Pharmac Review

Summary of Submissions

2 September 2021

Prepared for the Pharmac Review by Allen and Clarke

CONTENTS

GLOSSARY

HTA	Health Technology Assessment
NICE	National Institute for Health and Care Excellence (United Kingdom)
OECD	Organisation for Economic Co-operation and Development
Pharmac	Pharmaceutical Management Agency Te Arotake I Te Pātaka Whaioranga
Pharmaceutical Schedule (the Schedule)	A document that lists medicines the Government subsidises, and medicines that are not subsidised, and the rules that must be followed to prescribe and dispense them.
PTAC	Pharmacology and Therapeutics Advisory Committee. A committee set up to provide Pharmac with independent and objective advice on the consequences of proposed amendments to the *Schedule*.
QALY	Quality-adjusted life year

EXECUTIVE SUMMARY

The Review Panel commissioned *Allen + Clarke* to analyse submissions on the Review of the Pharmaceutical Management Agency Te Arotake I Te Pātaka Whaioranga (Pharmac). Public submissions were open from 11 June to 16 July 2021 and a total of 213 submissions were received.

Submitters' current experience with Pharmac and how it functions

Most submitters demonstrated a good understanding of what Pharmac does and how it functions. They understood that Pharmac's main functions are to decide what medicines and devices get funded within the constraints of a fixed budget, and to negotiate with pharmaceutical companies to get the best price for New Zealanders.

Although a few submitters, such as clinicians, reported some positive experiences working with Pharmac, most found their experiences to be negative, and identified a number of challenges with Pharmac's decision-making approach and processes.

Many submitters noted that Pharmac is constrained by a fixed budget, meaning that Pharmac's funding decisions are predominantly driven by a cost-savings approach. Many found that a focus on cost-savings means that Pharmac does not consider the long-term effects of its funding decisions on consumers or the wider health system.

A few individuals and consumer groups noted that using the metric of cost-effectiveness to prioritise funding worked well for the general population with common diseases or conditions. However, consumer groups and industry submitters argued that a one-size-fits-all approach disadvantages those with rare diseases or conditions due to their small population size.

Many submitters believed that Pharmac does not consider the latest available evidence or advice from experts in the sector when making funding decisions. This included concern and frustration at a lack of appropriate weight given to evidence from other jurisdictions.

Many submitters found Pharmac's decision-making to be opaque and slow-moving. Consumer groups and industry submitters often expressed frustration with how long it takes for medicines and devices to be considered, prioritised, and funded. They also did not know how medicines and devices are prioritised, how decision-making criteria is applied, or how long it would be before a decision is made.

Many submitters felt that there was a lack of meaningful engagement with sector stakeholders, particularly with consumers or consumer groups. Consumer groups expressed frustration that there were limited opportunities to input into decision-making.

What submitters know about Pharmac's processes and how they work

While several submitters could not comment on what worked well, those who did believed that Pharmac's strong purchasing power works well to provide New Zealanders with access to affordable medicines and devices.

Some consumer groups and industry submitters thought that the cost of medicines and devices has created a two-tier healthcare system where those who have the financial means to self-fund have greater access to modern, effective medicines and devices compared to those who rely on publicly funded treatment. The cost of going to a healthcare practitioner for a prescription also acts as a barrier for those who cannot afford the fees.

Some industry submitters and consumer groups indicated that international pharmaceutical companies are choosing to not provide medicines and devices to New Zealand. This is due to Pharmac's lengthy and complicated procurement process, and the low likelihood of funding success.

Many submitters noted that several other countries evaluate and procure medicines and devices effectively for their citizens better than New Zealand and have approaches that can be adopted. They found that other OECD countries, such as the United Kingdom and Australia, have greater access to publicly funded medicines and devices, make funding decisions faster, with greater transparency, and provide alternative assessment pathways for rare diseases or conditions.

What Pharmac's role should look like in the future

Submitters wanted to see a future Pharmac that was well-funded and placed greater priority on consumer health outcomes when making decisions. Developing a medicines strategy or separating Pharmac's evaluation function from its procurement function, were suggested as new ways forward.

Many submitters wanted to see a greater emphasis on meaningful consultation and engagement with sector stakeholders, especially with consumers and clinical experts. This was to ensure that decision-making was informed by both the needs of New Zealanders and appropriate clinical expertise.

Many recommended that Pharmac make its decisions faster and more transparently. This included providing clear explanations for why medicines and devices are not funded, adopting defined timeframes for all decision-making stages, and requiring the Pharmacology and Therapeutics Advisory Committee (PTAC) and subcommittees to meet more frequently and make their minutes publicly available in a timely manner.

Some clinicians, consumer groups and industry submitters called for Pharmac to consider the latest available evidence in all funding decisions, to give more weight to international research, and to actively search out innovations in medicines and devices.

Consumer groups and industry submitters urged for an alternative assessment and funding pathway for medicines and devices that treat those with rare diseases or conditions. This was recommended to address the inequitable health outcomes faced by those with rare diseases or conditions.

A few submitters believed that changes to the health and disability system could lead to a more integrated health system with Pharmac working in alignment with the wider health system to address equitable health outcomes. Others suggested that the changes would require Pharmac to emphasise equitable access to medicines and devices throughout decision-making.

How Pharmac should address the need for greater equity in its decisions

While a few submitters, particularly clinicians, noted that Pharmac has taken some positive steps, others found that more could be done to better reflect the principles of Te Tiriti o Waitangi. Submitters recommended that Pharmac prioritise medicine and devices for diseases that disproportionately affect Māori; utilse a te ao Māori perspective throughout funding decisions and increase Māori representation in governance and committees.

Some submitters suggested that a focus on engaging with marginalised communities and emphasising health outcomes in decision-making will help Pharmac to achieve more equitable health outcomes. Submitters noted that understanding and addressing the needs of New Zealanders with lived experience was integral to achieving this.

INTRODUCTION

Purpose and background

The purpose of the Review and the recommendations it makes are to ensure that New Zealanders can have confidence that Pharmac makes the best contribution it can to improving health outcomes for all New Zealanders, particularly Māori and Pacific peoples, as part of the wider health and disability system.

The Review Panel consulted with the public to enable consumer, family and whānau perspectives to inform the review, and to ensure that the public can have confidence in its findings. This report provides a thematic analysis of submissions received from the public.

Report structure

The report is in three sections: executive summary, introduction and methodology, and the substantive report which summarises the findings of the public consultation. The findings are in five parts based on the content of the submission document and structured by questions and sub themes. Appendix 1 provides a list of submitters.

METHODOLOGY

Data collection

Public submissions were open for a five-week period, from 11 June to 16 July 2021. A total of 213 submissions were received. Of these, 103 were received online on the Ministry of Health's Health Consultation Hub. Another 110 were received via email to the Pharmac Review. All submissions were allocated a unique identifier either automatically from the website or by the Pharmac Review Secretariat (the Secretariat), before being provided to *Allen + Clarke.*

Type of submitters

Submitters were asked to identify if they were submitting as an organisation. The Secretariat then classified all submissions as either individuals, patient or consumer groups, clinicians, industry, or academics to support the analysis process. The numbers and proportions of each submitter type is outlined in Table 1 on page 5.

Table 1: Submitter Types

Submitter Type	Description	Number of submitters	Percentage of total
Individuals	Self-identified as submitting a personal account generally based on their individual experience of Pharmac.	86	40%
Patient or consumer group	Identified as a group that is representing the interests of a particular condition requiring medicines (eg, cystic fibrosis) or who advocate for patient rights (eg, Patient Voices Aotearoa, Human Rights Commissioner)	51	24%
Clinicians	Medical professionals including pharmacists who submitted stating a professional view, and groups representing clinicians	46	22%
Industry	Pharmaceutical company or industry association	28	13%
Academics	Self-identified as submitting with an academic view and an affiliation with an academic institution	2	1%

Coding and analysis

All submissions were uploaded into NVivo 12 qualitative analysis software and coded to a comprehensive thematic framework based on questions asked in the survey and common themes within these questions. The thematic framework was agreed with the Review Secretariat prior to the commencement of coding.

All submissions were classified by submitter type. The analysis was supported by the query function in NVivo 12 that enabled the common themes from submissions to be analysed by submitter type. This showed the relationship between submitter types and particular themes.

Methodological limitations

As no personal, demographic or health information was collected during the survey it is not possible to analyse responses by attributes such as age, ethnicity, gender, or whether the submitter has a specific health condition.

