival rates for other cancers have improved due to focused research and intervention, it's time pancreatic cancer patients benefitted from the same commitment.

In our mission, we carry the hopes and pleas of thousands for ***equitable outcomes for pancreatic cancer patients***. However, our goals far exceed our individual capacity. A collective, national effort — encompassing funding, awareness, policy advocacy, and medical research — is paramount.



Today, we stand at a juncture. We can let pancreatic cancer remain an almost certain death sentence, or we can take robust measures to rewrite this narrative. We urge the Senate Inquiry to consider our recommendations and set in motion a series of actions that will alter the course of pancreatic cancer in Australia.

Thank you for your attention and commitment to this critical issue.

Warm Regards,

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Footnotes:

This submission not only highlights the clinical and research-based challenges associated with pancreatic cancer but also underscores the profound human cost of the disease. The poignant narratives of those affected, combined with hard data, present an undeniable case for urgent and comprehensive action.

ⁱ <https://ncci.canceraustralia.gov.au/outcomes/cancer-mortality/cancer-mortality>

ⁱⁱ Australian Institute of Health and Welfare (2022) Cancer data in Australia, AIHW, Australian Government, accessed 10 October 2022. Retrieved from <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia>

ⁱⁱⁱ Burmeister E, *et al.* Patterns of Care in Pancreatic Cancer. *Pancreas* 2015; **44**(8): 1259-65.