A joint submission to

The Senate Standing Committee on Community Affairs:

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

28th August 2023

This submission has been jointly prepared by Cancer Council Australia (Cancer Council), the Cancer Nurses Society of Australia (CNSA), the Clinical Oncology Society of Australia (COSA), Private Cancer Physicians of Australia (PCPA), the Medical Oncology Group of Australia (MOGA) and the Lung Foundation Australia (LFA).

Cancer Council is Australia's peak national non-government cancer control organisation and advises the Australian Government and other bodies on evidence-based practices and policies to help prevent, detect and treat cancer.

The Cancer Nurses Society of Australia is the peak national body for cancer nursing and strives to promote excellence in cancer care and control through the professional contribution of cancer nurses.

The Clinical Oncology Society of Australia is the peak national body representing health professionals from all disciplines whose work involves the care of cancer patients.

The Private Cancer Physicians of Australia is the peak body for private cancer physicians (Medical and Radiation Oncologists and Haematologists), dedicated to improving outcomes for all cancer patients, but particularly those seeking treatment in the private sector.

The Medical Oncology Group of Australia is the national, professional organisation for medical oncologists and the profession in Australia.

Lung Foundation Australia is Australia's leading lung health peak body and national charity. Founded in 1990, we are the trusted point-of-call for the 1 in 3 Australians living with a lung disease or lung cancer.

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Introduction

Cancer Council, the Cancer Nurses Society of Australia (CNSA), the Clinical Oncology Society of Australia (COSA), Private Cancer Physicians of Australia (PCPA) and Medical Oncology Group of Australia (MOGA) thank the Senate Standing Committee on Community Affairs (the Committee) for the opportunity to make this submission to the Inquiry into Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer (the Inquiry). This Inquiry provides much needed public attention to the impact and needs of rare and less common cancers including neuroendocrine cancer.

Our submission addresses all the Inquiry's Terms of Reference (ToR), noting that that the points made with respect to ToR a.(i) – (v) are applicable to barriers to accessing appropriate treatment for people with rare and less common cancers, including neuroendocrine cancer (ToR b.). Please note that alongside rare and less common cancers, when referring to neuroendocrine cancer in particular, this submission will use the term 'neuroendocrine tumours'.

a. Barriers to screening and diagnosis and treatment (ToR a. and b.)

Rare and less common cancers*

There is currently little investment or policy focus on the prevention of, and screening for, rare and less common cancers (see response to ToR d. below). Additionally, rare and less common cancers are often diagnosed through a process of exclusion or are more difficult to diagnose than more common cancers, and as a result, are more likely to be diagnosed at a later stage.[1] Compounding this situation is that as numbers for rare and less common cancers are relatively small, research often does not progress as quickly.[1] As a result, treatments for many rare cancers have not advanced at the same pace as treatment for more common cancers.[1]

Additionally, it is likely that more rare cancers will be identified as the potential of genetic testing and genomic medicine advances.[2] There is a need to ensure review and refinement to the regulatory environment to ensure people can access the benefits of genetic testing and genomic medicine to deliver best cancer outcomes while avoiding issues such as genetic discrimination in life insurance.[3]

While we call for dedicated investment in research to better detect and diagnose rare and less common cancers, it is recommended a broader view of the cancer data ecosystem be undertaken in parallel. Combined, these actions, detailed below, will wholistically address the needs of not only people with rare and less common cancers, but for people who have any type of cancer, including neuroendocrine tumours.

Investment to further develop standardised, well-established and specific diagnostic criteria

While this submission focuses on the 10 defined, identifiable, and classifiable rare and less common cancers, there are other cancers that may also be rare and less common, but they currently have not been sufficiently identified and understood enough to be formally classified as such. This situation is reflected in cancer registries that use general codes to capture these as-yet identified cancers, e.g. Neoplasm Not Otherwise Specified (NOS), Carcinoma NOS, and Non-Hodgkin Lymphoma NOS that are not categorised to a specific cancer that is considered rare.[4] The lack of investment to better understand rare and less common cancers limit the development of specific diagnostic criteria and appropriate diagnostic tools to identify those cancers that are already classified as rare and less common as well as cancers that are not sufficiently understood and remain 'undiscovered' yet still numerically rare and less common. Accordingly, the Committee is asked to recommend further investment in research into rare and less common cancers to help the standardisation of well-established and specific diagnostic criteria.