PART 1: SUBMITTERS' CURRENT EXPERIENCE WITH PHARMAC AND HOW IT FUNCTIONS

Submitters were asked the following questions in relation to their experience with Pharmac and how it functions:

1. *What is your understanding of what Pharmac does?*
2. *What has been your experience of working with Pharmac?*
3. *What are the challenges with Pharmac's functions for funding medicine and devices?*

There is a generally good understanding of what Pharmac does and how it functions

When asked about what Pharmac does, most submitters across all submitter types demonstrated a well-rounded understanding. However, a few individual submitters indicated that they did not know or were not entirely clear what Pharmac does.

The key functions of Pharmac that submitters discussed are outlined below.

Pharmac decides what medicines get funded - within a fixed budget

Many submitters, across all submitter types, understood that Pharmac decides what medicines and devices are funded in New Zealand. Some of these submitters discussed the financial constraints of the fixed Combined Pharmaceutical Budget and recognised that Pharmac has a challenging role to decide what medicines and medical devices to prioritise.

Most submitters who discussed this function recognised that Pharmac's legislative mandate is to work to achieve the best health outcomes for New Zealanders from within the amount of funding provided to them.

A few consumer groups and individual submitters spoke about how Pharmac uses an assessment of cost-effectiveness to inform its funding decisions. These submitters noted that using such an assessment can be problematic and lead to perceptions that Pharmac is a "cost-control[1]" agency that prioritises cost-savings over the medical needs of all New Zealanders.

A few industry submitters recognised that Pharmac utilises a number of specialised committees, such as the PTAC, throughout their decision-making process. Some of these submitters noted that, when making decisions, Pharmac committees will consider both clinical evidence regarding the medicine or device concerned, as well as the economic implications of Pharmac's funding decisions.

Pharmac negotiates with pharmaceutical companies to get the best prices

Some submitters, particularly individual submitters and clinicians commented that Pharmac negotiates directly with pharmaceutical companies on the price of medicines and devices. They acknowledged that Pharmac's negotiating powers have helped obtain the best prices for medicines and devices available in New Zealand. Some individual submitters attributed this

[1] C133 Cancer Society, Consumer group, Email

outcome to Pharmac's ability to undertake direct price negotiations with pharmaceutical companies on a global scale.

> *There are many health technology, pharmaceutical and clinical service agencies of different configurations around the world, but very few if any of them that I am aware of negotiate prices directly with the companies involved. (Academic)* [2]

Submitters also recognised other negotiation methods used by Pharmac when working to secure the best prices for medication and devices, including competitive tendering, bulk-purchasing, and promoting less costly, generic brands of medicine.

Although some experiences working with Pharmac have been positive, most appear to be negative

Submitters shared a range of stories about their experiences of working with Pharmac.

A few submitters, most of whom were clinicians, shared stories of positive experiences of working with Pharmac. These submitters generally described positive and productive working relationships.

> *I have dealt with PHARMAC over many years as a health professional involved in medicines governance and an academic teaching medical students. PHARMAC has steadily improved and is collaborative and engaged. (Clinician)*[3]

A few other submitters, most of whom were consumer groups, shared stories of mixed experiences, when some aspects of working with Pharmac had gone well, while other aspects were negative.

> *Relationships and engagement with individual staff at a day-to day working level have always been positive, however, experience of working with the organisation has been mixed. (Consumer group)*[4]

Most submitters who provided a response to this question shared stories of their negative experiences with Pharmac. This was evident across the range of submitter types, but particularly for individual submitters.

Specific themes relating to the negative experiences that submitters have had with Pharmac are outlined in more detail throughout the following question.

There are a number of challenges throughout Pharmac's decision-making approach and processes

Submitters identified a range of issues with Pharmac's decision-making approach and processes, often based on their experiences working with Pharmac, as outlined below.

---

[2] C006, Academic, Email
[3] KVQ8-U, Clinician, Online, Permission given
[4] C134 CFNZ, Consumer group, Email

Pharmac is constrained by its fixed budget

Although it was recognised that the size of Pharmac's budget was out of scope of this review, many submitters, across all submitter types, noted that Pharmac's ability to fund medicines and devices is constrained by its small and fixed budget.

> *I'd say PHARMAC's biggest challenge is working with a financial budget that is NOT adequate for the medicines and devices that kiwis desperately need and are missing out on. People like myself are not asking for the impossible, we just need to be at least on par with other developed countries and what they have access to. People are suffering and dying. But of course the budget is conveniently left out of this review. (Individual)*[5]

Cost savings are the primary driver of decision-making

Many submitters, across all submitter types, considered that Pharmac's fixed budget has meant that funding decisions are predominantly driven by a cost-savings approach. These submitters often described how Pharmac was too focused on obtaining medicines and devices at a low cost, and did not appropriately consider consumer needs or health outcomes. As an example, some of these submitters noted that a limited budget means that Pharmac prioritises and funds cheaper, often generically branded or outdated medicines and devices, instead of newer and more effective alternatives.

> *It seems that cost is the driving force, not patient need (Clinician)*[6]

> *Main challenge for PHARMAC is that they are too fixated on living within their means and not focussed enough on getting effective medicines to New Zealanders. (Individual)*[7]

Many submitters, particularly consumer groups and industry submitters, suggested that Pharmac's focus on saving money in the short term has meant that Pharmac does not consider the long-term impact of funding decisions on the consumer or the wider health sector. This has led some individual submitters and consumer groups to feel disillusioned and to lose confidence in Pharmac's mandate due to its repeated failure to apply a consumer-focused lens to its decision-making.

> *PHARMAC funding decisions are based on a cost minimisation strategy, and do not take into account the cost savings that can be achieved in other areas of the health system. (Industry)*[8]

Some submitters, particularly individual submitters, explained that when Pharmac's funding decisions are driven by cost savings, this can negatively impact on consumers' mental health, quality of life, and ability to participate in society. Other submitters explained that Pharmac's focus on cost savings was at odds with its legislative mandate to provide the best health outcomes for all New Zealanders.

---

[5] C003, Individual submitter, Email
[6] KV6B-A, Clinician, Online, Permission given
[7] KVCJ-Y, Individual submitter, Online, Permission given
[8] C151 Seqirus, Industry, Email

The prioritisation approach disadvantages those with rare diseases or conditions

Many submitters – particularly individuals, consumer groups, and industry submitters – indicated that taking a cost-savings approach to decision-making has meant that Pharmac largely relies on an assessment of cost-effectiveness to decide what medicines and devices to fund. These submitters suggested that Pharmac makes funding decisions primarily based on achieving the best outcome for the largest number of people. These submitters argued that this 'one-size-fits-all' approach disadvantages those who require an individualised approach – such as those with rare diseases – due to their smaller population size.

> *PHARMAC's criteria of funding the cheapest medicines for the greatest number of patients severely disadvantages people diagnosed with rare disorders. (Patient or consumer group)* [9]

> *[Pharmac] state that 'rare disorders medicines may compare favourably on other measures such as health need, but affordability and budgetary impact need to be taken into account due to Pharmac's fixed budget'. When you see funding decisions for flavoured condoms, it adds salt to the wounds. (Patient or consumer group)*[10]

Submitters who commented on this 'one-size-fits-all' approach considered it to be a major constraint to Pharmac's responsibility to provide the best health outcomes for all New Zealanders. They explained that a lack of consideration of the needs of those with rare disorders or conditions has resulted in inequitable outcomes for these groups as they are unable to access the high-cost treatment that they need to live well.

> *The prioritisation process applied by PHARMAC appears to favour mainstream medicines for the majority as opposed to life-saving medicines for the minority. (Industry)*[11]

Submitters also found it unfair that Pharmac has no alternative assessment pathway for medicines or devices to treat diseases or conditions that affect small population groups.

Appropriate evidence is not considered in decision-making

Many submitters – particularly consumer groups, clinicians and industry submitters – believed that Pharmac does not consider the latest available evidence or advice from experts in the sector when making funding decisions. These submitters were concerned that Pharmac does not give appropriate weighting to overseas advice or research, such as considering international guidelines or advice from international authorities. Some submitters expressed confusion as to why Pharmac sometimes cites insufficient evidence as a reason to decline funding for medicines and devices that are considered safe and effective in other jurisdictions.

> *One of the main obstacles we have found when working with PHARMAC is their baffling disregard and rejection of credible, convincing evidence. (Patient or consumer group)*[12]

[9] C140 NGO Council, Consumer group, Email
[10] C176 SMA. Consumer group, Email
[11] C111 Alexion, Industry, Email
[12] C122 PWSA, Consumer group, Email

> *If drugs are approved by Medsafe and are widely used in countries like Australia and UK why does Pharmac need to do further research to prove that it is effective. (Individual)*[13]

Industry submitters and consumer groups were also concerned that Pharmac's own committee (PTAC) would often disregard the advice from expert advisory groups or subcommittees when making funding decisions.

