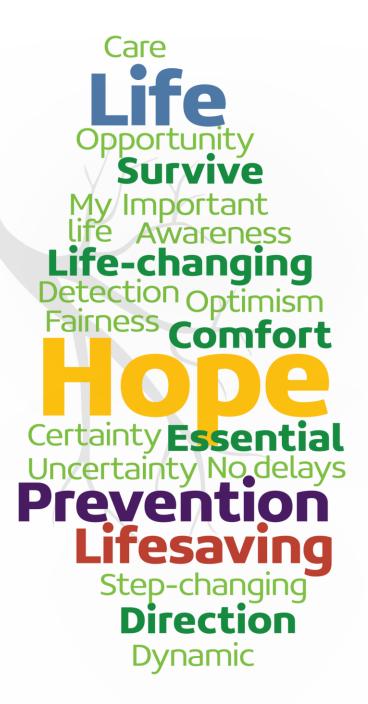
In one word what does lung cancer screening mean to you?

Vital Everything Equality **Cure** Survivors Lets-go Fight Future Longer life Why-not Equity Reassurance **Progress** Crucial Assurance Comfort 5 **FV N**a Heartache Change Time Possibilities Knowledge Family





celebrating

Lung cancer screening enquiry submission

Name	State
Carolyn	NSW
Alison	QLD
Alan	QLD
Natasha	SA
Tamara	WA
Gail	NSW
Elizabeth	QLD
Sandra	Qld
Helen	SA
Kate	VIC
Marg	VIC
Jessica	NSW
Sarah	Qld
Larisa	VIC
Elizabeth	VIC
Georgina	NSW
Ollie	NSW
Kristy	QLD
Lisa	QLD
Olivia	VIC
Carolyn	NSW
Sue	NSW
Judith	QLD
Vanessa	QLD
Christine	SA
Deb	NSW
Paul	NSW
Joy	SA
Jenifer	QLD
Shirley	TAS
Angeline	NSW
Bev	SA
Lisa	VIC
Willy	WA
Bron	QLD
Lily	WA
Susana	ACT

Anita	Qld
Victoria	QLD
Sacha	VIC
Fran	NSW
Kym	VIC
Phyllis	NSW
Jacqueline	VIC
Marg	VIC
Marg	TAS
Nasreen	NSW
Leanne	QLD
Eric	TAS
Sandy	SA
Rory	NSW
Elizabeth	NSW
Georgia	NSW
Chris	WA
Virginia	Qld
Madeline	NSW
Fran	NSW
Tricia	QLD
Arthur	NSW
Kathy	NSW
Sue	SA
Mark	QLD
Lisa	VIC
Antonia	NSW
Scott	NSW
Greg	VIC
Jane	ACT
Melissa	QLD
Zarli	NSW
Adele	VIC
Stephanie	NSW
lan	TAS
Robert	VIC
Chris	NSW
Roberta	NT

Graham	WA
Kirsten	QLD
Paul	NSW
Andrew	NT
Mike	NT
Cassandra	SA
Priscilla	QLD
David	VIC
Mal	VIC
Paul	VIC
Bob	VIC
Natasha	SA
Melissa	VIC
Melanie	QLD
Linda	QLD
Deb	QLD
Megan	TAS
Sue	VIC
Paige	VIC
Malinda	NSW
Kelcie	VIC
Kirsten	VIC
Fi	NSW
Claire	VIC
Sue	NSW
Melanie	NSW
Julie	VIC
Adam	VIC
Martin	NSW
Juanita	NSW
Kylie	QLD
Cassie	QLD
Nick	QLD
Lily	QLD
Mary	QLD
Mark	QLD





Introduction

In Australia, lung cancer is the leading cause of cancer death in both men and women¹. The ability to save lives by screening for lung cancer using low-dose computed tomography chest scans (LDCT) is no longer in doubt, following the publication and presentation of data from screening programs in the Unites States and the United Kingdom².

In 2020, Australia must determine the best way **to use** a national lung cancer screening program to: save Australian lives; develop innovative technologies and solutions with application to health services and broader industries; and strengthen our economy and community.

