Government of **Western Australia**
Department of **Health**

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

Submission from WA Health

The WA health system thanks the Senate for the opportunity to provide feedback into the inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer.

Contributors to this response include:

- Office of Population Health Genomics, WA Department of Health (DoH)
- Health Networks Cancer Network, WA Department of Health (DoH)
- The Cancer Network Western Australia, North Metropolitan Health Service (NMHS)
- Genetic Services of Western Australia
- PathWest Laboratory Medicine (PathWest)
- WA Country Health Service (WACHS).

(a) barriers to screening and diagnosis

Diagnosis – Clinical factors

Rare cancers are diagnosed and supported through multidisciplinary teams. Rare and less common cancers such as neuroendocrine tumours are difficult to diagnose for the following reasons:

- rare cancers and neuroendocrine tumours can occur anywhere in the body and symptomology is varied
- neuroendocrine tumours on average take 4-7 years to be diagnosed and symptoms may be similar to other conditions or absent
- diagnosis may require blood tests, imaging (computed tomography/magnetic resonance imaging/positron emission tomography), endoscopy, and biopsies (pathology), and access to specialist diagnostic equipment is limited in rural and remote regions
- all practitioners see patients with rare and less common cancers and specialists are predominately based in tertiary hospitals, which are in the metropolitan region
- there is a lack of referral pathways from primary care to tertiary care.

Surveillance clinics for people at high risk of inherited rare and less common cancers

Inherited cancer predisposition syndromes are caused by genetic mutations that place individuals at an increased risk of developing cancer. A number of these syndromes are associated with the development of multiple rare and less common cancers. It is important to identify people with inherited cancer predisposition syndromes early, preferably before cancer has occurred or in the

earliest stages of cancer. This allows for proper screening, possible prophylactic treatment, and early treatment for the best chance of survival.

There are evidence-based guidelines that guide clinicians regarding the identification, management, and surveillance of individuals with inherited cancer predisposition syndromes. However, evidence continues to emerge on additional genetic variants and expanded clinical symptoms associated with inherited cancer predisposition as well as opportunities to improve outcomes by widening genetic testing criteria and refining surveillance protocols.

The WA health system funds both paediatric and adult surveillance clinics for children and adults with inherited predispositions to rare and less common cancer syndromes, which are delivered by multidisciplinary teams including specialist staff from the Genetic Services of WA. These services provide potentially life-saving cancer screening and early diagnosis for those at higher risk of rare and less common cancers.

Several barriers impact on delivering services to individuals and their family members potentially at risk of inherited predispositions to cancer, including:

- ***Resourcing and expanding screening and surveillance to sufficiently meet demand:*** Existing Activity Based Funding mechanisms are not fit for purpose due to these clinic's important multidisciplinary nature, their requirement for a system-wide network of specialists with appropriate knowledge and experience, and attendance of various specialists at a range of multidisciplinary team meetings. Additionally, coordinating the regular imaging and other tests required to adhere to the necessary monitoring regimes is hampered by limited existing resources, as is then recording the related data in an appropriate clinical database.

- ***Inequity of access:*** Aboriginal people, people from culturally and linguistically diverse (CaLD) backgrounds, and people living outside of metropolitan areas experience inequity in accessing cancer predisposition syndrome services. Addressing these barriers will require workforce resourcing and education (e.g. for regional and Aboriginal health workers), availability of appropriate foundational genetics information in a range of languages, and co-designed innovative models of care that improve access for regional and remote patients and improve cultural appropriateness. Possible new models of care could include the co-delivery of dedicated cancer genetics clinics by health professionals at Aboriginal Community Controlled Health Services in conjunction with clinical geneticists and genetic counsellors, as well as the development of culturally appropriate tools to communicate the concepts of inherited cancer genetics. Cultural and language barriers can also be addressed by increasing awareness and improving access to interpreter services across WA.