Some submitters, particularly consumer groups, spoke about Pharmac's preference for large, randomised, phase three clinical trials when considering the evidence base of which medicine or device to fund. Submitters were concerned that the threshold for this preferred level of evidence was too high, and that this disadvantages those with rare diseases and conditions due to their smaller population base.

> *The criteria for funding some medicines is too high for some diseases, in particular rare diseases. The preferred level of evidence for treatment efficacy is a large, randomised, phase 3 clinical trial, however in diseases with small patient populations such trials can be very rare. (Patient or consumer group)*[14]

A few submitters, most of whom were clinicians, highlighted that Pharmac's funding decisions can become influenced by politics and strong public lobbying for a particular disease or condition. These submitters were concerned that this influence disadvantages other consumer groups or those with diseases or conditions that were not as influential or well resourced.

> *Funding decisions – sometimes the evidence base is poor but public opinion is strong (Clinician group)*[15]

> *Decision-making is influenced by lobby groups with a powerful public voice. This means sometimes funding is diverted from areas of need without the same public presence (Clinician)*[16]

One academic noted that Pharmac faces the challenge of considering medicines that have been passed through an expedited review by drug regulatory agencies in other countries. They considered this to be a challenge as an expedited review can result in less robust research methods and evidence available to make an appropriate assessment.

Decision-making is opaque and communication is lacking

Many submitters raised concerns with the rigidity and lack of transparency in Pharmac's processes and funding decisions. Consumer groups and industry submitters in particular expressed confusion around how decision-making criteria is applied, and frustration at the inability to clearly track the progress of a funding application.

> *PHARMAC's processes of evaluation and decision-making are neither open or transparent, making it difficult for patients, clinicians, healthcare providers, industry and the public to understand how a technology is*

[13] KVC8-D, Individual submitter, Online, Permission given
[14] C019 LSNZ, Consumer group, Email
[15] C178 RNZCGP, Clinician group, Email
[16] KVCH-W, Online, Clinician, Permission given

> *progressing through the system or how and why decisions about whether to fund it or not are made. (Industry)*[17]

As an example, some consumer groups and clinicians expressed their concerns with a lack of transparency and communication when medicine brand switches occur. They stated that Pharmac is not transparent about why it decides to switch medicine brands, nor does it communicate brand switches effectively with consumers or clinicians. They noted that the decision to switch brands often appeared to be due to cost savings rather than considering international best practice, current evidence and advice from experts, or the impact this might have on the consumer.

> *A particular concern for medical specialists pertains to decisions to switch drugs to save money. We are aware that each time a funded drug is switched to another drug to save money - even a generic drug that looks different but is the same drug entity - around 20% of patients lose effect from the new drug or get side effects due to the nocebo effect. In our view, these consequences are not appropriately considered by PHARMAC in its decision-making. (Clinician group)*[18]

A few clinicians and consumer groups reiterated that brand switching can have a negative impact on consumers and felt frustrated that Pharmac appear to give little to no thought on how to transition consumers onto the new brand.

Decision-making is slow

Some submitters, particularly consumer groups and industry submitters, expressed frustration with the time that it takes for medicines to be considered, prioritised, and funded by Pharmac. They found that a lack of defined timeframes across the different stages of decision-making meant that consumers and suppliers did not know how long they would have to wait before a decision was made.

> *The timelines for decision making and reporting deemed acceptable by PHARMAC are exasperating and would result in self elimination in a competitive marketplace. It takes four years, on average, to approve a drug's funding and yet the process is often, if not always, dealing with lifesaving medications. (Patient or consumer group)*[19]

A few individual submitters highlighted the negative impact that consumers can face while awaiting Pharmac's decision on whether to fund the medicines or devices that they need.

> *Some [are] dying in the process of waiting for the medicines to be funded by Pharmac or having to remortgage their house or crowd fund money in order to privately fund their medicine needs before they die waiting. (Individual)*[20]

A few consumer groups highlighted how the Pharmac price negotiation process or preference for medicine bundle deals can contribute to the extended wait-time between when a medicine is approved and prioritised, and when it is funded.

A few consumer groups and industry submitters expressed frustration with the long intervals between PTAC and subcommittee meetings, which can delay access to new medicines and devices.

---

[17] C110, Roche, Industry, Email
[18] C169 ASMS, Clinician group, Email
[19] C140 NGO council, Consumer group, Email
[20] C002, Individual submitter, Email

They noted that the PTAC meets too infrequently and takes a long time to publish the minutes from committee meetings. These submitters also discussed how funding applications can be pushed back to be considered at a later PTAC meeting without warning, which contributes to further decision-making delays.

Meaningful engagement with sector stakeholders is lacking

Some submitters – including individual submitters, consumer groups and industry submitters – found that Pharmac's decision-making processes lacked meaningful consultation and engagement with consumers or consumer groups. They described limited opportunities for consumers to provide input into the decision-making process, stating that engagement is restricted to one part of the process rather than being an important component throughout.

> *The consumer voice appears to be secondary and undervalued (Patient or consumer group)*[21]

These submitters considered that a lack of consumer input means that Pharmac is not prioritising or funding the medicines and devices that meet consumers' needs.

> *There is a lack of the patient voice in the decision making process. This results in a lower quality of data and information provided to decision makers. (Patient or consumer group)*[22]

> *PHARMAC's processes are not patient-centred. It does not formally involve or capture the perspectives of patients, patient groups, hard to reach communities or different ethnic groups in its decision-making or in the design of its methods (Industry)*[23]

A few submitters, particularly consumer groups, raised concerns about a lack of input from clinical experts during the decision-making process. This included concerns with a lack of representation of specific disease experts on advisory committees.

A few industry submitters described Pharmac's communication with stakeholders as "inadequate[24]" and mentioned that the funding application process was especially difficult to navigate as Pharmac did not take a collaborative approach to working with pharmaceutical companies or supplies.

> *A transactional, rather than collaborative approach – funding applications are submitted with little, if any engagement, throughout the formal process. (Industry)*[25]

[21] KU2K-E, Consumer group, Online, Permission given
[22] C005, Head and Neck Cancer, Consumer group, Email
[23] C110, Roche, Industry, Email
[24] C113 Biogen, Industry, Email
[25] C147 Takeda NZ, Industry, Email

PART 2: WHAT SUBMITTERS KNOW ABOUT PHARMAC'S PROCESSES AND HOW THEY WORK

Submitters were asked the following questions on what they know about Pharmac's processes and how they work:

> *4. What do you think works well with the processes Pharmac uses to assess the funding of medicines and devices?*
>
> *5. What do you think are the barriers to accessing medicines and devices?*
>
> *6. Is there any other country that does it better? What is it that it does better and would any of these systems apply here?*

Pharmac's strong purchasing power works well

Overall, relatively few submitters provided an answer to what they thought worked well about Pharmac's processes to fund medicines and devices.

Most responses to this question were from individual submitters or consumer groups who either did not know what processes worked well, or found that nothing worked well in their experience.

Many submitters who answered this question commented on Pharmac's purchasing power and expertise in negotiating contracts for medicines and devices. Clinicians, consumer groups, and industry submitters highlighted how Pharmac can obtain significant discounts and value for money compared to other OECD countries. A few of these submitters commented that Pharmac does well in constraining the cost of pharmaceuticals and limiting its overall pharmaceutical expenditure within a fixed budget. A few individual submitters and consumer groups commented that this purchasing power has meant that New Zealanders could access a wide range of medicines and devices that they needed. This was especially the case for the general population who had more mainstream diseases or conditions.

> *PHARMAC has been able to negotiate reduced cost medications and these cost savings result in being able to supply a reasonable number of low-cost medications to large population groups. (Patient or consumer group)*[26]

Few submitters provided other comments relating to what they thought worked well about Pharmac's processes. These comments included:

- A few industry submitters praised the collaboration and speed of Pharmac when there were supply shortages or urgent needs to find alternative sources for medicines. A few submitters described experiences of Pharmac working flexibly, quickly and efficiently for some decisions; engaging regularly to develop mutually sustainable commercial proposals; and found staff to be positive and constructive.
- A few submitters, particularly individuals and clinicians, considered that Pharmac takes an evidence-based approach when deciding what medicines and devices to fund. They described how the medicines and devices that Pharmac choose to fund were well

[26] C122 PWSA, Consumer group, Email

researched and validated, and that Pharmac does well at weighing the pros and cons of medicines and devices.

- A few submitters, including individuals, clinicians and industry submitters, commented on the strength, rigor and credibility of the PTAC and subcommittees in assessing efficacy and safety of medicines. This included noting that Pharmac utilised both PTAC's clinical advisers, as well as input from external clinicians from various clinical fields to inform decision-making.
- A few submitters, particularly industry submitters commented that Pharmac's decision-making processes worked well as they were relatively transparent. As an example, submitters considered that the application tracker and the initial feedback process to suppliers worked well. Others spoke positively of how information relating to funding applications is provided in a timely manner. This included providing information on PTAC timelines, agenda items, and minutes on the Pharmac website, as well as providing this information in advance to pharmaceutical companies.