Lung Cancer Screening in Australia – a best practice model

Attention/Information day

It is a cold, grey - almost lifeless - day in Canberra and Barb is attending the free flu vaccination clinic at her workplace in Woden. Waiting, somewhat grumpily, for her jab, Barb notices a series of posters promoting health services and initiatives. Barb's eyes glance along each poster, barely taking in any of messages; she's not pregnant – ha! at 64 that would be a miracle; she's not obese – she's a vegan and rides her bicycle to work, even on the cold days; she had a breast scan last year and was given the all clear; she was even hen-pecked into taking a bowel check by her partner when his father was diagnosed with bowel cancer last year. Barb rolls her eyes, she is fine, she expects to live to 101 – it will take that long to master some measure of patience and a croquembouche. But her breath catches in her throat as Barb's eyes land on the last poster. It's a challenge. Especially for Barb. The poster is factual and straightforward: smokers, or past smokers, over the age of 55, or First Nations people over the age of 50³ who have smoked around a pack a day in the last 15 years are eligible for a free lung health check⁴.

¹ 4,911 Australian Men and 3,351 Australian women died of lung cancer in 2019. *Deaths in Australia*. Australian Institute of Health and Welfare, 17 July 2019, https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia

² In 2011, the National Lung Screening Trial (NLST) in the United State reported a 20% decrease in mortality when low-dose computed tomography (CT) was used to screen people who had smoked at least one pack of cigarettes a day for 30 years and who were either current smokers or had quit within the past 15 years - National Lung Screening Trial Research Team. *Reduced lung-cancer mortality with low-dose computed tomographic screening*. New Engl JMed. 2011;365:395–409. Also see: John K Field, et al. "The UK Lung Cancer Screening Trial: a Pilot Randomised Controlled Trial of Low-Dose Computed Tomography Screening for the Early Detection of Lung Cancer." *Health Technology Assessment*, vol. 20, no. 40, 2016, pp. Health Technology Assessment, 01 May 2016, Vol.20(40). Ru Zhao, Ying, et al. "NELSON Lung Cancer Screening Study." *Cancer Imaging : the Official Publication of the International Cancer Imaging Society*, 11 spec no a, no. 1A, 2011, pp. S79–S84.

³ First Nations Australians are nearly twice as likely to die from lung cancer than no-indigenous Australians – *Ibid 1*.

⁴ Campaigns tailored to match the characteristics of the target audience; clear on requirements and benefits of screening, are more persuasive and allow audience members to more closely identify with the





Barb makes a mental note not to tell Peter (her partner) about this, or she will be harangued into yet another health test. Barb has smoked since she was 18. She remembered her first smoke – it was at a Rolling Stones concert; 1973 Melbourne; some guy in the crush passed her a roll-up; it may or may not have been a tobacco one. She's been smoking ever since; sometimes tobacco, sometimes not. She's always been pretty healthy; what would be the point of a lung check?

'Next,' yells the nurse from behind the blue curtain, Barb gets to her feet and heads toward the cubicle. She notes the web address for the lung screening program; it's actually quite funny and easy to remember, especially for someone from her generation. Curious now, Barb promises herself she will look into it on the weekend...

Curious day

While one hand is gently wrapped around the customary Sunday glass of shiraz, Barb uses the other to tap answers to the e-questionnaire⁵ on the lung health check webpage. After 5 mins and 15 or so easy-to-answer questions - some which to her surprise, sought answers about her health and life goals - Barb is advised she is eligible for a free screen; but she has to drive to the medical centre in Wagga Wagga or make a booking with the lung bus when it is in Griffith (NSW), which is, according to the webpage next week⁶ what! Surely Canberra would have at least one clinic with a lung scanner - although a bus doing medical things does sound intriguing. Barb checks the postcode she entered and realises that the Sunday shiraz has affected her one-handed typing skills; she's input the postcode for her hometown Griffith (2680) – a tiny little rural town surrounded by tall grey gums and

