



Funding for Research into Cancers with Low Survival Rates:
Submission to the Senate Select Committee
March 2017

About Rare Voices Australia:

Rare Voices Australia (RVA) is the national, non-profit, peak organisation for rare disease. RVA works with all stakeholders to influence public policy and advocate for all Australians living with rare disease.

Introduction:

RVA welcomes the opportunity to make a submission to this inquiry. RVA acknowledges the challenges of conducting research for cancers with low incidence (i.e. rare) despite low survival rates and thus urgent need. RVA agrees that these cancers need more research funding, however this is just part of the challenge requiring a systemic response. This is a common feature of rare disease more broadly, and an example of Australia's health system and health research agenda not effectively responding to rare disease. RVA strongly argues for the need for this to be contextualised more broadly as a challenge of the broader rare disease space.

The underlying premise of this Senate Inquiry seems to be that brain cancers and other cancers with low incidence rates (i.e. rare) do not receive a 'fair' or equal amount of funding in comparison with other types of cancer. RVA would argue that a fairer response to research funding is one that is guided by principles of equity and unmet need, rather than equality. The World Health Organisation's Universal Health Coverage programme focus on ensuring that all people have access to preventative, curative and rehabilitative health services: this should be a central focus of health service delivery. This is echoed by the United Nations Sustainable Development Goals and which are underpinned by the mission statement that 'no one be left behind'. Last year in her role with the United Nations, Helen Clark stated "No country can claim to have achieved universal health coverage if it has not adequately and equitably met the needs of those with rare diseases." These principles should also guide the health research agenda.

Terms of Reference

- A) Despite the Terms of Reference being specific to certain cancers, RVA asserts that a broader focus on rare disease is crucial. It is inequitable (and certainly inefficient) to respond to unmet research needs, one disease at a time. While the unmet need of brain cancers and other low incidence cancers is undeniable, low incidence and low survival rate (due to lack of effective treatment) is unfortunately a widespread challenge in rare disease (not just cancer) - including a multitude of rare diseases for which there is even less public awareness. Some rare diseases may only affect a handful of patients in Australia. These patient communities arguably will never be able to advocate for their needs, and influence the research agenda, as effectively as disease with larger patient cohorts or higher community awareness. Without a health research agenda that is responsive to rare disease, these patients will continue to fall through the gaps.

- B) Research is critical for rare disease because the inherent features of rare disease (lack of patient numbers) results in a clear lack of data, evidence and knowledge in rare disease. This has a direct negative impact on diagnosis, patient care, support, development of

With Compliments

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treatments and Government's reimbursement of these treatments (access). Recruitment and funding for clinical trials for rare disease can be difficult. Rare disease research and data collection should be systematically developed and prioritised. Clinical trials into rare diseases should be supported and actively encouraged. For many with rare disease, participation in a clinical trial could be their only way to potentially access any effective treatment.

- C) The urgency of the situation should never be understated. Many rare diseases, and certainly the cancers that are the focus of this inquiry, are progressive and life-threatening. A timely and effective systemic response is urgently needed. RVA has consistently advocated for rare disease to be recognised as a national health priority and called for the adoption of a national rare disease plan or framework. A national rare disease plan would identify and enable approaches to data collection and use that better meet the needs of people living with a rare disease. A nationally coordinated program of research informed by patients and carers needs to be established. Low survival rates and lack of effective treatments should be the primary driver for increased research prioritisation. The burden of rare disease, although largely hidden, is unacceptably high for patients, families, community and the health system. People living with rare disease need equitable and early access not just to coordinated research, but also diagnostics, treatments, services and coordinated care.