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ARTICLE

Life's Not Fair, but Pharmac Is: Defending Pharmac from Its Critics

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New Zealand's Pharmaceutical Management Agency (Pharmac) was recently subject to review. The review was instigated by interest groups' lobbying. This article explores the political environment of this review through the application of interest-group theory. Four case studies are used to reveal the personal interests of politicians, disease interest groups and pharmaceutical lobbyists. I argue that the criticisms of Pharmac surrounding the review have little weight and come from private interest groups. Pharmac's apolitical model has been highly successful and needs to be preserved.

I Introduction

In 2010, a patient was admitted to Auckland City Hospital. The patient was a 15-year-old male suffering from severe Crohn's disease, an autoimmune condition that inflames the digestive system. The young man was in a serious condition, suffering from dehydration and malnourishment. He had been diagnosed with Crohn's only two months prior and had already lost 10 kg. So far, all treatments had proved ineffective, and only two remained. The first option was surgery to remove the inflamed parts of the bowel, which could lead to lifelong complications. The second was new biologic medications that could target the rogue parts of his immune system. But there was a catch; the patient was told these new treatments were costly—upwards of $100,000 per year. Fortunately, the patient was in New Zealand, and Pharmac funded these medications. Doctors administered the new drug to the patient, who made a dramatic improvement. It took some time, but the patient could live a full life, attend university, and write this very article you are reading

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now. I have shared my story to illustrate the profound positive impact that Pharmac has had on people's lives.

Despite the enormous good that Pharmac does, it regularly receives harsh criticism in the media. It is common to read stories about patients who suffer from terminal illnesses and unfortunately do not have potentially life-saving treatments funded as I did.[1] Notwithstanding the negative media attention, Pharmac has maintained an apolitical decision-making process. There have been only two instances where the New Zealand Government has capitulated to public pressure and overruled a Pharmac decision not to fund medications.[2]

In March 2021, the Labour-led Government announced that it would review Pharmac.[3] This article was written before the report was released, but has been updated to address some of the implications and consequences of the review.[4] I will focus on Pharmac's role in the New Zealand healthcare system and the political forces that surround its current review. I argue that Pharmac should retain its apolitical status and that there is a risk that this might be lost, and to an extent it might have been. Applying the public choice and interest group theory model, I argue that certain interest groups will attempt to change Pharmac for their benefit.

Four case studies are used to illustrate the political pressure that interest groups can exert on government decision-making. I argue that groups that advocate for funding expensive treatments for serious illnesses (disease interest groups), typically rare diseases, are more likely to affect government intervention successfully, as these interest groups can gather significant media attention and political momentum. In addition to these rare disease interest groups, pharmaceutical lobbyists continually criticise Pharmac's decision-making processes. I will argue that the combination of these forces creates a dangerous political environment in which to review Pharmac.

In Part II, I will review the history and role of Pharmac. In Part III, I will explore the current Pharmac review and the political pressure on the Government. In Part IV, I will explore four case studies. In Part V, I will explain public choice theory and apply to it the case studies. In Part VI, I will make recommendations about what changes to Pharmac should be avoided. In Part VII, I will briefly consider the effect of some the changes the review has brought.

II History, Objectives and Processes of Pharmac

A *History and purposes*

In the early 1990s, the Government was on a warpath of austerity measures.[5] Cost-cutting occurred in all parts of government spending, and one such area was pharmaceutical spending. In 1993, the Government created Pharmac, an agency designed to centralise the

1 1News "Pharmac 'cruel' for failing to fund drugs for rare illnesses — advocate" (14 July 2021) <www.1news.co.nz>.

2 Jacqueline Cumming, Nicholas Mays and Jacob Daubé "How New Zealand has contained expenditure on drugs" (2010) 340 BMJ 1224 at 1226.

3 Jacinda Ardern and Andrew Little "Govt announces review into PHARMAC" (press release, 2 March 2021).

4 Pharmac Review Panel *Pharmac Review: Final Report* (Ministry of Health, February 2022); and Pharmac *Final Response to Outcomes of the Pharmac Review* (14 November 2022).

5 *PHARMAC: A 25 Year History* (2018) at 5.

nation's purchasing and funding of medications.[6] Since then, it has accrued more purchasing responsibility and is now effectively a monopsony; it is the sole purchaser of medications in New Zealand.[7] Being the sole purchaser has meant that Pharmac has had an effective bargaining position with pharmaceutical companies.

Consequently, Pharmac has been highly successful in reducing costs and enlarging the range of available medications for New Zealanders. Compared to the United Kingdom and Australia, New Zealand pays 30 per cent less for the same medications.[8] In one notable example, Australia pays 13 times more than New Zealand does for the commonly prescribed atorvastatin.[9]

Pharmac has been successful in its original objective—to obtain the best price for medications. However, Pharmac's role is broader than mere cost reduction; it has at least two other important and related objectives.[10] First, it is responsible for ensuring an optimal range of medications for New Zealanders, known as the Pharmaceutical Schedule (the Schedule).[11] Pharmac has a complex set of criteria that an expert board applies to ensure that New Zealand has the "best health outcomes".[12] Secondly, Pharmac directs the Exceptional Circumstance Scheme to manage drug funding for rare diseases.[13]

B *Processes*

To ensure the "best health outcomes" and efficient spending, Pharmac has a four-factor consideration system. The four factors are:[14]

- need;
- health benefits;
- costs; and
- savings and suitability.