* A rare cancer is one that has an incidence rate of less than 6 cases in 100,000 Australians per year. Less common cancers are those that have an incidence of between 6 and 12 (inclusive) per 100,000 Australians per year.1. Cancer Council Australia. Understanding rare and less common cancers. Sydney (AU): Cancer Council Australia,; 2021. These numbers may seem relatively small but each year, about 145,000 Australians are diagnosed with cancer and of these, about 52,000, or one-third, will have their cancer diagnosed as rare or less common. Collectively rare and less common cancers represent 7% of all disease and account for 40% to half of all cancer deaths.
Cancers that are considered rare and less common in Australia are: Adenoid cystic carcinoma (ACC), appendix cancer, ocular (eye) melanoma, gall bladder cancer, neuroendocrine tumours, penile cancer, pseudomyxoma peritonei (PMP) tumour, small bowel cancer, soft tissue sarcoma and upper tract urothelial cancer (UTUC). That list is not exhaustive as there is no consistent current definition of what constitutes a rare cancer. For example, there are haematological cancers that could be considered rare, such as multiple myeloma.

Recognising the increasing impact of genomics and genomic testing

The role of genomics and the shift from a cancer location classification of a common versus a rare cancer, to a molecular classification, has large implications that must be recognised. Genomic research will improve testing and diagnosis for many diseases, including for cancer and rare cancers, help personalise treatment options, improve health outcomes and reduce health system costs. For example, where lung cancer would previously have been considered a common cancer we now know it to be made up of many molecular sub-types which are themselves rare cancers. The existing challenges that apply to rare and less common cancers will likely increasingly apply to many cancers, as greater understanding about molecular drivers occur. While the Australian Government's Genomics Health Futures Mission (GHFM) is investing $500 million over 10 years (2018-19 to 2027-28) in genomics research under the Medical Research Future Fund (MRFF),[2] the true impact of genomics and genomic testing remains to be seen.

Ensure optimal utilisation of clinical quality registries

The Australian Government's National Strategy for Clinical Quality Registries and Virtual Registries 2020-2030, guides strategic investment in clinical quality outcomes datasets in areas of national priority and the gradual integration of this data with Australia's major health care datasets.[2] 'Clinical quality outcomes datasets' refer to datasets that include a combination of clinical and patient-derived data for a particular clinical domain.[2] This universal term is inclusive of clinical quality registries and other mechanisms like virtual registries.[2] Clinical quality registries monitor the quality (appropriateness and effectiveness) of health care within specific clinical domains by collecting and analysing longitudinal clinical and patient-derived outcomes data.[2] Clinical domains risk-adjust and benchmark this data against agreed clinical quality indicators to identify variation in clinical care processes and outcomes.[2]

One example of how such clinical registries can be used to benefit people with cancer, is the Optimal Cancer Pathways Data Project.[2] The Project examines optimal cancer care pathways and variations in those pathways, services, costs and health outcomes.[2] The project links Victorian Cancer Registry data with routinely collected Victorian data sets (admitted, emergency, death index, radiotherapy) and Australian Government Medicare Benefits and Pharmaceutical Benefits data sets.[2] Also, clinical quality registries have been valuable for medical research and clinical trials, and when linked with other datasets, can be effective tools for assessing whether evidence from these activities is applied in real-world practice.[2] Ensuring data collected within clinical quality registries are used in ways to improve health system performance, support the operation and reporting of clinical trials and is available to support research to improve outcomes for rare and complex cancers would maximise investment in registries and help the system to realise real and tangible benefits for rare and less common cancers including neuroendocrine tumours.

