

PHARMAC CONSUMER ENGAGEMENT WORKSHOP REPORT

FEBRUARY 2025

1. EXECUTIVE SUMMARY

This report summarises outputs from the November Pharmac Consumer Engagement Workshops, held over two days in November 2024. The workshops are intended as a first step towards re-setting Pharmac's relationship with key consumer representatives *"...by hearing and working through what they believe are Pharmac's issues and opportunities from a consumer experience perspective."*

1.1 WORKSHOP ONE

The first workshop was devoted to presentations from the 30 workshop participants. The presentations and personal experiences tabled during Workshop One were compelling, and suggest that re-setting the relationship between Pharmac and consumer advocates is long overdue.

The starting point

In many participants' eyes, there is a gulf between Pharmac management and the consumer/patient representative community as what they see as the starting point for re-setting the relationship:

- Consumer/patient representatives want to start with a blank page. Nothing should be off the table, including funding levels and possible legislative change.
- There is concern that Pharmac will take an *"...it aint broke"* approach to the reset, seeking to focus on limited process improvements.

Current engagement between Pharmac and Consumer/patient representatives

Because there is no existing framework for engagement, the way Pharmac currently engages with consumer/patient representatives is regarded as uneven, unequal and inconsistent. Pharmac's organisational culture is also a problem, seen as slow to respond, lacking respect for consumer/patient representatives, and highly defensive when called to account.

Consumer/patient views on process

Pharmac's Health Treatment Assessment (HTA) processes are seen by participants as slow and cumbersome, and out of step with international best practice. There are few points in the current process where consumer/patient organisations can play a part.

There is general agreement that Pharmac does a poor job of explaining how the current HTA process works, and has no interest in process improvements of any substance. Pharmac's approach to communications often leaves consumer/patient organisations unprepared to respond to unannounced press releases and changes in supply.

Synthesis

These and other factors have led many consumer/patient representatives to question whether Pharmac has the internal will to change its way of working. There is currently a *"...credibility and trust"* gap, not helped by the sector not being updated about how and when recommendations from the 2022 Chetwin Review and 2024 *Valuing Life* Summit are being implemented.

1.2 WORKSHOP TWO

1.2.1 Questions and Answers

The second workshop began with a Q&A session. Hon Paula Bennett discussed wider issues of funding and Pharmac's legislative remit. This was followed by a session with Pharmac management to discuss Pharmac's formal response to questions posed by participants at the end of Workshop One.

Discussion centred on:

- How equity issues could be elevated and better expressed in the assessment process?
- How consumer/patient expertise could be better harnessed?
- The financial and personal cost of participating in the HTA process?
- The impact of Pharmac managers' actions on individual participants.
- The impact of poor decisions on people (including some workshop participants) with lived-experience.

The session ended with no real movement on any of the issues discussed. The workshop mood was that nothing new was learned from Pharmac's formal responses, and that management had lost an opportunity to be more open / less defensive when dealing with the consumer/patient representatives present.

1.2.2 Focus Groups

The balance of the day was devoted to small group discussions focusing on four areas for improvement agreed-on after Workshop One:

- **Better decision-making processes:** that consider wider societal impact, separate cost from clinical benefit, and have the right specialist advice.
- **Faster and more efficient decision-making processes:** that address issues raised at Workshop I including (but not limited to) transparency, timeliness and learning from best practice.
- **Meaningful and respectful engagement:** that strengthens the consumer/patient voice across the whole journey.
- **Effective and transparent communications:** Improving the tone, timeliness and impact of communications.

The starting point

There was universal agreement amongst workshop participants that Pharmac's Health Technology Assessment (HTA) processes are flawed, and that focusing on a few operational elements will not deliver the result anticipated by the 2022 Chetwin Review or the 2024 *Valuing Life* Summit.

A more comprehensive approach is required, that will deliver an HTA process that is both patient-centred and outcomes-based. "*Transform don't tinker*" is a useful catchphrase to summarise the workshop mood.

As a result, many of the action points put forward by focus groups focus on systemic issues which may be regarded as outside of the original intent of these workshops. That was the choice of workshop participants.

The baseline

Participants recognised that the Board is committed to driving change in Pharmac, and building a better relationship with consumer/patient representatives. But there is a lack of confidence that substantive change will emerge if it is driven solely from within Pharmac, given the prevailing view that Pharmac does not trust or respect the consumer/patient representative community.

What is needed is a partnership-based approach that reflects where Pharmac wants to go rather than how it operates today.

As a first step, many participants favour an independent consumer/patient representative reference group, endorsed by the Board and comprising members selected by the consumer/patient representative community themselves. The role of the working group could include:

- Working with Pharmac management to further develop and prioritise options for improvement identified in this workshop.
- Monitoring the implementation of stakeholder engagement recommendations from earlier reviews.
- Providing a channel for discussing matters of immediate concern.
- Acting as a voice for wider reform, including overhauling the HTA.

Specific areas for improvement

Discussion within focus groups canvassed a wide range of areas for improvement, some of which could be followed through in the short term, while others would need to be considered as part of a wider reform programme.

Unsurprisingly, many of the areas canvassed were also raised at the 2024 *Valuing Life* Summit as part in the discussion and recommendations from its *Better Stakeholder Engagement in Decision-making Processes* workshop.

1.3 CONCLUSION AND RECOMMENDATIONS

1.3.1 Concluding Comment

In hindsight, the main objective of the Pharmac Consumer Engagement Workshops “...to reset relationships between Pharmac and key consumer/patient representatives...” was too lofty and one-sided to realistically achieve over two days.

At least two more days would have been needed to bring the participants together to sieve through the multiplicity of action points tabled during the focus groups. This does not mean however, that the workshops have not advanced the reset process.

What have the workshops achieved?

The workshops have brought together the views of the consumer/patient community as a collective voice – perhaps for the first time in recent years outside of the 2022 review and 2024 *Valuing Life* Summit.

They enabled us to hear and learn from compelling stories about trauma, separation and loss attributable to Pharmac’s way of working.

The workshops also highlighted the point that positive future engagement is highly contingent on consumer/patient representatives feeling that prior contributions - including to the 2022 review and 2024 *Valuing Life* Summit - have been valued and acted upon.

What the workshops didn't do

What the workshops didn't do was to come up with a list of prescribed actions that would result in an immediate reset of Pharmac's relationship with consumer/patient organisations. Nor did interactions with Pharmac management suggest that trust and respect issues have been allayed.

That is an incremental process that will require time, tolerance and goodwill on both sides of the table.

Where to next?

There is a clear expectation that consumer/patient inputs into these workshops will not be 'parked' or downgraded because of their lack of specificity. A "next step" is required to mould the discussions at this workshop (and the recommendations from the 2024 *Valuing Life* Summit) into actionable proposals that can be considered at Board (and where appropriate Ministerial) level.

In my view as Chair, the proposal for a Board-sponsored reference group to work in partnership with Pharmac management would be a useful first step, focusing on what can be done within the Board's existing remit.

Recommendations focused on wider reform are beyond my brief as Independent Chair for this workshop series, but I strongly suggest that the Board consider the big picture issues raised, and include a representative body like the reference group in future discussions about (and development of a terms of reference for) reforming Pharmac in line with international best practice.

