Thoracic Oncology Group Australasia

AUSTRALIAN CANCER PLAN SUBMISSION 2023-2033

1. **What would you like to see the Australian Cancer Plan achieve?**

   Think ahead to the next 10 years. What do you want the Australian Cancer Plan to achieve?
   Think big – what transformational change(s) should we be aiming to influence?

   The Australian Cancer Plan should aim to reduce the death and suffering for all people diagnosed with cancer. A coordinated national effort should seek to overcome jurisdictional barriers to care provision across primary, tertiary, and community sectors, and firmly embed and incentivise nationally-facilitated research as part of routine healthcare.

   Australian research and innovation must be supported to ensure consistent improvement in survival and quality of life for cancer patients. **Research, and particularly clinical trials**, **should be** appropriately pragmatic and **embedded into healthcare** so every cancer patient has an opportunity to access expanded treatment options through research and contributes to improved treatment for their particular disease. Improved treatments and demand are likely to see an enhanced focus on patient-centric care, but this must be accompanied by better care coordination across the sector, and adequate workforce planning to address gaps in care.

   As the highest cancer killer, appreciable gains in survival will not be gained without specifically addressing the poor survival in lung cancer. Survival in lung cancer care will not be significantly improved without addressing the variation in care across Australia, and in those of lower socio-economic status or under-represented groups, and in provision of coordinated and comprehensive care. Repeatedly apparent 'gaps' in lung cancer care around lack of psychosocial support, inadequate referral to palliative care and poor survivorship care, arise partly due to the low numbers of specialist nurses, compared to other high-burden cancers.

   Comprehensively collected data, analysis and public health burden must be used to drive funding allocation to research infrastructure and improvements in care.

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

   Think about what you would like the Australian Cancer Plan to achieve.
   What priorities need national action?
   In what areas could national action drive or accelerate progress?

   National action is required to ensure optimal and coordinated care for every patient diagnosed with lung cancer. As a matter of urgency for a high-burden cancer, Australia needs to invest in a **national Lung Cancer Clinical Quality Registry to capture comprehensive health data to assist in providing optimal care for Australians with lung cancer,** drive improvements in care, minimise variation, identify gaps and workplace shortages and appropriately evaluate any changes designed to address the poor survival rates[1]. A national CQR provides a more efficient, more cost effective, and likely more accurate model of auditing quality of care than the current approach of obtaining smaller datasets through research collaborations that have arisen through a collective desire in the lung cancer community to research and improve lung cancer

[1] Australian Commission on Safety and Quality in Health Care, Framework for Australian clinical quality registries. Sydney. ACSQHC, March 2014.

care. A Lung Cancer CQR will also be critical to identify any impact of lung cancer screening to identify earlier stage disease and increase the proportion of patients receiving treatment with curative intent.

A recently published paper showed that not all centres treating lung cancer had a **lung cancer multidisciplinary team (MDT)**[2]. Discussion of a patient's treatment plan by an MDT has been shown to significantly improve outcomes[3] and is a core component of the Lung cancer optimal care pathway (LCOCP). Lack of an MDT or an MDT without recommended core membership is likely to contribute to variations in quality of care.

Fifty-three percent of MDTs did not include a lung cancer nurse, despite the LCOCP recommending a nurse as part of the core MDT membership. Compared to overseas and other cancers, Australia has a significant lack of lung cancer nurses, equating to just 12 FTE nationally. A qualitative study found that several areas of a lung cancer nurse's role in an MDT increased access to treatment[4], and a more recent retrospective cohort study conducted as part of the English National Lung Cancer Audit, where the Lung Cancer CNS role is more widely employed, found that the contribution of nurse specialist working practices was occasionally associated with better outcomes for people with lung cancer, but that lung cancer nurse specialist assessments before/at diagnosis, were associated with a 5% lower rate of unplanned admissions, compared to assessments that occurred after diagnosis[5]. Further, and critically, assessment by a lung cancer nurse specialist is the strongest independent predictor for receipt of anticancer therapy, with early nurse specialist assessments being particularly associated with greater receipt of surgery[6]. The **lung cancer nurse is a critical position** ensuring optimal care coordination, timely referrals to palliative care, booking scans, smoking cessation and assisting with identification of clinical trials. They provide information about treatment and side effects, symptom management, optimisation of current function and provide much needed psychological support and survivorship care. Increasing the number of lung cancer nurses to approach the current nurse: lung cancer patient ratio in the UK would require up to 150 additional lung cancer nurses to be appointed.