Each factor has three aspects: the individual; the family, whānau and society; and the health system. Pharmac employs two common tools to analyse and apply the criteria: "maximum quality-adjusted life-years" (QALYs) and cost–utility analysis.[15]

In explaining the old Pharmac criteria, members of the Pharmac board stated that they do not subscribe to any distributive approach, such as utilitarianism.[16] Utilitarianism is a broad church, a theory of normative ethics that encompasses a diverse range of views and positions with the common theme being that the morally correct action is determined by

6 Robin Gauld "Ahead of Its Time? Reflecting on New Zealand's Pharmac Following Its 20th Anniversary" (2014) 32 PharmacoEconomics 937 at 938.
7 At 938.
8 At 940.
9 At 940.
10 Cumming, Mays and Daubé, above n 2, at 1224.
11 At 1224.
12 Pae Ora (Healthy Futures) Act 2022, s 68(1)(a); and compare, New Zealand Public Health and Disability Act 2000, s 47(a) where the same test applied.
13 Cumming, Mays and Daubé, above n 2, at 1224; and Pharmac "Exceptional Circumstances Framework" (26 August 2020) <www.pharmac.govt.nz>.
14 Pharmac "Factors for Consideration" (2 September 2020) <www.pharmac.govt.nz>.
15 Scott Metcalfe, Rachel Grocott and Dilky Rasiah "Comment on 'Ahead of Its Time? Reflecting on New Zealand's Pharmac Following its 20th Anniversary': Clarification from PHARMAC: PHARMAC Takes No Particular Distributive Approach (Utilitarian or Otherwise)" (2014) 32 PharmacoEconomics 1031 at 1031.
16 At 1031.

its consequences.[17] This is distinguished from other consequentialist theories (all of which define morality in terms of the consequences of actions) in that it focuses on maximising utility or, in more simple language, maximising happiness and minimising suffering. For example, undertaking a careful cost–benefit analysis of gains that a paralogical treatment offers in terms of its utility and reduction in suffering is unmistakeably utilitarian in nature. Pharmac did in practice use utilitarian analysis, such as when evaluating the gains in QALYs in the cost–utility calculation.[18] The centrality of a utilitarian analysis in Pharmac's decision-making serves to explain the difficult funding choices that Pharmac must make.

As mentioned earlier, there is consistent criticism about the lack of funding for rare (often terminal) diseases. As unfortunate as this is, it is the expected outcome for a decision-making process based on a utilitarian model. Utilitarianism is generally indifferent to individual suffering or hardship and is instead concerned with aggregate welfare.[19] Consequently, a very unpleasant rare disease (such as cystic fibrosis) may inflict tremendous suffering on a handful of individuals. But, in the aggregate, the suffering will be significantly less than a more common but less severe condition (such as high cholesterol). The maximisation of QALYs for the best price possible will inevitably mean that those with rare diseases will have unfunded medications.

However, Pharmac is not entirely utilitarian in its decision-making. Pharmac does consider factors other than welfare, such as equity–efficiency trade-offs, to ensure that the QALYs do not accumulate in particular groups in society.[20] Moreover, Pharmac manages the Exceptional Circumstances Scheme, which directly considers individual suffering that may have been overlooked by the utilitarian analysis used to manage the Schedule.[21]

Pharmac's use of a utilitarian decision-making framework supplemented by non-utilitarian considerations shows that there will almost always be a justified and fair reason why we, unfortunately, do not always fund treatments for rare diseases. I will argue that we need to protect the apolitical decision-making role and utilitarian processes.

III Background to the Pharmac Review

The Pharmac review was announced in March 2021. The review was instigated in light of mounting criticisms of Pharmac, as the Terms of Reference explicitly state.[22] Moreover, a review of Pharmac became a platform for the National Party during the 2020 election.[23] Before exploring the current criticisms of Pharmac, it is useful to explain the parameters of the review.

A *The terms of reference*

The Terms of Reference outline two main areas of review. First, Pharmac's level of effectiveness at meeting its current objectives.[24] Secondly, whether Pharmac's objectives

17 Walter Sinnott-Armstrong "Consequentialism" (4 October 2023) Stanford Encyclopedia of Philosophy <www.plato.stanford.edu>.
18 Metcalfe, Grocott and Rasiah, above n 15, at 1031.
19 Welfare being the combined positive and negative effects.
20 Metcalfe, Grocott and Rasiah, above n 15, at 1031.
21 Pharmac "Exceptional Circumstances Framework", above n 13.
22 Pharmac Review *Terms of Reference for the PHARMAC Review Committee*.
23 Jonathan Milne "Pharmac review: Drug firms challenged to cut prices" (30 October 2020) Newsroom <www.newsroom.co.nz>.
24 Pharmac Review, above n 22, at [1].

are best suited to maximise health outcomes.[25] Several considerations are relevant to these two inquiries: Pharmac's operating model, the extent of Pharmac's responsibilities, the timeliness of funding decisions, transparency and how Pharmac compares to overseas models.[26] There are three notable exclusions for the review: any commercial arrangements, Pharmac's fixed budget and Pharmac's independence.[27]

B *Pharmac's criticisms*

Pharmac's two most common criticisms are the failure to fund particular treatments and Pharmac's slow uptake of new medications to the Schedule. These criticisms usually come from two distinct groups: interest groups for people suffering from a particular disease and their families; or pharmaceutical lobby groups.

(1) Failure to fund treatments

Funding criticisms and media coverage generally follow a similar pattern.[28] A person will be suffering from a severe illness, and will have exhausted all currently offered treatments. There will be a promising new and expensive treatment that Pharmac is not currently funding. Some recent examples include Fiona Tolich's battle for her son to receive treatment for spinal muscular atrophy;[29] and the story of Jessica Port's struggle with Crohn's disease and the petition to fund ustekinumab.[30] These stories, while tragic, are intended to evoke strong emotions and deep sympathy for those suffering. Pharmac is portrayed as an agency that is unfair and miserly in its decisions. For example, one headline read, "Pharmac 'cruel' for failing to fund drugs for rare illnesses — advocate".[31] The agency's success at reducing the cost of medications is portrayed as cruelly quantifying and disregarding human suffering.