1.3.2 Recommendations

Based on these conclusions, the recommendations in this report focus on creating a framework for continuing the reset process, and bringing Pharmac and key stakeholders together on matters of shared concern.

That the Board invite workshop participants, in association with the wider consumer/patient representative community to select a reference group to work with Pharmac's Board and management to distil the action points arising from these Customer Engagement Workshops into a programme of action.

That the reference group also engage with Pharmac's Board and management on how stakeholder engagement recommendations from the 2022 Chetwin Review and 2024 Valuing Life Summit are being considered and actioned.

That resources be allocated to cover establishment and secretariat costs for the reference group, and for at least annual meetings between Pharmac and the consumer/patient representative community.

The full recommendations are included in the final section of the report.

2. INTRODUCTION

I am pleased to submit this report on the November Pharmac Consumer Engagement Workshops, for which I acted as Independent Chair. The report:

- Summarises discussions during the workshop sessions.
- Highlights key issues raised by workshop participants.
- Includes a high level overview of areas for improvement identified by participants.
- Includes my own observations on the workshops.
- Concludes with recommendations for the next steps.

2.1 CONTEXT

As I understand it, Board has made a commitment to improving Pharmac's working relationship with consumer/patient organisations and other community stakeholders. These Consumer Engagement Workshops are intended as a first step toward re-setting the relationship.

Advancing this relationship is both a requirement of the Associate Minister of Health (ref. 2024/25 Letter of Expectations #9) and Te Tahu Hauora, the Health Quality & Safety Commission's, *Code of expectations for health entities' engagement with consumers and whanau*.

The following from the 2024/25 Letter of Expectations provides some useful additional context:

"Collaborating and partnering with stakeholders in the health sector has the potential to greatly improve the health outcomes for New Zealanders. This joint work often produces better, more effective and sustainable outcomes. The process of collaboration and partnership also can build trust.

In order to build positive relationships with stakeholders and maintain public trust [Pharmac] also must have a culture which is professional and respects stakeholders."

The workshops also follow closely behind *The Valuing Life: New Zealand Medicines Access Summit* held on 29/30 April 2024, and reported-on in the white paper released in September 2024.

The 2022 Pharmac Review chaired by Sue Chetwin review is also fresh in the minds of many participants.

2.2 THE BRIEF

The initial brief for the two workshops was prepared by Pharmac management in September 2024, and is summarised below:

Purpose:

Through the workshops, Pharmac hopes "...to 'reset' relationships with key consumer representatives by hearing and working through what they believe are Pharmac's issues and opportunities from a consumer experience perspective."

Approach:

An independently-chaired and managed series of workshops was proposed as the best way to promote robust and open discussion.

Attendees to be limited to about 25 consumer representatives, selected Pharmac staff and (by invitation only) Pharmac Board members.

Workshop Output:

A short report summarising consumer insights and recommendations from the workshops in time for the Pharmac Board's meeting in February 2025

2.3 THE WORKSHOPS

The initial brief assumed that two workshops should be sufficient to deliver a series of actionable recommendations.

Workshop I was intended to enable all participants to provide a personal (and organisational) view of Pharmac from a consumer experience perspective. The aim of the workshop was to identify common themes for detailed discussion at the second workshop.

Workshop II was intended to take a more detailed look at the areas identified in Workshop I, with the aim of (by the end of the day) producing a set of prioritised recommendations to be incorporated into the February Board report.

In hindsight, this was a somewhat optimistic timeframe (ref. further discussion below), especially in view of the wide range of unresolved issues introduced into the discussion by workshop participants.

Workshop participants

The original list of workshop participants comprised about 25 consumer/patient and advocacy organisations, selected by Pharmac staff and the Board Chair.

Prior to Workshop One, I asked the Board Chair to augment the original list to include other organisations that had contributed to the 2024 *Valuing Life* Summit and the 2022 *Chetwin Review*, especially those in high cost (to Pharmac) fields surprisingly left off the original list of attendees.

A full list of consumer/patient representative participants is attached as Appendix I.

In respect of Pharmac participants, a decision was also taken to limit management participation in the first workshop, to enable other participants to speak freely about their experiences.

The Board's presence was also increased to include Hon Paula Bennett, Dr Peter Bramley, Dr Diana Siew, Dr Margaret Wilsher and Talia Tiori Anderson-Town (Workshop Two). I would like to thank these members for taking the time to attend the workshops.

Workshop management

Notwithstanding Pharmac staff involvement in setting up the structure of the workshops, the workshop process has been independently managed since my appointment as Chair. At my insistence, a respected independent report writer was engaged to draft the final workshop report. I am grateful to Brown Bread Limited (event organisation and hosting), and Arawhetu Gray from Gray Partners Limited (report writer) for their inputs before and during the workshops.

I am also grateful to the participants themselves, who helped to re-shape the agendas for both workshops, to ensure that the patient/consumer voice was front and centre during our discussions.

The result has perhaps resulted in a wider-ranging discussion of issues and concerns than originally anticipated but, in my view, this has made the workshops a more credible catalyst for future action.

Rules of engagement

From the outset, my intention as Independent Chair has been to promote a safe but challenging environment for workshop participants, where views could be exchanged and bad experiences can be laid bare – all within a forward-looking environment where settling past scores ranks well below positive proposals for change.

This has translated into the way participant views and comments have been articulated into this report. Names of those commenting are less important than the points themselves.

A small disclaimer

While every effort has been made to capture the views and experiences of workshop participants in this report, we are not experts in medical technologies or the processes used here and internationally to manage demand and supply.

We have also been impressed (and occasionally overwhelmed) by the quantum of knowledge and personal experience brought to the table.

We have done our best to synthesise this into a report that is both relevant to the brief, and which captures the mood of the workshops. Errors and omissions can be expected, but we make no apology for the tone and tenor of this report.

3. WORKSHOP ONE

The first workshop was held on Monday 7 November 2024 in the Bell Gully conference room.

3.1 WORKSHOP OUTLINE

Following opening comments from me as Independent Chair, Hon Paula Bennett then gave assurances from the Board that the workshops were part of a genuine commitment to reset the way Pharmac engages with consumer/patient groups. The attendance of Board members reflected this.

The balance of the workshop was devoted to presentations from the 30 consumer/patient representatives present, each including:

- An outline of their organisation's role.
- Who they represented (patient/customer base).
- Key challenges from a pharma perspective.
- Personal and consumer experiences when engaging with Pharmac.

Each participant was limited to under 10 minutes, to ensure all voices were heard. The day wrapped up with a short session to agree on outputs which would feed into the second Workshop to be held in late November.

3.2 RECURRING THEMES

Although each participant's presentation was unique, and individual stories compelling, there were a number of recurring themes that could serve as a reference point for future action.

Big picture vs. silo

The presentations served to highlight the gulf between Pharmac management and the consumer/patient representative community, both in terms of their mission and purpose, and what they see as a 'starting point' for re-setting the relationship.

For their part, Consumer/patient representative organisations work beyond the boundaries of Pharmac. They are focused on the health and wellbeing of the people they support and champion.

In short, they view Pharmac as an important player in the health and wellbeing journey, which works best when it collaborates with the wider network of health, community and family support systems that enable consumers/patients to live as best they can.

