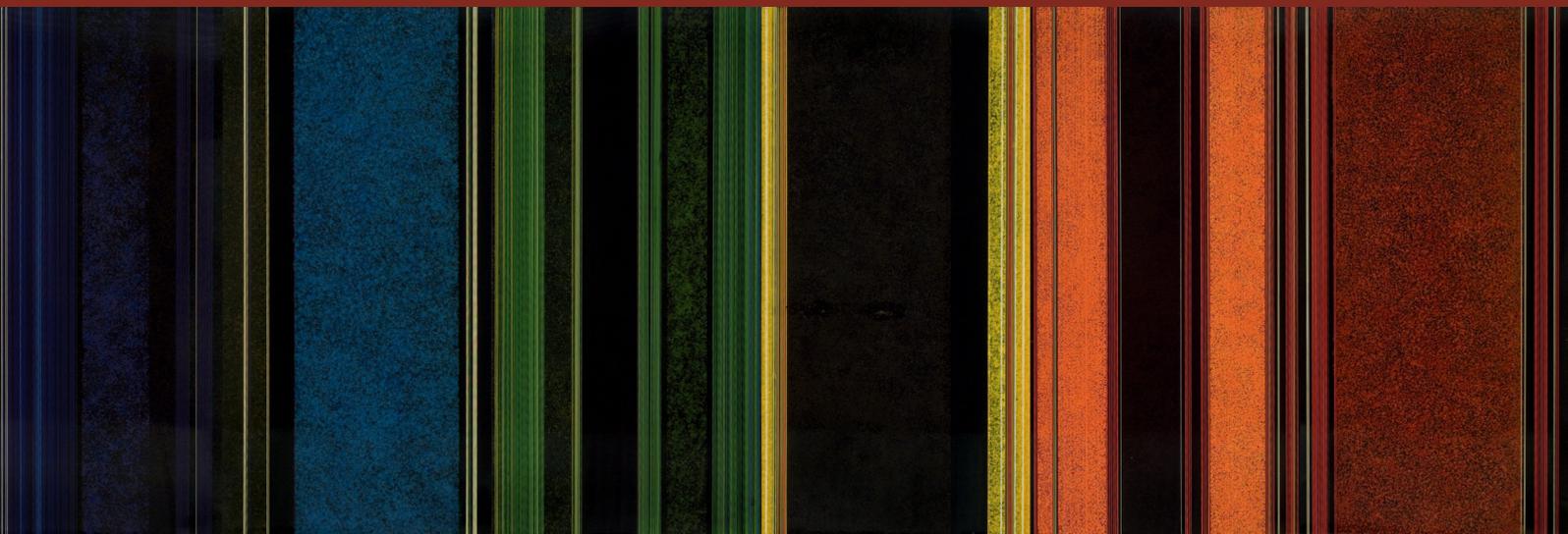
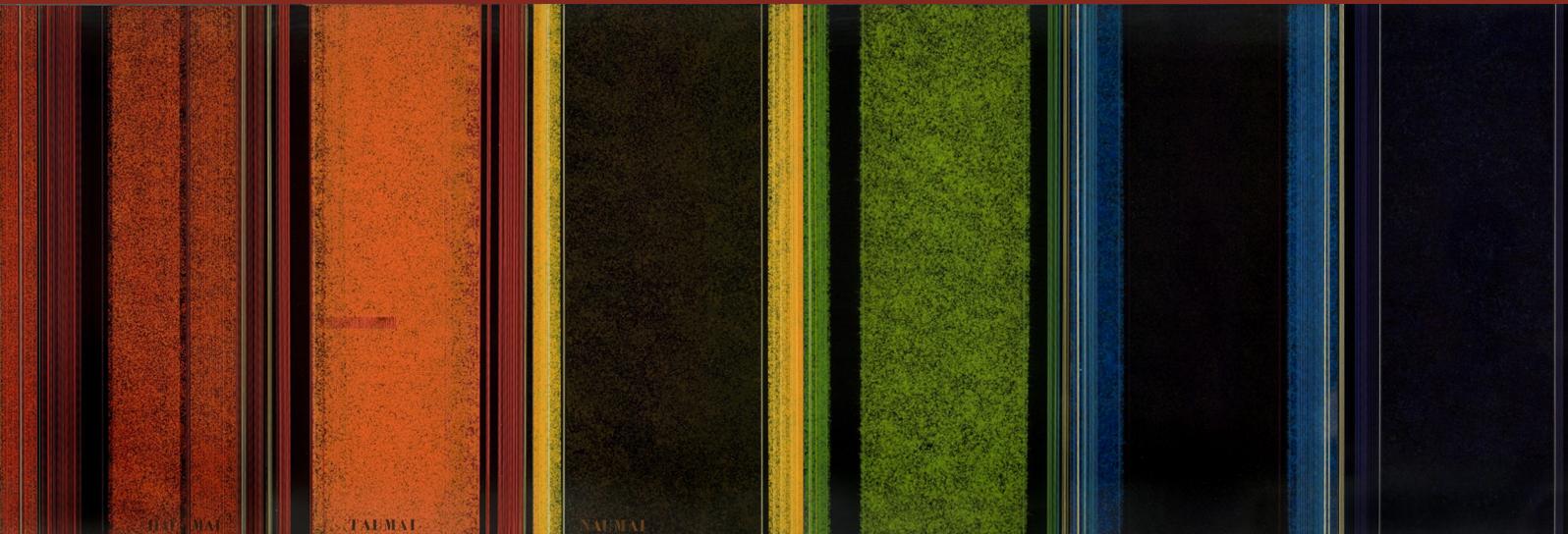


A window on quality 2021: COVID-19 and impacts on our broader health system

He tirohanga kounga 2021: COVID-19 me ngā pānga ki te pūnaha hauora whānui

PART 1: March 2020 to August 2021

WĀHANGA 1: Poutū-te-rangi 2020 ki Here-turi-kōkā 2021





Note on the cover image | He kōrero mō te uhi

The cover features a reproduction of Ralph Hotere's *Godwit/Kūaka*, 1977, enamel on board, 2,400 x 18,000 mm. Chartwell Collection, Auckland Art Gallery Toi o Tāmaki, gift of Auckland International Airport Ltd, 1997.

The Commission thanks and acknowledges Auckland Art Gallery Toi o Tāmaki, the Chartwell Trust and the Hotere Foundation Trust for their permission and support to reproduce the artwork for this report.

In 1977, Ralph Hotere was commissioned by Auckland International Airport to create an 18-metre long mural for installation in the Arrivals Hall of the Jean Batten Terminal building. Hotere's mural remained in the airport's welcoming area until 1996, when redevelopment of the terminal building began. The mural was removed from the airport's art collection, purchased by the Chartwell Trust and lent to Auckland Art Gallery Toi o Tāmaki in 1996.

At the centre of the mural, the poem reads:¹

Ruia ruia

*Kia hemo ake
Ko te kaka koakoa
Kia herea mai
Te kawai koroki*

Opea opea

*Kia tatata mai
I roto i tana pukorokoro
whaikaro
He kūaka
He kūaka marangaranga*

Tahia tahia

*Kotahi manu
I tau ki te tahuna
Tau atu
Tau atu
Kua tau mai*

Scattering

*Death/exhaustion rises up
It is the rope, koakoa (the cry
of the bird)
Binding you here to me
The cry/chattering of the flock.*

Gathering

*Come close together
From inside its throat—
a marauding party
A godwit
A godwit that hovers*

Forming a single unit

*One bird
Has settled on the sand bank
it has settled over there
it has settled over there
They have settled here[†]*

[†] Note: poet and friend of Hotere's, Bill Manhire, remembers Hotere occasionally reciting the poem at the dinner table, with a slightly different translation for the final stanza:

It has landed.

It has landed.

[pause, and then a slightly different inflection]

It has landed.



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Foreword – Dr Dale Bramley | Kupu whakataki – Tākuta Dale Bramley

Two years ago the unprecedented global COVID-19 pandemic hit Aotearoa New Zealand and the rest of the world. Thanks to the huge and continued efforts of so many, we have largely been spared the most severe effects experienced by so many countries.

Since August 2021, however, we have seen the significant impact of the COVID-19 Delta variant on Māori and Pacific communities, particularly in Tāmaki Makaurau/Auckland. Lower vaccination coverage for Māori has led to greater impact for tangata whenua.

We have seen deaths in recent months too, and we think of the whānau who have lost loved ones. The numbers of deaths and hospitalisations, including those requiring intensive care, are a constant reminder of the severity of COVID-19.

This Window report, *A window on quality 2021: COVID-19 and impacts on our broader health system – Part 1: March 2020 to August 2021 | He tirohanga kounga 2021: me ngā pānga ki te pūnaha hauora whānui – Wāhanga 1: Poutū-te-rangi 2020 ki Here-turi-kōkā 2021*, provides an insight into the secondary impacts of our efforts to fight this pandemic. Health care services and health care users have been affected to differing degrees, and it is vital we understand where, how and to what extent, so we can respond to this need and also be prepared for the future. In recent weeks, just prior to going to publication, we have also been reminded that new variants of the virus are an ever-present reality.

Creating a national response that can anticipate changes, as well as rapidly respond when changes eventuate, remains critical. Continuous learning from our own experiences, with rapid dissemination of that knowledge across the country, as well as learning from other countries, should be a hallmark of our response.

As we move into the next phase of our response to COVID-19, we will likely see spread throughout the country. Our priorities now must be equity in vaccination coverage, full engagement and empowerment of local health providers in the response and a high level of preparedness to deal with the effects of the virus. Providing high-quality health care to every single person and whānau in need is the ideal for which we must strive.

Kia kaha, Kia māia, Kia manawanui

Dr Dale Bramley

Chair, Health Quality & Safety Commission

Executive summary | Whakarāpopototanga matua

Introduction

Aotearoa New Zealand has been recognised internationally for a successful early response to the global pandemic of COVID-19. This year's *A window on quality 2021: COVID-19 and impacts on our broader health system – Part 1: March 2020 to August 2021* | *He tirohanga kounga 2021: me ngā pānga ki te pūnaha hauora whānui – Wāhanga 1: Poutū-te-rangi 2020 ki Here-turi-kōkā 2021* (Window) explores the secondary impacts of our response on selected aspects of the functioning of our health system so we can learn from that experience and shape resilient system responses in the future.

A second part of this Window, scheduled for June 2022, will explore other critical aspects not covered here, as data emerges from the system, revealing the effects of the Delta outbreak on other services.

The Window begins with a broad view of the conditions and context in which the Aotearoa New Zealand health system responded to the challenges of COVID-19 between 2020 and 2021. Since the beginning of 2020, we have, on average, experienced less-stringent restrictions than any comparable country. Our economy has been less badly affected than elsewhere, and lockdowns have had the effects of decreasing all-cause mortality since 2020 (mostly among older people) and increasing life expectancy, in sharp contrast to most other countries.

However, Aotearoa New Zealand's particular patterns of inequity before the pandemic were both a failure of the Crown's obligations under Te Tiriti o Waitangi (Te Tiriti), and presented fertile ground both for the virus and for the unintended negative effects of measures to contain it. The impacts of COVID-19 on health care must be considered in view of inequitable health service provision that has occurred historically and continues today, but also because pandemics compound and promote pre-existing social and economic inequities, especially in terms of precarity of housing, overcrowding and poverty.

The pandemic presents an opportunity to think about what a future health system in Aotearoa New Zealand can look like. A return to 'normal' is not desirable. A system that is underpinned by a whole-of-government approach to health, is pro-equity, complies with Te Tiriti and is anti-racist must provide the transformative policies and actions necessary to address systematic, entrenched and pervasive inequities.

Chapter 1: Distraction: Primary care, immunisation and screening

Primary care has responded to COVID-19 with unprecedented focus, but the additional work under time and resource pressures has distracted from our system's business-as-usual work, exacerbating already entrenched inequities by ethnicity. Many Māori and Pacific provider organisations, general practitioners (GPs) and primary health services have felt shut out of meaningful input into the development and rollout of the COVID-19 vaccine strategy. However, once those providers were supported to lead their own approaches, there have been significant increases in vaccination rates for both Māori and Pacific peoples.

Despite a lack of readily available primary care data, we can see that immunisation and screening programmes have been substantially disrupted by the pandemic, in particular for Māori and Pacific peoples.

Immunisations of two-year-old and six-month-old babies have fallen steadily for several years and lockdowns have reduced immunisation rates further (from 91% in March 2020 to 83% in September 2021). Measures to contain COVID-19 appear also to have had the effect of increasing inequities by ethnicity.

- Coverage rates for two-year-old Māori children (already lower than those of other ethnicities and falling since 2017) have declined sharply from 86% in March 2020 to 70% in September 2021. Rates for two-year-old Pacific children have fallen from 94% coverage in March 2020 (and consistent coverage above 90% in the years prior) to 82% in September 2021.
- Coverage of all six-month-old babies was lower at 80% prior to lockdowns and by August 2021 this figure was only 70%, lower than rates in 2012. By September 2021 fewer than half (49%) of six-month-old Māori babies received their immunisations, down from 65% in March 2020. Coverage of six-month-old Pacific babies has dropped from 80% in March 2020 to only 57% in September 2021.

Breast and cervical cancer screening has also been disrupted, likewise with the effect of exacerbating inequities by ethnicity. At alert level 4 all screening appointments were paused.

- Breast screening data shows a sharp decline in coverage in 2020. For most ethnicities, this decline slowed by September 2021, however, coverage of Pacific women continued to steeply decline, from 71% in 2019 to 61% in September 2021. Coverage of Māori women remains lower than all other ethnicities and has declined from 62% in 2019 to 58% in September 2021.
- Cervical screening data shows a visible dip in 2020 in otherwise stable coverage for women of 'other' ethnicities (mainly those of European descent) followed by recovery to previous levels in 2021 (76%). In contrast, cervical screening coverage for Māori and Pacific women has declined since 2016, from 67% to 59% and from 76% to 61%, respectively.

Chapter 2: Difference: Primary care patient experience in 2020/21

Patient experience survey data shows how lockdown affected access to primary care and for whom, the reasons why people did not access care, what people did instead and how it worked for them.

People differed in their experience of access to care

Around one in three (34.4%) of respondents reported that the level 3 and 4 lockdowns in 2020 kept them from going to their GP in the way they usually would have. These respondents were more likely to be under 65 years old, disabled and live in areas of greatest socioeconomic deprivation. More than 40% of disabled people surveyed could not see their GP as they normally would.

The barriers to access

The most common reason cited for not accessing services (42.9%) was that alert level restrictions meant they weren't allowed – the people who cited this reason were more likely to be working aged and disabled. Those who decided their reasons for accessing care in the context of lockdown weren't urgent enough (38.9%) were more likely to be younger (15–24 years), not disabled and living in areas of least deprivation.

What people did instead

In general, people used telehealth options, delayed their care or substituted other options. One-third of people (35.4%) who were unable to access health care during lockdown as they usually would, delayed their care. One in five (19.6%) people who were unable to access health care during lockdown as they usually would, substituted care with other options like advice from family/friends, internet searches or using medicines at home.

To August 2021 COVID-19-related reasons for not accessing primary care fell but long waiting times to get appointments, however, grew as a barrier, to 14% of respondents from 11% in August 2020.

Limits of telehealth

Telehealth, in particular phone, appointments grew strongly from 9% of respondents to 55% of respondents under level 2/3 in 2020, while in-person appointments fell from 95% of respondents to 55%. Those who used phone appointments were more likely to be of Māori or Pacific ethnicities rather than European/other, aged 25–64 years, living in the most deprived neighbourhoods and living in the North Island outside of the Auckland metro area. Those who used video were more likely to be younger and living in the area of Auckland metro district health boards (DHBs).

When asked what they did not like about telehealth, 39.2% said they liked everything but just over one in ten (12.3%) didn't like anything about it, and these people were

more likely to be disabled (14.7% vs 10.9% not disabled). For telephone appointments in particular, people were less likely to have positive experiences in terms of being informed about and involved in care, and having enough time with the GP.

Chapter 3: Delay: Emergency departments

The response to COVID-19 in early 2020 caused dramatic falls in emergency department (ED) activity in both Aotearoa New Zealand and comparable countries. By June 2021 nearly 90,000 people had not attended an ED when we thought they would have, based on the data from the three previous years.

The initial large drop in presentations in early to mid 2020 was followed by slow returns to historically expected activity and, in some cases, periods when presentations of more acute cases increased beyond expected activity. In October 2020, when Aotearoa New Zealand went to its second alert level 1, the number of patients classified as triage level 1 or 2 (life-threatening or imminently so) at EDs began to rise above expected levels, putting pressure on services. This may to some extent represent deterioration in control of chronic non-communicable disease over lockdown periods.

European/other populations returned to expected levels of ED presentations by July 2020. The return to expected levels for Māori was far slower (finally back to expected levels in November–December 2020, then falling below expected again). There has been a cumulative shortfall of 40,000 Māori presenting to ED since March 2020. A similar pattern of slower return of lower presentations was visible for Pacific peoples.

Unlike in other countries, patterns of admission to hospital tended to follow patterns of ED presentation to June 2021, suggesting no changes in clinical thresholds for admission. As we enter a period of widespread community transmission of COVID-19 in the Auckland area and the spread of COVID-19 further through the country, we should learn from other countries' experiences in terms of their lower rates of admission to hospital (in response to stricter infection control procedures and protection of hospital capacity for COVID-19 patients). We must plan appropriately for the early months and the winter of 2022.

Chapter 4: Deferral: Backlogs of elective care

Many planned care services, or 'elective' procedures performed in hospital were cancelled, delayed and deferred because of pandemic restrictions between 2020 and 2021 in comparable countries and in Aotearoa New Zealand. This chapter looks at two different views of how big a backlog of care was created to mid-2021, whether we have managed to substantially reduce it and, if so, if we did it equitably.

DHBs submit annual plans of elective activity to the Ministry of Health each year then actual activity is compared with these plans. This data suggests that, after the April–June 2020 quarter, in which elective activity dropped 16%, DHBs over-delivered

elective activity to June 2021 when between 8% and 12% more procedures were carried out than planned.

However, using different techniques that exclude minor procedures such as skin lesion removal, and looking at the top eight surgical specialties by usual volume, we find a significant backlog – 16,000 fewer waiting list and arranged admissions occurred between March and June in 2020 compared with what would be expected based on three years' prior data. For a variety of reasons, including changed settings for elective care, coding changes and less disruption to minor procedures caused by COVID-19 restrictions and lockdowns, DHBs delivered more minor procedures than usual and fewer inpatient surgical procedures. Since the start of 2021 to June, progress in reducing this backlog stalled generally, though orthopaedics appeared to make progress to June 2021.

Shortfalls in elective activity decreased for all ethnicities. Yet Māori and Pacific peoples are still not receiving as much elective care as they were before the pandemic, however inequitable that amount may have been. That is, there is no evidence that recovery from COVID-19 prioritised or favoured those who already face the greatest inequities in access to health care.

Chapter 5: Delivery: Cancer care and COVID-19 – a case study in resilience

In some other countries, cancer screening, diagnosis, treatment and supportive care has been substantially disrupted by the pandemic. However, data from Te Aho o Te Kahu (Cancer Control Agency) suggests monitoring and reporting on service access and performance to inform coordinated national and regional decision-making minimised disruption in services in Aotearoa New Zealand.

Data to September 2021 show that there were lower numbers of new cancer registrations in the first level 4 lockdown in April–May 2020 (40%, or approximately 1,000 fewer) in comparison with 2018 and 2019. This was followed by increased registrations in 2021 (5% more compared with the 2018–19 average). For Māori, cumulative new cancer registrations from January to August 2021 were 9% higher than the 2018–19 average.

Diagnostic procedures also fell steeply in the first lockdown in 2020. However, the number of diagnostic procedures performed rapidly returned to baseline in 2020 and increased (notably including for Māori) in early to mid 2021.

Treatment seems to have been less effected. Numbers of curative prostate, colorectal and lung surgeries show minimal effect of COVID-19-related measures, including for Māori.

These apparently good results are attributed by Te Aho o Te Kahu to rapid clinical governance of the COVID-19 cancer response; development of an Equity Response Framework to identify how existing inequities might worsen and what should be

done; development of national 'minimum treatment' clinical guidance; rapid adoption of telehealth to deliver cancer care; escalation and central coordination of specific regional issues and issues for multiple centres; and close monitoring and reporting of the impact on cancer services.

Conclusion

Future decisions must be made in spite of the volatility, uncertainty, complexity and ambiguity of the situation we face. We identify how the cancer care response exemplifies four capacities of a system that allow it to perform resiliently: the capacities to anticipate, monitor, respond and learn.

Anticipating

Early recognition of the potential impacts that COVID-19 might have for cancer treatments, and a particular recognition that this impact was likely to exacerbate existing inequities within cancer care, meant a wide array of data was collected to help make visible the impacts, both intended and unintended.

Monitoring

Rather than being an exercise in reassurance, monitoring of nuanced data that reflects local conditions and priorities, bringing together multiple perspectives, should focus on making visible any unintended consequences of changes implemented.

Responding

Anticipated effects and early signals within the data should be responded to through coordinated actions across the system. Capacity to do this is key and is challenging to do in a system that is designed for optimal efficiency under existing conditions, but that may be surprisingly brittle when it faces dynamic changes.

Learning

Effective governance of complex, multi-provider problems seems to have involved forming a network of interested parties from many levels, using data to understand the impacts of actions and being able to mobilise resources from across the system.

Importance of data and how we make meaning from it

What we choose to measure determines how we respond. Building an equity lens into measurement from the outset, for example, shapes both what becomes visible and what the system responds to.

Do we use data to seek reassurance that the system is functioning as measured by often narrow performance targets or do we collect data to make visible the impacts of decisions on those providing care or controlling resources?

Collection of data alone will not lead to resilient performance; we must use data to inform a response. Without the ability to allocate resources or change our focus, we will be data-rich but fail to make meaningful improvements.

Summary

A health care system that performs resiliently is one where the system, at all levels, is able to adapt to shocks and change to ensure we provide high-quality care. The cancer response is one example of a resilient response but there are many more, including in the Māori community sector.

Recommendations

The fast pace and changing nature of the pandemic, and in particular the predominant impact on Māori and also Pacific peoples, means some of the recommendations below arise from the findings of this Window and some relate to the emerging issues of the impact of the COVID-19 Delta variant.

1. District health boards/Health NZ, from July 2022, must, with some urgency, find a stronger approach that is appropriately resourced, to support the mana motuhake of Māori and Pacific providers and their unique knowledge of and abilities to serve their populations. This is even more critical in the context of these providers supporting community self-isolation and quarantine (CSIQ) arrangements while their populations bear the main burden of COVID-19 under the most challenging conditions.
2. Mechanisms that provide governance of quality (including clinical governance) need to be established, also with urgency, at local and district levels for the current and expected CSIQ responses. This must be based on a Te Tiriti partnership with iwi and Māori providers, given the lower rates of vaccination for Māori and the higher vulnerabilities to illness in affected Māori and Pacific peoples. Partnerships with Pacific providers must also be established, with active input into quality governance as well.
3. A formalised national network for data and intelligence sharing for EDs across the country should be established, or one of the existing network arrangements strengthened, with proper resourcing and data analytic capability.
4. DHBs/Health NZ, from July 2022, must approach addressing the backlogs of elective activity created by COVID-19 restrictions with greater thought and stronger emphasis on understanding the particular make-ups of their backlogs and prioritisation of work according to need. The Ministry of Health reports that it anticipates access to elective care and screening (and all other health care) would be improved under the COVID-19 Protection Framework (CPF).
5. What we have learned about the nature of patient experience of primary care during COVID-19 restrictions as discussed here is valuable but high level. Local primary health organisations should use their survey data to look at the

experience of their populations, consider evidence of difference in that experience for different parts of their populations and tailor services, including telehealth care services, appropriately.

6. A national primary care data set is a long-standing deficiency that needs to be addressed. There is a notable gap in our understanding of how the health system as a whole responded to COVID-19 due to the absence of consistent national primary care data, despite primary care having powerful local clinical systems.

Introduction | Kupu whakataki

The future seems implausible; the past seems incredible.²

Aotearoa New Zealand has been recognised internationally for a successful early response to the global pandemic of COVID-19, in 2020 and to mid-2021 in particular.^{3 4} This year's *A window on quality: COVID-19 and impacts on our broader health system, Part one – March 2020 to August 2021* (the Window) explores the effects of our response on selected aspects of the functioning of our health system, so we can learn from that experience and shape resilient system responses in the future to achieve 'quality health for all'.

This is the first Window to examine the effects of the COVID-19 response. The first expert advisory group meeting to discuss the structure and contents of this report was scheduled for 18 August 2021. On 17 August the Delta variant was discovered in the community and the country went into level four lockdown, and our EAG was immediately diverted to the response.

We have adapted our process and approach – this first part of the Window will assess a curated selection of the accumulated secondary impacts of COVID-19 on our health system from March 2020 (and prior) to August 2021, where data is available and robust. A second part of the Window scheduled for June 2022 will explore other critical aspects not covered here, as data emerges from the system revealing the effects of the Delta outbreak on other services.

Until the arrival of the COVID-19 Delta variant in August 2021 the **direct** effects of COVID-19 on the health system, in terms of infections, illness and deaths, were relatively limited. Since that time, the direct impacts of the virus on the health system have become more pronounced and complex, and are rapidly changing.

As the rest of this Window details, the **indirect** and secondary effects of measures to contain COVID-19 on the quality and safety of our system (outside of the effects of the virus itself) have also been profound.

The constant of change and the need for resilience

The last 20 months have seen global and national change on a scale unprecedented in living memory. The impacts of COVID-19 – and impacts of the response to it – have been distributed inequitably between and within countries. The most vulnerable populations, globally and nationally, have experienced the most severe impacts and existing inequities have become worse.⁵

In Aotearoa New Zealand, at the time of publication, we are now in the midst of another phase of this change as we transition to a post-vaccination world of re-opened borders, renewed mobility and new variants.

In reality, change – often rapid, ‘unexpected’ and on a large scale – is to be expected. It is a feature rather than a bug of contemporary existence. Some have referred to the pandemic as a ‘black swan’ event – that is, one that is a surprise, has major impact beyond the realm of normal expectations and is declared predictable only in hindsight.⁶ However, pandemics of this size and scale have been predicted from multiple quarters for many years.⁷ It was not only predictable but actively predicted, as was its inequitable impact.

We need to build a health system that recognises and embeds the now-obvious fact that, while the COVID-19 global pandemic has dealt a series of radical shocks to our society and to our health system, it is not going to be the last such shock. To build resilience into our health system we need to understand the conditions of our health system when this shock happened, including the presence and effects of pervasive inequity, what happened, how it happened, what good responses looked like and what we can learn from them in the unique context of Aotearoa New Zealand.

In doing so, we take the view that our health care system is an adaptive system responding to external shocks in complex and unpredictable ways. It is not ‘a linear production line where treatments are applied to relatively predictable demand’ and where backlogs can be simply addressed by increasing capacity.⁸ Accordingly we look, in brief and using existing data available to us at the time of writing, at some key areas of the system using national data and novel tools to understand changes in health care activity and patterns of recovery in services. We have focused particularly on highlighting the equity implications of the secondary impacts of COVID-19 on these aspects of the health system.

The five chapters in this report look at our system’s response to COVID-19 from early 2020 to mid-2021 along the following themes:

- Chapter 1: **Distraction** from our system’s business-as-usual work in primary care and the impacts of this on prevention and screening, particularly in terms of inequity
- Chapter 2: **Difference** in the experience of primary care for different parts of our population, in particular for different ethnicities, age groups and people who identify as having a disability
- Chapter 3: **Delay** in needed care in emergency departments
- Chapter 4: **Deferral** of scheduled care in terms of the backlog of cancelled, delayed and deferred elective procedures
- Chapter 5: **Delivery**: an examination of the method and results of the effective and resilient cancer care response to prevent interruptions to the care of people with cancer.