featured content - Hudson, Janella N., et al. "Evaluation of Promotional Materials To Promote Low-Dose Computed Tomography (LDCT) Screening to High-Risk Consumers and Health Care Providers." Journal of Cancer Education, vol. 33, no. 5, 2018, pp. 1043–1051. Tailored media campaigns coupled with recruitment through general practitioners and public health organisations must be considered. See Rodriguez-Gomez et al. (2020). Effectiveness of patient-targeted interventions to increase cancer screening participation in rural areas: A systematic review. Intl | Nur Studies, 101, 1-21. https://doi.org/10.1016/j.ijnurstu.2019.103401 ⁵ Validated Patient Decision Aids (PDA's) or online screening decision aids are a useful tool to facilitate patient knowledge and clarify values; preparing patients to participate in a decision-making process. See for example: Housten, Ashley J, et al. "A Review of the Presentation of Overdiagnosis in Cancer Screening Patient Decision Aids." MDM Policy & Practice, vol. 4, no. 2, 2019, pp. MDM Policy & Practice, November 2019, Vol.4(2). For an Australian study on materials which address potential barriers to prostate cancer screening, including insufficient knowledge about risk and benefit, unclear values, decisional uncertainty, and over estimate of individual risk, see: Watts, Kaaren J., et al. "Online Prostate Cancer Screening Decision Aid for At-Risk Men: A Randomized Trial." Health Psychology, vol. 33, no. 9, 2014, pp. 986–997. For breast cancer see: Hersch, Jolyn, et al. "Use of a Decision Aid Including Information on Overdetection to Support Informed Choice about Breast Cancer Screening: A Randomised Controlled Trial." The Lancet, vol. 385, no. 9978, 2015, pp. 1642–1652. And also: Should I Screen: Lung cancer screening decision aid [Internet) Available from: https://shouldiscreen.com/English/home.

⁶ Mobile low-dose CT scanning units are an effective method to screen underserved populations, especially those groups who usually present with advanced disease – For the US experience see: Raghavan, Derek, et al. "Initial Results from Mobile Low-Dose Computerized Tomographic Lung Cancer Screening Unit: Improved Outcomes for Underserved Populations." *The Oncologist*, 2019, pp. The oncologist, 26 November 2019. For the UK see: <u>https://www.england.nhs.uk/2019/02/lung-trucks/</u>. See also: Rodríguez-Gómez, Marina, et al. "Effectiveness of Patient-Targeted Interventions to Increase Cancer Screening Participation in Rural Areas: A Systematic Review." *International Journal of Nursing Studies*, vol. 101, 2020, p. 103401.





short wattle trees with spiky red flowers. Barb sighs, maybe she needs a holiday at home. She inputs the correct postcode, the webpage loads a new screen; it turns out her nearest clinic is co-located with her GP super clinic in Canberra, and she can make a booking online - appointments are available in two weeks-time - or call a nurse for a discussion and then book. Barb decides to phone the nurse; she's really not sure she needs a lung health check, she's pretty healthy, she doesn't want to waste medical resources when they are needed elsewhere. Barb decides to call the nurse during morning tea tomorrow and see if she recommends a screen or not.

Inquiry Day

During morning tea, Barb heads to the smoker's area; it's a tiny rotunda more than 100 metres from the main entrance. No one is around - smokers seem to be a dying breed these days - so she lights up a smoke and calls the lung health hotline. It is answered by a lung health nurse⁷. The nurse is warm and friendly, her name is Vanessa. Vanessa asks Barb how she is and what prompted her to call the appointment line. Barb tells the nurse she was inspired to call the hotline because of the screening poster she saw when she was receiving her annual flu shot. Barb says, she is wondering if a free screen would be useful for her at her age and with her smoking history - considering her general good health. After asking Barb some more questions, like when Barb might have last had a CT-type scan, and questions about her medical history and medications, lifestyle and activities, the nurse asks: "Barb, what is worrying you most about the scan?⁸"

"Well, I am somewhat scared of finding out there is something wrong with my lungs." Barb blurts. "I mean, I am a smoker, I've been smoking for years - I'm doing it now, while we have this chat - surely my lungs won't be perfect and anyways, why would the government give us smokers a free lung screen? We choose to smoke."

