# Submission form

To help us to consider your submission we are asking that you focus on the following questions. There is the opportunity to provide additional feedback at the end. We expect to get a high response and ask that, where you can, you are concise. Once you have completed your submission please send it to: pharmacreview@health.govt.nz

**Note that submissions are subject to the Official Information Act and may, therefore, be released in part or full.**

If your submission contains any confidential information please state this within submission, and set out clearly which parts you consider should be withheld and the grounds under the Official Information Act 1982 that you believe apply. We will consult with submitters when responding to requests under the Official Information Act.

## Submission questions

### **Tell us about your current experience with PHARMAC and how it functions**

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| What is your understanding of what PHARMAC does? PHARMAC is a Crown Entity charged with “secur[ing] for eligible people in need of pharmaceuticals, the best health outcomes that are reasonably achievable from pharmaceutical treatment and from within the amount of funding provided”. |
| What has been your experience of working with PHARMAC? Unicorn Foundation NZ is the national charity supporting around 3,000 New Zealanders living with neuroendocrine cancer. These complex cancers can occur almost anywhere in the body and typically take five years to be correctly diagnosed. By this time, the patient’s cancer has more often than not spread to other parts of the body. Despite this, patients often successfully live full and productive lives for many years after diagnosis.We have a good working relationship at all levels within PHARMAC. However, the staff of the agency can only work within the constraints of their mandate. Which means that they are largely unable to assist with issues, which are of access and funding.  |
| What are the challenges with PHARMAC’s functions for funding medicines and devices?Unicorn Foundation NZ proposes that PHARMAC be assessed against whether it is able to perform its statutory functions. Below, we have assessed whether the agency is fit for purpose against the three key pillars of its legislative mandate.1. Securing for eligible people in need of pharmaceuticals:

No two neuroendocrine cancers are the same. Every patient has a unique presentation, unique set of symptoms and requires a tailored treatment regimen. PHARMAC’s approach to funding medicines and devices does not support the individual. Currently, there are a host of neuroendocrine cancer treatments available in Australia (and other countries to which we like to compare ourselves) that are unfunded in New Zealand. Many patients have no funded treatment options (as their neuroendocrine cancer is unresponsive to these treatments) and so these **patients are in need of pharmaceuticals, yet PHARMAC is not securing any treatments for them** through the schedule. These patients are also being declined through PHARMAC’s NPPA scheme. 1. The best health outcomes that are reasonably achievable from pharmaceutical treatment:

For neuroendocrine cancer patients, there is a need to expand access to currently funded treatments. For example, somatostatin inhibitors are shown to slow the growth of neuroendocrine cancers. Yet these are only funded for patients that are suffering from symptoms associated with their cancer. As a consequence when patients remain untreated due to lack of symptoms, their disease is essentially being accelerated. Also, there are two main brands of somatostatin inhibitors available, yet only one is funded in New Zealand. Evidence from Australia shows that the market is split 50-50 between the two brands, and that many patients need to switch between brands from time to time due to tolerability issues. In New Zealand, this is not possible as only one brand is funded. This means that PHARMAC is not securing the best health outcomes reasonably achievable from pharmaceutical treatment, simply because they are opting to purchase only one brand. PHARMAC’s focus on achieving the lowest price means that it needs to contract the supplier to meet 95-100% of the market. The result is that for a marginal cost saving up to half the eligible patients may miss out on the best health outcomes from that category of treatment due to tolerability issues. **This is a failure by PHARMAC to meet its legislative mandate to achieve the best health outcomes … from pharmaceutical treatment**. 1. From within the amount of funding provided.

PHARMAC’s budget is out of scope of this review. However, the fundamental challenge with PHARMAC is that there is simply not enough funding for it to fulfil its mandate. PHARMAC has a legislative obligation to work within its budget. The consequence is that **no one within government is championing the need for increased medicines budget**. Unicorn Foundation NZ strongly urges the review committee to call on the government to review the budget for PHARMAC. This can best be done by the government asking PHARMAC to provide advice on the budget needed to adequately treat New Zealanders in line with international best practice.  |

### **What do you know about PHARMAC’s processes and how they work?**

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| What do you think works well with the processes PHARMAC uses to assess the funding of medicines and medical devices?Unicorn Foundation NZ is grateful for PHARMAC’s contribution to getting PRRT established in New Zealand. |
| What do you think are the barriers to accessing medicines and devices? 1. **Lack of consistent value of life across government agencies in New Zealand.**

In the transport sector, the value of a statistical life in Treasury’s CBAx toolbox is $4.5M. This is based on a survey that showed how much New Zealanders would be willing to pay for a safety improvement that results in the expected avoidance of one premature death (originally benchmarked at $2M in 1989/90 but updated yearly by indexing average hourly earnings). In contrast, there is no explicit value of a life or cost-effectiveness threshold used by PHARMAC for its considerations. This is on the grounds that cost-effectiveness is only one of nine decision criteria. There needs to be a single, consistent value of life across all government decision making. A life is not worth more on the road than on the farm, in the home or in hospital. Decision making must be transparent and consistent. Pharmac and all other agencies calculating cost-effectiveness should be mandated to use the same *value of life*. If the Pharmac value of life was consistent with the Treasury value of life, the cost-effectiveness calculations for new medicines would have very different results. It is likely that many more would qualify for funding - which would make the problem ’the amount of funding provided’ under PHARMAC’s statutory purpose. Instead, the current calculations use values low enough that medicines don’t qualify for funding - so the amount of funding provided isn’t the issue.  It appears that PHARMAC uses an artificially low value of life in order to fit within their funding envelope. In doing this, PHARMAC is failing in its statutory duty to “secure for eligible people in need of pharmaceuticals, the best health outcomes that are reasonably achievable from pharmaceutical treatment”.1. **Heterogeneity of disease presentation.**