- ***Insufficient identification of at-risk individuals*:** Despite the availability of effective interventions, an estimated 90% of high-risk individuals remain unidentified for certain cancer predisposition syndromes, such as Lynch syndrome and breast and ovarian cancer syndrome. This is because most people who have these variants do not currently qualify for publicly funded genetic testing (via Medicare and through state and territory funded clinical genetics services) due to restrictive criteria, resulting in underdiagnosis and lack of monitoring and preventive care. Widening these testing criteria and/or population-based screening programs (an example is mentioned in section d below) could help assist this issue from a public health genomics perspective.

- ***Genetic discrimination in life insurance*:** Concerns about difficulties accessing life insurance products prevent some Australians at risk of a cancer predisposition syndrome from

undertaking predictive genetic testing (Tiller et al, 2023a).[1] This fear of genetic discrimination reduces their access to possibly life-saving preventative measures including cancer surveillance programs, thus acting as a barrier to cancer screening and timely diagnosis. Greater regulation of genetic discrimination in life insurance underwriting via Australian government legislation is required to alleviate community concerns about accessing genetic testing for all inherited genetic diseases, including inherited cancer syndromes.

- ***Lack of support for contacting at-risk relatives*:** Unclear guidelines about contacting blood relatives of people diagnosed with a cancer predisposition syndrome is a barrier to these at-risk relatives accessing cascade testing, cancer screening, and early prophylaxis (Tiller et al, 2023b),[2] hence limiting potential population health benefits. The majority of Australians recently surveyed support being notified directly by a health professional about their genetic risk for familial cancer and other conditions. However, despite there being no legal barriers to this, the predominant practice in Australia is for health professionals to encourage individuals to contact their own relatives with the relevant information. However, this method can be challenged by complex family dynamics, and can be less effective in Aboriginal, CaLD and regional families. Presently, cascade testing occurs in less than 50% of at-risk relatives. Defined pathways and more resources to support health professionals to contact at-risk relatives at the request of their patients (including cultural liaison officers, interpreters, and digital and data tools), will be necessary to increase cascade screening rates.

Comprehensive molecular diagnosis as an essential tool for prognosis and matching to treatments and clinical trials

PathWest, the WA health system's state laboratory medicine service, has recently implemented a centralised, state-wide program for routine comprehensive genomic testing of cancers that forms part of the standard of care for patients with rare or less common cancers. This approach is providing a high quality, standardised, guideline- and protocol-based equitable diagnostic clinical service to WA persons with rare or less common cancers, regardless of age or where they live. Pathologist experience is dependent on frequent exposure to such rare tumours, therefore the new model implemented in WA has been critical to address the need for subspeciality areas such as in rare tumours of the soft tissue, endocrine system, bone and brain.

Increased capacity for molecular testing (including state-of-the-art next generation sequencing infrastructure and a highly specialised workforce) has been supported by time-limited funding from the Community Health and Hospitals Program. This has also enabled PathWest to host the WA node of the national cancer Molecular Screening and Therapeutics (MoST) program and join Omico's national network's Cancer Screening Program (CaSP).

Dedicated, sustained and strategic investment in the necessary infrastructure, technologies, and training of an expert workforce proficient in complex molecular testing and interpretation, would allow PathWest to continue genomic profiling of rare, uncommon, and neuroendocrine tumours.

[1] Tiller J, Bakshi A, Dowling G, Keogh L, McInerney-Leo A, Barlow-Stewart K, Boughtwood T, Gleeson P, Delatycki MB, Winship I, Otlowski M, Lacaze P. Community concerns about genetic discrimination in life insurance persist in Australia: A survey of consumers offered genetic testing. Eur J Hum Genet. 2023 May 11. doi: 10.1038/s41431-023-01373-1.

[2] Tiller JM, Stott A, Finlay K, Boughtwood T, Madelli EO, Horton A, Winship I, Nowak K, Otlowski M. Direct notification by health professionals of relatives at-risk of genetic conditions (with patient consent): views of the Australian public. Eur J Hum Genet. 2023 Jun 6:1–11. doi: 10.1038/s41431-023-01395-9.

Further, there is a shortage of expertise available in this field, in particular molecular pathologists, and scientists with expertise in massively parallel sequencing technologies. Currently, there are inadequate training pathways for these specialised workforces as well as limited opportunities for continuous learning that is required in this rapidly changing field.

