



16th July 2021

The Pharmac Review Committee
By way of Sarah Davies
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Kia Ora Koutou

Sarah, thank you for receiving this our submission and too for sending this to all members of the Pharmac Review Committee.

Firstly, everyone associated with Lung Foundation New Zealand (colleagues, patients, carers and whanau) acknowledge the mahi of the review committee and their collective effort which we hope will inform important improvements with reimbursement of medicines in the public health system.

Whilst we understand the pharmaceutical budget and the total amount of funding allocated for pharmaceuticals has been excluded from the scope of the review, we trust a thorough review will discover the degree to which policy settings that inform funding (or lack of funding when compared to comparable countries) is causing irretrievable loss of life for NZ's most vulnerable patient's.

Who we are -

Background - Lung Foundation New Zealand Inc.

About Us

Lung Foundation New Zealand (LFNZ) is a non-government organisation (patient advocacy group) dedicated to increasing survival for lung cancer.

The Lung Foundation provides information and support for lung cancer patients and carers and is devoted to advocating on a range of issues, including; prevention, early detection (screening), stigma, public access to more effective treatments, an increase in research funding and a commitment to Smokefree 2025.

Our Vision

New Zealanders know how to keep their lungs healthy and they investigate symptoms of lung disease earlier.

Our Mission

To increase survival for lung cancer



Our Goals

- Promote Lung Health
- Promote Early Diagnosis of Lung Disease
- Reduce Lung Cancer Deaths

Our Values

Rangatiratanga; we have integrity, we empower people, we say what we mean.

Manaakitaka, we nurture and respect people's mana.

Whanaungatanga, collaborating to improve healthcare in Aotearoa, also serves future generations.

Ehara taku toa i te toa takitahi engari he toa takimano

My strength is not that of an individual but that of the collective

What we want you to know about the burden of lung cancer in Aotearoa

Lung cancer kills more people in New Zealand every year, than breast cancer, prostate cancer and melanoma cancer combined.

Every day 5 people die of lung cancer and a further 6 people are diagnosed with lung cancer.

There is a major intersection with other determinants of health, including a quadrupled risk of suicide for lung cancer patients compared to the general population.

Lung cancer causes extreme inequity for Maori

Lung cancer registrations and mortality rates are FOUR times higher in Maori women and nearly THREE times higher in Maori men.

One Maori dies of lung cancer every day in New Zealand.

Lung cancer is the leading and second highest cause of death in Maori females and males respectively.

Lung cancer screening

Despite, lung cancer being New Zealand's biggest cancer killer, we do not yet have a national lung cancer screening programme in place...

Participants (including the writer) that attended a lung cancer screening symposium held earlier this year were told screening for lung cancer is some ten years off being implemented in Aotearoa.

What for equity?

Considering the extreme inequity suffered by Maori, who die prematurely as the result of lung cancer and NZ's responsibility to Maori (captured in Article 3 of the Treaty), the crown clearly has responsibility to protect the health and wellbeing of Maori from illness and premature death, so they can enjoy the same quality and level of health as others in Aotearoa.



Lung cancer petition

The writer delivered a petition to Parliament in 2019 with the support of hundreds of patients and carers right across NZ. This petition was signed by 7618 good people who care about lung cancer.

https://www.parliament.nz/en/pb/petitions/document/PET_86322/petition-of-philip-hope-for-lung-foundation-new-zealand

Sadly, the response to this petition by the Health Select Committee, does not acknowledge the entirety of the petition, nor did it even consider recommending a number of easy to introduce solutions, which would go along way to improving well-being and prevent the premature death of our most vulnerable patients.

Q. Why have we made reference to this in our submission to the review committee? Because, NZ's thrift funding policies and the culture of Pharmac impacts all stages of the continuum of care.

Successive governments have prevented access to countless medicines in the public system by employing thrift policy settings which has seen systemic underfunding continue.

Q. Why is NZ not prepared to invest in modern medicines that are the standard of care?

FACT: Access to treatment is access to life....

We need to treat the person, not just the condition. The vital role of precision led healthcare (informed by molecular testing) and access to the right treatment at the right time, is life changing for patients and far superior to standard chemotherapy in mono-therapy.

NZ's drug buying agency needs to negotiate supply agreements for multiple new medicines with increased frequency (for each condition), much faster and with transparency.