Cost to consumers and disinterest from international pharmaceutical companies are key barriers to accessing medicines and devices

Submitters often mentioned two main barriers to access to medicine and devices (outlined in detail below):

- the personal cost to consumers of accessing medicines and devices, and
- international pharmaceutical companies perceiving the New Zealand market as a deterrent.

The costs of medicines and primary care services impact on consumers' access

Some submitters – particularly individuals, consumer groups and industry submitters - discussed how Pharmac's decisions to fund selected medicines and devices have perpetuated both access barriers to medicines and devices, and inequitable health outcomes for consumers. These submitters described New Zealand as having a "two-tier healthcare system[27]" where those who have the financial means to self-fund have greater access to more modern, effective medicines and devices, compared to those who rely on publicly funded medicines and devices.

> *There is increasing economic inequity in NZ society […] New Zealanders who have the financial means to fund their own health care and purchase the medicines they need is resulting in a widening gap between those who can afford to pay privately and those who rely solely on government-funded health care. (Industry)[28]*

A few consumer groups noted that when medicines and devices are not funded by Pharmac, consumers without the financial means are either forced to fundraise or risk missing out on the treatment that they need. They stated that this can disproportionately affect Māori, Pacific peoples, disabled people and other marginalised groups, such as those experiencing socioeconomic deprivation.

[27] C110 Roche, Industry, Email
[28] C109 AbbVie, Industry, Email

> *So often we witness people liquidating assets and using Givealittle to self-fund medicines. This discriminates against lower decile populations who do not own assets to sell to fund needed medicines or have access to cash to help someone in the community. This inequity contributes to the unenviable life expectancy statistics (Patient or consumer group)*[29]

Some submitters, particularly clinicians, discussed how the primary care pathway can be a barrier for access for many consumers. They noted that going to a healthcare practitioner can be the first barrier that consumers face as many are unable to afford the cost of attending a healthcare appointment to obtain a prescription for cheaper medicines and devices.

> *Ultimately, subsidies that reduce the cost of prescription medicines cannot have their intended effect if appointments with healthcare practitioners are inaccessible (Clinician group)*[30]

International pharmaceutical companies are choosing not to provide medicines to New Zealand

Some submitters – including clinicians, consumer groups, and industry submitters – were concerned that international pharmaceutical companies were disinterested in registering their medicines and devices in New Zealand. This was due to Pharmac's long and complicated procurement processes and the low likelihood of funding success. A few of these submitters noted that Pharmac's procurement processes and cost-saving practices, such as sole supply agreements, meant that it was not economically viable for some international pharmaceutical companies to register their medicines or devices in New Zealand.

> *PHARMAC's procurement processes have resulted in fewer pharmaceutical companies doing business in NZ as the environment is not economically viable. (Industry)*[31]

Submitters raised concerns that Pharmac's practices could jeopardise the security of supply of medicines in New Zealand. They considered that international companies' hesitancy to approach New Zealand was a barrier that further limited modern medicines and devices being accessible in New Zealand.

> *PHARMAC has been very effective at cutting drug costs. However, we are aware that some pharmaceutical companies are choosing not to put in funding applications for new drugs because of PHARMAC's hard bargaining environment. As a result, New Zealanders are missing out on important drugs that are available in other countries because some new drugs are not being put forward for consideration for funding. (Clinician group)*[32]

[29] C140 NGO Council, Consumer group, Email
[30] C168 RACP, Clinician group, Email
[31] C109 AbbVie, Industry, Email
[32] C169 ASMS, Clinical group, Email

Several other countries do it better than New Zealand and have approaches that could be adopted

When considering whether other countries do it better, submitters discussed a range of OECD countries and the models and systems that New Zealand could look to follow. These countries included the United Kingdom (UK), Australia, Europe, and the Americas.

A few submitters pointed to other countries but did not provide further explanation of what they did better than New Zealand. Key themes from submitters who discussed what other countries did better are outlined below.

Other OECD countries have greater access to funded medicines and devices

Many submitters, across all submitter types, described New Zealand as falling behind in providing public access to modern medicines compared to other OECD countries. Industry submitters in particular, noted that New Zealand's pharmaceuticals budget is well below that of other OECD countries, which has resulted in fewer publicly funded modern medicines and devices. Some of these submitters suggested that limited access to medicines and devices has also contributed to poorer health outcomes for New Zealanders compared to other developed countries. Some individual submitters discussed the distressing experience of being forced to relocate to a different country, such as Australia or the UK, in order to access the medication or treatment they needed to survive.

> *NZ sits LAST in the OECD for access to modern medicines (Individual)*[33]

> *Firstly it is important to note that while no country does this perfectly it is our view that the approach taken in New Zealand no matter how you look at has resulted in access to a significant [sic] fewer number of medicines across a range of therapeutic areas than the majority of other OECD countries. This has undoubtedly resulted in or contributed to poorer health outcomes for New Zealanders. (Industry)*[34]

Some submitters, particularly individuals, consumer groups and industry submitters, believed that countries such as the UK, Australia, and Canada were able to provide greater access to medicines and devices because their budgets are not fixed, and because their funding models are more responsive to need. Some consumer groups and industry submitters highlighted the UK's National Institute for Health and Care Excellence (NICE) model, believing that this worked well.

> *We are aware that NICE in the UK is regarded as a standout in its field. We trust the Review Panel will be reviewing NICE's latest 5 year strategy as a model NZ could potentially aspire to (Patient or consumer group)*[35]

Other OECD countries make decisions faster

Many submitters, particularly industry submitters and consumer groups, found that New Zealand takes considerably longer to assess, prioritise, and fund medicines and devices compared to other OECD countries. A few of these submitters highlighted how the slow decision-making process in New Zealand can have a negative impact on consumers, such as being unable to access medicines

[33] KVCJ-Y, Individual submitter, Online, Permission given
[34] C146 AstraZeneca, Industry, Email
[35] C142 CLLANZ, Consumer group, Email

at the right time of their treatment cycle, despite the same medicines being easily accessible in other OECD countries.

> *New Zealand is much slower than other OECD countries in its funding of new medicines, taking an average of 4.75 years and counting from registration to reimbursement. (Industry)*[36]

A few industry submitters and clinicians highlighted the UK, Australia, Germany, and Singapore as countries that assess and fund medicines and devices faster than New Zealand. A few of these submitters spoke in favour of how the UK and Australia have clearly defined timeframes for decision-making processes, such as the UK's 90 day requirement to make medicine available once a decision has been made. They suggested that this was a positive aspect that New Zealand could adopt. This theme is discussed further in Part 3: What Pharmac's role should look like in the future.

A few submitters highlighted how the United States has a pathway for conditional or accelerated approvals whereby new medicines can be approved based on lower evidence thresholds, provided that future clinical trials are conducted to validate the approval.

Other OECD countries have alternative assessment pathways for rare diseases or conditions

Some submitters, particularly consumer groups, pointed to alternative pathways – to expedite assessment and funding for medicines that address life-threatening diseases or conditions, or for those with rare diseases or conditions – in other OECD countries. In particular, submitters pointed to the Life Saving Drugs Program in Australia, the UK's NICE, and other countries such as Scotland, Italy and Japan. These submitters noted that New Zealand does not have an equivalent process. This theme is discussed further under Part 3: What Pharmac's role should look like in the future.

Other OECD countries have greater transparency in their processes and decision-making

A few submitters noted that other OECD countries, such as Canada and the UK had greater transparency in their decision-making processes. As an example, one consumer group noted that NICE will openly negotiate with pharmaceutical companies and inform them when a submission does not meet requirements or will not be funded.

[36] C110 Roche, Industry, Email

PART 3: WHAT PHARMAC'S ROLE SHOULD LOOK LIKE IN THE FUTURE

Submitters were asked the following questions on Pharmac's future role:

> *7. How might Pharmac look in the future, and what needs to change for this to happen?*
>
> *8. Are there additional or different things that Pharmac should be doing?*
>
> *9. What do the wider changes to the health and disability system mean for Pharmac?*

Submitters often did not distinguish between questions seven and eight when they provided responses. For this reason, themes relating to submitters' responses to these questions have been combined and discussed together.

A well-funded, transparent, and efficient Pharmac focused on consumer health outcomes

Submitters made many suggestions on what Pharmac could look like in the future, and what it could be doing differently.

Increase the pharmaceutical budget

Many submitters who discussed what Pharmac could look like in the future, particularly individuals and consumer groups, spoke about the need for Pharmac to have an increased budget so that it can meet the health needs of New Zealanders. A few industry submitters suggested that a ringfenced budget, which could sit as a "standalone appropriation[37]" was necessary.

