

National Action Plan Supplement 2026

One Australian is diagnosed with a neuroendocrine tumour every 90 minutes.

And the number of Australians contracting this disease is on the rise.

The burden of this disease impacts negatively on the individual and on the health system.

We need the ongoing support of the Australian Government.

Action Area 1 - NET Specialist Telehealth Nurses

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
5 NET Nurses servicing 31,000+ patients across Australia (in 5 States) But these nurses are not full time (at 3.0 FTE for 5 nurses in total) are funded by the Federal Gov for a set time frame which ceases June 2027. Then it will revert to patient funding again. Additional NET nurses required (potential to be McGrath Cancer Nurses) 1 nurse per State to ensure comprehensive collaborative care is accessible. Nurses roles: • Runs the Specialist Support Services • Moderates a Facebook group with 2,800 + members • Connects with patients and families • Facilitates NET support group meetings • Supports patient treatment enquiries • Online cancer education programs • Develop resources for patients and HCPs	“ I didn't know who to turn to for support. I eventually found the NeuroEndocrine Cancer Australia Instagram page then contacted the NET nurse. She gave me so much support and information. This NET nurse service is absolutely priceless, NET Patient, Denae, SA 31,000+ Australians with neuroendocrine cancer need specialist care to improve their quality of life and treatment outcomes.	Fund specialist telehealth nurses to service regional and remote Australia. The state based specialist NET tele-health nurses will provide sustainable care and develop a supportive care model. \$600,000 per year.	6,000 patients per nurse. They will provide disease-specific advice and resources to patients and carers. They will provide referrals to Allied Health specialists and other services, being integral to shared care models. They will provide healthcare and professional education. Facilitate NET patient support groups both in person and remotely. Collaborative work with NET specialist nurses in hospitals ensuring continuity of care, referral pathways and providing equity of care for regional and remote patients.	Grant to be paid quarterly to meet the needs of the community. Funding is until 30 June 2027. Ongoing funding needed to maintain the support our patients need.

Action Area 1 - NET Specialist Telehealth Nurses
Senate Inquiry Recommendation 21

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Senate Inquiry supporting Action Area 1. Recommendation 21 The committee recommends that the Australian Government explore the provision of at least one specialised neuroendocrine tumour nurse, and paediatric cancer nurse, in each Australian jurisdiction.	Recommendation 21 Collaboratively chosen by CAG with NECA as one of the first 5 key recommendations. NECA will strive to obtain the specialist NET nurses for neuroendocrine cancer patients around Australia.	Continue to fund this vital service (past 30 June 2027).	Ensure there is a specialist NET telehealth nurse in each state to support patients, and their families whilst coordinating multidisciplinary shared care in the community.	Grant to be paid quarterly to meet the needs of the community. Funding is until 30 June 2027. Funding needed to continue to achieve this outcome.

Action Area 2 - Information and Resources

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Funding now depleted. Over the past 2 years NECA has printed and distributed 38,000 resources to hospitals, GPs and community-based health services. Multimedia resources were made available to patients and healthcare professionals. NECA has two multilingual explainer videos, further translation of explainer videos is planned dependent on funding.	“ I just wish that NET patients had the resources available that other cancer patients have, such as breast cancer patients, and there was more awareness about NETS, because it is so individual and is so often misdiagnosed. NET Patient, Tracey, WA Each year, 5,700+ Australians are diagnosed with neuroendocrine cancer. Access to vital information and resources helps them navigate their journey.	Federal Government to provide funding for resource development, awareness promotion for general and HCP communities, NET Patient Education Forums - requested amount \$200,000 per year for 3 years.	We will produce resources in multiple languages to reach diverse communities. NECA will host three in person NET Patient forums per year (bi-annually in each state).	Website refreshed utilising donations to NECA.