Delaying reimbursement to push prices down is an OUTDATED model that is causing countless patients to die prematurely, or suffer the unnecessary side effects of outdated treatments. Many of these patients re-enter the hospital system which is already strained and at capacity...

New Zealand employ's a third world approach to the detection, treatment and care of lung cancer and mesothelioma and our failure to reimburse standard of care treatments (targeted therapies and immunotherapies), all of which are life changing for patients, sees NZ falling further and further behind comparable counties of the OECD.

An instrument of government, Pharmac is now institutionalised, it is slow, bogged down by years of its 'unfit for purpose' thrift thinking and intransparent practises, which have largely remained unchallenged, enabled/led by individuals and committees too compliant or unsupported to question the status quo...

NB: We have a number of examples to back these statements up. Examples whereby hundreds of patients have died prematurely.



Click the link below to view an infographic which illustrates just how far behind NZ is with reimbursing treatments that would be life changing for our patients.

<https://lungfoundation.org.nz/wp-content/uploads/2021/01/ROC00470-Lung-Biomarker-Graphic-7.0-1.pdf>

Following is a report that compares the treatment of Non-Small Cell Lung Cancer (NSCLC) in New Zealand, with Australia and Europe (NSCLC = 85% of all lung cancers).

It is disgraceful, that NZ funds just a third of the treatments funded in Australia for what is our BIGGEST CANCER KILLER. Ultimately it is this lack of access that is causing so many patients to die prematurely (unless they have money to self-fund access in private clinic and then face another chronic illness known as financial toxicity).

<https://lungfoundation.org.nz/wp-content/uploads/2020/04/Non-Small-Cell-Lung-Cancer-Treatment-Guidelines-NZ-Compared-FINAL-28-February-2020.pdf>

Following are some outstanding questions and too our request of the review committee:

1. Pharmac says it looks to other international treatment guidelines and recommendations or key advice from similar countries.

Q. How is their evaluation of cost effectiveness different from New Zealand?

Pembrolizumab (Keytruda) is reimbursed by Australia for all first line lung indications (including, irrespective of PD-L1 expression) and therefore the PBAC sees this product as cost effective in lung cancer. As well as more than 40 other countries funding Pembrolizumab (Keytruda) for first line lung cancer, many with much lower GDPs than NZ.

Prior to announcing an RFP, Pharmac stated its view that PD-L1 immune checkpoint inhibitors were an “apples versus apples” situation, when this is simply NOT true. Head to head clinical trials of immunotherapy treatment disprove this statement.

2. Q. How does PHARMAC measure cost effectiveness for a drug that is extending life as opposed to a treatment that is treating a chronic condition?
3. Q. How can there be such a huge emphasis by PHARMAC on the “Factors for Consideration” which evaluates health disparity, inequity and Maori health outcomes; and yet PHARMAC has still not been proactive around investing in lung cancer treatments?

These treatments have been on PHARMAC’s waiting list for many years despite lung cancer being over-represented in a high needs population.

4. WHY hasn’t NZ’s Biggest Cancer Killer, Lung cancer and mesothelioma been declared a national health priority?



Lung health for life

Specialists, patients and family's dealing with a lung cancer diagnosis ask, is it really the will of our leaders that lung cancer remains an imminently fatal disease, rather than a chronic illness? Do we not matter?

5. We ask that all targeted therapies and immunotherapy treatment/s for all known biomarkers and genetic profiles be reimbursed by Pharmac in accordance with ESMO magnitude of clinical benefit scale.
6. We ask that all patient's (Maori and non-Maori) have access to molecular testing for ALL known biomarkers at the time of diagnosis. Currently molecular testing for lung cancer in New Zealand is compromised.
7. We ask the review committee to urge the recommendations outlined in Hauora Report WAI 2575 by the Waitangi Tribunal: Chapter 9, Pages 161 – 170 be implemented without delay and informed the result of co.design.
8. We ask that patients be represented on all committees that inform the assessment and reimbursement process.
9. We ask that Pharmac provide a patient and carer engagement role.
10. We ask that lung cancer specialists who treat lung cancer (private practice) as a primary condition be engaged to assist with the review and assessment of lung cancer treatments filed for reimbursement.
11. We ask at least one specialist from overseas is engaged in the assessment process so that they be independent of the NZ public health system.
12. We ask that patient advocacy groups such as LFNZ be able to participate in and inform the annual budgetary planning process.
13. We ask that financial / cost / investment modelling for medicines take in the savings achieved downstream in the health system. We acknowledge the research conducted by Prof Frank R. Lichtenberg which proves investment in modern medicines is cost neutral and extends life.

