



Response to the Cancer Plan launched 1st September 2019

We are really pleased after two years to now have a draft cancer plan to review and acknowledge the work that has gone into this draft plan.

First up, we should record how disappointing it was, for our cause, and CANGO (Cancer Non-Governmental Organisations) of which Lung Foundation NZ is a member, to not be consulted during the creation of this cancer plan, subsequent to the forum hosted by the Ministry of Health seven months ago.

That said, we do support the priority framework recommended, but need to see more detail about WHAT resourcing is allocated to individual tasks to demonstrate HOW words will be turned into actions.

We also ask for a further breakdown (clarification) of the specific / measurable goals that together will deliver the priority actions.

It is most important the Ministry of Health clarify what they mean by the word "equity" and how equity will be assessed and measured. Furthermore, does Pharmac and the Cancer Control Agency acknowledge they have the SAME understanding of the word equity.... and a commitment to act to the fullest extent possible to achieve equitable outcomes?

A 3% increase in Pharmac budget is a drop in the ocean and it is another indication the government don't understand the impact, nor the role of precision medicines (new molecular entities) and the future which is precision led healthcare.

New Zealand continues to fall further behind the OECD and our most vulnerable patients are dying prematurely. The government needs to double its investment in modern medicines and there must be a ring fenced budget for cancer medicines.

Some key questions we have;

- Q. Where is the TOR (terms of reference) for the new agency and its officers?
- Q. Will the board of Cancer Control include a patient advocate?
- Q. How will patients, carers and specialists have input into key decisions?
- Q. What are the priority cancers?
- Q. What screening is going to be delivered, other than bowel cancer screening?
- Q. How will the transparency of Pharmac be improved?
- Q. What is being done to change/improve the culture of Pharmac and the Ministry of Health?
- Q. How are the recommendations of the Waitangi Tribunal "Hauora Report", reflected in the plan and delivered on the ground with outcomes?
- Q. How will the QPI's (Quality Performance Indicators) that inform standards of care, and treatments, ensure Pharmac fund standard of care treatments, in a timely manner?

Subsequent to the NZ lung cancer standards launched in May 2016, NO NME's (new molecular entities) have been funded in the last three years... Really? = premature death for lung cancer patients continues. The preventable loss of life is so significant, it is now a humanitarian issue.

Delivering this cancer plan to improve continuum of care and preserve life, requires two/three crown entities to work together...



Q. What are the TOF (terms of reference) for how the crown entities work together and make good decisions. Who has ultimate authority?

Q. Given a key objective is to end the post code lottery of cancer care, how can this be achieved without reducing the number of DHB's?

Screening

Important Note: Lung cancer screening for people most at risk, especially those who are disadvantaged is a MUST - yet it is NOT included in the plan... Screening SAVES lives.

Q. Will the Cancer Control Agency and the Ministry of Health commit to saving lives by introducing screening for lung cancer which is NZ's Biggest Cancer Killer?

Tobacco Control and Smokefree 2025

NO serious commitment to resourcing Smokefree 2025 at the level required to achieve a Smokefree 2025. Aspirational words, BUT nothing new for; harm reduction, regulation, wrap around support for people to quit.

Q. Will the increase in tobacco excise scheduled for 1st January 2020 in the governments first wellbeing fiscal year, be directed into resourcing MORE harm minimisation initiatives?

If there is NO increase in funding equal to, or greater than the revenue generated by the increased tax take, this would be a missed opportunity and could even be considered irresponsible.

Pharmac

Given the increase in budget for Pharmac, so far as lung cancer, we are dismayed there was NO funding announcement for lung cancer treatments.... especially Keytruda.

Lung Cancer is NZ's Biggest Cancer Killer (5 people die every day) of Maori and non-Maori and it's the most brutal cancer, especially when it not treated with standard of care treatments.

We ask on behalf of 1500 patients per year that would be suited to Keytruda, who continue to die prematurely, WHY is Keytruda not yet funded?

Keytruda was assessed and endorsed as efficacious for first line treatment of advanced lung cancer on 5th April (1500 patients per year could benefit), yet we know Pharmac have NOT sought supply of Keytruda. Reimbursement of Keytruda for lung cancer would be the greatest step forward for improving treatment of the largest number of lung cancer patients on record!