PHARMAC’s system is designed for conditions that have a clear clinical care pathway. That is, where a person presents with a specific disease or condition, and there is a best practice treatment pathway, that may include a specific medicine or a progression of medicines. This means PHARMAC can use their purchasing system to obtain the best possible rate for a category of medicine, based on the bulk volumes for the prevalence of the condition/disease. Neuroendocrine cancer does not fit the PHARMAC model. Based on research data, there are between 2,000 and 3,000 New Zealanders living with neuroendocrine cancer. These patients all have the same type of cancer, but the presentation for every patient is different. This is a complex cancer to treat, which is why New Zealand has a nationwide multidisciplinary meeting every week, which brings together a diverse set of specialists to assess cases and decide on the best treatment pathway. No two neuroendocrine cancers are the same. Every patient has a unique presentation, unique set of symptoms and requires a tailored treatment regimen. Because of the heterogeneous nature of neuroendocrine cancers, they are complex to treat and standardised patient pathways are not possible.For example Unicorn Foundation NZ data shows that among approximately 3,000 New Zealanders with neuroendocrine cancer, only 1-2% each year are likely to be suitable candidates for specific treatments such as PRRT (recently established in NZ) or Selective Internal Radiation Therapy (SIRT, unfunded in NZ) or Everolimus (unfunded in NZ). PHARMAC touts the NPPA policy as being designed to support individuals that have specific clinical circumstances that may be different to a wider patient population. But in practice these applications are routinely declined. Our patients consistently fall through the gaps – 30-60 patients per annum needing a specific treatment is too many to qualify for NPPA and too few to justify listing on the pharmaceutical schedule.  |
| Is there any other country that does it better? What is it that it does better and would any of those systems apply here?**Australia**Neuroendocrine cancer patients in Australia have better access to medicines. The Australian system also allows side-by-side treatment of public and private patients in centres of excellence such as the Peter MacCallum Cancer Centre in Melbourne. This is a model that New Zealand should consider as part of the restructure of the health sector.  |

### **What should PHARMAC’s role include in the future?**

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| How might PHARMAC look in the future? And what needs to change for this to happen?Cancer care is changing, and PHARMAC’s current structure is unable to address the heterogeneity of cancers. PHARMAC needs to shift to a model of personalised medicine. This means focusing on, and funding, the individual who needs treatment. This is also a route to address inequities in health, as the treatment can be whānau-centric and account for the worldview of the person with cancer and their family.  |
| Are there additional or different things that PHARMAC should be doing? Cancer is a disease of mutagenesis. Increasingly, new treatments are being developed to target specific mutations in key genes that contribute to cancer cell growth. So treatments are becoming less about where in the body the cancer originates and more about the nature and extent of the accumulated mutations in the cancer. This creates specific challenges within the current PHARMAC model, which is based on a typical pathway of care and a standard therapy or progression of therapies. The current system is deeply ill-equipped to address the changing nature of cancer treatments and the shift to co-dependent therapies (i.e. test & treatment or personalised medicine). From a Unicorn perspective this is a pressing issue that needs to be addressed for New Zealanders to have any real access to modern cancer treatments. |
| What do the wider changes to the Health and Disability system mean for PHARMAC? |

### **How should PHARMAC address the need for greater equity in the decisions it takes, in particular for Māori, Pacific and disabled people?**

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| How well does PHARMAC reflect the principles of Te Tiriti o Waitangi? |
| How can PHARMAC achieve more equitable outcomes? For uncommon diseases such as neuroendocrine cancer, PHARMAC needs to shift to a model of personalised medicine. This means focusing on, and funding, the individual who needs treatment. This would also enable a shift to whānau-centric care and prioritise te ao Māori for the person with cancer and their whānau. |

### **Additional feedback**

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| Is there anything else that you think the Review Panel should consider?Equity of access is currently considered in a range of ways, such as Māori vs non-Māori or rural vs urban access. However, as the national charity representing neuroendocrine cancer we know that some cancers are luckier than others when it comes to what funded treatments are available. Neuroendocrine cancer is the ‘poor cousin’ with few funded options. There needs to be an emphasis on equity across cancers so that **all cancer patients should have equitable access to the right treatment at the right time**. The review of PHARMAC, without a review of the budget is only a half-review. The current legislative mandate meshes both purpose and budget, so to review one without the other is illogical. |

## Contact information

Your feedback is important to us. If you are comfortable for us to get in touch if we have any questions or points of clarification regarding your feedback, please provide your name and contact email address below.

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| **Name**  | Michelle Sullivan |
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| **Organisation**  | Unicorn Foundation New Zealand |

If you do not want your personal details to be shared for any other purpose (for example if we receive a request for information under the Official Information Act) please signal this using the box below.

[ ]  I do not want my personal details to be shared for any purpose other than this review.

Thank you for providing your feedback.

Tēnā koe mō tō tuku urupare mai.