

Innovative model for treating Australians with a rare disease and those of high unmet need – Petition No. 173

Thank you to the **Honourable Samantha Rowe MLC** for tabling a petition on behalf of WA Neuroendocrine Tumour patients in the Legislative Council on November 10, 2020. We are grateful that the petition has been referred to the Standing Committee on Environment and Public Affairs for further review and would like to supply the following supporting information.

NETs and NECA

Neuroendocrine Cancer Australia (NECA), is the peak not-for-profit body dedicated to **Neuroendocrine Tumours, or NETs** as it is commonly referred.

NETs are indiscriminate. The disease strikes men and women, young and old alike. It is a disease of the endocrine system and is made up of complex tumours that develop predominately in the digestive (GEP-NET) or respiratory tracts (LUNG-NET) but can occur in other areas of the body (skin, ovaries, appendix). Tumours can grow slowly or aggressively, and can secrete hormones that can cause debilitating side effects. NET patients may live with the disease burden (and associated costs) for many years. As a result, they are a highly disadvantaged patient group.

Once categorised as a ‘rare cancer’, the incidence of NETs now surpasses commonly known cancers such as bladder, liver, ovarian, brain and kidney cancers, with more than **4,972 new patients each year**¹. Due to the heterogeneity and lack of awareness of NETs by the community and healthcare professionals, it is vital that patients be referred to a multidisciplinary care team (MDT) based at an expert centre, such as Fiona Stanley Hospital.

Australia plays a leading role in a number of new therapies, such as **Theranostics** which includes Gallium 68 PET scans and Peptide Receptor Radionuclide Therapy (PRRT), which have been shown to be of benefit to NET patients.

Background

NECA was established in 2009 with a vision for early diagnosis and a cure. As such, NECA has been instrumental in supporting clinicians with innovative solutions for treating patients and providing Australian patients with support, information, and specialist referral pathways, and it is through this experience around Australia that has led to the identification of need for a central “centre of excellence” at Fiona Stanley Hospital in WA. NECA sponsors a national neuroendocrine tumour registry (PLANET) housed at public hospitals around the country including Fiona Stanley Hospital.

Due to the emergence of new diagnostic tools and therapeutics across the treatment spectrum for neuroendocrine cancer over the last 5 years, multidisciplinary teams (MDTs) have organically developed into what should be considered a novel disease management system, which sits across a number of specialties within the public hospital system.

There is currently a convergence of a number of different traditional specialties, like surgical procedures and therapeutics, with evolving developments in nuclear medicine, immunotherapies, genetics and big data informatics in a shift towards a more patient specific treatment, or what is termed, **Precision Medicine**.

¹ Cancer Australia www.canceraustralia.gov.au 8y

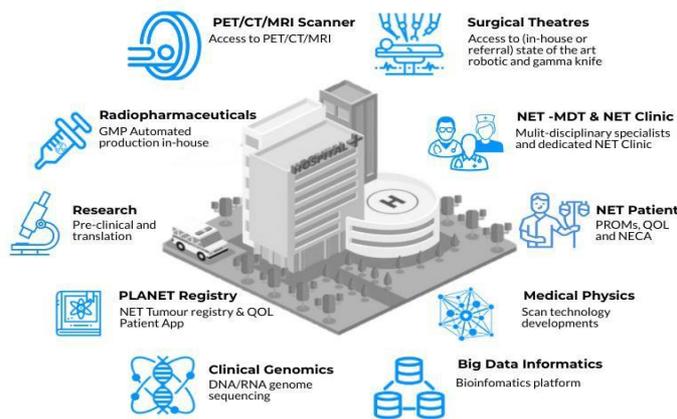
Due to specialised treatments such as PRRT, Neuroendocrine Cancer is one of the most mature areas in precision medicine. Treatment is currently being delivered by Fiona Stanley Hospital (which has considerable experience in this area 15 + years) and a number of public hospitals across Australia.

Leveraging the resident expertise from the hospital campus, alongside local and international pharmaceutical companies, Fiona Stanley Hospital undertakes world leading research and targeted treatment for optimal patient care. We have termed these as **Patient Precision Centre – NETs** and have presented this concept to a House of Representatives Inquiry. It is this framework that we would like to brief the Standing Committee on Environment and Public Affairs and Health Minister Roger Cook, as we believe it may present a solution to meet the needs of many Western Australians that currently fall within the optimal care gap.

We believe our framework for the **Patient Precision Centre – NETs** model solves many of the hurdles that currently exist for patients with rare diseases and provides policy makers with a way to provide equity and access to these patients like it is afforded to the majority of Australians.



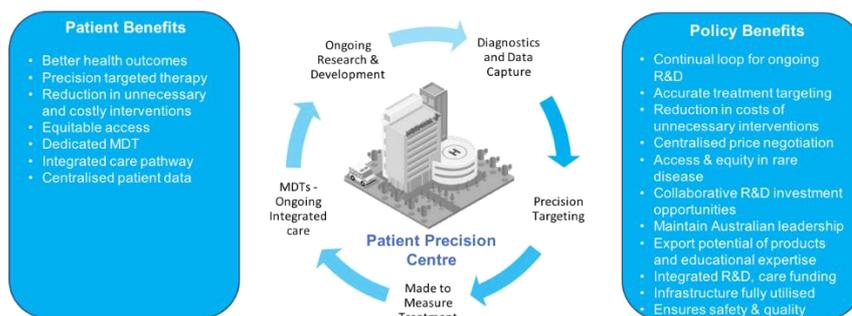
Patient Precision Centre



What benefits do the innovative model deliver?

Primarily the goal is for the most optimal outcome for NET patients. This can only be achieved through referral and access to Patient Precision Centres, world leading specialists and multidisciplinary care and support, and innovative research. This framework ensures the reduction of unnecessary, costly and ineffective interventions and safeguards delivery of the right treatment at the right time.

Benefits of unified research, development and care



Patient Precision Centre: Similar in make-up to other centralised centres of excellence, such as hyperbaric chambers, heart/lung units and burns facilities

This model leverages investments already made in in public health, R&D and technology infrastructure, to maximise the taxpayers return on investment. Currently the infrastructure and expertise is already in place for Fiona Stanley Hospital, we therefore respectfully request the State Government to recognise it as a **State NET Service**, ensuring all WA NET patients are referred for review, treatment and support no matter their geographical location.