

20 January 2020

Professor Dorothy Keefe PSM MD
Chief Executive Officer
Cancer Australia
Via email: luncancerscreening@canceraustralia.gov.au

Dear Professor Keefe,

Re: Lung Cancer Screening Enquiry Report – Feedback

Thank you for the opportunity to provide comment on the Cancer Australia Report on the Lung Cancer Screening Enquiry.

We appreciate and commend Cancer Australia for your respectful and open engagement during the enquiry. We are pleased to read a report that reflects those consultations and current evidence; and acknowledges the opportunities that a national lung health screening program will provide to individuals, communities and the Australian economy.

The Lung Foundation Australia (LFA) and the Thoracic Society of Australia and New Zealand (TSANZ) are pleased to offer feedback to the Enquiry Report and look forward to working with Cancer Australia, the Government and the lung cancer community to secure the necessary funding to make the Enquiry Report recommendations a reality.

Yours sincerely



Mark Brooke
Chief Executive Officer
Lung Foundation Australia



Prof Bruce Thompson
President
Thoracic Society of Australia & New Zealand

Lung Cancer Screening Enquiry Report Feedback

About Lung Foundation Australia (LFA)

Lung Foundation Australia is Australia's only national for-purpose organisation working to strengthen the lung health of all Australians and supporting those experiencing a lung disease and lung cancer. We are Australia's oldest and most trusted lung cancer organisation. We fund life-changing research and deliver support services that give hope to people living with lung disease or lung cancer.

Since 1990, we have been working to ensure lung health is a priority for all; promoting good lung health and early diagnosis of disease, advocating for policy change and research investment, raising awareness about the symptoms and prevalence of lung disease, and championing equitable access to treatment and care. Lung Foundation is the only national service with a dedicated 1800 Help Line for patients with lung cancer and their carers.

Lung Foundation Australia represents the collective views of our members and supporters; people living with lung disease and people caring for or treating people experiencing lung disease and lung cancer.

About the Thoracic Society of Australia and New Zealand (TSANZ)

The Thoracic Society of Australia and New Zealand (TSANZ) is the only peak body in Australia that represents all health professionals working in all fields of respiratory health. The society's mission is to lead, support and enable all health workers and researchers who aim to prevent, cure and relieve disability caused by lung disease.

TSANZ has a membership base of approximately 1800 individual members from a wide range of health and research disciplines. TSANZ is a leading provider of evidence-based guidelines for the treatment of respiratory disease in Australia and New Zealand, undertakes a large amount of professional education and training, is responsible for significant research administration, and coordinates an accredited respiratory laboratory program.

About our response

Our collective comments on the proposed national targeted screening program are below.

As you can appreciate TSANZ and LFA represent different but closely aligned constituencies. As such our comments, whilst complimentary, may focus on different perspectives and may in some cases differ. Any differences do not affect our collective commitment to a national targeted lung cancer screening program.

We considered the published evidence base and actively sought feedback from our members and supporters, including medical specialists and lung cancer patients.

Lung Foundation Australia and the Thoracic Society of Australia and New Zealand are pleased to endorse your recommend program subject to comments below.

Chapter 2 Context

LFA and TSANZ generally agree with the context as presented. We particularly note the disparities for Aboriginal and Torres Strait Islander people and those residing in rural and remote communities and low socio-economic communities.

However, this chapter does not acknowledge the pervasive stigma faced by current and former smokers and lung cancer patients and their families; and the associated impact on access to diagnostics, care and much needed psychosocial support.

People living with lung cancer experience stigma, including from their communities, health providers, employers and even themselves. One study suggests that approximately 30 per cent of people living with lung cancer blame themselves for their diagnosis. Smoking is viewed as the main contributing factor for lung cancer and as a result, current and former smokers and non-smokers alike who have lung cancer often feel blamed for their illness.

This judgment negatively impacts the perceived worthiness the broader community has of lung cancer patients accessing medical services, and diminishes patient claims to basic human rights, dignity of care and empathy. A national consumer survey conducted by Lung Foundation Australia in 2017 found over a third of Australians believe people living with lung cancer 'only have themselves to blame'¹. Health professional attitudes were just as negative as those of patients, caregivers and the general public.

