New South Wales

Special Commission of Inquiry into Healthcare Funding

Submission Number: 78

Name: NeuroEndocrine Cancer Australia

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NeuroEndocrine Cancer Australia
Champions for early diagnosis and a cure

NSW Government: The Special Commission of Inquiry into Healthcare Funding

NSW Government inquiry submission by NeuroEndocrine Cancer Australia

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NECA respectfully requests to appear at an NSW Health hearing into this inquiry

About NeuroEndocrine Cancer Australia (NECA)

NeuroEndocrine Cancer Australia (NECA) was founded in 2009 and is the only not-for-profit medical charity providing support, information, and advocacy specifically for Australians living with neuroendocrine tumours (NETs). NECA represents more than 24,000 Australians currently living with NETs, last year alone over 5,400 people were diagnosed with neuroendocrine tumours, and each year incidences continue to rise 1.

Over the last 14 years since the inception of NeuroEndocrine Cancer Australia we, as patients and advocates, have worked passionately side-by-side with our dedicated clinicians, nurses, researchers, and specialists to face the many challenges with little assistance from governments.

On a national and international level, we have:

- developed clinical guidelines,
- published studies on unmet needs and quality of life,
- developed and designed patient and healthcare information and education tools,
- funded clinical trials and research including a national tumour registry, and
- funded and facilitated much-needed support through connecting to peer groups and a specialist Telehealth NET nurse service.

All these initiatives have been a first of their kind globally and have been adopted by numerous clinicians and Centres of Excellence across the nation and the world.

NeuroEndocrine Cancer Australia's achievements are wide and wonderful. They have been made possible by the strong partnership with our passionate community whose generosity in time and money makes our lofty vision of success achievable.

Terms of Reference:

A: The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care, and health services to the people of NSW, now and into the future.

Support for NET patients is paramount

Navigating the healthcare system is extremely challenging, especially for a cancer that is little known or understood. Funding for access to further Specialist Neuroendocrine tumour (NET) Nurses through NECA and NSW Health embedded NET Nurse cancer care coordinators would provide NET patients, their families, and the healthcare professional community with access to the timely care they require via communication of vital information regarding

referral pathways, disease, and symptom information, and most importantly a true understanding of the impact this cancer has on their life.

No Government Funding for Specialist NET Nurses in NSW or Australia

NECA recommends funding to be made to NECA for Specialist NET nurses to provide a sustainable service for the 1000's of patients we support. Initially we are only asking for 1 NET nurse per state and territory for the NECA specialist tele-health nurse service.

This need is reflected in Recommendation 21 5.176 from the Select Committee Report into Funding for Research into Cancers with low survival rates (2017); The committee recommends that the Australian government, in conjunction with its state and territory counterparts, works to improve access to specialist cancer care co-ordinators or nurses for low survival rate cancer patients in every state and territory

B: The existing governance and accountability structure of NSW Health, including:

I: the balance between central oversight and locally devolved decision making (including the current operating model of Local Health Districts);

NECA advocates for continued scrutiny of the balance of decision making to ensure rural and regional services are continually assessed for equitable access to cancer services.

ii: the engagement and involvement of local communities in health service development and delivery;

NeuroEndocrine Cancer Australia is the only Australian (inclusive of NSW) charity at the forefront of efforts to raise awareness and understanding of neuroendocrine tumours both within the medical profession and the wider Australian public.

There is a huge inequity in accessing support services for Australian NET patients and their families when compared to the majority of other cancer patients. Currently, the only support available is by way of one full-time specialist NET nurse provided by NECA, to support potentially 24,000 Australians, funded through donations. This is unacceptable.

NECA is at the heart of community patient centred care, support, and resourcing for neuroendocrine cancers as our patients, carers and families, and NET specialised health care professionals are involved at every level across all our operations and as a community funded patient medical charity organisation we strive and vigorously advocate for engagement and involvement at every level of health service development and delivery in

order to truly action patient-centred care delivery. As a Health Consumers NSW taskforce committee member NECA supports closer consultation amongst groups across NSW Health.

Our NET patients are continually impacted by inadequate support services pre, during and post diagnosis, and there is no government funding for full-time specialist NET nurse services for neuroendocrine cancer in NSW – a service requested by our patients, carers, and NET community.

Unlike more common cancers there is no clear diagnosis and treatment pathway for NET patients. Each patient's experience and disease are different, requiring a very personalised approach. For this reason, specialist, dedicated NET nurses are essential in ensuring the patient is informed, feels supported and gets access to the most appropriate treatment and care. With NET patients living longer with active, often debilitating disease, their reliance on these nurses is not one off, or whilst on active treatment, but over many years.