***Continued funding is required to support comprehensive genomic profiling of cancers*:** Without appropriate financial support, it is anticipated that some patients with rare and less common cancers will be unable to afford comprehensive genomic profiling of their tumours following the conclusion of the current research programs. This will likely prevent them from accessing appropriate clinical trials (which require a genomic profile for selection), thus increasing inequity in cancer treatment for patients with rare and less common cancers. Funding was previously provided to the WA Government through the Community Health and Hospitals Program and it is vital that a national decision is reached on how these tests are funded indefinitely before the conclusion of these studies.

Conducting Molecular Tumour Board meetings: These essential multidisciplinary meetings for data interpretation and to personalise treatment and management regimes require financial and human resources, including the contribution of medical professionals, oncologists, scientists as well as data management, information technology and administrative support. These meetings do not currently meet the criteria for Activity Based Funding.

(b) barriers to accessing appropriate treatment

Equitable access and specialised and timely cancer diagnostic services and molecular testing are critical to treat individuals with rare or less common cancers, including neuroendocrine tumours. The pathological diagnosis essentially dictates prognosis, treatment and access to clinical trials. Some of these tumours can only be defined by molecular investigations, therefore emphasising the importance of molecular diagnostics becoming part of the routine diagnostic workup of these tumours.

Furthermore, there has been a huge growth in the number of significant actionable targets that enhance the ability to diagnose, establish prognosis and predict response to treatment. As the identification of potential diagnostic and therapeutic targets has rapidly evolved, preclinical studies have followed, leading to drug development and new clinical trials. Previously, opportunities were lacking to molecularly profile the tumours from WA patients with rare cancers and for patients who had failed to respond to conventional treatment strategies and to subsequently offer alternative treatment strategies through clinical trials. Additionally, a shortage of clinical trials within WA sometimes required patients to regularly travel interstate to receive treatments.

However as explained in section (a), comprehensive genomic profiling testing capacity and capability at PathWest has been successfully implemented into the clinical workflow for many patients with rare or less common cancers, including neuroendocrine tumours. This has enabled WA patients to become part of national cancer programs. The MoST program and the Omico network's CaSP mentioned above, along with the Zero Childhood Cancer program, of which Perth Children's Hospital (PCH) is a clinical partner are critical for enabling coordinated access to local clinical trials for rare and less common cancer patients. Currently, Sir Charles Gairdner Hospital (SCGH), Linear Clinical Research and Fiona Stanley Hospital (FSH) trials units provide clinical trials for rare and less common cancers. Without these initiatives, WA patients with rare and less

common cancers who fail to respond to conventional treatment strategies are less likely to be able to access potentially life-saving alternative therapies.

- ***Limited access to specialist equipment:*** Regarding neuroendocrine tumours specifically, an important part of case management is access to specialist nuclear medicine facilities for imaging and targeted radiopeptide therapy. Ongoing support is required to provide these facilities at tertiary hospitals such as FSH and SCGH.

- ***Out of pocket costs***: There are significant barriers for patients to access affordable treatment for many rare cancers. Off-label drugs offered to patients for rare cancers are expensive and significant out of pocket costs occur. Applications to drug and therapeutics committees at each hospital may help with these costs. Special access programs through pharmaceutical companies may be an option for some patients. Rare Cancers Australia also have a financial assistance program to help Australian cancer patients pay for their cancer treatments and other expenses that are a direct consequence of cancer.[3] All cancer patients will have out of pocket costs related to transport and parking. Patients living in rural, regional and remote areas have significant out of pocket expenses related to travel, accommodation and time away from work.

(c) adequacy of support services after diagnosis

- ***Cancer Nurse Coordinators:*** The WA Cancer Network fund a state-wide cancer nurse coordination service comprised of a team of specialist senior cancer nurses located in metropolitan Perth and country WA. These specialist nurses have a strategic and clinical function and support patients by:

    - Assisting them through the health care system and finding the best services to help them and their families
    - Acting as a central point of contact for patients, families and health care professionals
    - Assisting with coordinating appointments
    - Providing and explaining information on diagnosis, treatment and all aspects of the cancer journey, and
    - Liaising and linking with other services both within the treating hospital and the wider community.