Action Area 2 - Information and Resources

Senate Inquiry Recommendation 18 & 19

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Senate Inquiries which support Action Area 2 (#18 and #19). Recommendation 18 The committee recommends that the Australian Government provide appropriate funding to key cancer advocacy organisations supporting patients with rare and less common cancers by providing informative resources and support services that: • increase health literacy; • empower patients to make informed decisions regarding their health; and • are culturally appropriate and accessible in a variety of languages. Recommendation 19 The committee recommends that the Australian Government provide sufficient funding and resources to ensure that the supportive care aspirations of the Australian Cancer Plan are delivered on for all Australians, including for those affected by rare and less common cancers.	Recommendation 18 Collaboratively chosen by CAG with NECA as one of the first 5 key recommendations NECA will strive to obtain for neuroendocrine cancer patients around Australia.	Also supported through the Australian Cancer Plan (ACP) we want to enhance patients experience through supportive care in all areas ensuring culturally safe, equitable and responsive cancer care. Currently neuroendocrine cancers do not receive equitable funding. NECA requests Government to action the recommendations of the Senate Inquiry.	Increase patient awareness, knowledge, and health literacy to help with symptom identification. Having high levels of health literacy, through having access to comprehensive information about NETs from diagnosis, will empower patients to make informed decisions regarding their health. Provide resources and education that is culturally safe in a variety of languages to all Australians, including those in rural and remote areas. NET patients will have supportive care and access to the resources they need and deserve.	Appointed NET Specialist Counsellor and Dietitian - funding needed to continue to provide this support for patients and their families.

Action Area 3 - Education of Healthcare Professionals

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
4,800+ healthcare professionals educated through online modules to date. NET education sessions. NET Educator partially funded by a private donor. \$0 Government investment. Optimal Care Pathway developed and requires ongoing promotion and awareness to HCPs.	“ I went to doctors and specialists for 8 years and I kept getting fobbed off. Two years later I had my first crisis and I was stage 4 by then. NET Patient, Margaret “ Very good document for guidance, might help GPs in rural areas. Would have been useful at diagnosis, and to broaden knowledge of NETs in general. The further it gets out there, the better. NET patient 60% of NETs are advanced at diagnosis, often with stage 4 cancer. Educating healthcare professionals ensures earlier detection and better patient outcomes.	Government to fund a dedicated education position to deliver education, continue to develop education modules for healthcare professionals, provide in-services, facilitate, co-ordinate and participate in seminars and webinars, \$130,000 per year (2.a). Government to fund ongoing awareness campaign for symptom awareness, \$100,000 per year.	1000+ healthcare professionals per year to be educated through online modules. The greater the knowledge base the greater potential for our patients to have an earlier diagnosis. 200+ health professionals per year) to be educated by Nurse Educator. Delivery, podium presentations and posters at International and National Conferences.	No government action to date to action this.

Action Area 3 - Education of Healthcare Professionals

Senate Inquiry Recommendation 28 & 30

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Senate Inquiries which support Action Area 3 (#28 and #30). Recommendation 28 The committee recommends that the Australian Government prioritise and monitor the implementation of the recommendations from the National Medical Workforce Strategy 2021–2031, and ensure it addresses the needs of rare and less common cancer patients, including neuroendocrine cancer patients. Recommendation 30 The committee recommends that state and territory governments provide sustained funding and participation incentives for staffing positions and training opportunities for medical professionals and researchers interested in specialising in rare and less common cancers, including neuroendocrine cancers.	No Australian should experience extensive delays in diagnosis. 63% of patients report that their initial symptoms were either severe or very severe. Recommendation 30 Collaboratively chosen by CAG with NECA as one of the first 5 key recommendations NECA will strive to obtain for neuroendocrine cancer patients around Australia.	Specialty training is not matching current or predicted community needs. To build best practice workforce through education of healthcare professionals through a funded educator to support and provide training through in-services. There are insufficient NET Specialist Nurses in the hospital settings.	Increase clinical awareness of NETs and their treatment. Earlier diagnosis before the disease has metastasised will improve survival. Encourage nurses and other healthcare professionals to specialise in NETs.	None to date.

Action Area 4 - National Awareness Campaign

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
National NET Awareness Campaign funding completed May 2024. Unsuccessfully applied for funding for NET Symptom Awareness Campaign. Patients are donating to assist funding Awareness Campaign - not enough funds to truly achieve and promote this.	“ I wish that someone had taken my symptoms seriously much earlier. I had a feeling it would be neuroendocrine cancer after seeing Michael Usher interview Dr David Chan speaking about NETs on TV and most of the symptoms seemed to fit, I literally felt my stomach sink with realisation. NET Patient, Denae, SA “ I only wish the GPs and HCPs I saw before my diagnosis when I was looking for answers for 3 years could have read similar material like in this campaign. NET Patient Australians wait over 5 years on average for a correct diagnosis. Increasing awareness leads to quicker diagnosis and timely treatment for patients.	Government to provide funding for promotion of NET cancer symptoms to the general public and healthcare professional community. Digital Awareness campaign, investment of \$200,000 per year. (4).	NET Nurse line has surged by over 100%, website over 700% when our awareness campaign was running. Patients seeking the correct advice earlier in the diagnostic cycle. Patients being referred to the Optimal Care Pathway earlier in the diagnostic cycle. NETs are understood and acknowledged enabling equity & care.	Nil achievements due to a lack of funding.

