LUNG FOUNDATION AUSTRALIA

"When you can't breathe... nothing else matters"™

Budget Submission

Two-year pilot program for Lung Cancer Nurses:

Improving lung cancer patient care and outcomes

Lung cancer patients in Australia who are diagnosed and cared for by multidisciplinary teams (MDTs) can have improved survival rates.[1] Unfortunately, many patients presenting with lung cancer in a primary care setting are delayed in their referral and access to a specialised lung cancer MDT.[2]

Lung Foundation Australia (Lung Foundation) is seeking to address this delay and improve patient care by implementing a two-year lung cancer nurses pilot program.

A pilot program will aim to demonstrate that increasing lung cancer nurse roles in Australia will result in shorter delays for patient referrals from primary care to lung cancer MDTs; decreases in emergency admissions; shorter length of hospital stays; reduced number of follow-up appointments; and decreased medical consultations. Most importantly, lung cancer nurses will be shown as the mechanism to improve patient care and treatment outcomes.

Executive Summary

Lung cancer is the fourth most commonly diagnosed cancer and the biggest cancer killer in Australia.[3] It kills more than 20 people each day – more than breast, ovarian and prostate cancers combined.[3] The economic and social burden of lung cancer is high. Survival is low.

Despite the severity of the current situation, there exists a huge deficit in the care that Australian lung cancer patients can access. This is especially marked when compared to other countries. *The Clinical Practice Guidelines for the Treatment of Lung Cancer*, commissioned by Cancer Australia, state that best-practice lung cancer treatment is delivered by an MDT[4], of which lung cancer nurses (LCNs) are an important component. Unfortunately, there is a critical shortage of LCN roles within Australia.[4]

In addition, many patients presenting in a primary care setting who have or may have lung cancer are delayed in their referral and access to a specialised lung cancer MDT.[2] Several factors may explain this including varying levels of awareness about the appropriate referral pathway; gaps in the coordination of a complex diagnostic pathway; perceived nihilism of some referring doctors and other clinicians; and limited sharing of information from multiple providers across different information platforms.[4]

In lung cancer, a small number of available studies have found improved survival of patients who had been diagnosed via an MDT.[2] MDTs have also been associated with improved patient satisfaction, increased rates of surgical resection, radical radiotherapy, chemotherapy and timeliness of care.[1] The existence of lung cancer MDTs across Australia provide the mechanism to improve patient care, outcomes and address variations in care.

Lung Foundation is ready to take a leadership role to improve patient care by demonstrating that LCNs play a core role in enabling rapid patient access to a lung cancer MDT. The economic and social benefits of LCNs have been reported overseas and include decreases in emergency submissions; shorter length of hospital stay; reduced number of follow up appointments; decreased medical consultations and importantly, improved treatment outcomes for patients.[5]

Using evidence gained from local and international consultation, Lung Foundation seeks $12.6 million over two years ($6.3 million annually) in the 2014/15 budget to enable us to implement a lung cancer nurse pilot program. The program will recruit and fund the placement of nurses in national services that have lung cancer MDTs. Data will be collected to demonstrate their value in Australia, and importantly, how they will complement existing policy to close the access gap for patients between primary care and lung cancer MDTs.

About Lung Foundation Australia

Lung Foundation is a national organisation with a long history of providing unique support to approximately 2.6 million Australians who are affected by lung disease each year. The organisation aims to reduce the impact of lung disease for future generations by ensuring lung health is a priority for all in Australia.

We work with a broad range of stakeholders including government, health professionals, industry, key opinion leaders and consumers, to provide information and support to patients and their carers. This includes people with lung cancer, chronic obstructive pulmonary disease, respiratory infectious diseases and rare lung diseases.

Lung Foundation has an established Lung Cancer National Program which works with our communities to reduce the impact of lung cancer. We play a lead role in improving outcomes for patients, carers, families and the community we serve by:

- Developing and providing information, coordinating and participating in educational programs relating to the prevention, detection, treatment and management of lung cancer;
- Promoting and facilitating lung and thoracic cancer research, particularly research into causation, prevention and treatments; and
- Developing, promoting, providing and coordinating services and resources for patients, their family members and carers.