MDTs at regional centres were significantly less likely to have a thoracic surgeon (55%) than MDTs at metropolitan centres (85%)[2]. If a National Lung Cancer Screening Program is implemented, with the expected higher numbers of patients diagnosed with earlier stage disease, a surgical opinion in an MDT and access to surgical resection and curative therapy will be critical to realise the expected benefits in survival. Acknowledging that it's not possible to provide all aspects of care locally in a regional centre, **mandating access through MDTs thus encouraging referral networks for streamlined and equitable care can be done through a national mandate within the Australian Cancer Plan.** This is particularly important in lung cancer if lung cancer screening is implemented, where resourcing and training is vital to expand workforce or address service gaps to ensure provision of appropriate care and timely action on screening findings.

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[2] Brims FJH, Kumarasamy C, Nash J, et al. Hospital-based multidisciplinary lung cancer care in Australia: a survey of the landscape in 2021. BMJ Open Resp Res 2022;9:e001157

[3] Stone E, Rankin N, Kerr S et al. Does presentation at multidisciplinary team meetings improve lung cancer survival? Findings from a consecutive cohort study. Lung Cancer 2018: 124;199.

[4] Tod AM, Redman J, McDonnell A, et al. Lung cancer treatment rates and the role of the lung cancer nurse specialist: a qualitative study. BMJ Open 2015;5: e008587

[5] Stewart I, Leary A, Khakwani A, et al. Do working practices of cancer nurse specialists improve clinical outcomes? Retrospective cohort analysis from the English National Lung Cancer Audit. Int J Nursing Studies 2021;118: 103718

[6] Stewart I, Khakwani A, Hubbard R et al. Are working practices of lung cancer nurse specialists associated with variation in people's receipt of anticancer therapy? Lung Cancer 2018;123: 160

Lung cancer is associated with a higher symptom burden than other cancers, with psychological distress among patients particularly notable[7]. This symptom burden appears to derive from the physical effects of disease and demands of treatment[8] and health-related stigma[7]. A recent systematic review[9] has identified a relationship between lung cancer patients' QoL and unmet needs during treatment and recovery, and a prior pilot study demonstrated that a cognitive behavioral intervention can substantially decrease the levels of health-related stigma in lung cancer patients[10]. However, lung cancer patients are currently not routinely screened for supportive care needs[11], referred to support services, nor are patient-reported outcomes (PROs) for unmet needs or psychological distress routinely collected. **Routine collection of PROs could identify those patients most in need of support services, with the opportunity for tailored provision**.

In addition, **the high symptom burden of advanced lung cancer often necessitates a need for early or ongoing referral palliative care** to optimise QoL, but uptake remains low. Facilitating palliative care in a range of settings, including community-based and primary care, to accommodate patients' choices is likely to facilitate uptake and contribute markedly to QoL of people living with lung cancer.

Survivorship in cancer care seems to suffer from the lack of a coordinated set of national principles and centres offering best practice survivorship care. Specific survivorship needs in lung cancer are rarely catered for in survivorship programs, and the needs of people with lung cancer who are receiving ongoing therapy but enjoy relatively good quality of life require a type of survivorship care (eg supporting the impacts of financial toxicity and poor mental health) that is not fulfilled by follow up in tertiary centres, but is not catered for in many survivorship clinics. Better coordination with primary providers and the ready availability of a lung cancer nurse would also benefit these patients. Incorporating survivorship as a key focus of the Australian Cancer Plan will facilitate positive outcomes for individuals living with cancer, with potential cost-savings and benefits for the health system overall.