Welcome the opportunity to provide more detail for the review committee.

Naku noa na

Philip Hope (Williams-Potae)



Article 3 of the Treaty outlines the crown's responsibility to protect the health and wellbeing of Maori from illness and premature death, so they can enjoy the same quality and level of health as others in Aotearoa.

Q. How is the government and Pharmac (an instrument of Government) meeting these Treaty responsibilities, not just for lung cancer, but ALL cancers and health in general?

Gift Acceptance Policy

LFNZ is an independent non-government organisation and is reliant on philanthropic support to sustain its mission. We have a sincere commitment to the ethical practice of philanthropic fundraising.

View our gift acceptance policy <https://lungfoundation.org.nz/support-us/gift-acceptance-policy/>

NB: LFNZ acknowledges, inequity and financial toxicity exists in healthcare (especially for access to lung cancer treatments) and for this reason, our cause DOES NOT seek donations from patients.

Special Advisory Committee

LFNZ has assembled a Special Advisory Committee (SAC) of highly respected healthcare professionals, invested in improving outcomes for patients with lung cancer. These good people consider our cause to be their charitable priority.

Medical Director & Associate Professor of Oncology, Chris Atkinson, is Chair of LFNZ SAC.

<https://lungfoundation.org.nz/about-us/our-people/>

Associate Professor of Oncology, Chris Atkinson;

Life Member RANZCR

Life Member TROG

Scientific Advisory Board MSD

Life Member Psycho-oncology NZ

Board Member CHOMNZ

Chair St Georges Cancer Care JV Board

Member St Georges Cancer Institute Board

Philip Hope, Chief Executive, Lung Foundation New Zealand;

Member, International Association for the Study of Lung Cancer

Member, The Union for International Cancer Control's (UICC)

LFNZ is an advocacy partner of the International Association for the Study of Lung Cancer (IASLC).

<https://www.iaslc.org/patient-advocacy>

For further information, please contact;

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Visit us online <https://lungfoundation.org.nz/about-us/>

Connect with us on Facebook <https://www.facebook.com/LungFoundationNZ/>



- **Medical Director & Associate Professor of Oncology, Chris Atkinson talks about a new approach, informed by equity is a must to improve outcomes for lung cancer.**
<https://drive.google.com/file/d/1pjdZVvMtlRz5uyZGJzTVg972Q8fm7xv/view>
- **Lung Foundation's submission for the Inquiry into health inequities for Maori**
<https://lungfoundation.org.nz/wp-content/uploads/2019/11/2019-September-Lung-Foundation-NZ-Maori-Affairs-Committee.pdf>
- **Lung Foundation's response to the Governments Cancer Action Plan 2019 - 2029**
<https://lungfoundation.org.nz/response-to-the-cancer-action-plan-2019-2029/>
- **Lung Foundation NZ declares lung cancer a National Health Emergency**
<https://lungfoundation.org.nz/wp-content/uploads/2019/07/Media-Release-World-Lung-Cancer-Day-2019.pdf>
- **National lung cancer screening programme could save kiwi lives**
<https://lungfoundation.org.nz/wp-content/uploads/2019/02/2019-February-Lung-Cancer-Screening-Position.pdf>
- **Lung Foundation's submission to Pharmac in March 2019** - includes letters from patients
<https://lungfoundation.org.nz/lfns-submission-to-pharmac-includes-patient-letters-etc/>
- **Staggering imbalance with cancer treatments funded by Pharmac** - the top 3 lung cancer drugs funded by Pharmac (2017/18) is just 2.3% of the top 5 cancer drugs (\$122 million)
<https://lungfoundation.org.nz/staggering-imbalance-with-cancer-treatments/>
- Know the symptoms of lung cancer - click to view the BREATHE POSTER.
<https://lungfoundation.org.nz/wp-content/uploads/2019/04/LFNZ-BREATHE-Symptoms-Poster.pdf>
- Lung cancer Patient Toolkit to empower patients and carers to navigate their cancer journey
<https://lungfoundation.org.nz/wp-content/uploads/2018/11/LFNZ-TOOLKIT-A4-Poster.pdf>
- Make a gift - Support our fighting fund and help us save lives
<https://givealittle.co.nz/donate/org/lungfoundationnz>