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A seven-year study of violence towards staff in the Christchurch Hospital Emergency Department was undertaken from 2014–2020 (excluding 2017). This involved an annual audit during each May of incidents of violence and aggression, including verbal and physical intimidation or assault and sexual innuendo/threat. Additional demographic data was collected from 2015 relating to the perceived aggressor. Most events reported involved verbal abuse from patients and occurred on weekend and night shifts.

Deactivation of implantable cardioverter defibrillators towards the end of life: a survey of perceptions and practice among New Zealand clinicians

Tamara Brodie, Amanda Landers, Richard Troughton

This nationwide survey examined perceptions of cardiologists, general physicians, and geriatricians on deactivation of implantable cardioverter defibrillators in terminally ill patients. Most doctors agreed that it was ethically appropriate to deactivate these devices prior to the end of life, but identified a number of barriers to having discussions. Further support and training to certain groups of clinicians is likely to be helpful to promote this in appropriate cases.

The changing use of anticoagulants in New Zealand

Paul Harper, Alison Chang, Matt Stephens

Ten years ago, warfarin was the only blood thinner available in New Zealand taken by approximately 46,000 people. Since 2011 two new blood thinners, dabigatran and rivaroxaban, have become available. The number of people on blood thinners has more than doubled during this time to over 100,000, which means approximately 15% of people over the age of 75 are on a blood thinner. This may be beneficial as blood thinners help to reduce the risk of stroke, but it can make surgery and hospital admissions more complex with an increased risk of bleeding.

An exploration of Aotearoa New Zealanders' attitudes and perceptions on the use of posthumous healthcare data

Jon Cornwall, Sylvia English, Brendon Woodford, Jim Elliot, Kathryn McAuley

Posthumous healthcare data, the healthcare information of persons that have died, are ever-increasing in volume. Despite their potential usefulness, there have been no studies that have asked the public if or how they may want this information utilised after they die—this is becoming more relevant as digital healthcare records are now becoming 'the norm'. This study asked Aotearoa New Zealanders these questions, finding that they generally support the notion of their healthcare information being used for the future benefit of family and society, while commercial benefit arising from their healthcare information was viewed as likely and acceptable. Other findings included Māori healthcare data preferentially being managed by Māori, while a centralised, Government supported database was suggested as the preferred vehicle for data management. The information provides the first empirical evidence of social support for posthumous healthcare data use and guides a potential future for healthcare data use in Aotearoa New Zealand.

Establishing a database of patients with diabetes and an interest in research participation

Ry Yves Tweedie-Cullen, Audrey Tay, Yiping Zou, Rebecca Brandon, Ryan Yeu, Stacey Ruru, Holly Carmichael, Ole Schmiedel, Rinki Murphy

There is modest interest (18%) of adults with diabetes attending a diabetes clinic who responded favourably to a text message inviting them to enrol in a diabetes volunteer database to be contacted for future research or teaching opportunities. Motivates centred around a hope to improve their own diabetes and that of others.

The Southern Health system's Community Health Council: establishment and processes to engage with communities, whānau and patients

Sarah Derrett, Charlotte Adank, Karen Browne, Kelly Takurua

Following support from the Iwi Governance Committee and Southern DHB and WellSouth PHO Chief Executives and their leadership teams, advertisements called for people interested in joining the CHC. After group interviews, the 11-member CHC was established in 2017. The CHC then developed a Framework for Engagement, a large team of CHC Advisors (>120), and a Roadmap to support engagement activities. This paper describes the practical establishment of the CHC, the resources and support for the 120 CHC Advisors and staff working on over 95 engagement activities.

Lockdown Level 4 V2.0: different trauma patterns in Auckland in 2021?

Keith Teo, Sunder Balasubramaniam, Ian Civil

Coronavirus disease 2019 (COVID-19) has resulted in public health restrictions known as lockdowns in New Zealand to reduce spread of the disease. Only Auckland had a comparable time frame of lockdowns in 2020 and 2021. Of note, in the 2021 lockdown, there were increased reports of reduced compliance to the restrictions. In our study, we report increased trauma-related activity in the 2021 lockdown compared with the 2020 lockdown. This resulted in more trauma hospital admissions with major injuries and more road-related injuries. Lockdown fatigue may have contributed to reduced compliance in Auckland in the 2021 lockdown, with subsequent increase in trauma activity. If future lockdowns are implemented, it may be less effective, therefore, hospitals need to be adequately resourced to manage trauma activity during lockdowns.

Effectiveness of a preschool asthma education programme, compared to usual care, on the frequency of acute asthma events: a community-based cluster randomised trial

Natalie Walker, Taina von Blaramberg, Janet Mackay, Wendy McNaughton, Janine Strickland, Janice Van Mil, Joanne Moorcroft, Caroline Funnell, Lynne Smith, Emma Bettle, Kylie Power, Marama Parore, Varsha Parag, Christopher Bullen, Scott Springford Metcalfe

The 'Space to Breathe' asthma study aimed to find out whether better communication between whānau/caregivers, doctors, nurses, and preschool teachers about dealing with asthma, can improve the health of preschoolers with asthma or at high risk of asthma. The study ran in the Auckland region and 675 preschool children took part. The study was a randomised trial, which meant that half the preschoolers received extra support and information on asthma management with the 'Space to Breathe' programme, and half were in the 'usual care' group. The study found the 'Space to Breathe' programme:

- Helped preschool teachers learn more about asthma and feel more confident in supporting children with asthma.
- Supported children with asthma or at high risk of asthma to use their asthma preventers more often, and have less wheezing and coughing, both during the day and at night.

Even though the children in the 'Space to Breathe' group had good medicine use and better control of their asthma during the 12 months of the study, children still attended the doctor or emergency department for asthma as much as those children in the 'usual care' group.

Trauma, COVID-19 and healthcare investment

Ian Civil

Just over two years have passed since the first cases of COVID-19 were recognised in New Zealand. In that time, there have been a range of restrictions and lockdowns during which individuals' ability to travel and engage in a range of work-related and personal activities have been severely constrained.

Trauma is associated with physical activity and the severity of injury generally correlates with the forces involved and the degree of risk. Road traffic crashes are a well-known cause of death and serious injury and falls, sporting activities and assault are among the main contributors to the national injury statistics.

As expected, during Level 4 lockdown in 2020, there were such significant constraints on personal activity that trauma incidence actually did drop,[1, 2,3,4] but in in the latter half of 2020 and the first half of 2021, despite ongoing restrictions of various sorts, trauma incidence remained high. The report from Teo et al[5] in this issue of the journal has flagged that the second Level 4 lockdown in Auckland in August–September 2021 did not suppress trauma presentations as the similar level of lockdown did in 2020.

In the recently released annual report of the National Trauma Network (NTN), the incidence of major trauma (where the severity is such that there is some risk of death) was the highest recorded (51/100,000/year) in the period since 2015 when the National Trauma Registry has been operating. [6] This increase seems to have particularly focussed on the older cohort (65+ ages), where there were incidence drops in 2019–2020 but significant increases beyond the pre-COVID-19 baseline in 2020–2021. The report also highlights the known inequitable burden of trauma in Māori and in those living in rural areas. Serious traumatic brain injury is the most common cause of death, and is associated with significant long-term morbidity and reduction in quality of life for survivors.

While the natural tendency is to focus on any new threat to healthcare, particularly where there is uncertainty with regard to the outcome, much more is now known about COVID-19, and the most recent variants seem to carry only modest threats to life. Although "long-COVID" remains an unknown quantity at this stage both the paper by Teo et al in this issue and the annual report of the NTN attest to the fact that major trauma is largely immune to COVID-19, and occurs at a similar incidence despite standard COVID-19 restrictions. Only full Level 4 lockdown seems to reduce major trauma presentations, and that effect might have been less in 2021 than in the initial Level 4 lockdown in 2020.

Despite the efforts being presently put into the fight against COVID-19, we must not lose sight of the fact that many other diseases remain prevalent in the community. In particular, physical injury may have even been stimulated by the lockdown periods of activity restriction, and overall rates seem to be increasing. Our healthcare system must retain its capability to prevent and treat all types of illness and injury. The timely investment now being put into our health system must be used in a rounded way so that not only will COVID and like infections be able to be managed in the short and long term, but age-old endemic afflictions such as trauma will also be able to be managed and the systems for treating them improved.

COMPETING INTERESTS
Nil.

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REFERENCES

1. Christey, G., Amey, J., Campbell, A., Smith, A. Variation in volumes and characteristics of trauma patients admitted to a level one trauma centre during national level 4 lockdown for COVID-19 in New Zealand NZ Med J 2020; 133(1513): pp. 81-88.
2. Hamill, J.K., Sawyer, M.C. Reduction of childhood trauma during the COVID-19 Level 4 lockdown in New Zealand. ANZ Journal of Surgery 2020; 90(7-8): 1242-1243.
3. Fan, D., Scowcroft, H., McCombie, A., et al., A comparison of major trauma admissions to Christchurch Hospital during and after COVID-19 lockdown in New Zealand. NZ Med J 2021; 134(1540): 46-55.
4. McGuinness, M.J., Harmston, C., The Northern Regional Trauma Network. Association between COVID-19 public health interventions and major trauma presentation in the northern region of New Zealand. ANZ Journal of Surgery 2021;91(4): 633-638.
5. Teo K., Civil, I., Balasubramanian, S. Lockdown Level 4 V2.0: different trauma patterns in Auckland in 2021? in New Zealand N Z MJ 2022;135(1554): pp. 73-79.
6. NZ National Trauma Registry and National Trauma Network Annual Report 2020-2021.https://www.majortrauma.nz/assets/Annual-reports/NZMT-Annual-Report-2020-2021.pdf Accessed April 2nd 2022.

Challenging the culture of Emergency Department violence and aggression

Sandra K Richardson, Paula C Grainger, Laura R Joyce

ABSTRACT

aims: To examine reported levels of violence and aggression within a tertiary level emergency department in New Zealand, and to compare incident reporting within a dedicated yearly audit period to standard organisational reporting procedures.
method: A prospective, longitudinal cohort study involving repeated yearly audits of violence and aggression reported by emergency department staff from 2014–2020.
results: Episodes of violence and aggression were reported at high levels during audit months compared to standard reporting, suggesting current systems do not accurately reflect the presence of violence and aggression. Levels of reported violence and aggression remained relatively static over a seven-year period, despite increasing emergency department attendances. Most events reported involved verbal abuse from patients, and occurred on weekend and night shifts. A number of potentially contributing factors were identified.
conclusions: Persistently higher levels of violence and aggression were reported during the targeted audit months, while reporting via the organisation's formal system during the intervening months remained at low levels. Further research is essential to monitor trends, assess the effectiveness of interventions to improve reporting, modify factors contributing to violence and aggression, and to address the impact on staff and bystanders affected in emergency departments.

Continuing interest and awareness regarding violence towards health workers in New Zealand[1–3] mirrors that which is seen internationally.[4–6] Certain areas within healthcare are under high risk for violence and aggression (V&A), notably emergency departments/urgent care (ED), mental health care, and aged care.[7] Emergency care settings are sites where staff are frequently exposed to violent language and threatening behaviour. Considerable research has been published, leading to increased awareness of the significance of this issue.[8–14] A 2018 New Zealand study identified the impact and consequences of failure to accurately report V&A within a major hospital emergency department (ED).[3] It highlighted that the absence of accurate data significantly increases clinical risk by reducing recognition and response. Risks for staff exposed to workplace violence extend beyond the immediate physical and psychological impact. Exposure to occupational violence has the potential to initiate, contribute to, or exacerbate emotional exhaustion, excessive drinking, moral distress, anxiety, depression, suicidal thoughts, burnout, and post-traumatic stress disorder.[4–6] The consequences for health organisations include absenteeism, decreased job satisfaction leading to staff turnover, diminished productivity, and difficulties with recruitment and retention of staff. Legal significance includes the potential failure of employers to meet obligations to provide a safe workplace. This article outlines findings from a longitudinal study of V&A reporting within Christchurch Hospital ED.

Methods

This prospective, longitudinal cohort study involves repeated yearly audits of ED staff reporting V&A during the same month each year. The setting is Christchurch Hospital ED, which sees patients of all ages, and all types of presenting complaint, receiving both referrals and walk-in presentations. It is one of the busiest departments in Australasia in terms of both acuity and patient numbers, and there is no alternative ED in the city.

Repeated "May – It's Not Ok" campaigns occurred within the ED, targeting staff awareness and willingness to report V&A, from 2014. This involved a single month (May) of data collection, with department-wide focus and reminders to report all V&A. The study uses an audit approach, focussing on the accuracy of routine reporting. Formal ethical approval was not required for this study. More detailed discussion of the studies development and methodology has previously been published.[3]

Data captured by the audit form asked for the professional group and gender of the staff member completing the form; the category of V&A (verbal abuse, verbal threat, physical threat, physical assault and sexual assault); date and location of incident; and, from 2016, data about the individual who committed the violence.

Data collection

Data were collected from 2014–2020 (excluding 2017). As part of the quality cycle, minor amendments were made with each iteration, in response to feedback and observations. In 2014, the initial data collection tool was introduced to provide a more efficient platform for reporting than the paper-based process then in use. This was in response to reports that the time taken to complete formal, paper-based reporting was a barrier. In 2016, an electronic system was introduced called "Safety1st". Despite expectations that this would reduce the burden on staff, it was reported that it required a minimum of 30 minutes to complete, and also necessitated that staff found an available computer. The data collection tool used for this study was specifically designed for ease and speed of completion by busy ED staff and has been described previously.[3]

Data analysis

Simple descriptive statistics were applied to the numerical data, with graphical representation of key elements. The qualitative data is used as a descriptive adjunct in illustrating the categories of V&A reported.

Results

The study is now an established, ongoing quality project. Overall, similar numbers of reports have been received during each "May – It's Not Ok" audit period, aside from 2015, when a lower response rate was received. This was believed to be due to the concurrent roll out of a V&A survey.

The relative stability in reports is interesting when considering the increase in overall patient numbers during the study period. Patient attendance numbers, admission rates, and markers for acuity (in the form of triage 1–3 statistics), together with mental health and drug/alcohol numbers, are illustrated in Table 1.

Study findings

A summary of the data collected, and the participants is outlined in Table 2. All ED staff were invited to participate in the audit, but the most consistent responses were from nursing, medical and allied health groups.

Once data collection relating to the aggressor began, it was apparent that some incidents affected multiple individuals, and some individual aggressors were responsible for multiple incidents. Many incidents affected multiple people—16 separate events in the most recent year generated more than one report, with an average of 18 such events per year over the 8 years that this data has been collected. This is based on the formal completion of forms—at times these identified that others were present or involved who did

Table 1: ED presentations 2014–19.

Year	2014	2015	2016	2017	2018	2019	2020
Total attendance	92,443	92,130	96,397	98,540	101,377	102,987	100,040
Admission rate	**44%** 40,512	**43%** 40,064	**44%** 42,291	**46%** 44,864	**46%** 46,500	**45%** 46,705	**42%** 41,790
Triage 1–3	**60%** 55,295	**60%** 55,428	**60%** 58,531	**64%** 62,985	**65%** 65,445	**66%** 67,590	**66%** 65,289
Triage 1–3 admission rate	**59%** 32,665	**58%** 32,372	**59%** 34,291	**59%** 37,416	**59%** 38,683	**58%** 39,213	**54%** 35,468
Presentations for mental health/drug or alcohol	**4%** 3,921	**4%** 3,912	**4%** 4,113	**4%** 4,328	**5%** 4,659	**4%** 4,364	**4%** 4,368

Table 2: Summary of the data collected.