Action Area 4 - National Awareness Campaign
Senate Inquiry Recommendation 18

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Senate Inquiry supporting Action Area 4 (#18) Recommendation 18 The committee recommends that the Australian Government provide appropriate funding to key cancer advocacy organisations supporting patients with rare and less common cancers by providing informative resources and support services that: increase health literacy; empower patients to make informed decisions regarding their health; and are culturally appropriate and accessible in a variety of languages.	Recommendation 18 Collaboratively chosen by CAG with NECA as one of the first 5 key recommendations NECA will strive to obtain for neuroendocrine cancer patients around Australia.	Government to provide funding for promotion of NET cancer symptoms and support that is available to empower them throughout diagnosis and beyond. Digital Awareness campaign, investment of \$200,000 per year.	Funding towards an awareness campaign will ensure the general public have more health literacy and information about NETs to help with symptom identification and diminish delayed diagnosis. Awareness of resources and support will empower patients to make informed decisions regarding their health, improving their prognosis and quality of life.	None to date.

Action Area 5 - Optimal Care Pathway

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Optimal Care Pathway has been created and was launched in January 2023. As part of 23/24 Awareness campaign OCP has been promoted to HCPs via social media targeting and industry website/magazines. OCP NET NSW – report completed and highlighted inequity of access, lack of referral process and lack of funding for HCP resourcing.	 OCP Quick reference guide or "Summary" at the very front - referral, investigation process staging and planning is paramount. This appears to be an excellent document, a direction that addresses our unmet needs and to be promoted to all HCPs, specialists and patient. NET Patient 63% of patients experience severe symptoms. Streamlined care pathways prevent delays, ensuring patients get the care they need promptly.	Awareness of NETs and the OCP is still extremely low, we seek funding for promotion of this vital OCP as part of the awareness campaign. Investment of \$50,000 per year (5).	Awareness of all OCPs is low, even more so for a lesser-known cancer. When surveyed only 29% of NECA patients were aware of the OCP.	The Australian Government and Cancer Australia provided funding to OCP for NETS in 2022. Optimal Care pathway was launched in 31 January 2023. Ongoing funding for promotion and awareness are still required.

Action Area 5 - Optimal Care Pathway
Senate Inquiry Recommendation 1

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Senate Inquiry supporting Action Area 5 (#1). Recommendation 1 The committee recommends that the Australian Government further develop clinical guidelines and local pathways for rare and less common cancers and ensure that they are accessible and available for general practitioners at the point-of-care.	“ The participant was aware of the OCP, and indicated that it would have been useful to give to their GP after diagnosis. Helps elucidate the path to take and provide better information. Very good document for guidance, might help GPs in rural areas. Would have been useful at diagnosis, and to broaden knowledge of NETs in general. The further it gets out there, the better. Participant indicated it would be useful if more GPs knew about the OCP, and that it is a clear document. NET Patient	Funding and support to promote and increase awareness of OCP. As above.	Awareness and education on OCP to Clinicians to not only highlight the existence of NETs but also ensure timely accessibility which will significantly impact patients' initial diagnosis, reduce financial toxicity, and clarify the path of referrals and treatments.	None to date.

Action Area 6 - Data Registry (PLANET)

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
PLANET Data Registry App that is a patient reported outcome registry. Currently: 243 patients can access the App. 190 are using the App. Applied for funding through Cancer Patient Support Program Grant. Unfortunately due to ongoing applications for funding and these application being unsuccessful no enhancement have been achieved for the PLANET App to collect vital PROM / PREM data.	The PLANET registry has 2,421 patients, crucial for tracking outcomes and improving care. Patient-reported outcomes empower self-advocacy and ensure equitable treatment.	Funding is needed to support a data manager and part time nurse to co-ordinate with the various sites utilising PLANET. Work with the design team at the University of Melbourne and design and disseminate information about PLANET and recruitment to the PROMs app. Investment of \$100,000 per year in NET Research via the PLANET registry, and an additional \$100,000 for further app enhancements (6).	The registry holds accurate and up-to-date individual patient clinical data to ensure correct treatment options. Patients have many symptoms in between medical appointments – this app holds all the information in one registry ensuring concise reporting and optimal care.	No funding provided and PLANET Registry / App will be suspended.

