

## **Technical Report:**

# **Effects of the COVID-19 lockdown on the healthcare experiences of medical crowdfunders in Aotearoa New Zealand**

**Dr Ella J. Robinson and Dr Susan Wardell**

Social Anthropology Programme

School of Social Sciences

University of Otago

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## Executive Summary

New Zealand went into a strict, nation-wide lockdown at 11:59pm, on Wednesday the 25<sup>th</sup> of March 2020, in an early effort to stem community transmission of – and later, eliminate – COVID-19. This lockdown was justified by protecting public health, but it also involved a variety of rapidly-implemented changes to standard healthcare delivery and access, including access to medical facilities and personnel, postponement of many routine or non-urgent procedures, and move to ‘virtual’ consultations wherever possible.

Literature has established that studying the growing phenomena of medical crowdfunding can be a useful way to examine systemic inequality, and precarity, within different national healthcare systems. In the context of dramatic (though temporary) changes to healthcare delivery during lockdown, we consider crowdfunding as a way to understand the experiences of those who were *already* unwell or fell ill (with non-COVID-related illnesses) during this time, as they engaged with these systems.

The data is drawn from a larger research project on medical crowdfunding in New Zealand, which happened to be collecting quantitative data directly after the return to Level 1, and covering campaigns that had run prior to and throughout Levels 4, 3, and 2. We asked the following question: **In what ways did medical crowdfunding campaign narratives reveal some of the effects of New Zealand’s pandemic response on the healthcare experiences of those already living with health needs, during the 2020 lockdown?** We approached this question through a qualitative analysis of 50 medical crowdfunding campaigns which mentioned COVID-19 as part of their narratives. The majority (74%) of these campaigns were for people experiencing illness – the remaining (26%) were for those with injuries; differences or disabilities; mental health needs; seeking gender-affirming healthcare; and other. Campaigns were often co-constructed by the recipient and a third party. Campaigns sought mainly support with general living expenses during illness (including rent, bills, travel costs, childcare, etc) with a minority of campaigns fundraising directly for medical treatment or equipment.

The findings convey how campaigns narrated institutional change (including delays or cancellations, the impacts of travel restrictions on access to healthcare, backlogs in the healthcare system, and the change to virtual consultation), economic impacts that also affected the ability of people to support themselves during periods of illness (including job or income

loss, and change to fundraising plans), and wider effects on wellbeing (in terms of changes to social support systems, and pressures on mental health).

We lay out some conclusions about the value of and possibilities for crowdfunding as a window into the pressures and precarities various people within New Zealand faced, during this time. In particular the campaigns we studied went against trends noted in other campaign studies, to directly address the entanglements between personal states of health, and personal healthcare needs, and wider political, bureaucratic, and economic, systems and structures. Gaps in existing systems, and populations who were unevenly affected, can be identified through studying crowdfunding patterns, and crowdfunding narratives. The need for continuing critical attention to the state's actions, even in times of crisis, is emphasised. We suggest some directions for future research that develops the critical, theoretical, and applied potential of this approach and this data.

# 1. Introduction

## 1.1. Background to New Zealand's Lockdown

New Zealand went into a strict, nation-wide lockdown at 11:59pm, on Wednesday the 25<sup>th</sup> of March 2020, in an early effort to stem community transmission of – and later, eliminate – COVID-19. The potential for the pandemic to overwhelm the health system of a small nation was frequently raised as one justification for these measures, with New Zealand's media keeping a close watch on the devastating effects overseas (Checkpoint, 2020; NZ Herald, 2020). In March, Radio New Zealand stated that the country's public hospitals only had “153 intensive care beds” available, “and that could be expanded to just over 560 by co-opting space from other units” (Checkpoint, 2020). In April, New Zealand public health and pathology experts Baker, Kvalsvig, Verrall, Telfar-Barnard and Wilson (2020, 10) reported that:

one of the more likely scenarios if the country's current elimination strategy fails, New Zealand could expect approximately 14,400 deaths. In addition, large numbers of people who are ill and hospitalised could swamp health services at all levels and prevent the delivery of elective services and preventive care.

As part of the lockdown protocol for reducing all non-essential contact, and to reserve space for the potential influx of COVID-19 patients, healthcare providers including hospitals, emergency departments and general practices began restricting access to their on-site facilities. Many routine, non-urgent and elective procedures were postponed, and the public were encouraged to consult virtually with their health professionals, rather than in-person. The social landscape began to shift in other ways too, with the government steadily phasing in travel and socialisation restrictions (Long et al., 2020). The added pressure these changes brought to the population's mental health was acknowledged as a significant factor to contend with (New Zealand Government, 2020b).

The widespread social and institutional restrictions of the lockdown successfully suppressed the direct effects of COVID-19, with no community transmission for 80 days by late July 2020 (Baker, Kvalsvig, & Verrall, 2020, 1). As of the 21<sup>st</sup> of December, New Zealand had only 59 active cases, (all at the border), with 2037 recovered and 25 deaths in total (Ministry of Health, 2020c), since the first New Zealand case on February 28<sup>th</sup>, 2020 (Jefferies et al., 2020). But, as Jefferies et al. (2020, e621) note, effectively containing the virus is not without flow-on effects in terms of healthcare and wellbeing and “there remain questions about the costs and

sustainability of these measures”. The pandemic has already highlighted systemic health inequities as “a global topic of concern”, at the same time as the precarity of individuals and families experiencing health needs have been impacted by medical shortages, and rising unemployment (Paust, 2020, 9). However, little is known yet (academically speaking) about the lived experiences of people *already* in the healthcare system when COVID-19 took hold around the world.

As a very recent, ongoing event, scholarly literature mapping out the flow-on effects of a global pandemic of this type and scope, or the specific lockdown response of individual governments, has begun emerging. For instance, Jefferies et al (2020, e612) summarise New Zealand’s national response to the pandemic, investigating its “impacts on the epidemiology of the first wave of COVID-19 in the country and response performance measures.” Using data from official, national repositories – including all confirmed and probable cases, as well all those tested in New Zealand between February the 2<sup>nd</sup> and May the 13<sup>th</sup>, 2020 (Jefferies et al., 2020, e612) – the authors conclude that:

[New Zealand’s] early, intense response, which also enabled relatively rapid easing while maintaining strict border controls, prevented the burden of disease experienced in other high-income countries with slower lockdown implementation, including Australia, the UK, and Italy (Jefferies et al. 2020, e621).

Also emerging are broader takes on the impacts of COVID-19 on a local and global level, as is discussed in an article by 13 Australian-based scholars from various disciplines (from public health, to economics, to industrial relations). The authors comment on the way COVID-19 has revealed “vulnerabilities caused by neoliberalism” and how “the lack of global leadership, undermining of the WHO and other inadequate global responses have exacerbated the present humanitarian crisis” (van Barneveld et al., 2020, 135, 148). The authors describe some general flow-on effects on ‘healthcare systems and health inequalities’ (136); the ‘environment’ (138); ‘First Nations peoples’ (139); ‘supply chains and localised manufacturing’ (143); ‘development’ (144); ‘Australian industrial relations regime and labour markets’ (145); ‘young workers and immigrants’ (146); as well as the ‘gender dimensions’ of the pandemic (140). They end with a call to rethink global trading systems as well as local health/welfare infrastructures, with an aim to “leave no one behind” in an eventual recovery (van Barneveld et al. 2020, 148).

This report takes a more experiential focus, than van Barneveld et al. (2020), to observe the flow-on effects of the pandemic on healthcare systems and delivery in the small country of Aotearoa New Zealand. We do this by examining the personal health narratives of people already navigating (or trying to access) healthcare/welfare systems when the pandemic hit, as communicated online as part of their crowdfunding campaigns. The data we share is from a wider, Marsden-funded study of crowdfunding in Aotearoa New Zealand (see section 2.1.).

## **1.2. About Medical Crowdfunding**

### **1.2.1. How crowdfunding works**

Crowdfunding is a way for people to fundraise online – usually through a platform. Different platforms exist for different kinds of crowdfunding, including rewards-based (offering something in return); equity-based (offering shares); and donations-based/charitable models. A growing phenomena (Renwick and Mossialos 2017), online medical crowdfunding (OMC) involves utilising donation-based platforms, such as *Givealittle* (NZ-based), or *GoFundMe* (US-based), to raise funds for either one’s own, or another’s health/medical-related costs<sup>1</sup>. The money is usually raised from “generally small contributions from numerous participants (i.e. the crowd)” (Renwick & Mossialos, 2017, 48). When a person or group (the page creator/s) starts a campaign, *Givealittle* prompts them to write a title, a main story, a summarising statement, and a section called ‘Use of Funds’; that is, “what will the money be spent on?” (Givealittle, 2020c). This allows the creator to share their own or someone else’s medical need/s in narrative form, with the option of uploading photos to accompany the story. Page creators also pick a closing day for the campaign, and choose whether to display a specific fundraising goal, or to leave it open-ended. In addition to the main page, once a campaign is launched, page creators can post ‘updates’, which are often used to keep donors informed (through text and/or images) on any changes to a beneficiary’s medical needs, or how a treatment plan is going.

Crowdfunding platforms have become a place where people tell stories of health, illness, and treatment, to others. Paust (2020, 87) describes medical crowdfunding as “an economic enterprise that is imminently social”, making it a fitting entry point for analysing the extensive

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<sup>1</sup> These platforms can, of course, be used for other fundraising needs as well e.g. education, travel, gifts, sporting equipment etc.

and ongoing impacts of the pandemic and the institutional responses to it through individual experiences.

### **1.2.2. Crowdfunding in New Zealand**

As aforementioned, the most popular donations-based crowdfunding platform in New Zealand is *Givealittle*. Originally owned by the telecommunications company, Spark (2012-2019), the not-for-profit is now run by its new owners, Perpetual Guardian – a trust company specialising in estate planning. In a press release announcing the hand-over in January 2020, *Givealittle* was reported as having seen more than \$130 million in donations since its creation, including, “most notably \$10.7 million to the Victim Support page in aid of the Christchurch mosque shooting victims, and \$2.2. million to buy a beach near the Abel Tasman National Park in 2016” (Spark Foundation, 2020). Indeed, *Givealittle* regularly features in New Zealand media, with online news sites quick to cover viral campaigns (such as the Christchurch mosque shooting mentioned above [Stuff, 2019], and the Australian bush fires in January [Tapaleao, 2020]), in addition to regular reporting on the platform’s donation figures (which is often filled with nationalistic discourse, patting ourselves on the back for our “Kiwi generosity” [OneNews 2013]).

