

Prioritising Medicines, Negotiating Lives

An Anthropological Inquiry of Pharmaceutical
Access in New Zealand

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Abstract

Pharmaceuticals have become synonymous with ideas of health and wellbeing. The consumption of pharmaceuticals has become the gateway to restoring, maintaining, or improving one's health; in turn becoming deeply entrenched in everyday life as treatment for disease. Given the use of pharmaceuticals for treatment, the question needs to be asked how individuals are able to obtain the medication they need. There is little anthropological literature concerning how patients negotiate and lobby for access to pharmaceutical treatment in New Zealand, particularly so in the face of Pharmac as the government entity which heavily regulates pharmaceuticals. Through conducting interviews with nine participants who are patients, general practitioners, and employees of Pharmac, I argue that in utilising policies such as cost utility analysis Pharmac prioritise which medicines are publically funded, and in doing this determine how health is conceived and calculated within the New Zealand health care system. In determining which medicines should be funded the state is making judgements over which lives are prioritised, and, in turn, who is left to die. I suggest that in the face of being denied access to life-saving drugs patients become mobilised through seeking access to experimental therapies via pharmaceutical companies. By taking these experimental treatments we come to understand that experimentation and risk have become crucial in patients fight for life against the prognosis of an early death from disease.

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*Throughout this thesis participants will be identified using pseudonyms in order to protect their identities.

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Introduction:

Health, Life, and Pharmaceuticals

“I probably would have raised prices higher, is probably what I should have done. I could have raised it higher and made more profits for our shareholders. Which is my primary duty. And again, no one wants to say it. No one’s proud of it. But, you know, this is a capitalist society, capitalist system, and capitalist rules, and my investors expect me to maximise profits. Not to minimise them, or go half, or go seventy percent, but to go to one hundred percent of the profit.”

Martin Shkreli, former CEO, Turing Pharmaceuticals

“It’s comparable homicide in my view. It’s just pure and simple greed. It’s just obscene greed.”

Greg Jefferys, Hepatitis C patient

“They have to fund it. I shouldn’t have to do this. Imagine if I was worse off? I am able to do this. What about everyone else that isn’t able?”

Jeff Paterson, Cancer patient

In September 2015 the CEO of Turing Pharmaceuticals, Martin Shkreli, announced that the company was raising the price of Daraprim, an HIV drug, from \$13.50 to \$750 per pill, an increase of almost 5,000 percent. The news prompted a congressional hearing, and in the weeks that followed he appeared on several cable news networks to defend his position. He drew widespread condemnation from the public for his actions, including presidential candidate Hillary Clinton who called his move “outrageous”. Speaking at the Forbes health care summit in New York in early December 2015, Martin Shkreli was asked the question if he could go back in time whether he would have increased the price of Daraprim. Shkreli responded with

the statement above. In his words, “price drugs really low, you won’t last very long...It’s people that are willing to make these hard choices. Growing [profit] for their shareholders” (Shkreli 2015). Turing Pharmaceuticals later announced that they would no longer raise the price of Daraprim. Yet while Martin Shkreli was criticised in the media, less has been said of his statements accusing other pharmaceutical companies of also raising drug prices. As he states in defending the price hike, “we’re certainly not the first company to raise drug prices...At the end of the day there has been much larger drug increases by much bigger drug companies...For us to try and exist and maintain a profit its very reasonable” (Shkreli 2015).

In the eyes of Greg Jefferys, a Hepatitis C patient living in Tasmania, it is the motivations of pharmaceutical companies to maximise profit that encourages the high cost of medicines, to the point where many people can no longer afford them. In an interview on the New Zealand television program *Sunday* in March this year Greg explained that after his diagnosis he found that the medicine he needed for treatment, Sofosbuvir, was largely unaffordable for himself and many others. Greg sought out a generic version of the drug in Chennai, India, paying significantly less for the treatment, which resulted in him being cured of the virus. It is a similar situation for Jeff Paterson, a student and cancer patient living in New Zealand. Jeff Paterson was diagnosed with melanoma in 2009, his condition worsening in 2015 where he developed tumours in his brain and later his lungs. He requires access to the drug Keytruda, fearing that his body will reject current treatment. But the problem here is that Keytruda is expensive and Pharmac do not currently fund the drug. Thus Jeff and his family have spent much of their time, money, and energy fundraising for his medicine. For Jeff funding his own treatment is something he believes he should not have to do, and that he is only able to because he is well enough to advocate for himself. For Jeff access to pharmaceutical treatment will ensure that he continues to live. In all three of these examples what is revealed is the complexity that underlies issues of pharmaceutical access both globally and within New Zealand, highlighting the myriad of actors that interact and navigate realms of pharmaceutical production, regulation, and consumption.

Pharmaceuticals have become synonymous with ideas of health and wellbeing. As people become increasingly defined by their pursuit of health, consuming pharmaceuticals become the gateway to restoring, maintaining, or improving one's health (Petryna and Kleinman 2006:1; van der Geest et al. 1996:164). The consumption of pharmaceuticals has become a multi-billion dollar industry, driven by their promise "to wipe out disease and alleviate suffering in the world" (Petryna and Kleinman 2006:1; also Dumit and Greenslit 2006:127). The focus on health has become integral to one's daily life, constantly shaping and reshaping one's identity through individuals spending much time, effort, attention, and money on their health. Pharmaceuticals, in turn, have become deeply entrenched in everyday life as treatment for disease. With health being tied to pharmaceuticals and prescriptions, we are experiencing shifts in understandings of health, illness, life, longevity, and identity (Dumit and Greenslit 2006:127; Oldani 2014:273). These shifts having largely been influenced by the pervasiveness of the pharmaceutical industry in issues of public health care (Dumit and Greenslit 2006:127).

Given the use of pharmaceuticals for treatment, one must ask how individuals are able to obtain the medication they need. As argued by Adriana Petryna and Arthur Kleinman, behind the staggering figures that constitute global pharmaceutical spending are entanglements of economic and moral paradoxes (2006:2). A paradox exists where the prevalence of life-extending technologies, such as pharmaceutical treatment, can co-exist with the fact that essential medicines remain unavailable in certain locales; the ethnographic challenge, as they argue, is to make sense of this paradox and "plum its technical, political, and social depths" (2006:4). I became interested in how economic, political, and cultural practices have shaped health and illness in New Zealand, paying special attention to the prevalence of pharmaceutical treatment as the dominant model for treatment of disease. A significant reason why the study of pharmaceuticals has been, until recently, a neglected site of research is because medicines are so commonplace. They are omnipresent in daily life, a realm that for a long time anthropologists dismissed as being too familiar (van der Geest 2006:304). More recent study however, in line with the emergence of anthropologists conducting more fieldwork 'at home', the rise of medical anthropology, and the growing criticism towards pharmaceutical industry practices, has allowed for greater analysis of the phenomena of pharmaceuticals (van der Geest 2006:304).

In spite of recent efforts however, there is a dearth of ethnographic, especially anthropological, literature concerning the medical institutions and actors that reside and interact in New Zealand's contemporary medical field, especially those that advocate and lobby for equal

access to medicine. Understanding the experiences of these health-related actors are important as they uphold different and competing notions of health, illness, and the role citizenship and human rights play in the pursuit of pharmaceutical treatment. Understanding the role of medicines, and more specifically pharmaceuticals, is an important endeavour because, as van der Geest (2006:303) contends, studying medicines allows us to gain understanding about the place of pharmaceuticals in health and how we come to value life. In pinpointing where my research project lies I must first address the existing literature in studies of pharmaceuticals, both globally and more locally in New Zealand.

Anthropology of Pharmaceuticals

Pharmaceuticals “are substances that have the capacity to change the condition of the living organism – for better or for worse. The secret of their attributed power lies primarily in their concreteness or their ability to transform a problem at hand into ‘thinginess’. By applying a ‘thing’, we transform the state of dysphoria into something concrete, into some thing to which the patient and others can address their efforts” (van der Geest et al. 1996:154; see also Petryna and Kleinman 2006:8). The ability for medicines to make something subjectively felt into something concrete aligns with the understanding that throughout time and across cultures people have “attributed special transformative powers to material substances” (van der Geest et al. 1996: 153). Early anthropological studies argued that the logic of medicines in what were called ‘primitive societies’ were to be understood as magic, fetishism, or animism. Yet it is only from the 1980s onwards that anthropologists have turned their attention away from ‘exotic’, ‘other’ sites towards an interest in Western culture and understandings of biomedicine. Anthropologists became attentive to pharmaceuticals – how they are “synthesized, manufactured, and commercially distributed therapeutic substances that constitute the hard core of biomedicine” (van der Geest et al. 1996:154). Dumit and Greenslit (2006) emphasise this point when they argue that studies of pharmaceuticals “document the deep, intricate relationships of national and international standards, research, practices, pills, diagnoses, and identities” leading to greater understanding of this anthropological phenomenon as an object of inquiry (128).

The modern pharmaceutical industry began in the 20th century, with major pharmaceutical breakthroughs occurring during WWII. These breakthroughs, which included the discovery of penicillin, tuberculosis treatment and anti-biotics, were patented from the late 1940s (Petryna

and Kleinman 2006:2; also Dumit 2012: 89). Post WWII, the pharmaceutical industry started to incorporate more sophisticated means of marketing products, as seen through the formation of large pharmaceutical firms and greater investment in research and marketing. By 2003 global pharmaceutical spending reached \$500 billion, influenced to a large extent by pharmaceutical advertising directed at the consumers themselves; what eventuated was a growing logic of pharmaceutical consumption through wellbeing being altered as a commodity (Petryna and Kleinman 2006:3; Dumit and Greenslit 2006:127). Yet concurrent with this “consumption-oriented logic” of disease was the reality that many diseases, particularly those found in developing regions, were viewed as “hopelessly untreatable” (Petryna and Kleinman 2006:3). The reality that there exist treatments for some diseases and not others is indicative of the fact that “illnesses can be valued and treated differently” (Petryna and Kleinman 2006:3). Thus, as some begin to lead pharmaceutical lifestyles from having access to the treatment they need, there are also others who live in “benign neglect” (Petryna and Kleinman 2006:3).

In issues of pharmaceutical access the state plays a significant role, especially in regulating how drugs are manufactured, labelled, advertised, and reviewed. For instance, scholarly work has focused on the regulation of clinical trials, where the focus on acquiring data from these trials has transformed notions of health and illness as dependent on “techniques of measure” (Dumit and Greenslit 2006:128; also Petryna 2006; Dumit 2012). Dumit (2012:101) argues that the logic of clinical trials has enabled medicines to become entrenched in our lives. Yet as Petryna and Kleinman argue, states have been inconsistent in how they regulate pharmaceuticals across the globe. Some countries, such as New Zealand, “are more active in controlling their pharmaceutical markets than others” (2006:16). However for many states when it comes to pharmaceutical regulation there is no globally unified bureaucratic policy, meaning that regulatory bodies have less control over the realms of health care, specifically where drugs are bought and sold (Petryna and Kleinman 2006:17). The concern with this is that state policy often misses the “alternative and complementary medicine settings” where drugs are consumed, such as the homes of patients, family members, and members of the wider social network (2006:17).

As states vary differently in how they regulate pharmaceutical flows the question becomes whether states have lost sovereignty over their citizens, especially in light of the fact that non-state actors, such as pharmaceutical companies, are taking a more active role in public health delivery. The reason for this, as Petryna and Kleinman argue, is that governments’ have been accused of failing to ensure the basic health rights of their citizens, leading to greater

acceptance of the market as the solution to issues of health inequalities (2006:18). Yet although many scholars have dismissed the state as having little influence in controlling flows of pharmaceuticals, others argue that, “states continue to exercise power by influencing the size of pharmaceutical markets. They can undercut industry attempts to establish market strength by imposing strict regulations and procedures for product approval and advertisement...States can dramatically reshape the landscape of everyday survival” (Petryna and Kleinman 2006:19; also Rose 2007).

The globalisation of pharmaceuticals is a “multiscaled movement with political, economic, and ethical dimensions”; the intersections of these dimensions creating what Petryna and Kleinman call the pharmaceutical nexus (2006:20). Inherent within this nexus is not only the workings of the pharmaceutical industry in the global prevalence of pharmaceuticals, but also encompasses the role of the state and other regulatory bodies who are influential in determining the availability of life-saving medicines (Petryna and Kleinman 2006:21). Yet the nexus also constitutes another key element – how patient groups respond to and conceive the issues of pharmaceutical access. Patients view pharmaceutical access as a “crucial life-saving tactic” or as a space of competition among patient communities for support and access to these pharmaceuticals (Petryna and Kleinman 2006:21). For João Biehl in his exploration of the Brazilian AIDS model, the ability of the country’s poorest to receive universal access to antiretroviral medicine was due to the combined interests of the “Brazilian state, international agencies, multinational and national pharmaceutical enterprises, and social activism” (Biehl 2006). Because this model was largely successful this policy created novel forms of patient-citizen inclusion and exclusion. The AIDS model has both enabled citizens to be included through their new-found capacity to navigate treatment regimens and incorporate scientific knowledge into their bodily understandings of health and disease, but citizens are also marginalised and excluded when not entering into this form of pharmaceutical governance (Biehl 2006:235). What occurs is a form of “state triage” where some patient citizens achieve the treatment access they need while others are often made invisible (Petryna and Kleinman 2006:28).

What the case above reveals is that investigation of the “cultural, scientific and economic practices” that contribute to the expansion of pharmaceuticals in the global sphere also requires consideration of how this expansion figures in how treatments are distributed and what affects this has on issues of inequality and health practice (Petryna and Kleinman 2006:5). Dumit and Greenslit (2006) argue that pharmaceutical dependency is viewed as normal, meaning

questions of “identity, control, and risk are simply no longer formulated as choices for or against drugs in general, but are, rather, always questions of *which* drugs and in *what* combinations” (130). I seek to explore how pharmaceuticals have become the dominant form of treatment for New Zealand citizens in their pursuit of health and wellbeing, specifically addressing how individuals gain access to the pharmaceutical treatment they need. In examining inequalities in pharmaceutical access two questions arise: who is entitled to pharmaceutical treatment? And secondly, how is this shaped by competing notions of health, life, and their value?

Studying Pharmaceuticals in New Zealand

As I mentioned briefly above, there is little anthropological literature concerning the nature of pharmaceutical access in New Zealand. As such, my research project seeks to gather knowledge on the inequalities that exist in access to treatment, particularly how individuals respond to being denied access to the essential medicines they need. In conducting this research project I aim to uncover how, through pharmaceutical regulation, conceptions of health, illness, and inequality have transformed over time. What I will discuss below are recent studies that explored the operation of Pharmac, primarily its effectiveness in securing an “adequate” range of government-subsidised medicines (Gauld 2014:937).

Pharmac has existed for more than two decades as the government arm responsible for delivering tax-payer subsidised medicine within a fixed annual budget (Dew and Davis 2014:138; Gauld 2014:937; Ragupathy et al. 2012:367). Specifically, Pharmac are tasked with managing the Pharmaceutical Schedule, a list of around 2,000 publically subsidised prescription medicines. This enables New Zealanders who are prescribed a medicine that features on this list to only need to pay NZ\$5.00 per item (Gauld 2014:937). Moreover, Pharmac works by negotiating with pharmaceutical companies over medicines pricing. In order to be effective in these negotiations Pharmac are largely free from restrictions in the marketplace and are protected against litigation (Dew and Davis 2014:146). Pharmac, in its creation and operation, is a “single independent company able to use monopsony power to manage the Pharmaceutical Schedule”, infusing core neoliberal values of business and science – through seeking the best deals and ensuring safe and cost-effective medicines within a fixed budget (Gauld 2014:938). These core values themselves stem from the belief that New Zealand

was, until the early 1990s, paying too much for pharmaceuticals (Dew and Davis 2014; Gauld 2014:938).

Pharmac's main objective is to "purchase an adequate range of pharmaceuticals for New Zealanders (maximising the contribution of medicines to the health of the population)" (Gauld 2014:938). In meeting this objective Pharmac utilises techniques of 'best practice', namely, evidence and economic analysis. Pharmac uses these forms of analysis to inform decision-making around which medicines should be state-funded. However, these forms of analysis also allow for Pharmac to focus on 'cost containment' and 'prioritisation' of medicines (Gauld 2014:939). The issue with this, as stated by Gauld, is that:

The agency may need to balance whether a new and more expensive medicine, which perhaps benefits a small number of patients, provides a better investment than another already listed medicine that benefits a wider population. As in any country, there are periodic community demands for high-cost pharmaceuticals for specific conditions that affect a very small number of patients (2014:939).

Here lies the foundation for a significant site of contestation. In prioritising medicines Pharmac draws on a utilitarian argument that defends their right to base pharmaceutical spending on what will benefit the population. In advocating for the 'collective good' Pharmac legitimates its legal-political model of medicines regulation (Dew and Davis 2014:148). However the ethical and moral concerns that underpin this ideology has generated little scholarly discussion. As Gauld acknowledges, "to be fair, information about the impact on patients unable to access specific medicines is limited and more research into this is needed, along with research into the impact of delays in accessibility of some medicines" (2014:940). Gauld is right in that very little study has sought to understand the lived experiences of those who are denied access to certain treatment options¹. Qualitative studies understand patients as having an ever-changing relationship with medicines, but primarily there is more emphasis on viewing patients as consumers (Gabe et al. 2012:2357). Dew and colleagues (2014:1) argue that taking pharmaceuticals has embedded within it moral concerns relating to issues of responsibility, identity, stigma, agency, and power, as well as exploring the meaning of pharmaceuticals in everyday life. As they argue:

¹ Quantitative research has mainly focused on the relationship between health inequalities and ethnicity (Jeffreys et al. 2005; Tobias et al. 2009), geographical inequality (Haynes et al. 2008), racism (Harris et al. 2006; Pearce and Dorling 2006), and the impact of the health care system on mortality rates (Tobias and Yeh 2007).

People express themselves through their everyday activities, and the consumption of medication is an everyday activity for many people. Our relationship to pharmaceuticals is thus tied to our identity, what we want to show of ourselves, what sort of person we want to be seen as, and what sort of world we want to live in (2014:8).

There is less understanding of the relationship between individuals and pharmaceutical use in New Zealand, especially how patients have responded to being failed by the health care system in pursuing treatment access.

As pharmaceuticals have become the dominant means by which people manage their health the question of who has access to these treatments is one of contentious debate and salience in wider society. It is clear that there are individuals who are not prioritised for pharmaceutical treatment. In thinking about health as a collective good, individuals become a necessary sacrifice in the pursuit for near-universal treatment access. Yet, as mentioned by Gauld (2014) we know little about the impact that unequal treatment access has on patients in New Zealand. It is here that I situate my research project.

The Research Project

In undertaking this project I was interested in the commercial, legal, and political factors that have shaped how pharmaceuticals are sold and regulated in New Zealand, paying special attention to the role of Pharmac as the primary purchaser and regulator of pharmaceutical products on behalf of the state. How has the operation of Pharmac allowed for the proliferation of certain forms of treatment? What political, cultural, and moral logic does Pharmac use in regulating which pharmaceutical treatments will be made available to the public? Moreover, I wished to explore the consequences that come with heavily regulating pharmaceutical use in New Zealand. Specifically, the effect that pharmaceutical expansion has on health inequality and practice. Although Pharmac support the position of biomedicine in the delivery of health care (Dew and Davis 2014:138-139), the fact that pharmaceuticals are heavily regulated in New Zealand means that Pharmac inevitably experiences hostility from pharmaceutical companies, patient lobby groups, and health professionals because of these restrictions. Thus, in examining how New Zealand regulates pharmaceutical use, it is necessary to consider the effect that this has on health inequalities.

Anthropological studies have sought to understand the relationship between income inequalities and health. These works demonstrate that health inequalities, vis-à-vis pharmaceuticals, are contingent on socio-economic and political dimensions and among ethnic and racial lines (Petryna and Kleinman 2006:4). Within these studies was the fact that institutions tasked with dealing with health problems, such as state bureaucracies, had significant influence over health policy and the resultant outcomes of health and disease (Elliott and Abadie 2008:2317; Petryna 2006). Moreover, I argue that in the regulation of pharmaceuticals the New Zealand state has played a significant role in the shaping of health policy. Pharmac's main objective is to secure the best health outcomes for New Zealanders within the funding provided. In order to meet this objective Pharmac must prioritise which medicines will result in greater health benefits to as many people as possible, and it does this by using techniques that allow for 'best practice'. In prioritising which medicines should be funded Pharmac utilises a "utilitarian argument based on what [is] best for the population" (Dew and Davis 2014:145). Pharmac uses this argument as a defence against patient groups and health professionals who lobby the New Zealand government for greater access to the pharmaceutical treatments that are not usually prioritised – particularly high cost medicines such as those that treat rare diseases and cancer. This is aligned with Petryna and Kleinman's argument that there exists a 'values gap'. Populations have differing levels of access to life-saving drugs, and in response individuals must rely on alternative forms of pharmaceutical distribution (2006:6). Pharmac argues that it has New Zealand's best interests at heart in its regulation of pharmaceuticals, with this aligned to the notion that the state has a "moral imperative to support citizens in matters of sickness and disease" (Dew and Davis 2014:148). Yet the fact that there are individuals who do not have access to the life-saving drugs they need begs the question of how this contradiction, or values gap, has come to exist within issues of pharmaceutical access in New Zealand. And further, what does this contradiction mean in terms of questions of responsibility, accountability, morality, and justice in thinking about pharmaceutical access?

