



The Pancare Foundation is a national not for profit established in 2011 to increase survival from pancreatic, liver, biliary, oesophageal and stomach cancers, and to provide support to people affected by these cancers. The cancers we represent have survival rates as low as 7% (pancreatic cancer), with little change over the last three decades.

Pancare welcomes the opportunity to provide constructive advice regarding the research funding of cancers with low survival rates on behalf of the 130 Australians who die each week from pancreatic, liver, biliary, oesophageal and stomach cancers.

Pancare advocates for a national strategic approach to improving the survival rates of these cancers. Without a national agenda, the system will continue to deliver very poor survival rates.

It is of national concern that pancreas and liver cancers are projected to surpass breast, prostate, and colorectal cancers to become the second and third leading causes of cancer-related death by 2030, respectively. (<https://www.ncbi.nlm.nih.gov/pubmed/24840647>).

A National, Coordinated Approach from Government is Required

The most important policy matter that underpins the issues faced in funding research for cancers with low survival rates is that there isn't a national strategic plan to increase survival, nor a definition on what constitutes cancers with low survival rates. This translates into uncoordinated plans instead of a long term, national coordinated approach across the government, medical, health and research communities.

"Cancer Australia was established by the Australian Government in 2006 to benefit all Australians affected by cancer, and their families and carers. Cancer Australia aims to reduce the impact of cancer, address disparities and improve outcomes for people affected by cancer by leading and coordinating national, evidence-based interventions across the continuum of care" (<https://canceraustralia.gov.au/about-us>)

Cancer Australia could be tasked via **policy** with the accountability to improve survival rates of these cancers.

Australian **national participation rates are not available for participation in clinical trials** in low survival rates cancers, these should be collected and be publicly available. Transparency would benefit the community, with targets set and publicly reported by Cancer Australia under a goal to increase participation rates.

Alternately, a national government commitment may be in the form of **legislation**, similar to the USA Recalcitrant Cancer Act. (<https://www.congress.gov/bill/112th-congress/house-bill/733>)

The Act calls on the National Cancer Institute (NCI) to develop scientific frameworks, similar to strategic plans, for pancreatic and lung cancers and other cancers with low survival rates. These scientific frameworks help provide the strategic direction and guidance needed to make true progress against low survival rate cancers, which are defined by the statute as those with a five-year relative survival rate below 50 percent.

Like the Recalcitrant Cancer Act, Australian legislation could ensure that:

- Each scientific framework includes a review of the literature and promising advances, examine the number of researchers investigating the cancer and identify opportunities for coordinating Australian research with research at other private and public entities, and identify public and private resources that can facilitate research into each low survival rate cancer.
- The scientific frameworks would be required to identify questions relating to basic, translational and clinical research that still need to be answered; to make “recommendations for appropriate actions” to address these questions; and to advance research in the prevention, detection, diagnosis and treatment of each cancer.

The frameworks could also include “appropriate benchmarks to measure progress on achieving such actions,” including ensuring adequate availability of researchers, promoting and developing initiatives and partnerships, and developing additional public and private resources.

The current NHMRC funding model for research is a ‘once size fits all approach’ is designed to favor research where there is already a well-established evidence base. Cancers with low survival rates do not have the advantage of previous decades of research infrastructure. Additionally, the grant funding rounds favours short term programs of research. By comparison there is less previous research to provide the data of the strength required for competitive funding rounds. Like the 2011 Government budget measure (*Strategic investment in mental health research priorities through the National Health and Medical Research Council (NHMRC) - \$26.2 million over the next five years.* (<https://www.nhmrc.gov.au/research/strategic-investment-mental-health-research-priorities>) a similar budget measure could be introduced into NHMRC funding to provide strategic investment into pancreatic cancer or other cancers with low survival rates over a number of years.

A Clinical Quality Registry could be developed for each low survival rate cancer. These registries have been shown to improve quality of care by bench-marking risk-adjusted indicators that measure compliance against best-practice. Once available the registry data allows research initiatives to be prioritized based on where such evidence suggests there is the greatest need.

Measuring quality of care has been associated with a 20% improvement in survival by improving care based on the current evidence base. The technology and expertise exists to develop clinical quality

registries exists and some seed funding has been received for an oesophago-gastric cancer, pancreatic, biliary and primary liver cancer clinical quality registry although these will need additional funding to capture all Australian patients in the medium to longer term.

It is well known that treating pancreatic cancer presents distinctive challenges and requires highly specialised care to achieve optimal outcomes. A recent study in Medical Journal of Australia noted fewer patients receive the recommended treatment than expected; that care is inconsistent and that socio-demographic factors influence the treatment of patients with pancreatic cancer. The study concluded that treating patients in centers with a higher pancreatic cancer case volume is associated with improved survival. ([Elizabeth A Burmeister, Dianne L O'Connell, Susan J Jordan, David Goldstein, Neil Merrett, David K Wild, Vanessa L Beasley, Helen M Gooden, Monika Janda and Rachel E Neale Med J Aust 2016; 205 \(10\): 459-465](#)).

Patients across Australia do not have access to information about treating hospitals to facilitate decisions about where to go to for treatment to receive optimal care that has been shown to maximize survival. **A system of recognition for Centers of Excellence** in pancreatic or other cancers with low survival rates, could be developed by the Australian Commission on Safety and Quality in Health Care (<http://www.achs.org.au/achs-nsqhs-standards>) to improve the quality of health service provision for people affected by cancers with low rates of survival in Australia. Special criteria for recognition could be developed, with the program of recognition aligned to the various state hospital accreditation programs to minimise the administrative burden.

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