### 티있 THE CANCER OF O UR GENERATION THE TIME FOR ACTION



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Cancer is a devastating diagnosis for both the individual and their loved ones. However, thanks to advances in medicine, research and government action - many cancers have treatment options and good survival prospects, but most importantly, hope.

However, when it comes to pancreatic cancer - this hope is in short supply. Despite being one of the most lethal cancers, it receives a fraction of the total cancer funding dedicated to research, patient support and treatment.

It is a travesty that a cancer which will kill around 3,000 people this year is not a higher priority.

This report seeks to underline the reasons behind this and more importantly chart a path to a future where this can be tackled. It is of vital importance that we can change this for the approximately 3,300 people diagnosed each year<sup>1</sup>.

Just how bad is it? Put plainly, for far too many people, pancreatic cancer is a death sentence. If you are diagnosed tomorrow, there is only a 9.8% chance you will be alive in five years<sup>2</sup>. And that's a number that has remained static for forty years.

To draw an accurate comparison, these numbers are vastly different for other cancers. Both breast and prostate cancer, the chances of being alive are 91% and 95% respectively<sup>2</sup>.





While we applaud the advocates of other cancers who have driven changes in these conditions - now is the time to apply the same focus to pancreatic cancer.

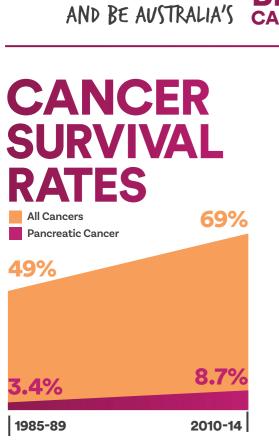
In 2019, as a society, we should not accept that the kind of cancer a person is diagnosed with has such an impact on their survival levels. The Avner Pancreatic Cancer Foundation is calling on government to break this vicious cycle.

A dedicated focus on the disease over the next five years, particularly around research and supporting current patients, will help us end this cycle and put us on the path to a future with hope for people living with pancreatic cancer.

As a Foundation, our mission is simple to dramatically increase survival rates for pancreatic cancer sufferers. However, the scale of the task means we cannot accomplish this on our own. Without more research funding from both government and non-government sources, pancreatic cancer will remain the cancer of our generation.

> This year virtually the same number of people will die from pancreatic cancer as breast cancer.

# THE CRISIS IN NUMBERS

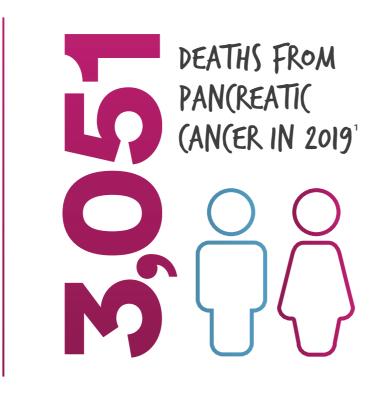


WITHOUT ACTION, EXPERTS

BELIEVE PAN(REATI( (AN(ER,

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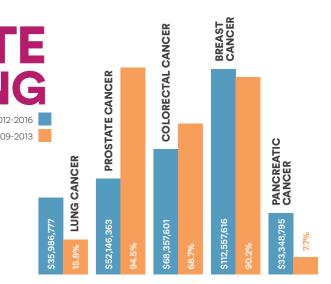
FIVE YEAR SURVIVAL RATE<sup>2</sup>

#### SURVIVAL RATE VERSUS FUNDING

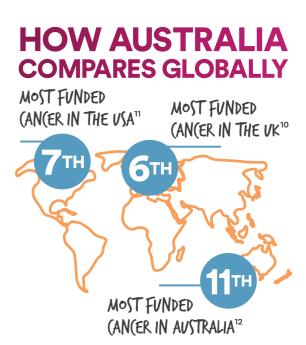
5-year relative survival from selected cancers 2009-2013







Pancreatic cancer is the 11th most funded cancer for research by the Australian government through the National Health and Medical Research Council<sup>5</sup>, despite being the 5th most common cancer killer in Australia<sup>6</sup>.



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# HOW DID WE GET HERE?

The core drivers of the pancreatic cancer crisis Australia finds itself in can be traced back to three core issues: Time, Treatment and Traction.

#### TIME: We only have a short window to fight back

Pancreatic cancer is a devastating disease - it is also incredibly difficult to diagnose early, which creates its own issues. It has no distinct symptoms or clear early warning signs. Therefore, often when a patient is diagnosed, they are close to death. This short duration creates challenges from a research perspective. It means having a cohort or group of patients to study and learn more about the disease from, as well as monitor the value of potential treatments much more difficult. The time factor also prohibits the creation of clinical networks and support systems. Pancreatic cancer is cruelly and ruthlessly effective.