Greater use and integration of real-world data

Cancer registries, electronic health records, administrative claims, and to a lesser extent smart devices such as wearables and apps are some examples of how individualised real-world health data is being collected.[5] These real-world health data have the potential to support not only health care itself, but policy and funding decisions to better diagnose, treat and care for people with rare and less common cancers.[6] The regulatory framework and how these opportunities can be leveraged to support people's healthcare needs to be carefully defined and trialled, while ensuring people with cancer's data remains private, secure and free from misuse.[7] These challenges should not deter governments from consulting and partnering with the health care, research, and technology sector and industry to explore how these opportunities can be meaningfully used for the benefit of people with rare and less common cancers.

Neuroendocrine tumours[†]

It is estimated that more than 5,400 people were diagnosed with neuroendocrine tumours in Australia in 2022 with the average age at diagnosis of 64 years.[8] Neuroendocrine tumours can be difficult to detect and are sometimes diagnosed when individuals are undergoing a range of different tests for different conditions.

There is currently no national screening program for neuroendocrine tumours available in Australia.[9]

a. i) Geographic location

Rare and less common cancers and neuroendocrine tumours are often diagnosed following a lengthy process of exclusion, and eventual diagnosis can require complex and less-used investigations/technology. These diagnostic challenges are more pronounced than the difficulties encountered to identify more common cancers and diagnoses of rare and less common cancers are often reported to be made later and following an exhaustive process plagued by inaccurate results, false positives and false negatives .[10] Those difficulties are compounded when people with rare and less common cancers and neuroendocrine tumours live in regional, rural and remote areas where access to diagnostic, healthcare and coordinated support services is more limited and difficult to access, and there are fewer oncology health professionals, including oncologists and medical general practitioners, permanently based.[11, 12]

[†] The neuroendocrine system is a network of glands and nerve cells that make hormones and release them into the bloodstream. These hormones help control normal body functions, for example digesting food. Neuroendocrine cells are found throughout the body, but mainly in the gastro-intestinal tract (including large bowel and small bowel), pancreas and lungs. Neuroendocrine tumours (also referred to as NET) are an uncommon type of tumour that forms in these cells. The type is generally defined by where the abnormal cells come from and can range from low grade (slow growing) to high grade (fast growing). Neuroendocrine tumours that produce extra amounts of hormones can cause certain symptoms and are referred to as functional tumours. However, not all neuroendocrine tumours produce extra hormones (non-functional). There are several types of neuroendocrine tumours including:

- Gastro-intestinal which start in the large and small bowel
- Pancreatic which account for about 7% of neuroendocrine tumours
- Lung
- Merkel cell carcinoma which involves the Merkel cells in the top layer of the skin
- Neuroblastoma which usually starts in the adrenal glands and affects immature or developing nerve cells in children.

a. ii) Cost

Significant burden related to the financial cost of cancer arises in a multitude of ways for many people affected by cancer in Australia. This burden disproportionately affects socioeconomically disadvantaged populations, promoting inequity in healthcare access. However, financial toxicity from cancer can affect anyone and at any time.[13, 14] The cost of cancer spans direct out-of-pocket costs, indirect costs and costs related to the changing circumstances of the person with cancer and those around them.[15] Increasing financial burden and the associated psychological and mental stress of managing those costs, can amount to financial toxicity where the ability for the person with cancer to undertake, complete and achieve optimal care outcomes, is severely impacted.[15]

Considering the lower public investment towards supporting diagnosis, treatment and support for rare and less common cancers and neuroendocrine tumours compared to more common cancers, cancer care costs for people with these cancers can be significant. For rare and less common cancers, cancer therapies have been estimated to cost approximately 50% more than the highest cost of current cancer therapies.[16] Additionally, when lung cancer is diagnosed in Stage I, the average cost to the treat per patient is $19.000 compared to being diagnosed in Stage IV which is 1.8 times more ($34,500). It is made worse with just 11.7% diagnosed in Stage I compared to 42% diagnosed in Stage IV. Concerningly, 28.5% of cases are diagnosed where the stage is unknown. If the diagnosis was earlier this would likely have a better impact on patients, families, the community, and the healthcare system as a whole. The benefits of timelier diagnosis are likely to similarly apply to rare and less common cancers and neuroendocrine tumours.