"Barb, thank you for trusting with me your concerns, "Vanessa says reassuringly, "It's helpful for me to know how you're feeling and why you're feeling that way, because it helps me provide meaningful answers for you."

"Firstly, it is important to remember that science tells us that smoking is not really a choice," nurse Vanessa continues in a calm, factual manner, "nicotine is highly addictive - your body and your brain get hooked on it. If you're interested, I can send you some information that explains how nicotine works and why it's so hard to quit. If you have the time today, I can talk to you about options to help you quit or we can talk about this later when you're ready? Whichever way you decide you'd like to proceed; I can offer you plenty of support and assistance with your next steps."

⁷ Evidence demonstrates that nurse-led interventions, including the delivery of smoking cessation education and involvement in targeted promotional campaigns, improves participation rates, particularly in underserved communities Davis et al. (2018). A systematic review of clinical and community intervention to increase faecal testing for colorectal cancer in rural and low income populations in the United States: How, what and when? *BMC Cancer*, 18, 40. doi: 10.1186/s12885- 017- 3813- 4. Duke et al. (2015). Effect of vaginal self-sampling on cervical cancer screening rates: a community-based study in Newfoundland. BMC Women's Health 15, 47.

⁸ The harms of screening are divided into four domains: physical, psychological, financial strain, and opportunity costs. Addressing concerns early, especially with a trusted adviser, can overcome any real or perceived barriers. See Harris, Russell P., et al. "The Harms of Screening: A Proposed Taxonomy and Application to Lung Cancer Screening." *JAMA Internal Medicine*, vol. 174, no. 2, 2014, p. 281.





"Well," Barb says, a little sheepishly, "I've heard that if you switch to vaping, you can quit. I don't think that's for me. Vaping looks, well, lame. But if it could work, I could consider it, especially if it is something the experts recommend? ⁹"

"There are a lot of myths out there about quitting nicotine dependency, Barb," nurse Vanessa answers, "and this is one of the biggest ones. The fact is vaping, or e-smoking, is not an approved nicotine cessation method in Australia. There are other evidence-based and safe ways of quitting nicotine permanently."

"Oh, thanks for that information," responds Barb, "that clears that up then."

"When it comes to your question about the Government paying for the screening," Vanessa continued, "the Government knows that if you screen people at risk of lung disease early - and Barb, that's not just smokers, it is people who have worked in high risk occupations like mineral or coal mining¹⁰, and First Australians¹¹ - we have a much better chance of managing whatever the screening detects in ways that generate better health outcomes for individuals, their families and the community, and in ways that are more cost effective to the health system. In fact, we know that if we detect lung cancer for example, in its early stages, we have the best chance of beating it."

"Oh, ok, that makes sense," Barb mutters as she stubs her cigarette butt into the ash tray.

"Also," Vanessa explains, "there is very little harm to you if you choose to have a scan. The scanning technique uses a low dose technique. This means that while the scan does expose people to radiation, the dose is minimal and has, in the overwhelming majority of cases, limited physical impact. The low dose scan, however, will still give you a really clear picture of your lung health. That said Barb, before anyone has a scan, we take a comprehensive medical history."

"So, are you saying that a screen could either show something or nothing?" Barb asks, acknowledging to herself that it may be a good thing to have a scan.