#### TREATMENT: Hard to treat means hard to discover treatments

The less time you have to study a cancer, the harder it is to develop effective treatments, and the clock is cruelly against those with pancreatic cancer. The tight window of time has a direct correlation with the availability of treatments, and it's not just treatments, but early detection too, there is currently no early detection test for pancreatic cancer. It is also a devilishly determined disease. Recent advances in types of therapy that have had a transformative effect on other cancers, have yet to show any promise in pancreatic cancer. This lack of treatment fails patients – but it is within a system of funding and public policy that this has been allowed to take place.

#### TRA(TION: Out of sight, out of mind

The low visibility of pancreatic cancer, thanks in no small part to its destructive efficacy, has led to a lack of public knowledge, public funding and research into this condition. It is therefore harder for the broad research community, and by extension the pharmaceutical industry, to invest time and research into pancreatic cancer. While there is a dedicated core group of researchers seeking to understand more about the disease, more must be done to encourage research, back translation and support current patients. Pancreatic cancer receives the lowest research funding from the NHMRC out of the top 5 cancers by mortality<sup>3</sup>, despite the shockingly low levels of survival. The Avner Foundation feels it is this disparity that shows pancreatic cancer is not just a health issue, but one of equity and fairness. Now is the time to focus on this national tragedy.

# THE NATIONAL RESPONSE NEEDED

The time for discussion on pancreatic cancer has passed. The shocking numbers associated with this disease tell a story thousands of words could not, and that is a story of inaction that cannot go on.

The Avner Pancreatic Cancer Foundation has been driving change in the sector, supporting a group of brilliant and dedicated researchers fighting to change the story for those living with pancreatic cancer.

To date, the Foundation has invested over \$7.6m in 28 high calibre research projects. These are primarily in early stage medical research initiatives.

However, research takes time. Time people living with pancreatic cancer do not have. We must, as a society, work together to dramatically accelerate the progress in this disease. This is why we are calling on others, including the government, to work with us to change this story. Australia should be commended for its broad response to many cancers. However, pancreatic cancer, for the reasons outlined in this report, has been left in the 'too-hard basket' for too long. This isn't about taking a disease response from good to great, it is about tackling an inequality thousands of Australians have lived, and died with, for too long.

The Avner Pancreatic Cancer Foundation is calling for urgent action on this issue and presents a blueprint for action.

# WHAT THIS RESPONSE SHOULD LOOK LIKE

We believe an approach that significantly accelerates research discovery, supports today's patients and provides a platform for a greater understanding of the condition is the way forward. Supporting our world class researchers, frontline healthcare professionals and today's patients will hopefully reduce the number of patients tomorrow.

#### \$52 million over five years will allow us to:



To broaden our understanding of pancreatic cancer: There are four key areas that are of paramount importance that require urgent and significant funding support:

- Identification of biomarkers, that is essentially triggers or signs of the disease, so we can hopefully develop early detection tests to boost patient survival hopes
- Learn more about why pancreatic cancer is traditionally resistant to even the most advanced cancer therapies
- > Understand the pancreatic cancer microenvironment in greater detail
- Identify novel therapeutics including the repurposing of existing medicines



The devastating pace of pancreatic cancer means there is little time for the traditional support structures and patient hubs to be developed that are commonplace in other cancers. This in turn sees patients suffer and die in silence and exacerbates the lack of voice, lack of understanding and lack of action.

By galvanising this group together, we create a single pathway to ensure every Australian affected by pancreatic cancer can gain instant support, guidance and care.

In addition, by unifying these patients, their carer's and healthcare professionals, we will be creating a unified body who can advocate for change and explain their unique challenges to relevant stakeholders.

#### A NETWORKS OF EX(ELLEN(E FOR PATIENT TREATMENT

There is a passionate and expert group of clinicians across Australia who are dedicating their lives to improving the sentence imposed on those unlucky enough to have pancreatic cancer. However, they are missing a vital piece of the puzzle; a common place to share their knowledge on methods, treatment and diagnosis.

Without a collaborative approach to the disease, and the establishment of a framework to connect pancreatic cancer specialists across Australia, there won't just be a disparity among the different cancers, there will be a disparity among those with pancreatic cancer, whose fate will be determined by their postcode.

So, by creating a Network of Excellence for Patient Treatment it will allow clinical and research experts to trial and error together in their quest to find a cure that works, faster. As at this stage in the pancreatic cancer cycle, the more cooks the better.



The Avner Pancreatic Cancer Foundation is calling on advocates, consumers, researchers and clinicians to work together to implement this clear plan to improve survival for people affected by pancreatic cancer.