	May 2014	May 2015	May 2016	May 2018	May 2019	May 2020
No. of reports	107	53	90	86	101	86
No. of aggressors	N/A	37	57	39	52	46
Incidents with multiple reports	N/A	13	23	16	20	16
Aggressors with multiple reports	N/A	N/A	1	1	6	3
Individual reporting						
Nurse	93	44	64	55	69	72
Hospital Aide	2	1	8	6	2	0
Clerical	3	2	6	6	4	2
Medical	14	8	7	5	17	9
Security	0	0	4	11	4	0
Student	0	0	3	0	0	0
Allied Health	0	1	0	3	4	3

Table 3: Type of event reported.

	2014 n= (%)	2015 n= (%)	2016 n= (%)	2018 n= (%)	2019 n= (%)	2020 n= (%)
Verbal abuse (swearing, shouting etc.)	98 (61%)	45 (57%)	76 (62%)	82 (64%)	88 (62%)	63 (58%)
Verbal threat (eg "I'm going to kill you")	22 (14%)	5 (6%)	17 (14%)	4 (3%)	9 (6%)	4 (4%)
Physical assault (eg punching)	19 (12%)	16 (20%)	15 (12%)	10 (8%)	12 (8%)	8 (7%)
Physical intimidation (physical threat)	21 (13%)	0	0	15 (12%)	18 (13%)	17 (16%)
Sexual inneundo/threat	0	8 (10%)	7 (6%)	4 (3%)	8 (6%)	3 (3%)
Sexual assault (eg inappropriate touch)	0	0	3 (3%)	3 (2%)	0	0
Property damage	0	3 (4%)	4 (3%)	0	0	0
Use of a weapon	0	2 (3%)	0	2 (2%)	0	0
Not stated	0	0	0	4 (3%)	0	5 (5%)
Other	0	0	0	5 (4%)	8 (6%)	8 (7%)
Summary (N=)	160	79	122	129	143	108

not go on to report the incident or its impact. A small number of individuals also had significant impact; as an example, three patients presented more than once during the audit period in 2020 (on 14 separate occasions), generating 22 reports.

Type of event reported

Participants were initially asked to categorise the event in terms of physical intimidation or assault, and verbal abuse or intimidation. Iterations that followed expanded the options to include categories related to sexual innuendo/threat and sexual assault, property damage and use of a weapon, and "Other". These additions were accompanied by brief definitions, and descriptions of the type of behaviours associated with these categories.

The most consistently reported event across the study was verbal abuse, which combined with verbal threats represented between 62–76% of all reported events (mean of 69%). Instances of physical threat or assault ranged between 19–25% of all events (mean of 21%). When combined, reports of sexual innuendo/threat and assault (over the five years this was recorded, 2015–2020) ranged from 3–10% of all events (mean of 6%). (Refer to Table 3.)

Examples of the brief summaries provided by staff reporting the incidents offer insight into the experiences and context within the ED:

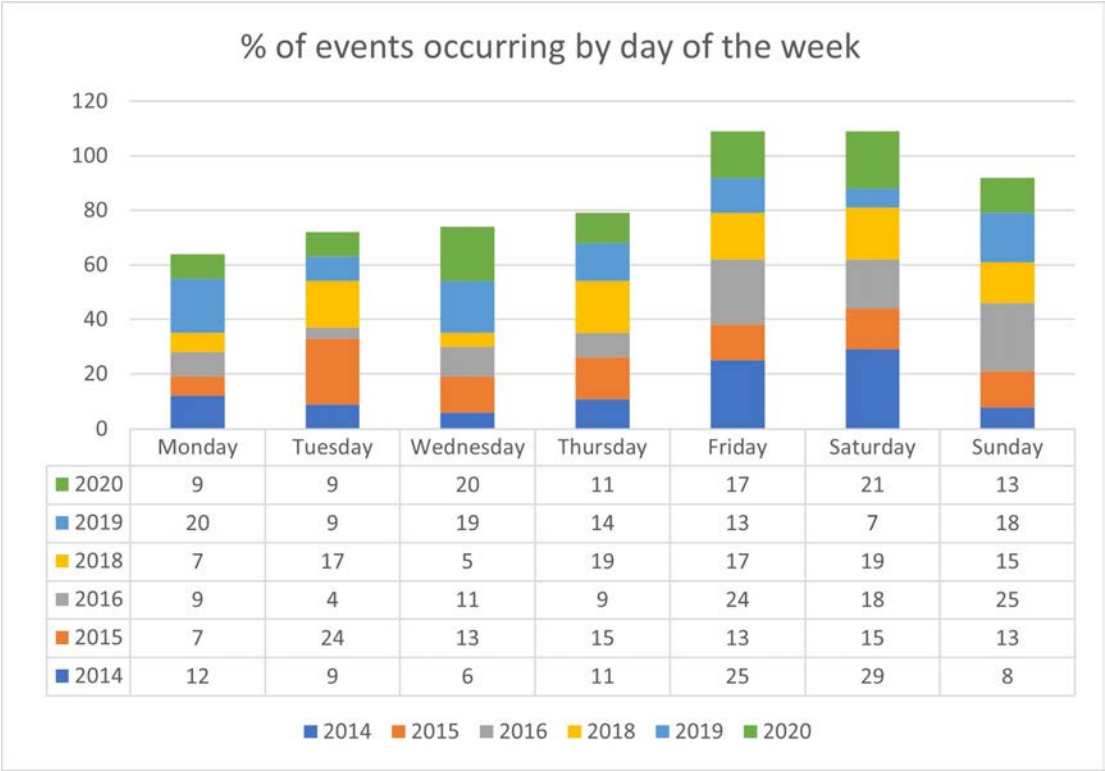
"Patient loud, aggressive and agitated, threatening and standing over nurse and clerical staff. Unsafe to send him through for assessment, appears to have non-life-threatening injuries. Asked to go home and sober up but continued threatening behaviour. Police called". (2020; RN)

"Patient brought in, intoxicated. Had already punched several paramedics and stood to urinate in back of ambulance. Vandalised R1 [room designation]. Punched ED staff. Police called and arrested patient. Patient restrained, spat in my face and tried to punch me several times. Dug fingernails into my hand. Very verbally abusive" (2019; Doctor)

"Multiple sexual innuendos suggesting I get into bed, take my clothes off, suggestions of what he would like to do". (2019, RN)

"Very intoxicated patient grabbing me inappropriately and fixating on me. Attempted to kiss me twice". (2018, Hospital Aid)

Figure 1: Frequency of events by day of the week.



	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
2020	9	9	20	11	17	21	13
2019	20	9	19	14	13	7	18
2018	7	17	5	19	17	19	15
2016	9	4	11	9	24	18	25
2015	7	24	13	15	13	15	13
2014	12	9	6	11	25	29	8

Figure 2: Frequency of events by shift.

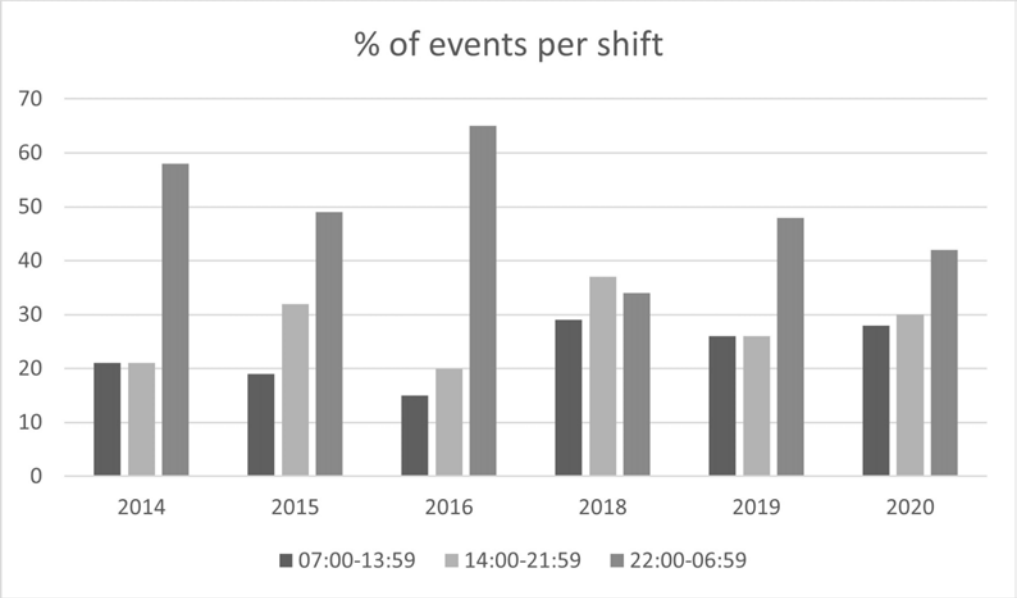


Table 4: Environmental factors contributing to V&A.

	2016	2018	2019	2020
Busy shift	6	0	21	8
ED crowding	5	0	4	1
Patients in corridor	0	7	12	0
Patient acuity	9	0	0	0
Other	0	0	0	1

Table 5: Aggressor designation.

	2015	2016	2018	2019	2020
Patient	48	78	85	91	82
Visitor	n/a	1	3	1	1
Relative	5	8	3	6	2
Other	n/a	0	2	1	1

n/a: not available

Frequency of events

Despite expected variation, there were identifiable patterns relating to the time of day and day of the week when V&A was more prevalent (refer to Figure 1). Friday and Saturday had the highest average percentage of violent events reported. Friday reports ranged from 13–25%, mean of 18% (N=99; mean n=17), and Saturday ranging from 7–29% mean of 18% (N=98; mean n=16). V&A was more likely to be reported on night shifts or later in afternoon shifts (refer to Figure 2). The hours when the most reports were received was 03:00–04:00 (N=29; mean n=5) followed by 01:00–02:00 (N=22; mean n=4). The time with the lowest number of reports overall was 14:00–15:00 with only five reports across the study period.

Contributing factors

From 2016, respondents could indicate if they thought an environmental factor contributed to the event being reported. (Refer to Table 4.)

Aggressor characteristics

From 2016, information related to the perceived aggressor or instigator of the V&A event was requested. This included the role of the aggressor (refer to Table 5) and a subjective assessment by the staff member reporting about additional factors which may have contributed to the situation; for example, that the patient was intoxicated, confused or having difficulty communicating with staff (refer to Table 6). Where the perceived aggressor was a patient, demographic data was obtained from the patient's medical record (refer to Table 7).

Inconsistencies in data entry in formal reporting systems

An ongoing issue with V&A data collection was highlighted in the initial iteration of the study.

A review of officially collected data by monthly quantity was undertaken to allow comparison between the May reporting and that completed at other times. This identified the discrepancy between these months, with inconsistent reporting. While "Safety1st" was formally introduced in 2016, Figure 3 indicates that the staff reporting that occurred in the May campaigns were also not entered into this system. It was not until 2018, when the May data entry role was taken over by an ED clerical officer in an effort to improve the reporting rates, that information was also entered into "Safety1st". Even with this assistance, discrepancies between the data collected from the "May – It's Not Okay" campaign and that retrieved from the "Safety1st" system remain—this is likely due to different ways of categorising and inputting data. Overall, this suggests remaining difficulties in gathering accurate representation of staff incidents, whether due to failing to report in the absence of additional clerical support, or difficulties in retrieving an accurate representation of events from the current system.

Discussion

The interest in V&A reporting is part of the wider response to violence in healthcare. This has received international attention, and increasingly is highlighted within the New Zealand health system.[15–16] Our study shows that repeated monitoring can reveal the presence of V&A within an ED, which raises several concerns. Comparisons with other months in the year show much lower reporting rates, suggesting that barriers to reporting remain. This is in line with international literature, which also identifies difficulties in achieving consistent reporting.[17–19] The use of a single, targeted audit month offers a simple way to achieve a representative sample, and a more accurate estimate of any problem. As well as identifying the issues associated with reporting, the findings acknowledge the continued presence of violent events overtime. While this article does not allow for a detailed review of the responses to V&A that have been trialled alongside the audit, these have also included: the creation of an ED specific working group; collaborative engagements within the healthcare sector; hospital and DHB policy, pathway and process development; and ED specific innovations. It is possible that in the absence of such developments, the recorded events may have been even higher, and that the apparently "constant" level, despite the increasing ED presentations, actually represents a relative improvement to the baseline. Equally, it is possible that a degree of fatigue over time has seen a reduction in the reporting rate, and that the findings are under-representative. There is clearly a cumulative presence of verbal and physical violence within the working environment. This implies for the staff and organisation that there is a need to maintain a safe workplace and a healthy work environment. These results could inform changes, such as security staffing levels at times of predicted increased V&A.

Over the time that the study has run several trends have emerged, including that nurses report the highest incidence of V&A. This is in

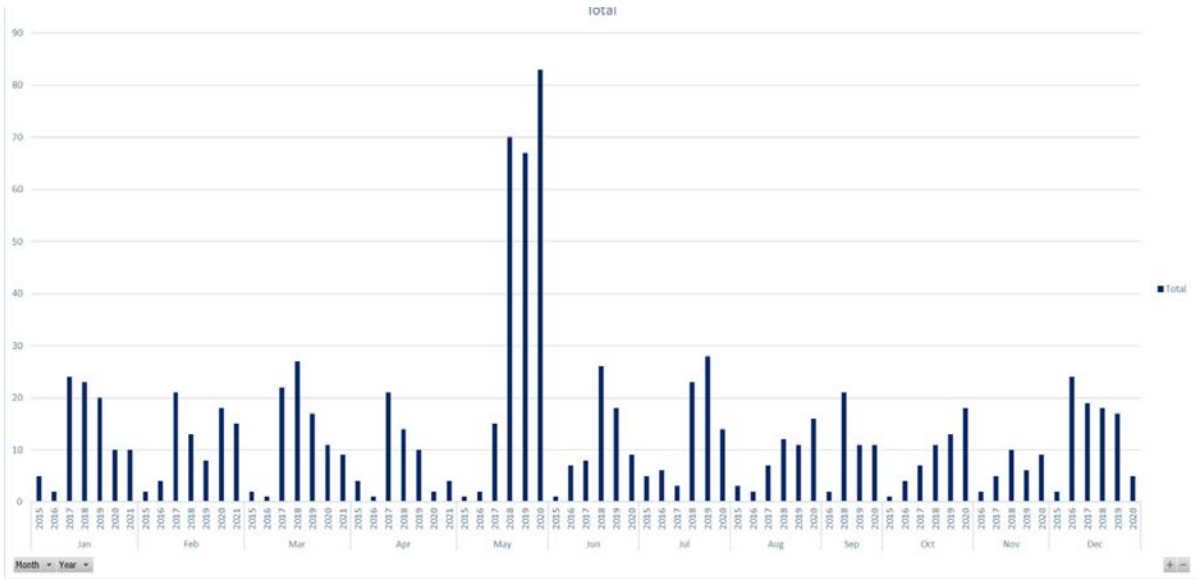
Table 6: Reporters perceptions of associated factors.

	2015	2016	2018	2019	2020
Mental illness	11	8	14	18	20
Dementia	0	0	3	2	0
Communication	0	1	8	4	2
Confusion/delirium	8	0	6	0	4
Manipulative behaviour (deliberate)	0	1	14	31	26
Intoxicated/substance affected	17	5	30	35	31
Emotion: stress, fear, anxiety	5	16	12	8	10
Clinical eg pain, acuity of needs	0	5	0	0	0
Other	4	1	0	1	0

Table 7: Aggressor demographics.