Kiwi crowdfunders also utilise the US-based *GoFundMe* for their health campaigns. As they do not have a New Zealand branch, however, donations are not available in New Zealand Dollars. Kiwi citizens based in Australia and further abroad often use the platform. Those using *GoFundMe* in New Zealand use creative means to access it, e.g. asking a friend in Australia to set up the campaign on their behalf, who then transfers the money to a New Zealand account.

### **1.2.3. Themes in medical crowdfunding literature**

Academic, empirical writing on medical crowdfunding is limited, but growing in number. Studies using quantitative methods (with data scraping tools and statistical analyses) are much more common than qualitative studies (for example using interviews and/or case studies, or applying ethnographic techniques).

Several studies use campaign pages themselves as data sets (as we do) and apply a critical lens on the tendency to frame medical crowdfunding as a safety net. For instance, as Kenworthy (2019) and Lee and Lehdonvirta (2020) argue, the relationship of medical crowdfunding to formal safety nets (e.g. national health coverage, health insurance, or social security/welfare

systems) is complex, and deserves closer scrutiny. Additionally, they ask whether crowdfunding is simply “friendfunding” (a continued reliance on “informal safety nets” [Lee and Lehdonvirta 2020, 18]), where people rely on a pre-existing network of friends and family for help. Paulus and Roberts (2018, 70) would certainly argue that “medical campaigns are targeted for existing [...] communities”, after reporting a “scarcity of appeals to strangers.” After conducting quantitative analyses (e.g. from data scraping and multiple regression analyses), however, Lee and Lehdonvirta assert that is *not* the case. Rather, they argue people are using medical crowdfunding when both their “formal and informal safety nets are failing them” (Lee and Lehdonvirta 2020, 20). However, they note that success is still partially reliant “on how well-off the fundraiser’s local community is” in general. This means those located in poorer areas, i.e., those that often need it most, are less likely to get the help they need – which, in turn, “places doubts on medical crowdfunding’s transformative potential” (Lee and Lehdonvirta 2020, 20). Kenworthy (a researcher involved in multiple projects on medical crowdfunding using both quantitative and qualitative methods) takes things further, arguing “most crowdfunding not only fails to fill gaps in health coverage: it also conceals and exacerbates the structural violence of austerity and inadequate social safety nets that fuel health disparities” (2019, 4).

Other key themes in medical crowdfunding literature include ‘deservingness’, and the ‘marketisation of care’; with researchers looking at the tactical, culturally influenced, narrative frameworks campaigners use to position themselves, or others as “*worthy* of support” such as describing or expressing “good character” or having a “third party request the money” (Paulus and Roberts 2018, 70, *original emphasis*). Similar studies illustrate how pervasive social inequalities and systems of oppression (i.e. racism, ableism, ageism) are reflected in crowdfunding success rates. For instance, some illnesses are more stigmatised than others and therefore harder to ‘market’ (Neuwelt-Kearns et al. 2021/Forthcoming), while others illustrate how some social/physical traits (like gender, geographic location, race, age, or even beauty) tend to predict campaign success just as much as ‘need’ (Kenworthy et al., 2020; Wardell, 2020). Indeed, there are a growing number of researchers focussing on the ethics of crowdfunding and its implications (Dressler & Kelly, 2018; Durand et al., 2018; Snyder, 2016), including issues of privacy and individual agency in the face of need (Gonzales et al., 2018).

### 1.3. Crowdfunding During COVID-19

Even at this early stage, crowdfunding has been acknowledged in mainstream media coverage as a significant feature of the landscape of altruistic responses to COVID-19. The most common trends reported internationally is the creation of campaigns raising funds for PPE and other medical equipment like masks and ventilators, including by researchers and scientists in Ireland (Rowan & Laffey, 2020); NHS doctors in the U.K. (Sayburn, 2020); and various individuals, such as an assistant film-producer in Belarus (Bienvenu, 2020). More widely than this, the economic upheaval of COVID-19 has seen individual citizens, community/charitable groups, and business owners turn to crowdfunding as an alternative ‘safety net’ to cover general life expenses (food, rent etc.), or to keep small businesses or “cultural institutions, such as theatres” afloat – as described in the US [Popper and Lorenz 2020; Cole 2020] and Japan [Wakui 2020, 317]. As Popper and Lorenz (2020) report for the New York Times, *GoFundMe* “is facing the greatest demand it has seen since its founding in 2010”. Within just four days in March 2020, “the number of coronavirus-related campaigns on *GoFundMe* shot up by 60 percent, from 22,000 to 35,000” (Popper and Lorenz 2020). Nevertheless, Moine and Papiasse (2020) note that research into crowdfunding trends during a crisis like COVID-19 offers good insight into what the “current needs”, “collective anxieties” and “behavioural responsiveness” are in various locales.

New Zealand’s donations-based crowdfunding platform, *Givealittle*, also saw a number of coronavirus-related campaigns appear – although much less than *GoFundMe*. The website had two pages dedicated to COVID-19. One was ‘COVID-19 Support’, which highlighted campaigns “helping to provide assistance and relief for people, families and communities affected by the Covid-19 pandemic” (Givealittle, 2020b)<sup>2</sup>. However, rather than for private citizens, most of these pages were created by groups raising money in support of small businesses and tourist-reliant attractions (such as Orana Wildlife Park), PPE and other medical equipment (e.g. “Help Protect our Medical and Emergency Heroes with Protective Face Shields”), vulnerable communities in New Zealand (e.g. “Feeding the community of Te Puke – Covid 2020) and overseas (e.g. “Urgent support for vulnerable refugees against COVID-19”) (Givealittle, 2020b). The second page, ‘COVID-19 Charities’, listed campaigns supporting

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<sup>2</sup>On this page, on the 10<sup>th</sup> of July, the authors counted only 14 active campaigns out of a list of 56. As of November 2020, only six campaigns were open for donations [<https://givealittle.co.nz/landingpages/covid19/>].

charities which, due to the pandemic, “had to change or cancel their annual fundraiser events” (Givealittle, 2020a).

Platform providers acknowledged their role in mediating the flow of charitable support towards those affected by COVID-19. *GoFundMe* started a fundraiser called “COVID-19 Relief Fund”, towards which 4.7K donors have given \$356,469 between March 12<sup>th</sup> 2020 and August 3<sup>rd</sup> 2020 (Gofundme, 2020a). They state that funds are going towards issuing “microgrants to individuals, organizations and communities that have either been impacted themselves or are dedicated to helping those affected by the crisis” (Gofundme, 2020a). They also posted several articles with advice and tips for how different groups of people impacted by the pandemic can receive help e.g. “Coronavirus Relief for Homeowners and Renters: A Guide”; “Four Crucial Resources for Single Parents During the Coronavirus”; and “Coronavirus Relief for Low-Income Families: Ways to Find Support” (Gofundme, 2020b). Meanwhile, in their winter newsletter, the Perpetual Guardian discuss how the “Givealittle team” successfully ran their “first online live crowdfunding event ‘Help from Home’”, which helped three organisations (Asylum Seekers Support Trust, The Kindness Institute and Aviva Charitable Trust) raise more than \$110k (Perpetual Guardian 2020, 5).

In the same newsletter, Perpetual Guardian report that “Despite the COVID-19 lockdown, New Zealand showed incredible generosity by donating \$2.83m in April,” which “is well above the usual \$1.9m monthly donations” (Perpetual Guardian, 2020, 5). Similarly Moine and Papiasse (2020) observe an altruistic “upsurge in solidarity” across three crowdfunding platforms in France during the pandemic, with a combined total of € 6,079,419, donated from 90,643 donors (Moine and Papiasse 2020). Indeed, it is not hard to see why people are tempted (even before the pandemic) to describe crowdfunding platforms as “the new ‘digital safety net’, as suggested by the CEO of the biggest platform” (Lee and Lehdonvirta 2020, 17). As reported in the *Lancet* (Usher 2020), even the World Health Organisation has turned towards crowdfunding to finance its COVID-19 response. It’s campaign, the COVID-19 Response Fund, is hosted by the United Nations Foundation, as well as the Swiss Philanthropy Foundation (and can be found here, <https://covid19responsefund.org/en/>). Reporter Ann Danalya Usher tells us that since launching on March 13<sup>th</sup>, it raised more than 71 million US dollars in just ten days (by “170 000 individuals and organisations” (Usher 2020, 1025). By the 23 of November 2020, it has “raised or committed \$238,175,362 from more than 651,000 individuals, companies and philanthropies” (United Nations Foundation, 2020).

However, just like medical crowdfunding literature in general there is a growing number of voices (academic and professional) that are hesitant to frame crowdfunding as a *viable* ‘safety net’ during a pandemic (Moine and Papiasse 2020). For instance, in the Lancet article, Usher also spoke to Suerie Moon (the “co-director of the Global Health Centre at the Graduate Institute of International and Development Studies in Geneva, Switzerland”) who, despite the success of the WHO campaign, critiques the fact that the WHO had to approach the international public in the first place (Usher 2020, 1025):

Ideally, governments would adequately fund WHO to do the work they have asked the agency to do”, she says. “The launch of the Solidarity Response Fund is a good sign that WHO is agile and responding quickly to a rapidly changing situation. But the real question is why do they need to do so in the first place? It reflects donors’ total failure to fund the response to this outbreak at the international level (Moon, in Usher 2020, 1025).

Substantiating this is van Barneveld et al. (2020, 137), who also decry the “chronic underfunding” of the WHO by neoliberal, “developed countries” who “regrettably deny that they have been weakening multilateral institutions”.