"Yes," the nurse answers, "And, Barb, we don't want to get ahead of ourselves with these things – there will be a nurse with you along the way - through the screening and afterwards. There are a couple of things to remember, the first is that one major lung screening trial found that after the three

⁹ This is a teachable moment. A teachable moment is a relational nursing activity that involves the transfer of knowledge of skills in self-care to patients. Many teachable moments will occur between nurses and patients during the lung screening process, the aim of which is to encourage patients to become selfregulated learners who are in control of their health journeys. See Brunelli, V. "A model of engagement to enhance the capacity of specialist cancer nurses to support people living with lung cancer to self-manage" QUT ePrints, 2019. Low dose CT lung screening research studies report smoking cessation rates of 11% to 24% in the first two years of screening versus a 5% to 7% annual rate among all smokers in the general population Isenberg, Jacob, et al. "Trends in Cigarette Smoking and Cessation among Medicare Managed Care Recipients, 2005-2012." Addictive Behaviors, vol. 58, 2016, p. 155

¹⁰ Including workers at risk of dust diseases; standardising the health screening process for at risk workers in all states and territories of Australia, is essential. See: Lung Foundation Australia submission to the Dust Diseases Taskforce.

¹¹ First Nations Australians must be involved in the design, content and delivery of education and promotion materials to encourage and ensure their participation in screening programs. See: Braun, Kathryn L, et al. "Testing a Culturally Appropriate, Theory-Based Intervention to Improve Colorectal Cancer Screening among Native Hawaiians." *Preventive Medicine*, vol. 40, no. 6, 2005, pp. 619–627.





screening rounds, lung cancer was detected in 200 of the 7582 participants¹². And the second thing to remember, is that a CT scan of your lungs will incidentally take pictures of your heart and blood vessels, which means you'll gain insight into your cardiovascular health too. This may help you made decisions about healthy ageing."

"Book me in for one then," Barb makes the decision on the spot. Barb feels comforted; the nurse has given her clear information. Mostly, though, Barb is reassured that there will be a nurse to support her through the procedure and results, and in any event, she figures like every other test it will be fine.

Screening day

Arriving at the clinic, Barb is greeted by a lung cancer nurse navigator¹³ called Julie. Barb likes Julie immediately; Julie is capable and informative in a warm, reassuring way. Julie talks with Barb about her health history, they share a laugh over all the tests Barb has had recently, and Barb feels at ease.

"How many cigarettes would you smoke each day, Barb?" Julie asks, as she types comments and answers into an electronic tablet.

"In the past, I would have smoked about 15 a day," Barb answers, "But I've cut down in the last 10 or so years to about 5 a day, because I was finding I was getting tired after the bike rides. I know smoking is bad for your health, but it is just so hard to give it up," Barb adds, a slight tinge of regret in her voice.

"Yes Barb, I understand how hard it is to stop smoking. It's not easy. How many times have you tried to quit?"

"About 6 or 7 times. But it only ever lasts for six months or less," Barb answers honestly.

"Barb, if you are lasting for 6 months each time you attempt to quit, you're making an impressive effort. Something must keep happening for you though, to go back to the cigarettes. Do you feel comfortable telling me about the times you've tried to quit and about the types of support you've had when you've tried to quit? Good support is essential Barb."

Barb tells Julie about her journey with cigarettes, Julie tells Barb things she never knew; about nicotine addiction, the health impact of nicotine and smoke, and how to maximise her chances of quitting¹⁴. Barb wants to know more, but it's time to have her scan.

¹² Shlomi, Dekel, et al. "Screening for Lung Cancer: Time for Large-Scale Screening by Chest Computed Tomography." *The European Respiratory Journal*, vol. 44, no. 1, 2014, pp. 217–238.

¹³ A lung screen nurse navigator is a specialist-level nurse employed in the nurse navigator post and who has a clinical interest in lung screening for lung cancer. Nurse navigators are advanced level nurses who support complex health care clients with their health journeys, with a focus on decreasing barriers, increasing health literacy and increasing self-efficacy for the consumer (Office of the Chief Nursing and Midwifery Officer [OCNMO], 2019. Nurse navigators: Key role principles.

https://www.health.qld.gov.au/ocno/nurse/nurse-navigators).