Sex	**2015**	**2016**	**2018**	**2019**	**2020**
Male	24	45	56	63	47
Female	12	39	30	35	37
Not stated	1	4	7	0	0
Ethnicity	**2015**	**2016**	**2018**	**2019**	**2020**
NZ European	n/a	52	41	68	64
NZ Māori	n/a	18	25	20	18
Other European	n/a	1	1	10	3
Pacific people (not further defined	n/a	0	0	3	1
Asian (not further defined)	n/a	1	1	0	0
Age	**2015**	**2016**	**2018**	**2019**	**2020**
0–10	1	0	0	0	0
11–20	4	7	4	12	10
21–30	5	25	25	24	35
31–40	3	18	20	20	17
41–50	8	6	15	18	12
51–60	4	14	9	11	6
61–70	0	2	8	4	1
71–80	4	2	2	4	1
81–90	3	0	2	1	1
91–100	0	0	1	0	1
Not stated	5	3	7	0	0

Figure 3: Violence and Aggression Reporting by month (2015–2016) from "Safety1st".



line with international research which identifies nurses and healthcare assistants at most risk of V&A;[20] however, willingness to report across all disciplines needs to be considered.[9] Evidence shows systemic under-reporting in nursing,[21] although other occupational groups may also find it difficult to recognise and report V&A. Further work highlighting this is necessary, with growing recognition of violence toward medical staff and reluctance to report this being recognised. [22] Future research could explore potential correlations between staff ethnicity, age and years of ED experience, and reported incidents.

The introduction of the Shorter Stays in Emergency Departments (SSED) 6-hour target in 2009 resulted in dramatic improvements in waiting times, but since their removal in 2017, there has been significant deterioration in these times.[23] It might be expected that the increase in waiting times may exacerbate the V&A reported. Recognition of characteristics within the patient group show connection to alcohol and drug use as associated factors, as well as a new patient group—describing those who present with a sense of entitlement and unrealistic expectations. Analysis of free text responses led to the addition of a new category description: "manipulative behaviour". This included the emergent theme of "it's all about me"—an identifiable group describing those who are demanding, threatening, and wanting to progress their own care regardless of other circumstances. This was typically associated with verbal abuse and intimidation, and at times physical intimidation.

Limitations

This study has several limitations. There were changes to the staff and to the audit instrument between the data collection periods. The participants effectively self-select by choosing to report the incidents of V&A. In the absence of external observation, it is difficult to confirm accuracy of the reporting, or the number of additional but unreported incidents that may occur. Data was not collected in 2017, as an in-depth staff survey into perceptions and attitudes around V&A was run during that year, and it was felt that both processes would be too burdensome for staff. The audit has continued over a period of years, and there is likely a degree of fatigue in terms of responder participation. It is possible, but highly unlikely, that the rates of V&A occurring in ED during May are different to other months of the year. There are no major public holidays or large events happening regularly during this month, and therefore V&A in May is likely similar to most other months—or perhaps less than certain months, such as December and January where alcohol-fuelled events are more common.

Conclusions

This study highlights that V&A remains an issue within the study site. Whether this is a reduction

in what might otherwise have occurred, or an ongoing trend that has not responded to interventions, is unclear. However, it also indicates that the processes of the "May – It's Not Okay" campaign offer a simple means of gaining insight into the realities of the problem, despite consistent under-reporting. There is clear need for further research into potential responses to V&A, the impact this has on staff and bystander wellbeing, and mechanisms for supporting affected staff as well as improving reporting systems.

COMPETING INTERESTS
Nil.

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REFERENCES
1. Marshall, B, Craig, A, Meyer, A. Registered nurses' attitudes towards, and experiences of, aggression and violence in the acute hospital setting. Kai Tiaki Nursing Research. 2017;8:31-36.
2. Baby M, Glue P, Carlyle D. 'Violence is not part of our job': a thematic analysis of psychiatric mental health nurses' experiences of patient assaults from a New Zealand perspective. Issues Ment Health Nurs. 2014 Sep;35(9):647-55. doi: 10.3109/01612840.2014.892552. PMID: 25162186.
3. Richardson SK, Grainger PC, Ardagh MW, Morrison R. Violence and aggression in the emergency department is under-reported and under-appreciated. N Z Med J. 2018 Jun 8;131(1476):50-58. PMID: 29879726.
4. Fedele R. Ground zero: standing up against violence in our healthcare sector. Aust Nurs Midwifery J. 2016 Jul;24(1):18-23. PMID: 29236431.
5. Pekurinen V, Willman L, Virtanen M, et al. Patient Aggression and the Wellbeing of Nurses: A Cross-Sectional Survey Study in Psychiatric and Non-Psychiatric Settings. Int J Environ Res Public Health. 2017 Oct 18;14(10):1245. doi: 10.3390/ijerph14101245. PMID: 29057802.
6. Shea T, Sheehan C, Donohue R, et al. Occupational Violence and Aggression Experienced by Nursing and Caring Professionals. J Nurs Scholarsh. 2017 Mar;49(2):236-243. doi: 10.1111/jnu.12272. Epub 2016 Nov 30. PMID: 27905189.
7. Phillips JP. Workplace Violence against Health Care Workers in the United States. N Engl J Med. 2016 Apr 28;374(17):1661-9. doi: 10.1056/NEJMra1501998. PMID: 27119238.
8. Pich JV, Kable A, Hazelton M. Antecedents and precipitants of patient-related violence in the emergency department: Results from the Australian VENT Study (Violence in Emergency Nursing and Triage). Australas Emerg Nurs J. 2017 Aug;20(3):107-113. doi: 10.1016/j.aenj.2017.05.005. Epub 2017 Jul 10. PMID: 28705687.
9. Copeland D, Henry M. Workplace Violence and Perceptions of Safety Among Emergency Department Staff Members: Experiences, Expectations, Tolerance, Reporting, and Recommendations. J Trauma Nurs. 2017 Mar/Apr;24(2):65-77. doi: 10.1097/JTN.0000000000000269. PMID: 28272178.
10. Han CY, Lin CC, Barnard A, et al. Workplace violence against emergency nurses in Taiwan: A phenomenographic study. Nurs Outlook. 2017 Jul-Aug;65(4):428-435. doi: 10.1016/j.outlook.2017.04.003. Epub 2017 Apr 13. PMID: 28487095.
11. Mikkola R, Huhtala H, Paavilainen E. Work-related fear and the threats of fear among emergency department nursing staff and physicians in Finland. J Clin Nurs. 2017 Oct;26(19-20):2953-2963. doi: 10.1111/jocn.13633. Epub 2017 Feb 9. PMID: 27805740.
12. Morken T, Baste V, Johnsen GE, Rypdal K, Palmstierna T, Johansen IH. The Staff Observation Aggression Scale - Revised (SOAS-R) - adjustment and validation for emergency primary health care. BMC Health Serv Res. 2018 May 8;18(1):335. doi: 10.1186/s12913-018-3157-z. PMID: 29739398.
13. Wong AH, Combellick J, Wispelwey BA, et al. The Patient Care Paradox: An Interprofessional Qualitative Study of Agitated Patient Care in the Emergency Department. Acad Emerg Med. 2017 Feb;24(2):226-235. doi: 10.1111/acem.13117. Epub 2017 Jan 30. PMID: 27743423.
14. Tadros A, Kiefer C. Violence in the Emergency Department: A Global Problem. Psychiatr Clin North Am. 2017 Sep;40(3):575-584. doi: 10.1016/j.psc.2017.05.016. Epub 2017 Jul 4. PMID: 28800811.

15. Brown K. Middlemore Hospital seeks to stop rising violence in emergency department. 24 April 2019. Radio NZ https://www.rnz.co.nz/news/national/387654/middlemore-hospital-seeks-to-stop-rising-violence-in-emergency-department
16. Donaldson RH. Alarming levels of ED violence now normalised and shrugged off, finds NZ study. 8 June 2018. Health Central.
17. Kumari A, Kaur T, Ranjan P, et al. Workplace violence against doctors: Characteristics, risk factors, and mitigation strategies. J Postgrad Med. 2020 Jul-Sep;66(3):149-154. doi: 10.4103/jpgm.JPGM_96_20. PMID: 32675451; PMCID: PMC7542052.
18. Arnetz JE, Hamblin L, Ager J, et al. Underreporting of Workplace Violence: Comparison of Self-Report and Actual Documentation of Hospital Incidents. Workplace Health Saf. 2015 May;63(5):200-10. doi: 10.1177/2165079915574684. Epub 2015 May 22. PMID: 26002854; PMCID: PMC5006066.
19. Gillespie GL, Leming-Lee T. Chart It to Stop It: Failure Modes and Effect Analysis for the Reporting of Workplace Aggression. Nurs Clin North Am. 2019 Mar;54(1):21-32. doi: 10.1016/j.cnur.2018.10.004. Epub 2018 Dec 3. PMID: 30712543.
20. Gillespie GL, Pekar B, Byczkowski TL, Fisher BS. Worker, workplace, and community/environmental risk factors for workplace violence in emergency departments. Arch Environ Occup Health. 2017 Mar 4;72(2):79-86. doi: 10.1080/19338244.2016.1160861. Epub 2016 Mar 15. PMID: 26980080.
21. Hogarth KM, Beattie J, Morphet J. Nurses' attitudes towards the reporting of violence in the emergency department. Australas Emerg Nurs J. 2016 May;19(2):75-81. doi: 10.1016/j.aenj.2015.03.006. Epub 2015 May 23. PMID: 26012889.
22. Berlanda S, Pedrazza M, Fraizzoli M, de Cordova F. Addressing Risks of Violence against Healthcare Staff in Emergency Departments: The Effects of Job Satisfaction and Attachment Style. Biomed Res Int. 2019 May 28;2019:5430870. doi: 10.1155/2019/5430870. PMID: 31275976; PMCID: PMC6558649.
23. Jones P, Le Fevre J, Harper A, Wells S, Stewart J, Curtis E, Reid P, Ameratunga S. Effect of the *Shorter Stays in Emergency Departments* time target policy on key indicators of quality of care. 2017 May 12; 130(1455): 35-44.

Deactivation of implantable cardioverter defibrillators towards the end of life: a survey of perceptions and practice among New Zealand clinicians

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ABSTRACT

BACKGROUND: Implantable cardioverter defibrillators (ICDs) have the potential to reduce the quality of life in patients with life-limiting illnesses. Despite this, the literature suggests deactivation of ICDs occurs infrequently, and there is a lack of guidance on this issue.

AIMS: This nationwide survey aimed to investigate perceptions and practices regarding deactivation of ICDs among New Zealand clinicians caring for patients with life-limiting illnesses, and to identify barriers to conversations about ICD deactivation.

METHODS: Cardiologists, general physicians and geriatricians across New Zealand were sent a survey that explored their views and practices regarding deactivation of defibrillators in terminally ill patients.

RESULTS: One hundred and forty-five out of 457 clinicians (32%) replied. Most (98%) of clinicians felt deactivation may be appropriate in this group. Key barriers to discussions were felt to include uncertainty over prognosis (77%), likelihood of causing anxiety in their patients (70%), lack of clarity of roles and inexperience in the field. Cardiologists were more likely than general physicians and geriatricians to start deactivation discussions in patients with terminal disease. Doctors with more years in practice felt more comfortable raising the topic of deactivation.

CONCLUSION: While most doctors were comfortable with the concept of device deactivation, issues such as uncertainty of prognosis, fear of causing anxiety, lack of role clarity and inexperience can be barriers to initiating conversations. Further guidance, education, support and shared care could benefit doctors caring for ICD recipients who have life-limiting illnesses.

Implantable cardioverter defibrillator devices (ICDs) have been shown to reduce the risk of sudden death from arrhythmia in primary and secondary prevention settings.[1] ICD implantation in New Zealand has been increasing over the past decade.[2,3] However, preventing a premature arrhythmic death will not prolong life indefinitely, and as patients proceed through the trajectory of chronic illness, the balance of harm and benefit related to ICD therapy, as well as their goals of care, may change.

Patients with ICDs at the end of life are at risk of electrical cardioversion (shocks), which can be painful and distressing in the conscious patient and for their family members. As patients approach the end of life, the frequency of shocks may increase,[4] which physicians acknowledge is disturbing to patients and their families.[5] A study of ICDs explanted post-mortem revealed that almost a third of patients experienced shocks in their last hour of life.[6] A survey of hospices that have cared for patients with ICDs showed that 86% of those patients experienced unwanted treatment and their sequelae, most commonly in the form of shocks.[7]

Studies from Europe and the USA reveal that at the end of life, fewer than half of patients with an ICD are offered a discussion about deactivation.[4,6,8] A retrospective review of Canadian ICD patients with terminal illnesses showed that deactivation was only included in the end of life care for a third of patients, and a majority of patients died with an active device.[9] More recently, a Japanese study showed that ICDs were deactivated in less than a quarter of patients dying of end stage heart failure.[10] When discussions happen,

they tend to occur in response to rapidly changing circumstances rather than a decision planned in advance.[4] Even in those patients with a do not resuscitate (DNR) order, ICD deactivation occurs in fewer than half of patients.[4,6,10]

The reasons why ICD deactivation is not discussed earlier in a patient's condition are complex. Earlier studies found that doctors feel uncomfortable discussing cessation of cardiac device therapy.[11–13] Almost half report feeling uncomfortable while deactivating an ICD.[14,15] Doctors may overestimate the patient's knowledge of their ICD, and assume deactivation discussions should be brought up by the patients themselves.[13,16] Despite this, surveys consistently show that patients have misconceptions about the risks and benefits of their devices.[17–20] This likely contributes to patients' unwillingness to initiate these conversations themselves. Further investigation is important to offer guidance for the medical profession on improving these discussions, and therefore unwanted ICD treatments.

There has not been any research performed evaluating the perceptions of New Zealand clinicians on deactivation of ICDs, or the barriers to discussion about this important issue. This study aims to survey the views of cardiologists, general physicians and geriatricians on these issues.

Method

Study design and recruitment

Ethical approval was obtained from the University of Otago. We sent an online questionnaire to cardiologists, geriatricians and general physicians in August 2020, to explore their perceptions of deactivation and barriers to having these conversations. Cardiologists and geriatricians received this through their national societies (Cardiac Society of Australia and New Zealand, and the Australian & New Zealand Society for Geriatric Medicine). General physicians were contacted through the general medical departments in 19 hospitals around New Zealand. Responses were collected for two months, and the survey was closed in October 2020.

Survey

The survey collected information on basic demographic data and explored views on deactivation of defibrillators in patients, barriers to conversations about deactivation, and usual practice regarding conversations about deactivation. The questions were graded on a Likert scale with five categories.[21] Questions regarding perceptions and barriers to conversations had the categories: "strongly agree", "somewhat agree", "neutral", "somewhat disagree", and "strongly disagree". Questions relating to clinical practice had the categories: "always", "most of the time", "sometimes", occasionally", and "never". In the absence of a known validated questionnaire, this questionnaire was developed specifically by the lead author, based on an extensive literature review of similar studies investigating this topic.[5,12,15,16,22,23] A copy of the questionnaire is included in Appendix A.

Data analysis

When analysing results, scores were treated as categorical values and results were analysed using nonparametric methods. Scores from questions relating to perception on deactivation and barriers to having conversations were grouped into three categories: "strongly/somewhat agree", "neutral", or "strongly/somewhat disagree". Scores from questions relating to clinical practice were also grouped into three categories: "always/most of the time", "sometimes/occasionally", or "never". Differences between types of specialists were analysed using the Kruskal–Wallis test. Comparisons between gender were made using the Mann–Whitney test.

When analysing results against years of experience, scores were treated as a continuous variable to see if a trend was seen against increasing years of experience. P values were derived using the Mann–Kendall test for linear trend.

The survey included two free text boxes: one to identify further barriers to having conversations, and the other to provide additional comments. A qualitative approach was taken to analyse these results, with two authors (TB, AL) independently reviewing and coding the comments. When there were discrepancies found, the authors met and negotiated a consensus. Overarching themes were analysed with the same method.