With such critiques in mind, it is important to note that not all crowdfunding platforms in New Zealand were doing as well as *Givealittle*. Both *Pledge Me*, and the New Zealand branch of *Kickstarter* saw an overall decline in donations over lockdown according to Nadkarni (2020, reporting for Stuff). This suggests, as Lee and Lehdonvirta (2020, 1) argue in reference to US medical crowdfunding, that patterns of giving are not simply based on need, “but on the basis of one’s ability to appeal to the audience and out-compete rivalling needfuls”. Thus, which crowdfunding platform one chooses to frame one’s ‘need’, likely plays a role in campaign success. For instance, it is possible the drops in *Pledge Me* and *Kickstarter* indicate that Kiwis preferred to give money to donations-based *Givealittle*, rather than entrepreneurially-framed crowdfunding platforms, but more investigation is needed to confirm. Indeed, *Givealittle* hosted a number of campaigns for small businesses: one was “Aiming to raise money for small hospitality businesses across New Zealand<sup>3</sup>” and another helping “small businesses with legal expenses<sup>4</sup>” in Auckland, during the pandemic.

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3 <https://givealittle.co.nz/cause/elemento-bins-x-nz-cafe-fundraising>

4 <https://givealittle.co.nz/cause/small-business-help>

## 2. Research Design

### 2.1. Research Context

The research covered in this article emerged from a longer multi-methodological study funded by the Marsden Fund (*Fast Start Research Project: Medical Online Crowdfunding in New Zealand* [PI: Dr. Susan Wardell]), which commenced in April 2020, with an overall qualitative and ethnographic methodological framework. This project aims to critically contextualise the role of crowdfunding within New Zealand’s healthcare funding system, and to provide insight into the lived experiences of health, illness, and need, within socio-political structures. While later phases of the project focus on case studies and interviews, the initial phase of the project aimed to fill a gap in research on the patterns of medical crowdfunding in New Zealand (and enable cross-cultural comparison). This involved a comprehensive analysis of individual medical crowdfunding campaigns, which were running in June 2020, across the two main donation-based crowdfunding platforms accessed by New Zealanders – the New Zealand-based, non-profit *Givealittle*, and the US-based for-profit *GoFundMe*<sup>5</sup>.

This sample was limited to:

- a) Citizens/Residents, and Non-citizens/Residents living *in* New Zealand and,
- b) New Zealand citizens/residents *outside* of New Zealand, needing health assistance.

This generated 563 campaigns in total, 427 from *Givealittle*, 136 from *GoFundMe*. There were 397 related to *illness/disease*, 35 to *difference/disability*, 63 to *injury/accident* and the rest (68) were across the following categories: *elective*, *dental*, *fertility*, *gender affirming healthcare*, *pregnancy and childbirth*, and *other*. The initial analysis (A1) was quantitative, focusing on the demographic details of the recipients and their stated health needs. A second analysis (A2) occurred concurrently where research assistants (Dr. Penelope Bilton, Dr. Ella Robinson, and Laura Starling) made note of any emergent themes of content arising from the campaign stories.

The timing of this research proved significant. Lockdown Level 4 (the most restrictive level) began on the 25<sup>th</sup> March for the whole country, and shifted to Level 3 on the 28<sup>th</sup> of April 2020. There was then a “staggered move to level two, beginning 14 May” and finally to alert Level 1 at 11:59pm on 8<sup>th</sup> June (Strongman, 2020). It was during this week that our data-collection

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<sup>5</sup> *GoFundMe* doesn’t officially list New Zealand as a country it’s services support, yet New Zealanders do use the platform, utilising various informal workarounds to do so.

officially commenced – with logging and coding occurring from June 8<sup>th</sup> to June 19<sup>th</sup>. Because of this the coders observed a growing number of active campaigns commenting on how COVID-19 complicated their precarious health situations. Subsequently, the research team was asked by the PI to note all campaigns which referenced the pandemic in some way. These were later extracted from the main data set of 563, resulting in 50 campaigns in total.

From this we developed a new research question to guide analysis of this specific dataset.

## **2.2. The Research Question**

We developed the following research question:

**In what ways did medical crowdfunding campaign narratives reveal some of the effects of New Zealand’s pandemic response on the healthcare experiences of those already living with health needs, during the 2020 lockdown?**

We approached this question through a process of examining the 50 medical crowdfunding campaigns we had identified which mentioned COVID-19, who were *already* ill or fell ill (with non-COVID-related illnesses) just as the pandemic took hold world-wide.

We summarise key aspects of their lived experiences of the flow-on effects of the COVID lockdown, on healthcare and wellbeing more broadly, as reported in this medium. In context of existing crowdfunding literature, which emphasises patterns of crowdfunding as indicative of gaps in wider social systems, this generates an analysis “informed by precariousness” (Paust 2020, 87), allowing us to feel out some of the stress-fractures in New Zealand’s health/social security systems. It also provides a first-person account of some of the wider social factors which may support or damage subjective experiences of health and wellbeing, and how these were shaped by the pandemic.

## **2.3. COVID-19 Dataset**

Below is a table of all 50 campaigns with their titles, followed by a general summary of the characteristics of our new dataset. Although this information is publicly accessible, we acknowledge we could not ask permission from each campaigner to quote from their pages. In respect of this, we have removed all names from the titles included below.

*Table 1: Campaign Titles*

<b>No.</b>	<b>Campaign Title</b>
1	Survived half of my life, trapped in Domestic Violence, only to find out I have Cancer. I NEED YOUR HELP PLEASE x
2	Run for X - Half Marathon Fundraiser
3	The "Baldest" Thing I've Done...
4	X's Fight for Life
5	Support X's with his ongoing Battle (a living nightmare)
6	Sometimes life sucks!
7	X's Journey
8	Help Improve X's Dancing Life
9	X and X's recovery
10	My little fighter Xs health journey
11	X's Fight Against Cancer - CDH1
12	X's Bucket List
13	Next Item on the 'Agender'
14	Fulfil Our Mum's Last Wishes - Terminal Cancer
15	X's 3rd Battle with Cancer
16	Tragic, Sudden Loss of Fiancé
17	Xs Overseas Adventure
18	Toxic mouldy in my rental and property lost
19	Supporting X, X, X, X and X
20	Give a quid for a squid - X
21	Help For X & Her Daughters
22	Mighty Xs Fight !
23	Please support X, X, X and X
24	Help X take back her life! HSCT Treatment for Multiple Sclerosis
25	X's MS Treatment - Reprogram Her Life
26	Help X Get Back On Her Feet
27	Please help my sister buy some more quality time!
28	X and her journey to Starship
29	X and X's run for X.
30	Travel to spend end of life with our Dad

- 31 Literally gutted after lockdown.
- 32 X's Fight Against the Baddies
- 33 Traveling with leukemia
- 34 For the happiest girl in the world
- 35 Therapy Dog for X and the Whangamata community
- 36 Making Memories with X around New Zealand
- 37 Help Heart Baby, X
- 38 Support for local Taranaki whanau and their little babies
- 39 Bubble Trouble
- 40 Help X's family fight their brave battle
- 41 Raising Funds for Surgery for USAF Vet, X
- 42 Help Young Family Victimized by Terrorist Attack
- 43 Lung Surgery For X
- 44 Help us get home to New Zealand
- 45 White Island Volcanic Eruption Survivors, X/X
- 46 X and X Relief Fund
- 47 Help X have her wish before her major surgery
- 48 Help X Beat Cancer!
- 49 Help X & his Stem Cells get to NZ
- 50 Xs fight to recovery

### **2.3.1. Campaign characteristics**

In terms of the type of health need, Figure 1 shows that, similar to our larger dataset, the majority of campaigns were related to illness. Notably, 20 of these were cancer patients; which again, reflects trends showing high numbers of cancer-related fundraisers in our larger dataset.

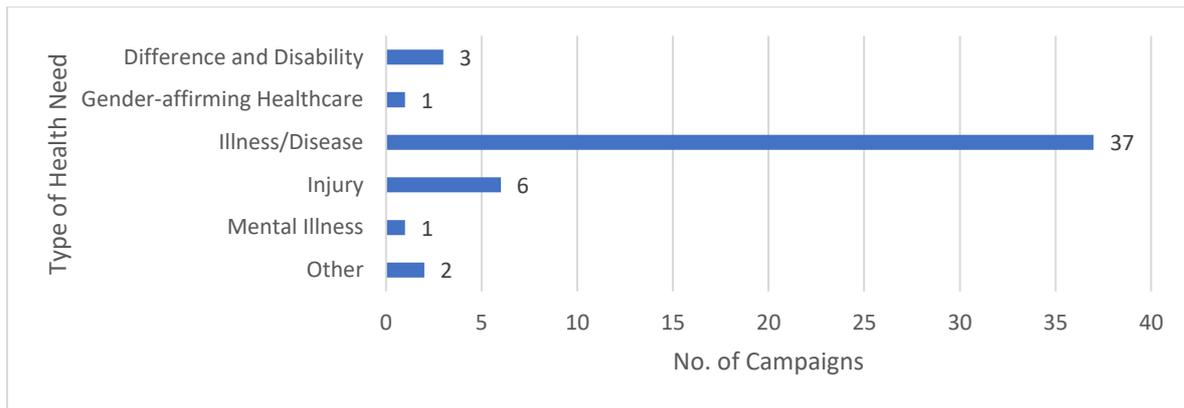


Figure 1: Recipient Health Needs

As per Figure 2, most campaigns were for New Zealanders based in New Zealand (41). There were only two New Zealanders overseas needing to return home that mentioned COVID-19. Thus, the dataset is broadly representative of experiences *in New Zealand*, and in the New Zealand healthcare system, during this time.