(2) Pharmac's "outdated" schedule

According to the critics of Pharmac, New Zealand is hopelessly behind the times. Compared to other OECD countries, New Zealand is consistently slow to fund new medications. In a report funded by Medicines New Zealand (a pharmaceutical lobby group), New Zealand ranks last of 20 comparable OECD countries for funding new molecular entities (NMEs).[32] Moreover, New Zealand lags behind most comparable OECD nations in the number of modern medicines it funds.[33] In addition to published reports,

25 At [2].
26 At 2.
27 At 3.
28 See Guyon Espiner "Family says choice is life in Australia or death waiting for Pharmac" (2 August 2021) Radio New Zealand <www.rnz.co.nz>; and Jenna Lynch "Human Rights Commission grants case against Pharmac for failing to fund rare muscular disorder drug" (16 September 2020) Newshub. <www.newshub.co.nz>.
29 1News, above n 1.
30 Milne, above n 23.
31 1News, above n 1.
32 IQVIA "A Decade of Modern Medicines: An International Comparison 2011 – 2020" (November 2021) at 5.
33 At 8.

mainstream media has also picked up these criticisms.[34] For example, New Zealand has been negatively compared to Australia as being far slower to fund new medicines.[35]

C *Political forces*

The interest groups applying the most pressure on the government are disease interest groups and pharmaceutical lobbies. It is no secret that the pharmaceutical industry is opposed to Pharmac. In addition to publishing negative reports of Pharmac's performance, pharmaceutical companies have filed multiple unsuccessful legal challenges under the Commerce Act 1986 for anticompetitive practices.[36] More recently, there was pressure on the New Zealand Government during negotiations of the Trans-Pacific Partnership free trade agreement, where American pharmaceutical interests sought Pharmac's disestablishment.[37]

These groups have successfully brought about the review, and arguably influenced the reforms. Although these groups may have radically different motives, they want the same outcome—to divert public funds to their interests, particularly the funding of expensive treatments for rare diseases. An illustration of these common interests is Janssen Biotech, the pharmaceutical maker of ustekinumab, donating money to Crohn's and Colitis NZ, who raised the petition for ustekinumab.[38] This point might seem conspiratorial and fanciful. However, I will illustrate that the Government has capitulated to these types of demands before.

IV Case Studies

The first two case studies are the only examples where the Government directly overruled a Pharmac decision. The later cases are current examples of Pharmac refusing to fund. However, as will later be discussed the review and its consequences have now led to funding of these two medications.

A *Interferon beta for multiple sclerosis*

On 26 December 1999, the newly elected Labour-led government announced its decision to fund interferon beta drugs directly.[39] Interferon beta is a treatment for multiple sclerosis (MS), a debilitating neurological condition. Pharmac had reviewed the treatment twice and

34 See Graeme Jarvis "Pharmac review misses political elephant in the room" (13 March 2021) Stuff <www.stuff.co.nz>; Robbie Nicol and Finnius Teppett "The comically large catch in the Government's review into Pharmac" (3 May 2021) Stuff <www.stuff.co.nz>; Zane Small "Jacinda Ardern: Not fair to compare Pharmac with Australia's system" (5 February 2019) Newshub <www.newshub.co.nz>; Penny Tucker "Pharmac works well. Unless you're sick" (2 June 2021) Stuff <www.stuff.co.nz>; and Breast Cancer Foundation NZ "Pharmac review a chance to end agonisingly slow drug approval process" (13 October 2020) <www.breastcancerfoundation.org.nz>.

35 See Small, above n 34.

36 *Roussel UCLAF Australia Pty Ltd v Pharmaceutical Management Agency Ltd* [2001] NZAR 476 (PC); and *Researched Medicines Industry Association of NZ Inc v Pharmaceutical Management Agency Ltd* [1998] 3 NZLR 12 (CA).

37 Deborah Gleeson, Ruth Lopert and Papaarangi Reid "How the Trans Pacific Partnership Agreement could undermine PHARMAC and threaten access to affordable medicines and health equity in New Zealand" (2013) 112 Health Policy 227.

38 Milne, above n 23.

39 Annette King "Beta –Interferon" (press release, 26 December 1999).

concluded that the evidence did not reliably establish a benefit for MS patients that justified the cost.[40] The treatment was expensive, costing over $14,000 annually per patient for a total of over $5 million.[41] The decision to ignore the advice of Pharmac was based on an earlier election promise by Labour.[42] During the 1999 election, a well-organised disease interest group, the MS Society, and clinical experts convinced Labour to promise to fund the drug if elected. Most likely, the decision for Labour to support this cause was motivated by the need to win popular support during a political campaign.

B *Herceptin for breast cancer*

In 2008, the newly elected National-led Government announced it would increase the treatment period for Herceptin from nine weeks to 12 months.[43] Herceptin is a treatment for HER2, an aggressive form of breast cancer. In July 2006, Pharmac and district health boards declined to fund the 12-month sequential treatment because there was insufficient evidence to support its efficacy over the nine-week concurrent regimen.[44] Like interferon beta, a group of patients wanted Herceptin, who the media dubbed the "Herceptin Heroines".[45] The Heroines even made an unsuccessful judicial review application for Pharmac's decision.[46] During National's election campaign, they promised to fund Herceptin if elected, which they did.[47]

C *Spinraza for spinal muscular atrophy*

Spinal muscular atrophy (SMA) is a genetic condition that affects the body's ability to create muscle. Those who suffer from the condition are physically disabled and have significantly reduced life expectancy. Spinraza is a new treatment with promising results and is viewed by those who suffer from SMA as their best chance to live.[48] Pharmac had declined to fund this treatment in New Zealand.[49] The cost–utility analysis has shown the high cost of the medication cannot be justified by its clinical benefits.[50] Disease interest groups have been very critical of this decision. However, it is arguable that these criticisms were part of the reason for the current review.[51]

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40 Catherine Masters "MS patients welcome move to fund drugs" *The New Zealand Herald* (online ed, Auckland, 30 June 2000) as cited in Harry McNaughton, Nicola Kayes and Kathryn McPherson "Interferon beta, PHARMAC, and political directives: in the best interests of people with multiple sclerosis?" (2006) 119 (1232) NZMJ 96 at 98.