The key concern for many participants is that Pharmac does not see itself as part of the bigger picture. Pharmac's mandate, assessment tools and the way it does business, do not support a patient-centered approach. Rather, the focus is on delivering pharmaceuticals within a limited mandate and (by OECD standards) an inadequate budget.

Previous reviews

Most workshop participants had also attended the 2024 *Valuing Life Medicines Access Summit*, and contributed to the 2022 Chetwin Review, both of which proposed shifting Pharmac's role and culture towards a more collaborative and whole-of-system approach. Concern was raised about whether the recommendations of these have been considered by Pharmac, are being implemented, or set aside.

The general consensus was that Pharmac had done little to communicate progress or otherwise to patient/consumer representatives and their communities, leading many participants to question whether recommendations from this workshop series would see the light of day?

Current levels of engagement with consumer/patient organisations

There was a high level of consensus that Pharmac's current level of engagement with consumer/patient representatives was uneven, unequal and inconsistent. Selected comments include:

"... engaging with Pharmac is a tale of David and Goliath. We are a very small organisation relying on volunteers. Why am I telling you this, because when you engage with us you need to know how stretched we are."

Larger organisations with close contacts inside the organisation were more likely to be heard. Smaller organisations - and those regarded as 'difficult' - were less likely to be responded to.

Organisational culture

There is a perception amongst consumer organisations that Pharmac has a 'fortress mentality' when dealing with consumer/patient representatives. Individual comments included:

- Several participants commented about how badly some management and staff interact with consumer representatives - ranging from unhelpful to disrespectful.
- Examples of Pharmac management elevating differences with individual consumers into the public domain were discussed.
- Many participants commented on a general lack of responsiveness, and a failure to acknowledge emails and other communication.

As more than one participant put it *"...They should be our greatest ally, but they are our greatest adversary at times."*

The Health Technology Assessment (HTA) process

For most workshop participants, Pharmac's core Health Technology Assessment process is seen as cumbersome, producing perverse outcomes and taking significantly longer from application to availability than counterpart organisations in comparable countries.

Some general themes:

- Why does the assessment criteria subordinate clinical benefit to costs?
- Why does Pharmac repeat safety and efficacy work already undertaken by Medsafe?
- Why does it take so much longer for Pharmac to consider new technologies compared to peer organisations?
- Why doesn't Pharmac make better use of real world evidence, and overseas evidence?
- Why have an 'Options for Investment (OFI) list if approved treatments are unlikely to be funded within a reasonable timeframe?
- On a more elemental level, why are Pharmac's application and decision-making systems so user-unfriendly?

As one participant noted *"...we understand that procurement needs a process and Pharmac must get the best deal but this is done at the cost of our patients lives. There must be a better way."*

Transparency

There is general agreement that Pharmac does a poor job of explaining how the current HTA process works. As one participant described it:

“Currently almost every element of the process is opaque and impenetrable. We don’t know how medicines are prioritised for evaluation or funding. We don’t know when vital medicines will be considered. We don’t know when approved medicines will be funded ...Patients, whānau, advocates and clinicians can remain in the dark for years.”

Pharmac’s assessment and decision-making process was a mystery to many participants, for example:

- What factors are taken into account during the assessment?
- What weightings are given to criteria other than cost?
- Why does prioritization take place behind closed doors and involve only Pharmac staff?
- Why does it take so long to communicate decisions to those most affected?

Representation

There was a strong consensus that consumer/patient representatives were sparsely represented within those parts of Pharmac’s business processes that were open to external participation.

- Does the Consumer Advisory Committee (CAC) really represent consumers/patients?
- Why is there only one consumer/patient voice on the Pharmacology and Therapeutics Advisory Committee (PTAC)?
- What is the role of specialist advisory groups, and do they have the right mix of skills to make the best choices?
- Why isn’t there a consumer voice at Board level?

Respect and empathy for the patient voice

Patient inputs into the current Health Technology Assessment (HTA) process were generally seen as unlikely to make a meaningful contribution to decisions on drug selection and funding. Participants cited examples of patients who did participate in advisory committee meetings being left in the dark about *“...what happened next?”* The story of a patient supplying a consumer voice to a Pharmac clinical advisory committee is a compelling example of this.

- *He was given a Zoom link, joined a zoom meeting, someone popped up and said “you’re on go”.*
- *He had 15 minutes to beg for his life, his brothers begged for his life. It was humiliating.*
- *They thanked him for his time and he hasn’t heard directly from the committee since.*
- *6 months later he was provided with minutes - which recorded neither his attendance or input, nor that of his brothers.*

There was a consensus that lip-service was paid to a patient-centered approach, but that lived experience was afforded little weight in the final assessment process.

“...Pharmac doesn’t seem to care if drugs improve quality of life...they are interested only in survival rates.”

Communications

The workshop consensus was that communication with consumers is often “...*too little too late*”. Points raised include:

- Announcements of new drugs that left representative groups scrambling to inform their networks “...*please... No more Friday PM surprises!*”
- A need to improve communication around the steps and timeframes for evaluating and approving new drugs.
- Ignoring the benefits of co-development of communications plans and roll-out strategies?
- A general view that Pharmac is not a good communicator.

Credibility and trust

There is a concern amongst some consumer organisations that Pharmac is seldom ‘called to account’ for its actions. Concerns raised by participants include:

- How Pharmac manages personal information provided in good faith by individuals and consumer representatives, but seldom acknowledged and sometimes not even passed onto subcommittees?
- Bewilderment around why Pharmac would return funding to Government instead of increasing funding support for new/existing medicines?
- Too quick to claim credit and too slow to acknowledge its mistakes?
- The fortress mentality referred to above has resulted in cases of open antipathy towards consumer/patient representatives, which has undermined the consumer/patient community’s trust in Pharmac and its management.

Wider considerations

During the first workshop, many participants expressed the view a re-set of the relationship between Pharmac and consumer/patient organisations should also mean working together to create a patient-centered statutory and funding climate that can deliver a better result.

Pharmac’s statutory objective:

Moving Pharmac’s statutory objective from a savings-based to outcomes-based is widely accepted by consumer/patient representatives as an essential first step.

Funding levels:

Participants cited several examples of medicines on Pharmac’s Options for Investment (OFI) list remaining unfunded for more than a decade. It was also noted New Zealand’s per-capita spend on medicines is amongst the lowest in the OECD. Greater investment is needed to enable medicines that are already part of international standards of care to be available in New Zealand.

In this vein, some participants were bewildered as to why Pharmac had returned funding to the Government in recent years, when the need was so great?

Role clarity:

In line with the Minister’s Letter of Expectations, several participants called on Pharmac to adopt international best practice by more clearly delineating the roles of value assessment and procurement.

The question of whether Pharmac should be setting its own diagnostic criteria was also raised, especially when internationally-accepted diagnostic criteria could widen access to disease modifying therapies.

3.3 WORKSHOP ONE - OUTPUTS

At the conclusion of the workshop, three work areas were identified for completion prior to Workshop Two.

1. Questions for Pharmac

The independent workshop team was asked to prepare a schedule of questions for Pharmac, referencing particular areas of concern to participants. The questions are attached as Appendix II. Pharmac management's response was provided prior to the second workshop on 28 November.