Recommendations to adequacy of support services after diagnosis:

No Government Funding for Specialist NET Nurses in Australia

- Funding to be made to NECA for Specialist NET nurses to provide a sustainable service for the 1000's of patients we support. Initially we are only asking for 1 NET nurse per state and territory for the NECA specialist tele-health nurse service.
- This need is reflected in Recommendation 21 5.176 The committee recommends that the Australian government, in conjunction with its state and territory counterparts, works to improve access to specialist cancer care co-ordinators or nurses for low survival rate cancer

iii: how governance structures can support efficient implementation of state-wide reform programs and a balance of system and local level needs and priorities.

Equitable access to care and standardisation of pathways for excellence in care delivery is documented in every major NSW Health Pillar organisation policy document therefore with consistent support from the highest level of governance implementation can be supported, with each local area supported to identify local level priorities.

iv: the impact of privatisation and outsourcing on the delivery of health services and health outcomes to the people of NSW.

Privatization and outsourcing of cancer care services have increased out of pocket costs for NET patients for tests, treatments, and hospital admissions. According to the authors (Gordan et al) of the research publication ***The Economic Impact on Australian Patients with Neuroendocrine Tumours, "imaging scans, surgery, and travel expenses were the most***

common cost burdens reported by patients", having private health insurance was the key determinant of higher out-of-pocket costs. Poorer quality of life was significantly associated with higher financial toxicity, not working due to cancer, nausea/diarrhoea, two or more comorbidities and younger age. The mean age of the 204 patients surveyed in the study was 59.

(Gordon, L.G., Elliott, T.M., Wakelin, K. et al. The Economic Impact on Australian Patients with Neuroendocrine Tumours. Patient 13, 363–373 (2020). https://doi.org/10.1007/s40271-020-00412-z (Pg. 363-373) 9)

According to ***The Economic Impact on Australian Patients with Neuroendocrine Tumours,*** two-thirds of participants had private health insurance and 69 (34%) were treated in both private and public hospitals. Of those privately insured, insurance did not cover expected expenses for a high proportion of participants (77 [58%]). Between 2 and 25% of participants had been refused some type of insurance product.

Travel can also be a major issue for patients to be seen by appropriate healthcare professionals due to less public healthcare options close by due to service outsourcing and privatisation and also due to the travel assistance schemes in each of the states are not sufficient or equitable. The Senate Inquiry in 2007 stated "Most of the schemes now in place in the States are under-funded, overly bureaucratic and unfairly restrictive. The schemes appear to be process driven and centred around bureaucratic control and management rather than being patient centred and focused on ensuring that Australians living in rural and remote areas have the same access to treatment services as their city counterparts. 16 years later this has not changed.

v: how governance structures can support a sustainable workforce and delivery of high quality, timely, equitable and accessible patient-centred care to improve the health of the NSW population.
an examination of existing skills shortages.

evaluating financial and non-financial factors impacting on the retention and attraction of staff.

existing employment standards.

the role and scope of workforce accreditation and registration.

We will not add to these TOR

C: The way NSW Health funds health services delivered in public hospitals and community settings, and the extent to which this allocation of resources supports or obstructs access to preventative and community health initiatives and overall optimal health outcomes for all people across NSW.

As per TOR point A:

Support is paramount. Navigating the healthcare system is extremely challenging, especially for a cancer that is little known or understood. Funding for access to further Specialist Neuroendocrine tumour (NET) Nurses through NECA and NSW Health embedded NET Nurse cancer care coordinators would provide NET patients, their families, and the healthcare professional community across NSW with further vital information regarding referral pathways, disease, and symptom information, and most importantly a true understanding of the impact this cancer has on their life. Linking our community patient and family organisation expertise and services across NSW Health services via a funded NET Nurse for NSW as requested by our NET patient community will improve overall health outcomes for all people across NSW living with a neuroendocrine tumour. Without funding for a state-wide NSW NET Nurse access to optimal health outcomes and care is severely limited due to the complex nature of this cancer.