41 At 96.

42 King, above n 39.

43 John Key "Government honours Herceptin promise" (press release, 10 December 2008).

44 Scott Metcalfe, Jackie Evans and Ginny Priest "PHARMAC funding of 9-week concurrent trastuzumab (Herceptin) for HER2-positive early breast cancer" (2007) 120(1256) NZMJ 80 at 80 and 85.

45 New Zealand Press Association "'Herceptin Heroines' lose high court battle" *The New Zealand Herald* (online ed, Auckland, 3 April 2008).

46 *Walsh v Pharmaceutical Management Agency* [2010] NZAR 101 (HC). The plaintiffs did succeed in their judicial review application, however when sent back to Pharmac they did not change their decision.

47 Key, above n 43.

48 Espiner, above n 28.

49 Espiner, above n 28.

50 Pharmac *TAR 398 – Nusinersen for Spinal Muscular Atrophy* at 3 (obtained under Official Information Act 1982 request to Pharmac).

51 See Pharmac Review, above n 22.

D *Ustekinumab for Crohn's disease*

Crohn's disease is an inflammatory bowel disease (IBD).[52] It causes a broad range of unpleasant symptoms for sufferers that can significantly reduce their quality of life.[53] Crohn's is difficult to treat because even the best medications are not guaranteed to succeed, and most treatments have long-term side effects.[54] Consequently, for many IBD sufferers, treatment involves trialling available medications hoping that one will work.[55] Ustekinumab is a new biologic treatment that could help patients who have exhausted all available treatments.[56] Unfortunately, like other biologic treatments, it is very expensive.[57] Prior to the review and its changes, Pharmac had declined to fund it because there are other similar medications available. Like for Spinraza and SMA, there is an active disease interest group.

V Application of Public Choice Theory

A *Theoretical lens*

Public choice theory is the economic analysis of political institutions and actors. Public choice is the "application of the principles of maximizing behavior and demand and supply to institutions and behavior in the political world".[58]

In the field of public choice, there is a theory known as interest group approach.[59] It argues that political changes are driven by interest groups who seek to redistribute wealth.[60] Politics is a "market for wealth redistribution", and "participants are self-interested politicians and citizens".[61] Nearly all political decisions can be viewed as allocations of wealth. Taxation policies or even public amenities such as parks will allocate more or fewer resources to particular citizens. In these wealth transfers, politicians act as middlemen and are paid with votes, positive public support and campaign contributions.[62]

It will be efficient for a "buyer" (an interest group) to pay for government intervention where the payment to the politician is less than the benefit of the intervention.[63] For example, it will be efficient for a lobbyist to pay a $100,000 donation to a politician if there is a corresponding tax cut of $150,000. The supplier is the section of the population that has resources taken by government intervention.[64] It will be efficient for the supplier to resist government intervention where the cost of resisting is less than the proposed

52 Andrew McCombie and others "Why does Pharmac neglect inflammatory bowel disease?" (2020) 133(1527) NZMJ 111 at 111.
53 At 111.
54 At 111.
55 At 111.
56 Pharmac *TAR 372 – Ustekinumab for severe Crohn's disease* (2019) at 2 (obtained under Official Information Act 1982 request to Pharmac) [*TAR 372*].
57 At 2.
58 Robert D Tollison "Public Choice from the Perspective of Economics" in Charles K Rowley and Friedrich Schneider (eds) *The Encyclopedia of Public Choice* (Kluwer, New York, 2004) 191 at 191.
59 Peter T Leeson and Henry A Thompson "Public choice and public health" (2023) 195 Public Choice 5 at 7.
60 At 7.
61 At 7.
62 At 7.
63 At 7.
64 At 7.

intervention.[65] For example, it would be efficient for a lobby to allow a wealth transfer through a new tax to occur if the cost of paying the politician to prevent transfer is greater than the tax liability.

The benefits secured extend beyond taxation and include laws that would effectively exclude competitors from a market or secure public funding for projects. The costs of resistance include any information costs. Information costs play a significant part on both sides of the transaction because many groups may be unaware that they are subject to a beneficial or negative transfer.[66] Generally, it will be easier for smaller interest groups (for example, pharmaceutical lobby groups or a disease interest group) to form and effect a wealth transfer because the information cost will be lower.[67] Information cost varies depending on the relative information of the actors:[68]

> Several possibilities are relevant in this regard: (1) The winners [those who benefit from a wealth transfer] and losers [those who suffer from a wealth transfer] on an issue are well identified and know who each other are; (2) the winners and losers are not easily identified, either to themselves or to each other; (3) obviously, winners can be easily identified while losers cannot, and conversely.