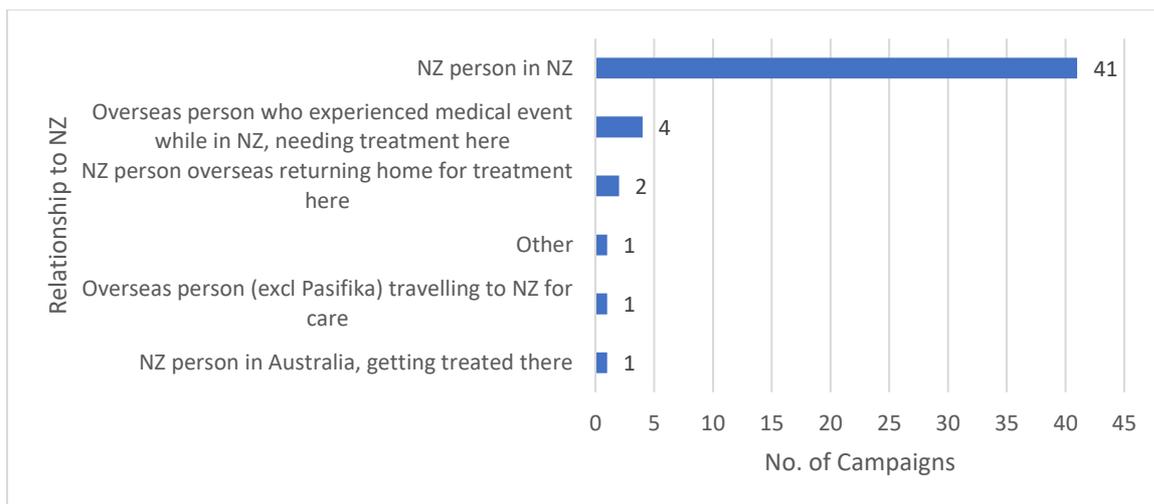


Figure 2: Recipient Relationship to New Zealand

However, not all fundraisers were directly for medical care. The most common purpose of fundraising mentioned (n=26), was to cover *general standard of living costs* (such as rent, power bills, food, caregiving for children), during the time of illness or care. *Travel and accommodation* costs within New Zealand was next common (n=13), often with a focus on caregivers and children travelling to and from hospital (this being both before and after the lockdown period, not only during). Families fundraising for *special activities* such as trips or family get-to-togethers with the recipient, were the next most frequent use of funds (n=8).

Less common, were campaigns mentioning: *Outpatient medical and diagnostic services; Inpatient care (curative and rehabilitative); Pharmaceuticals; Treatment costs overseas; Travel/accommodation costs within New Zealand (individual); travel costs for overseas treatment; medical/therapeutic/mobility equipment; Travel Costs to NZ; CAM (complementary alternative medicine); Counselling/Therapy; Funeral expenses; In-home care (curative and rehabilitative); organisation or charity; Outpatient rehabilitative care; Other; and Not Stated.* Usually pages described multiple use of funds, mentioning more than one of these uses.

### **2.3.2. A note on the use of funds**

Discussion of the use of funds has often been recorded with slightly different nomenclature than we have in this report. For instance, in the US, Rajwa et al. (2020) studied the crowdfunding response to the pandemic on *GoFundMe*, examining a total of 1579 campaigns between the 3<sup>rd</sup> and the 20<sup>th</sup> of March 2020. They noted the following ‘needs articulated’: *Living expenses, lost wages, and food* (88%); *Medical supplies* (8.7%); *Hospitals and healthcare workers* (3.3%); and *Research*. The category *Medical Supplies* was divided into the following: *PPE* (e.g. masks); *Critical Care Supplies* (e.g. ventilators) and *PPE testing equipment* (Rajwa et al., 2020). Another US-based study by Bian et al. (2020, 7, 8) collected *GoFundMe* campaign data from the 1st of January to the 4th of March 2020, recording “192,654 COVID-19 campaigns” in total. They distinguished between only three categories: *PPE*, *Economics*, and *Other*. Their ‘Economics’ category included “COVID-related campaigns to alleviate financial hardships, including unemployment and bankruptcy” (Bian et al. 2020, 25). *GoFundMe* itself has also outlined the main areas where people’s donations to the COVID-19 Relief Fund are likely to end up, including individual *Living expenses; Food, water, and other basics; small business and unemployment support; and emergency medical treatment, medication and equipment* (Gofundme, 2020b).

In France, Moine and Papiasse (2020) also looked at the general use of funds in an analysis of crowdfunding trends in response to the coronavirus in France. They collected data from 245 campaigns across three French-based crowdfunding platforms (*Leetchi, KissKissBankBank, and Ulule*), between the 21-22 of April 2020. They categorised campaigns under four headings: *Support to hospitals, medical staff, emergency services; Support to vulnerable populations (children, elderly, battered women, homeless, refugees etc.; Economic aid: economic support to business and non-profit organizations; and Individual help* (Moine and Papiasse 2020).

Across all three platforms, most of the funds raised went towards the first category (*Support to hospitals etc.*).

## **2.4. Analysis**

Having established our own COVID-19-related dataset, the first author conducted a qualitative, content analysis of these campaigns, observing when/how the COVID-19 virus was discussed, its stated effects on the recipient's experience of health and wellbeing during the period of the March-April Level 4 lockdown, and the period directly after. As Vaismoradi, Turunen and Bondas (2013, 400) explain, a qualitative content analysis is useful “for exploring large amounts of textual information unobtrusively to determine trends and patterns of words used, their frequency, their relationships, and the structures and discourses of communication”. When the research question is descriptive or exploratory (examining a new event, for instance) content analysis is particularly helpful “for the simple reporting of common issues mentioned in data” (Vaismoradi et al. 2013, 400).

Since the majority of the campaigns were created *before* COVID-19 reached New Zealand, references to the virus were usually found by scrolling to the updates made in March 2020, rather than the main page. Even so, each of the 50 main pages were read for narrative context. Sometimes, a page's updates were numerous/lengthy, so using key words (such as *COVID*, *Covid*, *Covid19*, *Covid-19*, *Corona*, *coronavirus*, *virus*, *pandemic*, *isolation*, *quarantine*, *lockdown*, and *lock down*) helped fine-tune the search.

We focus on the campaign narratives themselves, rather than the response to, or financial outcome, of the campaigns. After reading how the pandemic was mentioned or alluded to, common topics of concern became apparent, ranging from direct, practical dilemmas the pandemic caused (such as treatment delays), to more tacit evocations of increased suffering (impacting mental health). These were grouped into nine broad categories, unpacked below in our research findings (section 3). Finally, each of these nine categories (from section 3.1.1 to 3.3.3) were then used to conduct another literature search – mainly of online media and grey literature in New Zealand – in order to verify and contextualise the issues raised by campaigners.

Notably, online news media sometimes headlined with COVID-related crowdfunding campaigns, with three campaigns from our dataset featuring a link to a corresponding news article (Russell, 2020c; Star News, 2020; Witton, 2020a). Other studies have addressed the relationship between mainstream media and crowdfunding (pre-COVID19) in more detail (Murdoch et al., 2019; Zenone & Snyder, 2019). We mention media connections, and wider media reporting, where relevant, in our findings, without applying a direct analysis to the media framings ourselves.

## **2.5. Ethics**

The study functioned under approval from the University of Otago Human Ethics Committee (reference code 20/028). All data used for this phase of analysis was publicly available. However, as we take quotes out of their original context and intended purpose, we have chosen to remove the names of individual crowdfunding recipients (except where these have also appeared in mainstream, news media coverage), and also not to provide their direct campaign links.

## **2.6. Limitations**

There are limitations to this approach. Our sample size is fairly small, and in fact thousands of people already receiving medical care will have been affected in indirect ways by the lockdown procedures. Only a small proportion of people receiving medical care engage in crowdfunding in order to support their direct or indirect costs during this time. As such, we are not claiming to have captured all the possible complications the pandemic has had on New Zealand's healthcare system, nor do we present a representative sample of the population. Rather, we argue that qualitative and quantitative analysis of medical crowdfunding campaigns offers an important snapshot, or investigative path into the indirect impacts of the virus on health care systems in New Zealand and around the world. In particular it highlights the impacts on people who can reasonably be understood to already be in a precarious position financially, as well as in terms of health.

In addition we recognise that these are subjective rather than authoritative accounts of changes to the healthcare system – they represent understandings about the rapid changes and sudden restrictions being made, held by some of the people trying to navigate them, at the time. It is more than possible that, at times, this involves miscommunications or misunderstandings on

points that may have been clarified later, or policies that changed as new understandings emerged; especially as healthcare professionals and administrators were also grappling to understand the specific and rapid applications of lockdown protocol to their various services. Recognising this, and drawing on our ethnographic training, this study aims to simply take seriously the narratives of crowdfunders, as socially valid accounts of disruption, change, and restriction, that may have varied relationships to the legal, practical, or bureaucratic measures in place, and are, nonetheless, a relevant insight into lived experiences at this time.

In the next section we lay out our findings from within the crowdfunding narrative. In consideration of the above, and to give context to wider public communication and conversation happening at this time, we also link our findings to media reporting from New Zealand about the lockdown and its wider social effects.

### 3. Research Findings

Our analysis elucidated nine key ways in which COVID-19 impacted upon the healthcare experiences of 50 New Zealand medical crowdfunding campaigns (with health needs pre-existing the pandemic). These were: *Delays or Cancellations in Healthcare Delivery, Travel and Access* (including *Surgical Delays, Bone Marrow/Stem Cell Transplant Complications, Other Medical Delays, and Other Health Journey Delays*), *Lockdown Backlogs, Virtual Consultation Costs, Job/Income Loss, Fundraising/Event Cancellations, Other Economic Impacts, Distress over Restricted Visitation/Social Support, Distress over Immunity Suppression, and Mental Health and Resilience*. As none of the campaigns deal with people who actually contracted the virus, we count these as ‘flow-on’ effects of the lockdown procedures rather than ‘direct’ health impacts from the pandemic. As these titles suggest, the campaigns covered a diversity of experiences, and degrees of impact (some life-threatening) – they also covered different health conditions and needs (as Figure 1 illustrates above).

The effects range in scale, and type, with many idiosyncratic situations emerging among crowdfunders unique individual experience. However, to provide structure and highlight the diversity of impacts, we have arranged our nine initial categories into three broader areas: the institutional, the economic, and the social/emotional. These are not fixed or discrete categories, and some of the impacts we discuss involve more than one of these three areas. Our arrangement is but one way of portraying their interconnections, in hopes of responding to the seminal call by medical anthropologists Scheper-Hughes and Lock’s (1987) to pay attention to the “three bodies” (the phenomenological/individual body, the social, and the body politic), in order to better capture “the emotional, social, and political sources of illness and healing” (Scheper-Hughes and Lock 1987, 220).

Under each subheading, we present campaign findings first, followed by a contextualisation of each key finding with media reports or grey papers that reference or further explain the issues raised.