2. Update on progress implementing earlier recommendations

The Board Chair made an undertaking that Pharmac would report back prior to the next workshop, on progress against both the 2024 *Valuing Life* Summit recommendations and the 2022 Chetwin Review, and reasserted their commitment to moving forward.

3. A draft agenda for the second workshop

The initial draft agenda proposed three sessions:

1. **A Q&A session with Pharmac's Board and management** based on their responses to questions arising from the first workshop.
2. **A series of focus groups** targeting four areas for improvement:
 - **Better decision-making processes:** that consider wider societal impact, separate cost from clinical benefit, and have the right specialist advice.
 - **Faster and more efficient decision-making processes:** that address issues raised at Workshop I including (but not limited to) transparency, timeliness and learning from best practice.
 - **Meaningful and respectful engagement:** that strengthens the consumer/patient voice across the whole journey.
 - **Effective and transparent communications:** Improving the tone, timeliness and impact of communications.
3. **A wrap-up session** if time permitted, to discuss other matters, including legislation and funding impacts.

3.4 WORKSHOP ONE – CONCLUDING COMMENTS

Not all comments made during the presentations were negative, but enough was said to suggest that building a more positive working relationship between Pharmac and consumer/patient representatives will take time and commitment.

In many participants' eyes, Pharmac's failure to act on recommendations from previous reviews - or at least a failure to include the consumer/patient community in their implementation plans - reflects poorly on Pharmac as an organisation, and raises questions about whether anything will come out of this workshop series?

There is clearly a disjunct between the way Pharmac management have historically viewed engagement, and that of the consumer/patient representative community. What was made very clear is that consumer/patient representatives want to move beyond a transactional and (in many cases) adversarial relationship towards a more collaborative approach.

Many participants shared stories of lives lost, families forced apart, emotional and financial costs directly attributable to Pharmac's demand and supply management practices. There is a strong consensus that Pharmac doesn't understand or empathise with consumers and, without a major cultural shift, is unlikely to embrace a consumer/patient-centred way of working.

Participants recognise that Pharmac is a Crown agency, and subject to its own statutory and budget constraints. But this has not prevented other countries and other New Zealand Crown agencies, from adopting consumer/patient-centered business processes.

My overall observation from Workshop One is that consumer/patient representatives are looking forward to a re-set of the Pharmac consumer engagement process, along the following lines:

- *Engagement should be seen as a partnership, not a series of controlled inputs*
- *Engagement should be genuine, transparent, and respectful.*
- *Engagement should lead to meaningful change to Pharmac's culture and business processes.*
- *Engagement should not just focus on process, but also on wider reform, statutory change and growing the financial base for medicines in New Zealand.*

4. WORKSHOP TWO

The second workshop was held on 28 November at QT Hotel, Wellington.

4.1 SESSION ONE - Q&A

As agreed with participants, the first session was devoted to a Q&A session with Pharmac, and a discussion of the more substantive issues of funding adequacy and legislative change.

Legislative and Funding Change

Hon Paula Bennett led the discussion on wider issues outside the original brief. She asked workshop participants to recognise the difference between the Board's mandate, and that of the responsible Minister.

With respect to the quantum of funding available to Pharmac, and changing Pharmac's statutory base, this was clearly within the Government's sphere. The Board's role was to give effect to Government policy, by delivering against the Minister's Letter of Expectations (LOE).

As Board Chair, however, Hon Paula Bennett has frequent opportunities to discuss matters of substance with the Minister, and has agreed to raise the wider issues canvassed here with the Minister.

The Board has a greater role in determining how outcomes sought by the Minister (through the LOE) should be delivered, including:

- Providing advice to the Minister on funding levels and statutory change that could enable the outcomes sought.
- Oversight of Pharmac's strategic direction.
- As a sponsor of change to core business process to improve business performance.
- Monitoring Pharmac performance against KPI's.

In this context, the Chair has agreed to ensure that wider issues also remain part of Pharmac's internal work internal focus.

Q&A with Pharmac Management

Participants then turned their attention to Pharmac's responses to questions from Workshop One and the progress report on implementing the recommendations of the 2022 Chetwin Review – Pharmac did not provide an update on its response to the 2024 *Valuing Life* Summit.

The Pharmac panel for this session comprised:

- Sarah Fitt (Chief Executive)
- Dr Nicola Ngawati (Director of Equity and Engagement)
- Dr David Hughes (Chief Medical Officer/Director Advice & Assessments)

It would be fair to say that workshop participants were underwhelmed by Pharmac's written responses which (based on post-workshop feedback) were seen by many as adding nothing new and reinforcing the view that how Pharmac was approaching change was 'about Pharmac' rather than putting consumer/patients at the centre of change.

Much of the discussion (summarised below) reprised concerns raised in the first workshop.

Promoting equity

Pharmac staff reported that an equity impact statement has been recently incorporated into the application/decision process, and it is looking to work with other agencies to improve the way it collects and assesses equity information.

The general view was that a 'one-size fits all approach' to measuring equity impacts doesn't work. A finer grained assessment of equity impacts is required, that accounts for the different issues faced by different sectors.

For some mainstream areas, for example, the issue is how to ensure treatments reach high-need populations, in particular Māori and Pacific people, in a way that will make a substantive difference. For others, in particular rare disorders, the issue is whether treatments will be available at all:

"The victims we don't see, families ripped apart when patients have had to leave New Zealand for treatment and how it splits families, parents from children."

Making use of expertise that is home-grown

Participants expressed their concern that the groups at this workshop had the data, information and network connections to make a positive contribution to funding decisions. But world-leading research was often ignored. They are also closest to those most in need.

Moving to an outcome-based approach

Pharmac staff reported Pharmac is moving towards a more outcome-based approach, and is currently looking at outcome models that are accessible and reasonably easy to understand. The mood of the workshop was that not enough was being done in this regard and decisions were still about cost. Taking a whole-of-system approach is a Ministerial direction and should be prioritised.

The impact of unresolved issues

There was an inevitability that specific issues of conflict between some senior Pharmac staff and some workshop participants would be raised at this session. Those issues were raised, and there was general dissatisfaction about Pharmac management's response. Pharmac management had an opportunity to acknowledge and apologise for past behaviours, but this was not taken. As one participant commented at the close:

"...the very least they could have done was acknowledge the impact on the individuals involved and recognise that they had been deeply affected by Pharmac's communication, or lack thereof."

Consumer experiences

While some consumer groups stressed that their interactions with Pharmac staff have been positive, it was clearly not the same for many workshop participants. Those who had direct personal experience of the impact to them, and their families, of unfunded medicines, spoke of their pain, not only from the impact of the disease but the compounding impact of dealing with Pharmac, at times of greatest vulnerability.

"7 years ago I married the love of my life. 8 days later he died, [REDACTED] may not have made a difference, but we won't know as we didn't have it."