The metropolitan team includes a specialist Clinical Nurse Consultant for rare and less common cancers (which includes neuroendocrine cancer) and other tumour specific Clinical Nurse Consultants are across all rare and less common cancers as part of their tumour specific focus. WACHS also provides a Cancer Nurse Coordination service in each region. These regional cancer nurses care for all patients with cancer and work closely with the WA Cancer Network tumour specific cancer nurses including the Rare and Less Common Cancer Nurse Coordinator. Both services are supported by the State Government through recurrent funding and the service supports the cancer population in the state regardless of geographic location.

Hospital-based health professionals also provide support to patients. Specialist nurses at hospital sites in cancer centres, surgical departments and nuclear medicine support and educate patients.

[3] Rare Cancers Australia - Patient treatment fund terms & conditions

- ***Allied Health Professionals:*** Social workers, psychologists, and genetic counsellors are amongst many allied health professionals specifically trained to work through the various personal aspects of living post-diagnosis (diagnosis of the presence of cancer, but also diagnosis of being at high-risk for a cancer predisposition) and improving rare cancer patients' mental health and quality of life.

    - Mental health support is vital for aiding patient compliance with treatment and monitoring, their understanding of the diagnosis and communication with other health staff
    - Practical social work and psychosocial resources also support patients in coping with their everyday responsibilities during treatment and management
    - Ongoing support for education and training of these allied health professionals is necessary for the continued provision of psychosocial support for patients diagnosed with rare and less common cancers or diagnosed as being at high-risk of developing such a cancer
    - In country WA there is limited access to specialised psychosocial support and patients are at risk of not being able to access these services.

- ***Patient Assisted Travel Scheme (PATS):***[4] The PATS provides financial support for travel and accommodation (including designated cancer accommodation) for eligible rural patients needing to travel to access specialist medical services. PATS is funded by the WA government's Royalties for Regions program and is administered by WACHS. It aims to support WA country patients' access to specialist medical services wherever they live in the state. On average, PATS assists 35,000 country patients access specialist medical services and subsidises 99,000 travel journeys each year. PATS applications are assessed by regional PATS offices in line with current PATS policy and eligibility criteria.

- ***Non-Government Organisations (NGOs):*** NGOs such as Cancer Council, Rare Cancers Australia, Neuroendocrine Cancer Australia (NECA), and the Leukaemia Foundation also provide support to patients. NECA is the only Australian not-for-profit medical charity focused on neuroendocrine tumours. Patients with neuroendocrine tumours have their own support group that meets every three months. NECA also have an online education course aimed at increasing knowledge about neuroendocrine tumours amongst general practitioners and nurses. NECA released the first Neuroendocrine National Action Plan Preventing Australians from Slipping through the NET in 2022. Action 1 of this plan is support for specialist neuroendocrine tumours telehealth nurses and oncology social workers, and subsequently a national neuroendocrine tumour nurse hotline has been established by NECA.

(d) adequacy of Commonwealth funding for research into rare, less common and neuroendocrine cancer

Research into rare, less common and neuroendocrine cancers will improve outcomes for patients diagnosed with these conditions. However, it can be difficult to conduct research in a clinical setting, given the current workforce shortages and increasing demand on health systems.

[4] WA Country Health Service - About PATS

- It will be necessary to appoint dedicated rare cancer research nurses, genetic counsellors and other health professionals to support ongoing clinical research, which will require additional funding.
- It is also critical to involve representatives from Aboriginal and CaLD communities to co-develop a research model which enhances respect, understanding and engagement with patients from these communities in order to improve outcomes for these patients.

The WA health system strongly supports the investment made from Commonwealth funding bodies into rare cancer research, such as the 2021 Rare Cancers, Rare Diseases and Unmet Need grant opportunity by the Medical Research Future Fund. As already indicated in this response, large national research programs focussed on rare and less common cancers and the personalised matching of patients to clinical trials are crucial to improving health outcomes through discovering more effective treatments. The Precision Oncology Screening Platform Enabling Clinical Trials (PrOSPeCT) project supported by $185 million of investment is focussed on difficult to treat cancers, which includes rare cancers such as sarcoma. This project demonstrates the positive and powerful potential of partnerships across a range of stakeholders including the Australian government, industry, philanthropy, research institutions and hospitals.