Some submitters wanted to see Pharmac taking more of an advocacy role to lobby the Government for the appropriate amount of funding that it needs to achieve the best outcomes for the country.

> *PHARMAC governance needs to be stronger and fight more to ensure Kiwis get the medicine funding they deserve and need. (Individual)[38]*

Prioritise consumer health outcomes in decision-making

Many submitters who commented on what needs to change, pointed to the current decision-making model and approach. Individuals, consumer groups and industry submitters felt that Pharmac needed to place greater emphasis on taking a consumer-centred approach and consider the impacts of decision-making on the wider health system. A few industry submitters suggested that Pharmac's statutory objective be amended to ensure health outcomes are paramount when assessing new medicines and devices.

> *I would like to see a PHARMAC with a more compassionate, patient-centred approach instead of the current money-centred approach. This would see PHARMAC standing alongside and supporting the patient community,*

[37] C146 AstraZeneca, Industry, Email
[38] C002, Individual, Email

> *instead of standing against them and acting as a barrier. (Patient or consumer group)*[39]
>
> *This will require a change in PHARMAC's statutory objectives. That is, a shift away from a focus on a limited fixed budget to an emphasis on health outcomes, achieving equity and considering the broader implications of medicines funding in its assessments. (Industry)*[40]

Some industry submitters commented on the need to reform the Health Technology Assessment (HTA) process to take into account the wider social and economic impacts of its funding decisions and costs to society of not funding certain medicines or devices. This would include considering the level of unmet need, public health priorities and the severity of the disease.

Some clinicians, consumer groups and industry submitters spoke of the need for a national medicines strategy to safeguard patient wellbeing as the priority for future decision-making, and to recognise and respond to strategic issues such as security of supply, equity of access, and innovation and technological developments.

> *New Zealand needs a Medicines Strategy (Patient or consumer group)*[41]

A few submitters suggested revisiting quality-adjusted life year (QALY) calculations to put a greater value on human life and quality of life for chronically ill consumers. One consumer group raised concerns that, in New Zealand, the value of life of someone lost to a health issue could be considered less than the value of life of someone lost to a roading accident.

Some consumer groups suggested that Pharmac implement benchmarking against other OECD countries and align the approval processes and reporting standards with international best practice.

> *Performance indicators should be introduced which help PHARMAC lift its game so that NZ doesn't lag behind so many OECD countries in terms of medicines it funds and range of medicines it funds. (Patient or consumer group)*[42]

Separate the procurement and evaluation functions

When considering what Pharmac should do differently, some submitters, including consumer groups and industry submitters, suggested that Pharmac should separate its procurement function from its clinical assessment and evaluation function when making funding decisions.

> *We believe it is essential to separate the clinical and economic evaluation of a medicine from the purchasing of the medicine. (Industry)*[43]
>
> *Ensuring these are undertaken in separate organisations would enable clinical assessment to be undertaken independently, on the basis of evidence and patient need, and not contaminated or undermined by purchasing. (Patient or consumer group)*[44]

---

[39] C019 LSNZ, Consumer group, Email
[40] C147 Takeda, Industry, Email
[41] C070 FARA NZ (5), Consumer group, Email
[42] C027, Thyroid Association NZ, Consumer group, Email
[43] C145 Sanofi, Industry, Email
[44] C031 Breast Cancer Aotearoa Coalition, Consumer group, Email

A few of these submitters explained that Pharmac could continue to manage the procurement function, including price negotiations, but that clinical assessment, including HTAs, be undertaken by another organisation such as Health New Zealand and the Māori Health Authority.

Improve consultation with critical stakeholders throughout the decision-making process

When considering what Pharmac could do differently, almost half of all submitters discussed the need for greater consultation and engagement with consumers, clinical experts, and wider sector stakeholders throughout the decision-making process.

Many submitters, across all submitter types, wanted to see a Pharmac that listened to consumers and advocacy groups, took lived experiences seriously, and meaningfully incorporated consumer input into every stage of the decision-making process. These submitters explained that engaging with consumers is critical to understanding the needs of New Zealanders and how funding decisions impact on their lives.

> *PHARMAC needs to better embed and value the central role of consumers and patients to ensure participation in critical decisions. PHARMAC is making some in roads here but we feel more could be done. (Industry)*[45]

> *Patient representation either through patients or consumer advocacy groups would provide valued input beyond what the research data tells. It will help to humanise decisions, prioritise the patients and ensure unmet needs are prioritised. (Patient or consumer group)*[46]

Some of these submitters suggested that Pharmac needs to consider advice from clinical experts outside of Pharmac's own committees, and that they should engage more with clinical experts when making decisions such as by bringing in experts in disease areas to support advice to PTAC. Others indicated that Pharmac should work more collaboratively in partnership with industry stakeholders such as pharmaceutical companies and drug manufacturers.

When discussing consultation with stakeholders, a few submitters also discussed the need for Pharmac to have more diversity in their governance and committees. Submitters suggested that these groups should have more representation of consumers and better reflect the communities that they serve.

> *Formalise the role of industry, patients, patient organisations and representatives from ethnic groups in the evaluation process. This might include having members of the Consumer Advisory Committee represented on Specialist Advisory Committees, as well as PTAC, and ensuring more than one person representing the consumer view is appointed to any committee – individuals selected should be diverse and representative of New Zealand. (Industry)*[47]

Be more transparent throughout funding decisions

When considering what Pharmac should be doing differently, many submitters, across all submitter types, spoke about the need for Pharmac to be more transparent throughout their decision-making processes.

---

[45] C146 ASTRAZENECA, Industry, Email
[46] C155 MSNZ, Consumer group, Email
[47] C110 Roche, Industry, Email

> *Transparency is a key request from the sector. Even if there are no structural or statutory changes to PHARMAC as a result of the review, we must see more transparency in the processes (Industry)*[48]

Some of these submitters, particularly individuals and industry submitters, suggested that Pharmac needs to be more open about their funding decisions and provide clear explanations for why medicines and devices are not funded. A few of these submitters suggested that providing greater transparency in Pharmac's decision-making processed could help improve Pharmac's reputation among the public as being trustworthy and credible.

> *Pharmac should be more transparent when deciding why drugs are declined from the list. (Individual)*[49]

Submitters made the following recommendations for how Pharmac could provide greater transparency in their decision-making processes:

- provide clear definitions for each of the 'factors of consideration', including how each factor is weighted, and which factor is applied when a funding decision is reached
- require PTAC and other committee meetings to ensure agendas are published online beforehand, and minutes are always publicly published in a timely manner
- publish the range of lists that contain the medicines and devices Pharmac are considering, such as the Options for Investment list.

Consider the latest evidence when making decisions

When discussing how Pharmac might look in the future, many submitters pointed to Pharmac's role in research and how Pharmac considers evidence when making funding decisions. These submitters noted that Pharmac needs to do more to consider the latest evidence when making funding decisions. Submitters including clinicians, consumer groups and industry submitters suggested that Pharmac should give more weighting to overseas research and knowledge.

> *Independent review of data is important but some weight also needs to be given to overseas assessments/ guidelines. (Clinician group)*[50]

Some consumers and industry submitters suggested that Pharmac could move from being largely reactive and waiting for funding applications, to being proactive and responsive to emerging evidence, identifying innovations in medicines and devices that could benefit consumers.

> *We should have a health care system that is proactive in finding the best proven therapies as soon as they become available. (Patient or consumer group)*[51]

> *[Pharmac] should deploy a formal horizon scanning process, working with industry, so that they can start to think longer term about the way technology will impact on health care in New Zealand and how the Government considers future funding to support this (Industry)*[52]

---

[48] C128 Stryker, Industry, Email
[49] KUYG-H, Individual submitter, Online, Permission given
[50] C171 Auckland Lung Medical Oncology Team, Clinician group, Email
[51] C121 Crohn's Colitis, Consumer group, Email
[52] C180 MEDTRONIC, Industry, Email

Make decisions quickly and efficiently

Nearly a quarter of submitters referred to how long the Pharmac decision-making process takes when considering how Pharmac could do things differently. Some of these submitters generally discussed the need for Pharmac to assess and make funding decisions quickly and more efficiently.

> *We believe that it is appropriate for PHARMAC to review its structure, especially in terms of how it can be nimbler to deliver timely turnaround of applications, some of which appear to be inordinately delayed. (Clinician group)*[53]

Several submitters, particularly consumer groups and industry submitters, suggested that Pharmac adopt clear, reasonable and defined timeframes for each stage of the assessment and decision-making process so that decisions are made more quickly and consistently.