Lung Foundation leads global alliances, having established the Australia and New Zealand Lung Cancer Nurses Forum and the International Thoracic Oncology Nursing Forum. We are an active member of the Global Lung Cancer Coalition, comprising 28 non-government patient organisations around the world. We also serve as volunteers on the International Association for the Study of Lung Cancer's organisational committees.

About Lung Cancer

Lung cancer sits within Australia's national health priorities (cancer) and is the fourth most commonly diagnosed cancer and the biggest cancer killer in Australia.[3] It kills more than 20 people each day – more than breast, ovarian and prostate cancers combined.[3]

The pathway to a lung cancer diagnosis is complex. Entry points for people with suspected or confirmed lung cancer include referral from a GP, hospital emergency departments, or another hospital department or specialist.[2]

In 2009, there were more than 10,000 new cases of lung cancer diagnosed. The latest projections indicate this figure is expected to increase 40% by the year 2020.[6]

Alarmingly, the incidence of lung cancer in women has increased by 72% (18-31 cases/100,000), while the mortality rate for women has increased by 56% in the period from 1992-2007.[3]

In 2012, lung cancer was expected to be the leading cause of burden of disease due to cancer among men (57,300 DALYs*, accounting for 19% of the total cancer burden) and second highest among women (43,400 DALYs, accounting for 17% of the total cancer burden).[7]

Most lung cancers are diagnosed in the late stages of the disease making treatment more problematic. As a result, the overall survival rate is significantly reduced. Five year survival rates for lung cancer remain low at 14.1% while breast and prostate cancers have high survival rates at 89.4%[8] and 92%[9] respectively.

People with lung cancer often feel discriminated against, even by their doctors, with often incorrect assumptions that a smoking habit caused their cancer.[10] Stigma may lead to reluctance for patients to seek treatment as well as having increased feelings of distress about the cancer.[11]

*DALYs = Disability Adjusted Life Years: is a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death.

Australia's clinical practice guidelines for the care of lung cancer patients

The Clinical Practice Guidelines for the Treatment of Lung Cancer[4], commissioned by Cancer Australia, were launched in 2013 by a multidisciplinary team of clinicians to support best-practice treatment of lung cancer.

Multidisciplinary care is an integrated team-based approach to cancer care, where medical and allied health care professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient.[4] LCNs are included in the guidelines as an important component of these teams.

LCNs are the one constant health professional for patients diagnosed with lung cancer. They ensure all their care needs are addressed from referral to diagnosis; through treatment and survivorship; to, where relevant, end-of-life care. Their role is critical to coordinate and optimise care for patients, as well as to provide them with clinical and emotional support.

The guidelines state that after initial treatment, *follow-up by an LCN is associated with early recognition of symptoms which results in improved symptom and emotional outcomes.*[4]

Rapid referral of patients into multidisciplinary care is vital

Lung cancer patients in Australia that are diagnosed and referred to MDTs predominantly have improved survival rates and quality of life. They receive best practice care, improved coordination of care, and the provision of information and support.[1]

Unfortunately, many patients presenting with lung cancer in a primary care setting are delayed in their access to a lung cancer MDT.[2] Several factors may explain this including varying levels of awareness about the appropriate referral pathway; gaps in the coordination of a complex diagnostic pathway; perceived nihilism of some referring doctors and other clinicians; and the limited sharing of information from multiple providers across different information platforms.[2]

LCNs are core to rapid referral into multidisciplinary care

LCNs can help minimise this delay in access by:

- Complimenting Cancer Australia's GP Algorithm[1] by acting as the link from primary care to the lung cancer MDT through specialised coordination of their requirements;
- Collaborating with the Lung Foundation to deliver existing evidence-based education and awareness programs in their regions; and
- Implementing Cancer Australia's principles and elements as outlined in the *Best Practice Approaches to the Management Of Lung Cancer In Australia* report.[2]

Lung Foundation and LCNs partnering to support faster patient access into multidisciplinary care

Working with LCNs, Lung Foundation will utilise its strong links with Medicare Locals that identified respiratory and lung health as priorities in their population base. The following branches will be targeted to facilitate the introduction of primary care/GP education programs focusing on rapid referral and access to lung cancer MDTs:

- Northern Adelaide
- Central Adelaide Hills
- Sunshine Coast Qld
- Gold Coast Qld
- Greater Metro South Brisbane
- Metro North Brisbane
- Eastern Sydney
- Inner West Sydney
- Western Sydney
- Central Coast NSW
- Hunter NSW
- Grampians VIC
- Northern Territory
- Tasmania
- Perth North Metro

There is a critical shortage of LCN roles in Australia

There are currently 62 lung cancer MDTs in Australia in the public and private sector, the majority in metropolitan and public services.[2]

Clinical Practice Guidelines recommend there should be at least one LCN per MDT.[4] There are fewer than 20 LCN roles in Australia, placing us well short of best practice.