D: Strategies available to NSW Health to address escalating costs, limit wastage, minimise overservicing and identify gaps or areas of improvement in financial management and proposed recommendations to enhance accountability and efficiency;

We will not add to these TOR

E : Opportunities to improve NSW Health procurement process and practice, to enhance support for operational decision-making, service planning and delivery of quality and timely health care, including consideration of supply chain disruptions;

We will not add to these TOR

F: The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands and deliver efficient, equitable and effective health services, including:

We will not add to these TOR

the skill mix, distribution, and scope of practice of the health workforce;

the use of locums, Visiting Medical Officers, agency staff and other temporary staff arrangements;

the relationship between NSW Health agencies and medical practitioners;

opportunities for an expanded scope of practice for paramedics, community and allied health workers, nurses and/or midwives;

the role of multi-disciplinary community health services in meeting current and future demand and reducing pressure on the hospital system;

opportunities and quality of care outcomes in maintaining direct employment arrangements with health workers;

G*: Current education and training programs for specialist clinicians and their sustainability to meet future needs, including: placements;*

i: the way training is offered and overseen (including for internationally trained specialists);

We will not add to these TOR

ii: how colleges support and respond to escalating community demand for services;

We will not add to these TOR

iii: the engagement between medical colleges and local health districts and speciality health networks;

NECA advocates for closer collaboration between these entities to ensure currency of curriculums and community demand for care within specialities can be met for example in neuroendocrine cancer access to best care treatments is via multidisciplinary team (MDT) care for NETs in higher volume centres.

In addition to a lack of awareness of NETs in the HCP community, there is a lack of awareness about NET MDT meetings which can result in patients potentially receiving suboptimal care. The complexity of NETs is extremely challenging, and all newly diagnosed patients should be discussed before definitive treatment, so that a treatment plan can be recommended by the MDT for each patient, as per the NET Optimal Care Pathway (OCP). Difficulty of appropriate referrals to NET Specialists – many HCPs do not know who to refer to, including what investigations should be performed prior to referral. Many are naive to the intricacy of NET management and where NET MDTs are located so that management plans can be discussed and implemented. This is a very real issue for HCPs in regional and remote areas.

iv: how barriers to workforce expansion can be addressed to increase the supply, accessibility, and healthcare workers in NSW;

Collaborating with organisations such as NECA to provide a state-wide Telehealth NET Nurse service model of care can remove barriers to a specialised workforce in neuroendocrine cancer care.

***H**: New models of care and technical and clinical innovations to improve health outcomes for the people of NSW, including but not limited to technical and clinical innovation, changes to scope of practice, workforce innovation, and funding innovation; and*

To improve the health outcomes of people in NSW with neuroendocrine cancers, NECA advocates for the establishment of a NSW Health funded position of NSW NET Nurse to provide access via Telehealth models to the ongoing optimal care, support and resources at the minimal level required by NET patients similar to other funded cancers models of care across NSW.

NECA asserts that the government enacts the recommendations from the Select Committee Report into Funding for Research into Cancers with Low Survival Rates (2017) in particular:

Recommendation 9: 5.21 The committee also urges the federal, state and territory governments to consider the proposals made by the Clinical Oncology Society of Australia (COSA), and the role that optimal care pathways (OCPs) and rapid referral clinics could play in improving detection and diagnosis of low survival rate (LSR) cancers.

I: Any other matter reasonably incidental to a matter referred to in paragraphs A to H, or which the Commissioner believes is reasonably relevant to the inquiry.

NECA asserts that the government enacts the recommendations from the Select Committee Report into Funding for Research into Cancers with Low Survival Rates (2017) in particular:

Recommendation 9: 5.20 The committee recommends that the Australian government undertakes communication activities targeted at the public with the objective of reducing the amount of time taken to detect and diagnose low survival rate cancers.

Medication Administration Issues
NET Medications in particular somatostatin analogues (SSAs) should be administered by trained HCPs. A competency/training program should be introduced and maintained through funding to NECA and funded by government.