> *[We recommend that] PHARMAC adopts best practice timeframes for providing public access to new medicines following registration, such as the 90 day timeframe in place in other OECD countries and currently being considered by the Australian Parliament, to provide greater certainty of access to patients and clinicians in New Zealand. (Industry)*[54]

Other recommendations for how Pharmac could improve the timeliness of the assessment and decision-making process included:

- require subcommittee meetings to be held more frequently
- require PTAC meetings to be lengthened so that more funding applications can be considered
- allow the Medsafe approval process and Pharmac's assessment processes to be completed in parallel for all medicines to help make medicines available to consumers sooner.

Create alternative funding pathway for rare diseases or conditions

Some individuals, consumer groups, clinicians and industry submitters envisioned a future Pharmac where there is more equitable access to medicines and devices for small population groups, such as those with rare disorders. A few individual submitters suggested Pharmac move towards individualised treatment as a way of reducing inequitable access.

> *PHARMAC should adapt to the future of flexible and personalised care plans by ensuring the efficacy and effectiveness of the funded medicines and devices but leave the design of the care plan and the delivery of the medicines up to the clinicians, individuals, and whānau who have a better understanding of the person's needs (Industry)*[55]

Clinicians and industry submitters in particular suggested that a rapid assessment pathway be introduced for consumers with significant unmet need or where treatments could address life-threatening conditions, as a way of addressing inequity by gaining faster access for these consumers. Some consumer groups wanted to see Rapid Access Scheme or Special Authority criteria that better captures the value and benefits of medicines and devices for small consumer populations or minority groups.

---

[53] C136 NZSA, Clinician group, Email
[54] C144 Meck Sharpe Dohme, Industry, Email
[55] C112 Janssen, Industry, Email

> *[We recommend that] PHARMAC allows patients with high unmet needs rapid access to registered treatments that, emerging data has confirmed, have the potential to improve outcomes for those patients. A rapid access scheme of this kind is in place in many other OECD countries (Industry)*[56]

A more equitable Pharmac, integrated with the health and disability system

The majority of submitters who answered this question, particularly individuals and clinicians, commented that they did not know what the changes to the health and disability system meant for Pharmac. A few submitters indicated that the changes to the health and disability system will not mean anything for Pharmac.

Relatively few submitters provided other comments relating to the health and disability system changes and what this could mean for Pharmac. A summary of key themes discussed by these submitters is outlined below.

Changes may lead to a more integrated health system

A few submitters, across all submitter types, suggested that changes to the health and disability system could lead to more consistency and integration across the wider health system. This included the opportunity for Pharmac to work in alignment with the wider health system, and contribute to better health outcomes for New Zealanders.

> *Wider change to the Health and Disability system should deliver a more holistic and connected healthcare system. (Industry)*[57]

> *Through Health NZ and The Maori Health Authority there is an opportunity to integrate medicines into care pathways to ensure optimal and equitable health outcomes and realise the substantial economic and societal benefits that innovative medicines deliver. (Industry)*[58]

A few industry submitters in particular suggested that Pharmac's legislation should be amended so that their statutory objectives include a definition of best health outcomes. These submitters also suggested introducing an objective to consider the overall cost impact to the health system when evaluating medicines and devices.

A few submitters noted that it is difficult for any changes to the health and disability system to be successful if Pharmac remains the same. These submitters suggested that any improvements to, or reform of, Pharmac must be done at the same time as, and in alignment with, the changes to the health and disability system.

> *It is a vicious cycle at the moment. The H&D system cannot improve to adapt to the growing needs of the people because PHARMAC is stifling the system. Both have to be improved in tandem and succinctly. (Patient or consumer group)*[59]

---

[56] C144 Meck Sharp Dohme, Industry, Email
[57] C150 Vifor, Industry, Email
[58] C147 Takeda, Industry, Email
[59] C004 NZ Amyloidosis Patients Association, Consumer group, Email

Changes provide an opportunity to address equity issues

A few submitters suggested that changes to the health and disability system could mean that Pharmac is required to place a greater emphasis on achieving equitable access to medicines and devices when making funding decisions. This included placing a greater priority on the needs of those with rare or specific diseases and conditions.

> *The changes to the Health and Disability system means that PHARMAC has a greater responsibility to ensure that its funding decisions are made in an equitable context. (Patient or consumer group)*[60]

One clinical group cautioned that, if Pharmac retained the ability to "*close the door to any medication*"[61] then this could limit the Māori Health Authority's ability to address inequitable health outcomes for Māori in the future health system.

Changes may lead to a different funding model

A few submitters suggested that changes to the health and disability system could mean changes to Pharmac's funding model. This included the potential for greater flexibility of funding, a greater proportion of funding allocated to Pharmac, or a shift from a cost-savings approach to one that was health outcomes focused.

> *We hope that the changes will encourage a more holistic approach to investing in healthcare. The cost-based focus needs to shift to the long-term better-quality outcomes focus (Industry).*[62]

One industry submitter indicated that the establishment of Health New Zealand could result in the opportunity to separate Pharmac's evaluation and assessment function from its procurement function, as Health New Zealand would have greater capacity and expertise to procure medicines and devices.

[60] C070 FARA NZ (5), Consumer group, Email
[61] C168 RACP, Clinician group, Email
[62] C148 ATSNZ, Industry, Email

PART 4: HOW PHARMAC SHOULD ADDRESS THE NEED FOR GREATER EQUITY IN THE DECISIONS IT MAKES

Submitters were asked the following questions on how Pharmac should address the need for greater equity in decision-making, particularly for Māori, Pacific, and disabled people:

> *10. How well does Pharmac reflect the principles of Te Tiriti o Waitangi?*
>
> *11. How can Pharmac achieve more equitable outcomes?*

While Pharmac has taken some positive steps, more could be done to better reflect the principles of Te Tiriti o Waitangi

Relatively few submitters provided comments relating to how Pharmac reflects the principles of Te Tiriti o Waitangi. Most submitters who answered this question, particularly individual submitters, commented that they either did not know how Pharmac reflects the principles, or felt that they did not have enough expertise to comment on this matter.

A few submitters, most of whom were clinicians, considered that Pharmac was aware of the need to better reflect the principles and had taken some positive steps towards achieving this, pointing to examples such as the Māori Responsiveness Strategy, *Te Rautaki o te Whaioranga*.

> *I believe they are conscious of their need to better reflect the principles of Te Tiriti o Waitangi, and are starting to make changes to achieve this (Clinician)*[63]

Conversely, some submitters – including individuals, consumer groups, and industry submitters – indicated that Pharmac does not reflect the principles well or at all. These submitters noted that Pharmac's poor reflection of the principles was demonstrated by the following:

- a lack of funding for medicines and devices for diseases and conditions which disproportionally affect Māori
- a lack of consideration of Māori health outcomes throughout assessment and decision-making
- a lack of Māori representation in Pharmac leadership and committees
- a lack of partnership and engagement with Māori consumers throughout the decision-making process.

> *Not well - certainly Maori do not appear to be treated as a priority by PHARMAC, let alone aligned in partnership. (Patient or consumer group)*[64]
>
> *Embodiment of Te Tiriti means the facilitation of tino rangatiratanga and mana motuhake for Māori, which is largely incompatible with how PHARMAC operates in the current environment, due to its place as the sole*

[63] C164, Clinician, Email
[64] KVQ6-S, Consumer group, Online, Permission given

> *decision-maker and negotiator for medicines and related products in Aotearoa New Zealand. (Clinician group)* [65]

A few submitters provided the following suggestions for how to better reflect the principles of Te Tiriti:

- prioritise medicines and devices that have the greatest positive impact for Māori
- utilise a te ao Māori perspective throughout funding decisions
- monitor and report on outcomes relating to Pharmac's funding decisions
- employ more Māori in Pharmac and have greater representation on committees and in leadership and governance roles
- clarify how Pharmac intends to uphold the principle of partnership
- clarify how Pharmac intends to guarantee tino rangatiratanga and what this looks like in the context of their work.

> *Any changes made to PHARMAC's objectives or processes to support more equitable outcomes for Maori should be co-designed in partnership with Maori. (Industry)*[66]

A focus on engaging with marginalised communities and considering health outcomes could help Pharmac to achieve more equitable outcomes

Of those who answered the question on how Pharmac could achieve more equitable outcomes, a few individual submitters stated that all New Zealanders should receive equal and fair access to treatment, regardless of disability, ethnicity, religion, socioeconomic status, gender, or background.

Other submitters provided suggestions for how Pharmac could achieve more equitable health outcomes. These responses have been summarised below.