In contrast, the United Kingdom has some 300 lung cancer specialist nurses and has an auditable standard that at least 80% of lung cancer patients are seen by an LCN.[5]

Explanations for this shortage and unintended consequences

Funding for LCNs is currently driven at the hospital or clinic level. The consequence of this funding model is fragmentation in the LCN role and associated patient care. Several positions are unlikely to be renewed beyond 2014. Patients should not be disadvantaged based on where they live and whether their chosen hospital has available funding to employ an LCN.

Lung cancer patients and their carers understand the value of LCNs, however the Lung Foundation understands data needs to be collected to demonstrate empirically and conclusively their value in Australia to enable an ongoing investment in this critical resource.

A pilot program for LCNs – improving patient access to lung cancer MDTs and demonstrating the value of LCNs in Australia

Lung Foundation is ready to take a leadership role to improve patient care for those living with lung cancer and demonstrate the value of LCNs in Australia. International and local consultation has given us access existing nursing program frameworks that can be applied to lung cancer.

We support a centralised national model for LCNs, similar to that employed by the Prostate Cancer Foundation of Australia (PCFA).

The Prostate Cancer Specialist Nursing Service initiative funds the placement of nurses in hospitals across Australia in partnership with health service providers.[12] These specialist nurses work within agreed frameworks for practice and professional development which are based on nationally recognised best practice models. Through this program, the PCFA is also committed to providing ongoing professional development support for the duration of the program.[12]

This service was launched in 2012 by the Prostate Cancer Foundation of Australia utilising $3.6 million from the Movember Foundation. The federal government has since provided an additional $3.6 million in funding to expand the program to a wider range of hospitals.[12] The PCFA have generously shared their learnings and framework with us.

A similar program will allow Lung Foundation to clearly define the role of LCNs, identify a clear professional pathway for entry, career development and longevity. The program will also allow Lung Foundation to develop a structured leadership, support and mentorship system for these nurses.

Data will be collected during the pilot to demonstrate the effectiveness of the LCN role in rapid access of patients to lung cancer MDTs and their value to Australia.

Recommendations

Lung cancer is commonly diagnosed in the late stages and progresses quickly. There is a need for specialised nurses to rapidly identify patient needs and provide coordination of the lung cancer pathway from symptom investigation onwards.

Lung Foundation seeks federal government funding in the 2014-15 budget to implement an LCN pilot program. Funding such a program will help align Australia's healthcare standards with other countries – Australia currently lags severely in its care of lung cancer patients when compared to other developed countries.

OPTION 1

Lung Foundation seeks a 2014-15 federal budget commitment of $12.6 million to fund a two year pilot program for lung cancer nurses.

The program will place an LCN in each existing lung cancer MDT with the objective to minimise the delay in referral from primary care; provide timely access to diagnosis, treatment and care; and improve patient outcomes.

Budget Breakdown

- One LCN per MDT: (average salary of a FT LCN, on-costs and educational expenses) x 62 MDTs = $6.2 million per year
- Program administrator (establishment of LCN framework, data collection, report writing) = $100k per year

OPTION 2

Lung Foundation seeks a 2014-15 federal budget commitment of $8.4 million to fund a two year pilot program for lung cancer nurses.

The program will place an LCN in 41 of the 62 existing lung cancer MDTs, with the objective to minimise the delay in referral from primary care; provide timely access to diagnosis, treatment and care; and improve patient outcomes.

Budget Breakdown

- One LCN per MDT: (average salary of a FT LCN, on-costs and educational expenses) x 41 MDTs = $4.1 million per year
- Program administrator (establishment of LCN framework, data collection, report writing) = $100k per year

OPTION 3

Lung Foundation seeks a 2014-15 federal budget commitment of $4.2 million to fund a two year pilot program for lung cancer nurses.