- DNA Screen[5] is a coordinated national research program funded by the Medical Research Future Fund's Genomics Health Futures Mission. It is offering population genomic screening to 10,000 young adults aged 18 to 40 years, with those who screen positive provided with the opportunity of a referral into their local genetics centre as all state and territory health systems are involved in the program.
- The study screens for DNA variants for 3 high-risk, medically actionable genomic conditions all with risk reduction possibilities. Two of these conditions are rare cancer syndromes (hereditary breast and ovarian cancer, and Lynch syndrome; the third condition is familial hypercholesterolaemia).
- Whilst it is estimated that approximately 1 in 75 people from the general population have a high-risk pathogenic germline DNA variant for one of these 3 conditions, although only about 10% of these would already be aware through existing identification methods. It will be imperative for Australian governments to remain engaged in research programs such as this to ensure the evidence they generate are equitably translated into health systems in an appropriate and timely manner.

(e) any other related matters

Policy considerations

The WA DoH's WA Cancer Plan 2020–2025 (WA Cancer Plan) and the Priorities for Implementation provided direction for WA to achieve a well-coordinated, consumer focused cancer control system and to improve cancer outcomes for WA. The WA Cancer Plan has identified that comprehensive cancer care is important for ensuring equitable access to treatments and clinical trials, supportive care, survivorship care, provision of coordinated information and more action to improve outcomes for Aboriginal people and those living in rural and remote locations.

[5] DNA Screen – Secure DNA testing for your future health (monash.edu)

Priority 2 of the WA Cancer Plan is to improve patient outcomes through safe, coordinated and evidence-based care; this includes people with rare cancers. To address WA Cancer Plan priorities, future options need to include equitable access to bulk billed services and geographical distribution as some patients are experiencing out of pocket costs in WA. Future planning should consider inclusion of targeted services for Aboriginal people, provision of innovative models such as TeleTrials and TeleChemotherapy for those living in outer metropolitan, rural and remote areas, and accepting public referrals for those who cannot access services through their Health Service Provider (e.g., East Metropolitan Health Service patients requiring radiation oncology).

The WA DoH recently conducted a descriptive epidemiological study of rare and less common cancers in WA (Bilkey et al, 2021)[6]. Results indicated that:

- Rare and less common cancers comprised 21.5% and 26.9% of all cancers diagnosed in WA from 2013-2017, respectively
- Aboriginal cancer patients recorded a greater proportion of rare cancers amongst all cancers diagnosed in this population (38.3%) compared to non-Aboriginal cancer patients (21.3%)
- Patients diagnosed with rare and less common cancers experienced significantly worse outcomes than those with common cancers, with 5-year cumulative relative survival estimated at 58.2% (95% confidence interval [CI] 57.3-59.1%) for rare cancer and 48.1% (95% CI 47.3-49.0%) for less common cancer compared to 87.8% (95% CI 87.3-88.3%) for common cancer.
- Rare cancer patients living in remote areas and areas of highest socioeconomic disadvantage (as per the Australian Bureau of Statistics' Index of Relative Socioeconomic Disadvantage) had significantly poorer survival rates compared to those living in a major city and in areas of least socioeconomic disadvantage, respectively.
- Possible factors contributing to these poorer outcomes in patients with rare and less common cancers are outlined in each of the relevant term of reference above.

[6] Bilkey GA, Trevithick RW, Coles EP, Girschik J, Nowak KJ. Descriptive epidemiological study of rare, less common and common cancers in Western Australia. BMC Cancer. 2021 Jul 8;21(1):779. doi: 10.1186/s12885-021-08501-4.

