



cancer voices **australia**

**Cancer Voices is the independent, volunteer voice of people affected by cancer - since 2000.**  
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Committee Secretary  
Select Committee into Funding for Research into Cancers with Low Survival Rates  
Department of the Senate  
PO Box 6100  
Canberra ACT 2600

### **Cancer Voices Australia**

Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the consumer perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. Its networks work together on national issues identified as important, with consumers working to help others affected by cancer.

We appreciate the opportunity to provide a submission on the important matter of the impact of health research funding models on the availability of funding for research into cancers with low survival rates.

### ***Data***

Cancer Voices Australia notes that information about the inquiry does not provide a definition of 'cancers with low survival rates'. This provides an opportunity for the inquiry to develop an agreed definition of "cancers with low survival rates", which then creates an explicit group of cancers for greater consideration in future funding models. Cancer Voices Australia suggests that 'cancers with low survival rates' be defined as those cancers with low five year survival, that is, less than 30% five year relative survival rate (Cancer in Australia 2017, AIHW). These include:

- mesothelioma - 5.8%
- pancreas – 9.3%
- other digestive organs - 10.5%
- cancer of unknown primary – 13.3%
- lung – 15.8%
- gallbladder – 19.2%
- oesophageal – 20.1%
- brain – 22.1%
- acute myeloid leukaemia – 26.8%
- stomach – 28.5%

It must be recognised however that there are more rare cancers than those identified above and that these cancers should not be overlooked when considering research funding for cancers which currently have a low survival rate. These include childhood cancers and 'common cancers' that have rare status due to genetic knowledge.

There is also a need to gather data in order to better understand cancer biology and to consider funding for targeting cancers by their mutations and not just their location. Such an approach may offer the best opportunity to improve survival rates for people with rare and low survival rate cancers.

There is no available national data collection that identifies clinical trials for low survival rate cancers or the number of participants in such trials. There is no national repository for cancer research projects leading to potential for duplication and omission of important research projects, particularly for cancers with low survival rates. Such a repository could assist in building more collaborative approaches to research into these cancers and assist in attracting funding from both public and private sources.

Improvement in cancer outcomes has not been consistent. What we do know is that breast and prostate cancers attract far greater funding than less well known cancers which in turn impacts on survival rates. While the more prolific cancers affect more people, more people die from those less well researched. Cancer Australia report that rare and less common cancers receive about 20 per cent of cancer funding, even though they account for 50 per cent of cancer deaths. While funding for cancers with high survival rates is supported, it should not be at the expense of cancers with low survival rates. The current variation in survivorship outcomes is inexcusable and exacerbated by current funding models.

### ***A National Cancer Research Strategic Plan***

We are appalled that in a wealthy country such as Australia there is no National Cancer Research Strategic Plan. Such a document, co-designed by key cancer survivors, researchers and health care providers, would provide greater transparency of the focus and priorities for research funding. In the absence of a national plan, the current model of funding is not equitable in allocating funding to cancers with low survival rates and has resulted in a limited evidence base for these cancers. A National Cancer Research Plan should embed funding into cancers with low survival rates and require the establishment of a register for each cancer. This should include funding for the multiple and cumulative reasons for low survivor rates, for example, late or incorrect diagnosis, lack of access to appropriate therapies and clinical expertise, the very limited number of clinical studies due to the small number of patients and the apparent lack of interest in developing new therapies due to market limitations.

A national plan should include targets for research into cancers which currently have low survival rates, while at the same time providing a national focus for research into all cancers. A national plan should also support collaborative, baseline work, so necessary in identifying and prioritising gaps in research with consumers, researchers and health care providers to set research actions plans for cancers with low survival rates. Annual reporting to Parliament on progress towards targets in the plan should be mandatory. In addition it is recommended that the Australian Institute of Health and Welfare establish routine reporting of the category 'cancers with low

survival rates' to collectively report on the incidence and overall proportion of mortality contributed by this group, and to track positive or adverse changes within this group. It is also suggested that as part of this reporting rare cancers and higher incidence, but low survival cancers, are separately reported.

A National Cancer Research Plan and associated registry could provide information to the public about sites where research into cancers with low survival rates is occurring so that cancer survivors, their carers and the public can access information about treatment options, and cancer researchers can see opportunities for collaboration and/or innovation. Cancer Voices believes a new funding model should address identified unmet needs and move away from clinical trials that propose marginal improvement in care, particularly as more subsets of cancers are identified.

### ***National Collaboratives***

Cancer Voices believes funding criteria should include active collaborative research, within and across institutions. Creating a network of researchers, scientists, physicians, consumers, and potentially senior high school students, post graduate students and students of the University of the Third Age, would support innovation, clinical research capacity, understanding, improvement in methodology and enable the translation and publication of research in a more timely manner than currently occurs.