In chapter two I make the argument that in prioritising which medicines will be publically funded and will benefit the majority of the population, Pharmac are actually determining whose life has more value, as exhibited through who is entitled to the treatments they need and who misses out. Arguably, Pharmac not only shape health policy but also dictate how health and life is calculated, regulated, and understood. Thus, this 'values gap', in which people have varying levels of access to the health care they need, entails the "subtle and not so subtle ways

by which the significance of others' wellbeing is judged" (Petryna and Kleinman 2006:6). Human experiences of suffering have become tied to ideas of economic worth – that is, an individual's worth as human labour for the market – or economic worth in terms of costs of morbidity. The fundamental issue becomes, whose illness is worth treating? Whose life is worth saving? (Petryna and Kleinman 2006:6). In providing a response to these questions within my research project I found that, ultimately, the decision of determining who should live and who should die is made at the level of the state, through Pharmac. Thus the role of the state in prioritising life and death through performing "pharmaceutical triage", alongside its other role of "securing health as a fundamental good and right of citizenship, has never been more profound" (Petryna and Kleinman 2006:7).

Patients, when faced with being denied access to the treatments they need, respond by becoming self-managing and responsible for securing pharmaceutical access. In chapter three I argue that in becoming responsibilised for their health individuals create new social relations, specifically forming an alliance with the pharmaceutical industry. For these patients the government has failed to ensure their citizenry right to health, leading to these patients appealing to the pharmaceutical industry for access to the treatment they need. Furthermore, in fighting for their lives through consuming the treatment that they need, patients are more willing to take risks such as becoming human test subjects through participating in clinical trials or considering taking DIY treatment. In this regard, patients' bodies become sites of experimentation (Dumit 2012; Petryna 2006). What is revealed here is that our understanding of health has become innately tied with the consumption of pharmaceuticals, so much so that people are risking their health further in taking experimental treatments. Yet for these individuals' access to, and consumption of, experimental therapies are being increasingly viewed as a therapeutic commodity (Petryna and Kleinman 2006:7). In taking these experimental therapies what becomes evident is the lengths individuals will go in order to ensure their own survival, and further how taking these therapies has led to a shift in understandings of experimentation and risk as that of remedy and health.

Methodology

This thesis draws on my analysis of interviews I conducted with various patient activists, general practitioners (GPs), and an employee of Pharmac. Biehl (2007) argues that "fieldwork allows us to see the various forces and actors at work, reminding us that there is no shortcut to

understanding the ways pharmaceuticals move from the laboratory to professional medicine and public health policy, and how they affect the intimate realms of bodily experience” (1085). In an attempt to uncover the experiences that individuals have with pharmaceuticals in their daily lives I used qualitative interviews. Interviewing, being the process of directing information so as to collect information (Angrosino 2007:42), is considered one of the “most powerful ways [we can] understand our fellow human beings (Fontana and Frey 1994:361). In conducting these interviews I used the methods of email and word-of-mouth to recruit nine participants for my research project. These individuals ranged in age from 29-55 years old, with four of the interviewees being male and five female. All participants were of Pakeha² ethnicity.

I found the use of the snowball method extremely helpful in recruiting the first three of my participants. Maria, Alan, and Hamish are general practitioners who work at a non-for-profit community-based health care service in central Wellington. The clinic caters to the community’s most vulnerable people, such as migrants, low income families, and those who are unemployed. As well as this Maria, Alan, and Hamish also work as lecturers at the Otago Medical School. In interviewing Maria at her home I learnt that she works at a youth service as well as a for-profit medical centre in Wellington. The second interview with Hamish took place at the community-based health care clinic where he works. As well as being a lecturer at the Otago Medical School he also works at the Regional Public Health Unit as a medical officer. My third interview with Alan took place at his office at the Otago Medical School. Alan’s interests are in public health bioethics and health law, as well as being a teacher of GP registrars.

I used email³ to make contact with the remaining six participants. Robert works as a rare disease advocate and Chairs a rare disease support group. When we first met for an interview he had recently stepped down from being the Chair of a rare disease umbrella group. Robert first became involved in rare disease advocacy after his children were diagnosed with a rare disorder. We met for an interview at the university.

Sarah, like Robert, is a rare disease advocate and is Chair of the rare disease support group she created. She first became concerned with the issue of pharmaceutical access after she was

² Pakeha is the Māori term for New Zealanders who are of European descent.

³ In writing emails to participants I outlined my research project and attached a participant information sheet. These emails were sent to participants once I received ethics approval from the Victoria University Human Ethics Committee on 11 July 2015.

diagnosed with a rare disorder in 2010. She became a health advocate after finding out that the treatment she needed was not funded by Pharmac. We met for an interview at her home located two hours out of Wellington.

I met my next participant, Kay, after flying to Auckland. As well as being a patient advocate and Chair of a breast cancer organisation Kay also works as a scientist. She first became interested in issues of treatment access after she was diagnosed with breast cancer in 1998. She received treatment through the private system, but later decided that she wanted to help those who could not access the treatment they needed.

William is a patient advocate who created and is Chair of a rare disease support group. He also works for another patient support and advocacy NGO, and is an independent researcher. William first became involved in issues of pharmaceutical access after he was diagnosed with a rare disorder. William has been actively involved in trying to establish clinical trials in New Zealand.

Emily is a student based in Wellington who has experienced health issues since she was ten years old. She was born with a rare condition that has become more complex as she has gotten older. She moved to New Zealand thirteen years ago, and thus has been trying to obtain the medicine she needs both in the United Kingdom and here in New Zealand. Because of her ill health our interview was conducted over a series of email conversations.

The last participant I interviewed was Carol who has worked for Pharmac for just over three years and holds the position as a Pharmac Manager. Our interview took place in a conference room at Pharmac headquarters in Wellington. I mention Carol last because I want to highlight the difficulty I had in trying to find an informant who works for Pharmac. A significant focus of my research project was the operation of Pharmac as a government agency tasked with managing New Zealand's pharmaceuticals budget. I first emailed Pharmac in July 2015 outlining the research project and my contact details. I did not get a response. In October 2015 I emailed Pharmac again, receiving a response from the government agency three weeks later saying that they know of someone who was willing to be interviewed. A day later I sent an email to this potential informant explaining who I was and outlining my research project. However I did not receive a response until I sent a follow up email a month later. By this time the Christmas and New Year holidays had approached meaning neither of us were able to meet. I began email communication again in mid-January 2016; and after waiting a month for my potential informant to return from overseas travel as well as postponing the interview for a

week due to a scheduling conflict, we met for an interview at the Pharmac offices in mid-February 2016.

In reflecting on the difficulty of recruiting a participant who works for Pharmac I now realise that this is one of the many methodological challenges that comes with ‘studying up’ cultures of the powerful, such as bureaucratic agencies. The most difficult obstacle to studying up is the difficulty of gaining *access* to the field site (Gusterson 1997:116; Priyadharshini 2003:423). A common issue scholars’ stress in trying to recruit participants is that people are usually too busy to chat (Gusterson 1997:116). I also found this to be the main reason why I struggled to find a potential informant from Pharmac. Once Carol had agreed to be interviewed as part of my project we kept experiencing scheduling issues as Carol was either busy or needed to travel frequently for her job. Conversely, I had very little issue with recruiting patient advocates for the project, usually receiving a positive response within a few days of sending an email. Thus when it came to trying to contact key informants from Pharmac I realised that I needed to become more flexible with my time in order to reduce the issues I had of scheduling an interview time, but also needed to remain persistent in organising a time and date that suited us both.

The interviews ranged in length from 45 minutes to two hours. I let the participants choose the interview locations in an effort to diffuse the inherent power the interviewer has in the interview process (Edwards and Holland 2013:78). Yet I found that where the interviews took place greatly influenced the atmosphere and power dynamics of the interviews. I found that talking to people at their homes allowed for the creation of a casual and friendly atmosphere. Before I began my interview with Sarah we chatted about her animals as well as gifts she received in a parcel delivered from a friend overseas. In meeting Maria at her house I talked with her while she was making dinner, after which she offered to make me a cup of tea. In these small conversations we were able to build a rapport, making for a comfortable space in which to conduct an interview (Edwards and Holland 2013:77). Conversely when interviewing people at their place of work – whether that be in their office or a conference room – the interview was more formal⁴ with very little small talk before the interview. This formality also extended outside of the interview where on two occasions I was requested to sign in as a visitor. For instance, in travelling to Auckland to meet Kay at the Research Institute she works at I was

⁴ This formality was extended further in my use of two recording devices – Dictaphone and my iPhone. I share both Gobo (2008) and Heyl’s (2007) arguments of the merits of recording interviews, yet found that when conducting an interview in an office or conference room the inclusion of recording devices further added to my feelings of discomfort within some of these interviews.

required to sign in at reception and wear a badge while I was in the building. This badge had a barcode which needed to be scanned as I exited the building after the interview. Carol Warren (2001) contends that in qualitative interviewing the matter of where interviews take place is one that is continually negotiated, and moreover, can influence the level of comfort between the interviewer and interviewee, influencing how the discussion unfolds (14-15). I found that interviewing in settings such as offices and conference rooms shaped how I approached asking questions. In these settings I tended to follow my interview guide (a list of questions I prepared before each interview) more closely, asking fewer 'probing' questions based on what was said by those I interviewed. Yet when interviewing in participant's homes I was more comfortable and more readily asked follow-up questions to get a better understanding of the information participants were providing.

I found that in my interviews power was continually negotiated between my participants and myself. I mentioned above how the location of interviews influenced levels of comfort and how I approached certain interviews. But I also want to briefly mention how some of my participants exerted their own form of power in the interview process by requesting their interview transcripts. In creating a consent form for my participants to sign I included the question "I would like to be given a copy of the interview transcript", in which participants could respond 'yes' or 'no'. I was initially reluctant to include this question out of concern that participants, if they requested an interview transcript, would change key pieces of information that they had shared in the interview. This concern resulted in myself spending a greater amount of time transcribing certain interviews in order to make sure I was preserving the information as accurately as possible, including pauses, emphasis and non-verbal cues. In choosing to receive a copy of their interview transcript the interviewee exerts greater control over the knowledge that they share within the interview process. Upon the interview transcripts being returned I actually found that my participants made only minor changes to words that were either misspoken by the participant or misheard by myself while transcribing⁵. Conducting qualitative interviews can lead to the uncovering of important information on how individuals interpret their feelings, thoughts, and experiences (Heyl 2007:370; Holstein and Gubrium 1995:2). In recruiting informants for my research project difficulties arose in trying to gain access to the Pharmac field site. The location of interviews and the process of creating interview transcripts

⁵ Schensul, Schensul and LeCompte (1999) offer a good commentary of the process of transcribing audio field notes and the issue of translating conversation into written form (144).

are two of my own examples where issues of power and emotion can resonate strongly in the interview process.

Thesis Outline

The next chapter serves to contextualise the nature of pharmaceutical access in New Zealand within key anthropological frameworks. I argue that pharmaceutical access has been shaped by the emergence of neoliberalism, where responsibility for one's health and wellbeing is being increasingly taken up by the individual. Patients utilise their capacity as biological, therapeutic, and pharmaceutical citizens to appeal to both the state and non-state institutions for access to pharmaceutical treatment. Neoliberal understandings of health and illness have become significant in understandings of life and its value, with pharmaceutical treatment being perceived as the solution to disease.

Chapter Two will examine the emergence of Pharmac and its role in regulating pharmaceuticals. I argue that Pharmac utilises certain legislative and economic policies in order to prioritise which medicines are considered cost-effective and should be publically funded. Within these policies Pharmac conceptualises health and life as calculable and comparable across the New Zealand population. I argue that in prioritising which medicines should be publically funded Pharmac are determining who is entitled to treatment, hence will be saved, and conversely who misses out.

Chapter three will explore how patients respond to being refused access to life-saving medicines. I argue that in pursuing alternative means to treatment individuals are appealing to the pharmaceutical industry through trying to establish clinical trials in New Zealand. Patients, in joining clinical trials and taking 'DIY' treatment, have become willing to be subjected to human testing and experimentation in their fight to live and delay the potential death that comes with suffering from a debilitating chronic illness.

Chapter Four will conclude this thesis by highlighting the main themes that have emerged from my inquiries into the nature of pharmaceutical access in New Zealand.

Chapter One:

Citizenship, Life, and Pharmaceutical Access in New Zealand

This chapter seeks to contextualise pharmaceutical access in New Zealand using key anthropological frameworks. I introduce the concept of citizenship, arguing that the 21st century has seen the emergence of globalising flows of capital, technologies, and populations leading to individuals themselves assuming responsibility for one's security and wellbeing. In viewing this in relation to citizenship what becomes evident is that citizenry rights and entitlements have become linked to neoliberal criteria, where new spaces have opened for claims to be made both the state and non-state institutions for access to pharmaceutical treatment. I further argue that in the case of Pharmac we can see the concept of biopower playing out through its capacity to govern the population through the regulation of medicines. Furthermore, through the notion of biopower New Zealand citizens themselves have become increasingly self-monitoring of their own health and wellbeing within this neoliberal form of governance. I suggest that in a neoliberal model of health individuals make appeals for the right to pharmaceutical access through several citizenship projects, where individuals exercise their capacity as biological, therapeutic, and pharmaceutical citizens through grounding their appeals for access to drug treatments in biological terms. Furthermore, in these neoliberal understandings of health and illness the state and its citizens begin to conceptualise life and its value as a commodity, with consuming pharmaceutical treatment as the solution to alleviating human suffering.

Historical Transformations of Citizenship

Citizenship is commonly understood to be the link between an individual and nation-state. It is a concept defined in a myriad of ways “as the epitome of being human; as a set of rights and

obligations defined by one's relationship to the state; and as a sense of inclusion into larger social and political communities" (Trnka, Dureau and Park 2013:6). Citizenship offers a means of identifying groups of people through ideas of inclusion and exclusion, and through this identity-making individuals become "active and self-conscious agents, in the constitution of themselves as subjects of power" (Trnka, Dureau and Park 2013:6). Prior to the 17th century, citizenship was viewed in the West as that of civic responsibility, where the individual was concerned with being self-governing and actively engaged in political participation. This was in opposition with Roman understandings of citizenship which focused predominantly on legal rights. Modern notions of citizenship align more closely with the latter vision of citizenship – namely, that citizenship is to be understood in legalistic and protection-oriented terms (Trnka, Dureau and Park 2013:8). Citizenship became oriented around questions of who is entitled to citizenry rights, what these rights comprise, and issues of belonging and responsibility (Trnka, Dureau and Park 2013).

In the 1950s T.H Marshall wrote of citizenship as evolving over time. The 18th, 19th, and 20th centuries saw conceptions of citizenship change from the categories of civil to political, then later social. Within this evolution Marshall was most interested in issues of inclusiveness and how individuals participate in various citizenship activities (Trnka, Dureau and Park 2013:8). In the late 1980s Iris Marion Young conceived of a citizenship where minority and oppressed groups increasingly challenged the notion that formal rights entailed equal citizenship, with these groups mobilising around claims for greater inclusiveness and rights of belonging (Trnka, Dureau and Park 2013:8). Within this understanding Young stresses a bodily basis of engagement and exclusion, such as through "citizen claims of disabled groups and those who have manifestly suffered under regimes of de jure rights and de facto indifference to suffering" (Trnka, Dureau and Park 2013:8). Yet these citizen claims are not revolutionary; new economic, social and cultural conditions interact to articulate these claims as citizenship rights (Trnka, Dureau and Park 2013:8).

Turning to the 21st century, the citizen-state relationship has been altered over time through the globalising flows of markets, technologies, and populations. As an individual works within these new flows sites are created for making new claims for resources from the state as well as non-state institutions. Thus, an individual, or citizen, can "make political claims through pre-existing political membership as well as on the grounds of universalising criteria" of neoliberalism and human rights (Ong 2006:499-500). Neoliberalism first emerged in writings of economist Friedrich August von Hayek in the 1930s and 1940s, and found its roots in politics

through economic policy reforms and austerity programs in response to “the oil shocks, fiscal crises of states, perceived crises of welfare systems, declining productivity growth in many industrial countries, and the effects of collapsing world commodity prices on many non-industrialised countries” in the 1970s and 1980s (Hoffman et al. 2006:9; Kingfisher and Maskovsky 2008:116; Ong 2006:501). Neoliberalism reached global prominence in recent decades through policy shifts such as privatisation of public services, restructuring of welfare systems, and promoting of a mode of governance that was marketised, technocratic, and audit-oriented (Kingfisher and Maskovsky 2008:116). Ideologically, neoliberalism has sought to change the relationship between individuals, market, and the state. Individuals are given the ‘freedom’ or right to participate in markets, and the market themselves are free from government regulation (even though the government is significant in encouraging a free market).

What becomes evident through the transformation of these relationships is that citizenry rights and entitlements have become linked to neoliberal criteria. Populations that have become increasingly mobile claim rights and benefits as citizens even if many have limited protections within their own countries. Thus the nation-state features less in debates around citizenship as new spaces open up as “site[s] for new political mobilisations and claims” (Ong 2006:500). For individuals who are displaced or marginalised “bare life become the ground for political claims, if not for citizenship, then for the right to survive” (Ong 2006:500). From the perspective of the neoliberal state the responsibility for citizens’ security, wellbeing, and quality of life has become increasingly the responsibility of the citizen as they enact the freedom to calculate and invest in their own lives. The government, then, wants a self-actualising individual who is active in challenging global insecurities (2006:501). Yet with the shift towards market-opportunism and individuals interacting with these market forces in order to ensure their own security and wellbeing, new spaces have opened up for citizens to make claims for essential resources under the neoliberal rubric of democracy. Ong argues that one space in which citizens have become politically organised is when endangered or neglected by the state and non-state institutions. For instance “health-based claims have become an important part of citizenship rights in the West” in recent decades (2006:502-504). Individuals invoke notions of citizenship based on biology in making claims for resources, entitlements, and protection. These claims are “articulated in terms of needs as living beings”, thus, “attest to the contingent nature of what is at stake in being human today” (Ong 2006:504). What I argue is that in neoliberal understandings of citizenship how the state, and by extension non-

state actors, respond to citizen's claims for security and wellbeing is defined in terms of economic, biopolitical, and moral worthiness of the human being, thus creating diverse regimes of living (Ong 2006:504).

Health care in New Zealand has undergone neoliberal transformation since the 1980s. By the 1980s there were few barriers to regulating the expenditure of high-cost, brand-name medicines (Dew and Davis 2014:140; also Tenbensen and Gauld 2000:35). Free medicine was viewed as a "right and expectation of the New Zealand health system", in spite of the government being faced with an expanding pharmaceuticals budget (Dew and Davis 2014:140). The 1980s saw the state tackling of rising health care costs through reforms which enabled the government to be more competitive in negotiations with pharmaceutical suppliers, and in providing health services in general. Pharmac was established "as a separate business unit, outside of the Ministry of Health" in 1993 (Dew and Davis 2014:142). The agency was created to be an independent monopsony power, invoking the values of business and competition in its goal to "purchase an adequate range of pharmaceuticals for New Zealanders" (Gauld 2014:938). It is within this model that Pharmac supports the capitalist production of pharmaceuticals; it is enshrined in Pharmac's legislative obligation to ensure access to a range of pharmaceuticals. The state has become a responsive instrument to pressures from the market to provide health care resources, and being population-focused in legislation and implementation Pharmac represent neoliberal governance (Kanna 2010:102).

Citizens are "thinking, knowing and creative beings" (Jasanoff 2004:94) who understand that states cannot provide vital health care resources to all its citizens; this understanding is seen through citizens asserting a stronger voice in politics and governance (Jasanoff 2004:92). Below I discuss that in issues of pharmaceutical access in New Zealand citizens exist within a form of governance that is biopolitical in that it heavily regulates medicines funding, thus is influential in determining who is entitled to those medicines. I argue that this influence of the state over its citizens is an example of biopower.

Biopower and Responsibility for Health Care

The concept of biopower "refers to the techniques of governance of the modern state, where populations are governed through various practices that subjugate bodies" (Gardner, Dew, Stubbe, Dowell and Macdonald 2011:843; also Nguyen 2005:132). Rabinow and Rose (2006) argue that biopower exists in two poles. The first pole focuses on the politics of the individual

human body. The second concerns a biopolitics of the population as a whole (Rabinow and Rose 2006:196; Whyte 2009:9). The two poles are then conjoined through what is called “technologies of power” (Rabinow and Rose 2006:196), which involve practices of self-surveillance and self-management, in an effort to monitor and control both the individual and society (Gardner et al. 2011:843). Biopower is the expression of Foucault’s idea that power has become situated and exercised at the level of life itself (Marsland and Prince 2012:455; Rabinow and Rose 2006:196). Biopolitics embraces the specific strategies and practices of intervention that are placed on the population in order to achieve desirable and legitimate outcomes regarding vitality and mortality (Rabinow and Rose 2006:197). Biopolitics, as a term, “denotes a politics that deals with life” at the level of the population (Lemke 2011:2). With the advent of biotechnological innovations life is now seen as to an extent transformable and controllable, whilst at the same time marking a significant transformation of politics (Lemke 2011:4). Argued by Lemke, “biopolitics...aims at the administration and regulation of life processes on the level of populations” (2011:4). To then ‘govern’, or regulate, life is to work within practices of “correction, exclusion, normalisation, disciplining, therapeutics, and optimisation” (Lemke 2011:5). Biopower is underpinned by three key ideas: first, there are one or more truth discourses about the character of living human beings and authorities that claim to know this truth; second, approaches that seek to intervene upon the population in the name of life and health; and third, “modes of subjectification” in which individuals are made to work on the self in the name of their health, survival, family, or community (Rabinow and Rose 2006:197).