Out of pocket costs are also a significant concern, with Neuroendocrine Cancer Australia reporting that 15% of people with neuroendocrine cancer spend between 11-20% percent of their annual household income to address their cancer; which is higher than in any other country or region reviewed with the exception of the United States.[17] Common costs reported relate to transport, medication, doctors' visits, and hospital admissions, with the most common highest expense reported by 30% of patients for Positron Emission Tomography (PET) and Magnetic Resonance Imaging (MRI) scans.[17]

a. iii) Cultural and language barriers

Australia is a multicultural and diverse nation. Approximately 25% of people living in Australia were born overseas and 25% speak a language other than English at home.[18] People from cultural or linguistically diverse backgrounds may face challenges such as diminished access to health care, discrimination and difficulties in communication. Challenges can extend to the role of family and family members and alternative views of disease based on culture and the fear, stigma and taboos that can be associated with cancer.[18, 19] These can be additional challenges to those associated with having a rare or less common cancer, including neuroendocrine cancer.

Due to the uncertain and limited impact of conventional treatment (such as surgery, radiation therapy, chemotherapy, or newer treatments such as immunotherapy and targeted therapies) in addressing rare and less common cancers compared to more common cancers, people with rare and less common cancers are more likely to consider and participate in clinical trials.[1, 20] Despite this, clinical trials for

rare cancers typically involve a limited number of research sites recruiting from a small pool of patients dispersed over a large geographical area, creating challenges for people living in regional or rural parts of the country. These barriers combine to adversely impact the ability for people from culturally and linguistically diverse backgrounds to access, engage and participate in clinical trial research.[21] While this is the case, there has been work done to design strategies to enhance cancer research participation for people from culturally and linguistically diverse backgrounds. For example, in New South Wales the University of Technology Sydney's Cancer Symptom Trials (CST) investigated the underrepresentation of culturally and linguistically diverse communities in cancer clinical research in Australia.[22] The CST's project works to better understand the barriers and enablers by targeting Arabic speakers and collaborating with multilingual healthcare professionals working with these communities.[22]

The Committee is therefore asked to recommend that the Australian Government commits to funding to enable health and cancer sector organisations to partner and coordinate with culturally and linguistically diverse representative organisations based in the communities these priority groups reside. One opportunity to help build familiarity and understanding of rare and less common cancers by people from culturally and linguistically diverse backgrounds, is to have culturally and linguistically diverse representative community organisations work with cancer sector organisations to develop translated guides in community languages in such forms as fact sheets, video case studies and testimonials, shared across social media that these communities frequent. Culturally and linguistically diverse representative organisations are critically important as they have the trust and relationships with the communities they represent and are ideally positioned to work with health organisations to educate, raise awareness and identify the specific health and cancer services that impact and interest their communities.

As clinical trials are more likely to feature for rare and less common cancers, the Committee is asked to recommend a systems approach to improving engagement and participation by people from culturally and linguistically diverse organisations. The Australian Clinical Trials Alliance has been leading work in this area.[21] Funding investment to support the development of clinical trial resources, networks of culturally and linguistically diverse advisory groups and culturally and linguistically diverse researchers and a community of culturally and linguistically diverse participants is essential to ensure the sustainable clinical trials engagement, involvement, and participation of people from culturally and linguistically diverse backgrounds. Also, it should be noted that community insiders, representatives or supporters of those participating in clinical trials, should be funded in their roles.

a. iv) Type of cancer

As there are no screening programs for rare and less common cancers or neuroendocrine tumours, and these cancers are usually diagnosed following an extensive program of investigation, many people are diagnosed at a later stage and there is limited data available to provide an accurate prognosis. The rarity of these cancers also brings with it a lack of knowledge about the specific cancers among health professionals, and confusion as to the most appropriate treatment approach. This can further compound delays and contributes to the argument for ensuring patients are reviewed by subspeciality multidisciplinary teams discussed above in ToR a.(iii).

