Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer

The Senate Community Affairs References Committee is undertaking an Inquiry into Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer. Rare and less common cancers represent one third of diagnosed cancers, and represent more than 40% of cancer deaths in Australia.

Cancer Council Australia partnered with the Cancer Nurses Society of Australia, the Clinical Oncology Society of Australia, the Medical Oncology Group of Australia, the Private Cancer Physicians of Australia and the Lung Foundation of Australia, to make a joint submission to this Inquiry.

Our submission called on the Senate Committee to recommend:

- Dedicated investment in research towards improving detection and diagnosis for rare cancers and neuroendocrine cancer.
- Strengthening the cancer data ecosystem by:
  - Investing in the development of standardised, well-established and specific diagnostic criteria.
  - Recognising the increasing impact of genomics and genomic testing.
  - Ensuring the optimal utilisation of clinical quality registries.
  - Supporting the greater use and integration of real-world data by consulting and partnering with the health care, research, and technology sector and industry.
- Investing in the establishment and funding high volume centres to strengthen access to sub specialist care.
- Providing greater priority to and investment in supportive care services, in partnership with not-for-profit cancer organisations and the community sector.
- Providing investment and incentives to better engage and ensure participation of Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds in clinical trials.
- Directing greater Medical Research Future Fund investment towards rare and less common cancers, including neuroendocrine tumours.
- Continuing investment to implement and embed Optimal Care Pathways.
- Improving the affordability of medicines and the repurposing of medicines.
- Taking a human rights approach that advances equity through addressing needs of priority populations.

Information about the progress of the Inquiry, can be found on the Committee’s webpage.