In the process of pharmaceutical regulation and access, Pharmac become responsible for determining not only what pharmaceutical treatments are made available on the pharmaceutical schedule, but who is entitled to those treatments. As I argue in chapter two Pharmac make these decisions through methods of analysis—such as commercial and market analysis, clinical advice, consultations with the public, and other forms of economic analysis such as cost utility analysis. In utilising cost utility analysis, for example, Pharmac can determine whether a pharmaceutical treatment results in significant health gains compared to the relative costs associated with making that treatment available to the public. Health gains can be understood as the potential health benefits a pharmaceutical treatment can have on an individual’s quality of life. However, for the purposes of economic assessment health is made quantifiable in order to make decisions at the level of the population. For Pharmac then, if the potential health benefits are outweighed by the cost of accessing the drug, the pharmaceutical treatment is likely

to be declined funding; the reason for this being that Pharmac can use the money to invest in a therapeutic product that would provide greater health gains to a larger proportion of the population at less relative cost. What cost utility analysis allows is a means for the state to determine which medicines will be the most cost effective and impact on overall population health. This is especially important considering that the cost of most pharmaceutical treatments are so high. What results is that high cost medicines are less likely to be funded due to being considered not only expensive but only providing health gains to a small number of the population. As Pharmac work with a finite community medicines budget, extra care is needed when making important funding decisions for medicines.

Yet as well as the state monitoring the flow of pharmaceutical resources through the operation of Pharmac the individual also becomes self-surveilling in ensuring access to pharmaceutical treatment. In the face of government rationing of health care patient support groups are employed to respond to and challenge inequalities in pharmaceutical treatment options. This point is elaborated in the third chapter in a discussion of patient advocacy, revealing patients' "narratives of distress" as a means of fostering support from the wider public. As Nguyen argues "these narratives are used tactically – either to improve one's own chances of obtaining treatment or to select those who could best benefit from obtaining medications" (2005:133). In using personal narratives of everyday experiences of chronic illness and navigating treatment, individuals become active voices, challenging government understandings of not only health and illness but also how health imaginaries in New Zealand are embedded in questions of rights, moralities, and responsibilities for human life and its value.

I argue below that individuals incorporate three overlapping 'citizenship projects' in framing their demands for access to pharmaceutical treatment – biological, therapeutic, and pharmaceutical. These citizenship projects contend that citizenry rights and entitlements have become grounded in biology, with individuals making demands for access to the therapies they need. I argue that patients in New Zealand make appeals for treatment access through the use of these three forms of citizenship; as individuals become responsible for their own health, wellbeing, and genetics patients utilise their status as biological citizens through expressing their right to treatment in biological terms; secondly, patients, in being failed by the New Zealand government, are using their status as therapeutic citizens to make demands for therapies through the global order, namely pharmaceutical companies; thirdly, the emergence of the universal right to pharmaceuticals has given patients the capacity to demand access to drug treatments through their status as pharmaceutical citizens.

Biological Citizenship

Biological citizenship encourages citizens to view their nationality and identity in biological terms, allowing these individuals to make ethical demands that they feel impact on their life and wellbeing (Rose and Novas 2005:441). The kinds of claims that individuals can make in this bio-citizenship framework are against things that are seen to cause damage and suffering to life and violate their 'vital' rights as citizens (Rose and Novas 2005:441). In this Agamben's (1998) notion of 'bare life' becomes the basis for citizenship claims and protections, bound up in the practice of human rights.

Biological citizens form their subjectivities in relation to biopower through the act of responsabilisation. Fundamental to biological citizenship, therefore, is that it is both paradoxically individualising and collectivising. As individuals we have become not only responsible for our own health and illness but we have more recently become responsible for our own genetics. This responsabilisation for one's own health and wellbeing is in turn largely shaped by the neoliberal understandings of health and illness that are perpetuated by the state. Moreover, biological citizenship, and by extension biopower, is collectivising as "new forms of biosociality and new ethical technologies are being assembled around the proliferating categories of corporeal vulnerability, somatic suffering, and genetic risk and susceptibility" (Rose and Novas 2005:442). Collectives can make biological claims through the pursuit of activism, through performing such activities as campaigning for better treatment, ending stigma, gaining access to services, and so on – these being rights of bio-citizenship (Fitzgerald 2008:252; Rose and Novas 2005:442). In the creation of these "new-style biological citizens" what becomes clear is that decision-making over diagnosis and treatment is reflective of neoliberal goals of a population of rational, autonomous citizens (Fitzgerald 2008:252-253).

Ruth Fitzgerald (2008) argues that New Zealand is an intriguing site for exploring biological citizenship, for although the country is located at the periphery in terms of global flows of capital New Zealand is still a wealthy country and its citizens "hold aspirations for first world medical services (253). In spite of this however New Zealand has struggled to meet public expectations for 'high-tech' health care, leading to the citizen becoming responsible for ensuring their own health and taking the appropriate measures in order to extend life and delay death (Fitzgerald 2008:253). What is clear in the context of New Zealand is that the state exerts "an extraordinary degree of bureaucratic ethical regulation of medical procedures" (Fitzgerald 2008:253). Thus through the state regulating medical interventions, the state promotes certain

types of citizens within the population, based on biological characteristics (Fitzgerald 2008:252). We can see this unfold in the types of treatment that are made available for certain clinical conditions. In order for individuals to make demands on the state for treatment access, their physician on prescribing medication, and the pharmacist to fill those prescriptions, people need to consider their body and health in biological terms. For the patients I interviewed having a diagnosis allowed their illnesses to be legitimated, giving them a scientific language in which they could discuss their diagnoses with clinicians, pharmaceutical companies, and other medical authorities, as well as become a basis in which they can make demands of the state for treatment access.

In becoming biological citizens the citizen undergoes reshaping, or ‘making up’ in the way they are understood by authorities. The effect of having categories for diagnosis and biological language can be unifying in the sense that an individual’s suffering can be validated by these categories, leading to treatment, or can dividing, in that once categorised an individual takes on the stigma of being chronically ill or disabled (Rose and Novas 2005:445). This biological language can allow patients to converge through incorporating the language of diagnosis, conditions, symptoms, and treatment in support group forums and discussion as well as be used to judge a body’s limits, how an individual patient must act, “and the kind of lives for which they can hope” as dictated by these biological categories (Rose and Novas 2005:446). Citizens’ engagement with popular medical knowledge is hugely important in shaping the self as a biological being. We can see this in patient use of the Internet – an individual can use the web to research diagnosis and treatment as well as finding narratives of fellow sufferers. In these narratives patients discuss their illness, practical ways of managing illness, the impacts of therapies, and challenging issues of access to health care resources. Thus biological citizens are made up ‘from above’, in medical and political authorities creating biological categories, and ‘from below’, in patients’ using narrative techniques to ‘pluralise biological and biomedical truth, introduce doubt and controversy, and relocate science in the fields of experience, politics, and capitalism” (Rose and Novas 2005:446-447).

For those I talked to in interviews many used the biological language of diagnosis in creating patient lobby and support groups. For instance Sarah, who suffers from a rare disease, highlighted how important the creation of a website was for connecting her with other sufferers of the same rare disorder as herself:

When I was diagnosed there was three people already diagnosed. And one of them, a man in New Plymouth, he said ‘oh yeah I always thought it would be good to have a [network]. And we spoke about having a support group because...two of them didn’t know about one of the others anyways so they thought there was just two, you know. But no one had really got together and said let’s form a support group...So, you know, it’s grown over time and people contact me through that website which is good.

William, who also has been diagnosed with a rare disease, sought to create a patient support group that would allow individuals from around the country to become connected, and through this, create better health outcomes for those individuals. As he explains:

We’ve had contact from a few people around the country who have heard about us...and I think it’s helped them certainly, sort of in an informal way so when people get in touch with me and I can say, ‘well there’s someone else who’s got this condition in your area’...I’ll kind of make sure it’s okay with both people and set them up and they form relationships that way.

It is through the incorporation of this biological language of diagnosis that individuals can form collectives and give them a means of communicating with each other their experiences of illness. The use of websites that provide information of particular diseases as well as narratives of patients’ stories allows individuals a means to legitimating their experiences of ill health. It is through the creation of these virtual communities that results in a “biological citizenship of ‘bottom-up’ activism”, a space in which access to treatment depends upon ‘lay’ expertise and collective support (Fitzgerald 2008:255).

Therapeutic Citizenship

Vinh-Kim Nguyen’s concept of ‘therapeutic citizenship’ narrows biological notions of citizenship, referring to the totality of therapeutic treatment options in a geographical setting as well as how these therapies are accessed (2005:126). By therapies Nguyen means the practices, practitioners, forms of knowledge, and products that sufferers use to heal affliction. Nguyen argues that “treatments influence biology, and through these embodied effects representations of the disease, and in turn the subjectivity of those who are able to access them” (2005:143). In looking at global health, particularly around access to HIV/AIDS medication in

Africa, Nguyen proposes that therapeutic citizenship is a “stateless citizenship whereby claims are made on a global order on the basis of one’s medical condition, and responsibilities worked out in the context of local moral economies” (Nguyen 2005:142; Hörbst and Wolf 2014:195). Thus this is a form of citizenship also grounded in biology. In seeking access to therapies citizens make moral claims not to the state, but rather to multinational entities such as NGOs and pharmaceutical companies. These transnational entities, with their arrangements of power, cultural values, and understanding of treatments, are perceived as having the capacity to successfully claim patients’ rights to the treatments they lobby for (Hörbst and Wolf 2014:195). For the health activists themselves, in lobbying for certain treatments and mobilising resources what results is the creation of a therapeutic community, embedded in biological understandings of health and treatment. In utilising these therapies individuals must use a form of exchange, which may be monetary, or draw on ‘moral economies’ of obligation and reciprocity (Nguyen 2005:126). Thus, in accessing these therapies individuals and biosocial groups become embedded in wider economic and social relations. Nguyen explains this below.

Of those who were not already active NGO members, many joined and have joined others [and] become increasingly vocal in demanding access to treatment for their condition, setting a global stage for what I have called a therapeutic citizenship. In this new stage of biomedical globalisation, the humanitarian logic of health has inadvertently spawned a political movement. This is a biopolitical movement because what is eminently at stake is life itself, both in access to lifesaving and -shaping drugs and the new forms of life – therapeutic relations to drug-resistant organisms – that it spawns (2005:141).

However, access to therapies is not as simple as leveraging social relations and capital. Rather, access to treatments is constrained by global markets, including the pharmaceutical industry. Advocacy groups point out this structural barrier and thus is the site of contest between patient groups, states, and non-state institutions in issues of therapeutic treatment access (Nguyen 2005:142); this advocacy is termed as therapeutic activism.

Inherent within the concept of therapeutic citizenship is that individuals, in making demands for therapies, must first take on a biological understanding of the self as both an actor and a subject in issues of health. As Viola Hörbst and Angelika Wolf argue, “being a citizen means subjecting oneself to an authority that grants protection and certain rights. Simultaneously, this authority demands to be recognised as such and only grants these rights on its own terms – thus

it sets the rules of how to become this subject” (2014:195). Therapeutic communities, in making demands of the global order, must work within the framework of humanitarian interventions in seeking support from transnationally active groups. As argued by Hörbst and Wolf, both biological and therapeutic citizenship exist in settings where transnational NGOs and international philanthropic organisations intervene, and where activist movements have become established and influential in lobbying for treatment access (2014:195).

Sarah and William, who are both living with a rare disease, believe that the state has largely failed to satisfy their need for treatment. Thus, they have been exercising their capacity as therapeutic citizens through making demands of the pharmaceutical industry for access to the drug therapies they need. William, for instance, told me that he has actively communicating with multiple pharmaceutical companies:

We...weren't successful in gaining access to Soliris... [Yet] there are a number of other companies that are looking at other treatments...What we were hoping is that in the next six months is we'll see a phase two trial in New Zealand....I'm trying to keep a few pharma groups kind of entertained, keep them engaged, because until they're actually on the ground here any one of those groups could decide to move elsewhere.

William emphasises here that in making demands of non-state institutions for access to health care it is difficult trying to keep these institutions engaged and vested in the interests of a minority group of patient advocates in New Zealand. Furthermore, in order for these patient advocates to achieve access to the therapies they need, they are required to undergo certain obligations. For instance, in trying to get a clinical trial established in New Zealand Sarah explained to me that there is a concern that patients may be required to take a placebo whilst in the trial.

V: And so ideally [the trial will] start in February, and does it run for about a couple of years and after that they sort of release the results?

S: Well they release results sort of periodically anyway. The drug in the trial I think will probably be a minimum of three to four years, you know, and it won't be...oh, actually I think there's gonna be a placebo on this one. There wasn't on my one. But I'm not sure yet...Coz a lot of people are reluctant to go on a placebo if they've got a disease that's making them rapidly deteriorate. They want the real thing and they want it now. So that's another thing that they, you

know, with the trial design they'll say to us patients, 'well, would anyone go on a placebo?' And then promise that after six months they would get the real drug. So I said, 'well New Zealanders will probably sign up to that coz they're not getting anything anyway. And after six months they're gonna go 'oh yes pick me', you know.

In seeking alternative treatment through clinical trials patients must draw on certain obligations in order to receive particular therapies. In setting up clinical trials pharmaceutical companies dictate not only which patients can be involved in these trials but who is entitled to take 'real' treatment and who has to take placebos. Thus, in exchange for the opportunity to participate in clinical trials some patients must be willing to forgo treatment; a necessary condition in order for pharmaceutical companies to invest in the therapies that individuals want and need to live. Yet patients will meet these obligations because what is at stake is their survival. As Sarah explains above many patients have a debilitating chronic illness meaning that patients will more readily agree to conditions set out by pharmaceutical companies if it means access to the essential therapies they need.

Pharmaceutical Citizenship

Like therapeutic citizenship, pharmaceutical citizenship also narrows notions of biological citizenship. This form of citizenship is concerned with issues of belonging, exclusion, duties, and rights. Specifically, this form of citizenship asks about the relations between life-saving drugs and legal, political, and social rights (Ecks 2005:241; Ecks 2008:166). For Stefan Ecks pharmaceutical citizenship seeks to answer two key questions: How does legal citizenship determine rights of access to pharmaceuticals? And secondly, what implications does the taking of pharmaceuticals have for a person's status as a citizen? The first question examines issues of equality and entitlement between citizens for access to the pharmaceuticals they need. The second question explores how one's rights are impaired or regained through use of pharmaceutical treatment (Ecks 2005:241). Ecks uses the concept of pharmaceutical citizenship to explore the global prevalence of anti-depressants as a treatment for depression. As he argues:

The worldwide spread of antidepressant medications is part of a global monoculture of happiness', which demands that everyone be 'pain free,

completely comfortable, and ready and able to acquire and consume the greatest quantity and variety of the newest goods and fashions' (2005:240).

Ecks speaks of the monoculture of happiness as being tied to anti-depressant use, but this pursuit of happiness, and its ties quality of life, is indicative of all pharmaceutical treatments. For multinational institutions such as the World Bank, the monoculture of happiness is entangled with notions of consumerism. However, the U.S. American's President's Council on Bioethics in 2003 wrote that, in the face of the global use of pharmaceuticals as treatment for disease, people will only be happy, or 'live truly', if they engage with others. Thus, health is not to be commodified but realised through social integration (Ecks 2005:247). Further, the belief that pharmaceuticals are consumer products means the argument can be made that pharmaceuticals belong in the same category as thousands of other consumer products, suggesting that there really is nothing special about them (Ecks 2005:243). As argued by Marsland and Prince the "logic of choice" transforms patients into customers, and health products as a commodity to be bought (2012:458; see also Mol 2008). Bauman furthers this by contending that with the orientation towards prevention of disease through promotion of health, survival itself is construed as one's own choice (Marsland and Prince 2012:458). The pursuit of health, as means for survival, becomes a lifelong labour (Bauman 1992:141).

Alan, who works as a general practitioner in central Wellington, believes that pharmaceutical companies have created the demand for pharmaceuticals in New Zealand, to the extent that people will actively consume these medicines if it is perceived to have a marginal benefit to their health. Alan explains to me:

I would say...I am suspicious of the international pharmaceutical industry...in that they create the demand for pharmaceuticals and I am not comfortable with the ways in which that is created. And so in terms of access to pharmaceuticals, why do people want them? Well there is a chunk of them [that] want them because the drug companies have convinced them that they would be benefitting from having them. And I think that that's out of balance with the value of them compared to some other things that we might be spending money on... [For instance] I'm perfectly happy that my patients don't have access to the latest treatment for hepatitis C because I agree with the decision being made [by Pharmac] that currently that costs too much for the benefit [of the treatment].

As Alan emphasises to me, the pharmaceutical industry has been influential in creating the demand for pharmaceuticals as treatment for disease, even if the health benefits of the treatment are miniscule in relation to its cost. Patients, in this market model of health, are re-cast as consumers, with pharmaceuticals becoming commodities that are necessary to consume in order to satisfy their need for better health. However this line of thinking diminishes the fact that pharmaceuticals have the power to transform bodies and moods of individuals, as well as transforming social relations. Reducing pharmaceuticals to one of many consumer items that exist is to delegitimise those individuals who make a claim for access to pharmaceutical treatment in order to save their lives.

This viewpoint is particularly resonant in thinking about how pharmaceuticals have become embedded in popular conceptions of health and illness. They are playing an ever increasing role in people's lives, with predictions that global pharmaceutical spending will reach \$1.4 trillion by 2020 (IMS Health 2015). The increasing presence of pharmaceuticals in daily life has allowed scholars to argue for the emergence of 'pharmaceuticalisation'; the process "by which social, behavioural or bodily conditions are treated or deemed to be in need of treatment, with medical drugs by doctors or patients" (Bell and Figert 2012:775; also Abraham 2010:604). Essentially, pharmaceuticalisation is the transformation of social conditions, both that were and were not initially present in the medical domain (Bell and Figert 2012:778), into pharmaceutical matters of treatment (Abraham 2010:604). The theory incorporates the construction of the pharmaceutical regime, regulators, clinicians, and patients as consumers, with their activities contributing to the 'overall dynamics' of pharmaceuticalisation (Bell and Figert 2012:779).

One line of thinking concerning pharmaceuticalisation is that it reflects progress in medical science, for creating an increasingly pharmaceutical society allows for those who were previously undiagnosed or untreated for disease an opportunity to receive the medication they need (Abraham 2010:607). Central to the process of pharmaceuticalisation is marketing, for example in assigning those that were previously untreated to a certain disease label, thus allowing them access to prescription medication. In the process of pharmaceuticalisation marketing is used as a means of altering society's definition of health and abnormality. As John Abraham (2010) argues in his analysis of marketing and pharmaceuticalisation, marketing and advertising of medication is immensely important in the workings of the pharmaceutical industry (609). The pharmaceutical industry spends more money on marketing than on research and development; \$54 billion compared to \$24 billion in 2000 alone (Abraham 2010:609).

Pharmaceutical marketing in New Zealand is particularly influential considering it is one of two countries that allows for direct-to-consumer advertising. Marketing drugs to the masses enables pharmaceutical companies to profit from prescription sales, whilst justifying investments in mass-market medicines (Dumit 2012:56-57). Further, the pharmaceutical industry invests time and money on influencing medical knowledge by enticing medical professionals to write journals and editorials that favour the particular drug product, or invest in ‘ghost writers’ who write on behalf of the pharmaceutical industry (Abraham 2010: 609). Finally, much spending goes towards creating positive public relations, in part through preventing critics from speaking out by withdrawing funding from institutions that provide platforms to critics, preventing publication of critics’ data, and mobilising medical experts to undermine critics’ concerns (Abraham 2010: 610). Therefore, the push for marketing is seen to drive the notion that access to pharmaceuticals is evidence of progress in western society.

Yet, pharmaceuticalisation is more than simply the increase in volume of pharmaceutical spending and consumption. It is also issues around patient struggles for access to pharmaceuticals and the policy debate this creates, which are all part of broader transformations in public health (Biehl 2013:425; also Abraham 2010:605). Biehl, in his work on the Brazilian response to the AIDS epidemic, argues that the state, medical professionals, and patient activists work together to ensure that antiretroviral treatments (ARVs) are made universally available. In framing ARVs as a human right AIDS activists and health professionals lobbied the state to encourage treatment access through policy changes (2007:1087). The Brazilian government, in turn, promoted the production and use of generics as well as reverse engineering antiretroviral drugs. The Health Ministry negotiated price reductions with pharmaceutical companies. The result of this, a ‘policy of biotechnology for the people’, was found to have dramatically improved the quality of life of those living with AIDS (Biehl 2007:1088). Brazil’s response to AIDS is evident of a new state-society partnership, with citizens likened to consumers with interests rather than needs. Moreover, with AIDS activism converging with state policy making, the rights that are fundamental to demands for pharmaceutical access are no longer political but biologically-based (Biehl 2007:1096). In this new landscape law-making becomes the site of state action, whilst activism ensures that these laws are put into place. What exists in the Brazilian case is that all the actors involved “identify a logic [of a] pharmaceutical form of governance” (Biehl 2007:1099). As Biehl states:

Once a government designates a disease [as] “the country’s disease”, a therapeutic market takes shape – a captive market. As this government

addresses the needs of its population, the financial operations of pharmaceutical companies are taken in new directions and enlarged, particularly as older lines of treatment lose their efficacy, necessitating the introduction of newer and more expensive treatments that are demanded by mobilised patients (2007:1099-1100).