We intersperse the above with narratives from four community members engaged in different parts of our system in different parts of the country. These offer ‘lived

perspectives' on the changes to delivery, access, experience and outcome caused by COVID-19.

We conclude with a discussion about how our system can be built to perform more resiliently in future while restructuring is ongoing. We also make some key recommendations.

Other areas and aspects of the system will be examined in future Window reports devoted to the effects of COVID-19.

Overview of conditions and context at the start of the pandemic

We begin this report with a broad view of the conditions and context in which Aotearoa New Zealand responded to the challenges of COVID-19 between 2020 and 2021. We look in particular at some broad indicators related to stringency, economy, mortality and inequity to better understand how the system changed and adapted.

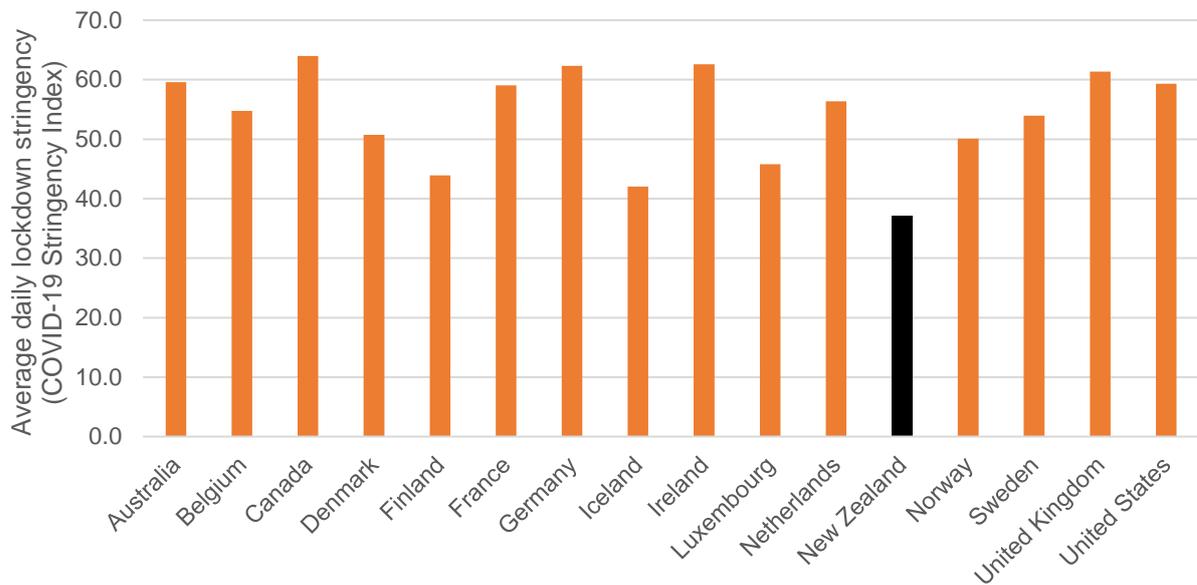
In 2019, Aotearoa New Zealand was rated as 54 out of a possible score of 100 on the Global Health Security (GHS) Index of national health security and pandemic preparedness. This placed us 35th out of 195 countries.⁹ However, the mode of response to the pandemic appears more important than an abstract measure of preparedness. The United States of America was rated first by a large margin among countries considered, but a politicised and inconsistent response to COVID-19 has cost nearly 800,000 American lives to November 2021.¹⁰ This number is likely an underestimate.

Stringency

Since the beginning of 2020, Aotearoa New Zealand has on average experienced less-stringent restrictions than any comparable country, because of short, hard lockdowns averaged over comparatively long periods of freedoms. This pattern remains even with the most recent data included.

Aotearoa New Zealand had the lowest COVID-19 Stringency Index¹¹ score of the selected countries shown in Figure 1.

Figure 1: Average COVID-19 Stringency Index, selected countries, January 2020–September 2021



Source: Our World in Data. COVID-19 Stringency Index. <https://ourworldindata.org/grapher/covid-stringency-index>

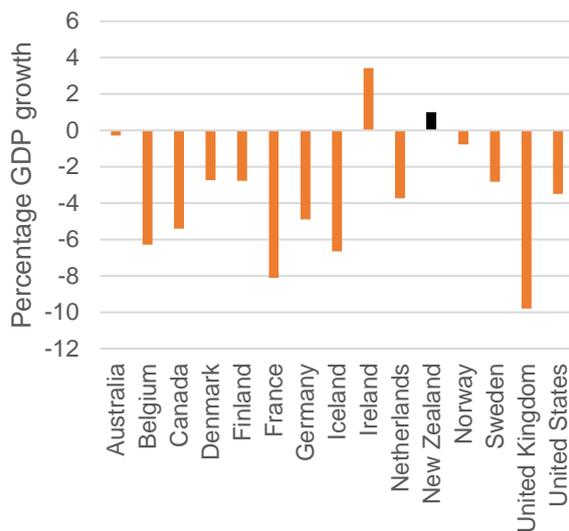
Note: International comparisons here include most Northern European and English-speaking developed countries, ie, excluding Asian countries that had prior experience of severe epidemics (such as severe acute respiratory syndrome (SARS)), including Singapore, Taiwan and Hong Kong.

Economy

Broad indicators suggest our economy has been less badly affected than elsewhere. As discussed below, however, this has occurred against a backdrop of widespread socioeconomic inequity.

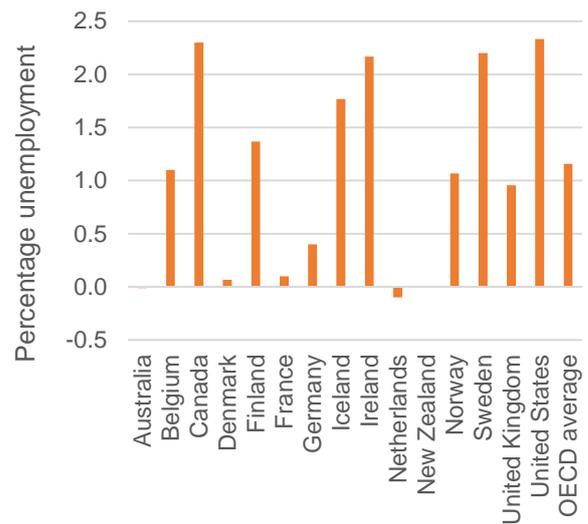
Aotearoa New Zealand's gross domestic product (GDP) grew in 2020, making it almost the only developed country to do so (Figure 2)...

Figure 2: Gross domestic product growth (World Bank definitions), selected countries, 2020



... and change in the unemployment rate was next to invisible (in Figure 3, lower is better).

Figure 3: Change in unemployment rate among selected Organisation for Economic Co-operation and Development (OECD) countries, 2020



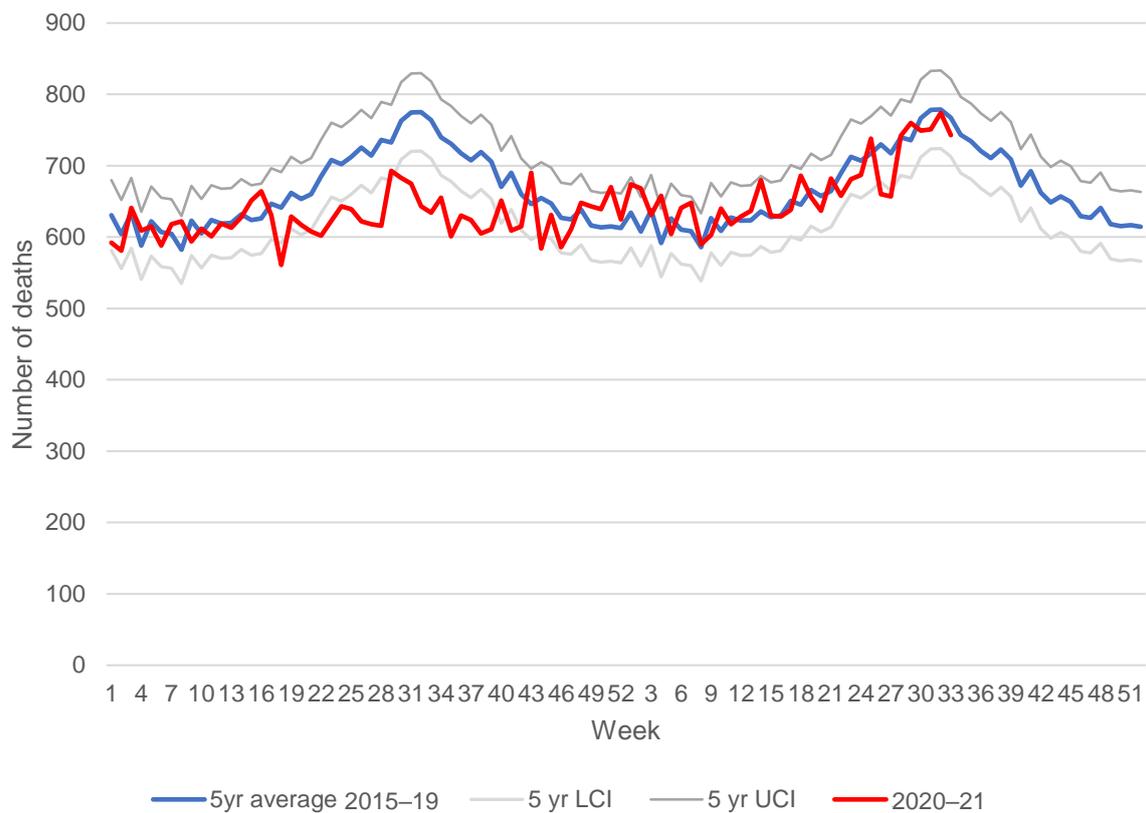
Sources: World Bank, World Development Indicators; OECD.

Latest data available at the time of publication (September 2021 quarter) shows Aotearoa New Zealand's seasonally adjusted unemployment rate, which peaked at 5.3 percent a year before, was the lowest since December 2007 (3.4 percent). The rate of underutilisation of labour in the September 2021 quarter was also the lowest since 2007.¹²

Mortality

Lockdowns obviously saved lives. Modelling in late March 2020 estimated a worst-case scenario of 27,600 deaths due to the virus, if no public health measures were in place.¹³ However, mortality rates due to any cause in Aotearoa New Zealand have actually decreased over the last 18 months. During the initial lockdown period in 2020, based on past trends, fewer people died than would be expected for the time of year and over winter 2020. By late 2020, our mortality rate (red line in Figure 4) had broadly returned to historical rates (blue line), but this reduction means that between April 2020 and July 2021 Aotearoa New Zealand had 1,900 fewer deaths than we would have expected.

Figure 4: Expected and observed deaths, Aotearoa New Zealand, 2020–21



Source: Stats NZ: COVID-19 data portal. <https://www.stats.govt.nz/experimental/covid-19-data-portal>

Note: Expected deaths = crude average death rate (2015–19) applied to each week of the year for Stats NZ overall 2020 population estimate. Observed deaths (red) line are weekly all-age deaths. LCI = lower confidence interval. UCI = upper confidence interval.

Looking more closely, we see that most of the lives saved due to the unintended effects of lockdown were among people over 60 years of age (Figure 6). Unfortunately, this data is not available by ethnicity.

The mortality rate of people aged under 60 years also dropped during the initial lockdown period, but returned quickly to the historical trend (Figure 5) ...

... while deaths of people over 60 years old dropped sharply during the initial lockdown and have since mostly remained below the long-term trend (Figure 6).

Figure 5: Observed vs expected mortality in people aged under 60 years, crude five-year rate, Aotearoa New Zealand, 2015–19 vs 2020–21

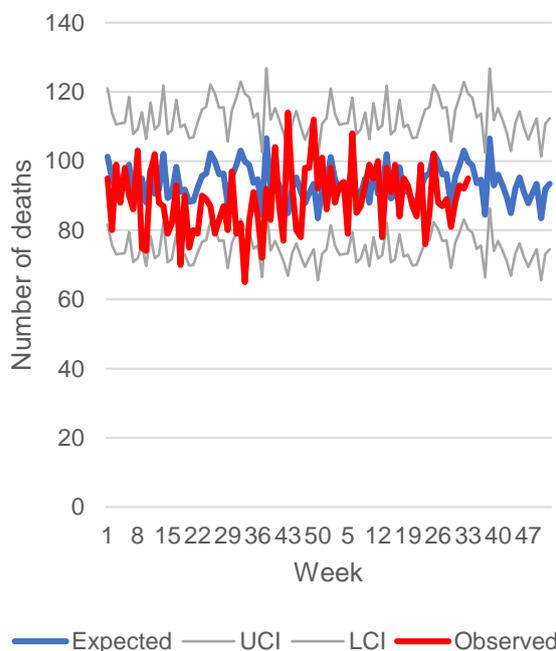
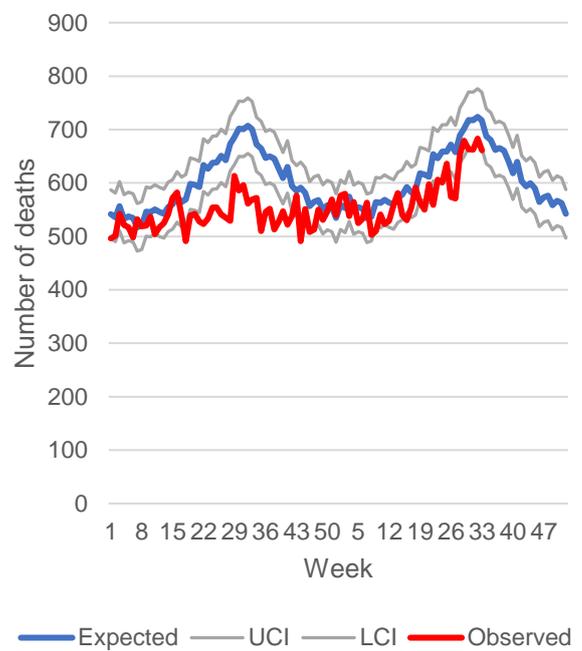


Figure 6: Observed vs expected mortality in people aged over 60 years, crude five-year rate, Aotearoa New Zealand, 2015–19 vs 2020–21



Source: Stats NZ: COVID-19 data portal. <https://www.stats.govt.nz/experimental/covid-19-data-portal>

Note: LCI = lower confidence interval. UCI = upper confidence interval.

Together the observations in Figures 4–6 suggest the effects of lockdown caused a slight ‘delay’ in a small number of deaths (around 400) from mid to late 2020. However, just under 2,000 people we would have expected to die based on historical trends did not die during lockdown and had not died a year later. They were nearly all older people.

A November 2021 *BMJ* study found that only Aotearoa New Zealand and Taiwan, of 37 countries examined, reported an increase in life expectancy in 2020.¹⁴

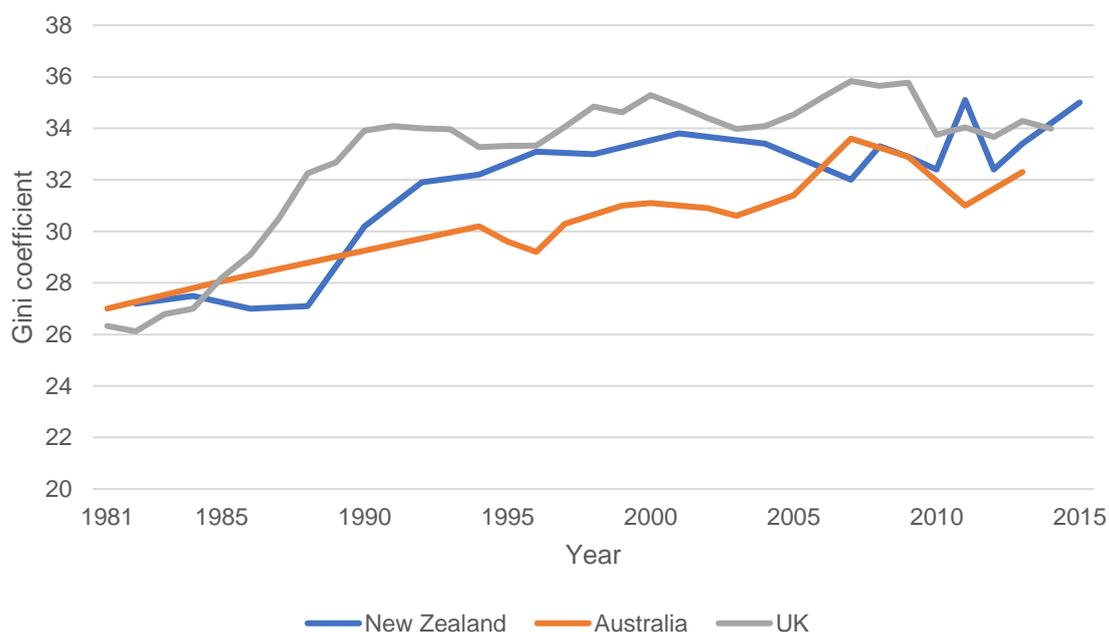
Inequity

These apparently positive results need to be considered in the context of inequity. Inequity is a key weakness in the armour of public health responses to contain COVID-19, leaving different groups in vastly different positions to weather the storm.⁵

Cruelly, the same responses that hold back the spread of the virus can also make inequities worse. Aotearoa New Zealand's particular patterns of inequity before the pandemic were a failure of the Crown's obligations under Te Tiriti o Waitangi (Te Tiriti) and presented fertile ground both for the virus and for the unintended negative effects of measures to contain it. Prior to the pandemic, national data showed health services were less likely to be accessible for Māori compared with non-Māori on the entire life course.¹⁵ Even once Māori accessed health care, years of evidence show inequity in the quality of those health services and treatments they received, lower scores for experience of care, and worse outcomes. Pacific peoples face the same or similar challenges.¹⁶

But the effects of an inequitable system sit on top of wider determinants of health that combine to the advantage of non-Māori, non-Pacific peoples. Many of these determinants gain greater weighting during a pandemic, such as income and housing status. In general, income inequality in Aotearoa New Zealand has been increasing for 40 years. Figure 7 presents Aotearoa New Zealand's Gini coefficient – a broad indicator where a score of 1 means complete inequality, where one person in the country has all income, while a score of 0 means complete equality, where all people have the same income. From relatively high levels of income equality before the 1990s, Aotearoa New Zealand has overtaken Australia and even the United Kingdom for income inequality twice in recent years.

Figure 7: Gini coefficient, equivalised income after tax and transfers, Aotearoa New Zealand, Australia and United Kingdom, 1981–2015

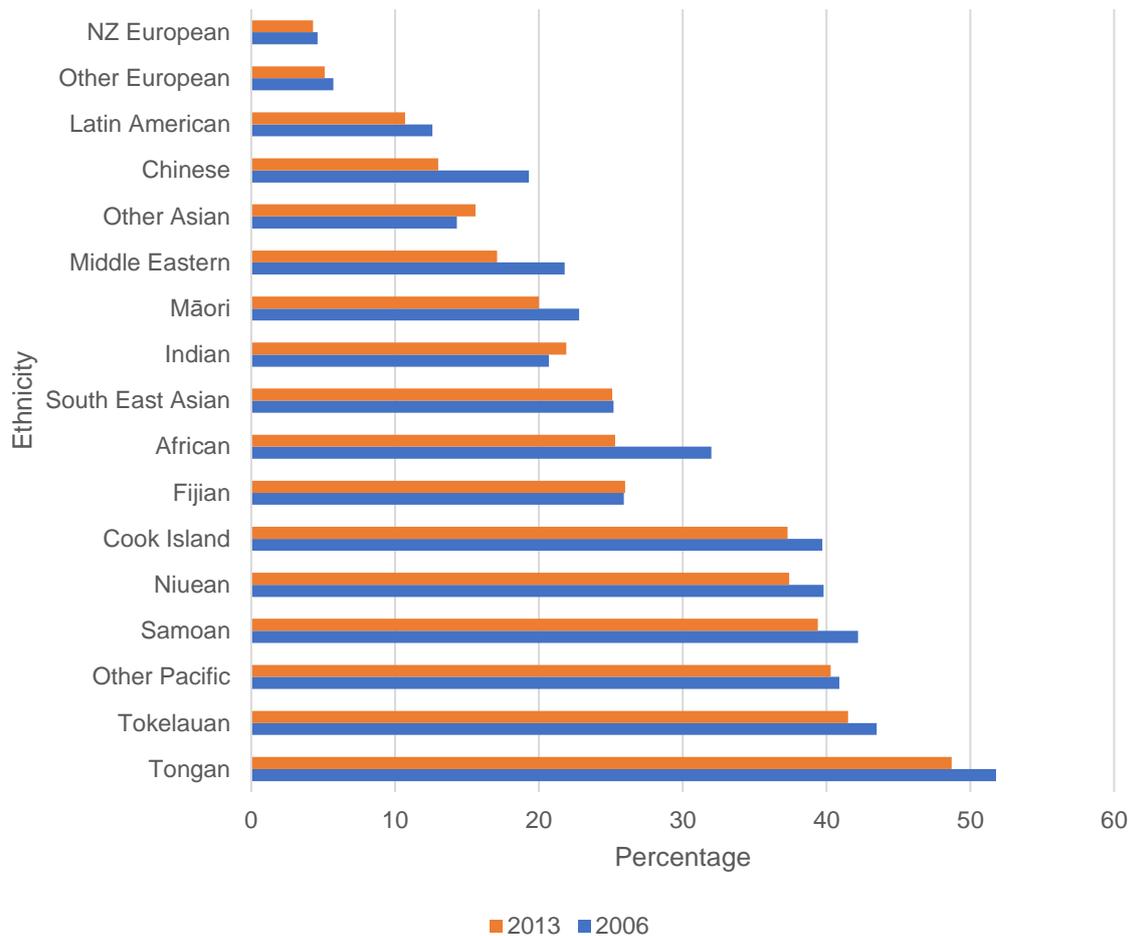


Source: Our World in Data, using Atkinson, Hasell, Morelli, et al. 2017. *The Chartbook of Economic Inequality*. <https://www.chartbookofeconomicinequality.com>

Lockdowns and restrictions on movement place enormous emphasis on where and how people live. Measures to contain COVID-19 have increased inequities in the rates of housing tenure, affordability and insecurity, and poverty. As well as contributing to the spread of the virus itself, these trends represent a number of further turns of the screw of inequity in Aotearoa New Zealand, for Māori and Pacific peoples in particular.

The Child Poverty Action Group’s July 2021 report on the first year of COVID-19 points out that in Northland and Waikato, ‘no Māori households were assessed as financially “secure” during lockdown, and in Auckland it was only 3.5% – in contrast to 30% of all Pākehā nationally’.¹⁷ Census data shows, out of all ethnic groups in Aotearoa New Zealand, seven ethnic groups within the Pacific population have the highest percentages of people living in ‘crowded households’, which is a risk factor for spread of close-contact infectious disease, including COVID-19.¹⁸ Forty percent of Pacific peoples lived in a ‘crowded’ house, which is eight times higher than for Europeans and compares with 20% for Māori. Nearly half of all Tongan people lived in ‘crowded’ homes (Figure 8).

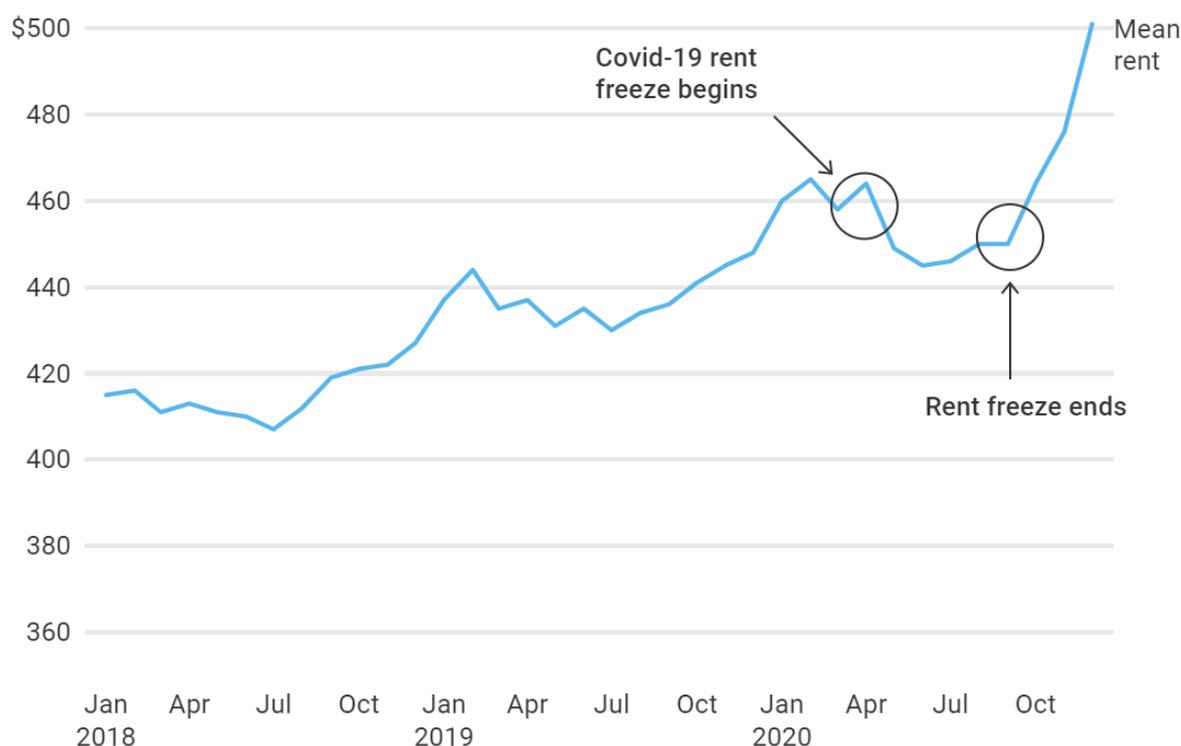
Figure 8: Crowded households by ethnicity, Aotearoa New Zealand, 2006 Census and 2013 Census



Source: Stats NZ Census 2006 and 2013.

Māori and Pacific peoples are less likely to own their own home and more likely to rent. Those who do not own their own home have less security of tenure and move more often, most commonly because their landlord ends their tenancy.¹⁹ Renters have faced increasing costs generally over the long term, but after the six-month rent freeze that began in March 2020 ended on 25 September 2020, Ministry of Business, Innovation and Employment data suggests average rents rose 11% by the end of the year (Figure 9).²⁰

Figure 9: Average weekly rent, geometric mean, Aotearoa New Zealand, 2018–20



Source: Chart: Kate Newton. 2021, 27 January. Rates soar after Covid-19 freeze ends. <https://www.stuff.co.nz/life-style/homed/renting/124052014/rents-soar-after-covid19-freeze-ends> Data: Ministry of Business, Innovation and Employment.

These rent price increases have in turn increased homelessness, housing precarity, overcrowding and inequity.¹⁷ All of these adverse circumstances have also made it easier for the Delta variant to spread in late 2021.

Facing up to the future with the past in mind

Given these conditions, in this report we examine some key parts of the Aotearoa New Zealand health system to understand both what happened and what we can learn to address health inequity, improve health and respond more resiliently to shocks to our system in future. Future Window reports will consider other key areas.

The impacts of COVID-19 on health care must be considered in view of inequitable health service provision that has occurred historically and continues today. To address long-standing inequities in health and socioeconomic status, an equity approach must be front and centre at all levels of decision-making. The extent to which this has occurred in Aotearoa New Zealand's COVID-19 response has been variable.^{21 22 23 24 25} Yet taking such an approach remains urgent, not only to deal with the current evolving situation but also to respond effectively to future pandemics and other inevitable shocks.