The advent of targeted therapies and accompanying molecular testing has substantially increased survival for a subset of Australian patients with metastatic non-squamous NSCLC (mNSCLC) who can live for many years with milder and manageable side effects of treatment. Current standards for molecular testing of Australian patients with mNSCLC do not adequately identify all genomic alterations that can be targeted by specific treatments, as it is typically limited to sequential testing for EGFR mutations, ALK and ROS1 gene rearrangements. Furthermore, the genomic profiling of mNSCLC has since identified multiple new oncogene targets including BRAF, RET, NTRK, HER2 or METex14 alterations, for which emerging targeted treatments are currently available and recommended by international treatment guidelines. TOGA is currently conducting the ASPiRATION cohort study, which aims to investigate whether routine comprehensive genomic profiling, which identifies all genomic alterations in a single test, can be integrated into Australian clinical practice for mNSCLC patients. Regardless of the outcomes of this specific study, **an Australian Cancer Plan will need to embrace the requirement and implement the**

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[7] Chambers S, Baade P, Youl P et al. Psychological distress ad quality of life in lung cancer: the role of health-related stigma, illness appraisals and social constraints. Psycho-Oncology 2015;24: 1569

[8] Li J, Girgis A. Supportive care needs: are patients with lung cancer a neglected population? Psycho-Oncology 2006;15: 509

[9] Cochrane A, Woods, S, Dunne S, et al. Unmet supportive care needs associated with quality of life for people with lung cancer: A systematic review of the evidence 2007–2020 Eur J Cancer care 2022; 31:e13525

[10] Chambers S, Morris B, Klutton A et al. Psychological wellness and health-related stigma: a pilot study of an acceptance-focused cognitive behavioural intervention for people with lung cancer. European Journal of Cancer Care 2015;24: 60

[11] Stirling R, Martin C, Brand M, Smith S, McNeil J, Zalcberg J on behalf of the Victorian Lung Cancer Registry. The Victorian Lung Cancer Registry Annual Report, 2019. Monash University, Department of Epidemiology and Preventive Medicine, Report No 5, pages 47

infrastructure for routine and ubiquitously available molecular testing that identifies all oncogenic driver mutations where a treatment option is available.

It is critical that the Australian Cancer Plan enhances the current commitment of the Australian government to research and innovation, research infrastructure and funding across all spectrums. For every dollar invested, Australian medical research returns $3.90 in benefits to the population[12], and this could be up to $5.80 for investment in investigator-initiated clinical trials[13] which play a critical role in providing medical evidence to answer questions that arise during clinical care of patients with cancer, including optimal duration and de-escalation of treatment. However, rising costs of clinical trials, duplication of resources and review, minimal allocation to competitive grant funding, lack of a career development pathway for clinical trials staff, lack of protected research time for clinicians and lack of commitment of hospitals to research as an embedded priority of cancer care, threaten the continuation of cancer clinical trials research in Australia and encourage 'siloed' research efforts. Clinical trials research at a national scale, as conducted by the Cancer Clinical Trial Groups such as TOGA, that bring together national experts in the field to collaborate in design and conduct of clinical trials, will ultimately promote implementation of research outcomes and improvement of care through a nationally coordinated effort and must be better fostered, facilitated, and funded. Uniform central ethics review, governance review and procedures, additional resource for hospitals that excel in the performance of research, and centralised research funding are a cornerstone of effective implementation of clinical trials into healthcare in both the UK and US. We support initiatives such as the National One Stop Shop, initiated by the Federal Government to provide a cross-jurisdictional ethics approval and site-specific authorisation platform that also incorporates the current Australian and New Zealand Clinical Trials Registry (ANZCTR) and Clinical Trial Notification (CTN) systems; and the Australian Commission on Safety and Quality in Health Care (ACSQHC) Clinical Trial Governance Framework, **to promote a culture of facilitating and prioritising research in Australia's hospitals. An Australian Cancer Plan that promotes clinical trial participation as the cornerstone of excellence** in service provision will drive States to provide appropriate infrastructure support and define excellence by performance indicators matched to clinical trial activity.