Improve consultation and engagement with priority populations to better understand and address their needs

Some submitters, across all submitter types, suggested that in order to improve equitable outcomes, Pharmac must improve its consultation and engagement with consumers, advocacy groups, Māori and Pacific communities, disabled people, and those with rare diseases or conditions. Submitters explained that engaging with priority populations and informing decisions based on lived experience will allow the voices of those with the highest level of health inequities to be heard. A few of these submitters suggested that priority populations should be well-represented amongst the decision-makers to promote engagement.

> *To achieve more equitable health outcomes, PHARMAC must understand the health needs of Māori, Pacific, disabled people, rural and other vulnerable groups and incorporate informed advice into its decision-making processes. (Clinician group)*[67]

---

[65] C168 RACP, Clinician group, Email
[66] C119 USL Medical, Industry, Email
[67] C169 ASMS, Clinician group, Email

A few other submitters discussed the need for more engagement with Māori and Pacific populations specifically, and suggested that Pharmac should co-design any new initiatives with these communities to ensure greater equity.

Consider equitable outcomes throughout decision-making

A few submitters discussed the need for Pharmac to understand the impact that its decision-making has on marginalised groups' ability to access medicines and devices, and how this contributes to inequitable health outcomes. A few submitters, particularly consumer groups, suggested that Pharmac focus on funding medicines and devices that treat diseases or conditions that disproportionally affect Māori and Pacific peoples. Others suggested that Pharmac sets clear equity targets and monitors how funding decisions have contributed to more equitable health outcomes.

> *Equity should be one of the primary considerations for all funding applications, applications should have to outline what benefits the medication or device has to priority population, and what engagement and partnership they have undertaken in their process (if any). Applications that have a higher equity focus and bigger potential for gains in achieving health equity should be prioritised. This may also result in some positive research and engagement of our priority populations. (Clinician group)*[68]

A few other submitters made the following recommendations for how Pharmac could achieve more equitable outcomes:

- take an end-user approach to funding medicine and devices for disabled people, such as considering the need for bespoke services and medical equipment which reflects the individualised need of each disabled person
- reduce the barriers to access faced by marginalised populations, such as travel and cost, by funding alternate medicines that can be taken orally or administered in an out-patient setting
- clarify how Pharmac intends to address equity issues for under-served populations in the community.

[68] C214 Pegasus, Clinician group, Email

PART 5: ADDITIONAL FEEDBACK

Finally, submitters were asked to provide any remaining comments that they thought the Review Panel should consider.

A few submitters shared positive comments that the review was taking place, that the Review Panel was seeking the views of New Zealanders, and that the review provides a good opportunity for Pharmac to evolve and better serve New Zealanders.

> *I acknowledge PHARMAC's willingness to consult with the public on this occasion as it looks, hopefully, to provide new options for its future development to government (Patient or consumer group).*[69]

However, two consumer groups raised concerns with the timeframe for the review, stating that the short timeframe has meant that some groups and organisations have been unable to meaningfully engage with the review panel face-to-face.

Many of those who answered this question reiterated their views about what was not working well currently, and what they suggested Pharmac should do moving forward.

Throughout their responses, many submitters – particularly individuals and consumer groups – shared stories of their frustration and disappointment that they or others have faced when Pharmac has not funded certain medicines or devices. Submitters mentioned the following diseases and conditions when sharing stories about a lack of funding for certain medicines or devices:

- Crohn's disease
- Thyroid diseases
- Pompe disease
- Diabetes (particularly type 1)
- Cancer
- Epilepsy
- Rheumatic diseases / Arthritis
- Cystic Fibrosis
- Fabry disease
- Short Bowel Syndrome
- HIV
- Spinal Muscular Atrophy
- GMB
- Classical Ehlers-Danlos Syndrome.

[69] C211 FARA NZ (6), Consumer group, Email

APPENDIX 1: LIST OF SUBMITTERS

Submitter ID	Submitter type	Submission method
ANON-JXX7-KU21-M	Individual	Online submission
ANON-JXX7-KU22-N	Individual	Online submission
ANON-JXX7-KU23-P	Individual	Online submission
ANON-JXX7-KU24-Q	Industry	Online submission
ANON-JXX7-KU25-R	Clinician	Online submission
ANON-JXX7-KU27-T	Individual	Online submission
ANON-JXX7-KU2A-4	Clinician	Online submission
ANON-JXX7-KU2B-5	Clinician	Online submission
ANON-JXX7-KU2D-7	Individual	Online submission
ANON-JXX7-KU2E-8	Individual	Online submission
ANON-JXX7-KU2F-9	Individual	Online submission
ANON-JXX7-KU2K-E Body Positive	Patient or consumer group	Online submission
ANON-JXX7-KU2M-G	Individual	Online submission
ANON-JXX7-KU2N-H	Clinician	Online submission
ANON-JXX7-KU2P-K	Individual	Online submission
ANON-JXX7-KU2Q-M	Individual	Online submission
ANON-JXX7-KU2R-N	Clinician	Online submission
ANON-JXX7-KU2S-P	Individual	Online submission
ANON-JXX7-KU2T-Q	Individual	Online submission
ANON-JXX7-KU2V-S	Individual	Online submission
ANON-JXX7-KU2W-T	Individual	Online submission
ANON-JXX7-KU2Y-V	Individual	Online submission
ANON-JXX7-KUS5-S	Individual	Online submission
ANON-JXX7-KUS6-T	Individual	Online submission
ANON-JXX7-KUS7-U	Individual	Online submission
ANON-JXX7-KUS9-W	Individual	Online submission
ANON-JXX7-KUSB-6	Individual	Online submission
ANON-JXX7-KUSC-7	Individual	Online submission
ANON-JXX7-KUSF-A	Individual	Online submission
ANON-JXX7-KUSH-C	Individual	Online submission
ANON-JXX7-KUSM-H	Individual	Online submission
ANON-JXX7-KUSN-J	Individual	Online submission
ANON-JXX7-KUSS-Q	Individual	Online submission
ANON-JXX7-KUSW-U	Individual	Online submission
ANON-JXX7-KUY3-W	Individual	Online submission
ANON-JXX7-KUYE-F	Individual	Online submission
ANON-JXX7-KUYG-H	Individual	Online submission

Submitter ID	Submitter type	Submission method
ANON-JXX7-KUYK-N	Individual	Online submission
ANON-JXX7-KUYU-Y	Clinician	Online submission
ANON-JXX7-KUYX-2	Individual	Online submission
ANON-JXX7-KUYY-3	Individual	Online submission
ANON-JXX7-KV61-S	Clinician	Online submission
ANON-JXX7-KV64-V	Individual	Online submission
ANON-JXX7-KV65-W	Individual	Online submission
ANON-JXX7-KV68-Z	Individual	Online submission
ANON-JXX7-KV6B-A	Clinician	Online submission
ANON-JXX7-KV6C-B	Individual	Online submission
ANON-JXX7-KV6F-E	Individual	Online submission
ANON-JXX7-KV6J-J	Individual	Online submission
ANON-JXX7-KV6M-N	Individual	Online submission
ANON-JXX7-KV6N-P	Individual	Online submission
ANON-JXX7-KV6P-R	Individual	Online submission
ANON-JXX7-KV6R-T	Individual	Online submission
ANON-JXX7-KV6S-U	Individual	Online submission
ANON-JXX7-KV6U-W	Individual	Online submission
ANON-JXX7-KV6V-X	Individual	Online submission
ANON-JXX7-KV6W-Y	Individual	Online submission
ANON-JXX7-KV9H-K	Individual	Online submission
ANON-JXX7-KVC1-6	Individual	Online submission
ANON-JXX7-KVC2-7	Individual	Online submission
ANON-JXX7-KVC3-8 NZ Pompe Society	Patient or consumer group	Online submission
ANON-JXX7-KVC4-9	Individual	Online submission
ANON-JXX7-KVC5-A	Individual	Online submission
ANON-JXX7-KVC8-D	Individual	Online submission
ANON-JXX7-KVC9-E	Individual	Online submission
ANON-JXX7-KVCA-P	Clinician	Online submission
ANON-JXX7-KVCC-R	Clinician	Online submission
ANON-JXX7-KVCD-S	Individual	Online submission
ANON-JXX7-KVCG-V	Individual	Online submission
ANON-JXX7-KVCH-W	Clinician	Online submission
ANON-JXX7-KVCJ-Y	Individual	Online submission
ANON-JXX7-KVCK-Z	Individual	Online submission
ANON-JXX7-KVCM-2	Individual	Online submission
ANON-JXX7-KVCQ-6	Individual	Online submission
ANON-JXX7-KVCR-7	Individual	Online submission