4.2 SESSION TWO - FOCUS GROUPS

The balance of Workshop Two was devoted to a more detailed dive into the ‘areas for improvement’ identified in Workshop One. Participants separated into four discussion groups, to enable as many participants to make a contribution within the limited time available. Four Pharmac subject matter specialists were also present to answer questions:

- Geraldine MacGibbon (Director Pharmaceuticals)
- Dr David Hughes (Director Advice and Assessments/Chief Medical Officer)
- Caroline De Luca (Manager, Expert Advisory)
- Jannel Fisher (Manager Public Affairs and Government Relations)

4.2.1 BETTER AND MORE EFFICIENT DECISION-MAKING PROCESSES

That consider wider societal impact, separate cost from clinical benefit, and have the right specialist advice.

The first two sessions focused on the Health Technology Assessment (HTA) process itself. There was considerable overlap between these sessions, so we have conflated notes from both and attempted to capture common themes in this report. Selected action points from individual discussion groups are included to illustrate the depth and tenor of discussions.

4.2.1.1 The Starting Point

There was universal agreement amongst workshop participants that Pharmac’s Health Technology Assessment (HTA) processes are flawed, and that tinkering with a few elements will not deliver the result anticipated by the 2022 Chetwin Review or the 2024 *Valuing Life* Summit.

A more transformative approach is required, that will deliver an HTA process that is both patient-centred and outcomes-based.

Many participants pointed out that the mandate for reform along these lines is already there:

- In the Minister’s 2024 *Letter of Expectations*.
- In the recommendations of the 2024 *Valuing Life* Summit.

In the eyes of many participants, any re-set of Pharmac’s relationship with consumer/patient organisations is contingent on implementing the recommendations of prior reviews, especially those within the Board’s power to act.

Participants recognise the Board is committed to driving change in Pharmac, and working more closely with consumer/patient representatives and other stakeholders. There is, however a lack of confidence that substantive change will emerge if it is driven solely from within Pharmac.

Action Points:

- Establish an independent working group, reporting to the Board and comprising consumer/patient representatives selected by the community themselves. The role of the working group could include:
 - Further developing and prioritising options for improvement identified in this workshop.
 - Advancing the recommendations from prior reviews.
 - Providing a channel for discussing matters of immediate concern.

- The working group could also work with industry, clinical and wider sector representatives, to develop a terms of reference (TOR) and timetable for comprehensive reform Pharmac’s HTA and associated decision-making processes, to move Pharmac towards a best-practice, patient-centred approach.
- We can learn a lot from other countries so, as an input into the terms of reference, the working group should be funded to commission an independent report that benchmarks key elements of New Zealand’s (Pharmac’s) HTA and decision-making processes against comparable countries.

4.2.1.2 Elements of a Better and More Efficient Process

The discussion below looks at more singular areas for improvement discussed by the focus groups, which could be actioned in their own right or made explicit in a TOR for more comprehensive reform.

Participants see benefit in both incremental and significant process improvements, but with a clear proviso that focusing only on operational matters is not enough. As noted above, “*transform not tinker*” is a useful catchphrase to summarise the workshop mood.

You will note that many of the points raised during this workshop were also tabled at the 2024 *Valuing Life* summit. Even though no update was given in the earlier session, there is a clear expectation that work has been progressing on at least some of the actions proposed at the *Valuing Life* Summit.

Be proactive

Participants see Pharmac’s current HTA process as largely reactive, triggered by an application for a medicine to be added to the Options for Investment list - generally from a pharmaceutical manufacturer or importer, although 20% of applications come from non-suppliers.

Participants favour a more dynamic approach, which ‘scans the horizon’ for new treatments, and ensures that New Zealand is responsive to shifts in international standards of care.

Action points:

- Consider and make a preliminary assessment of medical technologies before they are registered in New Zealand?
- Maintain an updated knowledge base including new research and information provided by consumer/patient representatives.
- Encourage manufacturers of successful new treatments overseas to participate in the New Zealand medicines approval process
- Take a continuous improvement approach by implementing an (annually?) updated benchmarking process that compares New Zealand’s pharmaceutical offerings with comparable countries and international standards – are we keeping up?

The application process

In some participants' eyes, an overhaul of the up-front application process is long overdue. As one participant noted "*...PharmConnect is a nightmare... we have asked Pharmac staff to improve things over many years but nothing has changed.*"

Improvements discussed within the focus groups included:

- Increasing character limits to enable a full description of the proposed change.
- Increasing space and fields in the application to properly articulate the case for funding.
- Enabling clinicians and consumers to provide more information.
- Acknowledgement of whether evidence submitted outside the portal has been considered and/or passed onto clinical committees.
- Simple administrative improvements such as enabling submitters to download a copy of their own submission - and amend or add to the application in response to new evidence and points arising from early engagement.
- Building in an ability to track the application's progress through the portal?

The suggestion by Pharmac in the earlier Q&A session that non-supplier applications take longer to process as *are "...not as comprehensive as supplier applications"* was refuted. Better engagement in pre-application stages, and a better application portal, will result in better applications.

Action points:

- Meeting submitters in advance to help ensure that applications are complete.
- Immediate improvements to *PharmConnect*, along lines suggested above.
- Practical and financial support for consumer/patient organisations to prepare applications?

Assessment criteria

There was almost total agreement amongst participants that the current assessment criteria produces perverse outcomes:

- By limiting the ability for clinicians to tailor treatments.
- By being driven by cost savings rather than clinical and total system benefits.
- By leaving high-cost and vulnerable groups unfunded unless they can secure an individual funding pathway via the NPPA process.

Whether or not the Minister's Letter of Expectations directs Pharmac to do so, workshop participants favour an HTA assessment process that provides an objective basis for measuring success against wider health system objectives, for example:

- Quality of Life (QOL).
- Total Health System Benefits.
- Equity – is this the best way to reach those most in need?

As one participant put it "*...it's a matter of when not if Pharmac will be expected to report on how it performs as part of the total health system ...why not start now?*"

Action points:

- Develop a consistent reporting template that reflects the trade-offs Pharmac makes between lowest cost and optimal benefit?

Better-informed decisions

Pharmac appears to rely heavily on published randomised clinical trials (RCT's) as its preferred evidence base during the assessment process, in preference to real world evidence (RWE), patient lived-experience, international guidelines and best practice in similar countries.

Early acceptance of information used to validate the value of medicines in other jurisdictions will result in a faster and more robust process. One example cited during the workshop is a good illustration:

Action points:

- Accept international evidence of clinical benefit.
- Consider partnering with other countries like Australia to jointly assess medicines?
- Acknowledge and reference patient voice and patient-centred inputs in decisions.
- Fast track new evidence and perspectives.

Better-informed decision-makers

There is a general view that the skill-set of PTAC and its specialist advisory committees is sub-optimal. Representatives come from a variety of backgrounds but, while they may be specialists in their fields, they become generalists when making decisions within the current HTA framework. Too often the focus is on cost rather than benefit.

Workshop participants strongly favour a better mix of skills at all levels of decision-making process, in particular:

- Pharma economists that can bring a total health systems cost-benefit approach to the table.
- Consumer/patient representatives that can represent the patient.
- Subject matter experts, including international expertise, that can ensure that decisions are measured against best practice

There was also agreement that community/patient representatives should play a greater role in the HTA process within the current Consumer Advisory Committee (CAC), PTAC and specialist advisory groups.