For disease interest groups, the last possibility is most common because each sufferer of a disease, or family member of such person, can self-identify as winner and readily identify other disease suffers. The losers are society at large, who must bear the cost of a transfer either by paying increased taxes or having that money not used elsewhere. Given the size of the loser group and inherent difficulty in identifying the exact nature of their loss they have a much higher information cost. Consequently, it will be less likely that a large interest group (such as all taxpayers) will resist a wealth transfer because the organisational and informational costs are much higher. Politicians maximise their gains "by transferring wealth from combinations of citizens who resist the least to those who value transfers the most".[69]

Importantly, this market of wealth distribution may not increase the overall social welfare but reduce it by inefficiently allocating resources—for example, a cartel of cobblers who petition to manufacture government-issued shoes exclusively. The cartel pays a sizeable contribution to a political party, ensuring their re-election and securing the exclusive dealing. As a result of the arrangement, cheaper and more efficient cobblers do not produce shoes. Consequently, the overall efficiency is reduced due to an interest group securing a rent.[70]

There is a long history of interest groups seeking rents or favourable government interventions in public health policies. For example, the prohibition movement and laws in the United States demonstrate how two different interest groups, the bootleggers and Baptists, benefited from and sought the same outcome. The Baptists were motivated by

65 At 7.

66 Robert E McCormick and Robert D Tollison *Politicians, Legislation, and the Economy: An Inquiry into the Interest-Group Theory of Government* (Martinus Nijhoff, Boston, 1981) at 17.

67 At 17.

68 At 17.

69 Leeson and Thompson, above n 59, at 7.

70 The Paretian rent concept is "the excess earnings over the amount necessary to keep the factor in its present occupation": Robert H Wessel "A Note on Economic Rent" (1967) 57 American Economic Review 1221 at 1222 as cited in A Ross Shepherd "Economic Rent and the Industry Supply Curve" (1970) 37 Southern Economic Journal 209 at 209

moral and religious virtue.[71] They sought to improve the health and moral character of citizens by prohibiting alcohol. The bootleggers were financially motivated—they sought to exclude legitimate alcohol manufacturers from the market via prohibition.[72] This alliance between commercial and moralistic interests has been termed the "bootleggers and Baptists" phenomenon and has been observed in other similar contexts.[73] In many cases, it is the combination of commercial and moralistic interests that make a government intervention possible. It is necessary to have both a virtuous interest group and another financially motivated one.

B *Application*

(1) Case-studies failures and successes: pre-review

Why did the MS society and Breast Cancer Society succeed in effecting Government intervention where the Crohn's and Colitis Society and SMA Society, at least initially, failed? Arguably, the success of these two interest groups can be attributed to their ability to "pay" the politicians to make such changes. There are some notable similarities between the two success cases that are not shared with the failed cases.

First, both interventions occurred during an election campaign.[74] For the politicians who made those election promises, there was an increased demand to secure popular support. The successful lobbying groups had accrued public backing, and the politicians wanted to take advantage of this.

Secondly, in both cases, the election promises were made by opposition parties. Since these parties were not in Government, overruling a decision of Pharmac could not be viewed as a personal failing in their governance. Moreover, they would be less concerned about wealth transfer because they were not managing the treasury budget. As one key informant remarked in a study, "[y]ou hate it in Opposition and you love it when you go on the Treasury bench."[75]

In terms of interest group theory, the supplier is the general population paying taxes. Consequently, there is not a well-organised interest opposing this wealth transfer. For politicians, the concern for these general wealth transfers will be in maintaining an effective budget, such as keeping taxes lower and reducing government debt and spending. As the management of the budget rests with the incumbent Government, budgetary failures are more concerning for them than for an opposition party. Therefore, in cases where no well-organised group opposes a wealth transfer, an opposition party is more likely to promise such a transfer than an incumbent Government.

Thirdly, the Herceptin Heroines were well-funded because they had sufficient resources to mount a judicial review application in the Courts.[76] Being well-funded enables an interest group to market its message more effectively.

Fourthly, it was important that the successful examples were serious diseases and were even terminal. The severity of a disease will correlate to the amount of public support

71 Leeson and Thompson, above n 59, at 9.
72 At 11.
73 At 9.
74 King, above n 39; and Key, above n 43.
75 Rajan Ragupathy and others "Key Informants' Perceptions of How Pharmac Operates in New Zealand" (2012) 28 Intl J of Technology Assessment in Health Care 367 at 367.
76 *Walsh v Pharmaceutical Management Agency*, above n 46.

that the disease can gather.[77] Greater public support will be more enticing for a politician because it casts them in a sympathetic light.

Finally, a part of the success of these campaigns could be attributed to the "bootlegger and Baptist" phenomenon. The combination of the moral virtue of the disease interest groups and the pharmacies' financial resources makes the intervention possible. It may have been that at the time pharmaceutical companies might have directly funded the "Baptists" (that is, the disease interests groups). For example, when Medicines New Zealand created a $150,000 fund for their "Election 2017 project", which promoted the creation of an interim drug fund and increased funding of emerging medicines.[78] However, direct collusion, cooperation or coordination may not always be present and the phenomenon is still applicable when these two different groups work in tandem to effect the same end.

(2) Motivations of interest groups

Interest group theory can also explain why pharmaceutical and disease interest groups seek to change Pharmac's policy or decisions. As a buyer in the market, it will be most efficient for disease interest groups to have the government pay for the medications rather than themselves. As interest theory group states, it will only be rational for the buyer to procure public funds where the cost of doing so is less than the benefit. In these cases, the cost of the medications is extremely high, so the benefit of the government purchasing the drugs is very high. In comparison, the cost of lobbying is low, and personally funding the medications is very high. This breakdown of benefits and costs explains why the lobby groups tend to advocate for very costly medications.

For pharmaceutical lobbyists, the potential profit from these medications is high. It is efficient for buyers to spend significant amounts of money lobbying to get medications added to the Schedule. Companies benefit from being on the Schedule because Pharmac is a monopsony, so they benefit from a lack of competition. They are essentially guaranteed a reasonable amount of market share.