We know that for each patient, even those that share the same diagnosis of cancer, has a unique set of genomic changes that can influence how they may respond to therapy. In order to select the best cancer treatment, a comprehensive profile of the tumour at the DNA level is needed. In doing so, it creates:

- Greater diagnostic accuracy
- Targeted treatment options
- Improved patient outcomes
    - Survival, including progression-free survival
    - Quality of life and mental health
    - Cost savings

The committee is asked to therefore recommend the Australian Government provide further research funding investment in genomic research for rare and less common cancers, including neuroendocrine cancer.

a. v) Availability of treating practitioners

Optimal cancer care is multidisciplinary in nature. Depending on the cancer, the range of practitioners involved in the cancer care team varies and can include (but is not limited to) a General Practitioner (GP), surgeon, medical oncologist, radiation oncologist, pathologist, palliative care physician, oncology nurses, specialist psycho-oncology professionals and a range of allied health professionals.[23] Rare and less common cancers, as well as neuroendocrine tumours, often require complex and lengthy treatment plans, with treatments given alone, in combination or sequentially.[9] Such treatment plans require input from the broad range of multidisciplinary practitioners, with the review and update of treatment plans very commonly occurring, given different responses to treatment. The intensive and diverse input into such treatment plans for a wide range of multidisciplinary practitioners therefore bears repeating that with respect to rare and less common cancers, including neuroendocrine tumours, non-metropolitan areas have fewer available treating specialist practitioners.

People with rare and less common cancers including neuroendocrine tumours benefit from review at high-volume centres that see a larger number of people with similar cancers, sometimes called centres of excellence. A high caseload at such centres means that latest updates in research and management of that cancer can be translated more quickly to practice by interested subspecialists (as opposed to generalists for whom rarer cancers represents a small proportion of practice) and teams have more capacity to flex to meet demand and participate in research and clinical trials. Equitable access to this model of subspecialist cancer treatment would likely improve outcomes for people with rare cancers and neuroendocrine tumours from communities with poorer outcomes such as lower socioeconomic communities and communities where English proficiency is lower.[24]

Subspecialty centre establishment (including funding) is recommended to ensure that people with rare and less common cancers and neuroendocrine tumours are supported to access optimal cancer care. Appropriate models of care, governance, networked and shared care, referral pathways and supportive care arrangements can be put into place to deliver such subspeciality care without necessarily requiring the establishment of physical centres.

c. Adequacy of support services after diagnosis

For all cancers, ensuring the delivery of adequate supportive care services and supports is a challenge given constrained resources in the health system. The health system is most focused on the delivery of medical/cancer treatment, and so in some cases the supportive care needs of people with cancer can be not prioritised or are even overlooked. This is despite evidence to suggest that for every dollar invested in supportive care, patients and the system can benefit from up to $9 in social return.[25]

A unique challenge for rare and less common cancers and neuroendocrine tumours is the lack of widespread knowledge about such tumours. Specialist practitioners anecdotally report incorrect or misleading advice given to neuroendocrine tumour patients by other health professionals who may be more generalist in scope. This leads to the provision of inadequate or sometimes inappropriate treatment and support services, and paradoxically increases the need of such patients for increased supportive services as more time is required to re-educate patients and build trust in the system with a subspecialty provider.