Action points:

- Replace and re-focus the Community Advisory Committee?
- Focus Clinical Committees on what they are good at – clinical advice.
- Increase consumer/patient representation at all decision-making points, including PTAC and its specialist advisory committees.

Better engagement – early and often

Participants had heard in the earlier Q&A session that some Pharmac staff had undertaken IAP2¹ training as a precursor to re-setting Pharmac’s engagement with consumer/patient organisations. This is seen as positive step but of little consequence unless the HTA process itself is changed to provide for multiple points of engagement.

There was a consensus that patient engagement should be approached on end-to-end basis, and occur on both an operational and a strategic level.

Action points:

- Work with Pharmac to map its HTA and other business processes and identify points of engagement, this could include:
 - At the strategic level, being part of the discussion when Pharmac is making a case for additional funding or updating the Minister’s Letter of Expectations.
 - Contributing to reviews of Pharmac’s business practices (as above).
 - On a more general level, establishing a formal basis for regular engagement with the consumer/patient community.

Timeliness

Pharmac management’s response to questions from Workshop One noted that the average time timeframe for considering new medicines is almost two years, but some applications are taking much longer. As one participant noted:

“We’ve just had a [redacted] medication funded after almost ten years...but several applications are still pending after 4-5 years...why?”

Although Pharmac management has a ‘performance metric of “...a reduction in the time taken to approve and fund new medicines”, the view of workshop participants is that not enough is being done to speed up the process. Pharmac should set itself more challenging targets, along the lines of peer organisations like the UK’s National Institute for Health and Care Excellence (three months) and Australia’s Pharmaceutical Benefits Advisory Committee (17 weeks).

As one participant noted:

“Pharmac needs to accept the imperfect. We will never have all the facts or the perfect process... we need to get on with saving lives! “

Opportunities for immediate improvement include:

- Streamline the process – focus on critical decision points, make better use of patient inputs and international precedents (discussed further below).
- Adopt predictable timelines – a due date for each step in the process.
- Speed up the transition between stages by increasing the frequency of SAC and PTAC meetings.
- Don’t wait until the next meeting to release minutes – release redacted versions as soon as possible so that stakeholders can understand and contribute to the next stage?

¹ An international standard for community engagement promoted by the International Association for Public Participation,

On a more fundamental note, many participants questioned whether medicines already approved for funding by peer overseas organisations need to go through another tortuous HTA process “...what can Pharmac add if 40 countries have already assessed and adopted a medicine?” A simple threshold along the lines of Medsafe’s ‘Rule of Two’² would make an immediate impact on the assessment backlog.

The question of resourcing was also raised. The HTA process needs to be properly resourced within Pharmac with the express aim of improving process quality and timeliness.

Action points:

- Revisit Pharmac’s HTA process to streamline the process and set timeframes around each stage.
- Develop a ‘fast track’ process for applications that are supported by real world evidence and international best practice - surely the issue then becomes when not if a new technology should be available to New Zealanders?
- Create a joint ‘stakeholder management plan’ to guide each application through the whole process to also address transparency issues below?

Transparency

More work is needed to ensure that the HTA process is available to and understood by all stakeholders:

- Each step in the process is visible to those most affected.
- Expectations of stakeholders are clearly articulated.
- Stakeholder expectations of Pharmac are also clearly articulated.
- Inputs are specified, including how they will be utilised in the assessment process.

The supply chain

In many participants’ eyes, the management of the Estradot HRT (hormone replacement) supply issue³ was a good illustration of why engagement with consumer/patient representatives should continue well beyond the HTA approval and ranking phase. Pharmac needs to adopt a “... no surprises” approach to supply:

Action points:

- Regular contact with consumer/patient organisations on supply matters.
- Flagging any issues well in advance, so that consumer/patient organisations can suggest alternatives and prepare their networks.
- Joint communications to affected consumers/patients and other stakeholders?

Removing barriers to access

Participants brought up a number of examples of where limitations of the HTA process, and the way Pharmac manages access to medical technologies, has had a direct negative effect on consumer/patient wellbeing, including:

² The ‘Rule of Two’ applies when two or more countries with similar health systems have already approved a medicine as safe for use.

³ Ref. Pharmac media release reported in RNZ news 26 November 2024

NPPA

As soon as an application for a medicine is received by Pharmac any new patients are blocked from receiving a medicine under the Named Patient Pharmaceutical Assessment (NPPA) route for that condition. As one participant noted:

“This is a particularly cruel policy that deters submitters from submitting a proposal as this will harm patients. This policy should be overturned with urgency.”

Rationing

Once a decision to fund has been made, Pharmac continues in some cases to constrain access by imposing further rules? Examples cited include:

- Restricting supply to a monthly basis rather than three-monthly, which requires patient/consumers to obtain new prescriptions?
- In the past, requiring patients to have a ‘relapse event’ before they could access treatment?
- Using one-off diagnostic criteria to limit access to a subset of those suffering from the same disease.

Alternative pathways

Under the current HTA process, some treatments will never be funded. Participants questioned whether the NPPA process was sufficient to enable those “...outside the box” to be supported by the New Zealand medicines system.

Action Points

- Audit Pharmac’s supply management practices to remove unnecessary barriers to access.
- As per the Minister’s Letter of Expectations, work with consumer/patient representatives to develop alternative pathways in line with the Rare Disorders Strategy.

Accountability

An end-to-end approach to consumer/patient engagement means that the consumer/patient voice should be there at the beginning (system design and strategic direction), at each major point along the way (evidence and decisions) and at the end of the journey (review and revision).

In this context, workshop participants would like to see more detailed measurement of Pharmac’s performance, with KPI’s for management at each step of the HTA process.

There was also consensus that Pharmac’s performance reporting was too often at the ‘tick-box’ level, with little input from other participants in the HTA process. Pharmac should celebrate success, but only when the wider medicines community agrees that the organisation is moving in the right direction.

Action points:

- Set more standards: backed by KPI’s for each step in the HTA process?
- Don’t self-assess. Decisions (or a selection thereof) to be independently audited by a multi-stakeholder panel?

4.2.2 Meaningful and Respectful Engagement/Effective and Transparent Communication

Workshop Two's final session focused on how Pharmac engages with patients and their representatives, and on Pharmac's formal communications and media approach.

Participant experiences working with Pharmac vary greatly, but there is a widely-held view that Pharmac's organisational culture is a problem when it comes to meaningful and respectful engagement. A more collaborative, no surprises approach to communications is also required.

Accessibility

In line with the accountability theme discussed above, many participants felt that Pharmac closely controls media access, especially where its performance is being called into account. Progress on implementing the 2022 Chetwin Review recommendations was cited as one example of this.

The strong consensus was that Pharmac as a public sector agency needs to be more open to scrutiny from the media, and from its consumer/patient base.

Action points:

- Take a positive not negative approach?
- Strengthen relationships with journalists covering the health sector.

Empathy

There was broad agreement amongst participants that Pharmac needs to change the tenor of its communications with consumer/patient organisations and those they represent. This can be as simple as answering emails, responding to requests in a timely manner, and recognising the time and resourcing constraints that consumer/patient organisations face.

