Submission by Australia and New Zealand Lung Cancer Nurses Forum to Australian Cancer Plan

About Australia and New Zealand Lung Cancer Nurses Forum

The Australia and New Zealand Lung Cancer Nurses Forum (ANZ-LCNF) is the peak group for lung cancer nurses dedicated to supporting people living with a thoracic malignancy. The ANZ-LCNF vision is to reduce burden and improve outcomes for people living with thoracic malignancies through the delivery of quality thoracic oncology nursing. We aim to achieve this by authentically representing and leading the thoracic oncology nursing community, to increase the prominence, recognition and influence of our profession through the delivery of evidence-based thoracic cancer nursing care for people living with thoracic malignancies in Australia and New Zealand. The ANZ-LCNF Steering Committee comprises representatives from all states and territories in Australia as well as additional representatives to reflect the needs of rural and remote regions. Representation of speciality practice areas such as survivorship, thoracic surgery, and precision medicine are also included as posts on the Steering Committee. A New Zealand representative also holds a post on the Steering Committee.

The ANZ-LCNF is auspiced by Lung Foundation Australia, the only national charity and leading peak body dedicated to reducing the impact of lung disease for all Australians.

Question 1. What do you want the Australian Cancer Plan to achieve? Think big – what transformational change(s) should we be aiming to influence?

There are significant, discrete challenges experienced by people living with lung cancer that impact their health outcomes. The diagnosis, treatment and subsequent aftermath of lung cancer are associated with upheaval, distress and confusion[1,2]. Moreover, people living with lung cancer experience higher distress and greater unmet need compared to those who are

diagnosed with other cancers[2-6]. As such, there are three key areas that ANZ-LCNF would like the Australian Cancer Plan to address:

1. Increase the critical mass of specialist lung cancer nurses.

As the cancer with the highest morbidity and mortality in Australia, appreciable gains in the health and wellbeing of people living with this complex, burdensome and most often fatal disease will not be realised without increasing their access to specialist lung cancer nurses. Compared to overseas and other cancers, Australia has a significant lack of specialist lung cancer nurses. A recent study published by Australian authors[7] identified that, of the lung cancer multi-disciplinary team meetings (MDTs) in Australia, 53% of these did not include the membership of a specialist lung cancer nurse, despite the Lung Cancer Optimal Care Pathway recommending a specialist cancer nurse as a core MDT member. This is disquieting as it falls well short of best practice guidelines[8,9].

Specialist lung cancer nurses influence every step in the lung cancer patient pathway[10]. A recent retrospective cohort study conducted as part of the English National Lung Cancer Audit, where the specialist lung cancer nurse role is widely implemented, found that the contribution of the work practices of this role is associated with better outcomes for people with lung cancer. For example, specialist lung cancer nursing assessments conducted before and around the time of diagnosis were associated with a 5% lower rate of unplanned admissions, compared to assessments that occurred after diagnosis[11]. Further, and critically, assessment by a specialist lung cancer nurse is the strongest independent predictor for receipt of anticancer therapy, with early nurse specialist assessments being particularly associated with greater receipt of surgery (RRR 1.85, 95%CI 1.63–2.11)[12].

Thus, the specialist lung cancer nurse role reflects a critical position in the care of people with lung cancer. The role ensures optimal care coordination, including the increased receipt of anticancer treatment, increased enrolment into clinical trials, timely referrals to palliative care, and the care of carers[13,14]. Specialist lung cancer nurses provide information, education and intervention on the disease and treatment and its side effects,

symptom management, performance optimisation, psychosocial and psychological support, and improved wellbeing with continuity in survivorship care[10].

Approximately 200 more specialist lung cancer nurses are needed to enable all existing lung cancer MDTs to meet their membership requirement and, importantly, for all people living with lung cancer to yield the benefits of the expert care of a specialist lung cancer nurse across their clinical pathway.

2. Implement lung cancer screening.

Lung cancer screening will save lives[15]. Early diagnosis through a national lung cancer screening program is essential to meaningful impact on lung cancer survival and outcomes. Such a program will truly transform outcomes for people at high risk. Indeed, a review, commissioned by Cancer Australia concluded that, if implemented, a screening program "would enable unprecedented changes in clinical management and address the poor outcomes (incidence, mortality, survival, psychosocial and quality of life) for lung cancer that have been observed over many years."

A lung cancer screening program identified in the Australian Cancer Plan will demonstrate government leadership and commitment to destigmatising lung cancer, as the key path to truly improving experience of people with this insidious disease. However, this is not without caveat. Equity of availability for screening must be ensured. Aboriginal and Torres Strait Islander people, rural and remote populations, private and public health settings, and culturally and linguistically diverse communities must be considered.

3. Comprehensive genomic profiling as standard of diagnostic care.

Comprehensive genomic profiling on all biopsies needs to be the standard of diagnostic care for all people. Streamlined, reflexive, comprehensive testing on all confirmed lung cancers will ensure all patients with a targetable oncogenic mutation are identified and have access to the best therapies at the right time. Comprehensive genomic profiling at diagnosis will lower the cost of treatment per patient due to the delivery of personalised treatment leading to increased progression free survival, overall survival, and response to treatment.

We urge the Australian Cancer Plan to include diagnostics as a priority area.

Question 2. What are the opportunities with the greatest potential to realise your vision?