Results

The survey was sent to 457 clinicians in total. One hundred and five cardiologists and 157 geriatricians received this through their national societies. General medical departments of 21 hospitals were contacted—of which 14 agreed to take part—and questionnaires were forwarded to 195 general physicians. In total, 145 of 457 clinicians completed the survey, resulting in an overall response rate of 32%. Response rates differed between specialty, with cardiologists, geriatricians,

and general physicians having response rates of 41%, 18%, and 38%, respectively. Of the completed surveys, 99.3% of the questions had been answered. Fifty-nine percent of respondents were male. Thirty-five percent had more than 20 years of experience in their specialty.

Quantitative results

A majority of clinicians (98%) agreed that it is ethically appropriate to deactivate a defibrillator on patient request, with 81% agreeing that deactivation is ethically similar to refusal of implantation. Similarly, the majority (92%) felt comfortable bringing up the option of deactivation with patients, with 93% feeling confident about their communication skills about end of life issues. Eighty-four percent of respondents felt they had received enough training and support to have these discussions.

Over three quarters (77%) of doctors felt that uncertainty over prognosis can make it difficult to have these deactivation conversations. A majority (69%) felt they had enough time to have conversations with patients when this was required. Seventy percent felt that having these conversations may cause anxiety in patients, although only 9% felt that these may negatively affect the doctor–patient relationship.

Seventy-nine percent of cardiologists responded to the question about implantation of ICDs. Half of these reported mostly or always discussing deactivation at the time of implantation, with 14% never discussing the issue at this time. Over half of doctors always or mostly discuss deactivation in patients with either terminal disease or rapidly declining quality of life (57% and 51%, respectively), however, fewer do so in patients with increasing hospitalisation (27%). Fewer than half of doctors (46%) felt that their patients were aware that deactivation would be an option if treatment were to become burdensome. Most doctors (68%) would not, or only occasionally, be present for deactivation of an ICD. Eighty-four percent of doctors would always or mostly bring up advance care planning in those with a rapidly progressive disease, and 49% would involve palliative care to help with decision-making in complex cases involving ICDs.

When comparing doctors by specialty, there was some variation in results. More geriatricians felt that conversations about deactivation have the potential to negatively affect their doctor–patient relationship (18%, as compared to 5% in cardiologists, and 8% in general physicians). Most cardiologists (90%) would discuss deactivation in patients with terminal disease, compared with general physicians (45%) and geriatricians (50%). Similarly, cardiologists were more likely to do so in those with declining quality of life and

Table 1: Characteristics of respondents.

Characteristic	N	%
Specialty		
Cardiologist	42	30%
Geriatrician	28	19%
General Physician	75	51%
Gender		
Male	85	59%
Female	60	41%
Years of experience in Specialty		
<10	47	32%
10–19	47	32%
20–29	32	22%
>30	19	13%

increasing hospitalisations (79% and 48%), than general physicians (43% and 20%) or geriatricians (39% and 19%). There was no disparity between general physicians and geriatricians. Cardiologists were more certain that their patients understood they had the option of deactivation if treatment was becoming burdensome. They would also be more likely to attend the bedside of a patient during deactivation.

When gender was compared, male doctors reported discussing deactivation more frequently in those patients with a terminal disease (68% vs 45%). Males were twice as likely to believe their patients were aware that deactivation was an option (60% vs 30%).

When assessing differences according to length of experience, there was a positive relationship between experience and confidence with having conversations (P=0.002). Doctors with more experience felt more comfortable raising deactivation discussions. In addition, doctors with more experience were less likely to feel that having conversations would negatively affect the patient–doctor relationship (P=0.003).

Qualitative results

The results of the comments revealed four major themes.

1. Time

Some answers raised having inadequate time for discussions, and others mentioned getting the time "right". There was variation in the comments as to what is the best time, with some comments recommending discussion at implantation, and others suggesting this is the wrong time.

> *"…being able to bring about all interested parties at the right time" (female geriatrician)*

> *"Time. Implant is not the best time" (male cardiologist)*

2. Lack of skills and resources

Inadequate knowledge and support was the most common theme raised. These included under-recognition of the ICD itself, as well as lack of experience or guidelines with how to conduct these discussions. The practical knowledge of how to achieve deactivation was also brought up by non-cardiologists:

> *"I don't think I always know when patients have defibrillators and don't think to ask" (female general physician)*

> *"I don't know how it is done clearly" (male general physician)*

3. Collegial relationships and ownership

Lack of clarity of roles was frequently mentioned as a significant barrier. Responses from some general physicians suggested a reluctance to address it due to perceived ownership from cardiology.

> *"I'm unsure if cardiologists or physicians need to have this discussion" (female general physician)*

> *"Team dynamics, prevalent power structures in the institutions and burden of responsibility. 'Passing the buck' strategy exercised very admirably" (male general physician)*

The involvement of palliative care or additional services was mentioned as being a positive, helpful factor.

> *"We have excellent pall care service at [anonymous] Hospital and a combined cardiology/pall care clinic which provides great service to patients with chronic cardiac conditions" (female general physician)*

4. Patient and family expectations

The most common theme within patient factors was unrealistic patient expectations, particularly with reference to information previously provided to patients.

> *"Patient expectations about what a defibrillator can or cannot achieve—influenced by prior information and education at time of implantation" (female general physician)*

> *"Patients sometimes have very unrealistic expectations of their prognosis" (male general physician)*

Table 2: Perceptions of physicians regarding ICD deactivation.

Questions	Response	Cardiologist (n=42)	General Physician (n=75)	Geriatrician (n=28)	P-value
In a competent patient with a terminal illness, I feel it is ethically appropriate to deactivate a defibrillator if they request this.	Agree	42 (100%)	74 (100%)	27 (96%)	0.19¥
	Neutral	0 (0%)	0 (0%)	0 (0%)	
	Disagree	0 (0%)	0 (0%)	1 (4%)	
I feel that deactivation of defibrillators at the request of a patient is ethically similar to refusal of implantation.	Agree	32 (78%)	62 (82%)	25 (89%)	0.65¥
	Neutral	3 (7%)	5 (7%)	0 (0%)	
	Disagree	6 (15%)	8 (11%)	3 (11%)	
I feel that family should all agree to the decision of deactivation before it is performed.	Agree	9 (21%)	12 (16%)	2 (7%)	0.43¥
	Neutral	4 (10%)	12 (16%)	3 (11%)	
	Disagree	29 (69%)	50 (68%)	23 (82%)	
I feel that active defibrillators have the potential to worsen quality of life at the end of a terminal illness.	Agree	41 (98%)	74 (99%)	25 (89%)	0.07¥
	Neutral	1 (2%)	1 (1%)	3 (11%)	
	Disagree	0 (0%)	0 (0%)	0 (0%)	
I think all patients with defibrillators should have timely discussions about deactivation.	Agree	42 (100%)	72 (96%)	28 (100%)	0.07¥
	Neutral	0 (0%)	0 (0%)	0 (0%)	
	Disagree	0 (0%)	3 (4%)	0 (0%)	

Table 3: Perceptions of physicians regarding communication about ICD deactivation.

Questions	Response	Cardiologist	General Physician	Geriatrician	P-value
I feel comfortable bringing up the option of deactivation with my patients.	Agree	42 (100%)	68 (91%)	25 (89%)	0.06[¥]
	Neutral	0 (0%)	6 (8%)	1 (4%)	
	Disagree	0 (0%)	1 (1%)	2 (7%)	
I feel confident in my communication skills about end of life issues.	Agree	39 (93%)	70 (93%)	28 (100%)	0.39[¥]
	Neutral	3 (7%)	3 (4%)	0 (0%)	
	Disagree	0 (0%)	2 (3%)	0 (0%)	
I feel I have had enough training and support to have these discussions.	Agree	35 (83%)	63 (85%)	25 (89%)	0.76[¥]
	Neutral	3 (7%)	4 (5%)	0 (0%)	
	Disagree	4 (10%)	7 (10%)	3 (11%)	
I have enough time with my patients to have conversations about deactivation when I need to.	Agree	30 (71%)	51 (68%)	20 (72%)	0.86[¥]
	Neutral	6 (14%)	8 (11%)	4 (14%)	
	Disagree	6 (14%)	16 (21%)	4 (14%)	
I feel conversations about deactivation might cause anxiety in my patients.	Agree	29 (69%)	54 (72%)	21 (75%)	0.32[¥]
	Neutral	7 (17%)	13 (17%)	1 (4%)	
	Disagree	6 (14%)	8 (11%)	6 (21%)	
I feel conversations about deactivation may negatively affect my patient-doctor relationship.	Agree	2 (5%)	6 (8%)	5 (18%)	0.03[¥]
	Neutral	1 (2%)	13 (17%)	2 (7%)	
	Disagree	39 (93%)	56 (75%)	21 (75%)	
I feel that uncertainty over prognosis can make it difficult to have deactivation conversations.	Agree	34 (81%)	59 (79%)	22 (79%)	1.00[¥]
	Neutral	3 (7%)	6 (8%)	2 (7%)	
	Disagree	5 (12%)	10 (13%)	4 (14%)	

Table 4: Usual practice of physicians regarding ICD decision making.

Questions	Response	Cardiologist	General Physician	Geriatrician	P-value
I discuss the possibility of future deactivation of ICDs at the time of implantation.	Most of the time/always	18 (60%) §	§	§	
	Occasionally/sometimes	10 (33%) §	§	§	
	Never	2 (7%) §	§	§	
I discuss the possibility of deactivation of ICDs with patients who have developed a terminal or rapidly progressive disease.	Most of the time/always	38 (90%)	33 (45%)	14 (50%)	
	Occasionally/sometimes	4 (10%)	34 (46%)	12 (43%)	<0.001¥
	Never	0 (0%)	7 (9%)	2 (7%)	
I discuss the possibility of deactivation of ICDs with patients who I feel have a rapidly declining quality of life.	Most of the time/always	33 (79%)	32 (43%)	11 (39%)	
	Occasionally/sometimes	9 (21%)	32 (43%)	15 (54%)	<0.001¥
	Never	0 (0%)	10 (14%)	2 (7%)	
I discuss the possibility of deactivation of ICDs with patients who have had increasing numbers of hospital admissions.	Most of the time/always	20 (48%)	15 (20%)	6 (22%)	
	Occasionally/sometimes	20 (48%)	41 (55%)	16 (59%)	0.005¥
	Never	2 (5%)	18 (24%)	5 (19%)	
My patients are aware that if treatment with an ICD were becoming burdensome, they would have the option of deactivation.	Most of the time/always	35 (83%)	27 (37%)	6 (23%)	
	Occasionally/sometimes	7 (17%)	38 (53%)	17 (65%)	<0.001¥
	Never	0 (0%)	7 (10%)	3 (12%)	
If I made a decision to deactivate an ICD, I would attend the bedside of a patient during the deactivation.	Most of the time/always	8 (19%)	11 (15%)	1 (3%)	
	Occasionally/sometimes	28 (67%)	30 (41%)	12 (43%)	0.003¥
	Never	6 (14%)	32 (44%)	15 (54%)	

Table 4 (continued): Usual practice of physicians regarding ICD decision making.

Questions	Response	Cardiologist	General Physician	Geriatrician	P-value
I bring up advance care planning with patients with terminal or rapidly progressive disease.	Most of the time/always	33 (79%)	65 (88%)	27 (96%)	0.152¥
	Occasionally/sometimes	9 (21%)	8 (11%)	1 (4%)	
	Never	0 (0%)	1 (1%)	0 (0%)	
I involve palliative care to help with decision making in complex cases involving ICDs.	Most of the time/always	15 (36%)	44 (56%)	13 (46%)	0.059¥
	Occasionally/sometimes	26 (62%)	26 (35%)	12 (43%)	
	Never	1 (2%)	4 (5%)	3 (11%)	

† P-value is derived using Kruskal–Wallis .
¥ P-value is derived using Fisher's exact test.
§ This question only relates to practice from relevant cardiologists. 71% of responding cardiologists answered this question

Discussion

We surveyed cardiologists, general physicians and geriatricians around New Zealand regarding the deactivation of ICDs as patients enter a more terminal phase of chronic illness. A majority of responding clinicians agreed that it was ethical and necessary that timely discussions should be undertaken with patients in this situation to help prevent unwanted and distressing ICD treatments. This is concordant with other research showing similar beliefs.[12,15,22]

In our survey, most cardiologists stated that they discussed deactivation at the time of implantation. This contrasts with other literature suggesting this is done rarely. [8,12] There is little data in the literature looking at the true frequency of discussions held at this time. Most clinicians agree that initiating discussions about device deactivation should start at the time of implantation,[5] although one survey revealed conflicting results, showing some cardiologists felt that the focus at implantation should remain solely on prolongation of life.[24] This variation of opinion over the right timing was also reflected in our qualitative results. Future discussions on deactivation, and deactivation itself, are more likely if they are initiated at the time of implantation.[25]

Perceived "ownership" or responsibility of the device may play an important role, with cardiologists potentially feeling a greater sense of responsibility for management of the device. This concept was reflected in both our quantitative and qualitative results, with non-cardiologists feeling more hesitant about approaching this issue. A Swedish study looking at deactivation rates in patients with a DNR order showed that those in a cardiology ward had higher rates of deactivation than those in a non-cardiology ward.[26] This could also reflect education and guidelines, as this study observed an increase in deactivation following publication of European guidelines on ICD management.[27] As these guidelines are directed at cardiologists, they may be more likely to read and benefit from this guidance. Lack of physician knowledge can therefore be a barrier to deactivation. Our study revealed uncertainty over the practical knowledge of deactivation. Inadequate knowledge, or awareness of guidelines has been found to be a significant barrier to deactivation.[28,29]

Further support and resources directed at these clinicians would be vital, given many patients with ICDs may be managed by general physicians and geriatricians at the end of life. An audit in the UK showed that using interventions such as grand rounds, posters, and teaching on this issue reduced the number of patients who died with an active ICD in place.[30] Similarly in the USA, teaching in addition to the use of an electronic decision-making tool improved both the rates of discussion, and the rates of deactivation.[31] Further research focussing on improving the rates of discussion and deactivation in New Zealand, using similar interventions, would be useful to identify the most effective method of further supporting doctors here. Clinicians may feel uncomfortable discussing deactivation. Several surveys have shown that physicians were consistently less comfortable discussing deactivation of cardiac devices compared with other life-sustaining therapies such as ventilation or dialysis.[11,12] We found over 90% of the doctors in our survey felt comfortable bringing up deactivation, although there was a significant difference seen between cardiologists and general physicians/geriatricians, with the former feeling more confident.

Accurate prediction of prognosis has previously been identified as an issue.[28] In our study, three quarters of doctors felt that unclear prognosis was a barrier for them. Other studies have shown that this may be more significant in patients with advanced heart failure who have been identified as being more challenging to predict disease trajectory for.[23, 32–34]

Lack of clarity of clinician roles emerged as a factor in our study. As patients may be involved with many different specialists during their illness, this "fragmentation of care" may lead to uncertainty of who is responsible for these discussions, or whether they have already occurred. [23,28,29,35] Shared care approaches have been suggested as a positive path through this uncertainty.[33]

Other research has revealed several other barriers, such as taking away hope, fear of frightening the patient, and a lack of rapport or time.[12,28] Our survey showed that one fifth of doctors did not feel they had enough time to have these discussions, and this issue was brought up frequently in the comments. Almost three quarters of doctors in our study felt that discussing deactivation may cause anxiety in patients. A UK survey of patients about ICDs at the end of life showed that none of those patients found deactivation discussions distressing to experience.[36]

Clinicians may assume their patients are aware that deactivation is an option and tend to overestimate their patient's understanding of their device.[12] In our survey, most cardiologists believed

their patients knew of the potential for deactivation, though fewer than half of general physicians and geriatricians believed the same. Doctors may also assume that patients have a good understanding of their devices; however, studies have shown that the opposite is true. Patients often have poor understandings of the role of their devices, and are rarely aware that deactivation is an option.[17–19] An Irish survey of ICD recipients showed that over half of patients felt that ICDs reduced the risk of heart attack, and improved the pumping function of the heart.[37] Some patients view deactivation to be akin to immediate suicide or euthanasia.[17,20,22,38] Insufficient knowledge of ICDs in patients correlates with unwillingness to discuss deactivation with clinicians.[20] This only increases the need for doctors to be able to initiate conversations and provide adequate information themselves. We did not survey patients to confirm similar patient views in this New Zealand population.