Development of an access pathway to enable **the use of government-reimbursed medicines in clinical trials that address important questions of practice** would encourage clinical trials research across a broad spectrum of cancer, and may generate substantial savings in use of drug in the trial population in future use of Pharmaceutical Benefits Scheme (PBS)-reimbursed medicines. For example, based on original Phase III trials, the current Pharmaceutical benefits Advisory Committee (PBAC) approval of first line treatment of NSCLC with immune checkpoint inhibitors provides reimbursed treatment for up to two years and only once in a patient's lifetime. Providing government-reimbursed medicines to conduct clinical trials to define the optimal duration of therapy may well determine that a shorter duration of therapy is as efficacious but minimises toxicity and costs of extended treatment duration. Furthermore, with evolving international clinical trial evidence supporting routine immune checkpoint inhibitor therapy after radical chemo-radiotherapy in Stage III NSCLC or post-surgery +/- chemotherapy in the adjuvant (early-stage lung cancer) setting, the current PBAC recommendations limit the use of immune checkpoint inhibitor treatment to once during a patient's lifetime. Patients who have received immune checkpoint inhibitor treatment in the adjuvant setting but relapse will not be able to access reimbursed immune checkpoint inhibitor therapy as treatment for their relapsed and potentially later-stage disease, despite ongoing international research indicating that this may be an efficacious and viable treatment option[14]. To be effective, the conduct of these clinical trials examining optimal use of reimbursed medicines would need to be accompanied by review of existing PBAC listings to keep

[12] KPMG, Economic Impact of Medical Research in Australia, 2018 https://www.aamri.org.au/wp-content/uploads/2018/10/Economic-Impact-of-Medical-Research-full-report.pdf Accessed 13 February 2022

[13] The joint ACTA/ACSQHC Working Group. The value proposition of investigator-initiated clinical trials conducted by networks. Med J Aust 2021; 214:159e1

[14] Steuer C, Ramalingan S. Advances in Immunotherapy and Implications for Current Practice in Non–Small-Cell Lung Cancer. JCO Oncol Pract 2021;17:662-668.

pace with emerging evidence, and implementation of streamlined submission processes for marketing and reimbursement approvals to incentivise submissions in less profitable markets.

An attractive idea is the creation of a federally supported Australian National Cancer Institute (ANCI) similar to structures in the UK, US and many European countries to oversee and ensure optimisation of the structures and guidelines for the care of all patients with malignant disease, underpinned by robust data collection, clinical trials and translational research. However, the sheer geographic spread of Australian healthcare centres will also require supplementation of centrally located services with innovative solutions to deliver best practice care in a variety of locations.

The use of tele-trials and telehealth had started before the COVID-19 surge but the pandemic and mandatory isolation periods of the last two years forced greater uptake oftele-medicine to maintain patient services without face-to-face consulting and to review existing practices for monitoring and coordination of remotely located patients within clinical trials. **A National Cancer Plan that promotes the use of Tele-trials, streamlines multi-jurisdictional governance review for tele-trials and allocates specific funding to provide a broader and more equitable clinical trial framework across Australia is warranted.** This would also include establishing tele-trial cluster networks for activation of trials at remote sites for rarer tumour groups, as is increasingly being demanded by the expansion of molecularly defined NSCLC sub-groups and accompanying new drug targets.

We propose the following to address the gaps in lung cancer care.
Within 2 years:

- Collection of PROs as routine care during a lung cancer patients' journey to identify people with lung cancer in most need of specialist support services at any time in the care trajectory
- Review the outcome and recommendations of the TOGA ASPiRATION trial that assesses the feasibility of integrating routine comprehensive genomic profiling into standard of care for newly diagnosed metastatic NSCLC patients
- Completion of the pilot implementation of the National Lung Cancer Screening Program and a review of the workforce requirements for more widespread implementation
- Full commitment to implementation of a National Clinical Quality Registry in lung cancer with optional biobanking
- Funding to support the appointment of an additional 50 FTE lung cancer nurses
- Seek expanded access of PBS-approved drugs within clinical trials to encourage trials addressing important questions of practice.
- Embedding clinical trials participation and activity as a performance indicator of core service provision.
- Embedding palliative care as a performance indicator of core service provision, and investigating the feasibility of implementing palliative care for lung cancer in a range of settings to maximise uptake
- Promote networking across sites and the use of tele-trials to provide equitable clinical trial access for patients