1. **Implement specialist lung cancer nurse-led clinics.**

   Person centred care is often espoused as 'gold standard' in contemporary health care settings, however, it is not consistently delivered[16]. The operation of specialist lung cancer nurse-led clinics can provide person centred care through the delivery of autonomous, holistic care through the acute and post-discharge phases, and the timely identification of individual needs and adaptation of care as those needs change[17]. The delivery of this type of care is as acceptable to people with lung cancer as clinics delivered by medical doctors[18].

   However, a Medicare Benefits Schedule (MBS) item number is essential for specialist lung cancer nurse-led clinics if the benefits of such are to be realised. The Australian Cancer Plan must acknowledge the current gaps in health care that specialist lung cancer nurse-led clinics can address through the timely assessment of the holistic needs of people and in turn the coordination of individualised, comprehensive care.

2. **Investment in nurse-led lung cancer research.**

   It is critical that the Australian Cancer Plan enhances the current commitment of the Australian government to nurse-led lung cancer research and innovation funding. While nurse-led research produces quantitative evidence, qualitative approaches should not be overlooked or discounted as less rigorous by assessment review panels. To the contrary, the burden of lung cancer is best reflected in qualitative approaches. Hence, increased funding for nurse-led research – for both research paradigms – is essential, not only to raise parity of funding to lung cancer compared to other cancers[19] or to strengthen the lung cancer evidence base, but, critically, to raising the patient voice through research. For these reasons, we strongly recommend nurse-led lung cancer research be included in the Australian Cancer Plan as a key objective of a strategic research pillar.

3. **Reduce stigma.**

Lung cancer is no longer a "smoker's disease". One in three women and one in ten men have no history of tobacco smoking[20] yet, people living with lung cancer experience more stigma than those living with other cancers[21]. Such stigma negatively affects every aspect of a person's life[22]. Clear public messages for continued advocacy to reduce stigma, nihilism and bias against people with lung cancer demands a priority in the Australian Cancer Plan.

4. **Invest in a national clinical quality lung cancer registry.**

Unwarranted variance in the quality of cancer care across Australia is a significant driver for the well documented inequities in lung cancer-related outcomes. The use of big and real time data in cancer care is now well understood and accepted in regard to supporting health system integration and operability, and service transparency through efficient reporting. The UK Lung Cancer Registry is a model of excellence that has served to demonstrate, through its collection and utilisation of data, a relationship between quality of lung cancer services and 1-year survival rate[24]. There is overwhelming supporting for such a registry in Australia by the Australian lung cancer community.

The comprehensive collection of data and analysis must be used to drive funding allocation, infrastructure and improvements in care. As a matter of urgency for a high-burden cancer, Australia needs to invest in a national lung cancer clinical quality registry to drive improvements in care, identify gaps and workplace shortages, minimise variation, and evaluate changes designed to address poor survival rates.

Question 3: What examples or learnings can we build on as we develop the Australian Cancer Plan.

1. **Early access to palliative care**.

In view of the seminal paper by Temel et al.[25] and the subsequent support by cancer health professionals of the importance of early referral to palliative care, we must continue to promote the benefits of early involvement of palliative care in the lung cancer patient pathway. Equally, we must provide education both to lung cancer patients and health

professionals on the taboos associated with introducing palliative care early and in turn advocate its benefits.

2. Smoking cessation including vaping cessation.

In view of the overwhelming data that demonstrate the importance of smoking cessation at all stages of the lung cancer trajectory[26] – from prevention to reduced complications, to increased success of treatments including surgery, to performance optimisation – we must continue to advocate for a nationally funded, coordinated smoking cessation program. Moreover, we must advocate for the education of health professionals in theory-driven learning and development approaches to ensure that we, as health professionals, are engaging meaningfully with people in their behaviour change efforts. As a collective we must, however, ensure that we promote smoking cessation in ways that do not cause additional stigmatisation of this population.

3. Specialist breast and prostate cancer nurses.

We have a duty of care to provide competent lung cancer nursing care to all people who have a diagnosis of lung cancer. People living with lung cancer advocate loud and clear that they desire and need specialist lung cancer nurses, nurses who specialise in the field of lung cancer and practise at an advanced level. In view of the successes of the specialist breast and prostate cancer nursing models, ANZ-LCNF recommends the articulation of a specialist lung cancer nursing model in the Australian Cancer Plan for lung cancer.

In the 1990s, specialist breast care nurses were formally introduced into the Australian health care system to facilitate better continuity of care and psychosocial support for women with breast cancer. Today, there are more than 400 specialist breast care nurses working throughout Australia[27]. Evaluation of the specialist breast care nurse role reflects a valuable strategy in improving the care, experience and outcomes of people living with breast cancer across Australia[28].

In May 2012, the Prostate Cancer Foundation of Australia launched the Prostate Cancer Specialist Nursing Service, a three-year pilot program funded by the Australian government. Today, there are nearly 100 specialist prostate cancer nurses working

throughout Australia[29]. Evaluation of the implementation of the role reported that the specialist prostate cancer nurse service results in significant improvements for men, in such areas as sexual dysfunction and better overall care experiences[30]. Evaluation also identified that the specialist prostate cancer nurse service results in increased referral to the services of allied health professionals. This is due in part to the nurses' active role in care coordination and participation in the multidisciplinary environment[31].

ANZ-LCNF will continue to advocate for equity in access to specialist lung cancer nurses for all Australians living with lung cancer.

End.

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