In the words of one participant, Pharmac needs to *"... stop talking from the playbook and start talking like it cares."*

On a deeper level, it is about recognising the sacrifices that those with lived experiences make when participating in the HTA process. As one participant expressed it:

"... Please stop calling us consumers. We are people with lived experience. We are not buying vacuum cleaners here. We are asking you to understand what it's like to live with these conditions".

Action points:

- Review the tone and tenor of Pharmac communication with consumer/patient organisations. Start from a position of trust and respect.
- Develop a protocol for engaging with lived experience, to include:
 - How and when lived experience will be utilised in the HTA process
 - Minimum standards around being kept informed, and how lived experience will be reflected in decisions
 - Safety protocols?
- Review and apply the Te Tahu Hauora, Health Quality & Safety Commission's, *Code of expectations for health entities' engagement with consumers and whanau.*

A formal partnership?

Most participants see the relationship between Pharmac and their organisations as heavily one-sided. Consumer/patient organisations are regarded as inputs into an internally-managed process.

Participants recognise that Pharmac has its own accountabilities, but perhaps a more collaborative approach would help achieve these? Perhaps anchored in a formal partnership agreement along the following lines.

Action points:

- Develop a charter or memorandum of understanding between Pharmac and individual consumer/patient organisations? This could include:
 - Each partner's expectation of each other
 - Agreed points of engagement
 - An agreed, annually-updated work programme
 - Protocols for 'managing the message including joint communication on important issues (discussed further below)
 - A process for resolving differences?

Harnessing the collective voice

As independent Chair, I have been struck by the consistency of the messages from consumer/patient representatives participating in this workshop, yet there appears to be limited opportunity for consumer/patient representatives to engage with Pharmac as a collective.

Action Points:

- A similar charter/MOU between Pharmac's Board and the working group above?
- An annual or biannual forum for Pharmac and the community to discuss areas of shared concern, and reflect on how the partnership between them is progressing.
- Regular meetings with the collective of consumer/patient representatives and smaller sector-specific groups, to help clear blockages, share new information etc.

Learn from others

Reference was made by a number of participants to learning from other organisations, including IRD, and the recent Medicines Australia HTA Review. This overlaps with our earlier point about benchmarking Pharmac's HTA processes with comparable organisations, but focuses on the engagement process itself.

Action points:

- Talk to other organisations that have moved further along the engagement path?
- Look at how peer organisations have put consumer/patients front and centre in the process.
- Work with consumer/patient organisations to map out:
 - Where Pharmac sits now on the IAP2 continuum compared to exemplar organisations.
 - What can be done to move along the continuum in the short term?
 - What needs to happen to fully reset the relationship?

Better communications

Participants provided a host of examples where Pharmac communications left them blind-sided and scrambling to keep their communities up to date with latest developments. The consensus is that this is unhelpful and unnecessary.

A joined-up communications approach featuring pharma, Pharmac and consumer/patient organisations will deliver a better result, based on the principle of “...no surprises.”

Action points:

- Advance warning of upcoming issues/decisions – no more Friday PM releases?
- Agreed timetable to allow organisations to properly-prepare their networks
- Joint communications plan for communications of substance?
 - Agreement on planning tone and roles
 - Focus on operational matters and patient benefits

As a subset of a better communications approach, participants called on Pharmac to demonstrate a little more humility in their communications, and being more supportive of other players?

- Less self-promotion for Pharmac?
- Don't overstate the outcomes?
- Put lived experience front and centre of communications?

4.3 WORKSHOP TWO – CONCLUDING COMMENTS

Sadly, time pressures meant that Workshop Two came to an end before participants had time to synthesise discussions at each table into a single, prioritised list. We can however, identify some recurring themes:

- *Engage early and often.*
- *Engage at all levels – strategic, system design, delivery and review.*
- *Increase representation – by consumer/patient representatives at key stages.*
- *Partnership - create a formal basis for working more closely together.*
- *Put patients at the front and centre of Pharmac's culture and business processes.*

It is worth noting that many of the actions put forward by participants could be actioned in the short term, for example, redesigning the applications portal and adopting a more collaborative approach to media releases. Others would need to part of an overhaul of the HTA process itself, but could still be achieved within the Board's remit.

Concern was expressed after Workshop Two however, that the wide-ranging discussion might allow Pharmac to 'cherry pick' action points that could be easily accommodated within Pharmac's existing operating systems and culture.

There was a strong consensus amongst participants that this would not meet the workshop objectives.

5. CONCLUSION AND RECOMMENDATIONS

5.1 CONCLUDING COMMENT

In hindsight, the main objective of the Pharmac Consumer Engagement Workshops “...to reset relationships between Pharmac and key consumer/patient representatives...” was too lofty and one-sided to realistically achieve over two days.

At least two more days would have been needed to bring the participants together to sieve through the multiplicity of actions tabled during the focus groups. However, this doesn't mean that the workshops have not advanced the reset process.

What have the workshops achieved?

The workshops have brought together the views of the consumer/patient community as a collective voice - perhaps for the first time in recent years outside of the 2022 Chetwin Review and the 2024 *Valuing Life* Summit.

Because they had the Board's blessing, the workshops have also provided a safe space for participants to talk about Pharmac and the way it interacts with consumer/patient representatives - the good and the bad. It also enabled us to hear and learn from compelling stories about trauma, separation and loss attributable to Pharmac's way of working.

The workshops have also highlighted the point that positive future engagement is highly contingent on a culture shift within Pharmac, and consumer/patient representatives feeling that prior contributions have been valued and acted upon.

The workshops have illustrated wide support for a total reform of Pharmac's business model, and exploiting opportunities for resetting the relationship as part of the reform process.

What the workshops didn't do

What the workshops didn't do was to come up with a list of prescribed actions that would result in an immediate reset of Pharmac's relationship with consumer/patient organisations. Nor did the workshops narrow the 'trust and respect' gap between Pharmac management and many participants.

That is an incremental process that will require time, tolerance and goodwill on both sides of the table.

Where to next?

There is a clear expectation that consumer/patient inputs into these workshops will not be 'parked' or downgraded because of their lack of specificity. The question now becomes how to mould the discussions at this and previous workshops into actionable proposals able to be considered at Board (and where appropriate Ministerial) level.

In my view, the proposal for a Board-sponsored reference group to work in partnership with Pharmac management would be a useful first step, focusing on what can be done within the Board's existing remit.

Based on experience in other organisations, I suggest a reference group of up to eight people, reflecting the breadth of the consumer/patient representative community, including a convenor with widespread respect and reach within the community.

Decisions on who should be part of the reference group should be driven from within the wider consumer/patient representative community - perhaps preceded by a smaller establishment group to negotiate such things as:

- A terms of reference and budget for the group
- An initial work programme

Meeting frequency for the reference group is a matter for further discussion, but I would envisage at least quarterly meetings as a group and (say) six-monthly meetings between the Board and reference group to discuss the work programme and other matters of shared concern.

Recommendations focused on wider reform are beyond my brief as Independent Chair for this workshop series, but I strongly suggest that the Board consider the big picture issues raised, and include a representative body like the reference group in future discussions about (and development of a terms of reference for) reforming Pharmac in line with international best practice.