An open approach is supported, whereby institutions are not given a competitive advantage over other institutions and all funded researchers are required to provide timely feedback on what is being accomplished as a result of funding received.

A national cancer plan could embed a team approach to research with researchers working on a common research agenda, building capacity and supporting cooperation amongst teams of researchers. A team approach could maximise the infrastructure required to progress research, including, equipment, biobanks, data repositories, facilities and technical services.

In terms of funding support for national campaigns designed to raise awareness of the need for further research, including clinical trials, it is recommended that this form part of an overall national plan, with a particular focus on the need for further research and the importance of clinical trials as an integral part of this. It must be said however that any campaign must only be conducted alongside a real increase funding and access for participants in clinical trials, or it will result in further despair and distress for people with cancers with a low survival rate. A campaign should not detract from actual research which makes a difference in outcomes for people with cancers with low survival rates.

### ***International Collaboratives***

A reserve for rapid funding of international collaborative work in priority areas of health and medical research, capable of leveraging multiple agency, discipline, and industry investment is supported by Cancer Voices Australia.

The International Rare Cancers Initiative is a joint initiative between Cancer Research UK, the National Institute of Health Research Clinical Research Network: Cancer, the National Cancer Institute, the European Organisation for Research and Treatment of Cancer, the Institut National

Du Cancer and the National Cancer Institute of Canada Clinical Trials Group.

This initiative aims to facilitate the development of international clinical trials for patients with rare cancers in order to boost the progress of new treatments for these patients. The initiative hopes to encourage the use of innovative methodologies to maximise the potential for answering research questions and to identify and overcome barriers to international trials to allow international collaborative trials to run smoothly. It is recommended that Australia consider joining this collaborative initiative as a way of linking with international experts in rare cancers and those with low survival rates. In this way Australian's can benefit from the accrual base of the cancer research being undertaken in the initiative's member countries.

### ***Funding Process***

Cancer Voices Australia supports changes to the current grants and funding process which disadvantages research into rare cancers and cancers with low survival rates because it requires co-funding, thus favouring partnerships with larger, well funded organisations focused on cancers with high survival rates. The number of survivors of various cancers should not be the only criteria for funding applications, otherwise the disparities in survivorship outcomes will not reduce but continue to grow.

It is recommended that funding models prioritise funding for cancers with low survival rates and that consideration be given to better funding for much needed clinical trials. Such a funding model needs to be cognisant of access to trials for trial participants. Currently access to clinical trials is not uniformly supported by the Patient Transport Assistance schemes, creating inequitable access and a deterrent to trial participation for many in rural and remote areas of Australia. This is not an administrative cost but an essential component of clinical trials.

The new funding model must ensure sustainability of funding for cancers with low survival rates. Cancer Voices believes this will need to be at least a ten year time frame in order to embed research expertise and commitment, through junior to senior research transitions and across the research translation spectrum, from laboratory discoveries to clinical trials and treatment guideline implementation.

A change of the review process is also suggested as reviewers may be less familiar with rare cancers and cancers with low survival rates, with the unintended consequence that cancers with which they are familiar are scored more highly.

### **Recommendations**

In closing Cancer Voices Australia present our recommendations for consideration by the Committee. We recommend that:

1. A clear definition of 'rare cancers' and 'cancers with low survival rates' be articulated.
2. A national data collection that identifies clinical trials for low survival rate cancers and a national repository for cancer research projects be established.
3. The current variation in cancer research funding be addressed, so that cancers with low survival rates receive more than the current 20 per cent of cancer funding, even though

they account for 50 per cent of cancer deaths.

4. A National Cancer Research Strategic Plan is co-designed with key cancer stakeholders, and that consumers with rare cancers and those living with cancers which currently have low survival rates are included in the development of the plan.
5. Annual reporting to Parliament on progress towards targets in the plan be mandatory and that the Australian Institute of Health and Welfare establish routine reporting of the categories of rare cancers, cancers with higher incidence, but low survival, and 'cancers with low survival rates'.
6. Funding criteria should be include active collaborative research, within and across institutions and ensure equitable access to clinical trials for trial participants and their carers, particularly those in rural and remote areas.
7. Any public campaign must only be conducted alongside a real increase funding and access for participants to clinical trials.
8. A reserve for rapid funding of international collaborative work in priority areas of health and medical research be allocated and that Australia become a member of the International Rare Cancers Initiative.
9. Funding criteria be re-examined to: reduce disparities in cancer survivorship outcomes; give priority to cancers with low survival rates, specifically for funding clinical trials with funding being sustainable to grow research expertise and realise translation into treatment guidelines; and consider giving funding to cancers by their mutations and not just their location.
10. The review of research proposals be re-examined to ensure that review panels include people familiar with rare cancers and cancers with low survival rates.

Yours sincerely

*C. E. Christensen*

**Executive Team Member  
Cancer Voices Australia**

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