Not-for-profit cancer organisations and the community sector offer support services such as cancer information, practical, emotional and financial support, and self-management tools and resources, that cover both general and cancer-specific information and support. The (soon to be released) Australian Cancer Plan recognises the need to directly identify and address the supportive care and cancer navigation needs of people with all kinds of cancers in a person-centred way. To ensure equity in cancer care is achieved, particular focus, attention and resources must also be allocated to deliver on the aspirations of the Australian Cancer Plan for rare and less common cancers including neuroendocrine tumours.

d. Adequacy of Commonwealth research funding

<u>Rare and less common cancers, including neuroendocrine tumours</u>

Anecdotally, clinical trials for rare and less common cancers, including neuroendocrine tumours are not attractive to research sites/sponsors, as they are less financially viable than trials for more common cancers, with larger patient pools to draw from. This reinforces the need for greater investment and incentives to undertake research and clinical trials to improve access and outcomes for people with rare and less common cancers. Awareness of what trials are available and how to access and refer to them is also a barrier. Additional barriers are experienced by people from culturally and linguistically diverse backgrounds discussed earlier in this submission. Clinical trial participation by Aboriginal and Torres Strait Islander people will be improved if Aboriginal and Torres Strait Islander leadership is prioritised; supporting multidirectional capacity-building and workforce development including with Aboriginal Medical Services is supported; and the issues of Indigenous data sovereignty is addressed.[21, 26, 27]

The Medical Research Future Fund's (MRFF) Clinical Trials Activity Initiative will provide $750 million over 10 years between 2022-23 and 2031-32 to increase clinical trial activity in Australia.[28] The initial focus of this initiative was on clinical trials addressing rare cancers, rare diseases, and unmet needs, and on bringing investigator-led international clinical trials to Australia and has since been expanded to fund research projects focused on any disease or condition that meets the objective specified in

each grant opportunity.[28] We are concerned that the Clinical Trial Activity Initiative's expansion of focus could inevitably result in less priority and funding investment towards rare and less common cancer research. Our analysis of grant recipients who received MRFF funding (2017 - 2022) has identified 111 recipients who received approximately $216 million in funding for rare cancer research. This pales in comparison with the MRFF's total allocation of approximately 1,100 grants to the tune of $2.67 billion over that same time period; that is, Australia's investment in medical research for rare and less common cancers, represents less than 10% of total medical research funding. Over the same 2017-22 time period, $5.19 million in MRFF grants were provided to three research projects involving neuroendocrine tumours, representing 0.19% of total medical research funding. Considering that rare and less common cancers represent one third of diagnosed cancers and represent 40% to half of cancer deaths in Australia, this investment falls short of the level of need.[1, 29]

Neuroendocrine tumours

There is a large disparity between the prevalence of neuroendocrine tumours (that have been increasing significantly over the last 20 years), and the paucity of specific research funding available. For instance, the Australian Brain Cancer Mission announcement in October 2017, involved the Australian Government committing $60 million from Medical Research Future Fund, while also obtaining funds from philanthropy, other governments, industry and the private sector.[30] However, this funding is to brain cancers, neurological malignancies which are entirely a different group to neuroendocrine neoplasm. This means that neuroendocrine neoplasm, a disease with greater incidence than brain cancers, is receiving significantly less research funding.

Additionally, competitive rare cancer peer review applications are made more difficult as a paper of equivalent impact generally attracts fewer citations compared to a publication in for example, bowel cancer or prostate cancer (e.g., if a breast cancer paper attracts 20 citations and a neuroendocrine neoplasm paper attracts 10 citations, since fewer neuroendocrine neoplasm papers are published which means fewer citations can "be distributed"). This effectively means that there is a structurally lesser field weighted impact for "oncology" built in for any neuroendocrine neoplasm researcher. There remains a desperate need for both recognition and dedicated funding research being done in less common tumour streams.

Currently, the causes of most neuroendocrine tumours are not understood, and so the evidence base has not evolved to the required level to adequately provide informed prevention advice and develop public health prevention measures. Despite this, while Australia leads the way in certain aspects of neuroendocrine neoplasm research and treatment (particularly the use of Positron Emission Tomography [PET] imaging and theragnostics), only through increased funding that is commensurate with the complexity and prevalence of these diseases, can Australia continue to flourish in this field and optimise treatment for people with neuroendocrine neoplasms.

e. Any other related matters

Continued investment to implement and embed Optimal Care Pathways

Optimal Care Pathways are a framework for the delivery of consistent, safe, high-quality, and evidence-based care for people with cancer.[31] Covering every step from prevention and early detection through to recovery, living with a chronic disease, to end-of-life-care, they aim to improve outcomes through promoting quality cancer care and ensuring that all people diagnosed with cancer receive the best care, irrespective of where they live or receive cancer treatment. The Optimal Care Pathways can guide, support and inform increased collaboration, more effective care, improved healthcare provider–patient communication and patient experience.