Chapter 5 Guiding principles

LFA comment:

We support the fundamental principles which inform the core policy elements of the program, in particular:

- *Accessibility* – ensuring a broad range of referral methods: self/facilitated/organised and opportunistic, promote strong participation,
- *Person-centred* – an individualised approach to care, including tailored smoking cessation services, will support participation and deliver health benefits,
- *Evidence-based* – a target population of current and former smokers aged between 55-74 in the general population, and Aboriginal and Torres Strait Islander people aged 50 to 74 years, will capture most Australians at high risk of lung cancer,
- *Best practice* – the use of low-dose computed tomography at two-yearly intervals with specialist respiratory health practitioner,
- *Research and data driven* – the results of screening tests will be held at a screening register.

¹ PWC. *Making Lung Cancer a Fair Fight: A Blueprint for Reform*. 2018

LFA recommends the addition of 'respect' as a guiding principle, or at a minimum referencing 'respectful' delivery of services and support within the person-centred principle. This would acknowledge that patients with lung cancer, particularly those who are current or former tobacco users, experience stigma, and that stigma has no place in health service delivery. All patients, regardless of cause of illness, must be supported and cared for without judgement and afforded human dignity at all steps in the screening process.

We believe explicitly acknowledging and incorporating respect in the guiding principles is a step towards addressing the patient and health professional nihilism commonly associated with lung cancer.

Chapter 5.2 Screening and assessment pathway

LFA and TSANZ comment:

We appreciate and support this depiction of the screening and assessment pathway subject to our comments on individual elements of the program below. However, the definition of "low", "moderate" and "high" risk is not immediately clear.

It would be helpful to footnote that these categories/qualifiers are based on PanCan and Lung-RADS protocols as defined later in the Enquiry Report.

Chapter 5.3 Participant recruitment

LFA and TSANZ comment:

We support the four modes of participation for new program participants.

LFA comment:

We acknowledge that the recommendations generally, but particularly participant recruitment, include considerable investment in community promotion and communication of the new screening program.

A successful program will depend on strong engagement and participation. Our patients, carers and family members possess a unique understanding of the barriers and motivations people at high risk of lung cancer face when accessing or considering accessing public health programs and services.

These perspectives and approaches have been, and will continue to be, highly influential in creating successful promotion and participation campaigns. We strongly encourage the Government to work with and through Lung Foundation Australia when developing promotion and communication materials.

Health promotion communication campaigns must be co-designed with the targeted populations. We acknowledge that Cancer Australia has respectfully engaged with First Nations and Culturally and Linguistically Diverse (CALD) communities when developing its Enquiry Report and developed a program which seeks to address the health gap experienced by First-Nations Australians.

We encourage the Government to continue to support Cancer Australia and community groups such as Lung Foundation Australia to co-design communication campaigns with impacted communities. We highlight the need for communication in multiple languages and styles to meet the needs of a varied targeted audience.

Noting that three of the four entry routes involve decision making and communication by health practitioners, we strongly recommend a support/awareness/training package be delivered to HPs to facilitate an understanding of the barriers patients face when offered access to screening services and to develop strategies to combat those barriers.

Chapter 5.4 Eligible population

LFA comment:

The lung cancer community has positive views on the Enquiry Report and proposed program, as many view the proposed program as a necessary and long-overdue step towards providing equitable access to health services for lung cancer patients.

However, many lung cancer patients acknowledge that the focus on current and former smokers, while proven to be effective in targeted trials, has the potential to reinforce stigma and also exclude Australians who have never smoked but are at high risk of lung cancer.

This "excluded" group would include people exposed to occupational and environmental hazards and those possessing genetic or familial characteristics that heighten their risk of lung cancer. We strongly encourage Cancer Australia and all participating Governments to consider the potential expansion of the program to other at-risk groups, based on scientific evidence, and to fund research to address research gaps in this expanded population.