Within 5 years

- Appointment of an additional 50 FTE lung cancer nurses and review of FTE required for the next 10 years to maximise care coordination
- A fully implemented lung cancer National Screening Program
- Provision of funding to enable 60% of hospitals treating lung cancer to contribute data to a set of national standards through a Lung Cancer Clinical Quality Registry with optional biobanking

Within 10 years

- A renewed commitment to MRFF program or a similar funded research program dedicated to funding clinical trials research

- Appointment of an additional 50 FTE lung cancer nurses, or the FTE that as determined at 5 years after implementation of the Australian Cancer Plan

3. **What examples and learnings can we build on as we develop the Australian Cancer Plan?**
   Think about great examples of work within or outside the cancer sector in Australia and internationally.
   How can we learn from these examples and build on them to improve cancer outcomes and experience for all Australians?

The UK Lung Cancer Audit is an example where the collection of data has successfully driven improvements and decreased variations in care (e.g increased early stage diagnosis, increased surgical resection rates, decreased geographical variance and increased survival)[15]. The Danish, Dutch, Japanese, Swedish and British all have national lung cancer registries that collect treatment data linked to outcome data to enable improvements to be made and reduced unwanted variation in lung cancer care.

The NCI's National Clinical Trial network consists of 6 network groups that receive funding for network operations, statistics and data management. These network groups also operate biobanks with common protocols for high-quality tissue collection, and a shared sample management system. Savings are made through other shared resources, such as all using a common clinical trial electronic data capture system with the licensing fees paid by the NCI. The program also funds other essential services to conduct clinical trials such as centralised ethics committees, resource for clinical trial regulatory submissions and drug distribution to participating clinical trial sites. Sites with demonstrated ability to enrol high numbers of clinical trial participants and enabling scientific leadership in the design and conduct of clinical trials receive additional funding to help with the data management, administration of recruiting large numbers of clinical trial participants and scientific leadership. Other sites can participate in clinical trials and received funding either as part of one of the six network groups, or through the community Oncology Research Program.

Over time the program has added other funded program in translational research, biomarker research, imaging, radiation oncology and QoL research. The centralisation and minimisation of duplicated services results in costs savings. In recent years the program has implemented key performance indicators around the time taken to develop clinical trial protocols and start up studies[16].

The NIHR Clinical Research Network (CRN) in the UK is comprised of 15 local clinical research networks across England and likewise meets the costs of staff, facilities, equipment, training and support services dedicated to research.

Australia already has developed and high-performing cancer clinical trials collaborative groups that design and conduct investigator-initiated clinical trials in cancer healthcare[17]. These groups receive some infrastructure funding but meet the costs of clinical trials through other forms of competitive funding. Scientific leadership, design and oversight of clinical trial conduct is provided in a voluntary capacity from clinical research experts that are members of these cancer clinical trials collaborative groups. Many well-designed clinical trials that would improve cancer care are not conducted due to lack of funding or inability to fund high-cost

[15] Foy R, Skrypak M, Stoddart J et al. Revitalising audit and feedback to improve patient care BMJ 2020;368:m213

[16] https://www.cance.gov/research/Ifrastructure/clinical-trails/nctn Accessed 13 February 2022

[17] https://consumerlearning.canceraustralia.gov.au/who Accessed 4 March 2022

treatments. There is no centralised funding or access to biobanking, data management or for participating clinical trial sites. These well-established groups are akin to the network groups that exist in the NIHR or NCI systems, albeit individually conducting national cancer clinical trials in their own particular aspect of cancer care, but there is significantly less funding and access to central resources.

About the organisation making the submission:

The Thoracic Oncology Group of Australasia (TOGA) Ltd is the leading thoracic cancer collaborative trials group in Australia and New Zealand comprising clinicians, health professionals, researchers and patient advocates with an interest in thoracic cancers who collaboratively design and conduct clinical trials in lung cancer, thymic cancers and mesothelioma https://thoraciconcology.org.au/