The Optimal Care Pathways are endorsed by Cancer Australia, the former National Cancer Expert Reference Group and all States and Territories.[31] Recently new Optimal Care Pathways developed for neuroendocrine tumours and several blood cancers were endorsed by the Health Chief Executives Forum.[31] The only other Optimal Care Pathway available for a rare and less common cancer is for soft tissue sarcoma.[32]

The Optimal Care Pathways have Australia-wide acceptance and government support and are being implemented nationally.[31] The Committee is urged to call for continued and increased investment and support by all Australian governments to establish develop, implement and embed the Optimal Care Pathways for all rare and less common cancers, including neuroendocrine tumours.

Improve affordability of medicines and repurposing of medicines

The nature of rare and less common cancers means existing treatment modalities are not always as targeted or optimal as they could be. That said, challenges exist for people with cancer, including rare and less common cancers, when they are prescribed medicines that may not attract Commonwealth subsidy under the Pharmaceutical Benefits Scheme, because its subsidy approval was for a different indication and not for the repurposed aim of supporting the treatment and care of that person's particular cancer. This is even when that medicine is recommended by evidence based clinical guidelines to deliver optimal cancer care.

Cancer Council, COSA, MOGA, PCPA and other cancer consumer organisations have previously reported on people with cancer's confusion and frustration when confronted with the scenario where their medications that are approved by the Therapeutic Goods Administration (TGA) for reimbursement for one purpose, but are not approved for their condition.

This counter-intuitive situation results in considerable out of pocket expenses, increasing financial toxicity and often exacerbating the level of distress people with cancer already experience due to their cancer diagnosis and treatment.[33] People with cancer often ask their clinicians and our organisations for clarity on why this situation is happening and are rarely satisfied with our explanations of Australia's medicines approval and reimbursement process. This frustration is increased when the medicine has been approved for use (and possibly reimbursement) for their indication by a similar international regulator. In our experience, directing patients to the TGA website is currently not particularly helpful in meeting their needs, and that plain English and multimodal resources from the

TGA, particularly addressing the Australian environment compared to international circumstances, would go some way to assisting in this situation. Explaining the context underpinning the current constraints to access for people with cancer does not in and of itself, remove those constraints that are compromising people's cancer care.

In June this year, Cancer Council, CNSA, COSA, MOGA and PCPA made a submission to the current Health Technology Assessment (HTA) Review process.[34] That Review is examining how health technology assessments inform Government decisions to fund and subsidise health technologies through subsidy schemes and funding programs such as the Pharmaceutical Benefits Scheme.

Advancing equity through addressing needs of priority populations

The priority populations that will be the focus of the Australian Cancer Plan are Aboriginal and Torres Strait Islander people; lesbian, gay, bisexual, transgender, queer, and asexual people; people from culturally and linguistically diverse backgrounds; people living in low socioeconomic areas; people living with a mental health illness; older Australians; adolescents and young adults; children and people living in rural and remote areas. The challenges for individuals with rare and less common cancers including neuroendocrine tumours to access timely diagnosis, appropriate treatment and adequate support services; and the inadequacy of research funding, are especially pronounced for people from these priority populations.