Thus, it is not just about guaranteeing access to medicines available today, but also access to new treatments in the future. What becomes clear in Biehl's understanding of pharmaceuticalisation is that different parties come together and unite under one goal of securing pharmaceutical access. I argue that we can see this process of pharmaceuticalisation through the actions of the New Zealand state in its mandate to manage pharmaceutical spending. Pharmac operates with the objective to ensure pharmaceutical access within the funding provided. In its efforts to fund pharmaceutical products Pharmac negotiates drug prices with pharmaceutical suppliers. However, as Pharmac have a fixed budget for purchasing community medicines not all treatments are funded, particularly high cost medicines. This is juxtaposed with health activists who lobby the state for increased pharmaceutical funding. These activists, similar to those demanding access to ARVs in Brazil, use human rights discourse in arguing for universal treatment access.

A critique of pharmaceutical citizenship is that much of the research that focuses on the relationship between biomedicine and citizenship is specific to less-developed, resource-poor settings. The question, as posed by Asha Persson and others, is how we can understand this relationship in resource-rich settings where medicines are more readily available, often more affordable, and a highly commonplace response to illness (2016:2). As they argue, "with the ascendancy of biomedicine and the increasing emphasis in global public health discourse on medication as a human right, anthropologists have turned their ethnographic gaze to questions of "citizenship" across a range of cultural settings" (2016:2). Persson and others are concerned with how the contemporary trend towards biotechnologies, such as pharmaceutical treatment, are used to not only treat disease but also manage risk, de-marginalise people, and regulate populations (2016:2-3).

I argue that the concept of pharmaceutical citizenship can be extended to understandings of the relationship between people and pharmaceuticals in New Zealand. Although New Zealanders have the right to access and consume a range of medicines, there exists two overlapping concerns: firstly, the state is the authority which determines what pharmaceuticals are made

available to the public, and secondly not all New Zealanders are able to access all the pharmaceutical treatments they want and need. Entwined within these concerns are questions of citizenship, responsibility, and accountability. Who is entitled to treatment access in New Zealand? And how does questions of entitlement become tied to how the state and patients conceive of health, illness, and more significantly, life and death?

Neoliberal Ideas of Life, Value, and Responsibility for Health

Debates about the rise of biomedicine and biotechnologies of ‘life’ raise questions about what it means to be human (Marsland and Prince 2012:453). Contemporary understandings of biopolitics is concerned with the effects of power on human life – how does biopolitics shape the principles and morals by which individuals are treated and valued? Marsland and Prince offer two ways of viewing life value: the first is measured in economic terms. Value is determined as the maximum amount one will pay to keep a person alive (2012:458). The second is linked to morality and ethics, where one is forced to question what kind of life is worth living, figuring into opinions about who deserves to live and who deserves to be “rejected into death” (2012:459). These two viewpoints on life value overlap and affect each other. The third way value is conceived is through determining one’s ‘vital’ value. Vital value is the product of the interaction between an individual and their environment. In this interaction, such as through adapting to a chronic illness, the individual learns which values and norms become necessary for survival (2012:459). As Marsland and Prince argue further, a new site of research has become the examination of how human life and its value are created and what consequences result from the enactment of these values in issues of health care (2012:459).

The value that we place on human life is one that is being increasingly influenced by a neoliberal understanding of health. In working within a neoliberal market model health becomes commodified, with health care shifting from the realm of care and protection of individuals to a space of economic value and consumer choice (Marsland and Prince 2012:459-460). Health products are likened to consumer items, with a ‘logic of choice’ then employed by patients in their pursuit of consuming these products. Thus, a patient’s good or bad health practices are reframed as matters of responsibility and choice (Marsland and Prince 2012:459-460; also Mol 2008). Having poor health is then seen as a moral shortcoming of the patient as they are “incapable of living up to the new requirements of market competitiveness and

profitability” (Marsland and Prince 2012:460). This is one of the new ways that economic value is extracted out of the human body and life.

Health within New Zealand is no exception in that it is becoming commodified. One instance in which thinking about health in economic terms has emerged is through the creation of the ‘Price of Life’ calculator. The online tool, developed by a group of public health researchers at Otago Medical School in Wellington, was designed to help decide how much society should pay for life-saving interventions. As Nick Wilson, one of the researchers, argues “it’s...about...what you should invest to save lives by investing in certain interventions. And it’s hopefully a tool that policy-makers can use to help decide in marginal cases whether they should invest more in doing a more thorough cost effectiveness analysis to see if it really is worth it [to invest in one’s life]” (Radio New Zealand 2015). The tool utilises results from the New Zealand Burden of Diseases, Injuries and Risk Factors Study (2006-2016)⁶ as well as patient information in order to determine the Estimated Maximum Intervention Cost (EMIC), that is, how much money could theoretically be invested in an individual whilst still being cost-effective. Included within this initial calculation is “the cost of the health care system” – the cost of intervention for instance – as well as other values such as productivity (Radio New Zealand 2015). Tony Blakely, another Otago Medical School researcher, contends, “I think things like those productivity costs are going to be increasingly important with an ageing population” (Radio New Zealand 2015). The tool is aimed at the policy maker, yet as Nick Wilson and Tony Blakely state it is possible to have “more sophisticated calculators” that could help a clinician decide whether to invest in expensive medicines. Thus for clinicians and policy makers the tool allows them to make decisions about what one can rationally spend on an individual.

One of the concerns of using tools such as the one described above is that human life is monetised – life is simplified down to one’s vital statistics, with the question of restoring health determined by whether the individual *will* be a productive citizen if treated, hence *will* be saved. As Tony Blakely states, “this calculator is giving you the max amount you can spend for that wonder treatment, that wonder drug, wonder intervention which saves a life, where someone is definitely gonna die and returns into full health” (Radio New Zealand 2015). Viewing ill

⁶ The Burden of Diseases study “analyses health losses sustained by New Zealanders of all ages, both sexes and both major ethnic groups (Ministry of Health 2014). Health loss refers to how much healthy life is lost due to premature death, illness, or impairment. The study allows for health comparisons across different population groups, providing an understanding of how disease, injury, and risk can impact on one’s health (Ministry of Health 2014).

health as a loss of productivity in society was expressed by Maria who works as a general practitioner. She stated that inequalities in access to health care meant that we were missing out on people who could contribute to society, but were unable to because of their poor health (2015). Yet commodifying health in this way fails to take into account the lives of those that are prioritised less – that are selected as worth less. But to acknowledge both those who are prioritised less and the need to assist everybody leads to a contradiction in care. For instance Robert, who is Chair of a rare disease organisation, states that a conflict exists in how the public perceives of sick individuals. There is an understanding or “solidarity” in the New Zealand community that individuals should be protected and defended, yet at the same time there is a “hostile reaction” to the idea of spending large amounts of money to save one’s life. William, who suffers from a rare disorder, also speaks of this conflict when discussing how people occupy two, contradictory, positions – individuals who suffer from illness should be allowed access to the therapeutic treatments they need, but not if the treatments are considered too expensive. In entrenching health in economic terms what results is a shift in how we respond to individuals who are the most vulnerable to these neoliberal understandings of health and illness. We empathise with the plight of individuals who cannot access the treatments they need to survive, this being shown in the public response to media stories about patient narratives of illness. Yet because the state prioritises who is entitled to receive treatment, based on presumptions of productivity, the individuals who miss out are those that are perceived as being unable to regain their status as productive citizens even after receiving treatment. What results is that there are individuals who are sacrificed because their life is not worth saving. These individuals are left to die; a necessary consequence for the state when investing in our health.

For the patient advocates I interviewed – Robert, William, Kay, Emily, and Sarah – thinking of life and its value in economic terms does little to address the liberating effects that many medical (and pharmaceutical) interventions can have on enabling life in the face of death (Marsland and Prince 2012:460-461). Rather, thinking about health in terms of ‘the good life’ allows for interventions in health care to stem around the values of solidarity, justice, and care, as well as the principles of individual choice and autonomy (Horton et al. 2014:2; Marsland and Prince 2012:461). Considering life as something beyond merely economic value is to situate concerns around access to health within, and central to, the individual. Further, it is also important to understand that “the value we place in biological life is itself an artefact of historical processes, and that, therefore, the value of life can be cast in broader terms” (Marsland and Prince 2012:461).

In addressing questions of human rights, citizenship, and the role of biopolitics in understandings of human life and its value what becomes a core site of debate and controversy is that of accountability; specifically *who* is assigned responsibility for ensuring equitable access to pharmaceutical treatment. In the New Zealand health care context inquiries about who is responsible, hence held accountable, in ensuring citizens have access to vital health care resources is intrinsically tied to processes of rationing health care expenditure, as well as conflicting public and governmental beliefs on questions of life value, survival, justice, and sacrifice in ensuring the continuation of life through the investment of publically funded services.

In order for Pharmac to be successful in managing the health sector's pharmaceuticals budget, politicians distance themselves from responsibility for Pharmac's actions. Robert, who is a health activist and Chair of a rare disease organisation, argues that in "abandon[ing] their responsibility" politicians have left the process of pharmaceutical purchasing to a group of "bureaucrats who didn't see the bigger picture and thought that...driving this cost effectiveness was actually a good thing when in fact they were doing some bad things, and they...either didn't see it or they saw it and didn't care". Here Robert stressed to me that the process of securing funding for pharmaceutical spending is inherently political. The pharmaceuticals budget must be decided jointly between Pharmac, DHBs, Ministry of Health, and the Minister of Health ultimately approves of the final budget. Robert argues that it is the very same individuals who approve of Pharmac's budget that then remove themselves of ultimate responsibility for how Pharmac later operates.

Moreover, issues of accountability are not only tied to the politics that surround the operation of Pharmac but also that of ethics. Kay, a patient advocate and Chair of a breast cancer organisation, argues that access to pharmaceutical treatment is "a serious issue for our country" and that "a responsible government would look more closely at it and would bring about some reform". William, a patient advocate for rare disease, contends that leaving decisions about health care access in the hands of technocrats is "dangerous" and "anti-democratic" for it removes patients of the ability to have a right or stake in making sure they get access to the most effective treatment for illness. Thus, in issues of pharmaceutical access patient activists are aligned in the fact that in order to be responsible for their health patients need to be supported by a state that will provide them with the health care resources they need to better their health and ensure their survival. In thinking about the underlying political and ethical considerations that are intrinsic within issues of pharmaceutical access, patient activists have a

certain understanding of equality in health care delivery. For patients who experience significant barriers in accessing essential medicines they feel they have become marginalised and neglected by the state. For them, equitable access to treatment is a democratic right and responsibility of the state.

Conversely, there is the argument that the state cannot, and should not, be responsible for ensuring all New Zealanders have access to treatments they want and need. For instance Alan, who is a general practitioner, argues that people should stop complaining about the fact that not all pharmaceutical treatments are funded by Pharmac. As he states:

We're never going to be doing all of that stuff coz it's always gonna cost more than we have to pay, especially if we can't manage what we're doing now...So I guess my wish for the future is that we do a better job of controlling the pressure groups that are attempting to make us spent money...because of their particular self-interest as opposed to keeping the view of the best outcome for the whole community.

Further Alan argues that in making demands for access to certain pharmaceutical treatments there are often other voices that are not heard, thus miss out:

The newspaper makes money out of shroud waving in my view. That they cover things that 'this poor person hasn't got this medication and without it they're going to die'. Well we're all gonna die anyway. All of us die...And the risk is that those that ...have conditions which people feel sorry for, children, and what have you...have the ability to use that tool, and things which are less glamorous...don't get funded and the people I look after are often the people who don't get funded.

Alan is reflecting here that the issue of treatment access is not only prevalent amongst individuals who cannot access high cost medicines. In his work as a general practitioner for many vulnerable members of the Wellington community, such as migrants, low income families and the unemployed, he found that these individuals also experience barriers to treatment access. For Alan the reality is that there are individuals who cannot access the public health system because of issues of poverty or compliance in taking the appropriate medicines. However, the voices that we hear more clearly are those in more 'privileged' positions, who seek access to high cost cancer and rare disease medicines, as opposed to marginalised groups that have less access to more affordable subsidised medicines. Thus Alan is stressing to me that

priority in entitlements to health care services should fall to those that suffer from illnesses that are socio-economically motivated and met with cheaper medicines.

Alan's argument is further reiterated by Carol, who works as a manager at Pharmac, in her argument that one of the issues that Pharmac "struggles with" is working out how, as a government agency, it can contribute to reducing the health disparities that exists within the New Zealand population. As she argues pharmaceutical access is a complicated issue, referring not only to the number of pharmaceutical treatments that are made available to New Zealanders but more significantly that the treatments that are provided should be aimed at improving health outcomes. Inevitably a trade-off exists in which either money is spent on funding new treatment options or 'brands', or money is instead spent on funding pharmaceutical treatments for illnesses that have no therapeutic alternatives. And as Carol concludes:

This trade-off exists no matter what you do...in no possible scenario could we fund every single pharmaceutical product. No country in the world funds every single pharmaceutical product that's available.

This concept of pharmaceutical trade-offs is important in thinking about pharmaceutical justice. For patients, access to pharmaceutical treatment is a question of politics, ethics, and morality. As I explained above patients feel that politicians have largely distanced themselves from responsibility for the operation of Pharmac, which in their eyes is an undemocratic form of governance. The lack of government accountability thus becomes counter to ideas of what is right and fair in access to health care. For Pharmac however, the fact that a trade-off exists in issues of pharmaceutical access also de-politicises issues of pharmaceutical justice, for states are unable to fund all pharmaceutical products that patients need. As Pharmac works within a set budget for purchasing community medicines their focus becomes securing an adequate range of pharmaceuticals. Thus, when facing pressures from medical professionals, patients, and the public, Pharmac's argument that it cannot afford to invest in all medicines presumes that issues of pharmaceutical access are ultimately outside of their control, as opposed to being a political, economic, and moral issue around social justice in health care. What also becomes evident in discourse about pharmaceutical justice is questions of equality, marginality, and privilege. For Alan and Carol, what is most important is supporting those who occupy certain marginalised positions in society, namely low income, refugee background, or unemployed. Contrarily, the patient advocates I spoke with occupy a different marginalised position, one that has formed due to difficulties in accessing high cost medicines to treat cancer and rare

diseases. Thus, what results is contradictory understandings of who is identified as marginalised and how this feeds into how one views the issues surrounding inequalities in health care access.

Conclusion

With a fatal disease and you've got young children, you're gonna do anything to try and save your life. And if I'd taken their advice I would probably be dead, you know – Sarah

In reflecting on the issue of pharmaceutical access in New Zealand what is evident is that both the state and its citizens are significantly invested in securing pharmaceutical treatments to meet individual health needs. The state, operating through Pharmac, is charged with regulating which subsidised medicines are made available to the population. Yet it is through medicines regulation that concerns are raised about who is entitled to medicines access. For the patient advocates I spoke with the state has largely failed in ensuring treatment access for all New Zealanders, thus individuals, taking on a neoliberal understanding of health, pursue treatment access on their own terms mainly in the form of patient activism. It is through activism that patients can make demands for treatment access through their status as biological citizens. What results from neoliberal understandings of health and wellbeing is that one comes to view health, and by extension life, as a commodity. Thus the consumption of pharmaceuticals serves as a solution to problems of disease and potentially death. What is important to understand, and is reflected in the quote said by Sarah above, is that in issues of pharmaceutical access for individuals who have fewer entitlements to treatment what is at stake is survival.

Chapter Two:

The Role of Pharmac in Prioritising Life and “Letting Die”

The previous chapter was concerned with situating the issue of pharmaceutical access in New Zealand in relationship to citizenship. As health care costs rise, more attention has been paid to the ethical issues that surround rationing and the actors involved in making decisions about the allocation of health care resources. It is widely acknowledged that although health care services have the goal of providing preventative, curative, and rehabilitative treatment, “no one country can provide completely unlimited health care services for all its citizens” (Coyle 2012:15; also Brock 2002). Thus the question becomes *who* should be prioritised when it comes to health care access? In this chapter I examine the emergence of Pharmac and its role in regulating what medicines are made available to the New Zealand public. Pharmac’s policies are designed to determine which medicines are cost-effective, so deemed worthy of investment. Embedded within these policies is the belief and understanding that health, and life itself of citizens, is calculable. In prioritising which medicines should be publically funded Pharmac is determining whose health, and indeed whose lives, are most worthy; and conversely who should be neglected unto death.

Emergence of Pharmac

Medicine prices prior to the early 1990s were rapidly increasing, and the New Zealand government was concerned that their growing expenditure on medicines would lead to restrictions in other healthcare funding (Dew and Davis 2014:140). Pharmac, more formally known as the Pharmaceutical Management Agency, was first established in 1993 as a non-profit company designed to negotiate with suppliers of pharmaceuticals (with its budget being distributed by Regional Health Authorities) (Coyle 2012:7; Dew and Davis 2014:142). Pharmac, in taking over pharmaceutical spending, inherited the management of the Pharmaceutical Schedule, which by that time had a list of 2,000 pre-existing subsidised

medicines (Coyle 2012:7). However, with government health reforms between 1999 and 2000, Pharmac became a Crown-owned agency as passed in the New Zealand Public Health and Disability Act 2000 (NZPHD 2000:47). As per the Act, the main objective of Pharmac is “to secure for eligible people in need of pharmaceuticals, the best health outcomes that are reasonably achievable from pharmaceutical treatment and from within the amount of funding provided” (NZPHD 2000:47). Pharmac signed a funding agreement between itself, DHBs, and the government, and enacted a National Medicines Strategy. This involved Pharmac-run panels of medical experts who worked together to establish subsidy schedules in order to examine the relative costs and benefits of medicines (Coyle 2012:7).

Pharmac’s budget is set after consultation between District Health Boards (DHBs) and the Pharmac board. The budget recommendations that come from this consultation are then referred to the Minister of Health who confirms the budget in association with the government’s budget in May each year (PHARMAC 2016). Keeping under budget for each financial year is a requirement by law of Pharmac, as Pharmac’s spending directly affects DHBs who hold funding for medicines. If Pharmac overspends DHBs would have to “increase debt or reduce their spending in other areas in order to meet this overspend, which could impact other important health areas” (PHARMAC 2016). In negotiating with DHBs and the Minister of Health for pharmaceuticals funding Pharmac are responsible for making sure health spending remains sustainable. Thus, in order to work within the budget given Pharmac uses particular tools to review funding applications for medicines; these tools enabling Pharmac to prioritise which pharmaceuticals will be made available to New Zealanders.

Cost-Utility Analysis

Pharmac operates using taxpayer funding meaning that Pharmac’s decisions regarding funding for pharmaceuticals needs “to represent good value for money for the benefit of all New Zealanders” (PHARMAC 2016). As Pharmac acknowledges, funding is limited and thus involves making “some tough choices” (PHARMAC 2015:1).

As Pharmac must work within a fixed budget, it is impossible to fund every new pharmaceutical that may potentially benefit someone. The demand for pharmaceuticals will always exceed our ability to pay for these pharmaceuticals. In short, choices are inevitable (2015:8).

In order to determine which pharmaceuticals to fund Pharmac uses cost-utility analysis (CUA). CUA is an analytical tool that is used to assess the additional health benefits and costs associated with a pharmaceutical treatment. In this assessment Pharmac wants to know how the pharmaceutical treatment under assessment compares to other pharmaceutical treatments that are publically available (PHARMAC 2015:1). Pharmac argues that CUA is a beneficial tool as it helps reveal the relative value of the pharmaceutical product under scrutiny as well as offer a means to compare different pharmaceutical treatments and identify which options provide the best health outcome (PHARMAC 2015:8).

In calculating the CUA of a particular pharmaceutical product the data is obtained from results of clinical trials. Ideally clinical evidence comes from conducting randomised controlled trials, and are included in the funding application. However, as noted by Pharmac, applications include clinical evidence of varying quality. As Pharmac state in its 2015 report *Cost-Utility Analysis (CUA) Explained*, the more uncertain Pharmac are of the benefits and costs associated with purchasing a pharmaceutical product, the more difficult it is to make a decision. Pharmac can mitigate the risk associated with this uncertainty by sharing the risk with the pharmaceutical supplier, targeting funding to groups most likely to benefit, or declining to fund the medication until more clinical evidence is presented (PHARMAC 2015:6). It is then Pharmac's job to assess this evidence, using CUA methods, and as conducted by the Pharmacology and Therapeutics Advisory Committee (PTAC) and clinical advisors on specialist subcommittees. These CUA results are considered along with Pharmac's decision criteria (formerly known as Factors of Consideration⁷) (PHARMAC 2015:3). A CUA result is established when the benefits and costs are combined giving a figure expressed as quality adjusted life years (QALY) gains per \$1 million; that is, how many healthy years are gained from each million spent (PHARMAC 2015:3,6). It is important to note here that in calculating the CUA for a drug treatment under review, Pharmac are driven by certain understandings of health and its value, specifically the belief that health is a commodity the state invests in through funding particular pharmaceutical products. The pharmaceutical treatments that are then funded are ones determined by Pharmac to be cost effective, due to their clinical

⁷ The 15 factors of consideration considers the three levels of impact of funding decisions—to the person, the person's family/whanau and wider society, and the broader health system—across different dimensions (need, health benefits, costs and savings, and suitability) (PHARMAC 2015a). Pharmac cites that these Factors can take into account a wider breadth of impact by acknowledging that health impacts can lie beyond the person receiving treatment (PHARMAC 2015a).

effectiveness and low cost. I outline below the cultural assumptions that underpin the process of conducting a CUA of pharmaceutical treatments under Pharmac review.