### 3.1. Institutional Changes/Responses

#### 3.1.1. Delays or cancellations in healthcare delivery, travel and access

During Level 4 lockdown, just over 50 percent of campaigns (n=26) reported the suspension or cancellation of various modes of medical care (of different levels of urgency), and delays that were not strictly medical, but which significantly impacted campaign-recipients health journeys in a range of ways. This included delayed/cancelled surgeries and transplants (particularly for bone marrow/stem cells for people with cancer and MS); and various general appointments or therapies (including chemotherapy). Delays in medical care ranged in cause – from international travel being suspended, to a hike in the cost of treatment, or because New Zealand hospitals were reserving facilities for an expected rush of COVID-19 patients.

The 26 reported delays are categorised below into four key types: surgery, bone marrow/stem cell transplant complications, other medical delays, and other health journey delays.

##### 3.1.1.1. Surgical delays

Eight different crowdfunders in our dataset experienced cancelled or delayed surgeries, or were told surgery would *potentially* be delayed. One *Givealittle* recipient – whose story was picked up by *Stuff* – was told his surgery for stomach cancer was cancelled due to the Wellington Region Hospital reserving beds for an anticipated influx of COVID-19 patients (Witton, 2020a). As a result, he had to take chemotherapy for eight weeks instead: “I wouldn't have needed to have chemo if it wasn't for Covid” (in Witton 2020a). He is aware of being “one of thousands of patients that have had ‘non-urgent’ operations cancelled during the eight-week lockdown to clear beds for a surge in covid-19 patients that never eventuated” (Witton 2020a). As Akoorie (2020) describes, District Health Boards were “trying to provide outpatient services in a non-contact environment to help minimise any risk of Covid-19 transmission, prioritising acute care and urgent planned care surgery, and deferring some cases.” Another *Givealittle* campaigner was told their eventual surgery may be delayed due to a lack of respirators, and a woman in Australia was unable to get to New Zealand on time for her surgery because of the 14-day quarantine requirement at New Zealand's border. As a result of cancelled or delayed surgeries, private hospitals have been asked to offer more “elective surgeries, including cancer operations, to help district health boards catch-up. Senior doctors have warned it will take years to clear the surgical backlog” (Witton, 2020a).

In April 2020, RNZ reported “An estimated 30,000 people,” as having missed out on their surgeries – mostly elective – due to the lockdown (Quinn, 2020b). The campaigns that brought this to our attention are thus merely the tip of an iceberg, with New Zealand’s media picking up on a handful of similar cases. For instance, *The NZ Herald* told the story of Jennifer Rouse (66yo) who was told her breast cancer surgery was classified as ‘elective’ and therefore, “because of the Covid-19 issue, no private or public non-urgent breast surgeries were being done in Northland and no information was available as to when this service might be resumed” (Rouse in Akoorie, 2020). Rouse argued, “cancer treatment is not elective. I have fallen through the cracks and feel very let down by the system” (Rouse in Akoorie, 2020). She decided not to wait and organised her surgery privately, paying \$15000 when it could have been free. She wrote to her local MP about her situation and was told that others in similar predicaments had also gotten in touch, and that he would “lobby for ‘high priority attention’ for Northland women with breast cancer when the lockdown lifted” (Akoorie, 2020).

At the time of the article (23rd of April 2020), the Health and Disability Commissioner (Anthony Hill) had “received 50 complaints related to coronavirus, including cancelled and delayed treatment. He said the consequences would be particularly serious for patients where early diagnosis and treatment was key to survival, including cancer and coronary disease” (Akoorie 2020b). Similar headlines by multiple New Zealand-based journalists hint at the extent of this particular flow-on effect for cancer patients, including: “Cancer sufferer in limbo as surgery pushed back in Covid-19 crisis” (Neal, 2020) and, “Man with terminal cancer loses 'precious days' in hospital wait” (Quinn, 2020d).

### ***3.1.1.2. Bone marrow/Stem cell transplants complications***

There were five campaigns (four clearly evident, one imputed) where recipients’ potentially life-saving bone marrow/stem cell transplants were delayed by the pandemic. One campaign recipient had to narrow their search for a bone marrow donor to New Zealand only, which lowered their chances significantly of finding a perfect match. Another New Zealand patient had to have their stem cell transplant suspended because neither the donor, nor the donor’s stem cells (with a 10/10 match) could be transported from Germany to New Zealand. As a result, the procedure looked likely to go ahead with a donation from the patient’s mother instead, which has a lower chance of success as they only have a 5/10 match with the recipient. Another case features a Kiwi in the UK, who had their stem cell transplant suspended due to high pressure on the NHS. He was trying to get himself (and his stem cells) back to New

Zealand in order to undergo the procedure. However, he cannot afford the travel costs on his own, turning to crowdfunding for help.

On the 14<sup>th</sup> of June, the Bone Marrow Transplant Society of Australia and New Zealand published the first edition of their “COVID-19 consensus position statement”. They acknowledge some of the challenges the viral pandemic presents, including that “travel restrictions and illness are likely to reduce the unrelated donor pool” (Hamad et al., 2020). Nevertheless, the Society proposes that “Centres will identify backup donor options for patients undergoing allogeneic transplant from interstate and overseas unrelated donors, including haploidentical related donors and cord blood donors” (Hamad et al., 2020). Furthermore, they say “Centres will cryopreserve all international and possibly interstate unrelated donor products before starting conditioning” (Hamad et al. 2020). Their official statement also includes advice on triaging transplants, describing who should be considered ‘high’, ‘intermediate’ and ‘low’ priority patients. Those classified as ‘low’ can be “delayed with low risk of adverse outcome”; ‘intermediate’ patients can be delayed using “bridging therapies to stabilise disease while awaiting transplant” and ‘high priority’ patients are those where “adverse outcomes are expected if transplant is delayed for any reason other than patient factors” (Hamad et al. 2020). Other likely challenges they acknowledge are the “reduced availability of highly specialised health care staff due to illness or allocation to other areas, as well as compromised infrastructure and acute care bed capacity” (Hamad et al. 2020).

### *3.1.1.3. Other medical delays*

Six campaigns mentioned different forms of medical delays (diagnostic or treatment), both in New Zealand and overseas. For instance, two recipients were due for overseas treatment (Australia and the UK) and neither could attend due to travel restrictions. A New Zealand cancer patient (diagnosed in March) was initially told her chemotherapy was “off the table” because it would lower her immunity and make her too vulnerable to the virus. In contrast, the Cancer Control Agency [CCA] (2020) state in a May report, that “[a]ttendances for intravenous chemotherapy remained largely stable over the lock down period” (Cancer Control Agency 2020, 5). According to the CCA, “nationally agreed upon guidance” for lockdown was to both keep “day unit capacity and minimise spread of COVID-19,” which involved looking at “switching from IV therapy to a comparable oral therapy if possible and selection of comparable therapies that require less frequent attendances to hospital” (2020, 5). It is possible the crowdfunding recipient in question was caught in the transition phase between hospitals

receiving guidance from the government and actually putting it into practice. In an update dated 28<sup>th</sup> of May, they report being finally allowed to continue chemotherapy (however, by this time the country was already back in Level 2).

New Zealand media picked up on other medical delays too, including that, “Thousands of fertility treatments have been cancelled or postponed because the services are not considered essential” (Quinn, 2020a). This has caused severe emotional distress for some IVF patients who fear they’ve missed the window “to have a family” (Quinn, 2020a). As one woman described,

‘I was completely hit for six. I was so devastated. I felt like I had been building up for this for so long,’ she said. She and her partner had been having treatment for five years. ‘I was so hopeful this time... this would be it. I cried and cried,’ she said (Quinn 2020a).

Other groups suffering delays in treatment, included (but are not limited to) those awaiting joint replacements (van Delden, 2020), back, brain and gynaecological surgeries (Quinn, 2020b) and those seeking dental treatment (Radio New Zealand, 2020c). For instance, Radio New Zealand report lockdown as exacerbating already lengthy waiting times for dental treatment, with 135,000 children in Auckland alone “overdue for a routine dental appointment” (Radio New Zealand, 2020c).

Medical delays are occurring overseas as well, with one *GoFundMe* campaign telling the story of a couple returning to the US for ongoing medical treatment after surviving New Zealand’s White Island volcanic eruption in December 2019. In a campaign update in June, they describe COVID-19 as having “suspended” their treatments since mid-March 2020. International examples were also covered by New Zealand media (see Loomes 2020, and Gramenz 2020). For instance, the NZ Herald shared the story of Kelly Smith who, at 31, died from bowel cancer, Stage 4 in the UK. She had been battling the disease for three years and, according to BBC reporter Deborah James, Smith’s “chemotherapy was stopped in March as the effects of the pandemic worsened across the UK” (Loomes, 2020). Smith was quoted in a BBC programme (Panorama) saying, “I’m angry at Covid and that I got put on this break because I don’t think I should have” (Loomes 2020). The NZ Herald also reported on a Melbourne-based family who tried to fundraise for Jahleel who was “diagnosed at just 3 months old with the rare disorder that is known colloquially as “children’s Parkinsons”, or Amino Acid Decarboxylase

Deficiency (Gramenz, 2020). He was due to receive gene replacement therapy in Poland, and “travel restrictions because of the Covid-19 pandemic meant it had to be postponed”. Jahleel sadly died at age four. “Now the coronavirus pandemic that denied the family a chance at life-saving surgery overseas is also affecting funeral preparations” (Gramenz 2020).

#### *3.1.1.4. Other health journey delays*

Other (not strictly medical) delays to recipient’s health journeys included (amongst others): a child having to delay their enrolment/attendance at a specialist school in New Zealand; a family unable to leave their rental home during lockdown, despite the presence of toxic mould; and the delay of a terminal cancer patient from moving into their new home (a campaign we revisit in section 3.3.1).

One campaigner experienced a delay in accessing accommodation in Auckland while their child was in a hospital during the Level 4 lockdown. There is a charity, Ronald Macdonald House (RMHC®), which usually provides this service. In a media statement RMHC® describe how every year, they “offer more than 4,600 families across New Zealand accommodation and support free of charge. This helps to relieve stresses like paying for a place to sleep near the hospital, organising family meals and needing a friendly ear to listen on tough days” (RMHC® New Zealand, 2020, 2).