Strangely, the motivation to criticise and change Pharmac will correlate to how successful Pharmac is in managing the Schedule. An optimised schedule will mean the fewest number of funded drugs because it is best to reduce redundancy in treatments.[79] This efficiency causes a loss for pharmaceutical companies because they do not have their entire range of treatments funded. It also causes a loss to patients who have exhausted the entire range of available medications. The cost savings that Pharmac is so good at are a wealth transfer from pharmaceutical companies and untreatable patients to New Zealand taxpayers and those who receive effective medical treatment from the Schedule.[80]

77 Linda Yamoah and others "Evaluating New Zealanders' Values for Drug Coverage Decision Making: Trade-Offs between Treatments for Rare and Common Conditions" (2021) 39 PharmacoEconomics 109 at 116.

78 Radio New Zealand "How Big Pharma operates in New Zealand" (21 August 2019) <www.rnz.co.nz>.

79 See, for example, Pharmac *TAR 372*, above n 56, at 2 and 33–34. Ustekinumab as a third line treatment was refused as it did not meet the threshold of cost-effectiveness. Pharmac noted that in assessing the medication that there would be approximately 130 patients likely to trial ustekinumab. It can be inferred that the low number is a product of the ustekinumab being a second- or third-line treatment, meaning patients are only eligible where other treatments have failed. The small pool of eligible patients necessarily means that the benefit is correspondingly small when measured in the aggregate.

80 Technically it is absence of a wealth transfer in the opposite direction.

(3) Pharmac's stability

This characterisation of the wealth transfer helps to explain the stability of Pharmac. It is remarkable that in the 28 years that Pharmac has existed (prior to the review), it has only been overruled twice. As mentioned earlier, the political gain to overrule Pharmac is weakest when a party is in Government. Politicians want to keep the broadest support possible, and Pharmac helps to do this. If the general public is the "supplier" who the pharmaceutical industry is attempting to 'buy' from, there will be significant resistance to this. Politicians will only favour the transfer of wealth where the resistance is less than the payment for the intervention. Pharmac is a mechanism to prevent the transfer and therefore protects the general public. Not only does it prevent wealth transfer, but it is also a more efficient system and thus creates more overall social welfare. Two pieces of research support this conclusion.

First, Rajan Ragupathy and others conducted a series of interviews with key players in the management and operation of Pharmac on their perspectives.[81] The interviewees included senior staff at Pharmac, medical experts, pharmaceutical industry members and, importantly, Members of Parliament.[82] The interviewees were generally positive about Pharmac. Some key points were that Pharmac was very good at reducing costs, and its political stability and independence comes from cross-party political support.[83] The views of these Members of Parliament demonstrate an awareness of the value that Pharmac brings in managing the budget, thereby protecting the interests of New Zealand's taxpayers.

Interestingly, the National-led government that introduced the 12-month treatment of Herceptin subsequently admitted that it was wrong of them to have overruled Pharmac. Health Minister the Hon Dr Jonathan Coleman conceded that overriding Pharmac turned it into a "political football".[84] This view reinforces the point that politicians understand Pharmac's value and are generally unwilling to override decisions once in power.

Secondly, Linda Yamoah and others conducted a survey gathering the views of New Zealanders on health-related values.[85] The survey asked participants to rank 13 different values, including disease-related values (rarity and severity of disease) and drug-related values (the ability of the drug to work and potential to extend life).[86] The participants were also surveyed on several trade-off scenarios, which questions how to allocate limited resources (whether to fund a drug to treat a common disease or another drug for a rare disease.)[87] The survey found that the most important values were the drug's ability to improve the quality and quantity of life, the drug's ability to work and the severity of the disease.[88] Moreover, in the trade-off scenarios, the participants favoured spending more money on treating common diseases and even preferred putting money to other uses rather than treating rare diseases.[89] The conclusion that can be drawn from these findings is that the general public's values are broadly aligned with the processes of Pharmac. Furthermore, the preference for spending money on other things rather than rare

81 Ragupathy and others, above n 75, at 368.
82 At 369.
83 At 370.
84 Sam Sachdeva "Govt wrong to overrule Pharmac on Herceptin in 2008 - Jonathan Coleman" (11 December 2015) Stuff <www.stuff.co.nz>.
85 Yamoah and others, above n 77.
86 At 111.
87 At 111.
88 At 113.
89 At 116.

diseases is direct evidence that the public is concerned with a wealth transfer to the pharmaceutical company and prefers efficient spending.

VI Defending Pharmac

Having explored the various motivations of interest groups, I will now argue that some of the criticisms of Pharmac either do not hold much weight or are an attempt by interest groups to secure favourable wealth transfers. Ultimately, I argue that the influences of these interest groups should be resisted, and we should preserve Pharmac's apolitical status.

A *Responding to the criticisms*

(1) Failure to fund particular treatments

Broadly, there are two ways for Pharmac to be unjustified in rejecting funding for treatments like Spinraza and ustekinumab. The first way would be if Pharmac had not assessed the relevant evidence against the current criteria used to evaluate medications. However, this would appear unlikely because Pharmac draws from a wealth of expert experience and knowledge when making determinations.[90] This article is not the place to challenge Pharmac's empirical findings, so it will be assumed on reasonable grounds that there has been no error.

The second way that Pharmac might be unjustified would be if its methodology was flawed. As earlier mentioned, Pharmac broadly employs a utilitarian analysis of the benefits of a particular medication. Perhaps we should not make health decisions on this basis. Instead, where treatment exists that can save an individual's life, such as with Spinraza, we might be obligated to pay for such a treatment. Fiona Tolich sums up this sentiment in her statement, "[w]hy would you pick kids with cancer to live and pick kids with SMA to die"?[91]

Arguably, disease interest groups play an important role in identifying cases where funding is needed to save lives to the public. Pharmac should be adjusted to take into consideration life-threatening health conditions and public support for treatments. Unless the budget for Pharmac is increased, which has been excluded from the review, these changes would be the only way for these treatments to be funded.