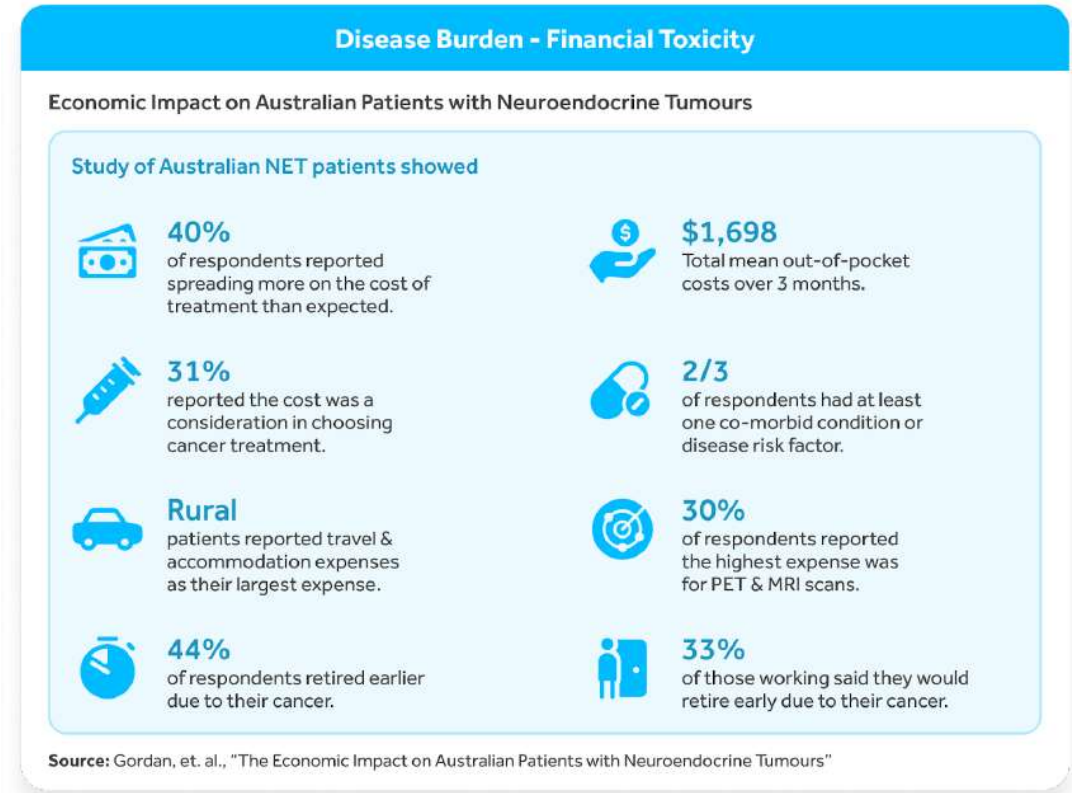
Funding should be made available by State and Federal Governments
Funding should be made available by State and Federal Governments for the provision of compatible software systems to streamline sharing of information for Telehealth and Shared Care Models such as the shared care model between Peter MacCallum Cancer Centre and Gippsland Regional Integrated Cancer Service (GRICS). Shared Models such as this would enhance continuity of care and the incorporation of Metropolitan / Regional Multidisciplinary Teams optimizing care of NET patients.

The aims of Shared Care Models are:
- Provide clinicians with a guide to deliver Shared care in partnership
- NETs patients receive high quality MDT coordinated care equal to that of metropolitan patients
- Optimise use of hospital resources by providing care in the community

NECA recommends that Medicare item numbers for Telehealth Services should be comprehensively reviewed to ensure consideration is given for various methods of Telehealth.

Phone, virtually for regional and remote areas and patient's access to IT and their IT literacy so that ongoing care occurs despite location.

NECA asserts the economic impact of standard of care cancer treatment for NET patients is prohibitive, and we draw attention to the research data below highlighting the highest ongoing expense cost is for PET and MRI scans, as ordered by their NSW Health clinicians for their care.



Importance of MDT Care and higher volume centres in accessing best treatments

In addition to a lack of awareness of NETs in the HCP community, there is a lack of awareness about NET MDT meetings which can result in patients potentially receiving suboptimal care. As presented in this submission the complexity of NETs is extremely challenging. All newly diagnosed patients should be discussed before definitive treatment, so that a treatment plan can be recommended by the MDT for each patient, as per the NET OCP.

Difficulty of appropriate referrals to NET Specialists – many HCPs do not know who to refer to, including what investigations should be performed prior to referral. Many are naive to the intricacy of NET management and where NET MDTs are located so that management plans can be discussed and implemented. This is a very real issue for HCPs in regional and remote areas.

Stage 4 disease potentially by delayed diagnosis - harder to treat

Delayed diagnosis has historically and continues to be a significant issue for neuroendocrine cancer due to it being misunderstood, misdiagnosed, and its low awareness amongst HCPs. The average NET diagnosis in Australia occurs 5 - 7 years after initial symptoms are experienced.

NETs are frequently diagnosed as an incidental finding or following an acute presentation to an emergency department – this accounts for approximately 30% of diagnosis.

60% have stage 4 disease at diagnosis (often spreading to the liver) and cure is not an option.

Management and access to treatments for stage 4 disease are much harder than if early diagnosis occurs and NETs are localised and can be surgically removed.

Delayed diagnosis – costs lives and the healthcare system and creates barriers to treatment

Lack of awareness and knowledge by HCPs of NETs, leads to a delay in diagnosis (median 9.2 years)

At the time of correct diagnosis, 60% have stage 4 disease (considered incurable and inoperable). This delay in diagnosis puts a substantial burden on patients and the health system with unnecessary investigations, travel to appointments, and admissions to hospitals.

This, in turn, results in time off work due to symptoms, side effects of treatment, decreased mental health and quality of life (QOL). Most NET patients are never cured. They remain in the health system, receiving ongoing treatment and monitoring until they unfortunately pass away.

Thank you for your time and consideration of our submission, NECA.