The page creator of the campaign posted on the 25<sup>th</sup> of April that the recipients “are currently in a hotel in Auckland, having to cover cost of Accommodation (Ronald McDonald house is closed during lockdown), pay for travel to and from the hospital and meals indefinitely until [their daughter’s] surgery.” They were probably some of the few who were caught out between the time the Level 4 lockdown was announced; the time it took for the charity to verify it’s services as ‘essential’ [essential services could still operate during Level 4, if they followed new safety guidelines]; and likely also the time it would have taken to process applications.

In their media statement on the 7<sup>th</sup> of April, RMHC® said it had “been recognised as an essential social service by the Ministry of Social Development and partnering DHB’s amid the COVID-19 outbreak, meaning they are able to continue to provide accommodation for families with children receiving treatment in hospital away from home” (RMHC® 2020, 1). Eventually, a

campaign update states that the use of funds raised would go towards covering the *initial* accommodation costs, “(which [is] now being covered by Ronald McDonald House)”.

### **3.1.2. Lockdown backlogs**

One campaign described a lack of institutional support systems that were “not in place yet due to the *backlog* because of Covid-19” (*emphasis added*). Indeed, all of the above delays or cancellations for various treatments and appointments resulted in what both campaigners and journalists have generally referred to as ‘backlogs’ from lockdown. One of the most commonly reported was a diagnostic backlog for elective surgeries and cancer patients (Neilson, 2020; Quinn, 2020c; Radio New Zealand, 2020b; Russell, 2020b; Witton, 2020b). For instance, the Cancer Control Agency reported a significantly lower amount of cancer diagnoses occurring due to the April lockdown, with “1031 fewer cancer registrations in April 2020 compared to April 2019,” which is a “47% decrease” (Cancer Control Agency 2020, 4). If we compare Jan-April 2020 with the same time last year, there are “500 fewer cancer registrations” (Cancer Control Agency 2020, 4). There was also “a 33% decrease in curative cancer surgeries (for prostate, lung and colorectal cancers) in April 2020 compared to April 2019” (Cancer Control Agency 2020, 5). The CCA thus recognised that this

...sudden unplanned disruption in usual care will inevitably lead to a backlog of unmet need. Any disruption will have an impact on cancer patients in general and may have a disproportionate impact on those who already experience greater barriers to accessing care, particularly Māori and Pacific peoples (Cancer Control Agency 2020, 6).

As a result, there were calls from the Cancer Society in New Zealand to prioritise catching up on cancer patients as soon as possible, which – according to Chris Jackson, the director of the Cancer Society of New Zealand “should include more surgery, weekend clinics and using private hospitals and facilities to help clear the backlog” (Quinn, 2020c). Fast-forward now to December, and Witton reports for *Stuff* that New Zealand’s hospitals have now “caught up with the cancer backlog”, showing similar numbers in diagnosis to last year (Witton, 2020c).

The creation of ‘backlogs’ (or exacerbation of pre-existing ones) in the health system is not just from decisions made at an institutional level. A contributing factor was that the general population delayed visitations/virtual consultations with their doctors or hospitals during Level 4 and 3, even when it was urgent. Kate Newton and Guy Espiner report that “Emergency

departments around the country said the number of people showing up each day had halved since the government began introducing Covid-19 restrictions” (Newton & Espiner, 2020). Further to this, “[p]athology testing had also dropped” and “staff in other specialities reported large drops in acute patient numbers to RNZ” (Newton and Espiner 2020). One of the biggest groups absent in hospital were cardiology patients. Newton and Espiner (2020) spoke to the chairperson of the Cardiology Association of Australia and New Zealand, Mayanna Lund. She revealed that “cardiovascular disease, including strokes and heart failure, was the country’s number one killer – bigger even than cancer” and that they are seeing a global drop in patients with a “STEMI – ST Elevation Myocardial Infarction” since COVID-19 took hold (Newton and Espiner 2020).

New Zealand Statistics also provided evidence of a backlog in health care during levels 4-2 of the lockdown. They released an analysis of medical and health care services spending over June 2020 (after the move to Level 1), showing that there was a 20% (\$43 million) increase in spending that month, compared to the same month the previous year (Stats NZ, 2020). This includes services such as: GPs, specialists, physiotherapy, optometry, ambulances, and dental care, which New Zealander’s could visit face-to-face during lockdown, so had to wait till June to return to (Stats NZ, 2020).

### **3.1.3. Virtual consultation**

Five campaigns brought up another institutional change – the use of virtual/phone consultations during lockdown (four directly, and one imputed). As Al-Busaidi and Martin (2020, 95) note, some clinics began preparing for virtual consultation before The Royal New Zealand College of General Practitioners issued its official institutional call for immediate ‘virtualisation’”, on the 23<sup>rd</sup> of March 2020 (The Royal College of General Practitioners, 2020). Below is a screenshot of requests from the College’s website:

The College requested:

- **Virtualisation:** We asked practices to start 'virtual first' triage (phone, email or video) for every patient as of 8.00am Monday 23 March. We asked them to expand the use of virtual GP consults where appropriate (without compromising patient safety) with the goal of reducing face-to-face consultations by 70%.
- **Routine care:** Continuity of care would need to be maintained, however non-urgent, routine care (including screening) may need to be deferred.
- **Frontline staff:** We asked practices to move their immunocompromised or pregnant staff, and those with co-morbidities, to be moved to non-contact functions.

Figure 3: Screenshot of Requests from the RNZCGP (2020) website

Kate Baddock (chair of the New Zealand Medical Association) frames the introduction of virtual consultations in a positive light: “a lot of what was delivered face-to-face is now being delivered virtually – innovation is occurring and what you want to be able to do is take some of that and embed it into our future” (Radio New Zealand, 2020a). Yet, while virtual consultations allowed for continued care “while maintaining the necessary public health measures adopted in the fight against COVID-19”, there were also some disadvantages (Al-Busaidi & Martin, 2020, 96). For example, at the end of April, Wade (2020) made note in the *NZ Herald* of a growing concern that the Government’s funding for primary care (including \$15million to cover “costs of moving to virtual appointments” and other infrastructure changes) was not enough to keep some general practices afloat, especially with the dramatic loss in cash flow from a lack of in-person consultations during lockdown. There are also *non-financial* costs to consider.

Al-Busaidi and Martin (2020) point out that, although most patients in their clinic seemed to adapt to the changes quite readily, others “particularly older adults” resisted for a variety of reasons, “including their preference of in-person visits, resistance to technology and perceived low value for cost”, as well as experiencing “technical issues” (95). Moreover, two campaigns mentioned receiving cancer diagnoses over the lockdown period, with one of them describing how they received this news over the phone and implied this was more emotionally distressing than being told in person. *The Spinoff* also featured the experiences of Chloe Irvine, who described the challenges of surviving breast cancer during lockdown, including the effects of not having face-to-face consultations (Morrison, 2020). She describes seeing a friend whose “chemo started right at the start of lockdown so she didn’t have any pre-chemo briefings with the nurse. She’d never met an oncologist in person until two weeks ago. She’d just had phone calls [...] She missed out on so much information and care” (Morrison, 2020).

## 3.2. Economic Impacts

### 3.2.1. Job/Income loss

Eight campaigns described the recipient or the recipients' caregivers as having job and/or income loss due to New Zealand's lockdown measures. This increased the financial burdens placed on campaigners, and thus their reliance on crowdfunding to support themselves or their loved ones during their health journey or medical event. People "are at a loss of how to provide for their famil[ies] going forward," said one campaigner. For instance, a Kiwi man (who described himself as the family "breadwinner" in his campaign) used up all his leave-entitlement over lockdown, when he realized his recently diagnosed illness would mean he would not be able to return to work during lockdown. He describes being at a loss of what to do. Another page described the recipient as being "90% unemployed for [the] foreseeable future", and another (particularly heart-breaking) campaign was set up for the bereaved partner of someone who took their own life during Level 4 of the lockdown. On top of this tragedy, the bereaved lost their job due to the lockdown measures, which the page creator described as "adding financial burden to this great emotional pain". Yet another campaign featured a Kiwi woman in the United Arab Emirates who fell ill in March 2020. She was laid-off because of the pandemic, which meant she could not afford medical insurance, the doctor's fees, or qualify for a working-visa. Although her partner was still working, it was not enough to cover the medical costs, or the increasingly expensive flights back to New Zealand. Another campaign described two daughters worried about going back to work when the country moved back to level 2, as they did not want to risk compromising their ill-mother's bubble. Again (like the distress caused by virtual consultation), income/job loss through lockdown obviously has a toll on people's emotional/mental wellbeing – something we return to later below.

Since data collection, there have been some forms of income relief for New Zealanders provided by the Government. The first relief package was announced on the 17<sup>th</sup> of March (for \$12.1 billion) including "\$2.8 billion for income support and boosting consumer spending" (Strongman, 2020). It involved raising "all main benefits" by the 1<sup>st</sup> of April, and according to estimates from the Ministry of Social Development, "about 350 000 low-income families will benefit" (Moir, 2020). Another "\$126 million is also being made available for those people unable to work because they're either in quarantine, sick from Covid-19, or caring for family in either of these situations", describes Moir (2020). A second announcement on the 14<sup>th</sup> of May was part of a "\$50 billion recovery package", which included "\$80m [...] committed to

social services, of which \$32m will go towards foodbanks and other community food services” (McCulloch, 2020). Since May, some schemes have been extended, and others are fast coming to an end, such as the Covid-19 income relief payment (CIRP) which was available for “people who lost their jobs between March and October” (Robson 2020). According to the Ministry of Social Development, “to the end of October, about 38,000 CIRP” were granted (in Robson 2020). “Since June, 27,000 have come off the payment. Of those 2,300 have cancelled it because they got a job,” however, by November, Sarah Robson (2020) reports that the 12-week payment is running out for approximately 23,000 people whose future income and job status is uncertain. New Zealand’s department of Work an Income have a [website](#) called ‘Covid-19’ where they provide links to the different benefits/schemes/payments available. However, as wider crowdfunding literature emphasises there are often gaps within formal social services and it is often the people who fall into these who turn to crowdfunding. In addition, announcements about relief-packages were successive, and not always clear in terms of application and scope, thus the crowdfunding data we analysed often predates or precludes full understanding of these support options.