As appealing as these changes might appear to be, there are significant issues with them. There is a limited resource pool to purchase pharmaceuticals. Any purchases will come with the cost that the resource has not been used for another purchase—the opportunity cost.[92] Choosing to fund Spinraza will come with the opportunity cost that another medication that might save a life is not funded. There is always going to be a trade-off between people's lives in these decisions; that is, a wealth transfer. Consequently, as unfair and regrettable as it might appear that we as a country do not take every measure available to save the lives of those suffering from SMA, there is a justified reason for why because we spend resources elsewhere, namely to save other lives. Fundamentally, an

90 See Pharmac "Specialist advisory committees" (20 February 2024) <https://pharmac.govt.nz>.

91 Guyon Espiner "Pharmac likely to end blanket funding for kids' cancer drugs" (3 May 2021) Radio New Zealand <www.rnz.co.nz>.

92 Peter Moodie, Scott Metcalfe and Wayne McNee "Response from PHARMAC: difficult choices" (2003) 116(1170) NZMJ 1 at 1.

objection that someone will die or suffer because a medication is not funded, albeit tragic and heartbreaking, is not a good reason alone to overrule Pharmac's decision or change its criteria.

Similarly, Pharmac should not give more weight to treatments that receive public support. That would allow a wealth transfer from those with funded medications to those with unfunded medications with sufficient public support. Such a system would be a popularity contest to determine who lives and dies, which is far less fair than the current system. Therefore, Pharmac should continue to apply the current criteria and act independently when determining the funding of particular treatments.

(2) "Outdated" Pharmac schedule

The criticism that Pharmac is "outdated" stems from two issues. First is the timeliness issue. Comparatively, New Zealand is slow to adopt new medications. Secondly, New Zealand has an older and narrower range of medications compared to other developed countries.

Pharmac has responded to these concerns about its "outdated" Schedule. The answer to this criticism is that assessing New Zealand by the novelty and quantity of medications in our range of treatments is a poor metric by which to assess our health outcomes.[93] New Zealand is often slow to adopt a new medication because there is limited evidence to support its efficacy, or there is an existing range of treatments for the same condition.[94] New treatments are often very costly relative to current treatments and their efficacy.

A more relevant concern about Pharmac's "outdated" Schedule arises from a desire for static efficiency.[95] The concern is that Pharmac is attempting to maximise gains from the limited budget for the present and immediate future.[96] Consequently, Pharmac might be less efficient because it is not funding medications that would provide greater long-term benefits. However, it is possible that the underfunding of medications that might result in long term benefits is merely a product of Pharmac's limited budget. Pharmac might not be valuing current benefits greater than long-term benefits but rather with the funds able is making the best investments possible, which happens to be the short-term benefits. Hopefully, the Pharmac review will determine whether there is an inefficient preference for shorter-term benefits.

Lastly, it needs to be acknowledged that the pharmaceutical companies' criticism of Pharmac's "outdated" Schedule has a clear financial motive. Funding more and newer medications would result in higher revenue for these companies. Caution is needed when reviewing this aspect of Pharmac's processes because of the risk of a wealth transfer from the New Zealand taxpayers to the pharmaceutical companies.

93 Peter Moodie, Scott Metcalfe and Matthew Poynton "Do pharmaceutical score cards give us the answers we seek?" (2011) 124(1346) NZMJ 69 at 71.

94 At 71.

95 John Black, Nigar Hashimzade and Gareth Myles (eds) *A Dictionary of Economics* (4th ed, Oxford University Press, Oxford, 2012). See definitions of "dynamic equilibrium" and "static equilibrium". At 388, the latter is defined as "[a]n equilibrium in which the values of economic variables do not change in the absence of external forces; an example is the Walrasian market equilibrium." Static efficiency, therefore, is a focus on maximising the efficiency in the present "economic variables" rather than dynamic efficiency which considers other states of "economic variables".

96 Ragupathy and others, above n 75, at 370.

B *Possible improvements*

This article has discussed the strengths of Pharmac and defended it from its main critics. There are, however, areas of improvement, some of which the review does identify (as discussed later). One potential change to Pharmac might improve the current system and may also impact its independence and effectiveness—increased transparency.

Pharmac has often been secretive about its processes. For example, Pharmac has declined to release its cost–utility analysis and expected QALYs per million for medications.[97] This lack of transparency has caused frustration for experts who wish to analyse and perhaps show an error in Pharmac's assessment.[98] Moreover, it has been demoralising for patients not to know the full reasons why a life-saving medication has not been funded.[99] Increased transparency could resolve these issues. Experts would be able to provide more effective feedback and criticism or be more confident that Pharmac has reached a reasonable decision. For patients, this measure might provide some closure.

However, transparency could come with a steep cost and should be limited in its scope. Increased transparency has two distinct risks. First, it might impact Pharmac's ability to negotiate with pharmaceutical companies effectively. Pharmac's most closely guarded secret is its priority list, which ranks medications in order of most needed to least needed.[100] If this information were publicly available, it would undermine Pharmac's bargaining position as pharmaceutical companies would know which medications are most important and could raise their prices. Therefore, transparency might be needed to be limited to the extent that it could affect commercially sensitive information.

The second risk is that greater transparency might allow interest groups to apply more pressure to politicians. With increased transparency will come greater scrutiny of Pharmac's decisions. Scrutiny will help to ensure that Pharmac is making decisions without error. However, if some errors or decisions are contestable, then the pressure will be on politicians to correct these errors. Transparency may amount to political oversight of Pharmac decisions. If political oversight is the natural response to increased transparency, this could increase activity and successes for disease interest groups in overturning Pharmac decisions.