The program will place an LCN in 20 of the 62 existing lung cancer MDTs, with the objective to minimise the delay in referral from primary care; provide timely access to diagnosis, treatment and care; and improve patient outcomes.

Budget Breakdown

- One LCN per MDT: (average salary of a FT LCN, on-costs and educational expenses) x 20 MDTs = $2 million per year
- Program administrator (establishment of LCN framework, data collection, report writing) = $100k per year

Minimum competences for LCN roles will be set to ensure those employed possess the right skills and knowledge to identify the needs and bridge the gaps.

Outcomes from investing in LCNs

The benefits of LCNs have been reported in the UK[5] and include:

- Decreased numbers of emergency admissions, shorter length of hospital stay, reduced number of follow up appointments, and decreased medical consultations;
- More streamlined treatment, increasing efficiency and reducing the burden on the healthcare system;
- Helping overcome the stigma associated with lung cancer and ensure patients receive the medical and emotional support they need; and
- 64.4% of patients seen by LCNs received anti-cancer treatment compared to 29.8% of those who did not – meaning those who don't access LCNs could potentially miss out on important life-enhancing or life-saving treatments.

We anticipate these outcomes will be replicated in Australia by an investment in the LCN pilot program.

Measurement, evaluation and reporting

Measurement, evaluation and reporting are imperative to demonstrate outcomes. As a pre-requisite to receiving funding, Lung Foundation will ensure LCNs utilise the PCFA's existing measurement criteria as a reporting tool to show:

- Referrals to lung cancer MDTs
- Education sessions delivered
- Education sessions received
- QI or Research activity
- Professional body activity
- Community/support group engagements (including GPs)
- Personal Professional Development

Lung Foundation would work with the federal government to agree on metrics and performance indicators to measure the success of the program. In addition, we would look to understand what economic and social data is of value to government.

Alignment to current policy and budget commitments

Cancer Australia has made an excellent contribution to best practice care through the establishment of an evidence-based professional development framework and mapping the pathways of care.

These accomplishments must be put into practice for lung cancer patients to receive the benefit of this work. A national LCN pilot program will take this existing work and place it into practice. Doing so will enable us to gain valuable data on the effectiveness of best-practice frameworks in practice; establish benchmarks and measure outcomes.

Lung Foundation is seeking to have the LCN pilot program included in the 2014-15 Budget and believes it is aligned with several of the Government's election commitments, including:

- Invest in general practice and primary care workforce through investing in the nursing and allied health workforce;
- Ensure older Australians have the care they need, when they need it, and wherever they need it; and
- Get every dollar away from administration and bureaucratic processes back to frontline services.

Conclusion

We recognise the constraints that Australia's budget is currently facing. However, this small investment will provide a great benefit to tens of thousands of future lung cancer patients and their carers – ensuring they have the care they need, when they need it, and where they need it.