The benefits of a pharmaceutical treatment are estimated using quality-adjusted life years (QALYs), which require looking at a combination of two things: a treatment's effects on how much longer we live, and also on how much better we live (PHARMAC 2015:1); in sum, this measurement is used to define the added benefit of a pharmaceutical treatment (Coyle 2012:25). In measuring the effect of a pharmaceutical treatment on quality of life, Pharmac looks at social factors such as impact on mobility, ability to self-care, ability to undertake usual activities, and levels of pain and discomfort. The subjective value of these factors are then quantified in order to be included in CUA calculations. According to Pharmac there is "extensive international information" about these factors (including a survey conducted in New Zealand) (PHARMAC 2015:4). In using QALYs, comparative analyses of a treatment can be made in order to determine that treatment's value for money.

Making evaluations of the potential health benefits of a pharmaceutical treatment is a contested process. An example of this is Pharmac's funding decision of the rare disease treatment Soliris (Eculizumab). As part of the application process for funding Soliris Pharmac needed to calculate the potential QALYs that people would gain if they used the treatment. The pharmaceutical company who made the funding application for Soliris submitted their evidence of how much survival gain the treatment gives to patients. Pharmac considered this evidence, as well as advice from the PTAC subcommittee, and in response stated that the QALYs patients would gain from using Soliris as treatment is 9.2 (6.8 QALYs from increases to quality of life, and 2.4 QALYs extension of life to patients); this figure being very different to what was quoted by the pharmaceutical company. However, Pharmac also notes that, "with a significant price reduction [of the Soliris treatment] we expect that the model will become more sensitive to other variables" (PHARMAC 2013:3). The other variables include 'quality of life' and 'additional health states', meaning these QALY calculations are not fixed but changeable. The difference in QALYs that the pharmaceutical company and Pharmac used to assess the health benefits of Soliris treatment is significant as QALY is one of two key components in analysing the cost effectiveness of a pharmaceutical treatment, hence, whether the treatment will be funded by Pharmac. For William who has a rare disease and requires Soliris treatment, he argues that the different QALY values used by both the pharmaceutical company and Pharmac is testament to the fact that determining whether a drug is cost effective is an overtly political process. As he explains:

What Pharmac are trying to do...is obviously...drive down the price. But it's also...that kind of flexibility that they kind of allow...it doesn't give you a great deal of confidence right? Who knows how much it would have changed the outcome...I'm some guy that doesn't have any medical background. I'm supposed to be saying 'no, Pharmac are grossly [changing] these numbers?' ...What weight does my voice have in that kind of argument?

The process involved in determining the health benefits of a medicine is complicated by the fact that there exist different understandings of how health is calculated. For William, a treatment is effective if it "stop[s] the destructive process" of a disease. Implicit within this explanation is the understanding that the pharmaceutical treatment does not necessarily have to cure illness so long as it extends to one's survival. Thus a treatment is considered beneficial if it results in even minimal management or improvement of one's health. For Pharmac, the impact of a pharmaceutical treatment on one's health is determined by impacts on one's quality of life – will the medicine under scrutiny allow the patient to live normally? That is, does the medication allow for an individual to regain their status as a productive citizen? Inherent within this understanding of health is that it is tied to neoliberal ideas of productivity and self-management. Sickness disrupts daily productivity, challenging one's agency and one's value in the world (Hay 2010:260). In thinking about productivity as "engaging in activities of personal or social value", medicines are considered beneficial if they improve one's ability to be employable, perform household tasks, or any other activity that contributes to one's wellbeing (Hay 2010:262). Therefore, in determining the health benefits of a treatment Pharmac utilise a neoliberal understanding of health and illness, in which the ultimate goal of a treatment is the re-establishment of a fully-functional, self-managing individual.

The second component that needs to be calculated in cost utility analysis is that of cost. In assessing costs of a particular pharmaceutical treatment this includes the 'direct cost' of the treatment itself (to purchase from a pharmaceutical company), 'direct patient health care costs' (such as general practitioner visits or pharmaceutical co-payments), and other costs that may impact the health sector occurring as a result of funding the pharmaceutical treatment (PHARMAC 2015:1,5).

Determining the impact of cost on a treatment's overall effectiveness is another site of contestation that was stressed to me by many of my participants and Pharmac itself. For

instance, in its 2014 discussion document *High Cost Medicines for Rare Disorders*, Pharmac stated that the problem faced with access to rare disorder medicines is that:

The issue of access to high cost medicines for rare disorders is likely to be an on-going one. It's likely that medicines in the future will be increasingly expensive and targeted at relatively few patients. Although Pharmac does fund some expensive medicines, a high price reduces the likelihood that a medicine will be funded...because of the impact that price has on two decision criteria—cost effectiveness and budgetary impact (2014:1).

As medicines become increasingly more expensive overseas pharmaceutical suppliers realise that they need to show clinical evidence of the health benefits of their pharmaceutical products in order for states to invest in the treatments. Moreover, as pharmaceutical suppliers continue to charge high prices for their medicines overseas, these suppliers have less incentive to cut their prices in New Zealand. The concern becomes that high cost medicines will continue to be underfunded, meaning that patients that suffer from a rare disorder will continue to miss out on treatment.

Robert, who is an ex-Chair of an umbrella organisation for rare disorders, and himself has two children who have been diagnosed with a rare disorder, reflects that Pharmac views cost effectiveness in CUA analysis as being tied to 'value':

Access to medicines [is] a major issue...there's a multitude of really important issues. There is...the state of the health system, economic realities, the limited budgets, the rationing process...within that there is the emphasis that's put on value for money. Which is a very strong thing here in New Zealand...And I think that's a cultural phenomenon for New Zealand where there is a much stronger emphasis on value for money...In many other countries [it's] about what's right to do...what's fair and things like that...even though the costs are high.

In referring to 'the health system', 'economic realities', 'limited budgets' and 'the rationing process', Robert is highlighting the wider politics surrounding health care in New Zealand. The size of the pharmaceuticals budget that Pharmac use for purchasing community medicines is politically determined by the state. In working within this budget Pharmac incorporate policies, such as CUA, that are designed to calculate and compare different drug treatments in order for the government agency to prioritise the most cost effective medicines. Prioritising medicines

is a consequence of the state promoting a neoliberal model of health care, where agencies such as Pharmac must conform to a set pharmaceuticals budget whilst also being competitive in the pharmaceuticals market. Thus, underlying Pharmac's policies for purchasing medicines are ideologies of investment and value. Yet this ideology of investment and value exists in opposition to ideas of fairness and justice that Robert espouses as important when dealing with health care inequalities.

Robert's perspective is very much aligned with Hamish, a GP in Wellington, for he argues that inequalities in health care will persist if the state continues to measure health and treatment in economic terms. He explains to me:

I think with the current emphasis on measuring everything in money that...inequality will increase further...if we keep going in the same direction...I expect at some point people will become unhappy with the current political direction and emphasis on measuring everything in money...I think the current model they're trying to simplify too much again...like in the 90s where the market works for everything. Well market works for some things...but it doesn't work for everything. And I think a bit more recognition of that...is likely in the future but there's no sign of it at the moment and just for some reason that doesn't seem to resonate with the voting public.

Carol, who works as a manager at Pharmac, herself contends that it is necessary for Pharmac to incorporate a value for money perspective when making funding considerations:

In practice with the budget [we have] is...to compare all the possible things that we can invest in...to decide which ones will result in the best health care....and we do that through a process of prioritisation. And what that means for us is that opportunity cost is really important. If we invest in something where there is maybe insufficient evidence about whether it works...relative to the cost....Those investments, if we invested in [them] that would mean we'd be giving up the opportunity to invest in something else that would result in better health outcomes.

The fact that Pharmac needs to be making smart investments in health care resources is one that Carol argues is not fully comprehended by the public but is significantly important in how Pharmac make funding decisions. Carol's comments reflect wider changes to New Zealand as a welfare state. Until the 1980s the New Zealand government championed an ideology of

collectivism, where individuals were entitled to social services by virtue of being New Zealand citizens, such as universal coverage to health care resources (Kingfisher and Goldsmith 2001:717; also Esping-Anderson 1990). However, the 1980s onwards saw the emergence of a neoliberal welfare model, where goods and services were provided by the market, and citizens became likened to consumers (Tensenbel and Gauld 2000:35); Jane Kelsey labels this shift ‘the New Zealand experiment’, encapsulating the state’s increasing focus on market liberalisation, free trade, limited government, and fiscal restraint (1995:x). As argued by Catherine Kingfisher and Michael Goldsmith (2001:716), neoliberalism “makes certain claims about the economy, the proper role of the state, and the nature of personhood”. In speaking about health, reforms in the early 1990s sought to establish the purchasers and providers of health as businesses, where government agencies were compartmentalised so that each only had one focus (Tensenbel and Gauld 2000:36). Moreover, the neoliberal welfare model also advocated for smaller government and restraining of government expenditure; the economy became the central focus for the state (Tensenbel and Gauld 2000:36). Yet as Chris Shore (2010:17) argues the state is necessary for the ‘neoliberal programme’ to function properly. We can see this in the emergence of Pharmac through the health reforms of 1993. Pharmac was established with one major objective – to secure the best health outcomes through pharmaceutical treatment and within the funding provided. Thus social goods, such as pharmaceutical treatment, are to be provided through incorporating an economic neoliberal focus; Carol contends that Pharmac do this by utilising policies that focus on investment, value, and opportunity cost. In the use of this neoliberal vocabulary Pharmac employs a business mind-set, and health care is a commodity in which the state becomes vested in.

In spite of this however, many of the patient advocates pointed out to me their frustration with pharmaceutical access being tied to cost effectiveness. Sarah, who suffers from a rare disease, shared with me her feelings towards Pharmac:

We call [Pharmac] the clobbering machine...because if we raise our heads and say ‘well, we really need this medication’, Pharmac will actually put in the media ‘oh well...we’ve got to balance it out. We can help this one woman or we can help 500 people with this medication’. And coz everyone’s going ‘don’t save this woman’, and they generally take the side of Pharmac coz Pharmac skew things to make you look like the bad person. You get made to feel guilty and bad for even daring to ask for medication. It’s how they make you feel.

Sarah is frustrated and angry that Pharmac incorporates a public relations strategy as a means to denounce those who disagree with its decision-making in the media. What is highlighted here is the difficulty that comes with being a patient advocate and challenging Pharmac in its perpetuation of notions of investment and cost effectiveness. The state, then, not only enforces this value for money perspective through policy, but this mentality has manifest in the financialisation of everyday life in the access of vital goods and services such as housing, education, and health care.

As Pharmac argue in its 2015 report *Year in Review*, access to medicines for rare disorders and cancer has been an issue of concern for years. In response to this issue Pharmac created a 'Rare Disease Fund' where \$25 million over five years would be made available to invest in rare disorder medicines. Currently, Pharmac has been encouraging competition among several pharmaceutical companies who supply these medicines, receiving twenty-eight proposals from eight suppliers of medicines for rare disorders; a result which caused Pharmac to remark that "we are optimistic that people with rare disorders will gain funded access to medicines as a result of this process" (PHARMAC 2015b). In August 2015 Pharmac approved funding for the first medicine submitted through the Rare Disease Fund process—Icatibant—a drug used to treat severe attacks that come with the rare blood disorder hereditary angioedema (PHARMAC 2015b). It is estimated that up to 90 people suffer from this blood disorder in New Zealand, with 25 people meeting the eligibility criteria for the drug (PHARMAC 2015b).

I asked William what issues he saw with the Pharmac model when it came to consideration of orphan treatments; a category in which rare disorder medicines fall under. He responded that there was much publicity surrounding the funding of Icatibant. Yet the issue underlying the decision to fund this treatment was that the pharmaceutical company who manufactures Icatibant is large, and with its size has the ability to negotiate with Pharmac on the drug's price. This enables Pharmac to still retain its dominance in negotiating the best price for Icatibant. However, as William states, many individuals will be without the medicine they need because much of the highly needed treatment are generally sourced from pharmaceutical companies who only manufacture a single pharmaceutical product. Therefore the pharmaceutical company are less likely to reduce their prices, nor even enter into negotiations with Pharmac in the outset. Joseph Dumit (2012) reasons that most pharmaceutical companies are not interested in investing in researching and developing rare disease treatments because they are not profitable. As Dumit makes clear, "a pharmaceutical company thinks of health directly in terms of number of prescriptions sold" (2012:94). Investing in research and development of rare disease

treatments will not result in many prescriptions sold, thus are not worth investing a significant amount of money. What results is that a smaller pharmaceutical company will invest solely in developing a small number of pharmaceutical products, thus becoming the sole supplier of those treatments. These pharmaceutical companies then have the power to set drug prices and command a greater share of the market for those drug therapies; Pharmac has less power in these negotiations, and are less likely to come to an agreement over these high cost treatments.

This viewpoint is epitomised by Carol when she explains that in trying to fund rare disorder medicines Pharmac found that pharmaceutical companies “weren’t willing to come to the negotiating table coz they thought that we weren’t ever gonna consider anything that they probably considered to be reasonable”. William argues that the reason why Pharmac does not negotiate with small pharmaceutical companies is because “most of the treatments are for one disease only, there are not multiple [pharmaceutical] suppliers for each condition. So you’re making a decision between different patient groups. Not necessarily based on efficacy or...survival benefit, but based on what sort of deal you can cut with a supplier of multiple treatments”. Thus, when making decisions about which pharmaceutical treatments should be funded the goal for Pharmac is not always about achieving health outcomes, but rather how favourable Pharmac’s position is after negotiations with pharmaceutical companies. The Pharmac model for negotiating medicines prices is based on an ideology of investment. In seeking to remain competitive in the pharmaceuticals marketplace by only negotiating with large pharmaceutical companies Pharmac prevent certain pharmaceuticals from being considered for public use – namely high cost medicines. Within the New Zealand health care system Pharmac perpetuates neoliberal ideology of investment and cost effectiveness as a means to restrict pharmaceutical spending. This combined with pharmaceutical companies wanting to profit through raising medicines prices has resulted in high cost medicines being prioritised lower in favour of purchasing pharmaceuticals which are cheaper and meet the health needs of a greater proportion of the population. Thus individuals who need access to high cost treatments must wait for Pharmac to fund treatments through either the Rare Disease Fund or wait until a generic version of a drug treatment is made available for Pharmac to purchase.

The Process of Pharmaceutical Funding

According to Pharmac anyone is entitled to submit an application for pharmaceutical funding, this including a pharmaceutical supplier, health professional, or patient. The application is referred to one of Pharmac's Therapeutic Group Managers (TGMs) who collates the application (and clinical evidence the applicant supplies) to then be considered by the Pharmacology and Therapeutics Advisory Committee (PTAC), and potentially a PTAC subcommittee. The PTAC is comprised of practicing doctors who consider the clinical evidence around funding applications, as well as taking into account other issues, before making recommendations to Pharmac (PHARMAC 2016). These recommendations include whether the pharmaceutical should be funded and what priority level it should be given. If Pharmac decides to fund the pharmaceutical then one of Pharmac's TGMs will negotiate with the pharmaceutical's supplier to reach a provisional agreement. Pharmac then consults with the health sector on the proposal and considers this feedback before making any final decisions. The final decision is usually made by the Pharmac board, which is made up of individuals that were appointed by the Minister of Health, and who is "ultimately responsible for all of Pharmac's decisions" (PHARMAC 2016).

In talking with Carol, who works as a manager at Pharmac, it became clear that the process of funding pharmaceuticals has contradictions. As I stated above, Pharmac claims that anyone is eligible to submit an application for pharmaceutical funding. The caveat, as Carol tells me, is that patients can put in an application for funding if the medicine is to be listed on the pharmaceutical schedule (thus available for any individual who needs the treatment), yet that patient is not entitled to submit an application for medicines funding through a scheme that funds patients on a case-by-case basis. The scheme Carol is referring to is the Named Patient Pharmaceutical Assessment (NPPA), which is a policy that enables Pharmac to review applications where an individual wants access to a pharmaceutical treatment that is not currently on the pharmaceutical schedule (PHARMAC 2016). The reason why patients cannot apply through the NPPA scheme is, as Carol explains, because "[Pharmac] needs...clinical information [that a] patient isn't able to give us by themselves". The patient then faces a significant barrier in trying to seek access to particular medicines for they are not considered to have the required clinical knowledge needed in order to make funding applications. Thus, although patients have an intimate knowledge of their diagnosis and what treatments may help manage their health they become reliant on their physician to submit a funding application – the physician then takes on the responsibility for seeking pharmaceutical access on behalf of

their patient; the patient's voice thus becoming subsumed within the physician's voice, and clinical knowledge becoming prioritised over a patient's knowledge of their own body. For patients then this creates a new type of dependency, for their ability to navigate within Pharmac's funding processes requires that their physician believes that the pharmaceutical treatment would be of benefit to the patient, and the physician needing to then support their client through submitting a medicines funding application. Sarah, who suffers from a rare disease, asked her doctor if they would be willing to submit a funding application on her behalf. Sarah recalled that her doctor told her she would not because, according to Sarah, "[she didn't] want to lose face with Pharmac". In her conversation with her doctor about why she refused to submit funding applications to Pharmac, Sarah was told that Pharmac explicitly asked her doctor not to submit any funding applications because they will be "turned down". This explanation angered Sarah:

...she's a doctor, she should be about the patients, not about doing Pharmac's bidding...So when you've got Pharmac who don't wanna know, and you've got doctors who don't want to lose face with Pharmac and won't put applications in for your medicines for a fatal illness, where does that leave patients? So basically, that's where it ends. If you can't get a doctor to put in an application for you what do you do?

The process involved in submitting an application for medicines funding leaves patients in a vulnerable position. Through determining who is eligible and has the clinical knowledge to make funding applications, Pharmac ultimately controls the process by which medicines get prioritised funding. Patients such as Sarah in the meantime are left without representation nor voice in the funding process.

Exerting Control in Medicines Regulation

Being the sole purchaser of medicines and medical devices on behalf of DHBs means that Pharmac has considerable power and influence over the market. The agency has "almost complete dominance over the setting of prices for medicines..." (Coyle 2012:113), with this power manifesting from Pharmac's exemption from Part II of the Commerce Act 1986. The Act allows Pharmac to be able to lessen competition, fix prices, and use a dominant position in the market (Coyle 2012:113; Dew and Davis 2014; Gauld 2014). For Pharmac being exempt

from Part II of the Act allows the agency to establish a national pricing policy for purchasing medicines from pharmaceutical companies (Coyle 2012:113).

Further the Commerce Act also allows Pharmac immunity against prosecution. The reasoning for this is that any single legal proceeding brought against it by a pharmaceutical company would cost up to \$1 million to defend, due to “the complex nature of the Act and the need to call international expert witnesses” (Coyle 2012:117). Consequently, the potential costs of such litigation would mean that Pharmac has less money to spend on purchasing medicines (Coyle 2012:117). However, the concern that it raised with this is that Pharmac, as a Crown agency, must be held accountable through defending its actions. As Coyle argues:

...it would not seem appropriate that Pharmac should be protected from this normal level of legal jeopardy. If the government were to provide Pharmac with an extraordinary level of legal protection this would create the impression that they are entitled to act in ways that lie outside that which would be considered normal commercial dealings by the courts (2012:118).

In response to the accusation that Pharmac, and by extension the New Zealand government, is not holding itself accountable for the decisions it makes in medicines purchasing, Pharmac contend that saving public funds from litigation outweighs any harm to pharmaceutical companies (Coyle 2012:118). This is an interesting response as it highlights the fact that Pharmac, in order to be effective in reigning in pharmaceutical spending, must act with impunity by having greater control over the pharmaceutical market and thus exert strength in negotiations with pharmaceutical companies. By having this autonomy – that is, freedom to be a dominant power within the pharmaceutical marketplace and freedom from being prosecuted for exerting this power – Pharmac is better able to secure pharmaceuticals at a lower cost, and the government, by extension, are better able to fulfil their responsibility to deliver health care resources.

The fact that Pharmac is protected from being prosecuted by the pharmaceutical industry suggests that there are limits to the neoliberal market model that Pharmac purports to follow. Under the rubric of a neoliberal model of health care Pharmac not only dictate which medicines are funded, but believe they need to do this with little interference from non-state actors in the market, specifically pharmaceutical companies who have their own goals and agendas in their pursuit of access to the New Zealand marketplace. As pharmaceutical companies are concerned with profiting from its pharmaceutical products they want to be competitive in negotiations

with Pharmac in order to command medicines prices, but also have the capacity to appeal Pharmac's funding processes if their applications for funding are declined. However, state legislation enables Pharmac to have power and freedom within the pharmaceuticals market, contrary to neoliberal ideas of little state interference and reliance on the market to provide social goods and services. I suggest here that in the provision of pharmaceutical treatment Pharmac's design both enables a form of neoliberal governance through the restriction of health care spending and focus on investment, yet also circumvents this form of governance through the state maintaining a dominant force in the pharmaceuticals market – a contradiction to neoliberal notions of the market as the provider of vital goods and services.

