

Response ID ANON-ZY6X-AQTZ-1

Submitted to **New Zealand Cancer Action Plan 2019–2029**

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Moving forward together

1 Do you agree with the four outcomes proposed in the Plan? (page 10–11)

Yes

If not, please explain why.:

2 Do you agree with the key areas within each outcome? (page 12)

No

If not, please explain why.:

Myeloma New Zealand believe the Cancer Action Plan lacks emphasis and prioritisation on achieving equitable and timely access to modern and effective drug treatments.

Myeloma is a blood cancer that affects multiple sites in the body where bone marrow is normally active in adults, including the spine, skull, pelvis, ribs shoulders and hips. Sufferers experience serious complications such as bone and kidney disease and serious infections. Although treatable, myeloma is incurable and follows a remitting relapsing course, necessitating continued interventions aimed at destroying the myeloma cells and controlling the symptoms they give rise to whilst preserving patient quality of life (Kumar et al., 2017).

As the cause of myeloma is not fully understood, efforts at prevention are futile (Cancer.net., 2018). In addition, given approximately 400 New Zealanders are diagnosed with myeloma per annum (Milne, Boyd, Chan, & al, 2019), screening is impractical. Early diagnosis may be helpful, although is difficult to realise as patients with myeloma present with a highly varied set of symptoms.

Improving treatment outcomes and living well with cancer are therefore the critical components of the Cancer Action Plan for New Zealanders currently living with myeloma.

The key treatment options are stem cell transplant for those fit enough to tolerate the procedure and various drug regimens (Kumar et al., 2019). Stem cell transplant is offered throughout the main centres; however New Zealand has fallen behind the developed world in providing clinicians and patients with modern, effective and targeted drugs ("precision medicine"). Myeloma New Zealand recently petitioned the government for urgent public funding of several agents to address the disparity.

We highlight that living well with cancer is a key area for myeloma given it is incurable. The quality of publicly available treatments will determine not just how well, but how long myeloma patients in New Zealand will live for.

Myeloma New Zealand request that the delivery of equitable and timely access to modern and effective drug treatments be included as a priority action in the Cancer Action Plan.

3 Do you think the actions in the Plan will achieve equitable health outcomes for the priority populations identified? (ie, Māori, Pacific peoples, people living in rural and/or low socioeconomic areas, people with a mental illness and disabled people)

No

If not, what suggestions do you have about how we can do this?:

Myeloma New Zealand welcomes a system that delivers consistent and modern cancer care, however, believes a national cancer drug fund is desperately needed to truly give the Cancer Control Agency the tools needed to positively impact cancer survival in New Zealand.

Our current drug funding model is failing to deliver for myeloma and other cancer patients. Implementation of a cancer specific drug fund has the potential to provide clinicians and patients with faster access to better treatments that are judged not just on their cost, but the outcomes delivered. A requirement to collect and share outcomes data in turn supports future clinical and investment decision making.

Alternatively, the Pharmac model urgently requires a substantial budget boost and a review of processes to enable New Zealanders with cancer faster and wider access to urgently needed treatments.

Myeloma New Zealand supports partnering to build collaborative and co-ordinated information. Achieving equitable health outcomes can only be achieved if we first have the information to measure our progress and the resources to correct the imbalances. A recently published report on the burden of myeloma disease confirmed that Maori and Pacific people suffer a higher incidence of myeloma than other ethnicities in New Zealand. A specific recommendation of the report is to develop "systems for collaboration, data collection and benchmarking to ensure equitable quality of care" (Milne et al., 2019). A solution for myeloma is to resource and expand uptake of the existing Monash myeloma registry ("Myeloma and related diseases registry (MRDR)," 2019). This will provide important clinical information to allow ongoing comparison and monitoring of patient outcomes throughout New Zealand.

4 Are there any other actions that should be included?

Yes

If yes, please explain what and why.:

Development of a national cancer drug fund.

Improving cancer survival for New Zealanders with blood cancers urgently requires investment in modern, effective and targeted drug treatments. Prevention and screening are unhelpful for myeloma, with surgery and radiation typically playing a small role.

Investment in drug treatments is therefore all the more critical to these patients. Unfortunately, the current model operated by Pharmac rations and delays while patients progress and die. The Pharmac model urgently requires a substantial budget boost and a review of processes. Preferably, a specific cancer drug fund needs to be established that provides faster and wider access to modern cancer drugs.

5 Are there other aspects in the prioritisation framework that need to be considered?

Yes

If yes, please explain further.:

Choice for clinicians and patients with respect to treatments remains to be addressed.

Myeloma and other blood cancers are highly heterogenous diseases and require more than a single approach to treatment (Kumar et al., 2019; Kumar et al., 2017).