5.2 RECOMMENDATIONS

The following recommendations will, I hope, provide workshop participants with some assurance that their voices have been heard. I am also conscious of the need to ensure any recommendations are within the Board's power to act, and have a reasonable chance of success.

I recommend that the Board:

1. **Invite workshop participants - in association with the wider consumer-patient representative community - to select a reference group** to work with Pharmac's Board and management to reset the relationship between Pharmac and the consumer/representative community by:
 - Advancing the many issues raised during these Customer Engagement Workshops into a programme of action.
 - Monitoring the implementation of stakeholder engagement recommendations from earlier reviews.
 - Providing independent advice on matters of immediate concern.
2. **Suggest that collaboration with the reference group should focus** initially on the following areas:
 - Improving Pharmac's communications practices, including opportunities for joined-up communications.
 - Improving the HTA application process, including upgrading the applications portal.
 - Developing a 'fast track' process for medical technologies already adopted overseas and supported by real world evidence.

- Developing recommendations on how consumer/patient organisations can play a greater role in the Pharmac’s decision-making processes, to include a review of the role and composition of Pharmac’s Consumer Advisory Committee.
 - Highlighting administrative and supply issues that create needless cost and hardship for patients.
 - Collaborating on a timetable and agenda for further engagement with the consumer/patient representative community.
3. **Agree that resources are allocated** to cover the secretariat costs for the work of the reference group, and future workshops with the wider community and/or smaller sector-based groups.
4. **Agree that the reference group should play an active role in any wider reform** of Pharmac, including:
- Developing the terms of reference for any future reform.
 - Oversight of the reform process, along with representatives from the pharmaceuticals industry and wider health sector.

Dame Kerry Prendergast
Independent Workshop Chair

APPENDIX I

WORKSHOP PARTICIPANTS

PHARMAC CONSUMER ENGAGEMENT WORKSHOPS – 7 & 28 NOVEMBER 2024

CONSUMER/PATIENT REPRESENTATIVES

Name	Role	Organisation
Dr Fiona Imlach	Deputy Chair and Co-Founder	Migraine Foundation Aotearoa New Zealand
Joe Rich	CEO	Burnett Foundation Aotearoa
Lisa Burns	CEO	Cystic Fibrosis New Zealand (CFNZ)
Theresa Kiddfoley	Epilepsy Educator	Epilepsy NZ
Philip Hope	CE	Lung Cancer Foundation
Ahleen Rayner	CEO	Breast Cancer Foundation
Amanda Rose	National Manager	Multiple Sclerosis NZ
Andrea Newland	CEO	Melanoma New Zealand
Andrew Baker	CEO	Kidney Health New Zealand
Barbara Horne	Trustee/Chair	Myeloma New Zealand
Deon York	CEO	Haemophilia New Zealand
Dr Malcolm Mulholland	Chair	Patient Voice Aotearoa
Heather Verry	CEO	Diabetes NZ
Libby Burgess	Chair	Breast Cancer Aotearoa Coalition
Peter Dickens	CEO	Prostate Cancer Foundation NZ
Philip Kearney	CEO	Arthritis NZ
Rachel Smalley	Director	Smalley Ltd
Tim Edmonds	CEO	Leukaemia & Blood Cancer NZ
Suzanne Cookson	Chair	ADHD NZ
Gerard Rushton	Chairperson	Meningitis Foundation Aotearoa New Zealand
Chris Tse	Chair	Brain Tumour Support NZ
Ria Earp	Chair	Te Kahui Piringa (Maori Partnership Group)
Tanya Louise Cooke	CEO	Endometriosis New Zealand
James McGoram	Chair	Rare Disorders New Zealand
Liam Willis	Executive Officer	Gut Cancer Foundation
Hannah Booth	Director Government Relations & Advocacy	Cancer Society
Joanna Turner	Deputy CE	Asthma & Respiratory Foundation NZ
Jo Lambert	CEO	Stroke Foundation NZ
Debbie Eastwood	Head of Care & Support	Heart Foundation NZ
Sarah Cahill	Co-founder and Chair	Migraine Foundation Aotearoa New Zealand

PHARMAC BOARD MEMBERS

Hon Paula Bennett	Chair Pharmac Board
Dr Diana Siew	Pharmac Board Member
Dr Margaret Wilsher	Pharmac Board Member
Dr Peter Bramley	Deputy Chair Pharmac Board
Talia Tiori Anderson-Town	Pharmac Board Member

PHARMAC MANAGEMENT TEAM AND TECHNICAL SPECIALISTS

Sarah Fitt	CEO
Dr Nicola Ngawati	Director of Equity and Engagement
Dr David Hughes	Chief Medical Officer/Director Advice & Assessment
Geraldine MacGibbon	Director Pharmaceuticals
Caroline De Luca	Manager, Expert Advisory
Jannel Fisher	Manager, Public Affairs and Government Relations

APPENDIX II

QUESTIONS FROM WORKSHOP ONE

Pharmac Consumer Engagement – Workshop One

Thursday 7th November 2024

Workshop Purpose

Pharmac aims to ‘reset’ relationships with key consumer representatives by hearing and working through what they believe are Pharmac’s issues and opportunities from a consumer experience perspective.

Questions from Workshop One

The following request and questions from workshop one will require a timely response to the independent chair, Dame Kerry Prendergast, prior to the second workshop on Thursday 28th November:

Request

Pharmac to provide an updated response to both the Chetwin Review, 2022, and the September 17th 2024, White Paper, from the Valuing Life, NZ Medicines Access Summit.

The response should include, the status of each recommendation, resources to complete and mitigations. Displayed in a spreadsheet would be helpful.

Questions

1. What does appropriate, genuine, transparent, consultation/engagement look like, and how quickly will this reset occur?
2. How can Pharmac make faster, better decisions including the ability to re-evaluate if new credible evidence comes to light during the decision process?
3. What factors do Pharmac takes into account/consideration as it undertakes its evaluation e.g. cost-benefit, equity, societal, environmental, cultural?
4. How are inequities weighted to give safer outcomes for Māori, Pacifica, who are overrepresented in many of the poorer health outcomes?
5. What budgetary changes are needed to deliver on making NZ the equivalent of its OECD peers for medicine/devices?
6. What accountability/monitoring processes are in place to hold Pharmac to account? For example, SOI and Letter of Expectation are avenues for governance and operational focus and change, are there others?
7. Does the Pharmac Act need review, and Regulations need changing?
8. What is Pharmac’s role post-supply, and can it describe this in detail?

9. How does Pharmac change its culture?
10. How can Pharmac co-create communication plans, with key consumer representatives for announcements?
11. Is there evidence that the closed priority list works?
12. If international countries/overseas jurisdictions, experts from within existing representative consumer groups in New Zealand, already have a strong evidence base, why is that not utilised to cut down on time to approval and supply?.
13. Why cannot Pharmac tell us the expected timeline between each step?
14. As funders, why does Pharmac have remit to set criteria of how a condition is diagnosed?
15. Why does it take 3 months for Board minutes to be made available?
16. Why are there no patients on the Pharmac Board?
17. Why does Pharmac not ask for the money they need?
18. Why has Pharmac returned funding to Government?
19. How much funding, and over which financial years, has it returned funding?
20. What are the strategies of compassion in a constrained fiscal environment?