Pharmac is the branch of government which is responsible for ensuring that citizens have equal share in entitlements to pharmaceutical treatments (Coyle 2012:27). Thus, when issues of inequalities in pharmaceutical access arise, Pharmac is the branch of government which is ultimately held accountable. Many of the individuals I talked to who suffered from a rare disease or cancer believed Pharmac were responsible for failing to secure access to the pharmaceutical treatments people wanted and needed. For instance Sarah argued that, "Pharmac need to...realise these medications are available in every other country, and you're gonna get more of these medications...New Zealand can't continue saying 'we're not gonna provide that for...fatally ill people'. They need to get with the twenty first century". Sarah then told me of the time where she and other sufferers confronted Pharmac at their offices – a response to Pharmac's lack of accountability in issues of pharmaceutical access:

...we went to Pharmac and there were several of the Pharmac people including Peter Moody who at the time was the medical director. And none of these people really know much about [the disease] at all. And they sat there stone-faced, and, really actually didn't care. Didn't care. It was horrible. Like you pour your heart out and think 'how can these people turn us down?' Here we are all in various states of decay, and they still can sit there stone faced. And...I came out frustrated, crying. I was so...annoyed and hurt that they didn't care".

Sarah uses evocative language in describing how Pharmac responded to patients appeals for access to the treatment they needed. For Sarah, the moral imperative is survival in the face of abandonment by the state. In deploying concepts of care, abandonment, and fairness Sarah is emphasising the vulnerability and fragility of patient's lives within the state health care system. This emotive discourse also serves to make Sarah's point more compelling through

highlighting the inhumanity of Pharmac, and more widely the state, in deciding who lives and who dies. Conversely, in my discussion with Carol about Pharmac's medicines funding process and public misunderstandings of the process, she explains:

...when we were looking at Eculizumab a couple of years ago we...worked out the fact that we could fund this treatment which would result in symptom management benefits for around five to six New Zealanders. But [at] the same price we could invest in a new cancer treatment that would benefit around 40,000 New Zealanders. I think the trade-off is not that apparent when you're looking at this treatment and the need of those patients...I mean particularly for rare disorders the illness is often really horrible, the patient's need is often really high, it's a really difficult situation...and obviously it makes complete sense for those patients, if there's any treatment, even if there isn't much clinical evidence that it works, that's still some hope for them, you know. That's still important to them because actually it could help...their situation.

Carol is also employing a language of care and hope in explaining why some individuals are denied access to pharmaceutical treatment. For Carol, in empathising with those who suffer from rare disorders, she is aware of the significance and value individuals place on pharmaceutical treatment for survival. Yet Carol is also deploying this evocative language of care in order to legitimise the moral complexity that surrounds Pharmac's processes of pharmaceutical funding. Thus, what is revealed in these narratives is that Sarah and Carol hold two different but valid epistemologies of health care, with competing notions of responsibility for ensuring treatment access. In using population figures to defend which medicines are ultimately funded, Pharmac create distance from patients' bodily suffering through the process of rationalisation. What results with thinking about pharmaceutical trade-offs in this way is that health is rationalised as opposed to being driven by emotion.

Thus it can be seen that questions of responsibility and accountability in issues of pharmaceutical access are multi-layered; but I wish to add another layer to this complexity. As Pharmac have absolute responsibility in decision-making concerning pharmaceutical spending, politicians have absolved themselves of the responsibility for not only ensuring that Pharmac acts with transparency when making funding decisions but more fundamentally responsible for

life and death (Dew and Davis 2014:138,148; Gauld 2014:940). During the Herceptin debate⁸ Kay and other members of the breast cancer group took a patient-led petition to Parliament, where the response was one of not only indifference but disdain:

We sat in Pete Hodgson's office with women with HER2-positive breast cancer. Put the evidence in front of him and he said to us, 'why should I listen to you. I take my advice from Pharmac and they give me very good advice'...And David Cunliffe refused to meet with...the breast cancer special interest group...who wanted to say to him 'actually your government's doing the wrong thing you need to push Pharmac on this. You need to persuade them to fund this medicine'. He wouldn't even meet with them.

For politicians, Pharmac exists as the agency that has sole responsibility over securing pharmaceutical treatments, and with this responsibility Pharmac becomes the sole government body accountable for its operations in the eyes of the public. Politicians can then use this to remove themselves of any responsibility over criticisms of Pharmac's actions. The relationship between Pharmac and politicians is then reciprocal – through legislation Pharmac maintains its autonomy, but through this autonomy politicians are able to disengage from debates surrounding the inequalities of pharmaceutical access. I argue here that in becoming an independent government agency moral questions concerning health become compartmentalised (Tensenbel and Gauld 2000:39; also Kingfisher and Goldsmith 2001), meaning that Pharmac becomes solely responsible for not only regulating medicines but also is the one held accountable when facing public criticism.

Prioritising (Whose?) Lives in Health Care

In needing to ration pharmaceutical spending Pharmac seeks to get as much benefit as is possible within the limited pool of resources it has. The consequence of this is that in order to evaluate which treatments will have the most health benefit Pharmac needs to prioritise which

⁸ Herceptin (Trastuzumab) emerged as a treatment for those with HER2-positive breast cancer. The treatment was initially declined funding by Pharmac due to not being cost effective, Pharmac citing that there was little clinical evidence of its effects. Many breast cancer lobby groups petitioned government for a reversal of Pharmac's decision not to fund. Members of the Breast Cancer Aotearoa Coalition sought a judicial review of Pharmac's decision-making process at the High Court. The Judge ruled that Pharmac acted consistently within its legislation, but did not consult widely enough with interest groups. The National party was elected in November 2008 and, as per its election promise, funded Herceptin for a 12-month treatment (Coyle 2012; Fenton 2011:187).

is the most cost effective treatment, and within this, whose life is worth investing in and whose life is not. In speaking with Carol about what Pharmac considers to be major barriers to pharmaceutical access in New Zealand, she responded that Pharmac has the responsibility to reduce health disparities that exist amongst different population groups; a responsibility that Pharmac continues to “struggle with”. As Carol further explains to me, Māori and Pacific populations have less access to pharmaceutical treatments, and experience less access to health care resources more generally. Moreover Pharmac understands that health disparities also exist in refugee populations as well as for family members and carers of patients. Carol surmises: “I think we can do much better in terms of inequalities, improving access to those who have the greatest health need and that health need which is currently population groups experiencing disparities. I would hope...that’s where...New Zealand can make some traction”.

Pharmac have identified the population groups they argue experience the greatest health disparities in accessing pharmaceutical treatment. In practice, when Pharmac is reviewing the potential health outcomes for a particular pharmaceutical product they consider which population groups would most benefit from the treatment. This does not necessarily mean the best health outcomes for specific individuals, but can also be a consideration on whether a particular ethnic group as a whole would benefit from the treatment. Thus health is valued not as maximum improvement to an individual, but valued as maximum improvement at the level of the population. In explaining how Pharmac places value on health when making decisions about pharmaceutical products Carol says,

...all our decisions about how can we use the resources we have to best effect to get the best health outcomes, that doesn’t mean the greatest health outcomes necessarily. So for example one of our decision criteria is the health needs of Māori and Pacific people, so it may actually be that we prioritise the treatment that is for an illness that disproportionately effects Māori and Pacific people, which may have a lower health gain but because the health disparity that exists...so best doesn’t mean most. But...what that means in practice with the budget is we have to compare all the possible things that we can invest in to decide which ones will result in the best health care. Best health outcomes. And we do that through a process of prioritisation.

In speaking about how Pharmac determines which population groups experience the greatest health disparities Carol uses the language of inequality. As explained by Tim Tensenbel and

Robin Gauld (2000), the shift to a neoliberal model of health care has led to the New Zealand state focusing less on service and society and more towards economic imperatives. The authors argue that this shift has resulted in a spawning of a less compassionate society, as individuals become rational, autonomous, and self-interested consumers (39), and this viewpoint extends to government. Pharmac are accused in the media and by patient advocates as being uncaring, unsympathetic, and dispassionate in decision-making regarding pharmaceutical funding. Yet in evoking a language of inequality, fairness, and care, Carol is legitimising how Pharmac determines which population groups are discriminated against in the health care system by acknowledging that there are individuals who have become marginalised through Pharmac's processes of medicines funding. Thus Pharmac, in recognising this marginality, are prioritising treatment that will benefit the health of certain population groups. Carol uses this language of inequality to not only acknowledge vulnerable groups within the New Zealand health care system, but also gives Pharmac a means of deflecting public criticism in the medicines funding process. In deploying this language of inequality Pharmac decide which marginalised groups are prioritised funding, resulting in individuals who are denied access to treatment based on issues of high cost are further disregarded.

There is a need to distribute health resources fairly and equitably, especially to those who are considered to be worse off. This perspective can be argued as a 'prioritarian' view, where "fairness requires that some priority in resource allocation be given to those who are worst off" (Fenton 2011:190), as opposed to a cost-effectiveness standard for prioritising health care (Brock 2002:363). As Dan Brock (2002) argues, if we favour using a prioritarian viewpoint when considering health care resource allocation, one must consider who are the worse off, how much priority must be given to those who are deemed worse off, and what is the moral justification for prioritising those who are worse off (363). In the case of Pharmac, ethnicity is prioritised over and above other forms of inequality, such as class, gender, or age. Thus, when applying a moral framework to issues of health prioritisation, it is important to appreciate that there are different contexts in which decisions about health are made (Brock 2002:372) – a myriad of institutions, interest groups, and individuals are involved in making decisions regarding who gets access to treatment options, and to what extent.

A major criticism that is raised of Pharmac is that it fails to give proper weighting to issues of fairness in making decisions about funding medicines; a matter in keeping with its utilitarian strategy. However, as noted by Fenton (2011), this criticism is underpinned by the assumption that in prioritising those who are worse off "means doing everything possible to improve their

condition” (193). There are two interpretations that can then be made of this assumption: first, doing everything possible would require a continual expansion of the health budget, in an effort to meet our moral priority to support those who are sick. The issue with this is that the health sector would become a drain on the national budget, affecting other sectors that produce other important social goods that the government deems as important. Thus, as Fenton summarises, “if we want to continue to provide for these other social goods, then we must accept limits on health care spending” (2011:193).

The other interpretation that Fenton (2011) suggests in this concept of “doing everything possible” is that government agencies prioritise those that are worse off, to the extent that agencies will fund resources that only provide marginal improvement to the health of an individual. The problem that Fenton raises with this is that morally there would be no finite cost to helping an individual that requires pharmaceutical treatment; refusing an individual treatment that would lead to better health would be viewed by the public as morally unjust and unfair (2011:193-194). Thus for Fenton “doing everything possible” for those that are worse off would sacrifice efficiency of these government agencies as well as increasing health care expenditure. Rather Fenton argues that when the benefits of a pharmaceutical product are small or uncertain, “it is neither ‘shameful’ nor ‘inhumane’, but rather ethically required, to consider how that money might alternatively be spent, or, conversely, what drugs or services must be cut in order to provide those benefits” (2011:197-198). Furthermore, Fenton concludes that “political pressure, patient lobbying, and media fervour ‘should not determine who is treated and what they are treated with’” (Barrett et al. 2006:1119 in Fenton 2011:198), and that setting a precedent where rationing is not always necessary when making funding decisions is “dangerous and unsustainable” (2011:198). Yet what must be considered here is how rationalising public health care serves to depoliticise both how the state determines limits to its pharmaceutical spending, and how it obscures from view the global marketplace and its pursuit of creating profit making objects out of pharmaceutical goods in the free market. The process of rationing medicines is influenced by many global and national factors; the global cost of pharmaceuticals, determining the percentage of GDP that will be spent on public health, what medicines fall under review for funding, the population groups Pharmac determine experience greater health disparities, and the clinical evidence provided by pharmaceutical suppliers on behalf of drug applications. Thus, rationing pharmaceuticals is not itself free from deeply rooted political and economic ideology, as Fenton suggests, meaning that the question of who

is entitled to treatment is an issue that is inherently politically, culturally, and morally motivated.

Conclusion

I'm not a martyr...people say you're brave. I'm not brave. I don't wanna die. I wanna see my children grow up. You know. I don't wanna die, ever actually. Even when my children are grown up I still don't wanna die then. But why stay here and be a martyr. I would be dead now if I hadn't gone on it. I knew that. I was deteriorating rapidly. If I hadn't got on that trial I'd be dead. – Sarah

In fighting for her right to life Sarah is viewed as a martyr, yet for her being an advocate for fair and equitable access to essential medicines is a matter of survival; it is fighting against being neglected and left for dead. Pharmac emerged as a government body with the aim of reigning in government spending of pharmaceutical treatments. Yet, in its implementation, questions have been raised as to the consequences of rationing drug treatments, particularly on the individuals who miss out. As Fenton wrote, and which I explained above, the current political and economic order exercises the belief that rationing health resources is both an inevitable and necessary decision that all governments must make lest health budgets become too expansive. Carol makes this point when she argues that “almost all public health systems in the world are facing issues about whether or not the system is financially sustainable, particularly in light of the global financial crisis...I think we're getting to the stage now where the products coming through are fewer but more expensive...so I think that's...going to create some challenge for funding systems around how do we actually afford these treatments” (2016). In its efforts to provide citizens with access to the pharmaceutical treatments they need, Pharmac utilises certain economic tools and legislation to control which medicines will or will not be funded. Cost utility analysis is used as an economic tool to determine the potential health benefits that come with taking pharmaceutical treatments. In this process health becomes tied with cost, as a medicine needs to be proven as cost effective; health then becomes commoditised and calculable. This, combined with Pharmac's protection from prosecution and

ability to exert dominance in the pharmaceutical marketplace, enables Pharmac to regulate which medicines are made available to the public. The state then determines how health is conceived and calculated, and in determining which medicines will be funded the state makes judgements over which lives are prioritised and, in turn, who is left to die.

In his work on AIDS and the state's response in Brazil, João Biehl argued that through modern politics government has become increasingly concerned with controlling the physiology of the citizen, this politics putting an individual's "existence as a living being in question" (Biehl 2005:249). For instance, in regulating how medicines are procured for the New Zealand population Pharmac have become involved in politics surrounding the human body, specifically how health is conceptualised and prioritised. In light of the involvement of the state in issues of health, life, and death, we need to understand and politicise who is made to live and who is left to die (Biehl 2005:249). What flows from this is questions about how life and death are imagined. Further, there is a need to understand the complex and contradictory ways that Pharmac's policies and neoliberal conceptions of health and wellbeing are "forged in local worlds" (Biehl 2005:267); where emerging biotechnologies allow for individuals to conceive of health and suppressing death through a "new political economy of pharmaceuticals" (Biehl 2005:266).

The following chapter seeks to address how individuals have responded to state policies surrounding pharmaceutical access. In navigating a health system in which they have been cast aside and left to their own devices, individuals become responsabilised through taking on notions of self-care and "risk taking" in order to preserve life. Biehl (2005) argues that one's worthiness to exist and claims to life has become subject to medico-scientific, legal, and moral dispute (267). For these individuals the pursuit of health and survival lies in consuming pharmaceuticals.

Chapter Three:

Patient Responsibility and Risk Taking in Pursuit of Pharmaceuticals

This chapter seeks to address how patients become mobilised in the face of being denied access to pharmaceutical treatment. In a pharmaceutical model of health, individuals become responsible and active consumers in pursuing good health (Mol 2008). For instance, patients become responsibilised through the formation of biosocial health movements, and it is via these health social movements that patient activists are able to lobby the state and pharmaceutical companies for access to pharmaceutical treatment. In pursuing alternative means of treatment, patient advocates, such as Sarah and William, have developed a fruitful relationship with pharmaceutical companies for access to the life-saving treatment they need. In this relationship pharmaceutical companies benefit from patients consuming their pharmaceutical products, or participating in clinical trials, yet Pharmac holds a contrary position, contending that the pharmaceutical industry is exploitative of patients' needs. I argue that the readiness of patient activists to work with transnational entities is a result of these individuals pinning their hopes for cures to disease in pharmaceutical treatment. Thus the ultimate goal of health lies in the pursuit and consumption of pharmaceuticals – this viewpoint reinforced by the state's investment in funding medical interventions. Moreover, when faced with these barriers to treatment access individuals are willing to be subjected to human testing and experimentation through participating in clinical trials or using 'DIY' treatment. As argued by Adriana Petryna and Arthur Kleinman, "access to experimental therapies is being broadened and drug trials are increasingly viewed as therapeutic rather than experimental commodities" (2006:7). I argue that in seeking alternative access to pharmaceutical treatment William and Sarah take on the identity of 'human subjects' in their pursuit of medical relief. The creation of these experimental bodies suggests the lengths people will go in order to survive, and in turn, fight against death.

The Responsible Patient

In contemporary notions of health care the individual, or patient, is an informed and active consumer in pursuing good health. Annemarie Mol (2008:14) contends that in using the language of the market patients are labelled as customers, where care is bought through the exchange of money. Health care, through these monetary exchanges, becomes tied to patient demand. Following this 'logic of choice' then, "if supply were to follow demand, care would – at long last – be guided by patients" (Mol 2008:14). In trying to ease one's suffering the pursuit of a healthy state of being allows one to "resume normal functioning" (Hay 2010:268; also Buckser 2008). Being sick, in turn, challenges "one's value in the world", specifically the ability to be a productive and responsible citizen (Hay 2010:260). This logic of choice that Mol argues links to notions of responsibilisation, where individuals are encouraged to take an active responsibility for ensuring their own health and wellbeing (Beckmann 2013:162; Miller and Rose 2008). For these individuals becoming responsibilised is linked to ideas of risk – in order to respond to health risks in the future individuals learn to calculate and manage this risk through targeted interventions (Beckmann 2013:162). This concept of responsibilisation promotes an individual who is "active, choosing, responsible, [and] autonomous" (Beckmann 2013:163). Yet although I agree with Miller and Rose (2008) and Mol (2008) that contemporary understandings of health has seen the emergence of individuals as rational actors with the capacity to be freely-choosing in their pursuit of good health, I argue that for the patient advocates I interviewed responsibility was borne out of necessity after being abandoned by the state in their need for access to life-saving treatment. For my participants who were declined access to pharmaceutical treatment they have become responsibilised through creating patient support and advocacy groups that seek to lobby the state and non-state actors for better drug access.

Biosocial Communities

The neoliberal processes that grant individual freedom, choice, and autonomy is the construction of new relations, dependencies, and potential for new forms of social action. As neoliberal processes place responsibility onto the individual, said responsibility is dissociated from the state; yet it can be argued that responsibility does not necessarily always fall to the individual, but rather goes into creating new collectivities (Brown et al. 2012:16; Trnka and

Trundle 2014:140). As argued by Rose (1996), these collectivities can be seen as spaces where collective action and responsibility can be enacted.

Intrinsic within the creation of these communities is that of identity, namely, individuals creating a sense of community through particular illness identities. As Trnka and Trundle (2014:140) argue, these collectives

...come together around a specific health issue to educate and support one another and further state and corporate interest in their health concerns. Such communities do not merely attempt to fill in the gaps of services vacated by the state, but rather make claims for new forms of social inclusion. Engaging in discourses of responsibility and accountability, these groups direct demands towards the state, (public or private) scientific entities, and corporate business, seeking not only care, research, and investment, but also the extension of decision-making beyond both the state and the realms of scientific enterprise through public-private 'partnerships' envisioned to enable greater degrees of 'patient choice'.

The communities that Trnka and Trundle describe above are biosocial in nature. By this I mean that in coming together around a particular illness identity people describe themselves and others in bioscientific and genetic terminology, as biomedical vocabulary becomes more commonplace in everyday language (Lemke 2011:97). Thus as knowledge concerning disease and risk grows, the process that results is known as 'biosociality'. The concept of biosociality was first envisioned by Paul Rabinow in 1992 through his research on the human genome mapping initiative (known more commonly as the Human Genome Project) (Lemke 2011:96; Novas 2008:137; Rabinow 1999; 2008; also Beard 2004:800). Rabinow was interested in the question of how sociality has changed given new understandings of genetics. He coined the term biosociality as an attempt at explaining the terrain where people respond to increasing genetic knowledge and change in power dynamics through creation and mobilization of patient and other interest groups (2008:190). As technological innovations and scientific classification systems create the conditions for new forms of socialisation (Whyte 2009:10) and identity, through knowledge, the individual is changed in terms of how they view themselves and others; the groups often have "medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene in, and 'understand' their fate" (Lemke 2011:97-98).