### **3.2.2. Fundraising/Event cancellations**

Four medical crowdfunding campaigns involved the page creators participating in an elected fundraising event (not an *official* fundraising page, which is a category of its own on *Givealittle*). One of these campaigns mentioned the cancellation of the National Remembrance Service for the Mosque attack in New Zealand, on March 15<sup>th</sup> 2019. Searching on news media revealed other examples of event or fundraising cancellations during lockdown, including those run by the charity for incurable breast cancer, Sweet Louise, which supports around 7000 women: “The kinds of community events that we may have had, have been cancelled. Any form of fundraising event, like most events, just isn't happening” (Philippa Reed in Espiner 2020).

As an example, when Auckland City returned to Level 3 lockdown in August 2020, it meant it’s Daffodil Day<sup>6</sup> street appeal was cancelled for the first time since it began 30 years ago (Anderson, 2020). Because of the pandemic, campaigners have turned to new online/digital campaigns, including the launch of Digital Daffodil – a QR code in the centre of a daffodil

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<sup>6</sup> Daffodil Day raises money for cancer awareness, education, support services and research

image which allows people to donate easily using their Smart phones<sup>7</sup>. Indeed, news media reported as early as March 19<sup>th</sup> 2020, that the pandemic would lead to a “squeeze on charities’ fundraising drives” as reported by Matthew Tso for *Stuff* (2020). With so many of New Zealand’s public health services relying on charity (such as St. Johns ambulance services, and the emergency air services) and with a loss estimated “to be in the millions” (Hutt, 2020), it is no wonder that the government included charities in their economic support package (Charities Services, 2020) with, for example, the COVID-19 Community Awareness and Preparedness Grant Fund which was available from the 26<sup>th</sup> of March until approximately mid-May (Ministry of Social Development [MSD] 2020). According to the MSD, over “900 community groups have benefitted from the fund” (MSD 2020).

### **3.2.3. Other economic impacts**

Another flow-on effect of COVID-19 is the drop in the New Zealand dollar causing an increase in overseas medical treatment costs. In an update to their campaign in May 2020, a sibling raising money for their sister with Multiple Sclerosis reports “the Covid-19 pandemic has reduced the value of the NZ dollar so the cost of treatment has increased by about \$15,000 at this point, and due to flight restrictions we have had to postpone the treatment date a further 6 months.” Another campaigner described seeing her donations slowing in number because of the pandemic. In an update in May 2020, she states, “[a]t the moment with covid my fundraising has stalled, and I am really doubting I will be able to meet this goal and get the treatment”. Other campaigners noted a similar trend, with some acknowledging the impact the pandemic must be having on their potential donors (an imagined audience), e.g. expressing how hard it must be to donate during these “hard times”, and sending out their well-wishes: “but we hope everyone is safe and healthy”. Campaigns revealed the pandemic’s impact on New Zealand’s economy in other ways, too. For instance, one campaign signalled New Zealand’s drop in tourism in their stated use of funds, i.e., making the most of the lack of tourists in the country by taking their sick child and his siblings travelling around New Zealand as soon as lockdown ended.

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<sup>7</sup> See <https://www.anz.co.nz/promo/daffodil-day/donate/>

### 3.3. Social and Emotional Components

#### 3.3.1. Distress over restricted visitation/social support

Out of 50 campaigns, 13 described a decrease in the social support available to them, while ill, during lockdown. Level 4 meant severe restrictions on travel, flight cancellations, limits on hospital visitations, and rules against the ‘merging of bubbles’ (with some of these restrictions extending into level 3 and 2). Add to this the need for ‘vulnerable’ people (those with higher risk of infection due to lower immunity levels – see section 3.3.2) and those sharing their bubble, to practice strict self-isolation for longer than the general population (before the rest of the country went into level 4 lockdown, or well after). For example, one crowdfunder had to pull her children out of school early, and one campaign told the story of the recipients’ carers not wanting to return to work at Level 2 because they didn’t want to risk compromising their mother’s “tight bubble”.

Some people described having to endure the entire lockdown self-isolating *in* hospital with little or no visitors allowed, and how distressing and alone this made them feel. This was often reported by campaigns whose recipients were receiving chemotherapy, as their lowered immunity ruled out *any* visitation. One campaign described how only one adult at a time was allowed into the Christchurch Haematology Oncology Centre (CHOC), and that being unable to socialise with other parents of sick children in CHOC, “made our time in hospital as an inpatient rather lonely”. Another campaign described the recipient as being allowed “only one hour a day for one person only [to visit] during lockdown”. Yet another stated that the lockdown “limits all of our whanau [family] support massively” and how hard it was to “awhi [help] each other through the phone”. The page creator from this campaign provided running updates as these restrictions changed under different alert levels, e.g. "In the last week we have been able to nominate one other family member to visit."

Such stories were also picked up by New Zealand media. One *Givealittle* campaign was featured in *The New Zealand Herald* with the title: “Covid-19 coronavirus: Dying mum reunited with family after three weeks in hospital alone” (Russell, 2020c). Another similar story was titled: “Covid-19 Coronavirus: Kiwi Father battles rare and deadly cancer alone. Pregnant wife shares heart breaking story” (Russell, 2020a). As aforementioned, *The Spinoff* related the experiences of breast cancer survivor, Chloe Irvine, who described the pain of being cut off from her support network during her chemotherapy treatments, and how this placed “huge pressure on her as a mother” (Morrison 2020). As she underwent her treatments, she

also bore witness to the suffering of others just like herself. For instance, she describes how patients had to go through a “screening process” before receiving hospital care:

I met a woman and it was her first treatment, she had just been diagnosed not long ago and because of Covid was coming in to have chemo by herself. I asked, “how are you?” and she just burst into tears (Irvine, in Morrison 2020).

Irvine described how she had her husband’s support during her first chemo session, and how she had still been terrified – “I just can’t imagine what it would’ve been like without that and to have to go through it alone” (Morrison 2020).

### **3.3.2. Distress over immunity suppression**

A theme closely related to restricted isolation (and often brought up by some of the same campaigns and media reports above) was the increased emotional distress felt by those with immunity suppression, either due to pre-existing conditions, or because of their chemotherapy. Eight campaigns mentioned this specifically. As one page creator described on behalf of the funding recipients, the lockdown and the fear of infection of the virus with a compromised immune system “added another level of stress to an already difficult time for these guys”. Another campaigner described how their fear of infection stopped them from flying home to New Zealand to be with family.

Supporting this finding is Espiner (reporting for *RNZ*) who writes that cancer patients are worried about their treatments reducing their immunity, asking their oncologists if they should even go through with them “because some procedures, such as bone marrow transplants, heavily suppress the immune system and a Covid-19 infection may be a greater risk than stopping the treatment” (Espiner, 2020). Chloe Irvine also described how COVID-19 “amplified” the fear she already had with cancer (Morrison 2020): “it was terrifying at the start of lockdown not knowing what was going to happen. My immunity was so low and I had my mum also at risk, so it was really scary”.

Their fears are not unfounded. Espiner (2020) cites research from the *Lancet* where data from China was analysed, suggesting cancer patients “have 3.5 times the risk of suffering a severe Covid-19 infection”. Desai et al. (2020) also cite early research from China that highlight cancer patients’ heightened risk, and describe some of the reasons why:

Patients with cancer form a unique subset of people who are often both elderly and immunocompromised, may have substantial comorbidities and may be receiving treatment that frequently worsens immunosuppression and the risk of concomitant infections. Given the prevalence of cancer worldwide and the high transmissibility of COVID-19, there is a pressing need to understand the effects of this new infection and its associated and potentially serious outcomes specifically for patients with cancer (Desai et al. 2020, 474).

China's early data, alongside data from Italy suggest "that more intensive attention must be provided to patients with cancer especially those with bone marrow or stem transplants, those with hematological malignancies and those in active treatment, given that they may be at higher risk." (Desai et al. 2020, 474).

### **3.3.3. Mental health and resilience**

Finally, a common thread throughout all the impacts mentioned above – but especially due to the social distancing – is the impact the pandemic has had on medical crowdfunders mental health. However, there were four campaigns that either *explicitly* mentioned or strongly *implied* that their mental health was affected by the pandemic, such as the campaign for the bereaved partner whose partner died from suicide during lockdown.

However, among these narratives are expressions of extraordinary resilience, exposing the emotional work gone into reframing experiences of suffering. For example, a bereaved family described how being in lockdown away from extended family and friends could be what their daughter (who died from her illness) may have wanted for them. They described this isolating period as

a time for us all to grieve and be okay with ourselves before heading back out into the world without her. Reminding us to be appreciative of all things and that with each day it will get a little easier even when it doesn't look like it...

Such resilience was also expressed by Chloe Irvine's (Morrison 2020). She describes how her experience during lockdown "wasn't all bad. I would go for walks up the maunga [mountain] with the kids and do Zoom dance parties on the days I felt good and we had some great times" (Morrison 2020). Similarly in the *New Zealand Herald*, Emma Russell describes the story of Arlo, cancer patient and father, who despite undergoing chemo during lockdown, unable to

hold his new-born, “continues to remain positive and keeps fighting for the love of his life, Indigo and their second baby on the way” (Russell, 2020a).

Nevertheless, the Ministry of Health is aware of the mental health impact of the pandemic on the general population and vulnerable groups. It has a web-page dedicated to Mental Health and Wellbeing resources during COVID-19. It acknowledges that the pandemic and the lockdown increases “stress and uncertainty” and will have a significant impact on mental wellbeing (Ministry of Health, 2020a). They state:

During this time, you may be looking for new or additional ways to help you feel mentally well and get through. This page connects you with tools that are available to support your own and others’ mental wellbeing, and places you can get help from when you need it (Ministry of Health, 2020a).

In a news article by Tracy Neal, the chief executive of the Cancer Control Agency (Professor Diana Sarfati) acknowledges the mental health impact of those cancer patients who have experienced delays (2020). She said “those working with cancer patients understood how the delays and uncertainty were worsening the level of mental stress, and psycho-social support was being put in place. There are social workers and psychologists available to talk to patients” (Neal, 2020).