We strongly recommend that all resources communicating the benefits of screening are made in multiple languages to support Culturally and Linguistically Diverse Australians. And we strongly recommend the use of gender-neutral language in all communications.

TSANZ comment:

TSANZ also notes that the report from the Lung Cancer Screening Enquiry has a major omission; there is not sufficient recognition of other risk factors for lung cancer, including the 27 agents listed by the IARC. Given that the carcinogens listed by the IARC account for 15-20% of lung cancer cases worldwide, there is a need for a greater focus on these risk factors.

Chapter 5.5 Informed consent

LFA comment:

Informed consent must be properly supported and obtained from all participants at all relevant points in the program. We believe that each individual participating in the program has a right to consent to all or part of the program and still receive care. We

also believe that each participant can choose to withdraw from the program at any point and still receive appropriate care. We support Cancer Australia's comments in this regard.

Accurate, accessible and patient-focused information is necessary for informed consent. Lung Foundation Australia welcomes participation in development of patient-focused information.

As outlined above, therapeutic nihilism is a major barrier to equitable access to health care. We strongly encourage Cancer Australia to ensure materials and processes that support and implement informed consent address the impacts of perceived and real biases towards smoking related illnesses and lung cancer in particular. This will include, as noted above, tailored training for health professionals to understand and address the impact of stigma on health offerings and choices.

Chapter 5.6 Smoking cessation

LFA and TSANZ comment:

This is a key and important feature of the program, and a more comprehensive description and approach is needed beyond linking patients with Quitline.

During screening visits there is an opportunity to provide brief advice to participants and engage in "teachable moments".

Brief advice promotes cessation and connects people who smoke with evidence-based tobacco dependence treatment; this includes multi-session behavioural intervention through Quitline and smoking cessation pharmacotherapy, as clinically appropriate.

The physician or other health practitioner is uniquely placed to be able to deliver brief advice on smoking cessation during screening visits. This advice must be appropriately supported after the initial session.

Chapter 5.7 Low Dose Computed Tomography (LDCT)

LFA and TSANZ comment:

We support LDCT as the best-practice method to conduct screening.

However, we note the proposed two-year interval. The NELSON screening occurred at baseline, year 1, year 3, year 5.5. The NLST screening trial involved three annual CTs. We would appreciate further advice on the recommendation to perform screening at baseline and thereafter every two years.

We strongly support the recommendation to deliver mobile screening vans to each Australian state and the Northern Territory, and encourage the Government to ensure these mobile screening units are delivered through a competitive tender process and implementation reaches all target populations to ensure equity.

It is critical that services are embedded within existing health and hospital systems.

Lung Foundation Australia also recommends that the services be promoted as **lung health checks** rather than lung cancer screening, acknowledging the importance of overcoming patients' mistaken belief that they only have themselves to blame for their diagnosis of lung cancer.

Noting the discussion on AI and CAD, we encourage Governments to consider regional cities for virtual diagnostic and assessment hubs to enhance local services and build regional capacity.

Chapter 5.8 Clinical assessment and management

TSANZ comment:

We appreciate that management beyond the screening program is beyond the scope of the program. However, it will be of interest/concern to respiratory professionals as to a feasible and sustainable way to manage increased referrals. In Victorian centres, there is a 40-day period from referral to definitive action of pulmonary lesions. The anticipated rise in workload has potential to impact timeliness of care.

TSANZ notes that there will be an increase in referrals to respiratory physicians and expresses concern and supports calls for specialist lung cancer nurses to address the needs of thousands of Australians. Compared to other cancers, lung cancer nurse numbers are terribly inadequate.

LFA comment:

We note that a screening program is likely to increase the numbers of Australians diagnosed with lung cancer and seeking best-practice medical care for their circumstances.

Best-practice medical care for patients diagnosed with lung cancer includes access to, and the support of, a specialist lung cancer nurse. Yet, there are only 12 full-time specialist lung cancer nurses in Australia to meet the care and needs of approximately 13,000 Australians currently diagnosed with lung cancer each year.