Restrictions applied to when and how a funded drug is used can remove the potential to get a better result for an individual patient. In myeloma, for example, lenalidomide is largely restricted to third line use (PHARMAC, 2017a), whereas outcomes are superior when its utilised earlier in the treatment pathway (Kumar et al., 2019). Similarly, bortezomib is well utilised in first line patients, but would also benefit many responders in later lines when its funded use is prohibited (Kumar et al., 2019; PHARMAC, 2017b).

6 What three actions across the entire Plan do you think should be progressed first?

Action one:

Develop options for early access to new medicines.

Although this action is highlighted in the plan as being already progressed, Myeloma New Zealand wish to express the urgency of this action as a priority. In addition, Myeloma New Zealand are pleased funding applications will be assessed earlier, however, strongly recommend a timeframe for which Pharmac is accountable to. Simply starting the process earlier provides little hope of faster outcomes.

Action two:

Develop advice on how equitable access and wider use of clinical trials can be achieved

Action three:

Partner with government, the health sector, academia and international experts to build collaborative and coordinated information

Myeloma New Zealand propose the Monash myeloma registry resourced and fully implemented in New Zealand.

Additionally, to "have a role in shaping the global cancer agenda", New Zealand clinicians need timely and equitable access to publicly funded effective treatments which will enable them to treat according to internationally recognised guidelines. This is not currently possible with existing funded treatments in myeloma. (Thalidomide, for example, is the funded second line option in New Zealand, a position that is not endorsed by any international guidelines given the availability of superior options.

We reiterate our proposal for a national cancer drug fund to urgently address unmet need in cancer drug reimbursement in New Zealand. Alternatively, the Pharmac model urgently requires a substantial budget boost and a review of processes.

Outcome 1: New Zealanders have a system that delivers consistent and modern cancer care (page 15–27)

7 Do you agree with the approach for creating a system that delivers consistent and modern cancer control?

No

If no, please explain why not.:

The delivery of consistent and modern care in blood cancer demands the equitable delivery of modern cancer treatments. In the current plan, access to desperately needed medicines is relegated to a sub-point of cancer care and treatment and entrusted to a drug buying process that fails New Zealand myeloma patients.

Myeloma New Zealand request that the delivery of equitable and timely access to modern and effective drug treatments be included as a priority action in the Cancer Action Plan.

8 Do you think the actions under 'Health Workforce' will address the current issues?

Not Answered

If no, please explain why not.:

9 Are there any further actions required to ensure New Zealand has strong leadership and governance in cancer control?

Yes

If yes, please explain further.:

Establishment of a blood cancer taskforce with direct input to the Cancer Control Director. Blood cancers are unique from many solid tumour cancers in that prevention, screening, radiation therapy and surgery play little, if any, role in improving patient outcomes.

Outcome 2: New Zealanders experience equitable cancer outcomes (page 28–32)

10 Are there any other actions that should be added or removed from Outcome 2?

Yes

If yes, please explain what and why.:

Myeloma survival in New Zealand is worse for people living in deprived areas, including Māori (Milne et al., 2019).

Myeloma, like many blood cancers, is highly heterogenous in terms of the disease itself and how individual patients respond to treatment (Milne et al., 2019). Investment in multiple modern drugs is needed to ensure equity of outcomes is possible for this patient group.

Including an action to prioritise patient and clinician choice will support equitable outcomes in situations where treatments can be delivered at, or closer, to a patient's home.

11 Do you think developing and implementing a mātauranga Māori framework and Māori led programmes could achieve equitable health outcomes?

Not Answered

If not, please explain why not.:

12 Do you think the actions in the section, 'achieving equity by design' will ensure equity is at the forefront when developing cancer services?

Not Answered

If not, please explain why not.:

13 Do you think the Plan will address racism and discrimination in cancer services?

Not Answered

Please provide details.:

Outcome 3: New Zealanders have fewer cancers (page 33–44)

14 Do you think the actions to support cancer prevention are right?

Not Answered

If not, what suggestions do you have to improve this?:

Outcome 4: New Zealanders have better cancer survival (page 45–62)

15 Are there any other actions that should be added or removed from Outcome 4?

Yes

If yes, please explain what and why.:

Improving cancer survival in myeloma is highly dependent on a system that delivers access to global standard of care drug treatments with the flexibility for clinicians to tailor treatments to each patient's needs.

The current approach of delay, ration, and eventually fund drugs in a 'one size fits all' approach is failing New Zealand myeloma patients.

The establishment of a national cancer drug fund which balances investment with outcomes and values the input of myeloma experts addresses this current failing.