Submitter ID	Submitter type	Submission method
ANON-JXX7-KVCT-9	Individual	Online submission
ANON-JXX7-KVCX-D	Individual	Online submission
ANON-JXX7-KVCY-E NZ JIA/AOSD Group	Patient or consumer group	Online submission
ANON-JXX7-KVCZ-F	Individual	Online submission
ANON-JXX7-KVQ1-M	Individual	Online submission
ANON-JXX7-KVQ2-N	Industry	Online submission
ANON-JXX7-KVQ3-P	Individual	Online submission
ANON-JXX7-KVQ4-Q	Individual	Online submission
ANON-JXX7-KVQ6-S Allergy New Zealand	Patient or consumer group	Online submission
ANON-JXX7-KVQ8-U	Clinician	Online submission
ANON-JXX7-KVQ9-V	Individual	Online submission
ANON-JXX7-KVQA-4	Clinician	Online submission
ANON-JXX7-KVQE-8	Clinician	Online submission
ANON-JXX7-KVQG-A	Individual	Online submission
ANON-JXX7-KVQJ-D	Clinician	Online submission
ANON-JXX7-KVQK-E	Individual	Online submission
ANON-JXX7-KVQM-G	Clinician	Online submission
ANON-JXX7-KVQN-H	Individual	Online submission
ANON-JXX7-KVQS-P	Individual	Online submission
ANON-JXX7-KVQW-T Rare Disorders NZ	Patient or consumer group	Online submission
ANON-JXX7-KVQX-U	Individual	Online submission
ANON-JXX7-KVT3-S	Clinician	Online submission
ANON-JXX7-KVT5-U	Individual	Online submission
ANON-JXX7-KVTA-7	Individual	Online submission
ANON-JXX7-KVTH-E	Individual	Online submission
ANON-JXX7-KVTJ-G	Individual	Online submission
ANON-JXX7-KVTY-Y	Individual	Online submission
ANON-JXX7-KVTZ-Z Cure Our Ovarian Cancer	Patient or consumer group	Online submission
C002	Individual	Email submission
C003	Individual	Email submission
C004 New Zealand Amyloidosis Patients Association	Patient or consumer group	Email submission
C005 Head and Neck Cancer Support	Patient or consumer group	Email submission
C006	Academic	Email submission
C019 Lynch Syndrome NZ (LSNZ)	Patient or consumer group	Email submission
C020 New Zealand Rheumatology Association	Patient or consumer group	Email submission
C021	Clinician	Email submission
C022 Bristol Myers Squibb (BMS)	Industry	Email submission

Submitter ID	Submitter type	Submission method
C023 Gastrointestinal cancer special interest group	Patient or consumer group	Email submission
C024 New Zealand Society of Oncology (NZSO)	Clinician	Email submission
C025 New Zealand Pompe Network	Patient or consumer group	Email submission
C026 Friedreich Ataxia Research Association of NZ (FARA NZ) (1)	Patient or consumer group	Email submission
C027 Thyroid Association NZ (TANZ)	Patient or consumer group	Email submission
C028 FARA NZ (2)	Patient or consumer group	Email submission
C029 FARA NZ (3)	Patient or consumer group	Email submission
C030 FARA NZ (4)	Patient or consumer group	Email submission
C031 Breast Cancer Aotearoa Coalition	Patient or consumer group	Email submission
C032	Individual	Email submission
C065	Clinician	Email submission
C066	Individual	Email submission
C067	Individual	Email submission
C068	Individual	Email submission
C069	Individual	Email submission
C070 FARA NZ (5)	Patient or consumer group	Email submission
C071	Individual	Email submission
C109 AbbVie	Industry	Email submission
C110 Roche	Industry	Email submission
C111 Alexion	Industry	Email submission
C112 Janssen	Industry	Email submission
C113 Biogen	Industry	Email submission
C114 Arthrex New Zealand	Industry	Email submission
C115 Complete Healthcare Solutions	Industry	Email submission
C116 Gillies McIndoe Research Institute (GMRI)	Clinician	Email submission
C117 GlaxoSmithKline New Zealand (GSK)	Industry	Email submission
C118 Pharmacy Guild of NZ	Industry	Email submission
C119 Universal Specialties Limited (USL) Medical	Industry	Email submission
C120 Melanoma New Zealand	Patient or consumer group	Email submission
C121 Crohn's Colitis NZ (CCNZ)	Patient or consumer group	Email submission
C122 Prada-Willi Syndrome Association (PWSA) NZ	Patient or consumer group	Email submission
C123 Tuberous Sclerosis Complex	Patient or consumer group	Email submission
C124 The FONO	Patient or consumer group	Email submission
C125	Academic	Email submission
C126 Medical Oncology Working Group (MOWG)	Clinician	Email submission

Submitter ID	Submitter type	Submission method
C127 Australia Leukaemia and Lymphoma Group (ALLG)	Patient or consumer group	Email submission
C128 Stryker	Industry	Email submission
C129 Friedreich Ataxia Research Association (FARA) of NZ	Patient or consumer group	Email submission
C130 Unicorn Foundation	Patient or consumer group	Email submission
C131 New Zealand Nurses Organisation (NZNO)	Clinician	Email submission
C132 Foetal Anti-Convulsant Syndrome NZ (FACSNZ)	Patient or consumer group	Email submission
C133 Cancer Society	Patient or consumer group	Email submission
C134 Cystic Fibrosis New Zealand (CFNZ)	Patient or consumer group	Email submission
C135 Breast Cancer Cure	Patient or consumer group	Email submission
C136 New Zealand Society of Anaesthetists (NZSA)	Clinician	Email submission
C137 New Zealand Medical Association (NZMA)	Clinician	Email submission
C138 New Zealand Health Research (NZHR)	Clinician	Email submission
C139 New Zealand Aids Foundation	Patient or consumer group	Email submission
C140 NGO Council	Patient or consumer group	Email submission
C141 Heart Foundation	Patient or consumer group	Email submission
C142 Chronic Lymphocytic Leukaemia Advocates NZ (CLLANZ)	Patient or consumer group	Email submission
C143 Breast Cancer Foundation	Patient or consumer group	Email submission
C144 Meck Sharp Dohme	Industry	Email submission
C145 Sanofi	Industry	Email submission
C146 AstraZeneca	Industry	Email submission
C147 Takeda NZ	Industry	Email submission
C148 Assistive Technology Suppliers (ATS) NZ	Industry	Email submission
C150 Vifor Pharma	Industry	Email submission
C151 Seqirus	Industry	Email submission
C152 Gut Cancer Foundation	Patient or consumer group	Email submission
C153 Pfizer NZ	Industry	Email submission
C154 Medical Technology Association NZ (MTANZ)	Industry	Email submission
C155 Multiple Sclerosis New Zealand (MSNZ)	Patient or consumer group	Email submission
C156 Medicines New Zealand	Industry	Email submission
C157 InterMed	Industry	Email submission
C158	Clinician	Email submission
C159	Clinician	Email submission
C160	Clinician	Email submission
C161	Clinician	Email submission
C162	Clinician	Email submission

Submitter ID	Submitter type	Submission method
C163	Clinician	Email submission
C164	Clinician	Email submission
C165	Clinician	Email submission
C166 Allied Medical	Industry	Email submission
C167	Clinician	Email submission
C168 Royal Australasian College of Physicians (RACP)	Clinician	Email submission
C169 Associate of Salaried Medical Specialists (ASMS)	Clinician	Email submission
C170	Clinician	Email submission
C171 Auckland Lung Medical Oncology Team	Clinician	Email submission
C172 ADHB Medication Safety	Clinician	Email submission
C173 Royal Australasian College of Surgeons	Clinician	Email submission
C174 Lung Oncology Special Interest Group (LOSIG)	Patient or consumer group	Email submission
C175	Individual	Email submission
C176 Spinal Muscular Atrophy	Patient or consumer group	Email submission
C177 Cancer Society NZ	Patient or consumer group	Email submission
C178 Royal NZ College of General Practitioners (RNZCGP)	Clinician	Email submission
C179 Chief Human Rights Commissioner	Patient or consumer group	Email submission
C180 MEDTRONIC	Industry	Email submission
C201	Clinician	Email submission
C202 Urata	Clinician group	Email submission
C203 Children's Commissioner	Patient or consumer group	Email submission
C204 Patient Voice Aotearoa (1)	Patient or consumer group	Email submission
C205 Patient Voice Aotearoa (2)	Patient or consumer group	Email submission
C206 Patient Voice Aotearoa (3)	Patient or consumer group	Email submission
C207 Patient Voice Aotearoa (4)	Patient or consumer group	Email submission
C208 Epilepsy NZ	Patient or consumer group	Email submission
C210 Boehringer Ingelheim	Industry	Email submission
C211 FARA NZ (6)	Patient or consumer group	Email submission
C212 Arthritis NZ	Patient or consumer group	Email submission
C213 Leukaemia & Blood Cancer New Zealand (LBCNZ)	Patient or consumer group	Email submission
C214 Pegasus Health	Clinician	Email submission