Yes, we acknowledge Pharmac confirmed on the 7th August (the same day we presented to the Health Select Committee alongside many other petitions for access to standard of care treatments), it will fund alectinib for ALK lung Cancer, as of 1st December (subject to public consultation). We are very pleased for ALK lung cancer patients, because this means life for 8 patients every month that are diagnosed with this type of lung cancer.

Q. What about the 1700 other patients per year who still do not have access to standard of care, first line treatment?

Following are the treatments we advocated for that are yet to be funded;

Keytruda = 1500 PD-L1 lung cancer patients

Osimertinib = up to 200 EGFR lung cancer patients

Crizotinib = up to 20 Ros1 lung cancer patients



Sadly, an audit of the lung cancer in the NZ public health system, shows NZ has a THIRD WORLD approach to prevention, early detection and treatment of lung cancer. It is unacceptable that almost 80% of patients diagnosed with lung cancer die within the first twelve months unless they self-fund standard of care treatments.

See how NZ's publicly-funded lung cancer treatment options compare to Australia & Europe
<https://lungfoundation.org.nz/how-new-zealands-lung-cancer-treatment-guidelines/>

This staggering imbalance is indefensible. The top three treatments funded by Pharmac (2017/18) for NZ's BIGGEST cancer killer equates to just 2.3% of the top 5 cancer drugs (\$122 million).
<https://lungfoundation.org.nz/staggering-imbalance-with-cancer-treatments/>

*Scores of 4 or 5 on the **European Society of Medical Oncology (ESMO), Magnitude of Clinical Benefit Scale (MCBS)** confirms that these drugs WORK - they are EFFECTIVE - provide substantial improvements in survival and quality of life. This ALSO means they are superior to standard chemotherapy.*

How the lung cancer drugs still sitting with Pharmac rate according to ESMO MCBS:

Immunotherapy treatments

- Pembrolizumab 4 (Keytruda) MSD Products - *monotherapy first line and second line; first line combination*
- Nivolumab 5 (Opdivo) Bristol-Myers Squibb - *second line*
- Atezolizumab 5 (Tecentriq) Roche Products - *second line, and first line combination*

Targeted therapies

- Crizotinib 4 (Xalkori) Pfizer New Zealand - *first line ALK (also international standard of care for Ros1)*
- Alectinib 4 (Alecensa) Roche Products - *first line ALK (also second line for patients on first gen ALK)*
- Osimertinib 4 (Tagrisso) AstraZeneca, Global Commercial Organisation, NZ - *second line EGFR T790M*

The European Society for Medical Oncology Magnitude of Clinical Benefit Scale (ESMO-MCBS) article
<https://www.ncbi.nlm.nih.gov/pubmed/26026162>

Access to ESMO Scorecard below -
<https://www.esmo.org/score/cards>

The ESMO score system is recognised globally. Professor Richard Sullivan of the UK (NOT Dr Richard Sullivan, Medical Oncologist of Auckland) is the co-inventor / co-author of the ESMO effectiveness system.

Conclusion

Lung Foundation NZ will be seeking input from patients and carers and specialists and will provide a submission to feedback on the cancer action plan. We will also be seeking clarification on the key points we have raised.

For further information, please contact;

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Key Lung Cancer Facts:

- Everyone with lungs has a chance of getting lung cancer
- Early detection and effective treatments will significantly improve survival
- Lung cancer is the most common cause of cancer death for men aged between 45-74 years and women 65-74 years.
- 70% of people diagnosed with lung cancer do not smoke
- One out of every five people diagnosed with lung cancer have never smoked.
- Lung cancer rates are four times higher in Maori women and three times higher in Maori men than non-Maori
- One Maori dies every day from lung cancer

Further information about Lung Foundation New Zealand's advocacy programme

- **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 to Pharmac in March 2019** - includes letters from patients
<https://lungfoundation.org.nz/lfnz-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/>
- How NZ's publicly-funded lung cancer treatment options compare to Australia & Europe
<https://lungfoundation.org.nz/how-new-zealands-lung-cancer-treatment-guidelines/>
- Infographic shows why lung cancer patients in New Zealand are dying prematurely
<https://lungfoundation.org.nz/infographic-shows-why-lung-cancer-patients-are-dying-prematurely/>
- 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>
- Plan an event - Help us raise awareness and funds
<https://nfp.everydayhero.com/nz/lung-foundation-new-zealand#>