Medicines Strategy Workshop

What should a good Medicines Strategy look like and have as core elements?

It needs to be patient-centric and contain mechanisms that will ensure the system delivers health benefits for people in the real world in a timely manner.

A good Strategy should have a clear Vision. This could be that:
New Zealanders have access to the most effective medicines to treat their diseases when they need them.

The Mission for those with responsibilities could be:
To ensure timely access to best practice medicines for New Zealand patients.
This must include reducing bureaucratic barriers that delay access to innovative medicines.

Values would include:
Aspiration for best patient outcomes, transparency, honesty, collaboration and partnerships, respect, positivity, willingness to advocate and facilitate change, being proactive, taking responsibility, equity.
The equity component recognises the need for a range of options to acknowledge and meet the needs of a variety of patients. One size does not fit all.

Objectives:

1. **To transform New Zealand's medicines system into a connected, collaborative entity that enhances patient health**

We need to break down the siloes and work as a team with everyone on board – Government agencies, expert patient representatives, clinicians, Māori and industry. We all need to be at the table and we need to bring our best.

2. **To innovate through horizon scanning and early adoption of emerging technologies**

We could look ahead to plan the early integration of transformative technologies into our health system to grasp opportunities that would benefit patients and society. This should also include ethical considerations of new technologies, for example preventing genetic discrimination by insurance companies and others, ensuring equitable access and considering the potential benefits and risks of transformative technologies. Horizon scanning would also help with forward budget setting.

3. **To deliver precision health through genomics and proteomics-based diagnosis, prognosis and treatment**

We can use this information and other elements of bioinformatics and AI to ensure patients are receiving treatments that will truly work for them and avoid those that won't – we can be more efficient and effective.

4. **To implement international best practice guidelines for New Zealand patients and speed the provision of medicines**

Guidelines are global standards defined by leading experts that set out the treatment options that work best for patient sub-groups. We should use them! It shouldn't take years for Medsafe to repeat the registration evaluations already completed in other similar countries. Likewise, if NICE in the UK, the PBS in Australia and other countries are funding a medicine it shouldn't take Pharmac years to decide whether to fund it. These time-consuming processes result in delays of many years for New Zealand patients. People are dying waiting for treatments to be approved and funded. We need to better use existing wisdom to increase efficiency.

5. **To actively ensure medicines funding is benchmarked to the OECD average or higher.**

This point is absolutely fundamental. If we don't take a completely different approach to the medicines budget there can be no significant change. Why has New Zealand refused to report our expenditure on medicines to the OECD since 2007? Presumably it's because we're ashamed of the pathetic level of funding we provide. We should transparently report this data and we should absolutely benchmark what we invest to other countries. It's not even ambitious to ask that we benchmark to the average OECD spend but this is what I ask – that we simply become average. As it stands, we sit at the bottom in terms of expenditure and access. This must change.

For breast cancer this has resulted in our missing out on at least 20 medicines and multiple indications for these that are recommended in guidelines but we don't have access to. Thirteen of these medicines and many more indications are funded in Australia and more are on the way there. Why does this matter? Cancers advance and people die earlier than they should. They can't contribute to their families, workplaces or communities.

Pharmac's capped budget results in other costs to our health system and our nation. Patients being given suboptimal cancer care end up in hospital EDs – their treatment there costs; they add to the burden of overcrowding in EDs with all the flow-on impacts we've heard about – other patients not receiving timely care, going on to need more costly late care, untreated patients sent home with conditions that prevent them from returning to work. There are also direct costs associated with giving cancer patients suboptimal care – when they can no longer work, care for their children or elderly relatives, or carry out voluntary community work. All of these outcomes have costs associated with them. They don't appear in Pharmac's budget line, but they are real.

The Breast Cancer Aotearoa Coalition communicates with companies to encourage them to bring their medicines to New Zealand to register them and seek funding. We consider this is a critical issue and will become more so if companies continue to exit NZ. There's a breakthrough medicine for triple negative breast cancer that was funded in Australia in 2022. We've been trying to get the company to apply for registration and funding here for over 2 years, but they see New Zealand as a non-reimbursed market so why would they bother. This is heartbreaking for the patients we support who

desperately need this medicine. The vast majority simply can't afford to purchase it in a private clinic. There are multiple effective targeted therapies for triple negative breast cancer, but we have none of these – we just slam patients with good old toxic chemotherapy with all its nasty side-effects.

All the other objectives I listed are important, but if we fail to bring our medicines budget up to a reasonable level nothing will change for patients. We will continue to have broadening socioeconomic and ethnic inequities, GiveALittle fundraising pages, medical refugees who are driven overseas to be treated and hundreds of medicines on Pharmac's Options for Investment and Only if Cost Neutral lists.

So, **benchmarking our budget is a fundamental element of an effective Medicines Strategy**.

What adjustments, if any, would be required in NZ's existing 2007 Strategy to achieve this outcome?