¹⁴ This interaction between Barb and the lung health nurse is another teachable moment. Many teachable moments will occur between lung health nurses and individuals during the lung screening process. Teachable moments can include but not limited to smoking cessation education or discussion on improving self-management of co-morbidities. See: Deppen, Stephen A., et al. "Lung Cancer Screening and





Julie promises Barb that after the scan they will discuss quit strategies and avenues of support, as well as what to expect in the next steps in the screening journey. Julie takes Barb to meet the radiographer. He explains, briefly, how the machine works and the process. Barb discovers from the radiographer that the first reading of the scan is done by a robot¹⁵ – and it takes just 10 minutes! Barb will have some idea today of what her lungs look like and what shape they are in. Barb muses that she's finally lived long enough to see the future predicted by the dystopian novels English teachers made her read in the '60s and '70s. Barb is impressed; all the health care professionals that she has interacted with have been professional and informative - not condescending or judgemental at all - so she feels supported and in safe hands.

The scan is quick; there is no discomfort. After the scan Barb is greeted, again, by Julie and they enter a lovely office. Barb feels at ease; even though, logically, she knows that there must be damage or some change to her lungs after 30 years of smoking. She wants to know more about quitting, so she asks Julie and Barb discovers more information on how to break a nicotine addiction. Even if nothing comes up on her scan, Barb, thinks she's had a pretty fruitful day; all the information on nicotine and quitting has changed her views on smoking and given her new options to consider.

After a while, there is a knock on the door, the initial advice is back. Barb can't wait to see what her lungs look like

The people Australia miss - Australia without lung cancer screening and specialist lung health nurses.

Sue McCullough OAM.

When I met Wendy in September 2019 she did not look well, but she talked with immense passion about her diagnosis of stage 4 lung cancer. She told me she disclosed to her General Practitioner (GP) that she had smoked for many years and that her mother had died of lung cancer; she had not been feeling well and wanted to investigate the possibility of having lung cancer. The GP sent her for an x-ray - it showed nothing unusual. Still feeling ill, Wendy asked her GP if she could have a CT scan, but her GP did not investigate further.

Wendy became quite sick a couple of weeks later and was admitted to hospital. While in hospital she was finally given a CT scan and diagnosed with stage 4 lung cancer. Unfortunately, the earlier investigations of Wendy's health, were not adequate.

Wendy told me that she was going to talk to her local MP about why Australia does not have lung cancer Screening because they screen for a number of other cancers; it seemed like common sense to try and reduce the number of deaths by screening. She said she would have fit into the high-risk category and screening would have detected her lung cancer earlier, making her journey a very different one.

Smoking Cessation: A Teachable Moment?" *Journal of The National Cancer Institute*, vol. 106, no. 6, 2014, pp. dju122-dju122.

¹⁵ Presentation by Dr. Brendan Adler at the Australia Lung Cancer Conference, 2020.





She was treated at Royal Prince Alfred Hospital, her brother taking her to treatments and appointments. Wendy's brother told me the standard of care she received was amazing; so caring.

Wendy had arranged an appointment to see Julian Lesser MP in early December, but unfortunately, she passed away a couple of weeks before hand. I only met Wendy twice but was so impressed with how passionate she was about screening and advocacy for people with lung cancer. I got to know Wendy, and then her family, while researching this submission; being able to pass on her thoughts and wishes in this appeal for screening, is definitely what she would have wanted.

I was also able to talk to a lovely gentleman from South Australia; he is retired now, married with two grown up daughters, but has been diagnosed with stage 4 lung cancer. He told me that he had smoked for 45 years - so he probably deserved to have Lung Cancer. I told him no one deserves to get cancer.

In April last year, he had quite bad pain in his spine between his shoulders, a CT of his upper spine showed a T3 vertebral collapse. After having a full body MRI, they discovered lung cancer that had already metastasised. After radiotherapy and chemotherapy, losing 20 kgs, and being very ill from the chemotherapy, the pain has reduced.

I asked him: if lung cancer screening was available, would he have been screened? He answered yes - and he is sure the cancer would have been picked up earlier.

This would have given him a chance of surviving the cancer, a better health journey and a lot more time to enjoy his retirement and family.

At the time of making this submission to Cancer Australia, this lovely gentleman, is at home with his family receiving palliative care.