Impact of palliative care and advance care planning

Palliative care involvement in end of life care of patients with ICDs is rare; however, when patients are referred the rates of ICD deactivation increase.[25] Doctors in our study tended to involve palliative care in complex cases around half the time. Involvement of palliative care services at the time of deactivation also results in increased attention toward symptom management and clarification of goals of care.[39] Sharing the load of decision-making and goals of care can be enormously helpful for these complex decisions.

Limitations

This study had some limitations. The response rate to our questionnaire was 32%, which is typical of similar questionnaires in other research, but may result in reporter bias.[11,40] In addition, the method of sending out surveys differed for general physicians compared with cardiologists and geriatricians. This was due to privacy restrictions of the national society for general physicians. Despite this, we were able to reach a majority of general physicians, and had a high response rate. There was the potential to have overestimated the denominator of total doctors being sent surveys, as some general physicians may have also been members of specialty colleges from cardiology or geriatric medicine. Response rates were not compared between hospitals, as the location of the respondents were anonymised. With this, it is possible that there was a difference in response rates for certain hospitals, resulting in underrepresentation of some centres. We only surveyed general physicians, cardiologists and geriatricians, and have not included perspectives from primary care. Given the involvement of primary care in these patients, further research in this area could add to our understanding of their practice and needs. Cardiac physiologists were not formally surveyed but play a central role in patient care and education, and should be involved in education and policy and development related to this topic. There are also inherent limitations in the self-reporting of confidence in the absence of objective measures.

Conclusions

This nationwide survey of New Zealand cardiologists, general physicians and geriatricians showed that most doctors agreed that there should be advanced planning of ICD deactivation in patients with life limiting illnesses. Most doctors were comfortable discussing deactivation of ICDs, but identified barriers including unclear prognosis, varying patient and physician understanding and fear of patients' emotional reactions. Geriatricians and general physicians felt less equipped to have these conversations compared with cardiologists. Future interventions, involving training and support, could be useful to reduce disparities in practice between specialties and prevent potential harm. Further education and guidelines are likely to be helpful in supporting doctors providing care to these patients as they approach the end of life. Shared care between specialties such as cardiology, general medicine, geriatrics and palliative care would help clarify complex issues such as prognosis and decisions on appropriate withdrawal of treatment.

COMPETING INTERESTS
Nil.

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REFERENCES
1. Goldberger Z, Lampert R. Implantable Cardioverter-Defibrillators: Expanding Indications and Technologies. 2016;295(7):809-18.
2. Larsen PD. Article in The New Zealand medical journal [Internet]. 2010. Available from: http://www.nzma.org.nz/journal/123-1309/3977/
3. Mond HG, Crozier I. The Australian and New Zealand Cardiac Implantable Electronic Device Survey: Calendar Year 2017. Vol. 28, Heart Lung and Circulation. Elsevier Ltd; 2019. p. 560-6.
4. Goldstein NE, Lampert R, Bradley E, Lynn J, Krumholz HM. Management of Implantable Cardioverter Defibrillators in End-of-Life Care Background: Implantable cardioverter defibrillators (ICDs) can [Internet]. 2004. Available from: https://annals.org/
5. Kelley AS, Reid MC, Miller DH, Fins JJ, Lachs MS. Implantable cardioverter-defibrillator deactivation at the end of life: A physician survey. American Heart Journal. 2009;157(4).
6. Westerdahl AK, Sjöblom J, Mattiasson AC, Rosenqvist M, Frykman V. Implantable cardioverter-defibrillator therapy before death: High risk for painful shocks at end of life. Circulation. 2014 Jan 28;129(4):422-9.
7. Fromme EK, Stewart T, Jeppesen M, Tolle SW. Adverse experiences with implantable defibrillators in Oregon hospices. American Journal of Hospice and Palliative Medicine. 2011;28(5):304-9.
8. Hill L, McIlfatrick S, Taylor BJ, Dixon L, Cole BR, Moser DK, et al. Implantable cardioverter defibrillator (ICD) deactivation discussions: Reality versus recommendations. European Journal of Cardiovascular Nursing. 2016 Feb 1;15(1):20-9.
9. Trussler A, Alexander B, Campbell D, Alhammad N, Enriquez A, Chacko S, et al. Deactivation of Implantable Cardioverter Defibrillator in Patients With Terminal Diagnoses. American Journal of Cardiology. 2019;124(7):1064-8.
10. Nakazawa M, Suzuki T, Shiga T, Suzuki A, Hagiwara N. Deactivation of implantable cardioverter defibrillator in Japanese patients with end-stage heart failure. Journal of Arrhythmia. 2020;(October):1-7.
11. Kramer DB, Kesselheim AS, Brock DW, Maisel WH. Ethical and legal views of physicians regarding deactivation of cardiac implantable electrical devices: A quantitative assessment. Heart Rhythm. 2010 Nov;7(11):1537-42.
12. Goldstein NE, Mehta D, Teitelbaum E, Bradley EH, Morrison RS. "It's Like Crossing a Bridge" Complexities Preventing Physicians from Discussing Deactivation of Implantable Defibrillators at the End of Life. Journal of General Internal Medicine [Internet]. 2008 Jan 19 [cited 2019 Apr 30];23(S1):2-6.
13. Mitar M, Alba AC, Maciver J, Ross H. Lost in translation: Examining patient and physician perceptions of implantable cardioverter-defibrillator deactivation discussions. Circulation: Heart Failure. 2012 Sep;5(5):660-6.
14. Mueller PS, Jenkins SM, Bramstedt KA, Hayes DL. Deactivating Implanted Cardiac Devices in Terminally Ill Patients: Practices and Attitudes. PACE - Pacing and Clinical Electrophysiology. 2008;31(5):560-8.
15. Sherazi S, Daubert JP, Block RC, Jeevanantham V, Abdel-Gadir K, DiSalle MR, et al. Physicians' preferences and attitudes about end-of-life care in patients with an implantable cardioverter-defibrillator. Mayo Clinic Proceedings. 2008;83(10):1139-41.
16. Goldstein NE, Bradley E, Zeidman J, Mehta D, Sean Morrison R, Hertzberg Palliative B. Barriers to Conversations about Deactivation of Implantable Defibrillators in Seriously ill Patients: Results of a Nation Wide Survey Comparing Cardiology Specialists to Primary Care Physicians NIH Public Access. J Am Coll Cardiol [Internet]. 2009 [cited

2019 Aug 12];54(4):371-3.
17. Goldstein NE, Mehta D, Siddiqui S, Teitelbaum E, Zeidman J, Singson M, et al. "That's Like an Act of Suicide" Patients' Attitudes Toward Deactivation of Implantable Defibrillators. Journal of General Internal Medicine. 2008 Jan;23(S1):7-12.
18. Stewart GC, Weintraub JR, Pratibhu PP, Semigran MJ, Camuso JM, Brooks K, et al. Patient Expectations From Implantable Defibrillators to Prevent Death in Heart Failure. Journal of Cardiac Failure. 2010 Feb;16(2):106-13.
19. Hadler RA, Goldstein NE, Bekelman DB, Riegel B, Allen LA, Arnold RM, et al. "Why would I choose death?": A qualitative study of patient understanding of the role and limitations of cardiac devices. Journal of Cardiovascular Nursing. 2019 May 1;34(3):275-82.
20. McEvedy SM, Cameron J, Lugg E, Miller J, Haedtke C, Hammash M, et al. Implantable cardioverter defibrillator knowledge and end-of-life device deactivation: A cross-sectional survey. Palliative Medicine. 2018 Jan 1;32(1):156-63.
21. Joshi A, Kale S, Chandel S, Pal D. Likert Scale: Explored and Explained. British Journal of Applied Science & Technology. 2015;7(4):396-403.
22. Kapa S, Mueller PS, Hayes DL, Asirvatham SJ. Perspectives on withdrawing pacemaker and implantable cardioverter- defibrillator therapies at end of life: Results of a survey of medical and legal professionals and patients. Mayo Clinic Proceedings. 2010;85(11):981-90.
23. Hutchinson RN, Gutheil C, Wessler BS, Prevatt H, Sawyer DB, Han PKJ. What is Quality End-of-Life Care for Patients With Heart Failure? A Qualitative Study With Physicians. Journal of the American Heart Association. 2020;9(18):e016505.
24. Matlock DD, Nowels CT, Masoudi FA, Sauer WH, Bekelman DB, Main DS, et al. Patient and cardiologist perceptions on decision making for implantable cardioverter-defibrillators: A qualitative study. PACE - Pacing and Clinical Electrophysiology. 2011 Dec;34(12):1634-44.
25. Stoevelaar R, Brinkman-Stoppelenburg A, van Driel AG, Theuns DAMJ, Bhagwandien RE, van Bruchem-Visser RL, et al. Trends in time in the management of the implantable cardioverter defibrillator in the last phase of life: a retrospective study of medical records. European Journal of Cardiovascular Nursing. 2019;18(6):449-57.
26. Kinch Westerdahl A, Magnsjö J, Frykman V. Deactivation of implantable defibrillators at end of life — Can we do better? International Journal of Cardiology. 2019;291:57-62.
27. Padeletti L, Arnar DO, Boncinelli L, Brachman J, Camm JA, Daubert JC, et al. EHRA Expert Consensus Statement on the management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy. Europace. 2010;12(10):1480-9.
28. - Stoevelaar R, Brinkman-Stoppelenburg A, van Bruchem-Visser RL, van Driel AG, Bhagwandien RE, Theuns DAMJ, et al. Implantable cardioverter defibrillators at the end of life: future perspectives on clinical practice. Netherlands Heart Journal. 2020;28(11):565-70.
29. Herman M, Horner K, Ly J, Vayl Y. Deactivation of Implantable Cardioverter-Defibrillators in Heart Failure. Journal of Hospice and Palliative Nursing. 2018;20(1):63-71.
30. Javaid MR, Squirrell S, Farooqi F. Improving rates of implantable cardioverter defibrillator deactivation in end-of-life care. BMJ Open Quality. 2018;7(2):1-7.
31. Choi DY, Wagner MP, Yum B, Jannat-Khah DP, Mazique DC, Crossman DJ, et al. Improving implantable cardioverter defibrillator deactivation discussions in admitted patients made DNR and comfort care. BMJ Open Quality. 2019 Dec;8(4):e000730.
32. Hauptman PJ, Swindle J, Hussain Z, Biener L, Burroughs TE. Physician Attitudes Toward End-Stage Heart Failure: A National Survey. American Journal of Medicine. 2008;121(2):127-35.
33. Selman L, Harding R, Beynon T, Hodson F, Coady E, Hazeldine C, et al. Improving end-of-life care for patients with chronic heart failure: "Let's hope it'll get better, when I know in my heart of hearts it won't." Heart. 2007;93(8):963-7.
34. Hanratty B, Hibbert D, Mair F, May C, Ward C, Capewell S, et al. Primary care focus group study. Bmj [Internet]. 2002;325(September):581-5. Available from: http://www.bmj.com/content/325/7364/581.pdf%2Bhtml
35. Momen NC, Barclay SIG. Addressing "the elephant on the table": Barriers to end of life care conversations in heart failure - A literature review and narrative synthesis. Current Opinion in Supportive and Palliative Care. 2011;5(4):312-6.
36. Raphael CE, Koa-Wing M, Stain N, Wright I, Francis DP, Kanagaratnam P. Implantable cardioverter-defibrillator recipient attitudes towards device deactivation: How much do patients want to know? PACE - Pacing and Clinical Electrophysiology. 2011;34(12):1628-33.
37. Groarke J, Beirne A, Buckley U, O'Dwyer E, Sugrue D, Keelan T, et al. Deficiencies in patients' comprehension of implantable cardioverter defibrillator therapy. PACE - Pacing and Clinical Electrophysiology. 2012;35(9):1097-102.

38. Kirkpatrick JN, Gottlieb M, Sehgal P, Patel R, Verdino RJ. Deactivation of implantable cardioverter defibrillators in terminal illness and end of life care. American Journal of Cardiology [Internet]. 2012;109(1):91-4.
39. Pasalic D, Gazelka HM, Topazian RJ, Buchhalter LC, Ottenberg AL, Webster TL, et al. Palliative Care Consultation and Associated End-of-Life Care After Pacemaker or Implantable Cardioverter-Defibrillator Deactivation. American Journal of Hospice and Palliative Medicine. 2016 Dec 1;33(10):966-71.
40. Bradley A MA. Clinician Attitudes Regarding ICD Deactivation in DNR/DNI Patients. Journal of Hospital Medicine. 2017;12(7):498-502.

Appendix A: Survey Questions.

SECTION ONE: Demographics

What is your role (select more than one if applicable)?

a) Cardiologist b) Geriatrician c) General Physician

What is your Gender?
a) Male b) Female

What is your age?

<40 b) 40–49 c) 50–59 d) >60

How many years have you been qualified as an SMO in your specialty?

<10 b) 10–19 c) 20–29 d) >30

SECTION TWO: Perceptions

This section aims to explore your views on deactivation of defibrillators.
These questions are on a Likert scale as follows:

1	*2*	*3*	*4*	*5*	*N/A*
(strongly agree)	*(somewhat agree)*	*(neutral)*	*(somewhat disagree)*	*(strongly disagree)*	

In a competent patient with a terminal illness, I feel it is ethically appropriate to deactivate a defibrillator if they request this.

I feel that deactivation of defibrillators at the request of a patient is ethically similar to refusal of implantation.

I feel that family should all agree to the decision of deactivation before it is performed.

I feel that active defibrillators have the potential to worsen quality of life at the end of a terminal illness.

I think all patients with defibrillators should have timely discussions about deactivation.

SECTION THREE: Conversations

This section aims to explore your level of comfort and training in regard to conversations, as well as barriers to communication.

These questions are on a Likert scale as follows:

1	*2*	*3*	*4*	*5*	*N/A*
(strongly agree)	*(somewhat agree)*	*(neutral)*	*(somewhat disagree)*	*(strongly disagree)*	

I feel comfortable bringing up the option of deactivation with my patients.

I feel confident in my communication skills about end of life issues.

I feel I have had enough training and support to have these discussions.

I have enough time with my patients to have conversations about deactivation when I need to.

I feel conversations about deactivation might cause anxiety in my patients.

I feel conversations about deactivation may negatively affect my patient-doctor relationship.

I feel that uncertainty over prognosis can make it difficult to have deactivation conversations.

What other barriers prevent you from discussing deactivation of ICDs? [free text].

SECTION FOUR: Practice

This section aims to explore your usual practice of communication with patients
Note that the Likert scale is slightly different to the previous questions.

These questions should be answered with a Likert scale as follows:

1	*2*	*3*	*4*	*5*	*N/A*
(always)	*(most of the time)*	*(sometimes)*	*(occasionally)*	*(never)*	

I discuss the possibility of future deactivation of ICDs at the time of implantation.

I discuss the possibility of deactivation of ICDs with patients who have developed a terminal or rapidly progressive disease.