One example of this is the contribution both the National Immunisation Program and the renewed National Cervical Screening Program (NCSP) is making to eliminate cervical cancer in Australia as a public health issue. Australia's NCSP is one of the world's public health success stories.[35] It is estimated that by 2022, the age-standardised incidence rate of cervical cancer will be 7.1 cases per 100,000 females which means that cervical cancer could be defined as a less common cancer and is close to being classified as a rare cancer.[36] However, targeted action to improve screening and immunisation rates, particularly in Aboriginal and Torres Strait Islander women and other under-screened groups, including the promotion of self-testing, will be critical to Australia leading the world in cervical cancer elimination.[37, 38] This example illustrates that although cancer incidence may decrease at the whole population level due to investment in prevention initiatives such as health promotion, immunisation, screening, and treatment investment, this progress should not obscure Australia's goal to completely eliminate cervical cancer.[38, 39] No matter which tumour type, cancer cannot be equitably addressed (and ultimately eliminated) unless adequate investment and attention is given towards the needs of people with cancer who are from priority populations as well. An example is the lung cancer screening program (announced by the Health Minister in May 2023) that is being developed with Aboriginal Community Controlled Health Services sector to support cancer care needs on the ground.

Raising awareness and committing to achieving equity in cancer treatment and care

The term 'rare cancer', while technically correct, unfortunately risks paradoxically undervaluing/undermining the importance of efforts to raise awareness of such cancers to the public. The public may reflexively impute that such cancers are not of direct importance and relevance to them, and because they are so rare, the public are unlikely to be diagnosed.

Accordingly, the Committee is urged to make recommendations for the Australian Government to invest and commit towards greater health equity so that no matter what kind of cancer a person is diagnosed with, they can access optimal treatment and care throughout each phase of their cancer journey. Cancer Council, CNSA, COSA, PCPA, MOGA and LFA await the launch of the Australian Cancer Plan and hope that sufficient policy and funding commitment is made towards its implementation so that all cancers, including rare and less common cancers and neuroendocrine tumours, are supported not only from a healthcare sector, health industry and support services perspective, but to ensure that people affected by cancer are empowered to meaningfully engage in that process. The Committee is urged to also recommend that the Australian Government invest sufficient funding towards the full implementation of the Australian Cancer Plan.

Cancer is a human rights issue

When considering what Australia can do to achieve a cancer free future, it is important to recognise that cancer is a human rights issue. Advancing human rights is key to addressing the underlying social determinants of health we see reflected in the unequal burden of cancer in Australia, including socio-economic status, financial burden, geography, and access to cancer care for rare cancers discussed in this submission. Human rights are engaged for a person affected by rare and less common cancers in terms of cancer prevention, research, treatment and care, and access to other economic and social supports such as workplace protections and social security and non-discrimination.

Australia is party to several international human rights treaties that impose obligations relevant to rare and less common cancers. This includes a commitment to respect, protect and progressively fulfil the right to the highest attainable standard of mental and physical health (right to health).[40] In the context of rare and less common cancers, the right to health includes ensuring access to cancer prevention, treatment and palliative care services that are available, accessible, acceptable, of good quality, culturally appropriate and non-discriminatory. Access to credible information to make informed health decisions, including the costs of care upon diagnosis, and the ability for people affected by rare and less common cancers to participate in and reap the benefits of cancer research, such as cancer clinical trials also falls within the Australia's obligations under the right to health.[40, 41]

Australia has also voluntarily committed to reducing the costs of treatment and care for rare and less common cancers by progressing universal health coverage and progressively expanding social protections in the case of sickness and the care of sick family members.[40, 42-45] The requirement to progressively realise these rights reflects the understanding that countries have resource constraints and that it can take time to implement human rights treaty obligations. But countries such as Australia must show that they are making every possible effort, within available resources, to better protect and promote these and other economic, social and cultural rights.[46, 47]

Though not automatically enforceable in Australian courts, by entering into these human rights treaties, Australia has chosen to comply with their provisions in good faith and to take the necessary steps to give effect to those treaties under domestic law. Additionally, even when human rights law treaties have not been directly incorporated into domestic legislation, they are an indirect source of rights in that they give rise to a legitimate expectation of compliance by the state.[48] They also provide guidance on how domestic laws and obligations should be understood.[49] Accordingly, Australia's commitments to people affected by rare and less common cancers under international human rights law and other international agreements should be considered by the Inquiry.

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