Action Area 6 - Data Registry (PLANET)
Senate Inquiry Recommendation 19

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Senate Inquiry supporting Action Area 6 (#19) Recommendation 19 The committee recommends that the Australian Government provide sufficient funding and resources to ensure that the supportive care aspirations of the Australian Cancer Plan are delivered on for all Australians, including for those affected by rare and less common cancers.	“ Having appropriate funding we can increase data input which provides us with information about incidence, prevalence and optimal treatment management. Meredith Cummins, CEO, NeuroEndocrine Cancer Australia	Supported through the ACP, we ask for our patients to have equitable cancer care across the continuum that is supported by the best available health intelligence from research, clinical trials, and meaningful, connected data. Funding towards PLANET for a data manager, nurse co-ordinator, improving design and disseminate information will allow for better patient outcomes. ACP Action 4.5.1 Design and embed patient reported experience and patient reported outcomes into national performance monitoring and reporting for all providers, to assess services for all population groups and establish an evidence base.	Support advances in scientific research and treatment of patients.	No funding provided and PLANET Registry / App will be suspended.

Action Area 7 - Centres of Excellence

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Centres of Excellence 5 NET Centres - Royal Brisbane and Womens (Brisbane, QLD). - Queen Elizabeth (Adelaide, SA) - Fiona Stanley (Perth, WA) - Royal North Shore (Sydney, NSW) - Peter Mac (Melbourne, Vic) ENETs Accredited Centres of Excellence - Royal North Shore - Peter Mac State funding is needed to support the employment of hospital NET Nurses, data management and any additional infrastructure requirements. Federal funding is required for access to Theranostics, highly specialist drugs, research and clinical trials. ** \$0 Government investment	 From the beginning we were with the right specialist in Perth. A lot of people on their journey realised oh no they're not with a NET specialist. NET Patient, Brad, WA Centres like Peter MacCallum, with 1,395, and Royal North Shore with 671 patients ensure NET patients are provided specialised care. Supporting these centres ensures every patient gets expert, coordinated treatment.	Patients deserve uniformity and equitable care across the country. As an example PET (GA68 Dotatate) scans are not available at the NET Centre – Queen Elizabeth Hospital in Adelaide. Patients require State and Federal funding so their state-based care is in line with our CoE's around Australia. Acknowledge and promote the ENETs Accredited CoEs.	All patients should have their diagnosis and management plan presented / discussed at a NET MDT. This will ensure that the patients will receive optimal care and current treatment options. Patients can then have their treatment delivered at a local facility (except if needing PRRT or TACE / SIRT). Royal North Shore Hospital and Peter MacCallum provides patients with all areas of care required, including scans, access to the multidisciplinary team (MDT), *a specialised NET Nurse on site and world class care. This needs to be replicated Australia wide. *Specialist NET Nurse (NB limited at RNS NET nurse 0.3 FTE).	No Federal or State support provided to these Centres of Excellence to ensure optimal care and support is available to NET patients ongoing deficit.