The Ministers expressed some great intentions in the 2007 Strategy but these were never realised. Medicines funding decisions remain opaque and there is very little trust or evidence that the system is fair and equitable. The hoped for changes that would include all stakeholders to build a world-class system ensuring the best health outcomes for NZ simply did not happen. The strategy had some worthy principles and ideas, but it **lacked mechanisms for transformation or pathways for change.**

The Strategy aimed to provide a strategic direction to draw the agencies and stakeholders together and referred to cross-sector collaboration and stakeholder engagement. But the old bureaucracy remains in place and **the system remains fragmented and siloed**. The page 3 diagram depicting those different elements showed one-way arrows downwards from Government with the consumer at the very bottom as the recipient. There were no interactions or collaborations shown among the contributors and the pharmaceutical industry sat isolated at the side. The Strategy ended up gathering dust with no implementation, and the status quo grinds on inexorably.

Consumers have had virtually no opportunity for input on medicines, but patients and patient groups have experiential wisdom and a clear understanding of the impacts of disease on people. **Consumer input should be valued, sought out and included in policy and decision making.**

The **pharmaceutical industry needs to be welcomed as an essential partner** in a Medicines Strategy, not viewed as the enemy. There will be innovative solutions to providing early access that companies can develop, as they do when working with NICE in the UK. The new Strategy should build transparency and trust into relationships with industry.

The old Strategy described budget setting process as a necessary check and balance in a robust system. In fact, **the budget and the way it's set remain a major problem**. It's the elephant in the room that must be dealt with. As long as our medicines budget remains around a third of the OECD average, New Zealand patients will continue to have the worst access to vital medicines.

We need innovative thinking and a new model based on a foundation of aspiration, inclusiveness, interaction, transparency and communication among all the stakeholders including Government agencies, industry, expert patient representatives, Māori and clinicians.

We need clear processes and mechanisms for change.

What actions are needed to start the enhancement processes and who would be responsible for them?

We need to break down the siloes and build a collaborative team that includes the key stakeholders, Government agencies, industry, expert patient representatives and Māori.

1. Action: build an inclusive, collaborative broadly representative team or Medicines Working Group to update our medicines system

Responsibility: Ministers, everyone at this Summit and colleagues

2. Action: Agree on the Vision, the Mission, Values and Objectives of the Strategy, then identify the Actions needed to achieve the mission and assign Responsibility for each of these.

Responsibility: The Medicines Working Group consulting stakeholders

In the longer term, we need to **establish a permanent broadly inclusive Medicines Team** to ensure ongoing collaboration and interactions and to advise Ministers. This must include and continue to actively communicate and seek input from Government agencies, clinicians, patients/patient groups, Māori and industry.

The Pae Ora legislation enshrines Pharmac's 1993 requirement to spend within allocated Budget. This continues the 31-year-old culture of rationing under a fixed budget and this must change for any significant transformation to occur. The responsibility for redrafting legislation sits with the Government and the Ministers of Health and Pharmac should take the lead in setting patient outcomes as the key driver. **We need to ditch the capped budget and instead measure the health outcomes of Pharmac's decisions**.

Ministers are responsible for the level of budget allocation but do they really take responsibility for the impacts of the level of funding? And are they well advised on the level of funding needed? Absolutely not. When Ministers are asked about yet another decision not to fund they often say "that's up to Pharmac, we can't have political interference in decisions on whether a medicine is funded". But **leaving the budget at**

its current level is effectively a Ministerial decision not to fund modern medicines. We all need to educate our politicians on this and challenge them to step up and take responsibility.

3. Action: Redraft NZ's medicines legislation to focus on patient outcomes; remove the budget cap

Responsibility: Ministers, Medicines Working Group with input from colleagues and other stakeholders

Judging by comments in PTAC and CTAC minutes, it's clear that Pharmac's committees understand their role is to both evaluate and to ration medicines. Their role should instead be to assess the evidence from clinical trials along with Real World Evidence and provide recommendations based on the clinical need for the medicine, its clinical effectiveness and its impacts on patients and whānau. This won't happen when these committees operate within Pharmac's capped budget silo. Pharmac's purchasing role clearly contaminates the clinical advice. **Purchasing should be done entirely separately from clinical assessment as happens in Australia, the UK and other countries**.

4. Action: Establish a new entity to assess clinical efficacy of medicines

With some permanent positions, clinical experts should be brought in from relevant specialties to participate in evaluations, along with relevant patient groups.

Responsibility: Ministers, clinical colleges and groups, patient groups

We need not only to build horizon-scanning into our health system, but we also **need to scan for existing technologies and medicines that we haven't adopted**. We've fallen so far behind that our patients can't participate in international trials because we don't deliver the standard of care needed for the control arm. We must break this downward spiral. We used to have a National Health Committee with this role but like other entities it was disconnected from other elements of the health and medicines system.

5. Action: Establish a new entity charged with horizon scanning for medicines and related technologies

This group should be broadly representative and connect with and provide advice to the Minister and other elements of the medicines system. Strong relationships and information flow must be part of the role of this entity, the Medicines Team and all other components of the new medicines system.

Responsibility: Ministers consulting all stakeholders

6. Action: Determine what further steps are needed to give the pharmaceutical industry confidence in the strategy so they will bring their medicines to market here.

We’re currently seen as not worth the effort by many companies. Changing this is a vital aim for an effective Medicines Strategy.

Responsibility: Ministers and strategy authors with input from industry groups