Specialist lung cancer nurses, like breast cancer and prostate cancer nurses, are proven to facilitate critical care and support for people diagnosed with lung cancer, by ensuring:

- Timely patient access to treatment and navigation of complex needs – by helping patients through avoidable and unavoidable health system delays,
- Increased receipt of anti-cancer therapy – principally through holistic assessment practice,
- Decreased inadvertent and avoidable hospital admissions – through timely accessibility via phone or in-person support and guidance, and
- Increased health-related quality of life in the post-treatment to end-of-life phase.

We strongly support multi-disciplinary team (MDT) care for lung cancer patients, and investment in the provision of a MDT register to provide information which empowers Australians to access their local MDTs.

For the proposed screening program to prevent over 12,000 lung cancer deaths and gain 30,000-50,000 quality-adjusted life years over its first 10 years, specialist lung cancer nurses must be incorporated into MDTs to deliver best-practice care and support after a screening diagnosis.

We strongly recommend that the report acknowledge the fact that, presently, patients diagnosed with lung cancer have very limited access to specialist lung cancer nurses to assist them in navigating the complexities of the health system and accessing appropriate psychosocial support. The report is silent on this critical issue and we recommend that acknowledgment of this existing unmet patient need, which will be exacerbated by an increase in diagnoses via a screening program, be made either in the context of clinical assessment and management, or later in the section on workforce.

We call on Governments to:

1. address the demonstrable deficit in specialist lung cancer nurses by adequate funding to achieve equity of best-practice care for lung cancer as for Australians diagnosed with breast or prostate cancer.
2. allocate resources in the screening program to ensure the efficient delivery of care from lung cancer MDT for all screen-detected lung cancer patients across Australia and to avoid inadvertently widening health disparities.

Chapter 5.9 Screening register

TSANZ and LFA comment:

We strongly support the establishment and maintenance of national screening register. However both LFA and TSANZ believe this recommendation should be enhanced by embedding the screening register within a more comprehensive Clinical Quality Registry in Australia.

TSANZ and LFA notes a need for longitudinal data capture. We recommend the lung cancer screening registry be established as a clinical quality registry (CQR) in accordance with the Australian Commission on Safety and Quality of Health Care (ACSQHC) framework. The current situation of multiple state-based systems of data collection and recording is sub-optimal and inefficient, and a national approach is required.

CQRs use clinical data to identify benchmarks and variation in clinical outcomes and feedback-essential risk-adjusted clinical information; to clinicians, patients, consumers, health service administrators and government to inform clinical practice and health service decision making.

A CQR of individuals undergoing periodic lung cancer screening will be useful to better understand lung cancer detection, development and prognosis, using

practice-based evidence. Furthermore, tracking the uptake and impact of smoking cessation management will offer valuable insight into the application and success of this tool. CQRs provide a foundation for continuous quality improvement, including the development of new guidelines and standards of care and the dissemination of relevant information to interested parties. CQRs are also robust data platforms upon which research can be conducted using a well characterised population.

A CQR has the potential to subsequently provide researchers and clinicians with insights on the clinical use, sensitivity and safety associated with the screening of lung cancer and developing technologies. This database will help researchers and clinicians to better understand the nature of lung cancer detection. It will assist in developing future clinical research projects as well as optimising clinical management strategies for screened individuals while potentially tracking the individual's journey and eventual patient experience for those with lung cancer detected. A CQR has the potential to achieve innovative approaches to care which may reduce variation in practice and achieve better outcomes.

In Australia, a CQR will be able to provide information on:

- The extent to which local screening differs from programs in Europe and North America, where health care systems differ from those in Australia
- Variation in screening practice around Australia
- Points of differentiation between the detection methods available to clinicians
- Variation in smoking cessation management in jurisdiction and location
- Local referral patterns
- CQRs provide regular reports, information and education for all stakeholders which improves care and patient outcomes.

Chapter 6 Workforce

TSANZ and LFA comment:

We disagree with the assessment that “overall, demand generated by the Program on the key members of the clinical workforce can be met by the existing workforce in Australia”. We seek to understand your reasoning for this statement further in an effort to resolve any potential challenges prior to implementation of the program.