I discuss the possibility of deactivation of ICDs with patients who I feel have a rapidly declining quality of life.

I discuss the possibility of deactivation of ICDs with patients who have had increasing numbers of hospital admissions.

My patients are aware that if treatment with an ICD were becoming burdensome, they would have the option of deactivation.

If I made a decision to deactivate an ICD, I would attend the bedside of a patient during the deactivation.

I bring up advance care planning with patients with terminal or rapidly progressive disease.

I involve palliative care to help with decision making in complex cases involving ICDs.

Do you have any other comments on this topic?

The changing use of anticoagulants in New Zealand

Paul Harper, Alison Chang, Matt Stephens

ABSTRACT

aims: To assess the change in the use of oral anticoagulants in New Zealand over 10 years since the introduction of dabigatran and rivaroxaban.

methods: Data were collected from the National Pharmaceutical database from January 2011 to March 2021. Seven and a half million prescriptions for oral anticoagulants were analysed.

results: The total number of people taking oral anticoagulants increased from 46,000 in July 2011 to 105,000 by March 2021. The growth was predominantly from the increased use of direct oral anticoagulants (DOACs). Initially, dabigatran was the only funded DOAC in New Zealand; approximately 50,000 people were taking this medication by August 2018, when rivaroxaban was introduced. Subsequent growth has predominantly been from rivaroxaban, with 23,000 users by March 2021. Warfarin use has dropped by 50% over the last 10 years.

conclusions: The introduction of the DOACs was expected to reduce the use of warfarin. However, the rapid rise in DOAC use was not predicted. The increase is most likely in patients with atrial fibrillation with the positive benefit of reducing the incidence of embolic stroke. However, having a high proportion of the elderly population (15% of people over 75-years) on anticoagulants has implications for the health sector, making hospital admissions and surgery more complex.

Since the introduction of warfarin over 50 years ago, the indications for anticoagulants have changed considerably. For many years warfarin has been the standard treatment for venous thrombosis and pulmonary embolus, and it has been used to prevent thrombosis in people with mechanical heart valves. Practice changed in the 1990s when studies showed that anticoagulants reduced the risk of stroke in people with atrial fibrillation (AF) by approximately 64%.[1,2] This led to a steady growth in warfarin use, and by 2010 approximately 60% of people on anticoagulants were taking it for stroke prevention in AF. Despite the clear benefit, studies at the time from the UK and the US showed that anticoagulants were underutilised, with over 50% of patients who could benefit from treatment not prescribed with anticoagulants.[3,4] Approximately 1% of the New Zealand population have AF, with the prevalence increasing with age to greater than 10% over the age of 70yrs. In New Zealand, this equates to approximately 55,000 people;[5] however, in 2011 only 27,000 were taking warfarin for stroke prevention in AF.

In the last 10 years, there have been further changes following the introduction of direct oral anticoagulants (DOACs). In July 2011, dabigatran became available in New Zealand. It was initially approved for the prevention of stroke in AF and for prophylaxis in orthopaedic surgery. Approval was widened in July 2014 to include the prevention and treatment of deep vein thrombosis and pulmonary embolus. It remained the only fully funded DOAC in New Zealand until August 2018, when rivaroxaban was approved for stroke prevention in AF and for the treatment of venous thromboembolic disease. In the last few years, the use of DOACs has widened further and replaced low molecular weight heparin for prophylaxis in some orthopaedic surgery, and rivaroxaban is used for the treatment of thrombosis related to malignancy.

The DOACs are more convenient, and have a better safety profile than warfarin with a lower incidence of intracranial haemorrhage. Therefore, since 2011, we have seen a shift from warfarin to the DOACs and an increase in the total number of patients on anticoagulants, as patients who were previously deterred from using warfarin by the frequent testing would find these drugs more acceptable. One potential barrier to the rapid up take of dabigatran was the lack of a reversal agent prior to September 2016. Since then, funding for idarucizumab has been approved by The Pharmaceutical Management Agency (PHARMAC), enabling this reversal agent to be used in New Zealand public hospitals. A reversal agent for rivaroxaban is not available.

Another factor that may have influenced the shift from warfarin to the DOACs was a potential change in practice during the COVID-19 pandemic. In April 2020, the Thrombosis & Haemostasis Society of Australia and New Zealand (THANZ) produced a statement on the management of warfarin monitoring during the COVID-19 pandemic. One of their suggestions was for doctors to consider changing patients from warfarin to DOACs to reduce laboratory visits.[6]

The primary aim of this study is to assess the impact of the introduction of DOACs on anticoagulant use in New Zealand over the last 10 years. A secondary consideration is to see if the advice given during lockdown altered practice with a trend away from warfarin use.

Methods

Data source

Data were collected from the Ministry of Health pharmaceuticals database from 1 January 2011 to 31 March 2021. Data on all prescriptions issued in New Zealand are recorded in this database. The following information was obtained for each prescription during the study period; the date the medication was dispensed, the patient's national identification number (encrypted), the medication dispensed (dabigatran, rivaroxaban or warfarin), the dose prescribed, the patient's gender and age at time of dispensing.

Data analysis

Data were analysed using Microsoft Excel power pivot software. Data analysis models were developed to calculate the total number of patients who received at least one prescription each month and the mean age at time of dispensing grouped by gender for warfarin, dabigatran and rivaroxaban. The prescription data were summarised as total counts for each drug plotted over time. The population data is presented as a proportion of total population as a percentage.

Patient numbers

Warfarin

Warfarin patients fill prescriptions irregularly, as their dose can change frequently based on the INR. A patient on continuous warfarin therapy can fill a prescription anywhere between monthly and every six months. To estimate the total number of patients on warfarin at a specific time we looked at the number of people who received at least one prescription over various intervals (three months, four months, five months and six months); the three-month interval is likely to underestimate the total as it fails to include patients collecting a script every four to six months; and the six-month total is likely to overestimate the total as it will include patients on short term treatment (for example, a patient who started three months treatment in January will still be counted as being on treatment in June). Based on our assessment, we concluded that using an interval of four months between prescriptions gives a reasonable estimate of the total number of people on warfarin.

We have assumed that an interval between prescriptions of four months or less implies the patient is on anticoagulants the whole time between prescriptions. If the interval is longer than four months, we have assumed the patient has discontinued anticoagulant therapy and restarted later. We have also assumed that a patient has continued treatment for three months after their last prescription (unless they had a new prescription for dabigatran or rivaroxaban).

Dabigatran and rivaroxaban

For dabigatran and rivaroxaban patients the interval between prescriptions is usually less than for warfarin as the drug is dispensed monthly, but patients on continuous treatment do not necessarily fill a prescription every month.

To calculate the estimated number of patients on treatment at a specific time, we have assumed that an interval between prescriptions of two months or less implies the patient is on anticoagulants the whole time between prescriptions. If the interval is longer than two months, we have assumed the patient has discontinued anticoagulant therapy and restarted later. We have also assumed that a patient has stopped treatment the month of their last prescription, as the DOACs are only dispensed monthly.

The following estimates were calculated for dabigatran, rivaroxaban and warfarin each month: (1) The total number of patients on treatment; (2) the total number starting treatment; (3) the total number stopping treatment; and (4) the total number changing between treatments.

The study was approved by the National Ethics committee; ref 14/CEN/135.

Results

Prescriptions

Seven point five million prescriptions for oral anticoagulants were issued during the 10-year study period. A total of 237,218 people received at least one prescription of an oral anticoagulant: Warfarin – 109,416; Dabigatran – 126,108; and Rivaroxaban – 61,918 (over 60,000 received more than one medication).

Warfarin

The number of patients filling warfarin prescriptions dropped by approximate 2,100 (~10%) at the time that dabigatran was introduced (July 2011). The mean number of patients filling at least one prescription each month for the first six months of 2011 (before dabigatran) was 20,530; the mean for the second six months of 2011 was 18,423. There has been a steady fall in prescription numbers over the last 10 years. The mean for

Figure 1: The number of prescriptions dispensed each month from January 2011 to March 2021.

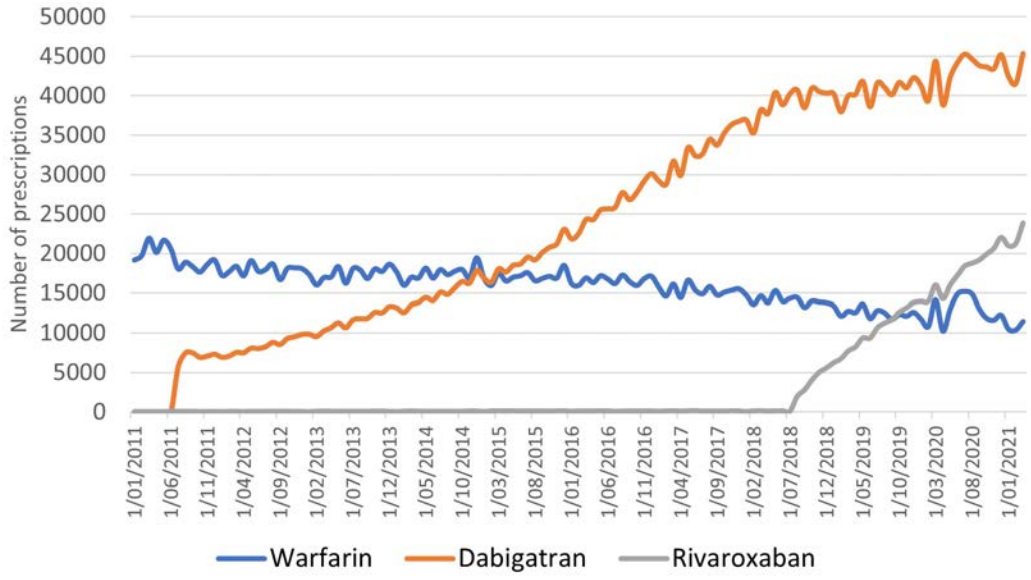
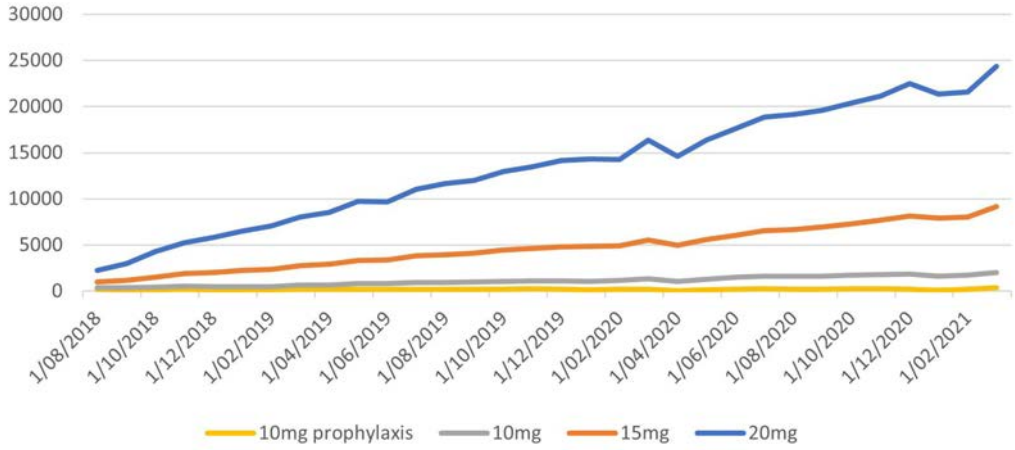


Figure 2: The number of rivaroxaban prescription dispensed each month by tablet size. Patients who received a single prescription for 10mg were assumed to be taking treatment for orthopaedic prophylaxis.



six months from October 2020 to March 2021 was 11,308; a fall of 45% from before the introduction of dabigatran and 38.6% since 2012 (Figure 1).

Dabigatran

The number of patients filling prescription for dabigatran had increased steadily since August 2011, until the introduction of rivaroxaban. Approximately 7,000 patients filled prescriptions for dabigatran each month immediately after its introduction. This has increased by approximately 2% each month since then to approximately 40,000 per month by July 2018, when rivaroxaban was introduced, and has increased more slowly since; the mean of six months from October 2020 to March 2021 was 53,000 (Figure 1).

Rivaroxaban

The number of patients filling prescriptions for rivaroxaban has increased steadily since its introduction in August 2018. We have assumed that patients who had a single prescription for 10mg were receiving treatment for surgical prophylaxis. An increasing number are receiving long term therapy at 10mg. In March 2021, 23,000 prescriptions were dispensed (Figure 2).

Patient numbers

Approximately 46,500 people were taking warfarin at the time dabigatran was introduced. The number dropped to approximately 41,600 within six months (~10%). The number of patients on warfarin remained constant until mid-2014, and subsequently the number fell to 36,000 by March 2017; 29,500 by March 2019; and 23,200 by March 2021—a fall of 50% since April 2011 (before dabigatran).

The number of patients on dabigatran rose to approximately 8000 in August 2011, and has shown a consistent increase to mid-2015, and faster growth to mid-2018 to a total of 51,000 patients. Dabigatran numbers only increased by a further 3,000 between July 2018 and March 2021.

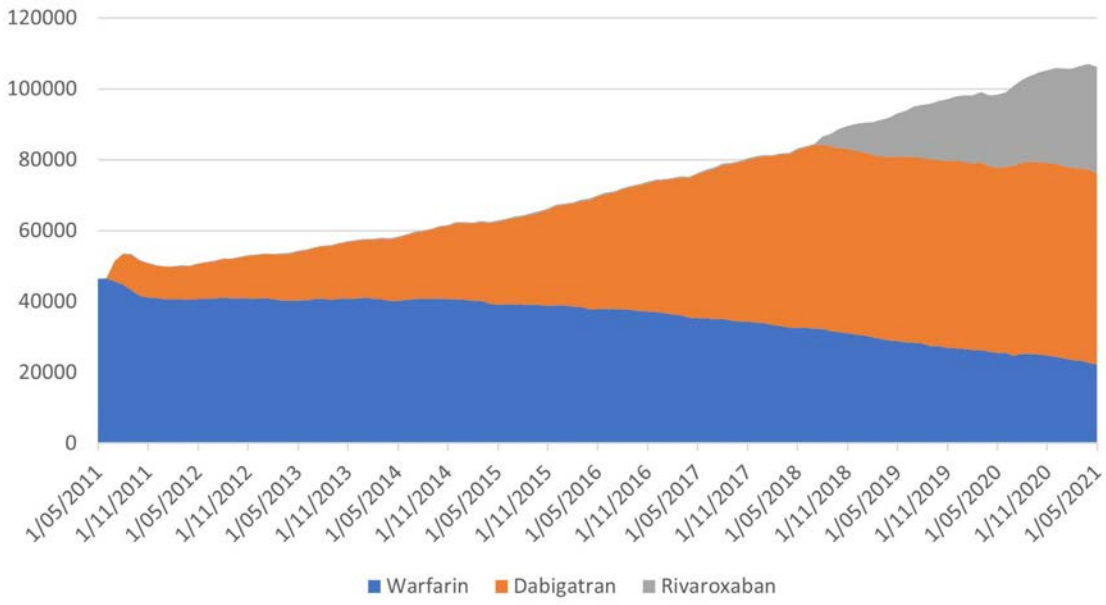
In August 2018, rivaroxaban was fully funded and use has grown rapidly since with approximately 30,000 people prescribed treatment by March 2021. The total number of patients on anticoagulants has risen consistently since the introduction of dabigatran from 46,000 to approximately 105,000; an increase of 140% over 10 years (Figure 3).

Changing anticoagulants

During the first month after the introduction of dabigatran, approximately 5,000 people switched from warfarin to dabigatran; however, a large proportion of these changed back to warfarin over the next six months.