The government released a media statement on the 7<sup>th</sup> of April 2020, announcing the launch of the mental health support schemes for Covid-19 (New Zealand Government, 2020b). The initiatives announced included the “*Getting through together*” campaign which shares ways to help Kiwis cope with the stress of COVID-19” (New Zealand Government, 2020b). It has “tools for parents, dubbed *Sparklers at Home*, which provides support for parents to talk with their primary-school aged children about their own mental health and wellbeing” (New Zealand Government, 2020b). Another programme is the “NZ Drug Foundation’s *#bestbubble* campaign”, which has information for those living with addictions “on coping with life in their bubble, and dealing with the impacts of alcohol and drug use” (New Zealand Government, 2020a).

The MoH also ran a COVID-19 Health and Wellbeing Survey (Ministry of Health, 2020b) to help guide the government’s response. It was launched on the 30<sup>th</sup> of March (four days after the level 4 lockdown began). Around 300 people, over 15 years of age, were interviewed daily

over the phone. Results from the fourteenth report (covering the 29<sup>th</sup> of June to the 5<sup>th</sup> of July) found that although less people were experiencing loneliness and isolation compared to the month of April, many (47%) were still feeling worried after accessing "their main source of COVID 19 information"; about 18% were "worried about the risk of getting COVID-19"; and 24% were feeling "nervous when they think about current circumstances" (Ministry of Health 2020b). The last of these reports (covering the 31<sup>st</sup> of August to the 6<sup>th</sup> of September) can be accessed through the Ministry of Health's [website](#) (Ministry of Health, 2020b).

## **4. Conclusions**

The manner in which COVID-19 featured in individual medical crowdfunders' campaign narratives, during and directly after New Zealand's 2020 lockdown, revealed several overarching points of interest. These are preliminary conclusions, that beg further development and discussion, but we believe have the potential to make a fruitful contribution to existing medical crowdfunding literature, and to emergent literature addressing sociocultural aspects of the pandemic with a critical and ethnographic eye.

### **4.1. Making Systems Visible**

In choosing to denote the ways in which institutional changes/responses to the pandemic affected individual health trajectories – including delays and cancellations to healthcare delivery (from surgeries, and transplants to various general or diagnostic appointments, travel and face-to-face access) – crowdfunders provide an important window into how global and local, economic and social structures or systems impact lived experience. Previous US-based studies have found that medical crowdfunding campaigns rarely call out the injustice of the American healthcare and health insurance industries in their campaigns, opting instead to focus on individualized concerns (Paust 2020, 38 [drawing on Berliner and Kenworthy 2017, Paulus and Roberts 2017; Snyder et al. 2017]). Yet “the individualized narratives publicized in medical crowdfunding campaigns are always linked to the powerful systems and institutions that produce health disparities” (Paust 2020, 23).

If not a direct critique of national or institutional policy, the crowdfunders in our study who did choose to mention COVID-19, are at least demonstrating an awareness of the complexities of globalised, biomedical healthcare systems, and contributing to making these more visible to the public by the public nature of their storytelling. Exploring how New Zealand page creators frame their difficulties, or worsening of their health, directly due to the government's lockdown measures can provide important records of multiple and diverse experiences of the changes to these critical systems, and insights into expressions of agency and resistance in the face of a nation-wide crisis.

### **4.2. Diagnosing Different Forms of Precarity**

Online crowdfunding is a vital, digital, primary source for illuminating “the precariousness of health funding” in various neoliberal nation-states around the world (Paust, 2020, 99). This can

be done by considering the political economy, as well as the specificity of different national healthcare systems. Considering crowdfunding as a new “non-profit insurance model” (Himmelstein and Woolhandler 2020) allows for a focus both on the precarities that lead people to this option, and the further ways in which crowdfunding may entrench these and other forms of precarity. A poll (conducted between the 8<sup>th</sup> to the 16<sup>th</sup> of November) found that, in the US:

[a]bout 8 million people have started a crowdfunding campaign to pay for medical care for themselves or a household member on sites such as GoFundMe. Another 12 million people started campaigns for someone outside of their household (Himmelstein and Woolhandler 2020, n.p).

This was *before* the pandemic took hold. By the middle of April 2020, Paust – in her thesis on online crowdfunding – observed “countless crowdfunding campaigns for medical bills, daily expenses such as rent and utilities, and continued online education” across the US (Paust 2020, 100). Both Paust (2020) and, Himmelstein and Woolhandler conclude that COVID-19 simply exposes just how “fragmented and insufficient” the health system is in the United States.

New Zealand’s public healthcare system, even as an early adopter of neoliberal policy, is quite robust by comparison, and by international standards; producing relatively good health outcomes compared to other OECD countries (Neuwelt-Kearns et al. 2021/Forthcoming). Since New Zealand *does* have high rates of crowdfunding, despite the public healthcare system, there is an indication that wider, or more subtle, forms of precarity exist. From the data in *this* report and the wider study – indicating campaigns are less for direct medical costs, and more for other important living costs during times of illness or disability that are not well supported by the welfare system (Wardell 2020) - we can conclude that wider social inequalities that affect socioeconomic stability and resilience, and in turn healthcare access, are also factors that are exacerbated during periods of enhanced restrictions on work, travel, and in-person social gatherings or fundraisers.

The virus has exacerbated pre-existing lines of precarity along “class-based and racial inequities in care and health outcomes” (Himmelstein and Woolhandler 2020). In New Zealand, this is significant to note in recognising systemic inequalities in health care for Māori and Pasifika peoples in New Zealand. For instance, the Cancer Control Agency writes that “Māori and Pacific peoples experience multiple and disproportionate barriers to accessing cancer diagnoses, treatment and care,” and that the pandemic can thus “accelerate systemic

drivers of inequity, including access to adequate income, shelter and food security” (Cancer Control Agency 2020, 1). Subsequently analysis of crowdfunding may note both broader systems that create precarity, and inequality within the populations they serve.

As well as falling unevenly across different populations, the effects of lockdown varied according to different health conditions. For example, cancer patients, who make up a huge proportion of the numbers of medical crowdfunders both overseas and in New Zealand, were notably present in this study, as a disadvantaged group. This is not just delayed or altered treatment plans, but delayed diagnosis. Several report on the drop in diagnosis and screenings conducted over March/April. Morrison (2020) reports that “According to Breast Cancer Foundation NZ, during Covid-19 lockdown restrictions around 400 women who would have received a breast cancer diagnosis missed on getting mammograms or a referral from their GP. The foundation’s nurses have assisted women who are desperately worried about what this delay will mean for their survival.” In addition, as Witton (2020c) points out, “while the report shows headway made against lockdown backlogs, it does not address the gaps which existed before the pandemic hit. A top oncologist warned New Zealand’s health service was already behind in cancer diagnosis, while a study found it is near the bottom for cancer survival compared to six other countries with similar health systems.” Even when treatment is normally well funded, compared to the rest, there are other degrees of precarity with cancer treatment made visible in times of crisis, and through narratives of crisis such as our report presents.

#### **4.3. Need for Critical Attention to Healthcare Systems, Even in States of Emergency**

From this research we conclude that there were numerous ways in which the lockdown response had negative impacts on the health and wellbeing of some people. While lockdown measures were justified, in particular, as protective of ‘vulnerable’ groups, such as older people, or the immuno-compromised, others clearly unevenly bore the costs of these protocols to their own health and wellbeing. Crowdfunding represents the experiences and voices of competing ‘needfuls’ (Lee and Lehdonvirta, 2020) whom may be more or less represented in official narratives of New Zealand’s actions and attitudes during and after the lockdown.

As Trnka (2020) writes, critical attention to the state’s action, even during states of emergency, is essential. As a low-cost way for citizens tell stories to large online audiences, and as a

medium attracting people already precariously positioned people, the stories gathered via crowdfunding platforms can help us appreciate that rhetoric of ‘unity’ did not necessarily mean that the ‘costs’ of the 80-day lockdown, on life, health and happiness, were equally shared throughout New Zealand’s ‘team of five million’. Our study affirms that there is room to dig deeper, behind the national messages of positivity, kindness, and solidarity (Trnka 2020), to recognise the people for whom the lockdown protocol created a challenging and even life-threatening time.

While we join with many in commending the successful efforts of the government, scientists, healthcare providers, and the general population, in controlling COVID-19 in New Zealand through these measures, we nonetheless suggest that scholars continue to work towards providing nuanced critical and theoretical understanding of the impacts of lockdown-type national responses, on the health and wellbeing of the general population, outside of (or alongside of) the prevention of infection.

#### **4.4. Future Research Directions**

There are many possibilities for future research which can build on this data, or on data in related areas. This could include applying a lens of biopower which can attend in more detail to the processes of power and governance through which lockdowns are established and enforced, and the authoritative discourses through which the citizenry are interpellated into particular modes of being and acting. The control of bodies, in terms of movement through space, and the impact on bodies, through changing or restricting access to healthcare services and facilities, could all be fruitfully considered through this theoretical lens.

Themes emerging in our findings suggest that during times of crisis healthcare experiences are characterised by delays, postponements, and experiences of waiting, which often cause stress and anxiety, as well as having real impacts on illness progression and treatment for some. Studies focussing ethnographically on experiences of time, or temporality, within biomedical systems, both in ‘normal’ time, and crisis time, could be fruitful. Narratives of crisis as conveyed through news media or social media circuits could also be explored in relation to time or waiting. Equally, subjective experiences of social relations in terms of intimacy and care, in relation to presence, and the role of technology in mediating this – including in terms of interactions between healthcare providers and patients.

A systematic review of New Zealand news media coverage of the pandemic, would also be a valuable way to close the gap between a ‘narrative’ approach to pandemic experiences, and a critical approach to discourses circulating around responsibility, care, and good ‘pandemic citizenship’. This connects again to the potential for considering biopower, in relation to expert knowledges and authorities as key parts of governance, which in turn could also consider where the possibilities for counter-discourses, critique, or resistance were found, and what responses were made to these when they did occur. Social media, including public comments on news stories, can be an excellent site for a dialogical analysis of these conversations, and pave the way for examining more informal registers of discourse.

Ultimately there is much work to be done, for many years to come, in order to listen to and tell the stories of people living through an unprecedented time in national – and global – history... especially acknowledging that for many nations, these and other crisis measures are a current reality still. We hope that the emergent findings from our own data will provide a useful contribution to this.

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