For Kay, one of my participants who is a breast cancer advocate and Chair of a breast cancer organisation, she found that having a medical oncologist and pharmaco-economist on the committee allowed herself and the organisation's committee to understand the scientific results that came from clinical trials. Specifically, Kay and the other members of the breast cancer organisation learned of a treatment option called Herceptin that, in its earliest testing phase, was shown to be hugely beneficial for those who suffered from HER2-positive breast cancer. Having an understanding of the genetic and clinical knowledge of breast cancer diagnosis and treatment then enabled the breast cancer organisation to submit an application for funding with Pharmac, as well as giving the organisation power to later dispute Pharmac's findings that the treatment was not clinically effective. The biosocial groups that are created are not passive recipients of medical care, nor lack the capacity to challenge the scientific knowledge promoted by specialists, scientists, and so on. Rather, as demonstrated by Kay, patients and lay persons are increasingly involved in scientific research through lobbying for particular drug therapies. Science in this respect then has a place of prominence, where hopes for therapies or cures are invested in an effort to overcome our biological fates (Novas 2008:140); patient groups then use this scientific language in order to make appeals to the state as biological citizens.

However, although it is common for support groups to work with medical experts, such as medical oncologists, economists, and pharmaceutical companies, this relationship is one that has differing power dynamics. Working with medical experts allows for individuals or collectives to gain a new understanding of scientific information concerning innovations in pharmaceutical treatment. Yet patient groups and medical experts communicate with each other in the dominant language of science and medicine, meaning that for a health activist it can be difficult to be taken seriously as an expert with knowledge of their own health and wellbeing. For instance one of my participants William, who Chairs a rare disease support group, found that in communications between himself and pharmaceutical companies who were interested in facilitating access to a particular pharmaceutical, discussion was "quite science-y", and "everyone [he's] spoken to has a science or medical background", making discussion very "technical". William said this to me in a tone that indicated the difficulties inherent in speaking to authorities on a largely scientific topic. This point is further reiterated by Kay who, in her interview with me, highlighted the power imbalance that exists in communications between patient support groups, government entities, and media. A journalist from the New Zealand Herald was interviewing a member of the breast cancer organisation for a story about cancer medicines where it was asked whether the organisation received money

from the pharmaceutical company that was manufacturing the breast cancer treatment. For Kay the reason why their relationship with pharmaceutical companies is questioned is because people think “we’re...mindless puppets of pharmaceutical companies which is the most insulting thing that could possibly be levelled at [us]”. What is revealed here is how patient support and advocacy groups can be de-legitimated by medical authorities and the media through questioning the patients’ utilisation of scientific and clinical knowledge. Although the creation of biosocial communities enables patients to be more knowledgeable and exert agency in scientific and medical domains, these groups can be discredited through accusations of exploitation at the hand of pharmaceutical companies thus challenging their agency, or in the case of William, communicating in a language that serves to remove him from participating in these scientific, clinical, and medical spaces. Kay further expresses this anger and frustration when she argues that patient support groups are perceived as being ‘stupid’ or ‘incompetent’. Kay attended a presentation run by Pharmac, which she called “a presentation for dummies”. In this presentation Pharmac described the medicines funding process – “[there is] this bucket. And this bucket that has...\$795 million....if we take something out for another medicine then...something that’s in here already will have to go. And that would be very bad wouldn’t it?” The statement was said by Kay sarcastically, further highlighting the issues that can stem from patients trying to exist in the same spaces as medical authorities and experts. As patients define themselves with scientific and biotechnological understandings of health and the body patients then use these labels to help negotiate for access to certain pharmaceutical treatments. However, patients to a large extent are still viewed as laypeople; individuals are made to feel incompetent and unknowing about their health, meaning that patients are then judged for taking an active stance towards their health care through their relationships with pharmaceutical companies.

Health Social Movements

The creation of biosocial communities through particular illness identities allows for a new form of social action to take place – that of health social movements. As argued by Phil Brown et al. (2012:16) health social movements are a relatively recent and understudied subset of social movements, referring “to ‘collective challenges to medical policy, public health policy and politics, belief systems, [and] research and practice which include an array of formal and informal organisations, supporters, networks of co-operation and media’” (Brown and

Zavestoski 2004:679 in Trundle, Singh and Bröer 2014:172). Integral to the creation of health social movements were specific social shifts that occurred in the 1980s which led to a loss of faith in medical authority. Individuals began challenging medical and technological expertise, whilst demanding a more democratic approach to the question of what scientific knowledge is deemed as legitimate. The question of democracy in scientific knowledge production is more than just a reaction to citizens' demands but calling for citizens' to make demands of the scientific and medical authority (Brown et al. 2012:17 in Trundle, Singh and Bröer 2014:173). In demanding more democratic modes of engagement health activists are not necessarily shifting away from expert knowledge (and this can be seen in my earlier discussion of biosocial communities), but refusing to allow health professionals to "determine the rules of diagnostic debates" (Trundle, Singh and Bröer 2014:173).

The question of democracy came up in my interviews with William and Kay. For William democracy was a term used to counter the 'technocrat view' that decisions regarding access to pharmaceutical treatment should be left to those in authority who make decisions at the governmental level:

I think it's hard to say that...patients don't have a right or have a stake in making sure patients get access to what is widely regarded as the most effective treatment for a particular condition. I don't know. I think others would disagree with that view, you know, leave it up to the technocrats they know what they're doing. They know what's best...I think that's a really dangerous view of government. I think that's a really anti-democratic view of what's going on.

Kay uses the term democracy to challenge how one can respond to injustices in the process of funding pharmaceutical treatment in New Zealand, and in particular Pharmac. As she argues, if Pharmac makes a funding decision that goes against the "will of the people", then the decision-making process can and should be rectified. This thinking is much in line with William's argument that the New Zealand population needs to be more willing to criticise government decisions around issues of health care access. Also inherent within both William and Kay's comments is the tie between democracy and rights to health. For them, the fact that individuals have a right to health, including right to pharmaceutical access, means that when a government is seen to be circumventing those rights, then the government is acting undemocratically. Citizens, thus, are barred from influencing the state's health care decisions. For both William and Kay, the fact that the government has declined pharmaceutical access to

New Zealand citizens has necessitated the need for New Zealanders to challenge government's decisions. Thus in these instances health social movements can engage the rhetoric of 'democracy' in order to challenge decisions made by health professionals and political forces that directly affect the ability of individuals to have access to the pharmaceutical treatment they need.

Another social shift that led to the development of health social movements is the rise of social media and the Internet, creating opportunities for these movements to "coordinate action, disseminate knowledge democratically, and support fellow sufferers" (Trundle, Singh and Bröer 2014:173). In the creation of these "virtual communities" (Rose 1996) patients become lay experts who engage in the medical sphere through patients being empowered to use medical knowledge (Rose 1996:333; Trundle, Singh and Bröer 2014:173). In this view of community the patient is a moral individual that is both self-responsible and "subject to certain emotional bonds of affinity to a circumscribed 'network' of other individuals" (Rose 1996:334). For the participants I interviewed who either created or led patient support groups, there was a desire to create a network that connected individuals throughout New Zealand who suffered from cancer or rare disease. For instance Sarah explained to me how she created a network for sufferers of a particular rare disease – I reiterate her comments from chapter one:

...when I was diagnosed there was three people already diagnosed. And one of them...said 'oh yeah, I always thought it would be good to have a [network]'. And we spoke about having a support group because two of them didn't know about one of the others...because I'd started interacting so much online with other people overseas I thought 'well it would be good to have one in New Zealand'...and now we have eleven patients.

For William, his role as chair of a rare disease support group primarily involves:

...communicating with the people who are sort of associated with us which is primarily patients, but there are a number of parents as well. It's a pretty small group but...yeah...we know each other quite well now.

Creating virtual networks for patients to navigate diagnosis and treatment options, as well as have access to information and connections between individuals, is extremely important in creating chronic illness support groups. As argued by Roger Burrows and others (2000:101), on-line self-help and social support groups, termed 'virtual community care', offers individuals access to information, advice and support for a range of health and social issues. It also allows

individuals within these groups to become bonded together through this model of peer support. As Kay states the cancer support group she chairs “matches up people with similar diagnoses...in order to meet someone who’s been through it and come out the other side....and just to see that you’re not alone”. The use of these virtual communities is seen to “provide greater choice in possible relationships liberating the individual and enabling network members to draw upon a greater range of social, emotional and knowledge based resources” (Burrows et al. 2000:105). The collectives that emerge connect individuals together as a means of providing useful information and emotional support in the face of being diagnosed with a disease that many of the New Zealand population never experience.

Health social movements seek to challenge the ways in which decisions are made regarding health care delivery, policy, and regulation, as well as seeking to produce changes in wider society by democratising the “institutions which shape medical research and policy-making” (Brown and Zavestoski 2004:687). In responding to inequalities in health care access patient groups have mobilised through creating relationships with pharmaceutical companies. Sarah, for instance, was diagnosed with a rare disorder in 2010, but when she and her doctor researched the diagnosis they found that there was a pharmaceutical treatment available. The issue was that the treatment was not funded by Pharmac. One of Sarah’s specialists put in an application to Pharmac for funding, but whilst Pharmac reviewed the application Sarah decided that there was more she could do in regards to her treatment:

So...I decided...while that application was in coz they don’t decide right away I thought ‘right what else can I do to help myself’, because I didn’t have any faith that I would get help in New Zealand...because people who had been through it previously with the same disease had been turned down [by Pharmac]. So I rattled around on the internet and found a clinical trial, and put my name into that. And...got accepted to do that, so I’ve been on that now for four years.

In believing that Pharmac would not provide the pharmaceutical treatment she needed, Sarah became responsible for her own health through researching other means to seek treatment – in this case a clinical trial based overseas. In being held responsible for ensuring one’s health individuals have turned to the pharmaceutical industry as a new medical authority in which people’s hopes lie for new treatment options. Yet it is not only individual patients but health social movements that have increasingly turned to non-state institutions for access to treatment. Through these movements demands can be made for access to pharmaceutical treatments; it is

through the vocabulary of ‘rights’ and ‘democracy’ that activists make these demands. It is at this juncture that the question needs to be asked how this relationship between patients, health social movements, and the pharmaceutical industry has emerged, and the political and ethical questions that arise from these relationships.

The Ethics and Politics of the Pharmaceutical Industry

William decided that one way that the patient support group he chairs could get access to the pharmaceutical treatment they needed was through the creation of clinical trials in New Zealand. In being denied access to the drug treatment Soliris William believes the state has failed in its duty to provide New Zealanders’ with the life-saving drugs they need, meaning that patient support groups are now turning to the pharmaceutical industry to intervene in state health care systems by providing patients with the drugs they demand. William reiterates this by contending that the pharmaceutical companies he has communicated with are “genuine enough [in] wanting to help patients”. Thus for William arguing that pharmaceutical companies are ‘genuine’ in wanting to provide patients with the drug treatments they need is a response to criticisms of the pharmaceutical industry as being exploitative through their concern for capturing the market and profit. Yet William also reflects that “I’m trying to keep a few pharma groups entertained. Keep them engaged because until they’re actually on the ground here anyone of those groups could decide to move elsewhere”. What is revealed here is that in communications with pharmaceutical companies patient support groups need to prove that their lives are worth investing in.

In addition to this, Sarah explained that she is on the Patient Advisory Board (PAB) for a pharmaceutical company based in the United States. The PAB has eleven members who are either patients or parents of patients. The Board meets in the United States every two years and periodically communicates via webinars. As Sarah mentioned to me, this Advisory Board has members from Germany, United Kingdom, the U.S., and New Zealand. The PAB was established to provide the pharmaceutical company with information about the needs of the patient community, disseminated through patient advocates themselves. The position Sarah holds on the PAB is voluntary, whilst the pharmaceuticals company pays for her travel, accommodation, and US\$300 dollars for attending each meeting. Thus for pharmaceutical companies patients are particularly useful as they can use their time, energy, and knowledge for little money. As part of her role on the Board Sarah is asked what the needs are of the patient

community who experience rare disorders similar to herself. Specifically, Sarah has been asked about the difficulties associated with recruiting individuals onto clinical trials. Providing the pharmaceutical company with this information then allows for the company to determine which locations a clinical trial should be set up. Sarah has been active in trying to get the pharmaceutical company to set up a clinical trial in New Zealand.

Yet, as part of working on the PAB Sarah must also disseminate information from the pharmaceutical company. Sarah states that the pharmaceutical company asks PAB members to advertise particular clinical trials and pharmaceutical treatments. Sarah reflected, “sometimes I sort of think we’re a bit like salesmen for them as well”. Pharmaceutical companies, in their formation of PAB’s, use patients in order to advertise and market their pharmaceutical products. For pharmaceutical marketers the goal is profit, specifically profit from pharmaceutical consumption (Dumit 2012). For instance, in talking to pharmaceutical marketers in the United States Joseph Dumit found that marketers regularly hold focus groups with patients, and argue that one of their strengths is “finding a patient who eloquently expresses a private insight about an illness that accords with [the marketers] mission to increase prescriptions. Their job is to then greatly amplify that insight so that others may come to identify with it” (2012:76). Thus, a tool in a pharmaceutical company’s arsenal is to extract a patient’s knowledge of their disease in order to utilise and exploit it for profit.

Accusations of patient exploitation reveal a pessimism that exists within Pharmac, for the GPs I interviewed, and more generally among the New Zealand public, of the intervention of the pharmaceutical industry in issues of treatment access. Alan, who is a GP at the Otago Medical School, believes that pharmaceutical companies create demand for pharmaceuticals that have little value. I reiterate thoughts that he shares in chapter one:

I am suspicious of the international pharmaceutical industry...in that they create the demand for pharmaceuticals and I am not comfortable with the ways in which that is created. And so in terms of access to pharmaceuticals...why do people want them? Well there is a chunk of them that they want them because the drug companies have convinced them that they would be benefitting from having them...and I think that that’s out of balance with the value of them compared to some other things that we might be spending money on.

Here Alan cautioned me about the role of the pharmaceutical industry in creating a market for pharmaceutical products. This is especially concerning when considering that certain

individuals, who cannot access treatment through the state, turn to multinational entities in pursuing therapies. However I am not suggesting that patients should be viewed here as merely vessels of pharmaceutical marketers. Sarah is aware that she is acting as a marketer on behalf of a pharmaceutical company, and further, uses this to her advantage. In circulating particular health knowledge Sarah exerts agency through using her position on the PAB to advocate for access to clinical trials in New Zealand. As Sarah tells me she has been working hard to promote the fact that many patients in New Zealand are naïve to treatment, thus the country would be an ideal site for establishing a clinical trial. Treatment naiveté is “the widespread absence of treatment for common and uncommon diseases” (Petryna 2006:41). Populations that are naïve to treatment are highly valued as clinical trial recruits because they do not take pharmaceutical treatments that could interfere with the results of a trial (Petryna 2006:41). In exerting agency in this way patients are able to advocate directly with pharmaceutical companies for access to clinical trials and health information that would ultimately enable individuals the access to the pharmaceutical treatments they want and need. Yet the fact that some individuals get treatment access in this way depoliticises inequalities of pharmaceutical access in New Zealand because it means that the pharmaceutical industry is not criticised by patients for their economic and highly exploitative model of health care. In order to get access to drug treatments patient groups must prove that their lives are worthy of investment by pharmaceutical companies, as seen through Sarah promoting New Zealand as a site where companies can use patients as human test subjects. Turning to the pharmaceutical industry for access to drug treatments also forgoes the state in its responsibility to provide health care access for its citizens.

Susanna Trnka (2014) argues that neoliberal health care reforms in New Zealand since the 1980s has led to patients becoming more responsibilised and self-managing for their health and wellbeing through the pursuit of alternative means to drug access (546). In this line of thinking the patient’s role is one that is pro-active where patients are encouraged to be more involved in taking on medical advice and decision-making in regards to their own treatment (Trnka 2014:546; also Rose 2007). However, in becoming self-managing and responsibilised for their health patients become “entangled within widespread ties, dependencies, and duties to others” (Trnka and Trundle 2014:139). In pursuing access to pharmaceutical treatment via the avenue of the pharmaceutical industry, patients are forming new ties of obligation and dependency with pharmaceutical companies. However, as patients appeal to the pharmaceutical industry for drug access what has resulted is the disintegration of other ties such as between patients

and the state. I argue that the relationship between patients themselves is one in which vast ties of obligation, dependency, and duty have both been created and destroyed. In being denied access to life-saving drugs patients have collectivised in forming patient support and advocacy groups, and through these has created solidarity between patient groups in fighting for wider social transformation in New Zealand health care. Yet, as Sarah argues, ties between patient groups can become constrained or broken. When asked about how Sarah created a rare disease network, she stated how there were two rare disease support groups that were not proactive as far as providing up-to-date information, such as the existence of clinical trials. Interestingly, they even asked Sarah to not take part in a clinical trial:

...they actively tried to tell me not to go. Said I was deserting a sinking ship. But, you know, with a fatal disease and you've got young children, you're gonna do anything to try and save your life. And if I'd taken their advice I would probably be dead...actually. So no I was gonna go on the trials.

When I asked Sarah about what was meant by 'sinking a deserting ship':

...this woman...said to me if you leave [the country]...it's showing Pharmac that...you're not really serious...they're not gonna have to worry about treating you...They're gonna think 'well, we don't need to give her medication so that's one less person to make a noise'...she thought I was leaving all the other patients...she saw me as deserting them/no longer staying here and fighting for them...not only them but for people in the future who would be diagnosed as well.

In making the decision to join a clinical trial, Sarah was entangled in ties of obligation—to her children, fellow sufferers, and herself. Sarah justified participating in the clinical trial through using a gendered notion of her obligation and duty to her kin in wanting to be alive for her children. For Sarah this obligation was more important than her tie to a health social movement, emphasised through being criticised by other patients for not fighting on behalf of other rare disease sufferers. Sarah thus framed her decision in terms of selflessness and care, and as a type of moral justification for herself and others. The individual negotiates this entanglement of ties, dependencies, and duties, often overlapping and coming into contact and conflict with each other. In order to make sense of this entanglement, in an effort to make decisions with the goal of bettering one's health, the individual prioritises which ties, dependencies, and duties to others is more important. In Sarah's case, being alive for her children is more important than

declining the clinical trial and becoming a “martyr”. This concept of de-collectivisation is an argument about what constitutes a good patient advocate. In prioritising her kin over and above the health social movement Sarah is criticised by other patients for not prioritising other patients, both at present and in the future. Sarah believes that for these patient groups there is a fear that losing health activists who seek treatment elsewhere will result in the health social movement collapsing. However, Sarah argues when it comes to patient advocacy it is important to advocate for oneself:

You gotta push all the time. Get out there and be a little mouthy, you know, but at the same time smile and be nice. Coz, you know, people said to me be someone that people want to help....and also be your own advocate coz no one else is gonna do it for you. And that's true they don't.

Here we see that responsibility within issues of health care is intimately tied to selfhood. In health social movements patient activists assume responsibility for not only their own lives but that of others. For Sarah however being your own advocate is an extension of this concept of de-collectivisation. In justifying her decision to join a clinical trial overseas as being morally tied to kin Sarah emphasises the importance of being responsible for your own health and wellbeing. I suggest here that a tension exists between patients in questions of responsibility for health and the issue of entitlement to health care access and who is left behind to be sacrificed. Secondly, these narratives reveal a tension between patient advocates over how they frame their citizenry right to health. For Sarah, health is a global right, and one that can be claimed through the globalised pharmaceutical industry. For the other patient advocates who Sarah believes wanted her to act as a martyr, right to health claims are made at the national level of the state.

Pharmaceuticals and Hope

The individuals I interviewed who are patient advocates exist within a form of biomedical living called expert patienthood (Dumit 2012:183). As Dumit argues “the expert patient is an expert at being a patient, at living the lifestyle of the good patient” (2012:183). The expert patient is knowledgeable of their diagnosis, symptoms, and stays on top of the latest treatment options. They are ever-vigilant and generally optimistic about the health facts that are produced and the potential they have in bettering health. The expert patient is a consumer who “adopts a public health attitude...and is always on the lookout for better information” (Dumit 2012:184).

This was particularly resonant in my interviews with Kay and Sarah. Kay and the other members of the breast cancer organisation thoroughly researched treatment options. Two members of the organisation were a medical oncologist and pharma-economist. Through these members Kay was able to learn of the health benefits of the breast cancer drug Herceptin on women diagnosed with HER2-positive breast cancer. The breast cancer organisation kept updated on the research surrounding Herceptin through reading journal articles of the drug's clinical efficacy as well as one of the members attending a clinical oncology conference in the United States. Thus, once the benefits of Herceptin became more known Kay and the breast cancer organisation took the results to Pharmac for funding consideration. Further when the clinical results of the drug were disputed by Pharmac the organisation continued to argue for the drug through resting on the clinical evidence they gathered. For Sarah, she created a website that acts as a support group for those who live with a particular rare disorder. As she stated to me, "I just felt there was nothing in New Zealand that was helping us. There...was a couple of groups, Lysosomal Disorders New Zealand and New Zealand Organisation for Rare Diseases, but they were very behind with their information and...they were definitely not...proactive as far as getting on [clinical] trials or anything like that". Expert patients take responsibility for their medical care "from beginning to end" (Dumit 2012:185).