Action Area 7 - Centres of Excellence

Senate Inquiry Recommendation 3, 29 and 30

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Senate Inquiries which support Action Area 7 (#3, #29 & #30) Recommendation 3 The committee recommends that the Australian Government undertake a review of Medicare reimbursement settings for diagnostic tests and services, with a view of ensuring patients with, or with suspected rare or less common cancer, receive prompt, appropriate and affordable diagnostic testing. Recommendation 29 The committee recommends that the Australian Government, in partnership with state and territory governments and the higher education sector, review the emerging educational and workforce skill needs in relation to precision oncology, genomics, molecular curation and theranostics. Recommendation 30 -The committee recommends that state and territory governments provide sustained funding and participation incentives for staffing positions and training opportunities for medical professionals and researchers interested in specialising in rare and less common cancers, including neuroendocrine cancers.	Recommendation 30 Collaboratively chosen by CAG with NECA as one of the first 5 key recommendations NECA will strive to obtain for neuroendocrine cancer patients around Australia.	Provide funding and resources to the ENETs COEs and extend the framework to other hospitals ensuring all Australians will have improved patient care by delivery of comprehensive patient management and data collection and access to best practice. Funding and support for hospital NET nurses. As per the ACP we ask for: "National strategies developed to enhance clinical and cultural safety training and accreditation processes, build workforce diversity, expand multidisciplinary roles and determine retention strategies."	Best practice access to diagnostics, novel therapies, precision medicine, disease management and research, reducing the number of inappropriate interventions that currently occur. Improve sustainability of health system. Mitigate inequities that exist both for patients living with NETs and specifically for those patients with NETs who live in regional and rural Australia. Will provide equitable access to all Australians, with dedicated MDT and integrated care pathway.	No Federal or State support provided to these Centres of Excellence to ensure optimal care and support is available to NET patients ongoing deficit.

Action Area 8 - Targeted Research

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Targeted Research Over the last 10 years a mere \$8.5 million has been invested into Neuroendocrine Cancer Research. This clearly shows inequitable allocation of funds and a low priority for this cancer.	“ I went on the control NETs trial. And something worked because for nearly 8 years I have been stable and it hasn't progressed at all. NET Patient, Gaynor, WA NECA's involvement in over 10 research initiatives leads to new treatments and better outcomes, giving patients hope for the future.	Targeted call for research (NHMRC/ MRFF) for NeuroEndocrine Tumours. There are exciting opportunities that Australian NET researchers could contribute to with regards to earlier diagnosis, combination therapies and innovative Theranostics.	Targeted call for research (NHMRC/ MRFF) for NeuroEndocrine Tumours. There are exciting opportunities that Australian NET researchers could contribute to with regards to earlier diagnosis, combination therapies and innovative Theranostics. Patients can access treatments which usually are not available to them.	Minimal to no funding provided to research - government needs to ensure NET patients are not disadvantaged.

Action Area 8 - Targeted Research

Senate Inquiry Recommendation 7, 8, 16, 17, 33, 34, 35

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Senate Inquiries which support Action Area 8 (#7, #8, #16, #17, #33, #34 & #35) Recommendation 7 The committee recommends that the Australian Government investigate opportunities to increase equitable uptake and access to genomic screening and profiling for Australians. Recommendation 8 The committee recommends that the Australian Government closely monitor the outcomes of the DNA Screen study, and the implications of the study for the future development of population wide, preventive genomic screening programs. Recommendation 16 The committee recommends that the Australian Government work with state and territory governments to implement the One Stop Shop and National Clinical Trials Front Door platform as a matter of priority.	Recommendation 34 Collaboratively chosen by CAG with NECA as one of the first 5 key recommendations NECA will strive to obtain for neuroendocrine cancer patients around Australia.	Funding and support to utilise collaborative networks through National Centres of Excellence model to strengthen national and international collaboration. Support and dedicated funding would provide access to resources to meet the current grant deadlines and criteria and encourage additional investigators and researchers to the field. Collaboration with international research bodies and pharma to have trials available in Australia. Ensure industry research / clinical trials can occur in Australia.	Through facilitating collaboratively between lab research and clinical research will drive forward improved outcomes for NET patients. Ameliorate the significant inequities that currently exist between patients with NETs and those with more common or familiar cancers, ensuring quicker access to diagnosis and enable patients to get more appropriate treatment earlier.	None to date.

Action Area 8 - Targeted Research

Senate Inquiry Recommendation 7, 8, 16, 17, 33, 34, 35

Current	What this means for patients	Our Ask	Potential Impact	Outcome Achieved
Recommendation 17 The committee recommends that the Australian Government ensure the Clinical Trials Activity initiative has an appropriate focus on funding clinical trials and research for people with cancer, including children, young people, and patients diagnosed with rare and less common cancers. Recommendation 33 The committee recommends that the Australian Government partner with organisations representing culturally and linguistically diverse communities to develop initiatives to increase participation rates in cancer screening, research, and clinical trials. Recommendation 34 The committee recommends that the Australian Government ensure continued funding for rare and less common cancer projects to reduce existing research and clinical trial disparities. Recommendation 35 The committee recommends that the Australian Government fund biobanking initiatives to ensure the availability of quality cancer samples for research.				