From 2012 to 2014, the number of people starting dabigatran each month has risen steadily and the majority are new to the medication, with only a small number switching from warfarin to dabigatran (<100 per month) and a similar number changing the other way. From 2014 to 2018, the number of people starting dabigatran increased

Figure 3: Estimated number of patients on anticoagulants.



more rapidly and more people switch from warfarin to dabigatran, but the latter group are still only a small proportion of the total (<10%).

The number of people who discontinue dabigatran every month is high, and almost half as many discontinue treatment as start each month. These are either people who stop dabigatran completely and have no further prescriptions, or people who have an interval of more than three months between prescriptions.

Following the introduction of rivaroxaban in August 2018, approximately 300 people each month changed from dabigatran to rivaroxaban and the growth in dabigatran use has declined (Figure 4)

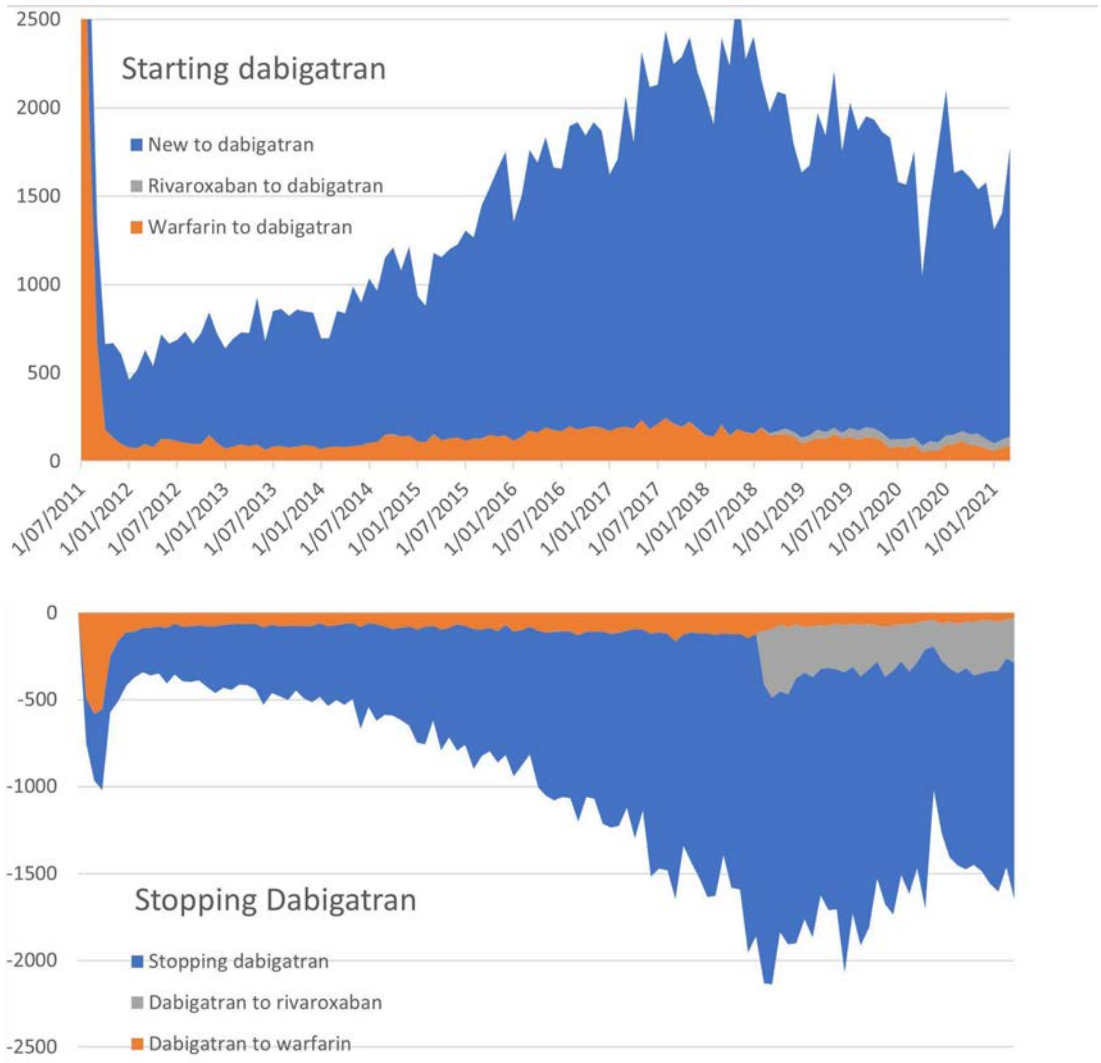
Patient age

The mean age for people on warfarin has risen progressively from 2011 to 2018 and has subsequently shown a slight fall. The age of people on dabigatran has been stable over the whole study period, but since 2018 there has been a trend to use the drug in older patients. Rivaroxaban was initially used in younger patients as it was probably primarily used to manage venous thrombosis but shows a similar trend to dabigatran (Figure 5).

Impact of lockdown

On 23 March 2020, the Government announced that New Zealand would go into Level 4 lockdown

Figure 4: Top half–the number of people starting dabigatran each month; dispensed either their first prescription or a prescription more than three months since their last. They were either new to dabigatran or changed from warfarin or rivaroxaban. Bottom half–the number of people who discontinued dabigatran each month. They either stopped treatment completely or changed to warfarin or rivaroxaban.



on 25 March. The country reverted to Level 3 on 27 April 2020. Our data shows that during the week immediately prior to lockdown the number of prescriptions increased. During lockdown there was a brief reduction in dispensing. There was no clear evidence that the number of warfarin prescriptions dropped following lockdown (Figure 6).

Estimates of anticoagulant use

Historical audit data prior to 2011 showed that approximately 60% of patients are on warfarin for AF, 20% for VTE treatment and prevention, 12% for prosthetic heart valves and 8% for other reasons.[7,8] On this basis, we estimate that approximately 27,500 patients were on anticoagulants for AF prior to the introduction of dabigatran.

The total number of patients on warfarin for mechanical heart valves and "other" indications would be expected to remain constant over time. Also, the total number of patients on treatment for acute VTE is likely to remain stable, although from July 2014 treatment would be split between dabigatran and warfarin. The management of the prevention of recurrent VTE has changed with more patients being advised to remain on long term

Figure 5: The mean age of patients dispensed warfarin, dabigatran and rivaroxaban calculated each month.

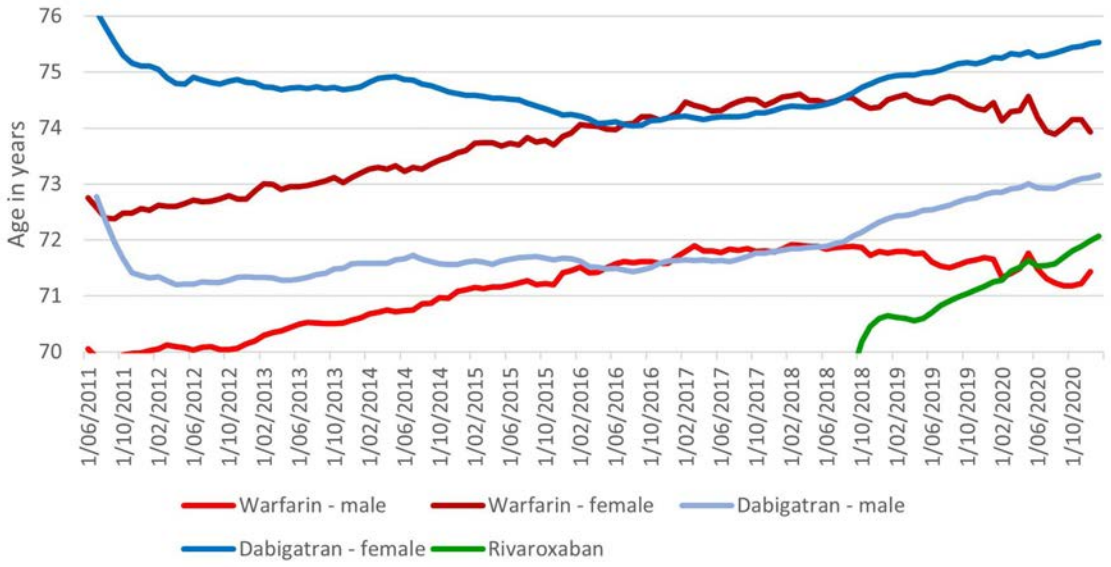
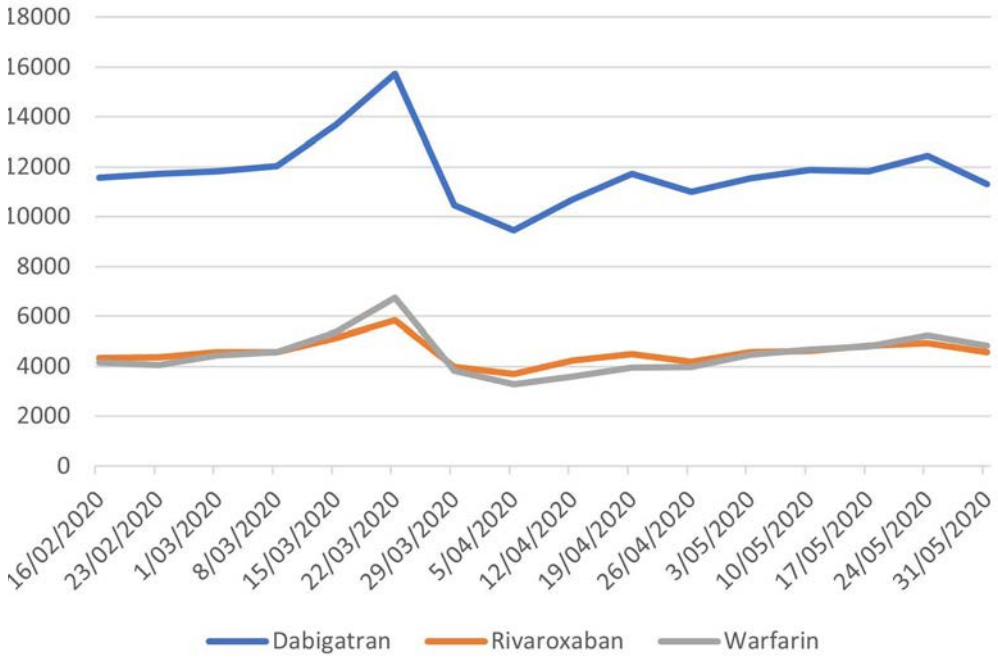


Figure 6: The number of prescriptions dispensed each week during lockdown.



anticoagulants especially with the convenience of the DOACs. We have estimated that anticoagulants for VTE could have doubled over 10 years.

Based on our estimates, the number of patients on anticoagulants for AF has increased 2.8 times from 27,500 in July 2011 to 78,000 by 2021.

Proportion of patients in New Zealand on anticoagulants

The number of people in New Zealand on anticoagulants presented by age group is shown in Table 2. This is based on population data from Statistics New Zealand (data for 2020).[9]

Discussion

The most striking finding is that the total number of people on oral anticoagulants in New Zealand has more than doubled over 10 years; from 46,000 in 2011 to over 100,000 by 2021 (Figure 3). Although we do not have clinical details of the patients, our estimates suggest that most new

Table 1: Estimates of anticoagulant use over time.

		July 2011	July 2014	July 2017	July 2020	Mar 2021
Warfarin total		46,000	40,500	35,000	25,000	23,200
Dabigatran total			18,500	42,400	53,500	54,200
Rivaroxaban total					22,500	29,000
Atrial fibrillation	Warfarin	27,500	22,000	39,400	11,000	9,700
	Dabigatran		18,500	29,000	46,000	45,200
	Rivaroxaban				19,000	23,000
Total AF patients		**27,500**	**40,500**	**68,400**	**76,000**	**77,900**
Management of VTE	Warfarin	9,500	9,500	7,500	5,000	4,500
	Dabigatran			3,000	7,500	9,000
	Rivaroxaban				3,500	6,000
Mechanical heart valves	Warfarin	5,500	5,500	5,500	5,500	5,500
Others	Warfarin	3,500	3,500	3,500	3,500	3,500

Table 2: Estimates of the total number of people on anticoagulants in various age groups in New Zealand.

	Number on anticoagulants	New Zealand population	% of population on anticoagulants
>65yrs	80,628	792,100	10.2
>70yrs	68,176	539,420	12.6
>75yrs	50,797	331,900	15.3
>80yrs	32,832	185,500	17.7
>85yrs	16,410	88,500	18.5
>90yrs	5,537	33,070	16.7

cases are likely to be receiving anticoagulants for stroke prevention in AF; approximately 27,000 people were on anticoagulants for AF in 2011 and this has increased to over 70,000 by 2021 (Table 1). This is in line with data from other countries which show that 90% of patients on DOACs are taking them for stroke prevention in AF. This marked increase in use means approximately 12% of people over the age of 70yrs in New Zealand are on anticoagulants, and this rises to 17% in those over 80yrs (Table 2).

It was predicted that the introduction of the DOACs would lead to a move away from warfarin, as the new anticoagulants are more convenient and have a better safety profile with a lower incidence of intracranial bleeding; however, the transition has been slower than many expected. One explanation is that there was some nervousness around the risk of bleeding soon after dabigatran was introduced. In July 2011, approximately 5,000 people switched to dabigatran, but within weeks cases of serious bleeding were reported[10] which led to a large proportion changing back to warfarin. Nonetheless, this initial enthusiasm for a new anticoagulant led to a 12% drop (46,500 to 41,300) in patients on warfarin by the end of 2011. The concern around bleeding led to a change in practice with both clinicians[11] and the dabigatran manufacturers, recommending that patients stable on warfarin should remain on treatment and that dabigatran should be primarily used for new patients. This would explain why the warfarin numbers remained relatively stable between 2012 and 2015 (Figure 3), supported by the data that shows only a small proportion of patients change from warfarin to dabigatran each month (Figure 4). The steady increase in the median age over time is also in keeping with the warfarin population being relatively stable (Figure 5).

The more rapid decline in warfarin since 2015 is probably due to dabigatran being approved for venous thromboembolic disease; the DOACs are now largely used as first line treatment for venous thrombosis and pulmonary embolus. Warfarin use is likely to reach a plateau as patients with mechanical heart valves, lupus anticoagulant or unusual thromboses need to remain on warfarin and there are some people who cannot tolerate either of the available DOACs. The baseline level is hard to predict, as warfarin use continues to fall steadily and there is currently no sign of a plateau.

During the COVID-19 pandemic in 2020, our results showed there had been no change in warfarin use despite the advice from THANZ. In March 2020, there was an increase in the number of prescriptions dispensed immediately prior to lockdown which subsequently dropped during lockdown itself. However, by May 2020 the number of prescriptions for all three medications had recovered to the pre-lockdown level, and there has been no clear evidence of a more rapid move away from warfarin use since (Figure 6).

The uptake of DOACs has steadily increased and continues to rise. The number of people on dabigatran exceeded those on warfarin by the end of 2016, and currently over 50,000 people take this medication. Practice changed following the introduction of rivaroxaban in 2018, and rivaroxaban appeared to have become the preferred DOAC. It has the advantage of being a “once daily” medication, and can be used for the treatment of DVT and PE from diagnosis without the need for a low molecular weight heparin; hence, it has become the drug of choice for managing acute venous thrombosis.

The clinical impact of these changes is uncertain, but it potentially has both positive and negative effects. The expected benefit is that a higher proportion of people with AF are receiving anticoagulants, and therefore the incidence of embolic stroke should be reduced. This is yet to be confirmed and is part of an ongoing study.