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~~The establishment of a national cancer drug fund which balances investment with outcomes and values the input of myeloma experts addresses this current failing.~~

Alternatively, as a minimum Pharmac resources should be substantially increased and the processes reviewed and improved to increase the availability of modern cancer drugs and reduce the time for patients to access them.

16 Do you think enabling people with the knowledge, skills and confidence to use cancer health information will ensure they have a better understanding of the early signs and symptoms of cancer?

Not Answered

If not, please explain why not.:

17 To get the best outcome, it may require travelling away from home to access specialist services. What support needs to be considered for someone who receives treatment for cancer away from their home or whānau?

Comments:

When available, the choice of oral treatments or closer to home infused/injected treatments must be considered as alternatives for cancer patients and their families.

18 Does the Plan address ways to improve patient experience of cancer services?

Not Answered

If no, please explain what and why.:

19 Do care plans need to be developed to meet the holistic needs of patients and families/whānau?

Not Answered

If no, please explain further.:

20 Does the Plan address access to follow-up and surveillance for recurrence, late effects and new cancer post treatment?

No

If no, please explain what and why.:

The plan lacks prioritisation of an urgently and desperately needed pathway to invest in drug treatments for blood cancers.

As an incurable, remitting and relapsing disease, myeloma requires more than a 'one size fits all' approach to drug availability. Clinicians and patients need more options, and the flexibility to use them in the best way possible for each individual. This is currently impossible with existing options.

Anything else?

21 Is there anything else you would like to tell us about the plan or cancer generally?

Comments:

Myeloma is the second most common blood cancer in New Zealand with approximately 400 new cases diagnosed per year and approximately 2,500 New Zealanders currently living with myeloma (Milne et al., 2019).

It is a treatable but incurable cancer that resides in the bone marrow, causing serious complications such as renal failure and bone disease. The disease follows a remitting relapsing course, necessitating several lines of therapy delivered with the aim of inducing remission for as long as possible whilst maintaining quality of life (Kumar et al., 2017).

Prevention and screening offer little benefit or are impractical given our current knowledge of myeloma (Cancer.net., 2018). The availability of effective treatments is therefore the most critical unmet need for myeloma patients in New Zealand.

Publicly funded drugs for myeloma in New Zealand are both limited and restricted. To deliver the outcomes now possible with personalised and targeted therapy (outcomes that move myeloma towards being a chronic illness as opposed to a terminal cancer), New Zealand clinicians must have access to novel drugs and be given the flexibility use them appropriately for their patients.

The current model of drug funding via Pharmac has failed myeloma patients in New Zealand. Only two of eight novel agents used globally are publicly funded in New Zealand, and these two are restricted (PHARMAC, 2017a, 2017b).

The single biggest difference that this plan could do for myeloma patients in New Zealand is to put in place the pathways needed deliver equitable and timely access to novel myeloma drugs.

References:

Cancer.net. (2018). Multiple Myeloma: Risk Factors and Prevention. Retrieved from

<https://www.cancer.net/cancer-types/multiple-myeloma/risk-factors-and-prevention>

Kumar, S. K., Callander, N. S., Hillengass, J., Liedtke, M., Baljevic, M., Campagnaro, E., . . .

Kumar, R. (2019). NCCN Guidelines Insights: Multiple Myeloma, Version 1.2020. J Natl Compr Canc Netw, 17(10), 1154-1165. doi:10.6004/jnccn.2019.0049

Kumar, S. K., Dimopoulos, M. A., Kastritis, E., Terpos, E., Nahi, H., Goldschmidt, H., . . . Durie, B. G. M. (2017). Natural history of relapsed myeloma, refractory to immunomodulatory drugs and proteasome inhibitors: a multicenter IMWG study. Leukemia. doi:10.1038/leu.2017.138

Milne, R., Boyd, M., Chan, H., & al, e. (2019). The burden of multiple myeloma: A study of the human and economic costs of myeloma in New Zealand. Retrieved from <https://www.multiplemyeloma.org.nz>

Myeloma and related diseases registry (MRDR). (2019). Retrieved from <https://mrdn.net.au>

PHARMAC. (2017a). Lenalidomide Special Authority. Retrieved from <http://www.pharmac.govt.nz/2017/06/01/SA1468.pdf>

PHARMAC. (2017b). VELCADE (bortezomib) Special Authority. Retrieved from <http://www.pharmac.govt.nz/2016/02/01/SA1127.pdf>

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If you selected other, please state.:

This submission:

is made on behalf of a group or organisation(s)

If you are submitting as an individual or individuals, please indicate which category best describes you.

Not Answered

If you selected other, please specify.:

If you are submitting on behalf of a group or organisation, please indicate which sector(s) your submission represents.

Non-governmental organisation

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Summary of submissions

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