Pandemics compound and promote pre-existing social and economic inequities, which is clear from the differential impact they have had on Indigenous populations

worldwide both now and in the past.^{5 26 27 28 29 30} Public health strategies have rarely meaningfully addressed Te Tiriti responsibilities; recent major reports highlight that the Crown has systematically acted against its obligations under Te Tiriti across the health sector.^{31 32 33} Systems that enable inequities are in place across the world, even at the level of who gets access to ventilators in intensive care units.^{34 35} These systems must not continue to be reproduced. Decision-making around health care must no longer reflect values aligned with structural systems that attach greater value to some people and to some lives.^{36 37}

The COVID-19 pandemic presents an opportunity to think about what a future health system in Aotearoa New Zealand can look like. A return to 'normal' is not desirable. A system that is underpinned by a whole-of-government approach to health, is pro-equity, complies with Te Tiriti and is anti-racist must provide the transformative policies and actions necessary to address systematic, entrenched and pervasive inequities – which otherwise will continue to blight the health and wellbeing of tangata whenua and future generations.

The New Zealand Health and Disability System Review³⁸ and current ongoing system restructure are a chance to build in a pro-equity, pro-resilience approach to our health care with all we have recently learned in mind.

Community voice: Tofilau Bernadette Pereira MNZM – ‘We know our people and we know what works’ | Te reo o te hapori: Tofilau Bernadette Pereira MNZM – ‘Ka mōhiotia ō mātou tāngata, me te mahi e tika ana kia mahia’



Bernadette serves on the board of trustees for a Pacific clinic in Ōtara, South Auckland, and speaks from her personal experience as a consumer of health services. She is the immediate past president for P.A.C.I.F.I.C.A Inc., and has done a lot of work helping Pacific mothers and families settle into their adopted country of Aotearoa New Zealand.

Collective health and individual health are connected and affected

In a Pacific environment, it's difficult to speak about yourself. We're part of the wider collective. Even though I had my own personal experiences, I was deeply involved in the community response [to COVID-19] and how to keep our people safe. We've been in there intensively pushing for the vax, as a priority, particularly here in Tāmaki Makaurau, whose people have suffered the worst.

The issues that come forth a lot – socially, culturally and economically – are that it's hard. When it comes down to it, the question is: can you pay your bills? Can you pay your mortgage? Can you continue with expenditures that are linked to your survival? It becomes really hard on mental health, on the mental wellbeing of our people.

Myself, I've been working bang, bang, bang since lockdown. As an individual, I was involved in providing back-room support to an essential provider that was responding to urgent needs. But when it came to my own health, I was so preoccupied I neglected what my own system was telling me, until three weeks ago, I realised I was just exhausted. I thought, 'Oh my god,' and I realised that for the first time, after looking out for others' wellbeing, I hadn't taken care of myself. I thought, I have to take stock of what my body is telling me, that I was very tired. I realised this could be mental fatigue. Even though I sensed it, I was pushing it aside. You become more laissez-faire about your own condition. There were pros and cons. It was good I still had things to do, but there was neglect.

I had specialist appointments that were ongoing, but because of my fear of what was happening at Middlemore, I had to cancel six times. I didn't feel confident going in, because there was information and updates coming that people in the emergency areas were being kept overnight. There were people who had contracted COVID-19 in the hospital. There was that message coming through to the community and I was talking with people and I wasn't alone in that fear. It exacerbated the experience for

people with long-term conditions. You need to have the confidence, because with a long-term condition there are periodic appointments, where you must see your GP. In lockdown we resorted to virtual phone consults and that was really insufficient in my view. It's impersonal. There are things you want to discuss that you can't.

A lot of our consumers with long-term conditions, where they're required to do blood tests, pop in to the Ōtara provider, but that access was compromised. The clinical people have created a system where they provide the script and you just turn up, but you still have to physically go and do your blood test. In the height of alert level 4, people were very scared to go. People were calling up the provider and asking, 'Is it safe to come and have an X-ray?' You can't blame the frontline staff. But how can the officials at the call centre say it's safe, in alert level 4?

Effects on the workforce

It's also impacted the workforce. My provider was also at the front line for vaccination and for testing. They had fewer people available and had to multiply them into many fields. So, the clinic was very much marginalised during that time, in the quality of the consults, for instance. The follow-up was compromised because of that heavy impact. Economically, a lot of us had lost jobs or had reduced hours. That had an immediate impact on household budgets, household needs and also mental health and wellbeing. For Pacific people, a lot of our essential workers all suffered mental tension, mental anxieties. You're in the front line providing, but you have to think about the safety of your own household when you return home, and yourself.

Lockdown fatigue, economic effects, the vaccination campaign and effects on mental health

It's lockdown fatigue that Aucklanders are feeling. And more so in our communities, in a household of 10 people, locked down for three months. There's a lot of social issues that have arisen as a result. Mental fatigue, mental wellbeing, violence has been on the rise, particularly in home situations. You've got children in there. The economic power to participate is zero. So, the poor become poorer. The gap is widened and inequalities continue. Economically COVID-19 has impacted badly on Pacific women on all fronts. That all has an impact on our mental wellbeing as well.

A lot of the communication was done through Zoom or electronically. Zooming became a liability to our mental health and wellbeing. I worked a lot more during the lockdown than I would in a normal day, when you go into work. Why? Because suddenly you think you have all this time, so you can gradually approach your work. But you don't – because of the urgency of the environment and the needs of people, you run, run, run. This was mental, physical, spiritual – you had to use all of your waking hours. We just haven't had a chance to properly sit down and take a break. I'm on the board of one of the health providers in Ōtara, South Seas. We've been leaders in the campaign for vaccination and last Saturday we had a huge vaccination campaign and cultural event for the Samoan community throughout Auckland. It went from 8.30 am to 9 pm at night. I took off at about 6 pm because I was too tired.

Luckily I was able to drive home safely. I realised I just conked out on the settee and woke up at 1 am. That was the impact on me. This is still going, towards Christmas. There's another three weeks of the vaccinations. Last week the booster became available, so there's all that also.

Support must be given to the people who know the communities

We're worried because the money gets tangled up in institutions; it takes a while to filter out to providers and communities. If we have learned anything, it's that support must be given to the people who know the communities and who are working with them 24/7. We know our people and we know what works. Don't continue to complicate things.

We wonder what the new health system is going to look like. Is it going to address the already systemic inequalities already highlighted, or is it going to continue to widen the gap between populations, depending on where you live, the colour of your skin, the pay that you bring in, the housing conditions you have? The only hope you have is when you work at your community level – if we can filter the information to our people, to the community. The system will only listen if there's a critical mass, consistently, of South Auckland, Pacific communities, to rise and speak.

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Chapter 1: Distraction: Primary care, immunisation and screening | Upoko 1: Whakawarea: Haumanu tuatahi, ārai mate me te mātai

Key points

Distraction from our system's business-as-usual work in immunisations and screening has exacerbated already entrenched inequities by ethnicity.

Immunisations of two-year-old and six-month-old babies have fallen steadily for several years, and lockdowns have reduced immunisation rates further (from 91% in March 2020 to 83% in September 2021).

- Coverage of two-year-old Māori children declined from 86% in March 2020 to 70% in September 2021. Coverage of two-year-old Pacific children fell from 94% in March 2020 to 82% in September 2021.
- Coverage of six-month-old babies declined from 80% in March 2020 to 70% by September 2021. Coverage of six-month-old Māori babies fell from 65% in March 2020 to 49% in September 2021. Coverage of six-month-old Pacific babies fell from 80% in March 2020 to only 57% in September 2021.

Breast and cervical cancer screening have also been disrupted.

- Breast screening coverage declined sharply in 2020. For most ethnicities, this decline slowed by September 2021, but coverage of Pacific women continued to decline, from 71% in 2019 to 61% in September 2021. Coverage of Māori women declined from 62% in 2019 to 58% in September 2021.
- Cervical screening coverage of women of 'other' ethnicities (mainly those of European descent) fell in 2020 from an otherwise stable rate, followed by recovery to previous levels in 2021 (76%). Coverage for Māori and Pacific women has declined continuously since 2016, and from 2019 to 2021 fell from 63% to 59% and from 66% to 61%, respectively.

In this chapter, we look at some key indicators of 'distraction' from our system's business-as-usual work and the impacts of this on preventive health care and screening, in particular for Māori and Pacific peoples.

Primary care providers have responded to the challenges of COVID-19, lockdowns, testing and the vaccination rollout with vigour and speed. The primary health care response has been unprecedented, multifarious, regionally unique and adaptive. Yet there is little we can say about its business-as-usual work from national data. Key among our recommendations at the end of this report is that better primary care data

must be made more widely available to enable better understanding and coordination.

Since the health system restructures of the early 1990s, Māori and Pacific primary care providers have played a critical but often unrecognised role in facilitating access to the health system for Māori and Pacific peoples.³⁹ These services work in a context of the ongoing failure of the health system to ensure quality of care and access to services for Māori^{15 39} amounting to breaches of Te Tiriti specifically relating to the primary health care sector.³¹ They also work to re-orientate services to focus on the effects of key determinants such as income, education, employment, and housing on Māori health.

This critical role has been achieved within restrictive timeframes and contractual agreements not aligned with the comprehensive knowledge around the health and wellbeing of their populations served as understood by provider organisations.^{40 41} Such knowledge, including the role of relationships, the importance of cultural safety, ensuring active and ongoing engagement in planning and delivery of services, a whānau approach, as well as the flexibility to respond in a rapidly changing health and social system, are precisely the skills and expertise that are vital during the pandemic. The pandemic has highlighted the critical role of information and how the quality of, and reception to, information is inter-related with the support structures of patients and whānau, with provider organisations and general practitioners (GPs) being central to this.

Many providers, GPs and primary health services, have felt shut out of meaningful input into the development and rollout of the vaccine strategy. However, once supported to lead their own approaches, significant increases in vaccination rates for both Māori and Pacific peoples have been achieved. As well as being largely responsible for addressing the effects of reduced access to the vaccine among Māori, providers, are now tasked with coordinating care and support for those with COVID-19 and their whānau who are isolating at home.^{42 43} The ability of providers and GPs to successfully undertake this work may be compromised by a lack of access to accurate and comprehensive data.

The right of Māori to self-determination and inclusion in nation-state governance (including data governance) is grounded in Te Tiriti.^{44 45} Crown failure to meaningfully include Māori in pandemic response decision-making was openly challenged early in the pandemic.⁴⁶ As Carroll and colleagues report, a 'by Māori, for Māori, about Māori' response strategy was called for by the national Māori pandemic group, Te Rōpū Whakakaupapa Urutā.^{45 47} 'Key to the strategy,' the authors write, 'is the critical need for reliable, routinely available and ethnicity disaggregated data and real-time monitoring to inform Māori decisions.'⁴⁵

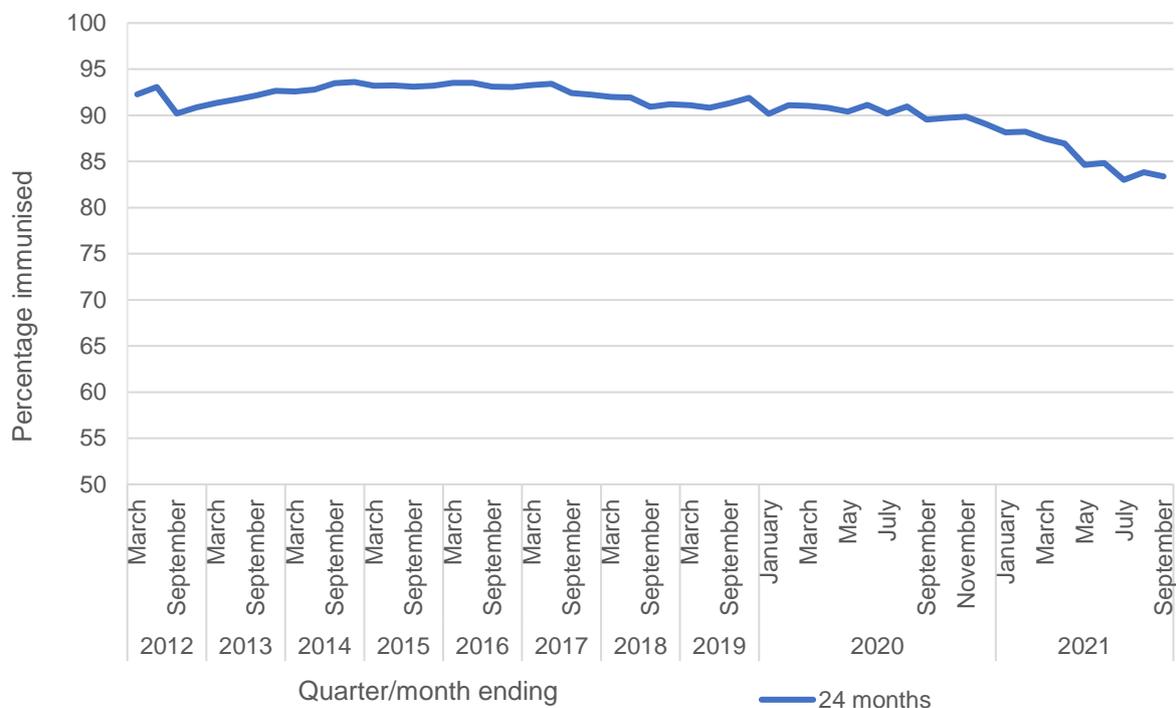
It is vital to remedy the absence of data on Māori and Pacific provider organisations in terms of their contribution to the health system and as an integral part of health service delivery envisaged for Aotearoa New Zealand going forward. At the same

time, it will also be necessary to ensure an equitable and sustainable funding environment that is consistent with adequate resourcing for the services they provide.

Immunisations

The percentage of two-year-old babies receiving the full schedule of immunisations has declined since 2017. This general downward trend was affected by a schedule change in October 2020 to some extent, but coverage has clearly fallen further since the 2020 lockdowns, dipping well below 90% for the first time in 10 years (Figure 10). Reduced access to primary care during lockdown periods has impacted on two-year-old children getting their full schedule of immunisations – something telehealth (see Chapter 2) is incapable of addressing.

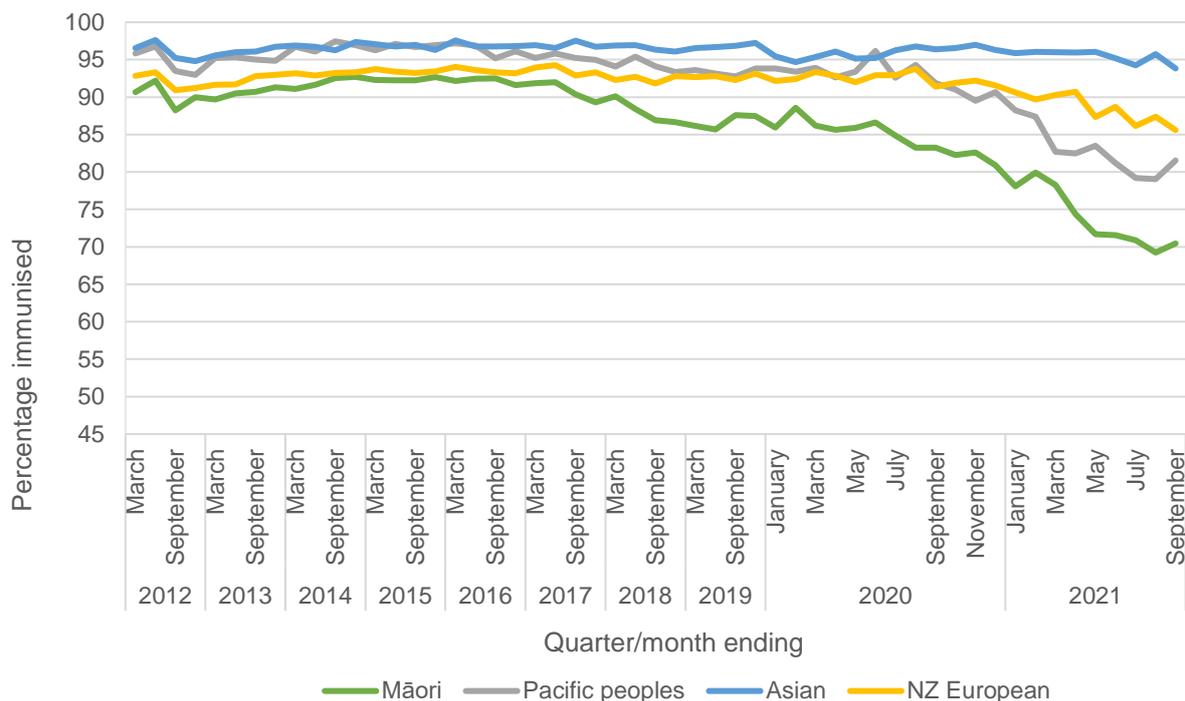
Figure 10: Immunisation coverage at 24 months of age, Aotearoa New Zealand, 2012–September 2021



Source: Immunisation Advisory Centre.

The equity issues here are profound. Rates for Māori children (already lower than other ethnicities and slowly falling since 2017) have fallen sharply by 15 percentage points since mid-2020 (Figure 11). For Pacific babies, coverage has steeply fallen by a similar amount since June 2020, after nine years of coverage that fluctuated between 93% and even 97% of two-year-olds receiving their full schedule of immunisations.

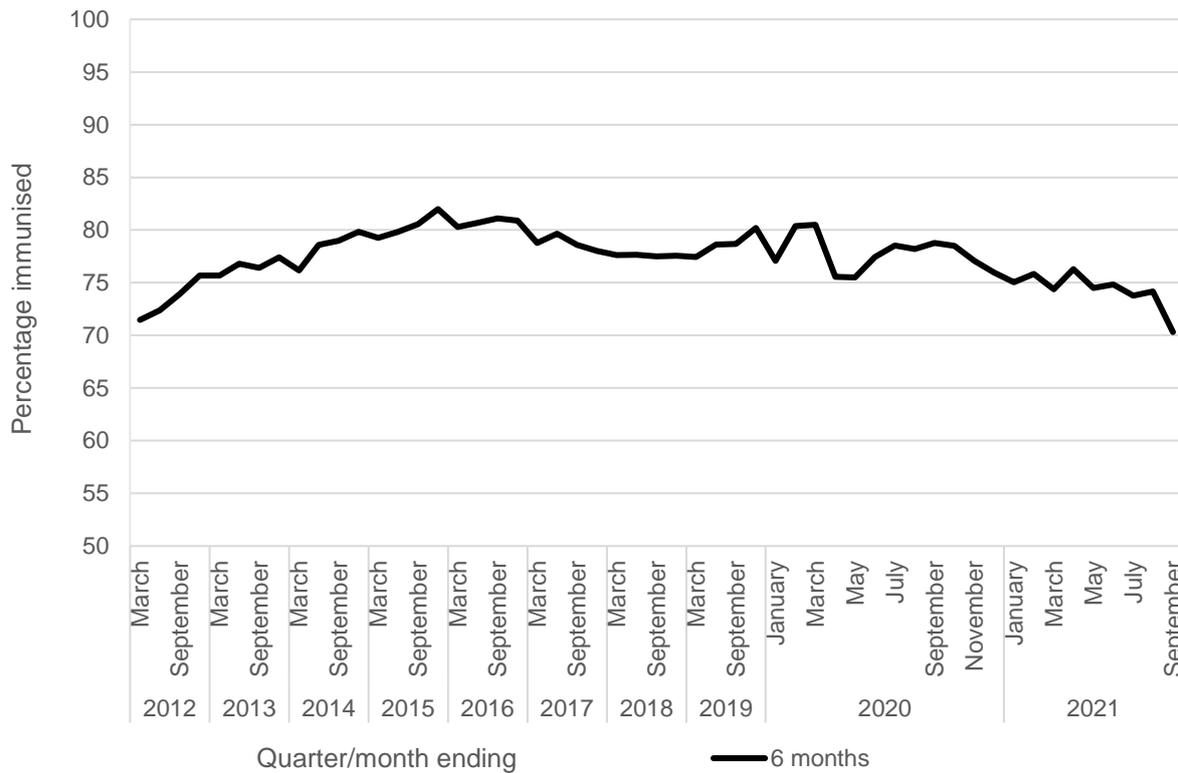
Figure 11: Immunisation coverage at 24 months of age, by selected ethnicities, Aotearoa New Zealand, 2012–September 2021



Source: Immunisation Advisory Centre.

Reductions in immunisation coverage at six months of age (Figure 12) are even more significant as the majority of serious and lethal vaccine-preventable disease occurs in the very young.⁴⁸ Coverage of six-month-old babies was already low at 80% in March 2020, then fell by 4 percentage points in one month. A small recovery immediately after that was followed by a steady and then a steep decline to date: by September 2021 only 70% of six-month-old babies were fully immunised.

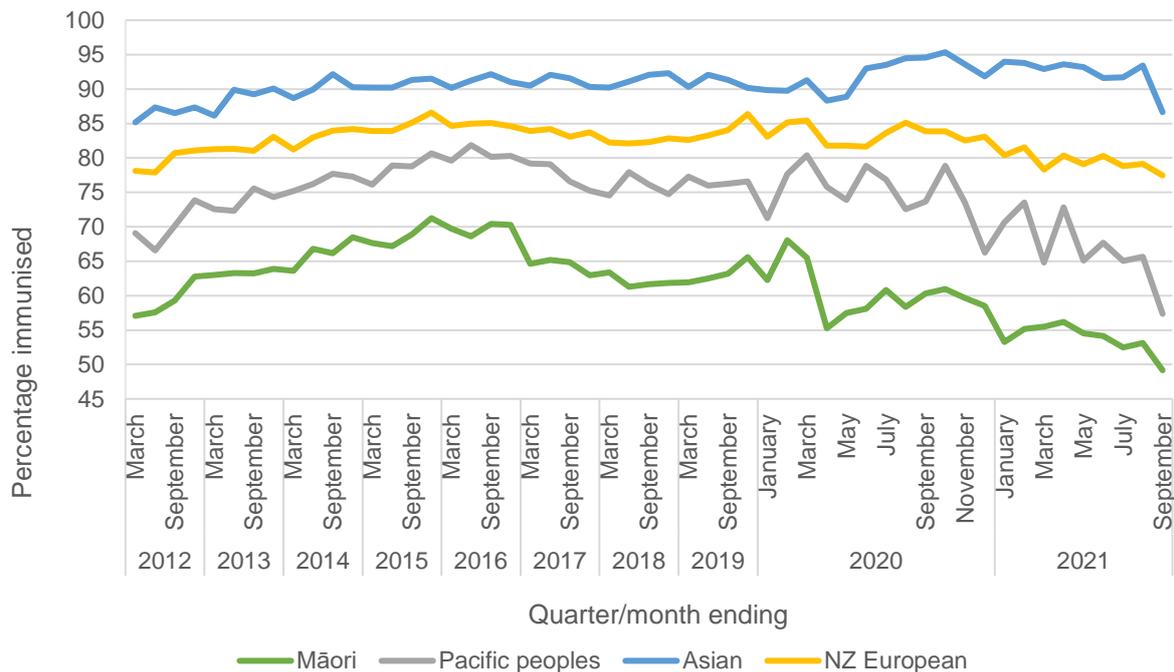
Figure 12: Immunisation coverage at six months of age, Aotearoa New Zealand, 2012–September 2021



Source: Immunisation Advisory Centre.

The same patterns of inequity are visible for six-month-old babies. Up to March 2020, coverage of six-month-old Māori babies was shockingly low though somewhat stable. However, rates fell by 13 percentage points immediately during the first lockdown period, and by September 2021 fewer than half of six-month-old Māori babies were covered. Coverage of Pacific babies has dropped from 80% in March 2020 to only 57% in September 2021.

Figure 13: Immunisation coverage at six months of age, selected ethnicities, Aotearoa New Zealand, 2012–September 2021



Source: Immunisation Advisory Centre.

The recent steep and inequitable falls in immunisation rates in 2020 and 2021 are plausible unintended consequences of the COVID-19 response exacerbating inequity due to lockdowns, reduced mobility, fear of perceived disease risk and additional barriers to accessing primary care. The distraction of COVID-19 from the health system’s work in scheduled vaccinations is likely to have compounded impacts of existing persistent and ongoing inequities within the primary care system, which for many Māori involve experiences of institutional and inter-personal racism.⁴⁹ It has also intensified the need for health institutions to build stronger and more sustainable relationships with communities.⁵⁰

If the disruption to the immunisation programme continues, it will create a cohort of children and families vulnerable to infectious disease when the borders reopen in the future, with the burden falling on Māori and Pacific peoples. Immunity gaps can quickly overwhelm our system for a period, as we saw with respiratory syncytial virus in mid-2021.^{51 52} Such disruptions are likely to further impact Māori and Pacific peoples (though perhaps in different ways)⁴⁸ and those living in socioeconomic deprivation, carrying with it the added risk that Aotearoa New Zealand will export vaccine-preventable disease to our Pacific nation neighbours again. The serious measles outbreak of 2019, which created such an issue for Samoa and other nations,⁵³ spurred a review that called for an urgent catch-up programme to boost immunity – from this too the system has been distracted by the COVID-19 response.⁵⁴

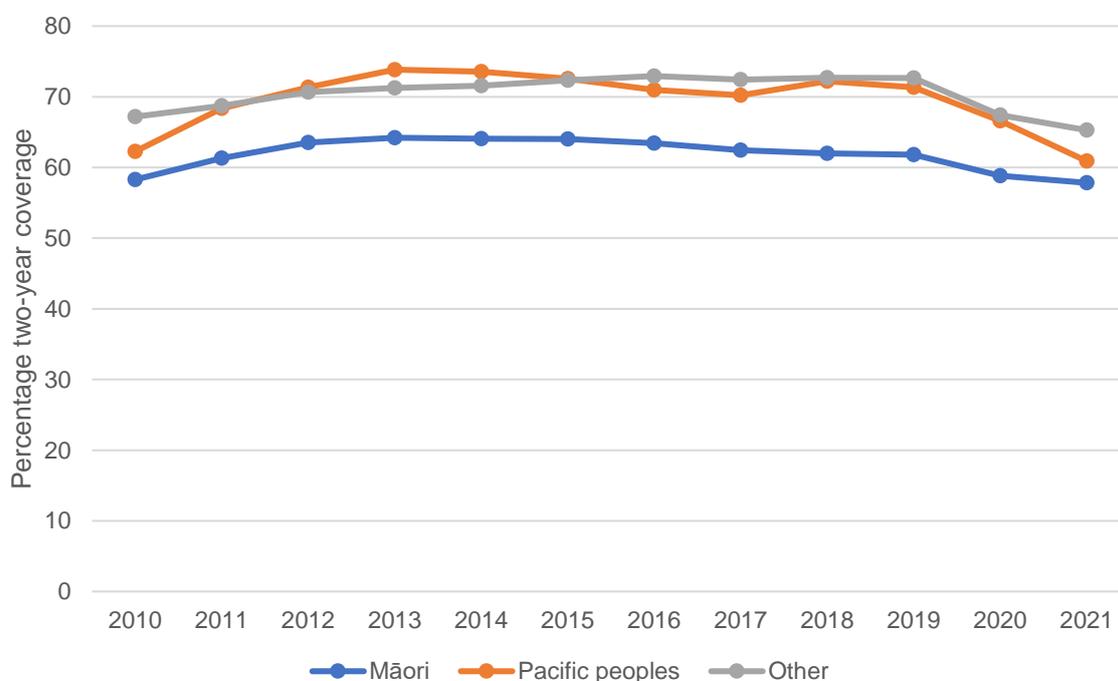
At the same time, Aotearoa New Zealand has opportunities to address the issues we have identified. In particular, we now have a well-trained and expanded vaccination workforce across a range of primary care services (such as pharmacy) that could be put to good use.

Screening

Breast screening is an essential preventative service that reduces the risk of women dying from breast cancer.⁵⁵ Conducting screening was considered safe under COVID-19 alert levels 1, 2 and 3, but the service was reduced as alert levels rise to allow for infection control measures.⁵⁶ Procedures were put in place to screen women for COVID-19 symptoms and risk before their appointments. Pro-equity invitation strategies to prioritise Māori and Pacific women were recommended to providers at all alert levels.⁵⁶

Under alert level 4, all screening appointments were paused. In March–April 2020 and August 2021, screening was paused nationally, however women with a high likelihood of malignancy were prioritised for assessment during that time. National breast screening data shows a sharp decline in coverage in 2020 (Figure 14). For most ethnicities, this decline slowed in August 2021. Against this trend, however, coverage of Pacific women continues to steeply decline. Coverage of Māori women remains lower than for all other ethnicities.

