



REFERENCES TO THE VICTORIAN ABORIGINAL COMMUNITY FOR LUNG CANCER SCREENING

Australia's Lung Cancer Screening Advisory Group

March 2022

General

The burden of cancer is not evenly spread in Victoria. People experiencing socio-economic disadvantage, Aboriginal and/or Torres Strait Islander people and their communities, culturally and linguistically diverse communities, people living with a disability, and those who live in regional and rural areas of Victoria have poorer cancer outcomes.

Incidence and Mortality

In 2020, over 13,000 Australians are expected to be diagnosed with lung cancer and the number of new cases of lung cancer being diagnosed is continuing to increase year by year. While lung cancer is the fifth most commonly diagnosed cancer in Australia (Figure 2.1), it is currently the leading cause of death from cancer for both men and women in Australia (Figure 2.2). In 2020, the Australian Institute for Health and Welfare (AIHW) anticipates there will be over 8,500 deaths from lung cancer – representing 1 in 5 of all cancer deaths. In 2012-2016, 5-year relative survival rate from lung cancer was 18.6% compared to 69.2% for all cancers combined. Unlike other Australians, for Aboriginal and Torres Strait Islander people, lung cancer is both the most frequent cancer diagnosis and the leading cause of cancer death, both occurring at a younger age.

- *Report on the Lung Cancer Screening Enquiry (Cancer Australia, 2020)*

Screening

- Multiple entry points to a proposed screening program would significantly benefit Aboriginal and Torres Strait Islander participants. Entry points could include GPs, primary health care facilities, Aboriginal Community Controlled Health Organisations (ACCHOs), Aboriginal Medical Service (AMS), emergency departments, and mobile units. It should be noted that emergency departments entry points could risk a loss of continuity of care away from primary care, and overload EDs with screening rather than acute management.
- Is there any financial support for primary care or radiology clinics to undertake this screening process? Or will there be out of pocket costs for clients depending on which service they use?
- The possible harms and overdiagnosis of lung cancer screening must be very clear for clients before proceeding. Limitations, especially false positives leading to unnecessary investigations, invasive procedures (biopsies), anxiety and stress, financial burden. Properly informed consent is essential. Clients must be aware of possible harms by engaging in the screening program.
- As per Victorian Aboriginal Health Service (VAHS) advice to the VCCC Alliance submission to the Lung Cancer Screening Inquiry, the Adult Health Check may be useful entry point for lung cancer screening.
- There should be strong evidence to support the implementation of a lung cancer screening program with Aboriginal and Torres Strait Islander people. The 3rd edition (2018) of the NACCHO/RACGP guide to a preventative health check had not yet recommended population screening for lung cancer: “Population-based screening of either high-risk or low-risk people with either chest X-ray or low-dose computed tomography (CT) is not recommended at this time. Further evidence from screening studies in high-risk individuals may change this recommendation in the future”.
- There should be clear roles, resources and responsibilities documented with medical software companies (e.g. Communicare, Medical Director, Best Practice, MMEx etc) and radiology companies, to ensure that the software will support incoming results and clear documentation of clients participating in Lung Cancer Screening Program.

Language

- Careful consideration of the language used around screening should be made. As per Cancer Australia's Report on the Lung Cancer Screening Enquiry (2020), terms such as 'lung health check' should be considered.
- As per VAHS advice to the VCCC Alliance submission to the Lung Cancer Screening Inquiry (2020) language should link in with other screening messages.

Access to treatment and care

- Pathways from the screening scan to diagnosis must be clearly mapped as there may not be a direct path for many with biopsies or incidental findings on CT. Pathways must also be mapped out for the incidental findings that will occur – e.g. COPD, thyroid or adrenal nodule, coronary calcification. This should include geographical and financially funded pathways for equitable access to treatment and care.
- Post diagnosis treatment and care pathways for Aboriginal people must be mapped out prior to the inception of a targeted screening program. Assumptions should not be made about the integration of these patients into the mainstream health system.
- Aboriginal patient navigators, Aboriginal Hospital Liaison Officers (AHLO) and Aboriginal Health Practitioners (AHP) should be included in the formulation of multi-disciplinary teams.
- Consideration should be made to options for treatment and/or palliative care on or close to Country, including use of a culturally appropriate advanced care plan to identify people's wishes.
- Ongoing management of co-morbidities needs to be considered.
- Consideration needs to be made and support provided for people to access services close to place of residence, or provided with transport along with the patient navigator/AHW.
- Consideration should be made for priority referral pathway in tertiary care centres to support the timely management of the screening findings. Increased wait time and lack of access to these specialties will increase anxiety and harm for participating clients.