As Dumit argues, for expert patients "health is a state that may never be fully achieved but that organises a part of one's attention, energy, and lifestyle" (2012:186). The reason for this is that of hope. Scientific, technological, and genetic discoveries has created a climate of potential for curing human ailments (Novas 2006:289; Rose and Novas 2005). Rose and Novas term this a political economy of hope. Within this terrain biopolitics is transformed, from political and medical authorities being responsible over life, to individuals demanding a say in shaping the biotechnologies that shape understandings of illness today. Having hope in scientific progress predominately exists in conditions of desperation and near-hopelessness. Hope is a "vocabulary of survival where survival itself is at stake" (Novas 2006:291; also Rose and Novas 2005:452). Thus, to live in hope is to take an active stance towards the future – the hope of cures and treatments for illness that lie in biomedicine. Individuals take charge of their health because the medical system, although is supposed to take care of everyone, is either unable to or we do not trust it when it does (Dumit 2012:186). This idea struck me in conversations I had with my participant Emily. She asked one day if I wanted to catch up for a coffee. I responded in jest that I would love too, and that I was free because I have no life (outside of my thesis). She responded that she too had no life and, rather than study, said "my health is my life". For Emily,

the focus on her health can be both debilitating in that being sick impinges on her ability to live a full and productive life, but it also gives her a purpose that is life sustaining and at one level positive. For those I interviewed health, or rather ill-health, is paramount. Illness is a daily experience and concern, and for several of those I talked to, their illness was chronic and debilitating, and without treatment would lead to further decline and eventually death. Thus in seeking to maintain or improve one's health, and avoid (premature) death, individuals fight harder than ever before. Individuals are constantly "inventing solutions" (Dumit 2012:183) to problems of pharmaceutical inequalities, health, and managing the risks that come with poor health.

Risk Taking and Experimental Bodies

Self-medication is defined as the act of consuming medicines "outside the control of medical professionals usually at home" (van der Geest et al. 1996:165). People usually self-medicate to treat minor ailments, and do so because it is convenient and economical. In developed nations, self-medicating allows the individual to take control over their health (van der Geest et al. 1996:164-165; Vuckovic and Nichter 1997:1287). Most of the literature surrounding the practice of self-medication suggests that people learn to treat illness themselves because pharmaceuticals are readily available in local shops, pharmacies, and supermarkets. People can buy pain killers, broad-spectrum antibiotics, and other medicines which treat a range of minor diseases (van der Geest et al. 1996:165). William first heard about a potential treatment for his rare disorder when he contacted a researcher based in Canada. This researcher then informed William that the drug is in very early stages of testing, but that a fellow GP who was researching the drug had been refining the compound and trialling it on himself; the treatment was what William calls a "homebrew version". The GP had told William at the time that the refined version of the drug was "working really well for him". For William, based on the positive results from the GP taking the drug as well as the fact that the treatment is not as difficult to access, became "interested in the idea of doing something similar for [himself]".

However, William stated that there were two reasons why he did not ultimately pursue this avenue of treatment. First, although the treatment is relatively inexpensive, the treatment was, as he states, "sort of a little bit beyond me means". And second, he was not overly confident of the side-effects of taking the drug treatment. At this point the drug had not been fully tested nor gained approval for use. As William explains the drug itself is "essentially a form of acid

that kind of intervenes in your immune system. It's gonna do something and...it may not all be positive". William ultimately decided against pursuing the drug treatment, although as he later mentions that he remained interested in the idea of drug treatments that are "off the shelf". In spite of the costs associated with taking a 'DIY' treatment William still felt that he "chickened out" by not pursuing the treatment further. Thus William decided against risking his health by taking an experimental drug therapy; yet his feeling that he was cowardly for not willing to become a test subject reveals that patients are expected to be risk taking in seeking to alleviate their suffering.

In neoliberal understandings of health care individuals are thought to be prudent and rational subjects, responsible for securing their health (Gray 2009:327; Hallowell 1999:598; O'Malley 1996:194). Yet in being perceived as a rational actor with freedom of choice, individuals are also responsible for the risks they take in regards to their health (Gray 2009:329). Anthony Giddens (1999:3) argues that risk has become bound up in societal aspirations to control the future, where individuals become increasingly preoccupied with managing future health risks. Beck calls this a 'risk society', where the rise of new technologies that chronically affects our lives leads us to become absorbed in dealing with future issues of security and safety (Beck 1987; see also Giddens 1999:4). Roberto Abadie (2010:65) argues that risk is inherent in questions of human safety of chemical compounds, and an integral feature of society more generally. Risk can be calculable and manageable, and in the case of clinical trials this risk is quantified and bound (Abadie 2010:72). Mary Douglas further contends that when it comes to experimental therapies the risk involved are culturally, socially, and historically constructed (Abadie 2010:69). In being responsible for his health William contemplated pursuing experimental drug treatment. Yet in exercising this responsibility William also assumes responsibility for the risks associated with taking an experimental therapy. William stressed to me that risk is a necessary part of managing one's future health, as demonstrated by his assertion that taking the experimental treatment can result in further harming his body. For William then the risks associated with taking the experimental treatment outweighed the experience of others who were choosing to take the drug treatment. Yet to not take risks in pursuing treatment access is seen as not be fighting hard enough to save one's life, this thought epitomised by William when he states to me how he "chickened out" by not consuming the experimental treatment.

It is a similar story for individuals trying to get access to Hepatitis C treatment in New Zealand. Greg Jefferys, a Hepatitis C patient, was interviewed on the television programme *Sunday* in

March this year, where he spoke of his experiences seeking pharmaceutical treatment. As Pharmac does not fund the Hepatitis C treatment Harvoni (which contains the key ingredient Sofosbuvir) because of its cost, Greg sought out the generic version of the drug that was available in India and was 22 times cheaper than the brand-name product. Greg, living in Australia, decided to help others around the world who could not afford Harvoni by creating the 'Hep C Buyers Club'. This club links patients with the more affordable generic version of the drug – Twinvir. One such individual who received the Hepatitis C treatment he needed was Chris Heazlewood. As he stated in an interview with *Sunday* without treatment he had a prognosis of death within three to five years (Sunday 2016). He could not afford the brand-name Hepatitis C treatment, thus sought treatment access through the Hep C Buyers Club. After a few days of taking generic medication Chris was already seeing benefits to his health. In spite of this however, there is controversy surrounding the consumption of generic medications. In the case of Hepatitis C treatment, the key ingredient Sofosbuvir is regularly partnered with a second chemical Ledipasvir. The concern here is that Ledipasvir can only be made through the use of high tech facilities, which are not available in some settings where generic medicines are manufactured. Thus, the concern is that when individuals are consuming generics one of the drugs – Ledipasvir – is not active, resulting in the drug not working as effectively. When asked whether generic medicines work less effectively than brand-name products a general practitioner and advocate of generic medicines James Freeman stated, "Look, naturally be cautious. You need to be sure of your supply chain". Therefore, in the pursuit of alternative therapies such as generic medicines, patients who are faced with the prospect of an early death exercise risk taking behaviour in their efforts to secure cheaper drug therapies.

Another example of patient risk taking behaviour that I discovered in my interviews with participants is joining clinical trials. Sarah became a participant in a clinical trial after thoroughly researching her treatment options and participating in webinars run by a primary investigator of a clinical trial based in the United States. Sarah repeatedly asked if she could join the clinical trial, getting little response. She then noticed that an Australian man had been accepted on the trial after applying after herself, leading her to become suspicious. She later found out that there was hesitation to allow a New Zealander onto the trial because of the stance Pharmac had taken in regards to funding high cost medicines. The difficulty in accessing a clinical trial overseas speaks to political issues of pharmaceutical access globally. Dunit argues that "pharmaceutical companies have found a way to grow health via clinical trials by

redefining health as treatment...Since medicine is so expensive, pharmaceutical companies are required to fund much of the research, and, as companies, they must be able to earn a return on these investments” (2012:95). Clinical trials are assessed by how much profit it will generate for a pharmaceutical company – determined through working out which diseases will encourage a greater number of prescription sales (Dumit 2012:96). I argue that pharmaceutical companies are being cautious about investing in health via clinical trials in New Zealand because these companies are not guaranteed market share when navigating the Pharmac model. Pharmaceutical companies need assurances that a deal can be reached with Pharmac over drug prices. Investing in health, then, is one which is dependent on relationships between the state and the pharmaceutical industry, yet these actors have very different motivations and goals. Turning back to Sarah, she was eventually allowed to travel to Florida to have tests taken to determine if she was eligible to join the trial as a participant. Six months after the tests were taken Sarah was accepted onto the clinical trial, where she spent the next three years travelling to Brisbane each fortnight for an infusion that ran in duration for several hours. After the clinical trial is completed Sarah hopes that she can still receive the enzyme replacement treatment on compassionate grounds. Compassionate grounds, or expanded access, refers to the use of an experimental drug therapy outside of a clinical trial setting. Pharmaceutical companies may decide whether to continue to provide access to a patient after a clinical trial has been completed.

Sarah’s participation in a clinical trial is part of a wider global trend. As Adriana Petryna argues, since the 1990s there has been an increase in the number of people participating in clinical trials. Patients are increasingly recruited into clinical trials in order to prove the long-term safety of a pharmaceutical treatment, especially as these treatments are to be widely prescribed in future (2005:185; Petryna 2006:35). Clinical trials have become increasingly more globalised as the pool of human subjects shrink in locations such as the United States. As populations, particularly in more developed nations, become more pharmaceuticalised due to treatment saturation, new locations are sought where there is a greater supply of participants who are still relatively naïve to treatment (Petryna 2005:185; Petryna 2006:40). For pharmaceutical companies, clinical trials are at the core. Pharmaceutical companies are invested in conducting clinical trials because approval from the FDA or MedSafe then allows the company to sell the product exclusively until its patent runs out (Dumit 2012:5). As argued by Dumit, pharmaceutical companies have found a way to grow health through clinical trials and the creation of treatments that will sell. And with health being defined as reducing risk,

there are no limits to treatment (2012:95-96). Clinical trials are thus viewed as a social good, for participants are provided with pharmaceutical treatment which helps with relieving a participant's ailment through the duration of the drug trial (Petryna 2006:41-42). Yet even though pharmaceutical companies see their use of clinical trials as a social good, there are ethical debates surrounding the invasiveness of pharmaceutical companies in national health infrastructures (Abadie 2010; Dew and Davis 2014). Pharmac works to contain pharmaceutical spending, and does this through being competitive in negotiations with pharmaceutical companies in efforts to keep medicines prices low. Yet when pharmaceutical companies intervene in health care delivery, as seen through the establishment of clinical trials, what results is the concern that these companies are in fact undermining the operation of Pharmac through offering alternative means to treatments outside of Pharmac's control.

In thinking about practices of self-care and participating in pharmaceutical testing, one starts to think of the body as under experimentation. Through being disconnected from the New Zealand medical system individuals, left to themselves to seek treatment, become more willing to research and use alternative means of pharmaceutical treatment. In deciding to participate in a clinical trial or pursuing drug treatments which are legally and medically questionable individuals are offering up their bodies as test sites for medical authorities or themselves, in an effort to improve one's health and halt the symptoms of illness and death; the individual is thus continually working on the body-self (Shaw 2015:140). This notion of experimental bodies is very much tied to ideas of health as risk, specifically, the risk of not treating illness soon enough. A historian of medicine Georges Canguilhem stated that "health is a set of securities and assurances, securities in the present and assurances in the future" (1943, in Dumit 2012:119). By this logic if health is an assurance for the future then unless we never get sick we are not actually healthy. Thus, the logic of health as risk reduction means that it is prudent to diagnose and treat people as early as possible (Dumit 2012:119-120).

Social scientists are challenged to consider how populations are "brought into experimental orders", particularly as the norms and delineations of human subjects are shaped in the face of global flows of drug production (Petryna 2006:34). As Petryna argues, there is an ethical variability in play in the globalisation of drug trials. As she points out, "ethical variability refers to how international ethical guidelines...are being recast as trials for global research subjects is organised (Petryna 2006:35; see also Petryna 2005). The ethical standards that underpin how clinical trials are created and run differ globally due to prioritising cost-effectiveness over the installation of a universal ethics for human subject testing. What has resulted is issues

surrounding how new subject populations are created in the face of “regulatory deliberation, corporate interests, and crises of health” (Petryna 2006:42). These issues are important, especially as many clinical trials use members of marginalised communities as test subjects. A second concern is the ethical variability surrounding the use of placebos in clinical trials. As Petryna found physicians decide who will get the drug treatment and who will be assigned a placebo. The issue with this being that although the trial data has integrity, the patient will miss out (2006:46).

In chapter one I discussed how, as therapeutic citizens, Sarah and William have demanded that pharmaceutical companies intervene in issues of access to health care in New Zealand by creating clinical trials. However, in this process of establishing clinical trials patients such as Sarah must meet certain obligations set out by these companies. One such obligation is that some patients in trials must accept the possibility of going on a placebo, which is a difficult demand to meet considering that these patients up until that point had been receiving no prior treatment for their debilitating chronic disease. Thus there will be patients who continue to miss out on the essential treatment they need even after accepting the risk that comes with becoming a human test subject. Faced with being denied pharmaceutical treatment access by the state, patients will continue to seek out alternative forms of treatment access, which includes the access to, and consumption, of experimental therapies. As patient advocates lobby for access to these innovative treatments through drug trials or ‘DIY’ medicines what results is that these experimental therapies are becoming conceptualised as therapeutic rather than experimental commodities (Petryna and Kleinman 2006:7). In consuming these treatments patients are self-imposed gatekeepers of their health, where they weigh up the pros and cons of these experimental drugs and how it will affect their lives. The increasing acceptance of experimental drugs as treatment for disease suggests the calculated risk that patients make in consuming these experimental therapies. What this reveals is that desperation for access to life-saving therapies has altered our understanding of how we conceive of health, risk, and treatment.

Conclusion

Within this chapter I have discussed how patients become mobilised in response to being denied access to pharmaceutical treatment. Patients, living within the neoliberal model of health, have become increasingly responsible for their own health and wellbeing, this itself

being epitomised in many of my participants seeking alternative means to treatment via the pharmaceutical industry. In utilising their capacity as therapeutic citizens Sarah and William, for example, actively communicate with pharmaceutical companies for access to clinical trials, specifically because these trials have become sites where individuals' health needs are met through access to experimental treatments. When faced with barriers in getting treatment access individuals are readily subjecting themselves to human testing through participating in clinical trials or taking 'DIY' treatments. The ultimate goal for these individuals is access to the treatments they need that will provide them with relief from chronic disease. In taking alternative, experimental treatments individuals are accepting of the potential side effects, or risk, that such treatments may generate. Yet it is through this phenomenon that we come to understand that experimentation and risk has become crucial in the matter of patient survival, a space in which they must fight for life against the prognosis of an early death from disease.

Chapter Four:

Conclusion

Pharmaceuticals have become integral to daily life. They have become important in understandings of identity and life itself; and in turn people have become more conscious about health and the role pharmaceuticals has in maintaining a healthy lifestyle. As Joseph Dumit argues, this “is neither shocking nor exciting, it has become ordinary” (2012:181). In talking to both patients and Pharmac it was unspoken that the ultimate goal for everyone was access to, and consumption of, medicines. However, it is important to understand that patients, clinicians, and Pharmac all have adopted “pharmaceutical lifestyles” (Dumit 2012:183). This pharmaceutical space is one which is biomedical, and pharmaceuticals lie at the heart of biomedicine. The emergence of pharmaceuticals as the solution to our health problems is a significant phenomenon considering that there are numerous ways we could conceive of health and illness, such as through preventative or palliative care models. In exploring issues of pharmaceutical access within New Zealand we can see how these pharmaceutical lifestyles have emerged as the dominant model by which we conceptualise health and treatment, and further how this model has encouraged notions of the right to life.

Thus, given that both the state and patients are becoming ‘pharmaceuticalised’ the question that arises is how individuals then access the pharmaceutical treatment they need to survive. This thesis aimed to explore the nature of pharmaceutical access in New Zealand. Through an examination of the political-legal structures that underpin Pharmac, what has become apparent is how influential the government agency is in health care policy, specifically in its procuring of pharmaceuticals for the New Zealand public. Pharmac is the government body in charge of securing access to pharmaceutical treatments, and in purchasing treatments Pharmac works in negotiation with the pharmaceutical industry in its pursuit of maximising health outcomes for its citizens. Yet this pharmaceutically driven health care delivery is highly unequal. The availability of essential, and usually high cost, medicines is subject to whether the drug therapy is seen as cost effective, clinically efficacious, and able to be purchased cheaply by Pharmac.

I argued in chapter two that the state legislation surrounding the establishment and operation of Pharmac has enabled the state to effectively regulate pharmaceuticals. For instance, in

utilising cost utility analysis Pharmac can calculate and assess the potential health benefits of a pharmaceutical product in relation to the costs associated with making that product available to the New Zealand public. What is revealed when using this form of economic analysis is that the potential health benefits of a drug reduces the subjective experience of health to a figure that is quantifiable and can be compared across the population. I argue that underlying this process is a logic which conceives health as a commodity. In calculating and assessing the cost effectiveness of a drug treatment on one's health, Pharmac are conceptualising health and life as tied to economic value. Pharmaceutical treatments are then assessed based on ideologies of investment, cost effectiveness, and value for money. In determining which medicines will be funded, the state is making decisions over how health is conceived and calculated, thus, making judgements over which lives are prioritised and who is left to die.

What this thesis also sought to understand was the consequences of Pharmac's operations on outcomes of health and disease. In the face of being denied access to life-saving medicines the patient advocates I spoke with have become responsibilised for their own health and wellbeing. I make the argument in chapter three that patients have become mobilised through the creation of health social movements; these groups forming communities around particular illness identities. Within these health social movements patients lobby for pharmaceutical treatment access through both the state, and more recently the pharmaceutical industry. For these patients they believe that the state has failed in its responsibility to ensure equitable treatment access, thus individuals are exercising their rights as therapeutic citizens in appealing to pharmaceutical companies for access to life-saving medicines. I suggest here that in seeking alternative means to treatment access through non-state institutions the pharmaceutical industry is becoming influential in New Zealand's public health care system through its capacity to intervene in issues of pharmaceutical access.

However I also contend that the relationships between patients and the pharmaceutical industry are ones of exploitation. As patients occupy voluntary positions on Patient Advisory Boards of pharmaceutical companies they become entrenched in new ties of obligation and duties. In effect by becoming salespersons for these pharmaceutical companies, patients' knowledge of diagnosis and treatment is extracted in order to maximise profit. Moreover, not only do pharmaceutical companies exert ultimate control over the sites of clinical trials, but they also dictate what drug treatments patients can consume in these trials. Patients may only be eligible to join a clinical trial if they agree to being given certain pharmaceutical treatment. What becomes clear in examining the relationship between patients and the pharmaceutical industry

is that patients must prove that their lives are worthy of investment by pharmaceutical companies. I also suggest that in seeking to join clinical trials patients are allowing their bodies to become sites of experimentation in efforts to better their health and prolong death. Yet for these individuals experimental therapies have become conceptualised as therapeutic commodities. This increasing acceptance of experimental therapies as a solution to alleviating disease suggests the calculated risk patients take in the consumption of these experimental drug treatments. I further suggest that the acceptance of the risks that come with consuming experimental therapies highlights how taking experimental therapies has become an expectation of patients in their pursuit of health and survival.

In examining pharmaceutical access in New Zealand through conducting qualitative interviews with patients, GPs, and employees of Pharmac, what is evident is that there is much to discover about how individuals have become embedded in, and navigate, New Zealand's health care system. Although Pharmac has been successful in securing pharmaceutical treatments for a majority of the population it is at the expense of a minority of individuals. As I made clear in the introduction there has been little anthropological study into the process of pharmaceutical regulation and the effects of this on those who are not entitled to the medicines they need at a fair price. Studies that refer to patient needs tend to be disregarded, or focus solely on processes of medicines lobbying and the role of the media. What I offer here is a means in which an anthropologist can orientate their study. I provide an overview of the myriad of actors involved in the process of securing pharmaceutical treatment. What is revealed is that these actors have often competing notions of health, illness, and care, and how these factor into inequalities in pharmaceutical access.

One of the major controversies that this thesis has addressed is the question of responsibility and accountability in issues of health care inequality. As pharmaceutical treatment has become entrenched in our ability to maintain or improve our health and wellbeing, being denied access to life-saving medication has led to contestation between different parties over who has ultimate responsibility for ensuring that all New Zealand citizens have access to a range of drug treatments. For patients, issues of responsibility for pharmaceutical access is intrinsically tied to notions of fairness, morality, and justice. Pharmac, in comparison, conceives of pharmaceutical access as bound in ideas of investment, cost effectiveness, and value. For individuals who are denied pharmaceutical access based on their medicines not being cost effective, many are turning to the pharmaceutical industry through becoming human test

subjects. These patients are motivated to join clinical trials as a matter of survival – taking experimental therapies provides patients with hope of a cure through pharmaceutical means.

As pharmaceutical access in New Zealand represents a transforming set of political and social practices, the conclusion of this thesis suggests lines of inquiry that social scientists should explore further. In participating in clinical trials research how does the patient body become a site of experimentation and commodification that Roberto Abadie (2010:10-11) argues, “not only exploits but dehumanises research subjects”? The increasing acceptance of experimental therapies as the solution to inequalities in pharmaceutical access warrants an analysis of the ethics that are involved in clinical trial research, and in biomedical research more generally. Furthermore, as New Zealand-based patients continue to seek alternative means of drug treatment via the intervention of pharmaceutical companies there is more to understand about what this means for the role of the state, specifically Pharmac, in its regulation of medicines spending. The question needs to be asked how patients, faced with barriers to treatment access, are circumventing the state in order to access the life-saving medicines they need, foregrounding the question of whose lives matter.

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