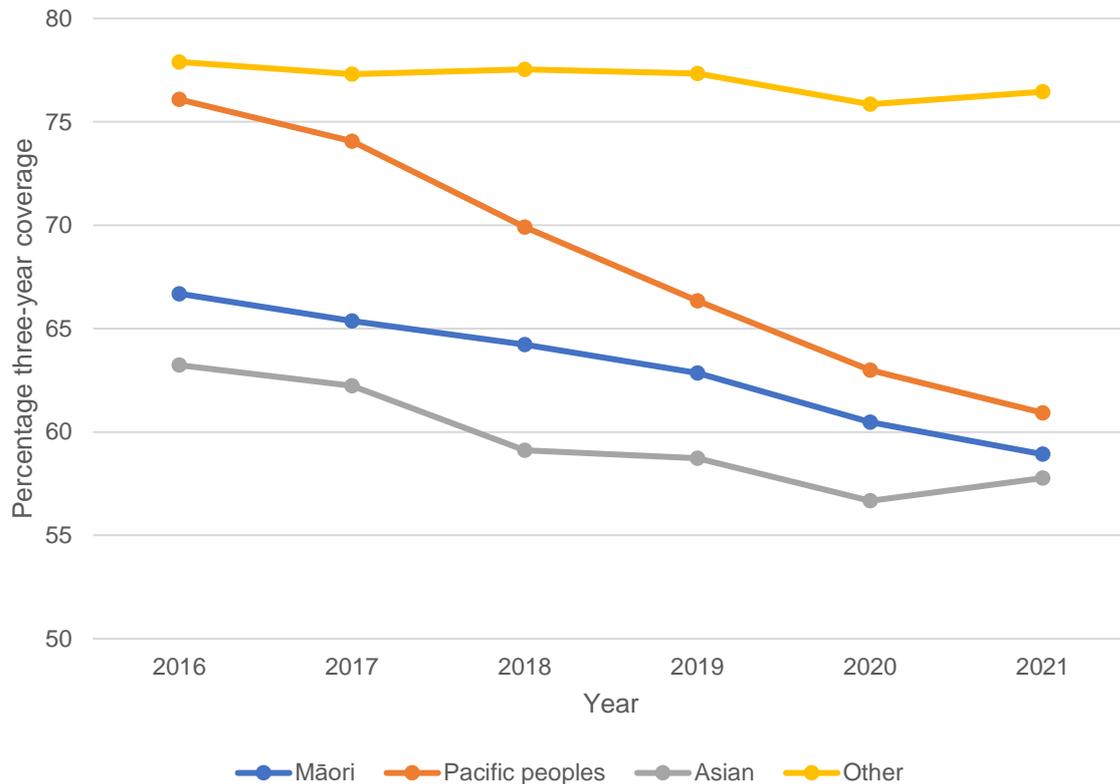
Figure 14: Breast screening, two-year coverage in women aged 45–69 years, by ethnicity, Aotearoa New Zealand, 10 years to September 2021



Source: National Screening Unit.

A comparable picture emerges from cervical screening data. Figure 15 shows how visible dips in 2020, followed by recovery to previous levels in 2021, occurred in the coverage of women of Asian ethnicity and ‘other’ ethnicity (ie, mainly those of European descent). In contrast, for Māori and Pacific women, cervical screening coverage continues to decline, and coverage of Pacific women has declined 15 percentage points in five years.

Figure 15: Cervical screening, three-year coverage in women aged 25–69 years, by ethnicity, Aotearoa New Zealand, 2016 to August 2021



Source: National Screening Unit.

Low coverage in these groups is particularly concerning (and unacceptably poor), given both Māori and Pacific peoples have a higher incidence of cervical cancer and higher mortality compared with non-Māori, non-Pacific.⁵⁷

Past trends sound a clear warning for how the August 2021 Delta outbreak will affect these key services, in particular for Māori and Pacific peoples. The data in this area is yet to emerge.

Community voice: Marlene Whaanga-Dean – ‘This year we were more prepared’ | Reo hapori: Marlene Whaanga-Dean: ‘I tēnei tau i te tino rite mātou’



Marlene Whaanga-Dean is a consumer representative at the Health Quality & Safety Commission and change development lead in Whānau Ora services supporting Whaiora, a very low cost access (VLCA) primary care provider in the Wairarapa, with an enrolled population of 70% or more high-needs patients.

Ko Marlene Whaanga-Dean tōku ingoa.

I think this year, for lockdown, we were more prepared. We could easily hit the ground running. It's always the most vulnerable that need attention more than anyone: our elders, and our vulnerable communities, that includes our homeless, and rural and disabled people.

As a service at Whaiora, we've managed to know what to do this time around. Even though last year was great there were a lot of questions to answer: 'How are we going to do this? What's it going to look like?' It created a platform this year to action it faster than we did last year.

Keeping immunisations going

This time around, we were more proactive as kaimahi. We had cartloads of people coming through at level 4 and level 3. When I was with whānau in the carpark, we had questions like 'Can I bring my 12-year-old in?' You couldn't just say, 'No, come back tomorrow.' You had to grab it then and there. There might be no tomorrow. We needed to accommodate instantly. We needed to keep immunisations for children up. It had to be business as normal. We zoned each area of primary care off, with three- and four-year-olds attending their appointments at a tent of their own out there with immunisation nurses. Last year we didn't have all the green zones, the red zones. This time we had our green zone, our red zone for COVID-19 tests, and we had the doctor zone. We had to split those areas up and we became really good at it – keeping to the guidelines, the distances.

We had to keep pushing to keep the mamas in here, to have a private area to carry on the immunisations. They'd beep the horn; we'd say, 'Come on through.' We knew we had to navigate that in our small primary care space, we knew that had to continue.

It took a while to get this all up and running, but when it did, it did. It turned out well.

The same challenges came up – food, heating and communication

We never stopped working all the way through. We continued to be creative and we continued to work to make sure that whānau, particularly those who were vulnerable in our community, were taken care of – I'm talking about kuia and koroua, with tangihanga. We were lucky enough to have hygiene packs stored away from last year, so we were always giving what we had out there to those family that had lost a loved one. Just accessing resources for them.

Firewood was huge – it was winter. Iwi came along and that's pretty much what they did – kai and wood. Without everyone overlapping; people were helping in other ways, so that we weren't overlapping. Having a process, working it, that worked really well for our rohe.

Last year we were often trying to help whānau navigate with Work and Income, for kai. We experienced that again. Food was the biggest thing ever. I'm sure we weren't the only one. It was food, mainly, for whānau, last year and this year.

We kept pretty consistent. But accessing the GP was hōhā [a hassle] this time, because of the screening, you couldn't just get in. We used teleconferences, communication from our practice to the community, to whānau that couldn't rock up here. Whānau getting transport to come in at level 4 posed a complex issue because nothing was running. We had one kaimahi that had to urgently pick up a client. We were aware of guidelines and whānau, and this was urgent around his cancer situation. So those really important things that are really quite dramatic for the whānau. They can't access things, can't get to where they need to go, it gets delayed. But that's beyond control when you hit level 4 COVID-19.

'People did it harder this year' – being prepared and having the vaccination conversations

I think with the isolation, people did it harder this year. It came out of the blue. No one was prepared. As an organisation, we had to be prepared, but whānau weren't.

Now we're emphasising this in home visits – you have to be prepared, you don't know, you can't assume things are going to be okay. It's going to rear its head. Our message to whānau has been, we just have to have you prepared. Preparedness is vaccination, it's making sure you've got what you need at home.

Vaccination has been a hit-home thing of late. Some roll their eyes. Me and my colleague last week thought we'd do business-to-business, to see if businesses needed our nurses to come in. We had to go door-knocking on this, because whānau are not going to come, particularly our Māori whānau. You much have to go to them, and say, 'Tell us, what are your fears, what are your worries?' The fact of the matter is that we want them to make their own informed decisions. We are not there to make them change their mind. We're just encouraging them. We have professionals who are happy to sit with them and assure them.

Pasifika working locally in our orchards further south in the Wairarapa got vaccinated. The last 14 staff were mostly Māori. They rolled their eyes, and I just said my spiel. I said, 'We don't want you to do what you don't want to do.' We're here to support, manaakitanga. We're trying to get it into the conversation. The employers were great. Those staff members were the last 14 to get vaccinated. They had a barbecue and we took nurses out there. That's where we had to go with it. We had to figure it out. You might get the eye-rollers, the questions, 'Is it 100% effective?' 'Is it magnetic?' That's where social media has really impacted on their decisions. And if you're not sure that's why we have to come and talk to you. It's been really hard for our kaiārahi to talk to whānau because of social media. We had one whānau who wouldn't come in. They said, 'The people protesting have put me off.' That's what we're battling as social services. You make them feel comfortable, confident, and they come in, in the end. We're still working towards it.

Keeping up collaboration is key

As much as we're worried about our practice, our primary care, mahi, our tangata, our whānau, we still need to reach out – it was my role to reach out there to see what everyone's doing, to email everyone in the area, to keep that collaboration strong. I think we can get that part a bit better in this region.

Chapter 2: Difference: Primary care patient experience in 2020/21 | Upoko 2: Rerekētanga: Te wheako o te tūrora haumanu tuatahi 2020/21

Key points

Patient experience survey data shows how lockdown affected access to primary care and how experiences of telehealth differed for different people.

- Around one in three (34.4%) respondents reported that the level 3 and 4 lockdowns in 2020 kept them from going to their GP in the way they usually would have.
- The most common reasons cited for not accessing services (42.9%) were that alert level restrictions meant they weren't allowed or their reasons for accessing care in the context of lockdown weren't urgent enough (38.9%).
- One-third of people (35.4%) delayed their care. One in five (19.6%) people substituted care, with other options like advice from family/friends, internet searches or using medicines at home
- More than one in ten people (12.3%) didn't like anything about telehealth, and these people were more likely to be disabled (14.7% vs 10.9% not disabled).

In this chapter, we use patient experience surveys to explore how lockdown affected access to primary care and for whom, the reasons why people did not access care (when most providers remained at least partially open), what people did instead and how it worked for them.

We look at the experience of telehealth care to learn whether it is the solution to access challenges over lockdown – who used it and its advantages and disadvantages compared with face-to-face services. We focus particularly on the age, ethnicity, disability status and socioeconomic deprivation level of people using telehealth, and how their experiences changed between 2020 and 2021.

In examining patient experience in these periods, we draw on:

- the results of our ongoing survey of adult patient experience of primary care,⁵⁸ which provides quarterly data
- the findings from a one-off COVID-19 patient experience survey undertaken in June 2020 to understand patients' experience of accessing health care during all alert levels, but particularly during level 3.⁵⁹

The adult primary care patient experience survey typically receives around 30,000 responses each quarter, while the COVID-19 patient experience survey received

around 26,000 responses, from a pool of those who already accessed primary care. Both surveys used strategies to improve participation and deliberately over-sampled Māori and Pacific patients.⁶⁰

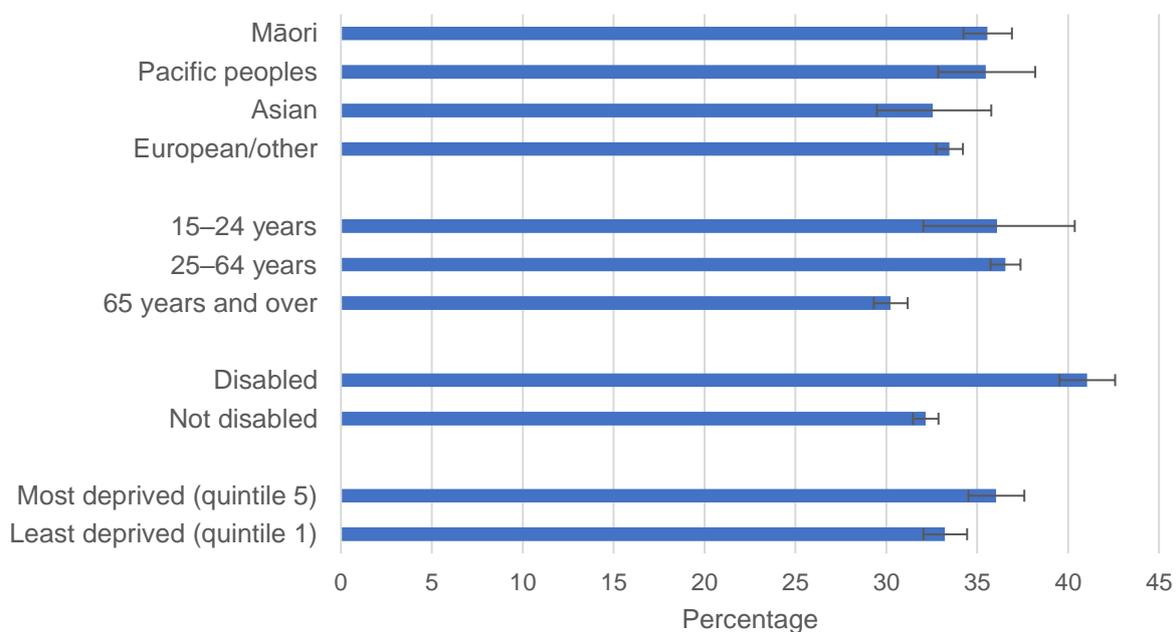
People differed in their experience of access to care

The COVID-19 patient experience survey unsurprisingly found people were not able to access health care in the way they normally would have. But lockdown (level 3 and level 4 in this case) affected access to health care to different extents, in different ways and for different reasons for different people.

The survey asked respondents about a number of ways they might usually access health care, and whether lockdown kept them from doing any of them.

Around one in three (34.4%) respondents reported that the level 3 and 4 lockdowns in 2020 kept them from going to their GP in the way they usually would have. These respondents were more likely to be under 65 years of age, be disabled and live in areas of greatest socioeconomic deprivation (Figure 16). More than 40% of people surveyed who identified as being disabled could not see their GP as they normally would.

Figure 16: Percentage of people that reported the alert level 3 and 4 lockdowns in 2020 kept them from going to their GP/doctor as they normally would have, by ethnicity, age, disability status and socioeconomic deprivation profile, Aotearoa New Zealand



Source: Health Quality & Safety Commission routine data analysis.

In reporting on their access to health services beyond the GP rooms:

- 5% of respondents reported that the lockdown kept them from going to after-hours services (5.0%) or an emergency department (5.1%)
- one in ten (10.1%) said they had an outpatient or specialist appointment or operation/procedure at a public hospital that was cancelled during lockdown. These people were also more likely to be disabled (19.6% vs 8.4% not disabled), older (12.6% of those aged 75 years and over vs 5.7% of those aged 15–24 years) and living in areas of greater deprivation (12.0% most deprived vs 8.7% least deprived).

The barriers to access

We asked people why they did not access health care – that is, why they did not see their GP, call Healthline, attend after-hours services or an emergency department, or attend a public appointment or operation.

The reasons people make decisions in unfamiliar situations are often complex. In this case, the reasons given for not accessing care included a mix of fear and altruism: people had concerns about the virus itself in health care contexts alongside an instinct to ‘follow the rules’, and did not want to put pressure on the health system.

The most common reasons cited for not accessing services (42.9%) were that alert level restrictions meant they weren’t allowed (Table 1) – the people who cited this reason were more likely to be of working age and disabled. Those who decided their reasons for accessing care in the context of lockdown were not urgent enough (38.9%) were more likely to be younger (15–24 years), be not disabled and live in areas of least deprivation. This response may reflect how access to non-urgent health care is generally easier for these groups.

A quarter of respondents (24.5%) who didn’t access health care did not want to make health care providers too busy – they were more likely to be younger, Māori and/or living in the South Island. Nearly a quarter (23.7%) avoided health care because they were worried about catching COVID-19 – these respondents were more likely to be younger, Māori, Pacific peoples or Asian, disabled, live in the regions of the Auckland metro district health boards (DHBs) and live in areas of greater deprivation.

Table 1: Reasons why people did not seek care health care as they usually would have during the alert level 3 and 4 lockdowns 2020, by ethnic group, age, disability status and socioeconomic deprivation profile

	Alert level restrictions meant I wasn't allowed		It wasn't urgent enough		I didn't want to make the health care providers too busy		I was worried about catching COVID-19	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Māori	831	42 (40–44)	792	40 (38–42)	555	28 (26–30)	549	28 (26–30)
Pacific peoples	219	44 (40–49)	196	40 (35–44)	84	17 (14–21)	212	43 (39–47)
Asian	116	39 (33–44)	125	42 (36–47)	64	21 (17–26)	138	46 (41–52)
European/other	2,451	44 (43–45)	2,160	39 (38–40)	1,374	25 (24–26)	1,047	19 (18–20)
15–24 years	80	40 (33–47)	104	52 (45–59)	81	40 (34–47)	59	29 (23–36)
25–64 years	2361	45 (44–47)	2,004	38 (37–40)	1,385	27 (25–28)	1,302	25 (24–26)
65 years and over	1,195	40 (39–42)	1,178	40 (38–42)	619	21 (20–22)	592	20 (19–22)
Disabled	858	48 (46–50)	568	32 (30–34)	465	26 (24–28)	525	29 (27–32)
Not disabled	2,488	43 (41–44)	2,435	42 (40–43)	1,470	25 (24–26)	1,244	21 (20–22)
Most deprived (quintile 5)	647	44 (41–47)	519	35 (33–38)	330	22 (20–25)	423	29 (26–31)
Least deprived (quintile 1)	827	41 (39–43)	844	42 (40–44)	498	25 (23–27)	419	21 (19–23)
Metro Auckland	1,211	43 (41–45)	1,088	38 (37–40)	643	23 (21–24)	831	29 (28–31)
Rest of North Island	1,619	44 (43–46)	1,408	38 (37–40)	885	24 (23–26)	812	22 (21–24)
South Island	1,212	42 (40–43)	1,160	40 (38–42)	778	27 (25–28)	588	20 (19–22)

Source: Health Quality & Safety Commission routine data analysis.

Note: CI = confidence interval.

What people did instead

When people reported they were not able to access health care during lockdown as they usually would, they were asked what they did instead. In general, people used telehealth options, delayed their care or substituted other options.

Telehealth

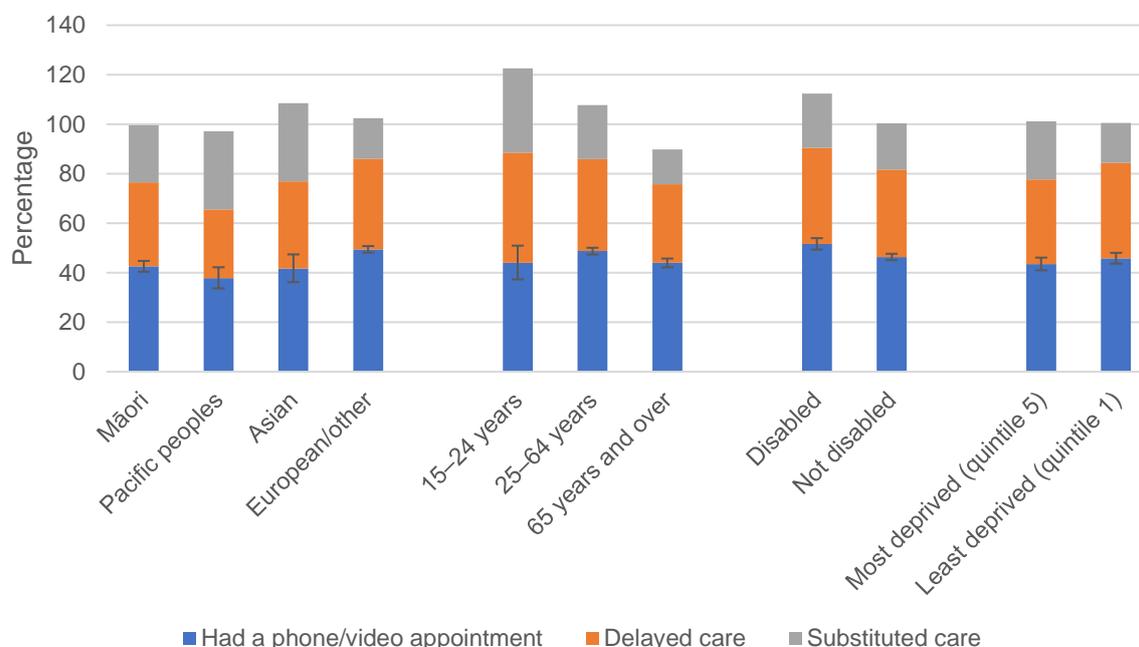
Nearly half of respondents had a phone or video appointment (46.7%) as their alternative to accessing care in the usual way. People using telehealth options were more likely to be of working age and be disabled (Figure 17). Māori, Pacific peoples and people of Asian ethnicity were less likely than those of European/other ethnicity to have used telehealth options.

Delay and substitution

One-third of people (35.4%) who were not able to access health care during lockdown as they usually would delayed their care. That is, they waited longer to seek care than usual, or rescheduled or will reschedule their care.

One in five (19.6%) people who were not able to access health care during lockdown as they usually would substituted care, potentially inappropriately. That is, they got advice from friends or family, conducted a Google or internet search, or used medicine that was at home. Pacific peoples and those of Asian ethnicity were twice as likely as those of European/other ethnicity to substitute care (Figure 17).

Figure 17: Percentage of people that reported they had a phone or video appointment, or delayed or substituted health care during the alert level 3 and 4 lockdowns in 2020, instead of accessing it as they normally would have, by ethnicity, age, disability status and socioeconomic deprivation profile, Aotearoa New Zealand

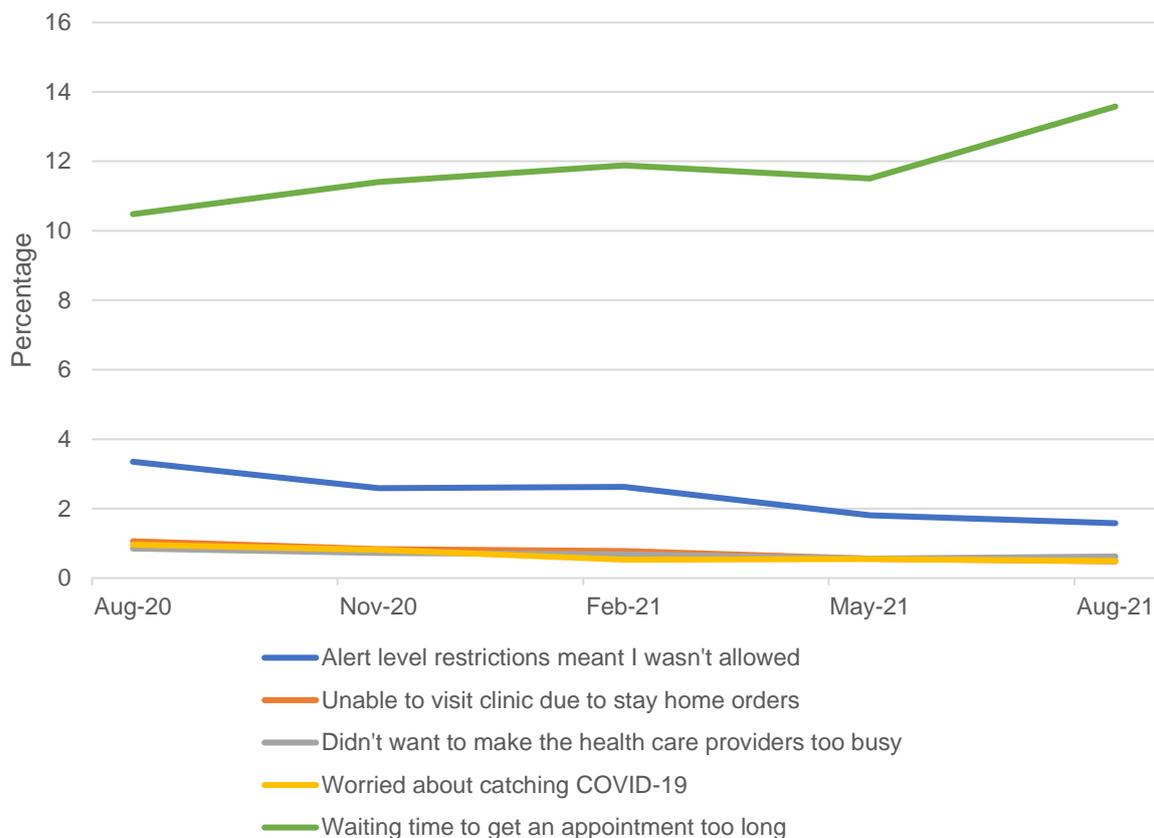


Source: Health Quality & Safety Commission routine data analysis.

Note: As respondents could give more than one answer to this multichoice question, responses do not add up to 100%.

The quarterly survey shows that, after lockdown, barriers to accessing primary care that directly related to COVID-19, such as alert level restrictions and fear of catching COVID-19, became less uncommon and have since decreased to close to zero (Figure 18). Over the same period, the differences between the Auckland metro DHBs and the rest of the country were vanishingly small. Long waiting times to get appointments, however, have grown as a barrier.

Figure 18: Percentage of people that reported reasons relating to COVID-19 to explain why they could not get health care from a GP or nurse when they wanted it in the last 12 months, over time, Aotearoa New Zealand, August 2020–August 2021



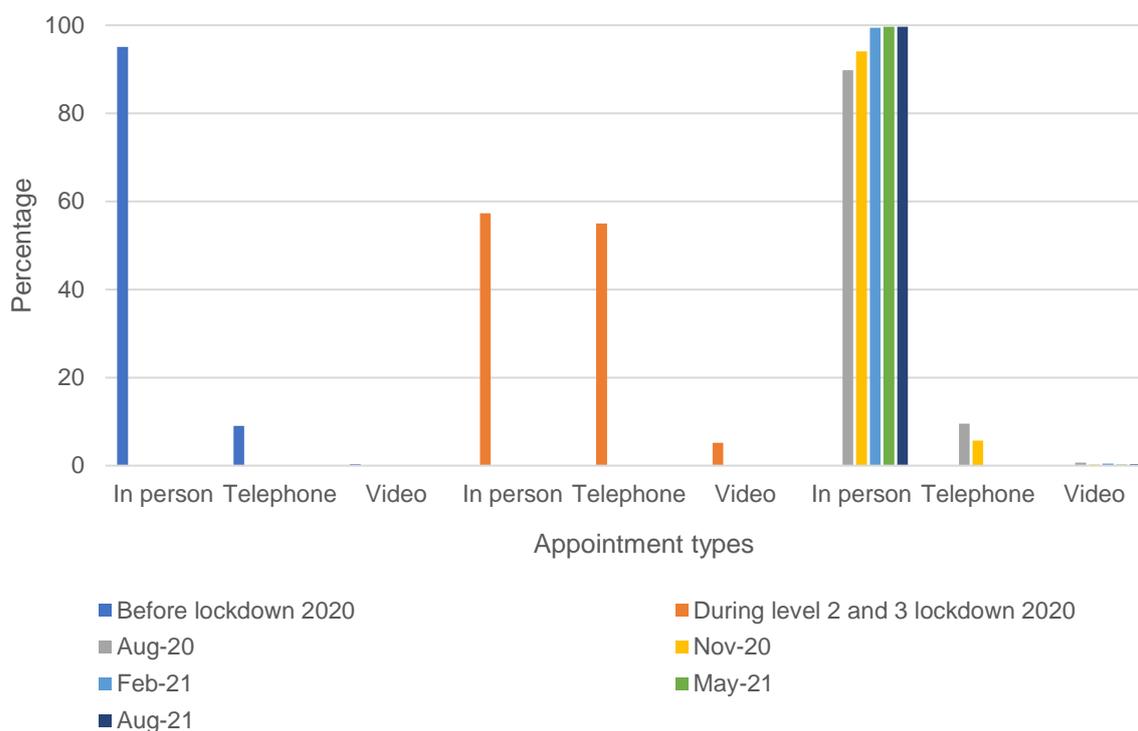
Source: Health Quality & Safety Commission routine data analysis.