Chapter 6.1 Key Workforce Groups

The Health Workforce Roles ‘Primary Roles within Pathway’ at Figure 6.1 omit any reference to health practitioners who will provide psychosocial services to patients and their carers during screening, assessment and management.

The psychosocial burden of lung cancer is significantly greater than other cancers including multiple myeloma, kidney, thyroid, prostate, leukaemia and breast². This is due to the stigma associated with lung cancer, generally late-stage diagnosis, lack of appropriate medical support and coordination during treatment, and low survivability rates. The prevalence of anxiety and depression in people living with lung cancer is relatively high when compared with other major cancers.

We strongly recommend that participants be able to access appropriate mental health support at the screening, assessment and management stages.

All people presenting for lung health screening should be screened for psychosocial support needs and if appropriate, referred to psychosocial support services as early as practicable in their treatment journey, guided by the stepped-care model. Those with more severe needs should be referred to psychosocial support from professionals with experience in an oncology setting.

The *Optimal care pathway for people with lung cancer*, a Cancer Council, Cancer Australia guideline provides an excellent model for addressing psychosocial issues which may arise with early detection and diagnosis.

We strongly recommend that Cancer Australia recognise and identify appropriate roles that will support the psychosocial needs of patients, carers and family members. We also strongly recommend that Cancer Australia consider and make provision for the potential need for referral to palliative care services for patients identified with late-stage disease through the screening process.

We recommend that specialist medical colleges and professional networks (e.g. RACGP) educate their members on lung cancer and the psychological impacts on patients and families, with a view to reducing stigma and increasing support and patient access to mental health care plans and psychology services. As mentioned above, this should be considered as appropriate at every step of the diagnostic and treatment journey.

We recommend that the pilot screening projects embed and deliver psychosocial support including telehealth options for people living with lung cancer, especially those living in regional and remote areas.

Implementation

TSANZ and LFA comment:

Any early screening program for lung cancer is most welcome and should result in earlier detection, therefore lowering lung cancer mortality over the next 10 years (given the five-year implementation plan).

² **PWC.** *Making Lung Cancer a Fair Fight: A Blueprint for Reform*. 2018. And also: Joshy, Grace, et al. "Disability, Psychological Distress and Quality of Life in Relation to Cancer Diagnosis and Cancer Type: Population-Based Australian Study of 22,505 Cancer Survivors and 244,000 People without Cancer." *BMC Medicine*, vol. 18, no. 1, 2020, p. 372.

We strongly encourage Federal, State and Territory Governments to implement Phase 1 of the recommended program this year.

We encourage Government to consider a pilot project in each State or Territory to ensure early consideration of jurisdictional issues in implementing lung cancer screening. This will also avoid the creation of inequitable access to health services for people at risk of lung cancer if they do not live in the planned 3 PHN jurisdictions.

We would like to be involved in assisting each PHN optimise recruitment strategies, by using our extensive contacts including LungNet.

We recommend that PHNs in northern Australia be prioritised in the phase 1 trial and that the results of the trials are published at least annually.

We strongly recommend an independent panel facilitated by Cancer Australia be convened to oversee the pilot projects. Consumer participation at each site must be mandated.

Chapter 8 Program Costings and Cost Effectiveness

LFA and TSANZ note the moderate level of investment by Government to establish the Program. We are concerned that the reports omit the costs from delayed diagnosis as a consequence of no screening program versus the gains associated with shifting the dial from stage III and IV diagnosis. We believe there is considerable merit in commissioning this work to demonstrate the advantages of screening to the economy.

We recommend further economic modelling be conducted alongside the pilot phase to measure the indirect economic benefit of screening including:

- increased and continued workforce participation,
- taxation and deadweight efficiency costs,
- benefits arising from the increased survivorship vs premature mortality,
- indirect costs associated with absenteeism,
- disability arising from psychosocial burden, and
- the costs of early stage treatments (i.e. surgery/radiotherapy) v later stage immunotherapy.