Without action, experts believe pancreatic cancer, will follow other countries and be Australia's second biggest cancer killer. In the US, pancreatic cancer will reach that status in the next 12-24 months. We can be the generation that stops this progression. We can slow it. We can even reverse it. But we cannot do anything without inclusive commitment to action.

We need to stop pancreatic cancer; before it becomes the cancer of our generation.

# **APPENDICES: OUR PLAN - IN**

#### CHANGING THE GAME WITH A MEDICAL RESEARCH STRATEGY

#### **RESEAR(H PROGRAMS**

Identification of new biomarkers and technologies for prevention, early intervention and early detection.

Unravelling pancreatic cancer's resistance to conventional chemotherapy and radiotherapy.

Understanding the pancreatic cancer microenvironment.

Identifying novel therapeutics including the repurposing of existing medicines and immunotherapy.

#### PROGRAM RATIONALE AND OBJE(TIVE

Early detection could improve survival significantly. Identifying biomarkers for pancreatic cancer would allow earlier, less invasive diagnosis, leading to better survival rates.

There is an urgent need to learn more about pancreatic cancers innate resistance to conventional therapies. The most promising treatment regimens need to be tested through a national program of clinical trials. Supporting clinicians to create national guidelines of best practice

In the pancreatic micro-environment or "stroma", tumours are protected from the body's natural defences by a dense, collagenous tissue.

A greater understanding of the microenvironment can lead to new strategies to treat pancreatic cancer growth, metastasis and improved drug delivery to the tumour site.

Treatment for patients, especially with advanced disease, is limited and often ineffective. New approaches to treatment are required, including new treatments and the use of combination strategies.

#### OUT(OMES FROM INVESTMENT

Improvements in early detection will be a breakthrough in pancreatic cancer survival. Patients diagnosed in time for surgery have 5-year survival rates approaching 30%.

A systematic, national program of clinical trials of conventional chemotherapy and radiotherapy would be world leading, resulting in a more personalised approach with patients receiving correct therapies and avoiding toxic, futile treatments.

Investment in increasing the understanding of the pancreatic cancer microenvironment would create new druggable targets, improve the ability of cancer treatments to reach the tumour and may alter the ability for the tumour to respond to treatments, including immunotherapy.

New approaches to treatment for pancreatic cancer, including immunotherapeutic approaches, may lead to the success seen in other cancers. Investment in clinical trials for pancreatic cancer would allow Australian's to have access to potentially effective medicines before they become otherwise available.

#### CARING FOR TODAY'S SUFFERERS WITH A PATIENT SUPPORT HUB

#### PATIENT AND (ARERS HUB OVERVIEW

DETAIL

Pancreatic cancer presents unique and confronting challenges for patients and carers.

The absence of survivors and an unconnected pancreatic cancer community mean that the support for PC patients and carers is fragmented or non-existent.

This is an unacceptable situation, where patients and carers are suffering – and dying – in silence. Things will not change until these patients and carers have a vehicle that will deliver a voice, support, resources, facilities, services and encouragement for them to pursue better outcomes.

Primarily, a PC Patient Hub will organise and galvanise the current disparate community of patients, carers and professionals – in doing so it will create a powerful vehicle to facilitate significant and urgent improvement.

#### RATIONALE AND OBJECTIVE

Putting **patients at the centre** of the effort to create real change is the natural place to start.

This will drive co-operation and funding from the medical, corporate and political communities, which will in turn urgently inform and address unsatisfactory patient care and provide much needed momentum toward improved survival rates.

Through the Hub we will facilitate the engagement, monitoring and support of patients and carers to address their medical and psychosocial needs.

This will **build trust and facilitate direct involvement,** identifying the PC patient and carer community and provide a platform for communication and engagement.

#### OUT(OMES FROM INVESTMENT

The primary benefit of the PC Patient and Carers Hub is that every Australian affected by pancreatic cancer will gain **instant access to advice, support and direction,** meeting an urgent need for patients with only months to live.

PC Patient and Carers Hub will:

- Guide patients to practitioners, facilities and support services
- > Provide a network for the community to garner support and share experiences.
- > Unlock access to patient data for use by the medical fraternity via:
   > Patient and carer feedback
- Patient involvement in crucial medical trials.
- Become a 'virtuous loop', driving progress with improved outcomes in research trials, diagnosis, treatment and awareness.

As a virtual facility, the **Hub will be established** quickly and efficiently.

### THE BIOLOGY **OF PANCREATIC** CANCER

Your pancreas is a critical part of your digestive system. It secretes pancreatic juice containing digestive enzymes that help digest food, and it secretes hormones such as insulin that regulate sugar levels in the blood<sup>13</sup>

Pancreatic cancer occurs when abnormal cells in the pancreas grow out of control. It can occur in the head, body or tail of the pancreas, but about 70% of Pancreatic cancers are found in the head<sup>14</sup>.