The limits of telehealth as an answer

It appears that telehealth is not the answer to restrictions on face-to-face health care for all, and worked differently for different people.

Before lockdowns in early 2020, nearly all respondents (95.1%) usually visited their GP in person and only 9% usually had telephone calls (some usually used both). From early lockdown to mid-July 2020, the proportions shifted dramatically: just over half (57.3%) had an in-person visit and a similar proportion (55.0%) had a telephone call. Only 5.2% had a video call. Since then, through to the August 2021 Delta outbreak, telehealth GP appointments have all but disappeared (Figure 19).

Figure 19: Percentage of people that reported they had GP appointments in person, by telephone* or by video call, over time, Aotearoa New Zealand, 2020–August 2021



Source: Health Quality & Safety Commission routine data analysis.

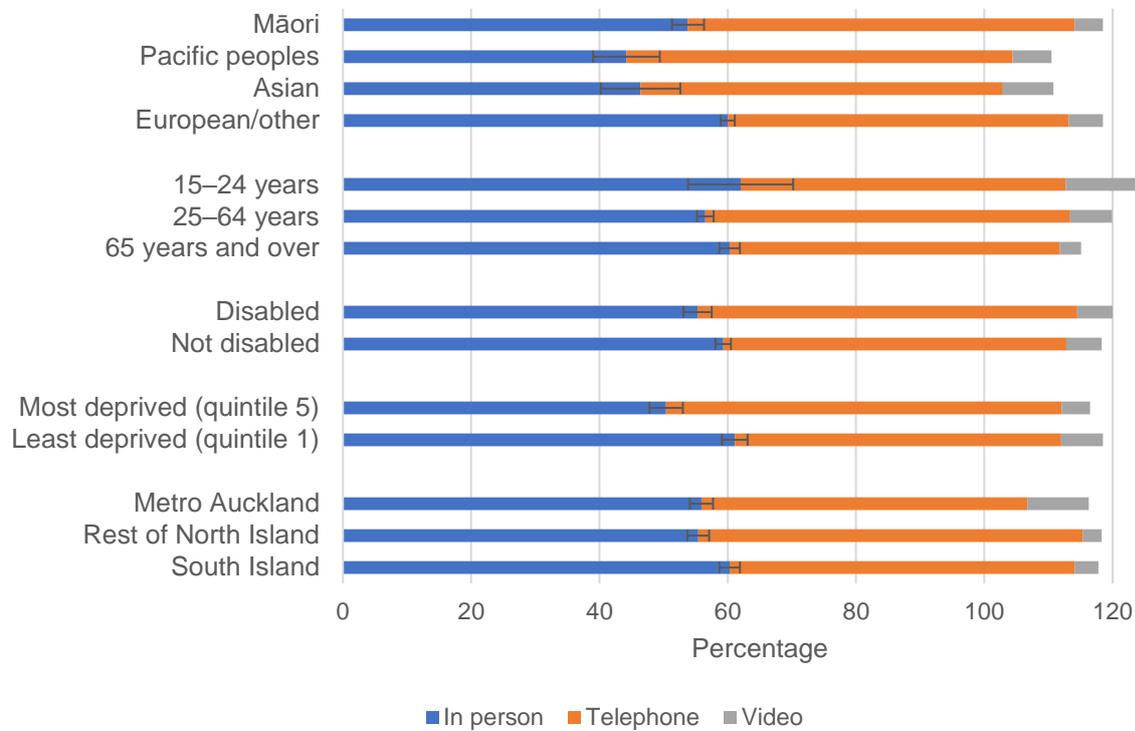
Note: For the questions on usual GP appointment prior to COVID-19 and GP appointments in level 2/3 lockdown 2020, respondents could select more than one type of appointment from multichoice options.

During the first lockdowns, those who continued to visit primary care in person were more likely to be of European/other ethnicity, not disabled, living in least deprived neighbourhoods and living in the South Island (Figure 20). Those who used the telephone to access GP care were more likely to be Māori or Pacific peoples than of European/other ethnicity, aged 25–64 years, living in the most deprived neighbourhoods and living in the North Island outside of the Auckland metro area. Those who used video were more likely to be younger and living in the area of Auckland metro DHBs.

The regular quarterly survey reveals similar findings: those more likely to have had telehealth GP appointments were not of European/other ethnicity (and were particularly likely to be Pacific peoples), and were younger, disabled, living in areas of greater deprivation and living in the region of Auckland metro DHBs.

* Due to a data collection error, the respondents included in the category for most recent telephone GP appointment is slightly different in August 2020 and November 2020 compared with later quarters. From February 2021 onwards, the telephone rate may include a small number of people who had a consultation with a mental health professional rather than a GP; we estimate this will be fewer than 10% of the telephone group for these quarters. Nevertheless, the trend is clear that telephone GP appointments decreased markedly between August 2020 and August 2021.

Figure 20: Percentage of people that reported they had GP appointments in person, by telephone or by video call during the alert level 2 and 3 lockdowns 2020, by ethnic group, age, disability status, socioeconomic deprivation profile and location, Aotearoa New Zealand



Source: Health Quality & Safety Commission routine data analysis.

Note: As this was a multichoice question responses do not add up to 100%.

How telehealth worked for those who used it

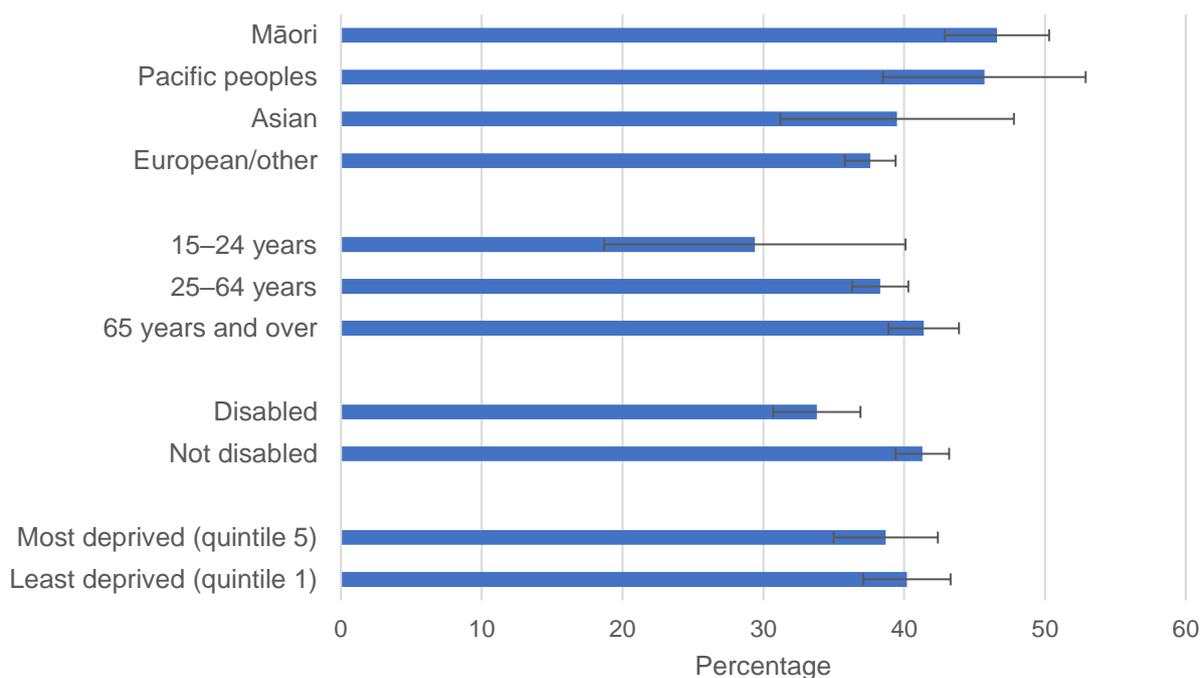
During the 2020 lockdowns, people seemed to have positive views of using telehealth to access primary care. The five aspects of care that were most popular among respondents were that:

- respondents didn't have to visit a place where others may be unwell (47.3%)
- they saved time because they didn't need to travel (38.4%)
- the appointment itself was faster (33.3%)
- they didn't have to wait as long (32.2%)
- they felt more relaxed when they were at home or in a familiar place (17.4%).

Respondents reported that telehealth options were a good way of getting quick access to care during lockdowns: 60% of respondents reported they could get a telephone (59.8%) or video (60.5%) GP appointment the same or next working day, compared with 51.5% for an in-person GP appointment.

When asked what they did not like about telehealth, 39.2% said they liked everything (Figure 21). Just over one in ten (12.3%) did not like anything about it, and these people were more likely to be disabled (14.7% vs 10.9% non-disabled).

Figure 21: Percentage of people that reported they didn't dislike anything about having a telehealth GP appointment during the alert level 2 and 3 lockdowns 2020, by ethnic group, age, disability status and socioeconomic deprivation profile, Aotearoa New Zealand



Source: Health Quality & Safety Commission routine data analysis.

Some respondents reported disadvantages about telehealth. The three aspects that people most commonly did not like about it were that they:

- could not show the GP their physical symptoms (34.4%)
- found it harder to explain themselves than in a face-to-face appointment (26.6%)
- found it harder to hear or understand the GP than in a face-to-face appointment (9.3%).

For telephone appointments in particular, people were less likely to have positive experiences in terms of being informed about and involved in care, and having enough time with the GP. A recent study broadly supports these findings; its qualitative data also reveals that some patients were ‘shocked’ at telehealth appointment costs, especially given that the charges were the same as an in-person appointment, while the service did not involve an examination or resolution of the issue.⁶¹

Building on experiences of telehealth for future resilience

What we have learned from people's experiences of telehealth is unsurprisingly complex: not all telehealth is equal – it cannot be used in the same way by everyone or accessed equally by everyone. However, telehealth is still a useful addition as an approach to delivering primary care and has particular benefits. We need to know how we can take advantage of the benefits of telehealth and offer it where appropriate. It is important to consider the diversity of communities and patients when implementing telehealth to improve access and experience.

During lockdowns, we must also make sure access to in-person appointments remains equitable for those who want or need them, as these have distinct advantages over telehealth appointments in some instances. For future resilience, we must answer the following questions.

- How can we better serve people with disabilities, considering they experienced more barriers to access and were more likely both to have had telehealth care during lockdowns but also say they did not like anything about telehealth?
- What can we do to make people's telehealth experience more positive, in terms of communication and partnership?

Chapter 3: Delay: Emergency departments | Upoko 3: Takaware: Ngā wāhi ohotata

Key points

- The response to COVID-19 in early 2020 caused dramatic falls in emergency department (ED) presentations. By June 2021 nearly 90,000 people had not attended an ED when we thought they would have, based on historical data.
- This was followed by slow returns to historically expected activity and, in some cases, periods when presentations of more acute cases increased beyond expected activity.
- European/other populations returned to expected levels of ED presentations by July 2020. The return to expected levels of ED presentations for Māori and Pacific peoples was far slower.

In this chapter, we look more closely at delay in needed care in emergency departments (EDs). We summarise international data and use the REACH tool (see Box below) to understand changes in Aotearoa New Zealand ED activity from 2020 to mid-2021.

In general, the response to COVID-19 in early 2020 caused dramatic falls in ED activity in both Aotearoa New Zealand and comparable countries. That was followed by slow returns to historically expected activity and, in some cases, periods when presentations of more acute cases increased beyond expected activity.

International comparisons

Visits to EDs in Canada and England dropped by around 50% between February and April 2020 compared with the previous year.^{62 63} In England, presentations in April 2020 were nearly half the volume of those in April 2019, rose steeply again within a few months to about 75% of the previous year, dipped again despite the northern hemisphere winter in response to the major set of restrictions introduced and then rose rapidly to near pre-pandemic levels in April–June 2021.⁶⁴ In Canada, the pattern of dramatic dip and slow recovery to near-normal ED activity was also visible, although by June 2020 Canadian EDs still had only 85% of their normal volumes of presentations.⁶²

In Australia, presentations fell by 38% between early and late March 2020 compared with those in the previous year.⁶⁵ The number of presentations then slowly increased to June 2020, when average daily presentations were 8.4% lower than in the same period in 2019.⁶⁵

A complex set of reasons have contributed to both the drop in presentations and the different levels of return, and the reasons were different in countries more severely affected by COVID-19. Contributing factors included:

- restrictions on activities that put people at greater risk for health care issues that often lead to ED presentation (including road trauma and injuries, and communicable disease) – so with reduced risk, ED presentations decreased
- changes in the way people sought health care
- changes in provision of services, including closures and restrictions to protect non-COVID-19 patients from infection, and to protect capacity to treat COVID-19 patients.⁶³

Activity in Aotearoa New Zealand EDs

In this section we use a novel tool developed by the Health Quality & Safety Commission called ‘Rapid Effects Assessment of COVID-19 on Healthcare’ (REACH – see Box) to compare ED activity in between 2020 and 2021 with expected activity based on data from three previous years.

Box: How REACH works and what it shows

The REACH tool compares expected activity in our health system based on past data with observed activity in 2020 as a way of understanding the effects of COVID-19 and associated public health measures, and the likely directions that activity is going in.⁶⁶ It is available to DHBs.

REACH provides an exploratory approach to the data and is designed to raise useful questions rather than provide explicit answers or judgements. It uses an open source forecasting tool^{67 68} applied to Aotearoa New Zealand’s national data collections for admitted and non-admitted patients in our public hospitals. The tool is written in R⁶⁹ and presented using the Shiny visualisation platform.⁷⁰

REACH was originally developed and trialled on one DHB’s data. It has since been applied to national collections: the National Minimum Dataset for admitted patients (NMDS) and the National Non-Admitted Patient Collection (NNPAC). REACH can quickly estimate, at multiple levels of detail, the expected level of activity during the lockdown period based on historical trends and patterns from three years of national data. The forecast is compared with actual activity to calculate the patterns of difference resulting from the pandemic.

Expected levels of activity in our public hospitals are calculated by applying the forecasting model to historical activity data from 1 January 2017 to 29 February 2020. This approach identifies both seasonal effects (such as seasons, day of the week and public holidays) and underlying trends, and applies to both estimated and expected activity, all else being equal.

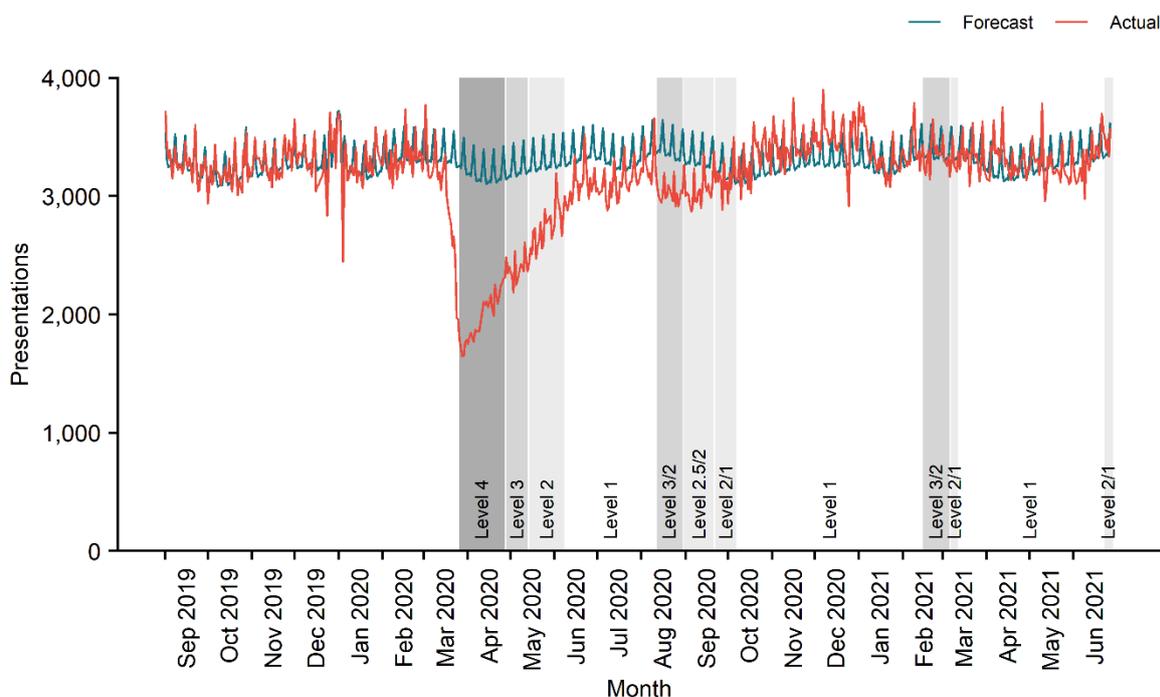
Because REACH works at granular levels, it is possible to use it to calculate activity levels by DHB, age group, sex, ethnicity, specialty, admission type or diagnosis-related group (DRG), or any combination of these.

REACH has a number of features to allow users to quickly explore data, as the figures in this chapter demonstrate. Activity in different parts of our hospitals is presented, by day, in two lines: the green line is expected activity based on a forecast from historical data, and the red line is the observed activity for 2020 and the first half of 2021, showing quickly how 2020 activity was affected by COVID-19 and associated public health measures, including lockdowns of different alert levels in different areas.

What happened to Aotearoa New Zealand ED admissions over the course of the pandemic? We saw, at least at first, similar patterns to those internationally: large drop-offs in emergency presentations with a slow return to historically expected activity over 2020.

Figure 22 shows that presentations to Aotearoa New Zealand EDs dropped dramatically at the start of level 4 in March–April 2020 and began a steady return to expected numbers as we went down alert levels. ED presentations stayed below forecast numbers until October 2020. Increased demand then followed in summer but presentations were back to forecast levels from about February 2021.

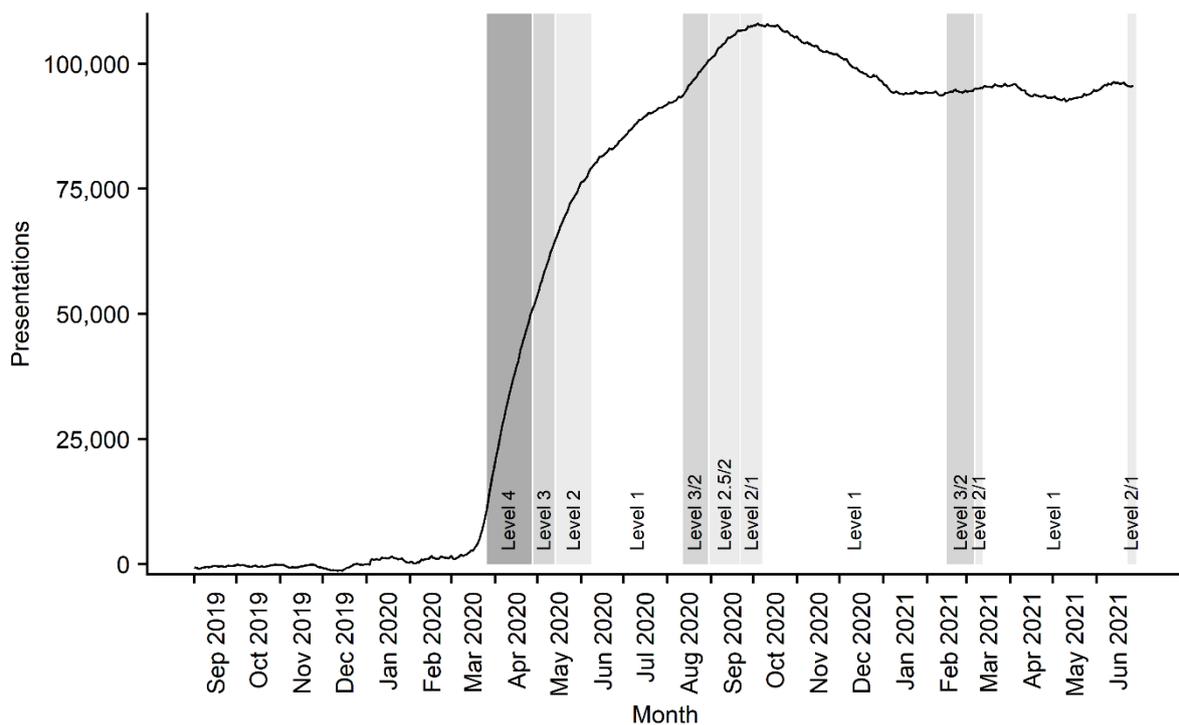
Figure 22: Actual and forecast emergency department presentations, Aotearoa New Zealand, September 2019–June 2021



Source: Health Quality & Safety Commission routine data analysis.

From these trends since the start of the pandemic, it is evident that by June 2021 nearly 90,000 people had not attended an ED when we thought they would have based on the data from the three previous years. Figure 23 shows how this shortfall in presentations grew larger over time. This cumulative effect is calculated as expected activity minus observed activity, so a positive number indicates lower than expected activity, or a 'shortfall'. A rising line shows more patients were not seen in an ED in comparison with numbers of patients in the three previous years.

Figure 23: Cumulative shortfall in emergency department presentations, Aotearoa New Zealand, September 2019–June 2021



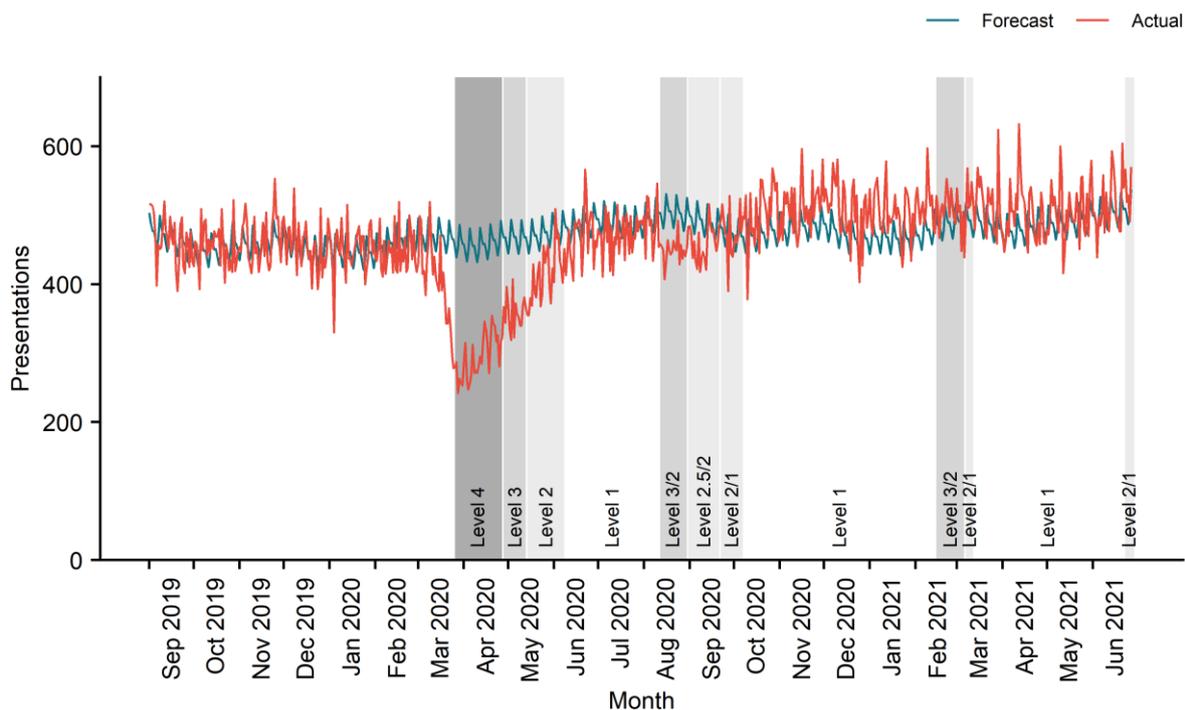
Source: Health Quality & Safety Commission routine data analysis.

The REACH tool allows services and users to undertake more granular levels of analysis. For example, in Figure 24 we examine only the most time-critical presentations to EDs: triage levels 1 and 2 on the Australasian Triage Scale, which ranges from 1 to 5. Triage levels 1 and 2 cover illness or injury that is ‘immediately life-threatening’ (triage 1) or ‘imminently life-threatening, or important time-critical’ (triage 2). Triage 1 requires immediate simultaneous triage and treatment, while triage 2 requires a maximum of 10 minutes’ triage time before treatment.⁷¹

In October 2020, when Aotearoa New Zealand went to our second alert level 1, the number of patients classified as triage level 1 or 2 (life-threatening or imminently so) at EDs began to rise above expected levels. Since then, numbers have broadly remained above expected levels, supporting media reports in early 2021 of higher than usual demand for ED services.^{72 73 74}

This rise above expected numbers of patients with immediately or imminently life-threatening conditions may represent deterioration in control of chronic non-communicable disease over our lockdown periods. It is possible that at least some of this reduced control may have occurred because people have faced more barriers to primary care, leading to more severe acute events and the resulting strain on ED capacity. To remain resilient, emergency medicine services may need to factor in these findings to be able to meet this demand in addition to the demand on services due to COVID-19 directly in the months and years to come.

Figure 24: Actual and forecast emergency department presentations, triage 1 and 2, Aotearoa New Zealand, September 2019–June 2021



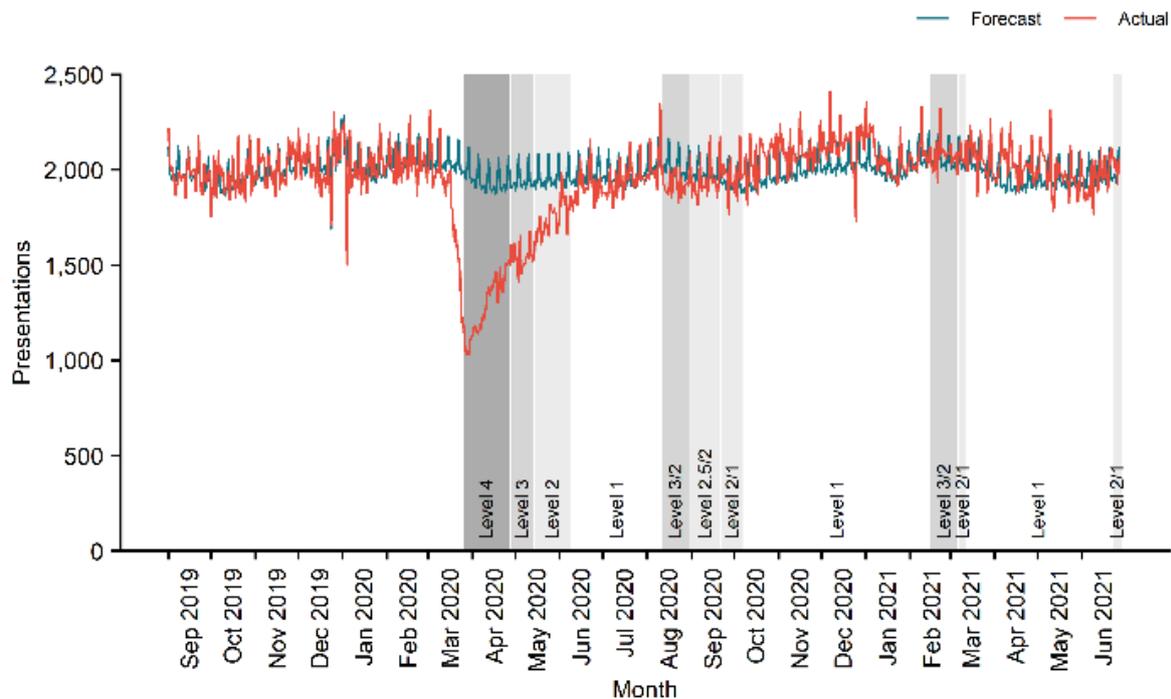
Source: Health Quality & Safety Commission routine data analysis.