References

1. Cancer Australia 2012. Investigating symptoms of lung cancer: a guide for GPs. Accessed 22 January 2014. http://canceraustralia.gov.au/sites/default/files/publications/lung-cancer-gp-guide-2012_509ae0cdd2e36.pdf.
2. Cancer Australia 2013. Best practice approaches to the management of lung cancer in Australia: Final report. Accessed 23 January 2014. http://canceraustralia.gov.au/sites/default/files/publications/lcfr_best_practice_approaches_to_the_management_of_lung_cancer_in_australia_-_final_report_52d607cd28762.pdf.
3. Australian Institute of Health and Welfare & Cancer Australia 2011. Lung cancer in Australia: an overview. Cancer series no. 64. Cat. no. CAN 58. Canberra: AIHW. Accessed 5 December 2013. http://www.aihw.gov.au/publication-detail/?id=10737420419.
4. Cancer Council Australia 2013. Lung Cancer guidelines. Accessed 4 December 2013. http://www.cancer.org.au/health-professionals/clinical-guidelines/.
5. Roy Castle Lung Cancer Foundation 2013. Understanding the value of lung cancer specialists. The National Lung Cancer Forum for Nurses.
6. Australian Institute of Health and Welfare 2012. Cancer incidence projections, Australia 2011 to 2020. Cancer series no. 66. Cat. no. CAN 62. Canberra: AIHW.
7. Cancer Australia 2013. Lung Cancer Statistics. Accessed 23 January 2014. http://canceraustralia.gov.au/affected-cancer/cancer-types/lung-cancer/lung-cancer-statistics.
8. Australian Institute of Health and Welfare & Cancer Australia 2012. Breast cancer in Australia: an overview. Cancer series no. 71. Cat no. CAN 67. Canberra: AIHW.
9. Australian Institute of Health and Welfare 2013. Prostate cancer in Australia. Cancer series 79. Cat. no. CAN 76. Canberra: AIHW.
10. It's My Health. 2012. The stigma of lung cancer. Accessed 10 September 2013. http://www.itsmyhealth.com.au/general-health/the-stigma-of-lung-cancer.
11. Chambers et al. 2012. Licensee BioMed Central Ltd. Accessed 4 December 2013. http://canceraustralia.gov.au/sites/default/files/publications/impact-of-stigma-and-nihilism-on-lung-cancer-outcomes_5181ff5359cc7.pdf.
12. Prostate Cancer Foundation of Australia 2013. Prostate Cancer Specialist Nursing Program. Accessed 4 December 2013. http://www.prostate.org.au/articleLive/pages/Prostate-Cancer-Specialist-Nursing-Service.html.

Elizabeth Ivimey, RN - left
Coral Fuata – Alex's wife - right

CASE STUDY Alex Fuata

A fit and active 55 year old father of three, Alex rarely visited the doctor. He was 'accidentally' diagnosed with lung cancer after a visit to his local clinic for what he thought was an infected bite.

To make the most of his visit, Alex asked for a full check-up and his results were normal. By chance, the radiologist was at the clinic that day so the doctor also recommended a chest x-ray. Within hours, Alex received a call referring him for an immediate CT scan. He was advised to return to the clinic as soon as it reopened the next morning.

Alex's wife, Coral, felt anxious that night but even more so the next morning when the couple were whisked into the doctor. Usually she'd have to wait at least an hour with the kids. Within minutes they were told Alex had terminal lung cancer and he needed immediate treatment. The same day the couple had an appointment with an oncologist. Alex passed away three months later.

Elizabeth Ivimey, RN
Lung Cancer Nurse Coordinator - Prince of Wales Hospital, NSW

"I remember the morning Coral and Alex came into our clinic. Their GP had called to say there was an urgent patient so we made space to see them that morning.

"My immediate priority was to establish a quick rapport with Alex and Coral, to help them through the diagnosis and make a very distressing and challenging time better. I believe there is always something you can do, no matter how difficult the situation.

"For the next three months, I supported Alex and Coral by ensuring they had coordinated care and were provided with the information they needed on treatment and a broad range of other topics.

"The emotional side of my job was just as important as the practical side. Alex made it clear he didn't want to be involved in any decision-making or know what was happening to him.

"Coral was the communicator, filtering everything Alex needed to know, so it was equally important she was supported. It gave Alex comfort knowing we would look after Coral as well."

Coral Fuata – Alex's wife

"The day Alex was diagnosed was just shattering."

"We had just gone through another difficult and challenging situation and I was already feeling vulnerable. We now had to deal with a situation that would have no answer and no positive ending.

"Alex had walked into the clinic thinking he had an insect bite and we were now off to an oncologist.

"I remember Beth was sitting to the back of the room behind the oncologist. It was clear she had a very good working relationship with her oncologist. She was smiling and had a firm but friendly look.

"We immediately felt at ease to be honest in our communication with her. We wanted to hear what she had to say. If I had a question, she had an answer, and if not, she would seek the answer.

"From day one, Beth's interest was to help us – not just Alex, but also me and the children.

"Beth was a rock for us and I am not sure what we would have done without her. I am still in contact with her three years down the track and will be forever grateful for the support she provided Alex and our family.

LUNG FOUNDATION AUSTRALIA

"When you can't breathe... nothing else matters"™

Website: www.lungfoundation.com.au

Email: enquiries@lungfoundation.com.au

Street address: Level 2, 11 Finchley St, Milton, QLD 4064

Phone: 07 3251 3600