My recommendation is that with increased transparency, there should be an external non-political body to oversee and correct any potential errors in Pharmac's decisions or processes. Overseas research has indicated a link between politicians "earmarking" funds towards particular diseases and an increase in government spending on pharmaceuticals.[101] Introducing transparency and political intervention will arguably have the same earmarking issues in New Zealand if we do not ensure separate apolitical oversight. Any earmarks on Pharmac's funds would likely be a less efficient allocation of resources than Pharmac's rigorous processes. Therefore, to promote efficiency and prevent wealth transfers, it is crucial that Pharmac does not become a political football.

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97 Pharmac *TAR 372*, above n 56.

98 Steffan Crausaz and Scott Metcalfe "PHARMAC's response on gemcitabine and transparency" (2005) 118(1225) NZMJ 89. Important to note that the lack of transparency partially stems from the pharmaceutical companies.

99 Guyon Espiner "Guyon Espiner investigates Pharmac: The secret list" (28 May 2019) Radio New Zealand <www.rnz.co.nz>.

100 Contrast Guyon Espiner "Pharmac invites entire staff to top secret drug ranking meetings" (16 August 2021) Radio New Zealand <www.rnz.con.nz>.

101 Deepak Hegde and Bhaven Sampat "Can Private Money Buy Public Science? Disease Group Lobbying and Federal Funding for Biomedical Research" (2015) 61 Management Science 2281.

VII The Review

The Pharmac review was finalised in February 2022.[102] The review was critical of Pharmac. The prominent areas of criticism were inequitable health outcomes and poor internal systems, resulting in Pharmac inconsistently applying its own standards and processes in reaching decisions.[103] The inequities resulted in Māori, Pasifika and disabled persons having poorer access to medications.[104] These are not acceptable outcomes. Equitable results are crucial. Efficiency is an incredibly important directive of Pharmac, the greater savings that can be made mean other medications can be funded and more lives saved. However, efficiency cannot be the sole objective, and Pharmac should have been trading-off efficiency in maximising QALYs for a more equitable distribution of QALYs.[105] The author welcomes the reforms in these areas.

The final area of note from the report were the findings on the rare diseases (or rare disorders as the report refers to them).[106] The report recommended that more medications to treat rare diseases be funded, making the following remarks:[107]

> … if we do want to fund more of these medicines, consideration needs to be given to where in the general appropriation for health this money will come from. There is no easy way forward and so the suggestions we make are a pragmatic extension of what Pharmac currently does.

The report also recommended the formation of a rare disorder strategy, the creation of a rare disorders advisory committee within Pharmac and the involvement of the lived experience of patients with rare disorders in the decision-making process.[108]

Following the review, the Labour Government announced a significant $191 million boost to the Pharmac budget, an increase of approximately 20 per cent.[109] A range of further medications were funded. Notably this included Spinraza and ustekinumab.[110] The funding of these medications and overall increase to the budget can be viewed as "wins" for the pharmaceutical lobbyists and rare disease interest groups who have succeeded in obtaining favourable reforms. The life-changing, newly funded medications will have a significant positive impact for affected New Zealanders. However, these wins may have come at others' loss. It may be that the most efficient QALYs were obtained when these medications were funded. Or, it may be that a less efficient decision was made but that the politicians were "paid" to make it happen. Either way the political pressure resulting from a critical review meant that, as with the funding of Herceptin and interferon beta, politicians stood to gain political capital by increasing funding.

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102 Pharmac Review Panel "Pharmac Review – Final report: Executive summary" (Ministry of Health, February 2022).

103 At 7–10.

104 At 5.

105 This is only the best case for Pharmac and in fact there may have been instances where there were inefficient decisions reached that were also inequitable.

106 Pharmac Review Panel, above n 102, at 13–14.

107 At 14.

108 At 14.

109 Bridie Witton "Budget 2022: Pharmac gets massive boost as $13.2b poured into health" (19 May 2022) Stuff <www.stuff.co.nz>.

110 Pharmac "Decision to fund nusinersen (Spinraza) for spinal muscular atrophy" (8 December 2022) <www.pharmac.govt.nz>; and Pharmac "Decision to fund ustekinumab for inflammatory bowel disease, and infliximab for inflammatory bowel disease-associated arthritis" (20 December 2022) <www.pharmac.govt.nz>.

VIII Conclusion

Pharmac has unquestionably succeeded in saving New Zealand a considerable amount of pharmaceutical spending and expanding the available medicines to New Zealanders. The critics of Pharmac, especially those who suffer from a serious illness, do deserve our sympathy. Life has been cruel and unfair to rob them of their health. The recent further funding of medications like Spinraza and ustekinumab will improve their lives. But one clear cost associated with the funding is the structural change that Pharmac will undergo in the foreseeable future. The extent to which the remarkable features that made Pharmac so effective will be retained remains to be seen. As the then Minister of Health, the Hon Andrew Little, stated following the review, "[t]he days of the independent republic of Pharmac are over."[111] Some of the changes to Pharmac will be for the better, but there is a risk that we may lose what has made the agency so effective. It is important to be wary of the risk that Pharmac's loss of independence may render it a political football.

This article started with how Pharmac saved my life. Funding my life-saving medication was only possible by the rigorous and careful allocation of Pharmac's budget. It is easy to criticise Pharmac with emotive stories. But stories like mine demonstrate the enormous good that Pharmac has done, a sentiment which is easy to forget.

This article has shown that some of the common criticisms of Pharmac do not hold up. The solution to the issues raised in this article, such as a lack of funding for new medications, does not lie with changing Pharmac but with increasing their budget. Pharmac's successes will only continue if it remains apolitical.

111 Radio New Zealand "Health Minister urges Pharmac to focus on equity and collaboration" (1 June 2022) <www.rnz.co.nz>.