It is important to note that triage levels represent a scale of urgency for a patient to be seen, not a scale of severity of illness. Some triage level 2 presentations (such as chest pain that diagnostics reveal is not time-sensitive acute coronary syndrome, or dislocated joints that need addressing urgently due to pain) may not result in an admission. Conversely, many triage level 3 or 4 patients have complex medical problems and serious acute illness so they are admitted to hospital.

Did lockdowns affect attendances at EDs in the same way for all ethnicities? We note that in the data below, the expected number of attendances at ED is based on data from previous years so reflects the previous norm rather than an equitable level of use of ED. In other words, existing inequity is part of these predicted trends.

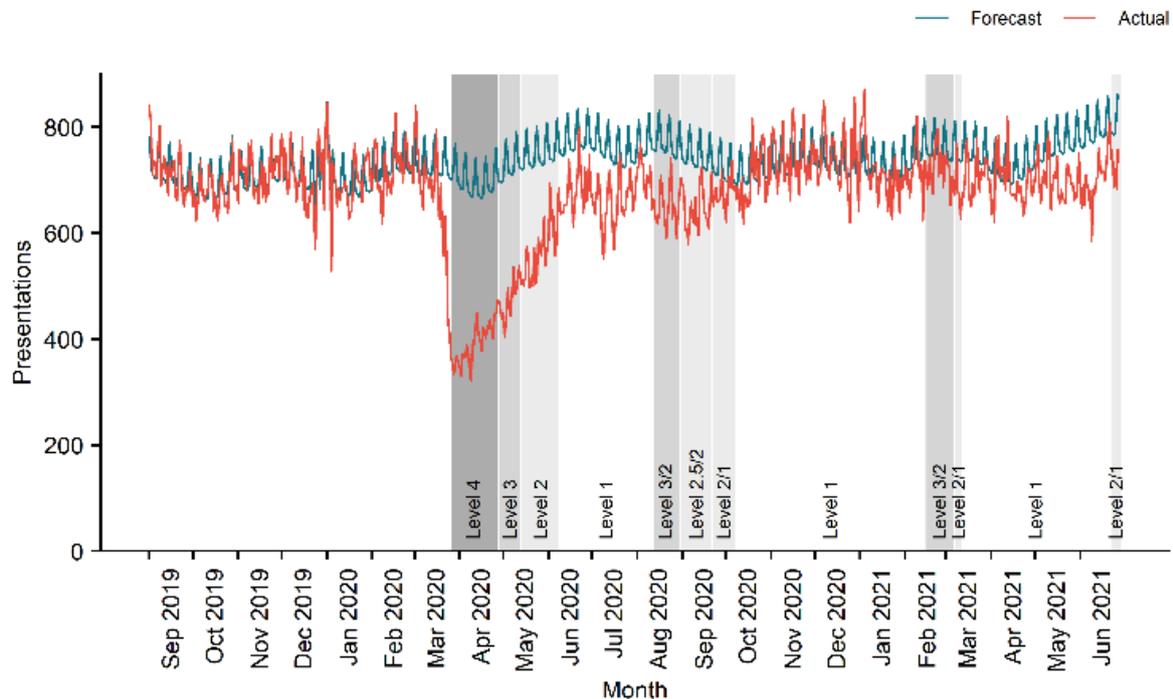
European/other populations returned to normal or slightly increased ED activity levels quickly (by July 2020) (Figure 25). One-third (approximately 8,000 of 27,000) of the cumulative shortfall were aged under 16 years.

Figure 25: Actual and forecast emergency department presentations, European/others, Aotearoa New Zealand, September 2019–June 2021



However, in contrast, the return to expected levels for Māori was far slower (finally back to expected levels in November–December 2020, then falling below expected again) (Figure 26). There was a cumulative shortfall of 40,000 Māori presenting to ED after March 2020.

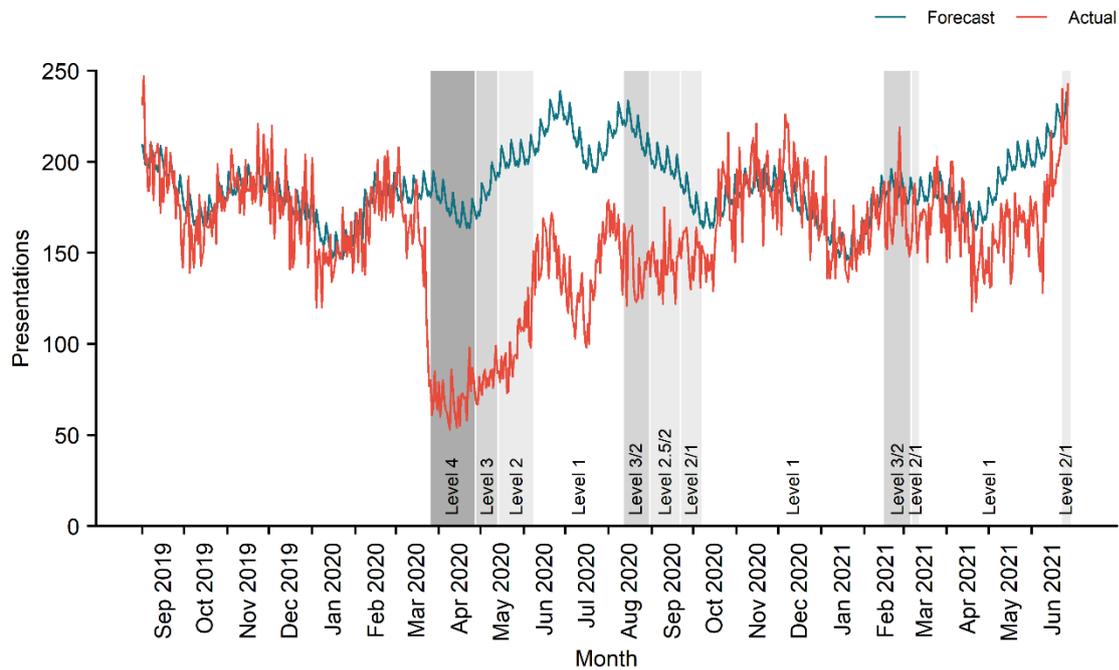
Figure 26: Actual and forecast emergency department presentations, Māori, Aotearoa New Zealand, September 2019–June 2021



Source: Health Safety & Quality Commission routine data analysis.

The group contributing the greatest number (nearly half) of those missing Māori ED presentations were Māori children under 16 years, who did not present to EDs in the numbers expected for most of 2020 and in early winter 2021 (Figure 27). At least part of the reason for these low numbers of paediatric presentations is that the first lockdown reduced levels of respiratory disease in children at that time. However, as we learned in winter 2021, seemingly positive situations can have complex effects: the immunity lost through decreased exposure to respiratory disease in the early period of lockdown 2020 led to an increase in presentations for respiratory disease, including for respiratory syncytial virus, in winter 2021, as infection made its way back into Aotearoa New Zealand via the travel bubble.⁵¹

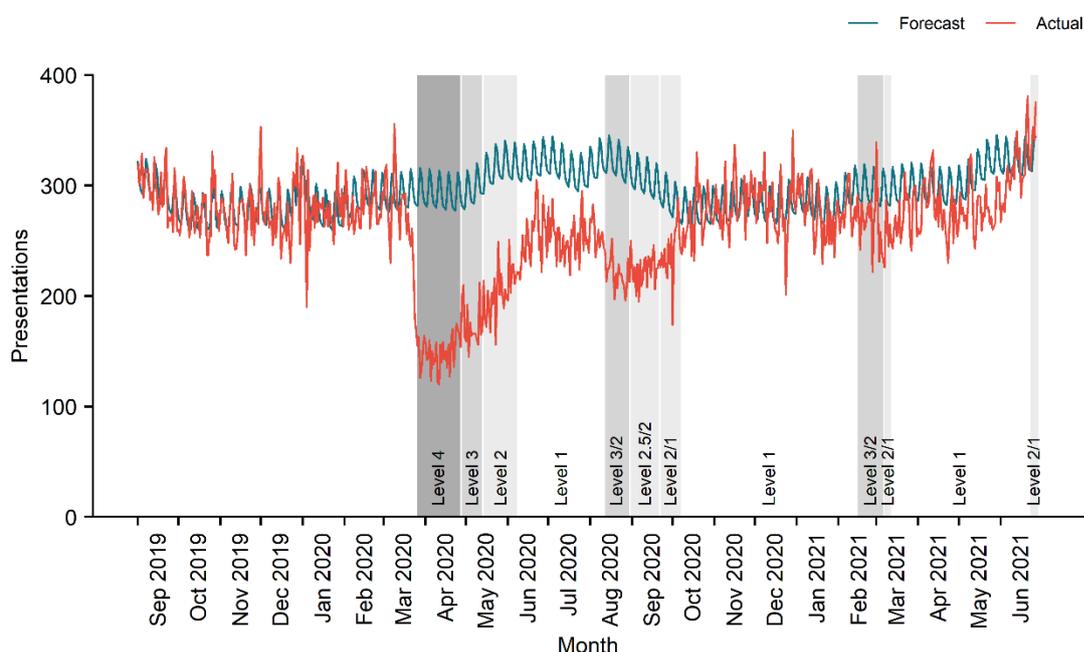
Figure 27: Actual and forecast emergency department presentations, Māori aged 0–15 years, Aotearoa New Zealand, September 2019–June 2021



Source: Health Quality & Safety Commission routine data analysis.

Similarly, Pacific peoples did not present to ED as much as expected for most of mid-2020 and again in the first half of 2021 (Figure 28). Also, like Māori children, Pacific children contributed significantly to the lower than expected numbers of presentations overall (potentially partly because of changes in behaviour but also due to reduced communicable disease, the burden of which is disproportionately borne by these populations).^{75 76 77 78}

Figure 28: Actual and forecast emergency department presentations, Pacific peoples, Aotearoa New Zealand, September 2019–June 2021



Source: Health Quality & Safety Commission routine data analysis.

Hospital admissions from ED

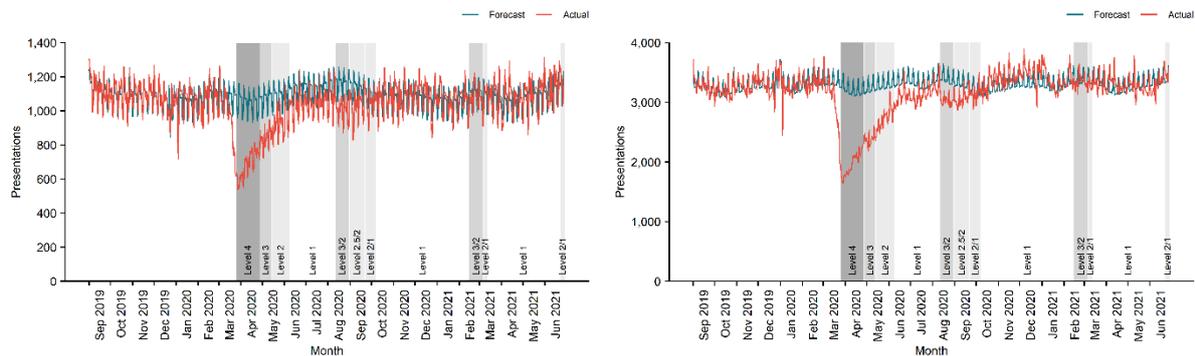
Patterns of admission from ED changed over lockdown and afterwards. This matters because any changes in patterns of admission after presentation at ED may occur for several different reasons, including changes in:

- patterns of illness or injury
- urgency of need
- patterns of care. For example, if admissions fell by a greater proportion than attendances, was it because services were protecting their capacity to deal with COVID-19 patients (who did not arrive), potentially at the expense of experience and outcomes of other patients?

On 21 March 2020 the number of ED presentations dropped by a quarter, while the number of patients admitted to hospital from ED nearly halved compared with three days earlier. A week later, at their lowest point in alert level 4, presentations and admissions had both halved.

By the time Aotearoa New Zealand reached alert level 1 in mid-2020, both presentations and admissions had returned to numbers just below what would be expected for the time of year. Both dipped again during the August 2020 outbreak before returning to around expected levels for the time of year, although numbers continued to fluctuate somewhat (Figure 29). Presentations and admissions track together reasonably closely, which may suggest clinical decision-making about admissions did not change much over these periods.

Figure 29: Actual and forecast emergency department presentations, admitted patients and all presentations, Aotearoa New Zealand, September 2019–June 2021



Source: Health Quality & Safety Commission routine data analysis.

In summary, the substantial reductions in ED presentations are similar to those seen in other comparable countries in the early periods of lockdown in March–April 2020. However, from data to date, Aotearoa New Zealand has not yet experienced the substantial disruption to activity and admissions that has occurred in other countries when the system reacts in complex ways to the combination of presentation of COVID-19 patients, seasonal effects and periods of restrictions. As we enter a period of widespread community transmission of COVID-19 in the Auckland area and the spread of COVID-19 further through the country, we should learn from other countries’ experiences and plan appropriately for the early months and the winter of 2022.

Chapter 4: Deferral: Backlogs of elective care | Upoko 4: Tautuku: Whakaputunga o te haumanu whiri

Key points

Many planned care services, or 'elective' procedures performed in hospital were cancelled, delayed and deferred because of pandemic restrictions. Two different sources of data show different views on this backlog.

- DHB annual plan data suggests that, after a dip in the April–June 2020 quarter, DHBs over-delivered elective care compared with their plans.
- However, using different techniques to exclude minor procedures such as skin lesion removal, we find significant backlogs in the top eight surgical specialties by usual volume – 16,000 fewer waiting list and arranged admissions occurred between March and June in 2020 compared with what would be expected based on three years' prior data.

In this chapter, we look closely at deferral of scheduled care by focusing on cancelled, delayed and deferred elective procedures between 2020 and 2021. In particular, to understand what has happened in our system, we examine two different views of our elective backlog that present very different results.

Planned care services, or 'electives', include both medical and surgical care in hospital for people who don't need to be treated right away.⁷⁹ Because of pandemic restrictions, many elective procedures were cancelled or deferred, creating a backlog of needed care. But how big was this backlog? What were the effects on elective care in Aotearoa New Zealand? Have we managed to substantially reduce the backlog of care created by pandemic restrictions and, if so, did we do this equitably?

International comparisons

In Australia, non-urgent elective surgical procedures in public hospitals were suspended from 26 March 2020 and then a staged re-introduction of elective surgery began on 27 April 2020.⁸⁰ In the first month from 27 April, weekly elective surgery fell to a third of normal activity, returning to near normal in late June. Together these trends led to a 9.2% reduction in elective surgical procedures between 2018–19 and 2019–20. Urgent surgical procedures, however, rose by 3.5% in the same period.⁸¹

In England, between January 2020 and July 2021, 6 million fewer people completed elective care pathways than would have been expected based on pre-pandemic data.⁸² The number of people completing elective treatment dropped from 16 million in 2019 to 12 million in 2020 alone. The trauma and orthopaedics specialty

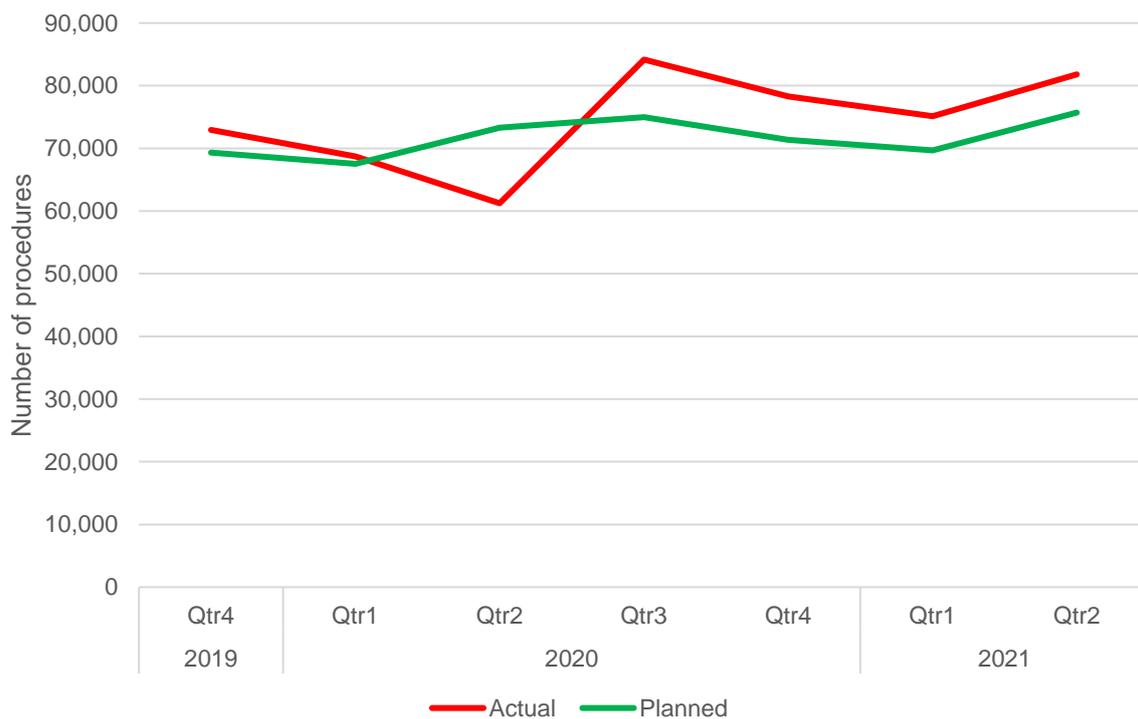
experienced the largest reduction in completed treatment pathways in 2020 compared with 2019 – only a quarter of normal activity occurred in May 2020.⁸² Furthermore, this elective care backlog was not distributed equally. In more socioeconomically deprived areas, waiting lists grew longer and recovered more slowly than those in less deprived areas.⁸³

Annual plan figures show a quick recovery for planned care

In Aotearoa New Zealand, planned elective care in the public hospital system is measured on a quarterly basis. Each DHB submits a plan of its annual activity to the Ministry of Health in the previous year, and then the actual elective care activity that it achieves during the year is compared with this plan.*

Figure 30 appears to show a positive story of the effects of the pandemic and lockdowns on planned care activity nationally. That is, the number of procedures drops in quarter 2 of 2020, but is followed by a rapid recovery to the point that more procedures were being delivered (red line) than DHBs had planned (green line).

Figure 30: Planned versus actual care procedures, Aotearoa New Zealand, quarter 4, 2019–quarter 2, 2021



Source: Ministry of Health data, personal correspondence.

* Planned care consists of:

- elective and arranged admissions reported to the NMDS
- surgical purchase units, and casemix included discharges from a medical specialty with a surgical DRG
- selected minor procedures and non-surgical interventions reported to NMDS and the NN PAC.

The reduction in the red line of planned care procedures from quarter 1 to quarter 2 in 2020 equates to 12,000 procedures not done, or 16% of what was planned, nationally. This is then followed by a year of over-performance against DHB plans (when between 8% and 12% more procedures than planned were carried out).

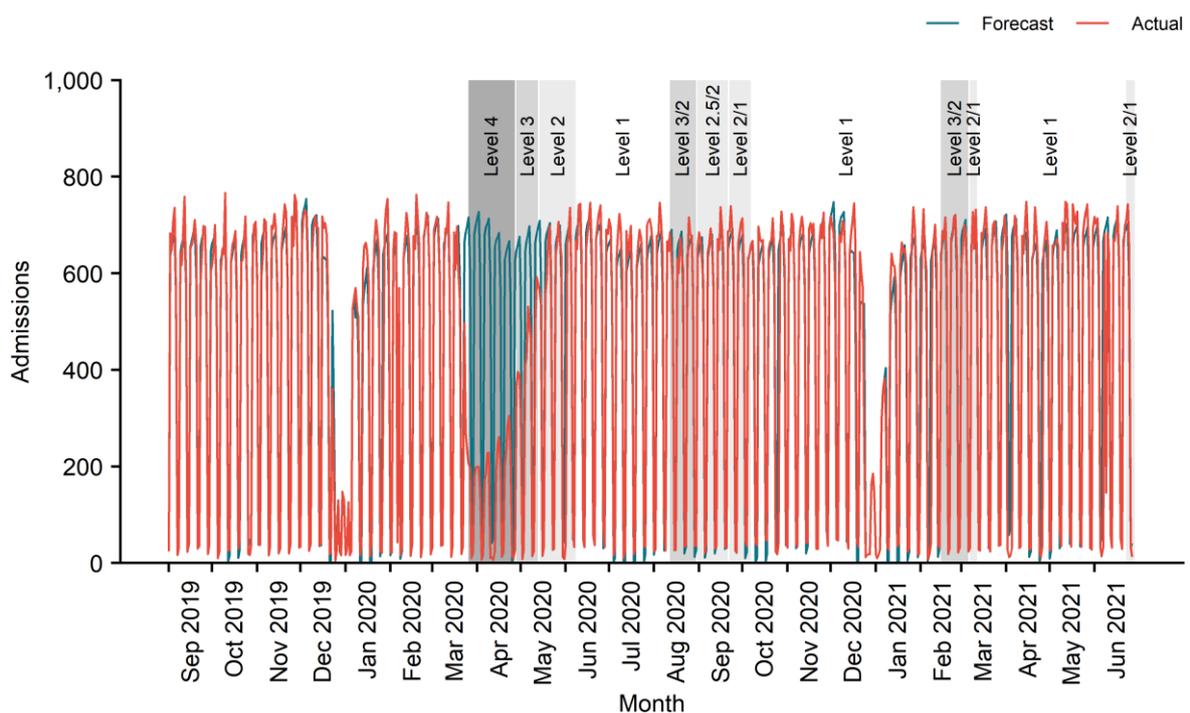
Overall, this seems to imply that in Aotearoa New Zealand COVID-19 measures had no long-lasting negative effect on delivery of elective care in that about 15,000 more planned care interventions occurred than DHB plans projected.

A different view shows a significant backlog

However, using the REACH tool (as described in Chapter 3), which compares daily activity across our hospitals with what we would expect based on the three previous years of activity, we get a different result.

Limiting our analysis with REACH to the top eight surgical specialties by usual volume* as derived from the NMDS, we find 16,000 **fewer** waiting list and arranged admissions occurred between March and June in 2020 compared with what would be expected based on three years' prior data.

Figure 31: Actual and forecast waitlist/arranged inpatient admissions, top eight surgical specialties, Aotearoa New Zealand, September 2019–June 2021



Source: Health Quality & Safety Commission routine data analysis.

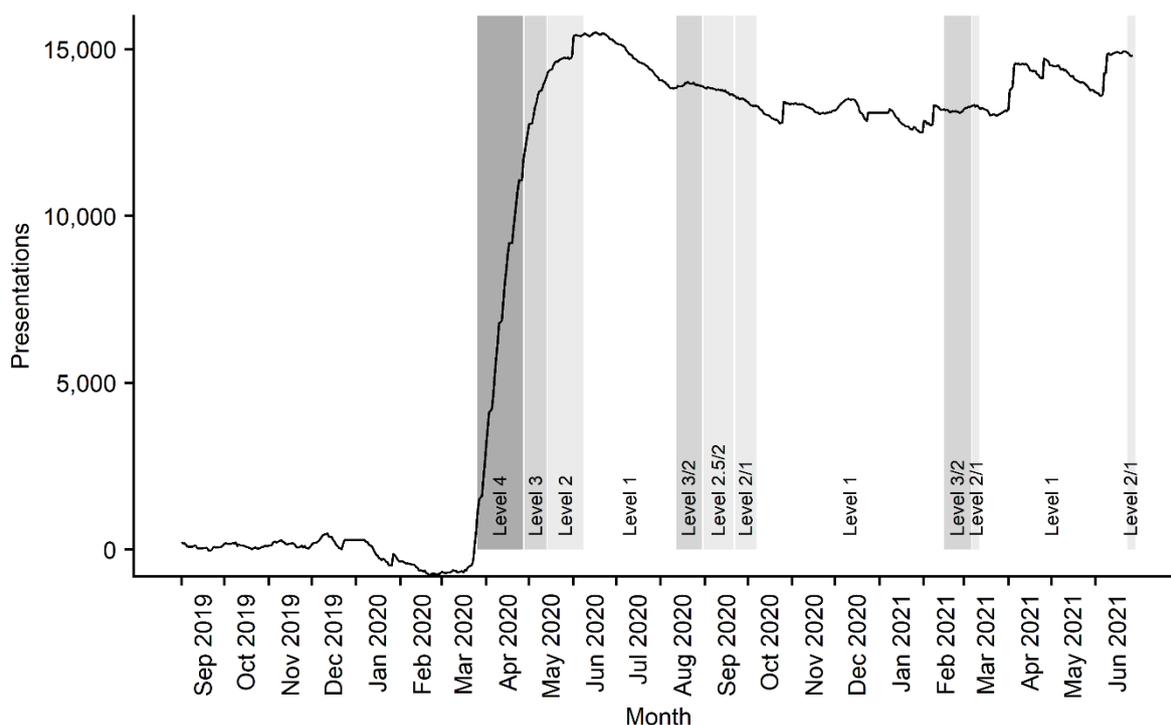
* These high-volume elective surgery specialties are: general surgery, orthopaedics, urology, neurosurgery, ear, nose and throat surgery, gynaecology, specialist paediatric surgery (other) and dental surgery.

From July 2020, we see a modest increase of about 3,000 admissions compared with historical data.

We can see this in Figure 32, which shows the same data as Figure 31 but presents it as cumulative shortfalls in activity compared with normal activity – that is, it identifies the amount of normal work that was not done. A curve rising from zero means a backlog of procedures has been created that is increasing. If the curve begins to fall, services are starting to reduce the backlog. A reasonably straight line about zero (as we can see from October 2019 to February 2020) means work is continuing as usual.

Figure 32 shows a shortfall in activity beginning with the March lockdown, which reaches a total of about 17,000 procedures by June 2020. The falling curve shows the shortfall slowly reduced by the end of 2020 to about 14,000 admissions that did not happen as expected. Further progress in reducing the backlog has stalled since the start of 2021.

Figure 32: Cumulative shortfall in waitlist/arranged inpatient admissions, top eight surgical specialties, Aotearoa New Zealand, September 2019–June 2021



Source: Health Quality & Safety Commission routine data analysis.

How do we understand this result in light of the official figures showing an over-performance of 15,000 procedures compared with DHBs’ annual plans in the same period, and a continuing over-performance against plan in 2021 (Figure 30)?

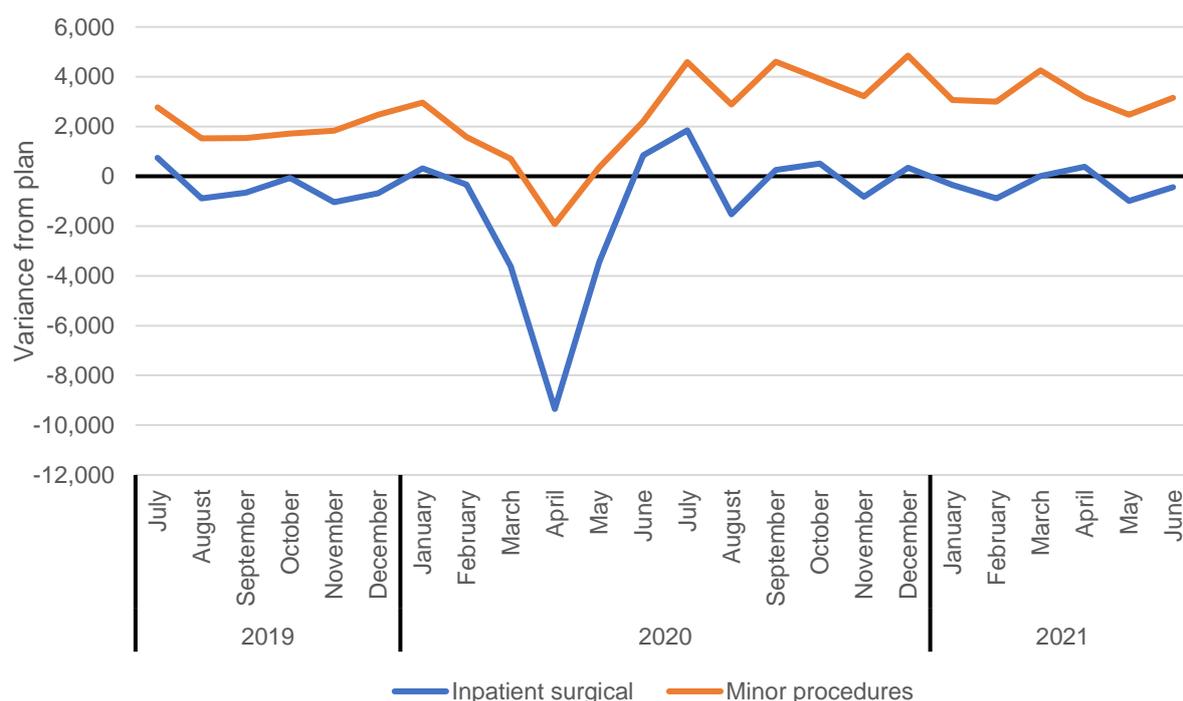
Reasons for the difference between the two views

Part of the reason for the difference between the two views is that planned care activity includes minor procedures as well as surgical admissions. REACH does not include minor procedures and non-surgical interventions. So, in the planned care data we see more activity than in REACH (about 75,000 procedures each quarter versus 40,000).