Table 1. Incident cases and percentages of cancers by rarity, sex, age, remoteness, socioeconomic and Aboriginal status for cases diagnosed between 2013-2017 in WA

	Rare		Less Common		Common	
Total	13,995	(21.5%)	17,462	(26.9%)	33,493	(51.6%)
Sex						
Male	8,085	(22.4%)	9,714	(27.0%)	18,245	(50.6%)
Female	5,910	(20.4%)	7,748	(26.8%)	15,248	(52.8%)
Age (years)						
0-≤20	476	(77.2%)	114	(18.5%)	25	(4.1%)
20-≤35	872	(45.2%)	443	(23.0%)	614	(31.8%)
35-≤45	924	(27.1%)	729	(21.4%)	1753	(51.5%)
45-≤55	1749	(21.6%)	1756	(21.6%)	4608	(56.8%)
55-≤65	2871	(19.9%)	3132	(21.7%)	8428	(58.4%)
65-≤75	3325	(18.5%)	4406	(24.5%)	10268	(57.0%)
75-≤85	2624	(20.6%)	4194	(32.9%)	5938	(46.6%)
>85	1,154	(20.2%)	2,688	(47.1%)	1,859	(32.6%)
Remoteness						
Major Cities	10,533	(21.3%)	13,470	(27.2%)	25,516	(51.5%)
Regional	2,686	(21.6%)	3,186	(25.7%)	6,543	(52.7%)
Remote	772	(25.7%)	804	(26.8%)	1,429	(47.6%)
Not mapped	<5*		<5*		5	
IRSD quintile						
1 Most Disadvantaged	1,856	(23.5%)	2,329	(29.5%)	3,722	(47.1%)
2	3,819	(22.0%)	4,706	(27.1%)	8,818	(50.8%)
3	2,577	(21.7%)	3,280	(27.7%)	6,001	(50.6%)
4	2,267	(22.5%)	2,575	(25.6%)	5,225	(51.9%)
5 Least Disadvantaged	3,469	(19.5%)	4,568	(25.7%)	9,715	(54.7%)
Not mapped	7		<5*		12	
Aboriginality						
Aboriginal	365	(38.3%)	290	(30.5%)	297	(31.2%)
Non-Aboriginal	13,554	(21.3%)	17,116	(26.9%)	33,038	(51.9%)
Not mapped	76	(26.2%)	56	(19.3%)	158	(54.5%)

Index of Relative Socio-economic Disadvantage (IRSD); *<5: Suppressed case numbers as cases <5 (17)

Incidence of neuroendocrine tumours: Data sourced from the Australian Institute of Health and Welfare's *Cancer Data in Australia 2022 web report and supplementary data tables*[7]*:*

- Neuroendocrine cancers made up approximately 3.4% of all new cancer cases diagnosed in 2022.
- In 2022, it is estimated that 5,437 new cases of neuroendocrine tumours will be diagnosed in Australia (2,846 males and 2,591 females).
- In 2022, it is estimated that a person has a 1 in 55 (or 1.8%) risk of being diagnosed with neuroendocrine tumours by the age of 85 (1 in 52 or 1.9% for males and 1 in 58 or 1.7% for females).

Table 2. Number of neuroendocrine tumours cases during 2015 to 2019

Geographic area	2015	2016	2017	2018	2019
North Metropolitan	85	107	88	96	90
South Metropolitan	118	108	123	111	116
East Metropolitan	110	123	122	99	99
Kimberley	4	3	9	3	2
Pilbara	3	5	2	3	6
Midwest	17	16	18	23	18
Wheatbelt	19	12	20	18	20
Goldfields	12	8	7	7	13
Great Southern	11	8	11	15	16
South West	26	39	38	34	37
Other	0	1	0	1	0
All	405	430	438	410	417

Treatment for neuroendocrine tumour patients: In WA, patients with neuroendocrine tumours can be treated surgically at all major metropolitan hospitals. Approximately 70% of patients with advanced neuroendocrine tumours are referred to the Medical Oncology Department at FSH. The remaining 30% are referred to SCGH Hospital Medical Oncology Department.

Statewide neuroendocrine tumour multidisciplinary team meetings are attended by specialists across disciplines and sites. Patients with advanced and progressive neuroendocrine tumours are presented to discuss treatment such as Peptide Receptor Radionuclide Therapy (which is available at FSH and SCGH).

[7] Cancer data in Australia, Data - Australian Institute of Health and Welfare (aihw.gov.au)