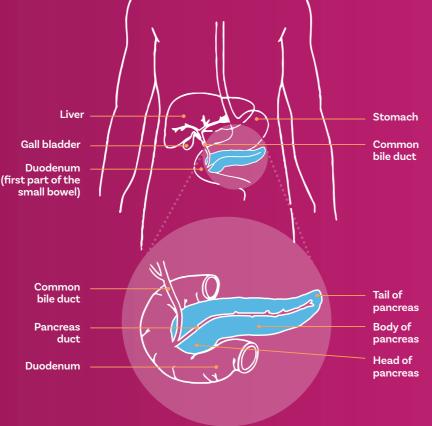


Figure 1. The pancreas in the body e credit: Cancer Council Victori

Early-stage pancreatic cancer rarely causes symptoms. In fact more than 80%<sup>®</sup> of pancreatic cancers have spread from the pancreas to other body organs when they are first diagnosed. It usually spreads rapidly, and in most cases surgical removal is impossible.

# WHAT



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# REFERENCES

- Pancreatic cancer statistics. Cancer Australia.
  https://www.aihw.gov.au/getmedia/8c9fcf52-0055-41a0-96d9-f81b0feb98cf/aihw-can-123.pdf.
   Published 2019.
- Pancreatic cancer statistics. Cancer Australia.
  https://www.aihw.gov.au/getmedia/8c9fcf52-0055-41a0-96d9-f81b0feb98cf/aihw-can-123.pdf.
   Published 2019.
- <sup>3</sup> The Senate. Select Committee Into Funding For Research Into Cancers With Low Survival Rates. Canberra: Senate Printing Unit; 2017:14.
- The cancer of your generation. Avner Pancreatic Cancer Foundation.
   http://www.avnersfoundation.org.au/who-weare/news/the-cancer-of-your-generation/.
   Published 2018
- Parliament of Australia, 28 November 2017.
  'Select Committee into Funding for Research into Cancers with Low Survival Rates - Report'.
   https://www.aph.gov.au/Parliamentary\_Business/ Committees/Senate/Funding\_for\_Research\_into\_ Cancers/FundingResearchCancers/Report
- Australian Institute of Health & Welfare,
  18 December 2018. 'Cancer data in Australia'.
  https://www.aihw.gov.au/reports/cancer/cancerdata-in-australia/contents/summary
- Cancer compendium: information and trends by cancer type. Australian Institute of Health and Welfare.

https://www.aihw.gov.au/reports/cancer/cancercompendium-information-trends-by-cancer/ report-contents/summary Published 2018. Accessed November 1, 2018

 Rahib, L., Smith, B., Aizenberg, R., Rosenzweig, A., Fleshman, J. & Matrisian, L. (2014). Projecting Cancer Incidence and Deaths to 2030: The Unexpected Burden of Thyroid, Liver, and Pancreas Cancers in the United States. Cancer Research, 74(11), 2913-21.

- Learn about Pancreatic Cancer.
  Avner Pancreatic Cancer Foundation.
  http://www.avnersfoundation.org.au/learn/
  Published 2018. Accessed November 6, 2018.
- NCRI Cancer Research Database. The National Cancer Research Institute. https://www.ncri.org.uk/ncri-cancerresearch-database/ Published 2018. Accessed November 10, 2018.
- Research Funding Statistics for FY 2016 Cancer Type. NIH: National Cancer Institute. https://fundedresearch.cancer. gov/nciportfolio/search/ funded?action=full&fy=PUB2016&type=site
   Published 2018. Accessed November 10, 2018.
- Australian Institute of Health and Welfare 2018.
  Colorectal and other digestive-tract cancers.
  Cancer series no. 114. Cat. no. CAN 117.
  Canberra: AIHW.
- Pancreatic Cancer. Radiation Oncology Targeting Cancer.
   https://www.targetingcancer.com.au/treatmentby-cancer-type/pancreatic-cancer/.
   Published 2017. Accessed November 6, 2018.
- Pancreatic Cancer. Cancer Council Victoria. https://www.cancervic.org.au/cancerinformation/cancer-types/cancer\_types/ pancreatic\_cancer. Published 2018. Accessed November 6, 2018.
- <sup>15</sup> Pancreatic Cancer Healthdirect.
  https://www.healthdirect.gov.au/pancreatic-cancer.
  Published 2017. Accessed November 6, 2018.
- 16 Garvan Institure of Medical Research. https://www.garvan.org.au/research/diseases/ cancer-pancreatic

Avner Pancreatic Cancer Foundation PO Box 1216 Manly NSW 1655 Australia **email** info@avnersfoundation.org.au

avnersfoundation.org.au