Figure 33 shows the pattern of activity for minor procedures was very different from the pattern for the more major hospital admissions following the initial period of lockdown. The graph shows that, prior to COVID-19, minor procedures were already out-performing plan. This divergence has increased since the end of the initial lockdown period (from about July 2020).

Figure 33 shows monthly differences (variances) from planned delivery of inpatient surgeries (blue line) and minor procedures (orange line). The black line shows the nationally planned level of procedures. Variance above the black line means over-delivery; variance below it means under-delivery.

Figure 33: Monthly national variance from plan – planned care interventions by type, Aotearoa New Zealand, July 2019–June 2021



Source: Ministry of Health data, personal correspondence.

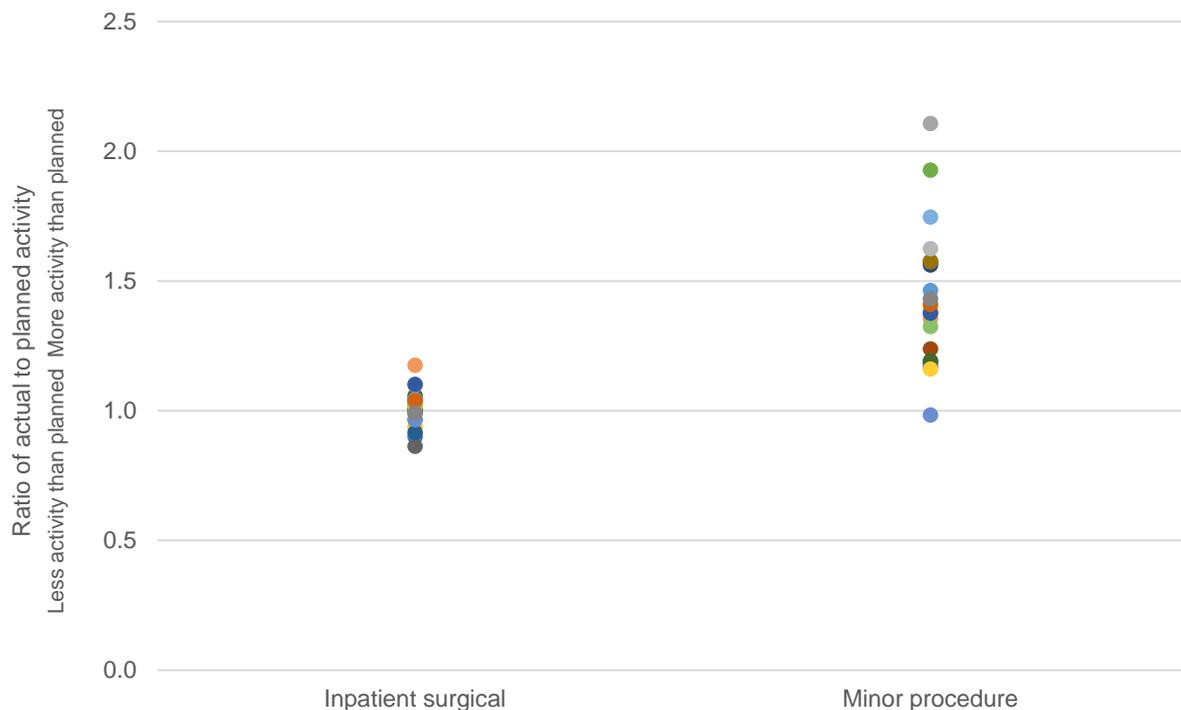
This pattern was seen to a greater or lesser degree everywhere around the country.

Figure 34 shows how each individual DHB delivered inpatient surgical care and minor procedures from June 2020 to July 2021, as compared with DHBs' plans (each dot is a DHB). Where dots are clustered around a ratio of 1, this means the

DHB is delivering according to plan. Where dots are above 1, this means DHBs are over-delivering – as all DHBs did for minor procedures in this period.

In comparison with baseline, all DHBs did a higher amount of minor procedure work than inpatient surgical work. There appears to be no relationship between relative performance against plan for inpatient surgical and minor procedure work.

Figure 34: Ratio of actual activity against plan, inpatient surgical procedures and minor procedures, by DHB, Aotearoa New Zealand, 2020/21



Source: Ministry of Health, personal correspondence.

We need a better understanding of this difference between minor procedures and surgical admissions. Does this shift to over-delivery of minor procedures mean that services are:

- treating a different cohort of patients (so that cases requiring an inpatient admission miss out) – that is, less impact on minor procedures
- innovating in the face of adversity and treating the same patients less invasively
- reclassifying cases?

Expert commentary suggests it is a combination of the following factors.

- 1. Arranging and delivering planned care in more appropriate settings.**
Services are working to shift procedures to settings that are more easily accessible to people while reducing demand on hospital services. These ongoing efforts influence this data. For example, some smaller procedures have been moved from the theatre to procedure rooms and so are recorded in different databases. Some procedures have been moved where appropriate from outpatient to community/primary settings as well.
- 2. Less impact on minor procedures.** Minor procedures are in general less resource-intensive and so COVID-19 restrictions and lockdowns were less disruptive to them than inpatient procedures. DHBs were able to keep doing these minor procedures when more major surgical work was cancelled, delayed or deferred.
- 3. Coding.** As a result of coding changes in 2019/20, some procedures previously classified as inpatient surgery were more accurately coded and included in the database of minor procedures.

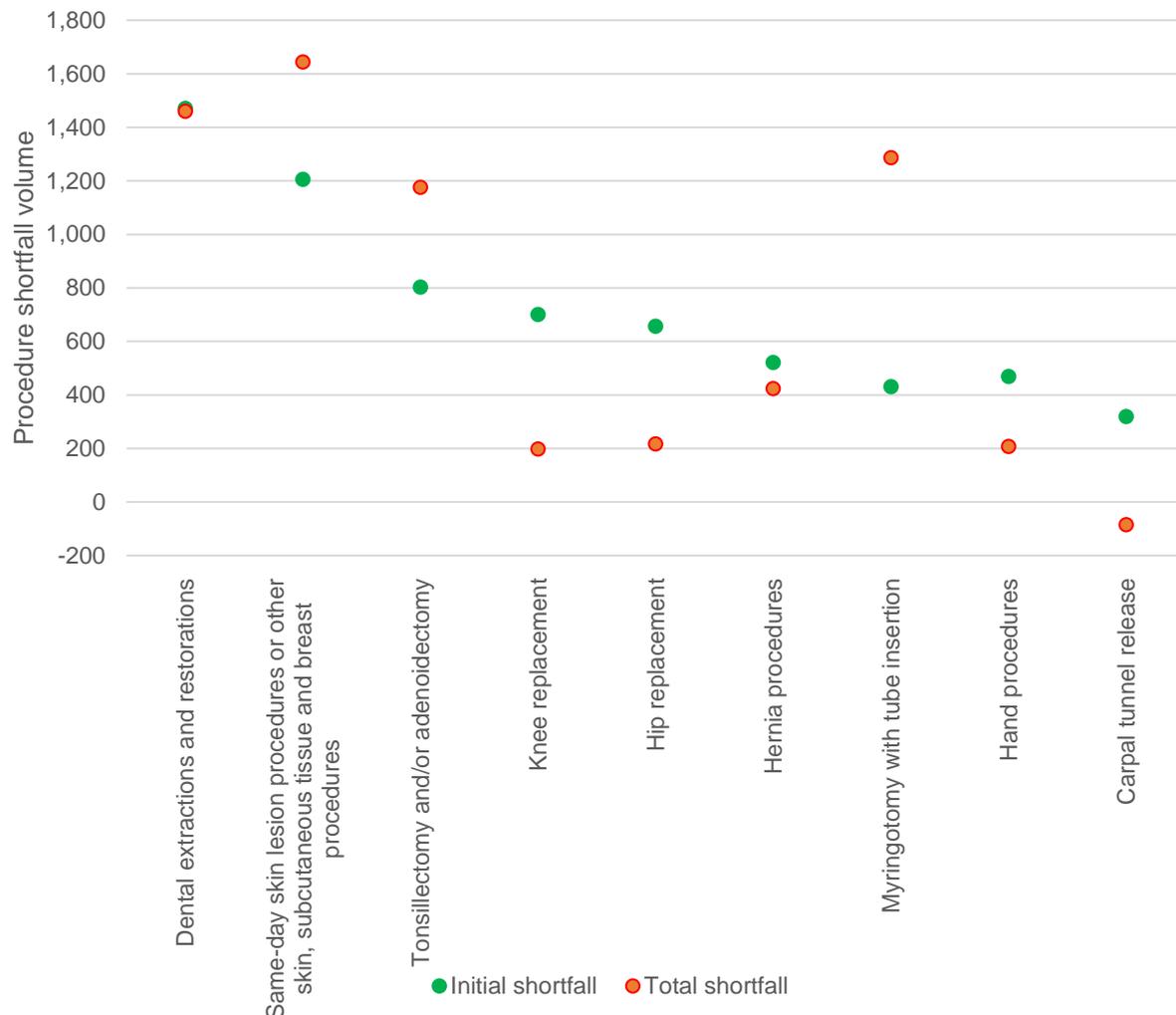
Success in reducing backlog differed between types of high-volume surgeries

Breaking down changes over time for several high-volume surgeries that had large shortfalls at first, we can see which specialties have been reducing the backlogs of elective care created by deferred work over lockdowns.

Figure 35 shows cumulative shortfalls in expected activity by several common surgical procedures in our system. For each kind of surgical procedure, the green dot shows how much it fell short of the number of procedures that would have been expected at 30 June 2020. The orange dot shows the shortfall a year later, that is by 30 June 2021. In an ideal world, the orange dot would have gone to zero, meaning all shortfall was eliminated – all backlog cleared.

As we can see, June 2021 backlogs are only smaller than June 2020 backlogs in orthopaedic procedures (knee and hip replacement and hand and carpal tunnel procedures), while those with increasing backlogs appear to be in more minor procedures, especially in ear, nose and throat (ENT), where total shortfalls increased after June 2020. The data indicates only orthopaedics is making progress. Yet, although other surgical procedures apparently are not, some of these procedures are precisely those that can be undertaken in less intensive settings, so the actual backlog is much smaller than it appears.

Figure 35: Initial and total shortfalls in selected high-volume procedures, Aotearoa New Zealand, to 30 June 2020 and to 30 June 2021



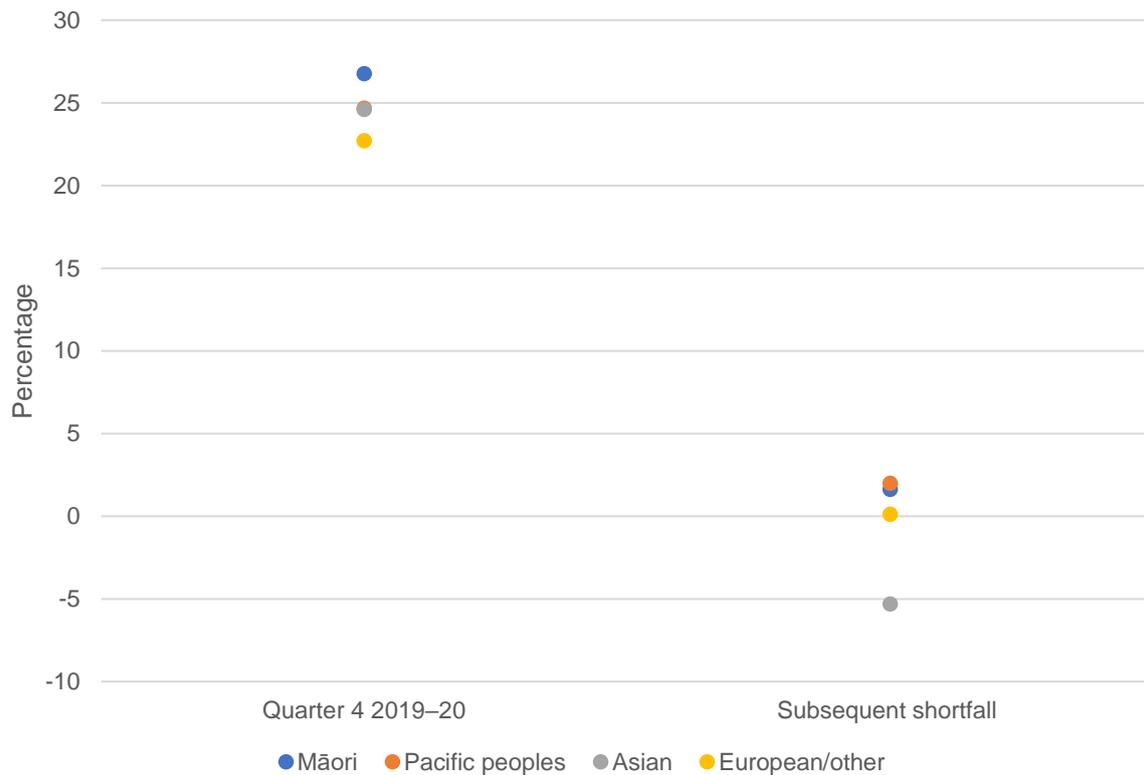
Source: NMDS.

Equity – the most affected groups

From an equity perspective, the obvious concern about the data reported in this chapter is that ‘bounce back’, recovery and efforts to reduce the backlog of elective care have entrenched inequity. That is, this response has delivered care only to those most advantaged by an inequitable system.

If we compare shortfalls in delivery of elective care by ethnicity at June 2020 with latest available data in Figure 36, we can see that shortfalls have decreased for all ethnicities. Yet Māori and Pacific peoples are still not receiving as much elective care as they were before the pandemic, however inequitable that amount may have been. That is, there is no evidence that recovery from COVID-19 prioritised or favoured those who already face the greatest inequities in access to health care.

Figure 36: Cumulative shortfalls in delivery of elective care, selected high-volume procedures, by ethnicity, Aotearoa New Zealand, June 2020



Source: NMDS.

In summary, immediately before the COVID-19 Delta variant outbreak, our system of elective care was adapting but the pattern was complex: in some areas it was recovering; in others the problem appeared to be growing. The picture is muddled by changes in settings for different procedures for a variety of reasons. Some changes occurred because of COVID-19, some were part of a long-term strategy and some simply involved changes in the codes attached to different kinds of surgery.

However, it seems at least possible that over-delivery of minor procedures hides the challenges that some if not all DHBs have experienced in delivering their expected numbers of more complex inpatient surgical procedures during COVID-affected periods. It also seems clear that whatever is happening, inequities in access have not improved in the last 18 months.

Community voice: Di Larkin – ‘Nothing seems to happen’ | Te reo o te hapori: Di Larkin – 'Te āhua nei kāore he aha kua pahure'

If I could describe my experience in one word it would be ‘shambolic’. In the system, nobody talks to each other. That’s the problem. I’ve got quite a few different things wrong with me and one person doesn’t consult the other.

Going back and forth

I have metastatic melanoma with tumours in my pelvis. I’ve been on Keytruda (pembrolizumab) for two years. In 2018 I had a washout on the Gold Coast for an infection in my knee replacement. I then was in Wellington Hospital for three weeks for a revision knee to be undertaken, which was subsequently cancelled. Then Palmerston for two weeks where I had a PICC line [peripherally inserted central catheter] for six weeks. From then on, I’ve been going back and forth and back and forth with hospitalisations in December 2019 and December 2020 with recurring infections.

I have an infectious diseases physician, an oncologist, orthopaedic surgeon and my GP. In the middle of last year, they cancelled all elective surgery due to COVID-19, so nothing was getting done. My infectious diseases physician is from New York. Halfway through my treatment, one of her family got COVID-19 so she went back to New York. I was going between orthopaedics and infectious diseases, and of course nothing happened because she went away, then had to go into isolation. This happened twice over the course of the year.

I would go to orthopaedics, and nothing got sorted out. I had a severe lymphedema in that leg, so I could not have the revision and could not have surgery. So I was now resigned to letting it break down and ending up in a wheelchair. I didn’t have any option. I had a bone scan in 2021, which showed I still had the infection from 2018.

In the meantime, at the beginning of June this year [2021], I got a sore at the back of my infected right knee, which is the one that needs the revision. I’m not sure what you’d call it, coming out about the size of a golf ball. I was concerned and happened to be going to oncology. It was the end of the orthopaedics clinic so I thought I’d call in. He told me it wasn’t his job and I’d have to go to the GP and get admitted to another doctor. Nothing was done there, so I went to the GP and he rang up Palmerston North hospital. Nobody wanted to know me in medical or surgical. He had me on speaker so I could hear it. They were quite adamant, both registrars. I went privately to a woman who took a biopsy. It came back okay – no cancer. I ended up going back to the GP. The district nurse came for a couple of weeks and was bandaging my knee every day, and then my husband took over. In the meantime my GP had sent a letter to the vascular surgeon to have it looked at. I had another biopsy which came back clear of cancer but no more follow-up.

I ended up with a vascular surgeon to have it looked at. I went to him under my GP and had another biopsy. They rang up and said the biopsy was all right, and there was no follow-up done. He told me he couldn't operate on the back of that either because there was no skin there basically and it was just breaking down. So that was the end of that one. I thought, 'What are we going to do now?' Unfortunately there are a lot of antibiotics that have side effects.

I had the orthopaedic surgeon have a look at it. Infectious diseases had thought it was an infection coming from the knee. The orthopaedic surgeon was speechless that nobody had done anything about it. So, now, I go to a wound clinic. And between the wound clinic and my husband, I just have it dressed all the time, and it's slowly coming down. It might have to be dressed forever as it just comes up and goes down. The wound clinic was the best of the lot, actually. The nursing staff were absolutely fantastic. They just took over. If I'd had that in June, none of that shemozzle would have happened. It was such a simple process. But nothing seems to happen. The outpatients now only have a couple of patients in the waiting room due to COVID-19. It's like the whole hospital stopped. It's been like it since the beginning of COVID-19 last year.

I have no issue with oncology. I changed hospitals from Wellington to Palmerston North this year as DHBs seem to have a communication problem; for example, CT scans were regularly done but both X-ray departments were reluctant to take me as I live outside the Manawatu zone and my oncologist was in Wellington. Really that's my story. Shambolic, going back and forth.

Learning to cope with the system

My tumours haven't grown in over a year. So I feel really good in that way. They're going to keep me off Keytruda until anything else happens. I've been off that now since 2019. My knee is breaking down. But I know that's going to happen. My husband is dressing the back of my leg and I go every three weeks to a wound clinic now. And I think I'm probably resigned to that's how it's going to be. That's the best it's been for ages. The wound clinic is in orthopaedics in Palmerston North. Very efficient. Really good. The staff are just doing the best they can with a minimum of staff. They're exasperated too. They're over-run in the wound clinic. There's not enough staff there.

They're simple issues that can be fixed quite quickly. And of course I'm using up all these people's time. That's what I get annoyed about. They say there are so many people who are waiting. I must have been dozens of times. That's something that could have been fixed. But we're all right. We're fine. We've learned to cope with the system.

Chapter 5: Delivery: Cancer care and COVID-19 – a case study in resilience | Upoko 5: Tuku ratonga: Haumanu mate pukupuku me te KOWHEORI-19 – he tiro pakaritanga

Key points

Cancer screening, diagnosis, treatment and supportive care has been substantially disrupted by the pandemic in other countries. However, data from Te Aho o Te Kahu, the Cancer Control Agency suggests there was minimised disruption in services in Aotearoa New Zealand.

- Lower numbers of new cancer registrations in April–May 2020 (40%, or approximately 1,000 fewer) in comparison with 2018 and 2019 was followed by increased registrations in 2021 (5% more compared with the 2018–19 average).
- Numbers of diagnostic procedures fell steeply in April 2020 but returned to baseline in 2020 and increased (notably including for Māori) in early to mid 2021.
- Numbers of curative prostate, colorectal and lung surgeries showed minimal effect of COVID-19-related measures, including for Māori, to September 2021.

In this chapter, we examine successful delivery of care during the pandemic response and the conditions under which it was achieved. To do so, we present a case study of the effective and resilient cancer care response that was designed to avoid interruptions to the care of people with cancer. In the light of the interruptions to screening covered in Chapter 1, and the experience of Di Larkin, a resilient cancer care response has been even more critical.

Te Aho o Te Kahu, the Cancer Control Agency, was established in December 2019 to provide leadership and oversight of all cancer-related activity in Aotearoa New Zealand.⁸⁴ Early in the pandemic, Te Aho o Te Kahu began monitoring and reporting on service access and performance to inform coordinated national and regional decision-making and minimise disruption in services.

International comparisons

In the United Kingdom in October 2020, *The Lancet Oncology* described ‘the devastating effect of the first UK lockdown... on cancer screening, diagnosis, treatment, and supportive care’.⁸⁵ Urgent referrals (median = –70.4%) and chemotherapy attendances (median = –41.5%) both declined to a lowest point in March–April 2020 and had not recovered by June 2020.⁸⁶ After restrictions eased,

numbers of referrals and treatment returned to near-normal levels but with the return of tighter restrictions later, services were paused again, making it unlikely they would be able to reduce the backlogs of missed screenings and treatment.

In Australia, service providers reported ‘substantial reductions’ in the expected numbers of procedures for cancer-related investigations and treatments in 2020, with the impacts varying by cancer type. Nationally, in 2020 diagnostic procedures fell by 8% (163,595 fewer services than expected for 14 cancer types) and surgical and non-surgical therapeutic procedures fell by 9% (14,600 fewer services than expected).⁸⁷

In Canada, screening programmes were suspended in March 2020 and began gradually reopening in June, creating a substantial backlog.⁸⁸ A ‘rapid and aggressive transformation in patient care delivery... [was] undertaken at a provincial level with some national coordination.’⁸⁹ This involved transitioning to telemedicine and reducing diagnostic work and new referrals. Impacts varied by province, territory and community – the services affected most were those where the pandemic hit hardest – and existing inequities were made worse.⁸⁸ Likewise the response varied by provincial authority.⁹⁰ Modelling reported in August 2021 suggests that disruptions to Canadian cancer care during the early phases of the pandemic could lead to 21,247 (2.0%) more cancer deaths in Canada in 2020–30, if treatment capacity in 2021 recovers to 2019 pre-pandemic levels. This represents an expected 355,172 life years lost due to pandemic-related diagnostic and treatment delays. The authors consider that reducing the service backlog could significantly cut back the resulting life loss.⁹¹

In contrast to the UK disruption, *The Lancet* editors characterised Aotearoa New Zealand’s cancer care response during the first year of the pandemic in this way: ‘in New Zealand, cancer treatment (surgery, medical oncology, radiation oncology, and haematology) continued during the COVID-19 lockdown and is still being provided at pre-COVID-19 levels.’⁸⁵

What did this response look like through 2020, especially given our knowledge of historical inequities in cancer screening, treatment and outcomes between Māori and non-Māori in Aotearoa New Zealand,^{92 93} and the likely inequitable effects of COVID-19 on cancer patients and their care?⁹⁴ How was it achieved and did the same response continue throughout 2021?

Cancer care and COVID-19 – the what and the how

What happened with cancer care delivery

In Aotearoa New Zealand’s first level 4 lockdown in April–May 2020, new cancer registrations dropped steeply (by 40%) in comparison with 2018 and 2019 (approximately 1,000 fewer). The sharp fall led to concerns that lockdown and reduced access to care had caused significant numbers of missed diagnoses.

However, in the later months of 2020, cancer registrations rose above 2018 and 2019 levels. Taken over the whole year, trends remained similar.⁹⁵ Then in 2021 cancer registrations increased by 5% compared with the 2018–19 average (Figure 37). The greatest increases in 2021 to date compared with 2018–19 are in skin (10%) and ‘other digestive’ (11%) cancers.

Figure 37: New cancer registrations, total population, Aotearoa New Zealand, 2018–19 average, 2020 and 2021

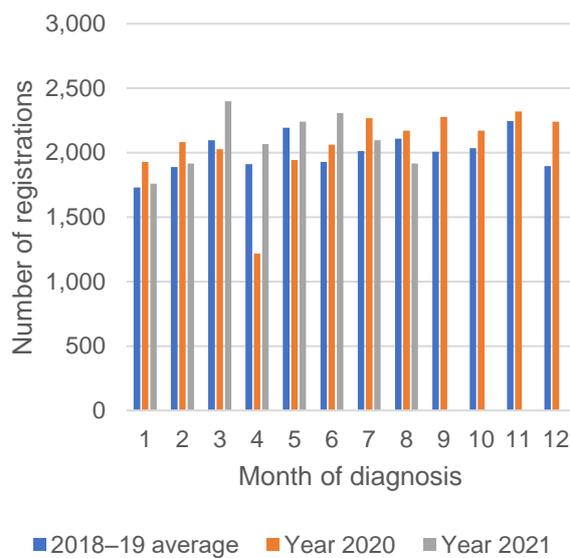
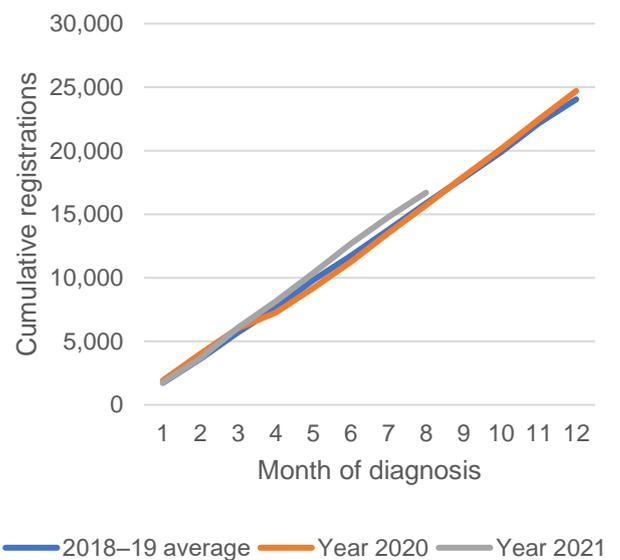


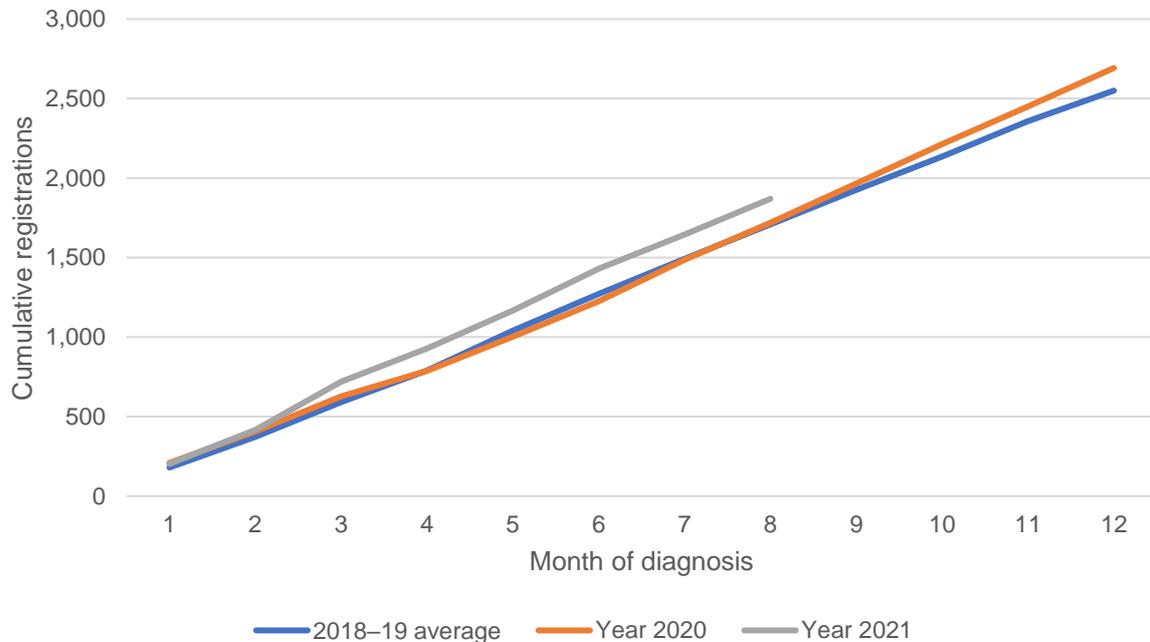
Figure 38: Cumulative new cancer registrations, total population, Aotearoa New Zealand, 2018–19 average, 2020 and 2021



Source: Te Aho o Te Kahu, the Cancer Control Agency.