Workforce

- AHLO, AHWs and AHP should be consulted in the early stages of any design of a lung cancer screening implementation program.
- AHLO and AHP should be part of the implementing workforce of any lung cancer screening program targeting Aboriginal and Torres Strait Islander participants.
- The anticipated increased workflow arising from screening will need to be adequately resourced and clearly mapped. How exactly are clients going to access a lung biopsy if they live regionally? How is this going to occur in a timely manner, with minimal costs to client, and support for them if they need to travel (costs, time, worktime lost, family support if they care for others at home, family support for them to attend for diagnostic workup etc)?
- Specialities requiring increased capacity include Radiology, respiratory medicine, thoracic surgery, radiation oncology, and medical oncology, as well as increased resourcing for other specialities that will need to manage incidental findings – thyroid, adrenal, cardiovascular.
- Adequate resourcing needs to be provided to participating ACCOs and AMS' (note no AMS in Victoria) to ensure lung screening follow-up can be undertaken.

- Patient Navigators for Aboriginal participants will be required in instances where they do not have regular primary care or GP contact. This workforce will have to be trained and recruited prior to inception of the screening program.
- Any non-Aboriginal people involved in the Aboriginal lung cancer screening program should undertake cultural safety training.

Psychosocial issues

- Greater risk of lower quality of life for people with lung cancer, generally.
- Increased rates of functional impairment either due to the disease or the treatment.
- Aboriginal people may not have or access culturally targeted information or support services.
- Limited access to Country and community while accessing cancer services and undergoing treatment.
- Emphasis to reduce the shame associated with lung cancer (whether a smoker or not).
- Psychosocial impact of screening and diagnostic workup must be supported, with preventative/planned measures in place to reduce these potential burdens to clients.
 - Waiting times between each step – screening, diagnosis, treatment
 - Access to specialist diagnostic services
 - Access to specialist treatment services
 - Time away from home/family/work to access these services
 - Financial impact (medical services, lost work time, childcare or elderly support etc)
 - Anxiety and stress from false positives and incidental findings
 - Anxiety and stress from lung cancer diagnosis and treatments (including treatments away from home).

Research

- Screening of Victorian Aboriginal populations should take place in the context of an ethically approved clinical trial environment, with particular attention paid to adapted plain language statements and consenting procedures.
- A clear evidenced-based harm vs benefits statement should be developed to support any implementation of a lung cancer screening program.
- There must be continual monitoring and evaluation of the program's performance at planned regular intervals to ensure that this program should continue or be modified. This includes both quantitative measures, and analysis to ensure that this program does not just create lead time bias. Qualitative measures of benefits and harms much also be measured for all participants of the program (both those screening positive or negative for this program, and those who follow medical workup for incidental findings).
- Analysis of the ability of the health system capacity to provide appropriate, timely and accessible screening/diagnosis/treatment for Aboriginal and Torres Strait Islander people.
- The program should provide evidence of the balance between benefits, harms and costs for Aboriginal and Torres Strait Islander people who are participating.
- Prior to implementation, the research should ensure that there is good quality baseline data – so that measures over time can be reliable.

- Advocacy for improved identification of Aboriginal and Torres Strait Islander people in all healthcare sectors involved – primary care, tertiary care, pathology, radiology, Cancer Registry.
- Research should aim to support the development of Indigenous Data Sovereignty in practice through the utilisation of existing tools to ensure that Aboriginal data and information work for Aboriginal and people and communities.
- Any research to follow the guidelines developed by the Victorian Aboriginal Research Accord.

Contributors

Dr Kalinda Griffiths, Research and Education Lead, VCCC Alliance

Dr Sarah McLean, Public Health Medical Officer, Population Health, Victorian Aboriginal Community Controlled Health Organisation

Ms Clare O'Reilly, Executive Manager, Chronic Disease/Aboriginal Cancer Journey Strategy, Population Health, Victorian Aboriginal Community Controlled Health Organisation

Dr Vijaya Joshi, Health Equity Manager, VCCC Alliance



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VCCC Alliance members