Registrations in 2021 increased for all ethnicities, but most notably for people of Asian ethnicity (21% more cancer registrations than for the 2018–19 average). For Māori, cumulative new cancer registrations from January to August 2021 were 9% higher than the 2018–19 average (Figure 39).

Figure 39: Cumulative new cancer registrations, Māori, Aotearoa New Zealand, 2018–19 average, 2020 and 2021

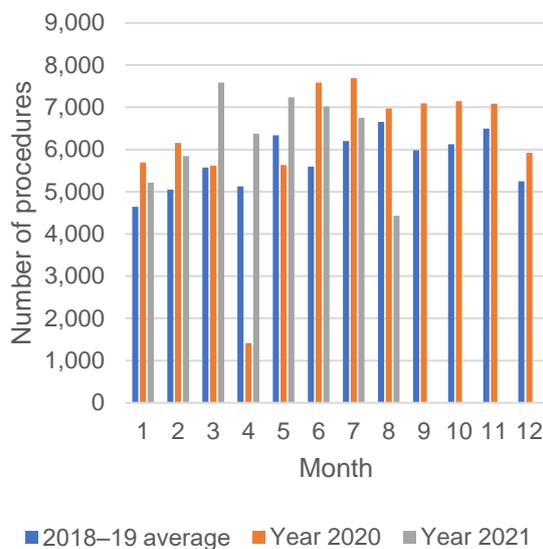


Source: Te Aho o Te Kahu, the Cancer Control Agency.

Diagnostic procedures also fell steeply in the first lockdown in 2020, including bronchoscopies and, as Figure 40 shows, gastroscopies and colonoscopies. Active monitoring and national management, however, largely enabled the number of procedures to rapidly return to baseline in 2020 and led to an increase in diagnostic procedural activity (notably including for Māori) in early to mid 2021.⁹⁶

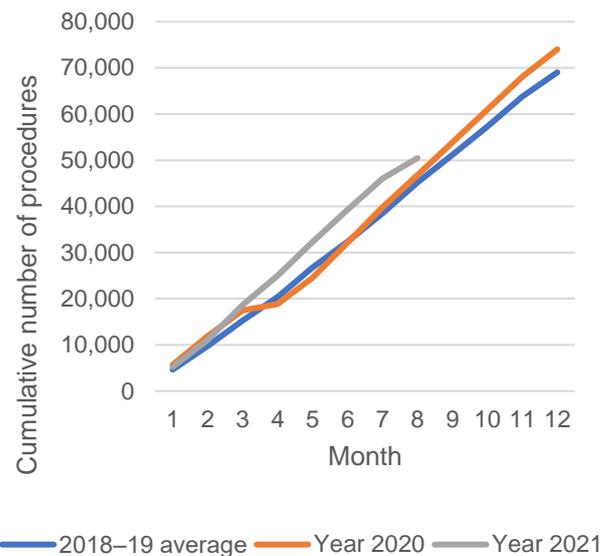
The number of gastroscopies and colonoscopies dropped sharply in the first 2020 lockdown (Figure 40). Numbers recovered strongly after that, until the August 2021 Delta variant outbreak...

Figure 40: Gastroscopy and colonoscopy procedures, total population, Aotearoa New Zealand, 2018–19 average, 2020 and 2021



... but data on cumulative procedures (Figure 41) shows increased work since March and June 2020 may have made up for any missed activity during those months.

Figure 41: Cumulative gastroscopy and colonoscopy procedures, total population, Aotearoa New Zealand, 2018–19 average, 2020 and 2021



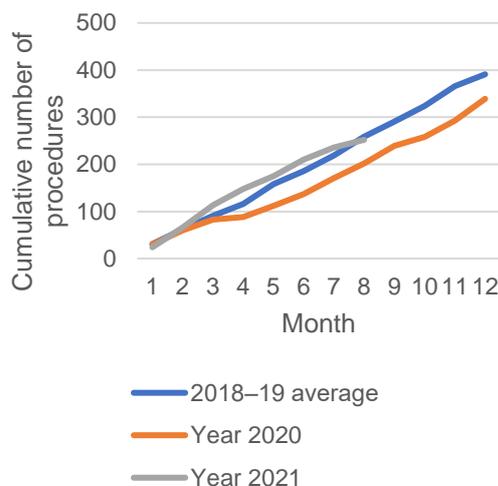
Source: Te Aho o Te Kahu, the Cancer Control Agency.

Access to and through lung cancer services for Māori was affected in 2020. This is significant given Māori have a higher incidence of lung cancer compared with non-Māori.⁵⁷ Furthermore, the age-standardised lung cancer mortality rate for Māori is more than three times that of non-Māori.^{97 98} In late 2020 bronchoscopies had reduced by 15% for non-Māori, non-Pacific,* but by nearly 28% among Māori.

* It is possible that bronchoscopy practice changed earlier than other diagnostic services, due to the anticipation of COVID-19 and caution with aerosolising procedures. It is also possible that this led to an increase in radiological investigation, which this data would not capture.

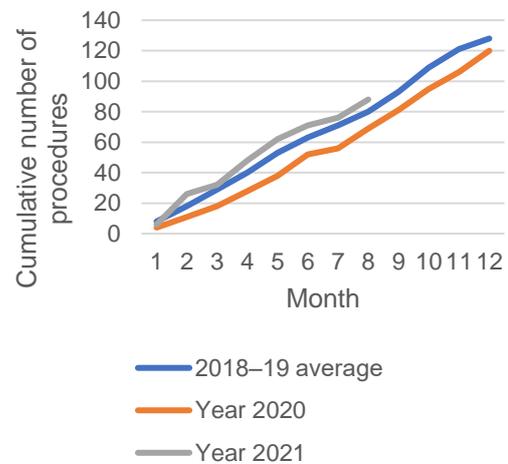
Increased awareness that lower rates of bronchoscopy affected Māori in particular in 2020 may have sparked action. Latest data shows the cumulative number in 2021 to date is higher than the 2018–19 average (Figure 42) ...

Figure 42: Cumulative bronchoscopy, Māori, Aotearoa New Zealand, 2018–19 average, 2020 and 2021



... and numbers of curative lung cancer surgeries for Māori have increased, although possibly not enough to have compensated for the 2020 deficit (Figure 43).

Figure 43: Cumulative curative surgeries, lung, Māori, Aotearoa New Zealand, 2018–19 average, 2020 and 2021

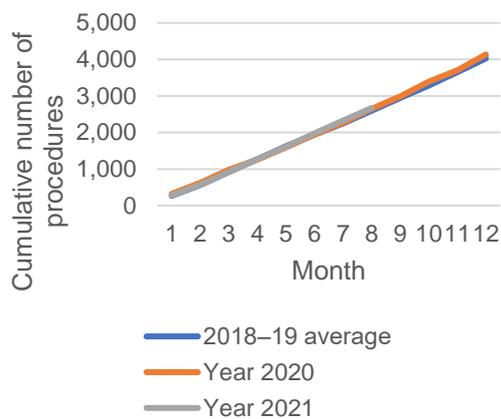


Source: Te Aho o Te Kahu, the Cancer Control Agency.

Cancer treatment services – including surgeries, first specialist assessments and attendances for treatment with medical oncology, radiation oncology and haematology – have continued with remarkable stability or even shown trends toward equity of treatment (given higher rates of disease and worse outcomes for Māori) throughout and after periods of lockdown.

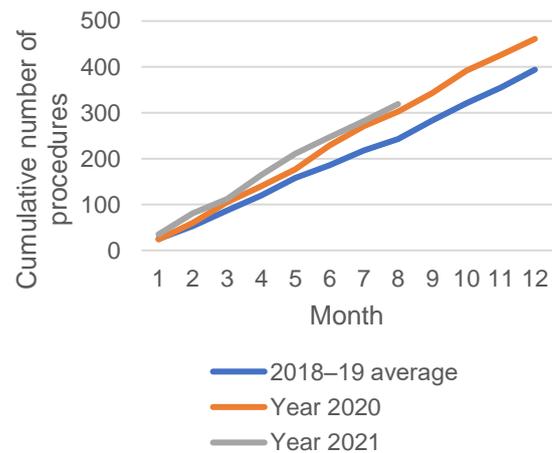
In 2020 and 2021, restrictions appear to have had minimal effect on numbers of curative prostate, colorectal and lung surgeries performed nationally compared with data from previous years (Figure 44)...

Figure 44: Cumulative curative surgeries, total population, Aotearoa New Zealand, 2018–19 average, 2020 and 2021



... and for Māori, numbers of curative surgeries for cancer in 2020 and 2021 are higher than in previous years (Figure 45).

Figure 45: Cumulative curative surgeries, Māori, Aotearoa New Zealand, 2018–19 average, 2020 and 2021



Source: Te Aho o Te Kahu, the Cancer Control Agency.

How cancer care delivery was achieved

Cancer clinicians worked exceptionally hard over this challenging period to ensure patients had access to and continuity of care.⁹⁹ Te Aho o Te Kahu identifies the following six key components of the rapid national cancer response to COVID-19 that also contributed to these promising results.¹⁰⁰

1. Clinical governance

In March 2020, rapid clinical governance of the COVID-19 cancer response was established via the Cancer Agency COVID Agile Response Team (CACART). Its members were senior agency leadership, chairs of oncological and haematological national working groups, equity and Māori health experts, and representatives for paediatric oncology, surgery, nursing and palliative care.

2. Equity Response Framework

Te Aho o Te Kahu liaised with Hei Āhuru Mōwai (Aotearoa New Zealand’s national Māori cancer leadership network¹⁰¹) on a daily basis early in the pandemic. Together with Māori researchers, it developed an Equity Response Framework¹⁰² to identify:

- where cancer inequities are known to occur along the cancer continuum
- how the COVID-19 pandemic might worsen these existing inequities

- actions that could be taken to mitigate the exacerbation of inequities
- residual issues related to equity in cancer outcomes that lie outside the pandemic response.

The Equity Response Framework includes the three key systemic drivers in inequitable cancer outcomes: 1. inequities in the incidence of poor-prognosis cancer; 2. inequities in receiving early diagnosis; and 3. inequities in receiving timely best-practice treatment (including inequities in psychosocial support).

3. Development of national ‘minimum treatment’ clinical guidance

Alongside and in line with the Ministry of Health’s National Hospital Response Framework, Te Aho o Te Kahu worked with clinical specialty working groups to develop cancer-specific guidance. The guidance provided step-wise advice on specific care that should continue within a specified level of health system compromise. Its aim was to prevent unwarranted regional variation in the delivery of cancer care, and to provide an equity-focused response in a context of high levels of uncertainty where disparities in care tend to worsen and evidence suggests standardisation of key steps of care can reduce inequities.^{103 104}

4. Using new ways of delivering care

Telehealth was rapidly adopted to deliver cancer care. Fifty percent of first specialist assessments and 80% of follow-up appointments were performed via telehealth in April 2020, compared with 0.5% percent and 1.3% respectively throughout 2018 and 2019.⁵⁷ These high levels of telehealth use occurred across all cancer specialties. The patterns of use were similar for Māori patients and rates were even higher for Pacific patients. Telehealth use largely transitioned back to in-person care by June 2020. However, virtual follow-up appointments remained higher than before lockdown, accounting for around 10% of follow-ups in November–December 2020, and around 7–8% in the first half of 2021. The capability to adapt to this way of working is there and can be drawn on quickly.

Also, in collaboration with PHARMAC, certain Special Authority conditions around ongoing monitoring and testing required for certain medicines were relaxed and alternatives provided to maintain access to care for people with cancer.

5. Identifying and addressing systems issues

Specific regional issues and issues for multiple centres were escalated to the agency and clinical working groups, and coordinated centrally. Many of these issues related to logistics and patient transport and accommodation under varying levels of restriction.

6. Close monitoring and reporting of the impact on cancer services

In April 2020 Te Aho o Te Kahu established a cross-sector group, the Cancer and COVID-19 Data Response Advisory Group, to assemble data to monitor impacts on access to cancer services and inform decision-making. Monthly reports on the status

of registration, diagnostic testing and treatments allowed the group to monitor national and local impacts at granular levels (including, crucially, by ethnicity), inform hospital and Ministry of Health decision-makers and signal areas where intervention was required. When this near real-time monitoring showed cancer registrations were decreasing, the information was used for timely public messaging around ongoing delivery of services.

Also illustrating the immediacy of this monitoring, in its most recent report *Te Aho o Te Kahu* clearly signalled a decrease in gastrointestinal endoscopies in August 2021 (by 34% overall; or 26% for Māori, 26% for Pacific peoples and 35% for non-Māori, non-Pacific) (Figure 40). This may mean that a decrease in colorectal cancer surgeries could occur in late 2021 and into 2022, because, in general, people with colorectal cancer would expect to receive surgery within a month on colonoscopy.⁹⁵

Most recent available data from August 2021 suggests some disruption to diagnostic procedures and a provisional decrease in numbers of cancer registrations associated with the August Delta outbreak. To date, disruptions to services appear to affect Māori less than non-Māori.⁹⁵

Community voice: Russ Aiton – ‘How about letting us just get on with it’ | Reo kiritaki: Russ Aiton: ‘Me waiho mātou kia mahia te mahi’



We live rurally on the West Coast, 34,000 people on a really long, narrow strip of land, and the majority is rural. So the initial lockdown for us was business as usual. When you went into Greymouth to do the shop, it was quite specific, quite metered: ‘This is what you do’, and that reflected the communication we got from the Government centrally, and what the expectations were in the community. There was a great degree of compliance.

Things started to change when we started to ask and challenge how health was delivered to us. For ED, information came through the DHB primarily and the primary health organisation (PHO). We asked, ‘Well, what happens if you have COVID-19 and you present with a broken arm? How do they know how to treat you?’ We were quickly told, ‘Well, you go down this route, you’re red or you’re green.’ But in Greymouth we have a health centre with a hospital attached. If you go for an appointment with your nurse practitioner, where’s the delineation? It wasn’t clear to us.

How specifics were communicated out to the community, especially in a rural context, was quite challenging. The consumer councils started to ask questions: ‘Well, hold on a minute, how about letting us just get on with it and we’ll work it out for ourselves, as we have done in the past?’

Existing relationships took the lead

The relationships that we have on the Coast, and I’m speaking personally as well as on behalf of comments made by consumer council members, was that the networks and the way we were doing things rurally took the lead. We did things not necessarily ‘through the back door’, but things that worked for us. Where possible and practicable, we worked with the DHB. But sometimes how the DHB expected communities to engage it, and how communities thought the best way to engage it in the provision and delivery of health services, was quite different and that dichotomy started to grow to where we are now, where we’re just completely different; it’s a different feeling.

Mobilising local knowledge, existing local groups and relationships, helps health care to continue as we wanted it to continue. You’ve got groups like the Rotarians, the Lions, with connectivity with people in the PHO, and the non-governmental

organisations (NGOs). They've all got expectations and they bring into the mix the expectations from what their networks are saying.

What did we learn?

As we eased and moved into level 3, level 2, then to level 2.5, there was a sense of reflection. 'What worked? What did we do differently during the lockdown? What do we do differently coming out of that?' It was that issue of value, and the unintended consequences, which were: we know there's a lot more people out there who need this provision of health, be that food, be that mental support, ongoing palliative care; and of course transport's a big thing on the Coast.

We learned not to over-complicate or make the message too prescriptive. The communications have to be appropriate for the audience and the community you intend it for. So be flexible in that.

We have three different communities represented at the Consumer Council: Buller, Greymouth and Westland. Before COVID-19 they all had their individual nuances of how they did things and saw themselves. COVID-19 came along, and a lot of those relationships solidified; then coming out, they took the chance to do something slightly different. And it worked. 'This worked for us, this is the way it's going to work now.'

The community prevailed. With my work through the Consumer Council – I'm chairing the national group as well – one of the things we discussed was simply, 'How are you guys getting on?' And whether rural or urban, albeit the bounds of expectation increased, pretty much through lockdown and out the other side, these unintended consequences, both negative and positive, were seen as an opportunity to tweak, to change, to address, to represent and figure out how services could be delivered in the new space. Which is kind of where they are now. They're busy getting on with getting on.

Struggles with the DHB model

The quality and safety marker* has been hovering in the background of consumer engagement at the DHB. The Consumer Council has been pointing to it and saying, 'Talk to the community. We've got exemplars of how the community has managed itself, and the community is saying to you, as a DHB, what we want to do is sit down and talk to you about the way things are delivered.'

Our DHB, in my own personal view, with my Consumer Council hat on, has been reluctant to be flexible, to be nimble. As an entity they've wanted to go back to the good old days prior to COVID-19 where health services were provided and that was it. But there are some DHBs that have rolled their sleeves up and said, 'Let's take the opportunity to work with consumers.' But on the Coast here, it's business as

* www.hqsc.govt.nz/our-programmes/partners-in-care/consumer-engagement-gsm

usual about the way communities are engaged. There's that kind of resistance to move forward.

With all the changes to the health system structure, we at the Consumer Council are holding the line, somewhat treading water, and we're saying, 'Look, there's an engagement process where we want to be spoken to as consumers.' There are the services we need, and the model is going to be locality-driven: individual localities in the districts and the regions. 'This is what works for us in Buller, this works in Grey, differently again in Haast and Hokitika.' There's a tremendous opportunity to make it work from a locality point of view and talk about what services need to be there. This is one of the unintended consequences of that initial COVID lockdown. The community has said, 'This works, why don't you provide it for us?' With that community leadership, the structure can be nimble, brave and confident enough to actually deliver. There's a resistance to go back to the way it was.

We're going to get on with it

I don't think the changes will be tripped up by the pandemic. I think we've accepted that COVID is going to happen. We're just going to live with it. We're going to cope with it. We don't really want to be spoken to like four-year-olds. We're going to get on with it. There's confidence in the community that isn't shared necessarily within the DHB, which is a shame, really. I think the DHB should back itself a bit more, in releasing some of that pressure, and just engaging with people at their level. I hope that's a fair view of the way things were pre-COVID and after, and the way the communities have healed and come out, and those wonderful unintended consequences that we've embraced.

Conclusions: Resilience and recommendations | Kupu whakakapi: Te pakaritanga me ngā whakatau

The COVID-19 pandemic has brought into sharp relief the need for the health care system to adapt in the face of novel challenge. As we describe in this report, the system has had to rapidly reallocate resources and reorganise the way care is delivered, while not losing sight of the overarching objective of delivery of high-quality health care for all. The system was failing Māori and Pacific peoples before the pandemic began and the effects of lockdowns have made these failures still worse. Future decisions must be made in spite of the volatility, uncertainty, complexity and ambiguity of the situation we face.

Yet these same issues are ever-present in health care, as staff navigate the dynamic demands and often conflicting goals of a system that is constantly evolving. Understanding how the system adapted to COVID-19 may therefore provide insights into how to build **system resilience**, which means the system has the capacity to adapt to challenges and changes at its different levels, to maintain high-quality care.¹⁰⁵

Four capacities for resilient performance

A system cannot **be** resilient, but a system can have a potential for resilient performance.¹⁰⁶

Hollnagel describes four capacities of a system that allow it to perform resiliently: the capacities to **anticipate**, **monitor**, **respond** and **learn**. We can examine these with reference to the example of the successful response to cancer care during the COVID-19 pandemic in 2020, and early to mid 2021.

Anticipating

There was an early recognition of the potential impacts that COVID-19 might have for cancer treatments, and a particular recognition that this impact was likely to exacerbate existing inequities within cancer care.

Rather than using a single measure of system performance, such as a target, a wider array of data was collected to help make visible the impacts, both intended and unintended.

The formation of the Cancer Agency COVID Agile Response Team (CACART) brought together diverse expertise and perspectives from across the sector to better anticipate the potential impacts on the provision of cancer care. Importantly, there was recognised need to understand the differentiated impacts that responses to contain the pandemic were likely to have, and an equity lens was made part of the response from the start.

In particular, Hei Āhuru Mōwai's role made it possible to develop a pro-equity framework early to predict and guide action on likely impacts for Māori. Early analysis of the effects of that framework appears promising.¹⁰²

Monitoring

The collated data was used to monitor the performance of the system. Rather than being an exercise in reassurance, this monitoring focused on making visible any unintended consequences of the changes implemented.

CACART was able to bring together multiple perspectives on the data, and to use these to develop a richer understanding of system performance, including how different contexts and populations are experiencing change.

To achieve this understanding requires a change in mindset about how to use data. The type of centrally imposed fixed targets that predominated over the last 10 years in health work well for simple problems but become less useful and sometimes even harmful in the face of complexity.¹⁰⁷ Instead, we need more nuanced measures that reflect local conditions and priorities, and close monitoring of changes to sentinel outcome measures. These approaches are reflected in the public health system reforms by the Health System Indicators (announced by Minister Hon Andrew Little in August 2021¹⁰⁸) and the Health Quality & Safety Commission's Quality Alerts programme for DHBs.

Responding

A key aspect of the success of the cancer network seems to have been its ability to take anticipated effects and early signals within the data and respond through coordinated actions across the system. This ability to direct additional resources or even reshape the system in response to novel challenges is at the heart of resilient performance.

Yet this ability to respond may be limited if the organisational 'slack',¹⁰⁹ the strategic reserves we can call on at times of challenge, has been depleted over time. A system designed for optimal efficiency under existing conditions may be surprisingly brittle when it faces dynamic changes. This leads to questions about who decides what is 'waste' in terms of organisational slack at a given moment, and over what timeframes we base these decisions.

As a contrasting case, we can see that although there was a recognition of the rebound load on EDs following the lockdowns, no extra resources were available to respond to this demand, placing the departments under enormous strain. So it is clear that monitoring alone is not enough; what matters is having the capacity to respond to the challenges and opportunities that monitoring identifies.

Learning

The capacity to learn is about making sense of the wider event and what it tells us about how systems normally function. An unexpected event places new stressors on the system, revealing unexpected brittleness as well as unexpected resilience.

One particularly interesting aspect of the cancer response was what it tells us about effective governance of complex, multi-provider problems. Rather than having a centralised 'command and control' system or control based on limited 'performance targets', the response involved forming a network of interested parties from many levels of the cancer care system. They used data to understand the impacts of their actions and were able to mobilise resources from across the system.

As this report has demonstrated, the growing complexity of health care requires us to work across traditional sector boundaries and involve many different groups in building high-quality care. This need is driving new approaches to governance,¹¹⁰ including the Health System Indicators framework programme,¹¹¹ which will be central to achieving the transformation hoped for in the upcoming health reforms.

Data and the pandemic

Data is central to the Window on COVID-19, yet we can see from the examples above that data is never neutral or passive. The decisions we make about what to measure, how we make meaning from it and how we respond to it are central to building a health care system that can perform resiliently. Here then are some questions to consider when thinking about data.

What to measure? Who gets to decide?

It is clear from our discussions in this report that deciding what to measure is an important first step, yet one that is not free of power relations and politics. What we choose to measure and how we categorise events have significant impacts on what the system is seen to value and give attention to.¹¹² This was apparent in how building an equity lens into the cancer response shaped both what became visible and what the system responded to.

Another idea that comes through the patient experience data is that we need to understand the **differentiated** experiences across the system. Data is useful not only in the aggregate but also in identifying difference that allows us to see 'what works, for whom, in what respects, to what extent, in what contexts, and how'.¹¹³

Data for whom?

This leads to the question of whom the data is for. Do we use data to seek reassurance that the system is functioning as measured by often narrow performance targets, or do we collect data to make visible the impacts of decisions

on those providing care or controlling resources? Understanding both the audience and the data they are interested in can guide what we choose to measure.

Data for what?

As the rebound in ED demand shows, collection of data alone will not lead to resilient performance; we must use data to inform a response. Without the ability to allocate resources or change our focus, we will be data-rich but fail to make meaningful improvements.

Summary

A health care system that performs resiliently is one where the system, at all levels, is able to adapt to shocks and change to deliver high-quality care. The cancer response is one example of a resilient response but there are many more, including in the Māori community sector.¹¹⁴

These responses are built on the relationships that exist, across networks and communities, and have found new ways of working in challenging times. Yet the lessons of COVID-19 tell us much about the health care system and how the priorities and ways of working of the past condition and constrain the present response.

Yet the COVID-19 response contains many lessons of resilient success. These stories may guide the way we work in future, helping us to navigate the challenges and opportunities ahead and create the high-quality care that we all want.

Recommendations

The fast pace and changing nature of the pandemic, and in particular the predominant impact on Māori and also Pacific peoples, means some of the recommendations below arise from the findings of this Window and some relate to the emerging issues of the impact of the COVID-19 Delta variant.

1. District health boards/Health NZ, from July 2022, must, with some urgency, find a stronger approach that is appropriately resourced, to support the mana motuhake of Māori and Pacific providers and their unique knowledge of and abilities to serve their populations. This is even more critical in the context of these providers supporting community self-isolation and quarantine (CSIQ) arrangements while their populations bear the main burden of COVID-19 under the most challenging conditions.
2. Mechanisms that provide governance of quality (including clinical governance) need to be established, also with urgency, at local and district levels for the current and expected CSIQ responses. This must be based on a Te Tiriti partnership with iwi and Māori providers, given the lower rates of vaccination for Māori and the higher vulnerabilities to illness in affected Māori and Pacific

peoples. Partnerships with Pacific providers must also be established, with active input into quality governance as well.

3. A formalised national network for data and intelligence sharing for EDs across the country should be established, or one of the existing network arrangements strengthened, with proper resourcing and data analytic capability.
4. DHBs/Health NZ, from July 2022, must approach addressing the backlogs of elective activity created by COVID-19 restrictions with greater thought and stronger emphasis on understanding the particular make-ups of their backlogs and prioritisation of work according to need. The Ministry of Health reports that it anticipates access to elective care and screening (and all other health care) would be improved under the COVID-19 Protection Framework (CPF).
5. What we have learned about the nature of patient experience of primary care during COVID-19 restrictions as discussed here is valuable but high level. Local primary health organisations should use their survey data to look at the experience of their populations, consider evidence of difference in that experience for different parts of their populations and tailor services, including telehealth care services, appropriately.
6. A national primary care data set is a long-standing deficiency that needs to be addressed. There is a notable gap in our understanding of how the health system as a whole responded to COVID-19 due to the absence of consistent national primary care data, despite primary care having powerful local clinical systems.

Endnotes | Tuhipoka

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