The downside to the wider use of anticoagulants is the increased risk of bleeding. The long-term use of both warfarin and DOACs has been associated with a higher incidence of bleeding complications particularly in the elderly.[12–14] This can be problematic for those admitted to hospital, especially if they require urgent surgery. Patients on anticoagulants admitted with trauma have a higher complication rate with more requiring surgical intervention.[15]

Anticoagulants are used directly as preventative medicine to reduce the risk of stroke in AF and to prevent recurrence in DVT and PE. It is appropriate that all patients who are likely to benefit have access to these drugs. However, the increase in anticoagulant use has been dramatic over the last 10 years, and it is important that clinicians have the necessary knowledge to use these drugs safely, are aware of the potential complications and the impact these have on our health system.

COMPETING INTERESTS
Nil.

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REFERENCES
1. Preliminary report of the Stroke Prevention in Atrial Fibrillation Study. N Engl J Med. 1990;322:863-8.
2. Petersen P, Godtfredsen J, Boysen G, et al. Placebo-controlled, randomised trial of warfarin and aspirin for prevention of thromboembolic complications in chronic atrial fibrillation: The Copenhagen AFASAK Study. The Lancet. 1989;333:175-9.
3. Ogilvie IM, Newton N, Welner SA, et al. Underuse of Oral Anticoagulants in Atrial Fibrillation: A Systematic Review. Am J Med. 2010;123:638-645.e4.
4. Pechlaner C. Anticoagulation for atrial fibrillation: Underuse? Am J Med. 2011;124:e11.
5. Tomlin A, Lloyd H, Tilyard M. Atrial fibrillation in New Zealand primary care: Prevalence, risk factors for stroke and the management of thromboembolic risk. Eur. J. Prev. Cardiol. 2017;24:311-9.
6. THANZ [Internet]. [cited 2021 Jul 26]. Available from: https://www.thanz.org.au/news/outpatient-inr-monitoring-for-patients-receiving-warfarin-during-covid-19-pandemic
7. Young L, Ockelford P, Harper P. Audit of community-based anticoagulant monitoring in patients with thromboembolic disease: is frequent testing necessary? Intern Med J. 2004;34:639-41.
8. Kirley K, Qato DM, Kornfield R, et al. National Trends in Oral Anticoagulant Use in the United States, 2007 to 2011. Circ Cardiovasc Qual Outcomes. 2012;5:615-21.
9. Statistics New Zealand. [accessed 2021 Jul 26]. Available from: http://infoshare.stats.govt.nz/ViewTable.aspx?pxID=83faf750-e860-4102-877d-9e6baedadd1c
10. Harper P, Young L, Merriman E. Bleeding Risk with Dabigatran in the Frail Elderly. N Engl J Med. 2012;366:864-6.
11. Baker R, Harper P, McLintock C. Avoiding adverse events with dabigatran by careful selection of eligible patients. Med J Aust. 2012;196:431-2.
12. Khan F, Tritschler T, Kimpton M et al. Long-Term Risk for Major Bleeding During Extended Oral Anticoagulant Therapy for First Unprovoked Venous Thromboembolism. Ann Intern Med. 2021;174:1420-1429.
13. Gunasekaran K, Rajasurya V, Devasahayam J et al. Review of the Incidence Diagnosis and Treatment of Spontaneous Hemorrhage in Patients Treated with Direct Oral Anticoagulants. J. Clin. Med. 2020, 9, 2984.
14. Wysowski DK, Nourjah P, Swartz L. Bleeding complications with warfarin use: a prevalent adverse effect resulting in regulatory action. Arch Intern Med. 2007;167:1414-9.
15. Bläsius FM, Laubach M, Andruszkow H, et al. Impact of anticoagulation and antiplatelet drugs on surgery rates and mortality in trauma patients. Sci Rep. 2021;11:15172.

An exploration of Aotearoa New Zealanders' attitudes and perceptions on the use of posthumous healthcare data

Jon Cornwall, Sylvia English, Brendon Woodford, Jim Elliot, Kathryn McAuley

ABSTRACT

AIM: Posthumous electronic healthcare data (PHCD) are ubiquitous and increasing in volume. Despite their potential utility and value, no empirically-derived, publicly-generated information exists to guide what uses society may view as acceptable. This study explores the attitude and perceptions of Aotearoa New Zealanders to PHCD utilisation.

METHODS: Focus groups explored topics focused around PHCD utilisation, including family access, consent models, infrastructure, anonymity, governance, and commercialisation. Data were transcribed and general thematic analysis utilised to explore themes and topics.

RESULTS: Sixty-seven people participated across 12 focus groups (mean=50 minutes). Participants indicated conditional support for a centralised, Government-managed PHCD repository allowing controlled, no-cost access for healthcare and research purposes. Public benefit from data was important. Participants prioritised any benefits being preferentially directed to family, then Aotearoa New Zealanders, then others. Commercialisation from data use was viewed as likely and acceptable. Māori PHCD was considered preferably managed by Māori. Participants struggled to define appropriate levels of family access, anonymity, and consent models.

CONCLUSIONS: This study delivers the first empirical evidence of social license for PHCD utilisation, providing guidance for establishing trustworthy data governance. Further exploration of the subject is warranted to guide development of frameworks to utilise PHCD in Aotearoa New Zealand.

Large sets of digitised healthcare records are widely used to increase healthcare efficiency and effectiveness,[1,2] examine patient and disease profiles,[3] and explore epidemiological trends. Such digital files can exist for a potentially infinite period, ushering in an era of digital "e-mortality" (electronic immortality) where healthcare records will far outlive the persons whose data is held within them.

Digitised posthumous healthcare records, referred to here as posthumous healthcare data (PHCD), are the digitised healthcare records of those persons who have died, and they constitute an ever-growing collection whose potential use and utility are little explored.[4] If these data are not erased or destroyed, they will become the largest repository of digitised healthcare information. Due to their ever-expanding volume, PHCD will become increasingly valuable for inter- and intra-generational analysis of health datasets, including genomic analyses, or to allow comparison with other non-healthcare datasets (eg other government information).[5]

While large healthcare datasets can provide benefit, there are risks and harms associated with their use, including erosion of trust between the public and healthcare professionals which may affect how healthcare users access services.[6] In addition, within Aotearoa New Zealand there exist different cultural perspectives on healthcare data use, with frameworks around Māori data sovereignty[7] highlighting the necessity to include different perspectives around the future use of healthcare data in this country to guide socially and ethically appropriate utilisation of such a resource.

At present, there are no publicly informed guidelines or data to assist the future utilisation of PHCD in Aotearoa New Zealand. Neither are there any contemporary empirical data, from any country, that exist to guide a conversation around public expectations and social license on this subject.[8] This study explores the public's views on the use of PHCD in Aotearoa New Zealand, in order to provide information that can guide responsible management or utilisation of this precious resource.

Methods

Focus groups were used to gather information from a cross-section of the Dunedin community. Potential study participants over 18 years of age self-selected by responding to advertisements placed on several local public notice boards, in local newspapers, a local general practice with established links to the local Māori community (Te Kaika, Caversham, Dunedin) and via social media. Respondents were sent information, and registrants allocated to focus groups by age groups including years of age 18–25, 26–35, 36–50, 51–65, and 65+, with participant numbers across groups guided by recent NZ Census data.[9] Registered participants were allocated to focus groups to balance gender representation. Ethical approval was received from the University of Otago Human Ethics Committee (18/090), and the Ngāi Tahu Research Consultation Committee (2018). Participants provided informed consent and were gifted $35 koha for their participation.

Focus group format and questions

Focus groups were delivered in a face-to-face setting (authors JC, KM) using a semi-structured format with open-ended, investigator-driven questions on a range of topics that aimed to elicit discussion around PHCD, focusing on how participants viewed aspects surrounding the use of their own healthcare data in a posthumous scenario. Topics included discussion around general access, family access, anonymity, commercialisation of data, consent processes, data governance, and scope of data use. Focus groups were audio recorded.

Data analysis

Audio recordings were transcribed, then checked for accuracy by investigators (KM, JC). Transcriptions were then entered into the software analysis programme ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). A generic inductive thematic analysis was conducted, through an iterative process that examined transcript themes, compared differences between datasets, and explored responses from different individuals.[10] Descriptive codes were established and organised into higher order thematic categories. The plausibility and explanatory value of the categories were independently assessed by two researchers (KM, JC). Where differences arose, discussion of data helped to reconcile where content should be most appropriately allocated.

Results

Demographic and general data

Twelve focus groups were held, with a total of 67 participants (Table 1). Forty-seven persons self-identified as NZ European, four as Māori, and 16 as other ethnicities with one non-responder (Table 1). There were 598 total minutes of data from 12 focus groups (average focus group 50 minutes). The mode for focus group participation was six persons.

The importance of the topic

Participants were generally unaware of the topic of PHCD; however, there was general agreement that management of PHCD was an important social issue, stating a necessity to explore issues and provide clarity on future options (Table 2). Overall, there were strong themes of altruism, usefulness, community, beneficence, and respect conveyed by participants. Specific posthumous interests were acknowledged, focusing on both a person's own and familial interest in being well remembered after death, and in being respectful towards someone after they have died. Participants linked the idea of posthumous interests with the concept of respecting the data itself as having come from a living person.

Utilisation

Participants broadly agreed if data were useful, they should be used to benefit others, with the importance and difficulties of controlling data use specifically highlighted. This use was interpreted as a hierarchy with family benefiting preferentially, then Aotearoa New Zealanders, then other persons. Participants raised concerns over personal exploitation, whereby data use was for purposes they did not agree with. Commercialisation of data, and also data use by insurance companies, were identified as two major potential sources of exploitation, with participants suggesting discrimination "would create social inequities". However, there was general agreement that commercial use and/or profit was acceptable if it provided benefit to the community, though some participants expressed a general unease over money being made from PHCD. The prospect of using data to generate profit for Aotearoa New Zealand was acceptable and spread evenly across age groups, while some participants were in favour of commercial profits being returned to communities. Family profiting or receiving honoraria from data was discussed, and was acceptable

Table 1: Demographic profile of study participants.

Participant Demographics	
FG Age-groups	**No.**
18–25	12
26–35	13
36–50	16
51–65	11
65+	15
Gender	
F	44
M	21
GD	1
DNS	1
Self-identified ethnicity	
NZ European	47
Māori	4
Chinese	2
Indian	2
American Caucasian	1
Asian Filipino	1
Australian	1
Cook Island Māori	1
Dutch	1
English	1
Lithuanian	1
Fijian Indian	1
Irish	1
Fijian	1
Sri Lankan	1
DNS	1

FG: Focus group; No.: Number of persons; F: Female; M: Male; GD: Gender diverse; DNS: Did not say

Table 2: Participant quotes from focus groups.

Theme	Topic	Participant quote
Importance of the topic	National importance	"I think it's really important… So, it needs to be at the forefront of people's mind about what is actually going to happen to this information when you do pass. And with research and development being so important, especially for our country, it is very crucial that we do actually have some parameters around the laws for how people are going to use this information. So, definitely a worthwhile topic to be discussing."
	Respect	"It's also about having respect for posthumous data, like it someone died it would be having respect to that person by using that data appropriately."
	Cultural importance	"I think it's important. I'm Māori and I, death is very important in our culture. And lots of mahi in your body, and you're not meant to be burned and things like that. So, I'm very interested in this [subject], personally."
Utilisation	Insurance companies	"I can see a scenario where an insurance company might just grab hold of it and then use it to basically tighten up, make things restrictive for people who had certain conditions and would create societal inequities."
	Insurance companies	"I think they're all evil, very evil. There is potential for discrimination."
	Royalties	"I wouldn't mind if my children profited off it, yeah. I would trust that they would use their best judgement to use it wisely."
	Royalties	"I don't really like the idea of my family profiting off my illness, not at all.".
	Commercialisation	"Commercialising the data itself makes me feel a bit unhappy, not very, but commercialising the results from that data might be something more practical and more useful anyway."
	Commercialisation	"I think that maybe commercial use would be okay on the big scale if it was a New Zealand company."
	Commercialisation	"I see no problem with people making money out of it if it is for the betterment of the health of future generations."
Māori perspectives	Sovereignty	"Most iwi's now have doctors and barristers, graduates. You know, the younger generations. And I think that possibly I know Tainui have stuff in place. You know, it varies from iwi to iwi but I think that perhaps iwi's should appoint kaitiaki's [custodians] you know, for the information."
	Sovereignty	"Yeah. I don't think that, I don't want you to take offense to this, but I don't think Pākehā have much right to govern such…records".
	Storage	"I don't feel like my wairua would be able to move on and be happy walking with my tūpuna knowing that there's still a bit of information about me sitting somewhere."

Table 2 (continued): Participant quotes from focus groups.

Theme	Topic	Participant quote
Consent	Information	"You've got to make sure though that people are informed about it, coz a lot of people probably would never think about what's happening to their healthcare data after they die."
	Ownership	"I see it as, it's like a chattel that I have, that after I die, I make provision before I die for what's gonna happen to my chattels when I do die."
	Opt-in	"Well, the [organ] donor programme is a, is a classic example of the opt in not working. I prefer to opt in, to be honesty with you. I can see the point in having a much larger dataset, and I can see the importance of that. But it feels like it's just another breach of interpersonal trust for me."
	Opt-out	"And in the interest of collecting as much as possible but still giving people choice, I feel like an opt-out system would be more beneficial than an opt-in where you're just not going to get enough people."
	Opt-in or opt-out	"If personal data, for me, isn't going to be used in a way that's equitable and accessible to all, then I think we should have the ability to opt-in or opt-out."
Family interest	Intermediary	"Because it's almost like someone has to be there to advocate for the dead."
	Anonymity	"At a personal level, I wouldn't mind, but I can see the situations when it would be a problem for a lot of people."
	Access	"Yeah some of your family will wanna know and some won't, you know, and then do the ones that know, how do they share with the ones that don't, you know?"
Infrastructure	Storage	"I don't care [where data is stored], as long as it's not accessible by Donald Trump."
	Storage	"I would be happy for my records, personally, to be held in perpetuity."
	Storage	"If the data's going to be accessible and pieces of information are going to be comparable across a large section of the population, which is potentially where it becomes valuable I think, then it has to be catalogued and stored and accessible in a uniform way and not through however different agencies just happen to have stored it."
	Who stores data	"I think it needs to be a government. I don't think it can be ay health or university because it's going to cost money to set it up and run it and that means it's money that one of those agencies can no longer spend on bandages and suture which isn't going toe acceptable to them. But I think it should be a taxpayer government initiative that holds the database in the same way that they have a database of car registration information or whatever."
Governance	Anonymity	"I think the more that you use software and the internet, stuff like that, the more probably sophisticated you've become in terms of understanding that there really is no anonymity. There's no privacy."
	Anonymity	"For me they [posthumous healthcare data] absolutely need to be anonymous"
	Custodian	"The aspect of control is so vital to this whole thing working or not. Who controls the data, and how's it shifted around, how's it accessed, free or otherwise."
	Custodian	"I mean that's my biggest concern, if this goes forward who's the guardian, who's the gatekeeper?"
	Cultural perspectives	"I think we need to be aware of the fact that we are asking a number of different cultures to accept this."

in some instances, particularly if data use brought substantial commercial benefit—although a few found the idea of family profiting from data unacceptable. Participants were clear that PHCD itself should not be sold.

Māori perspectives

Māori participants viewed healthcare data as taonga (treasure), saying these data held special value and required specific protocols for guardianship. Furthermore, they indicated Māori governance of such data are essential. Some Māori participants said Māori may not wish to have data stored due to beliefs surrounding death and spirit, with the wairua (spirit) being intimately linked with existing data, suggesting that ongoing data storage meant the wairua of the deceased remained tied to its existence on earth, and that permanent retention of PHCD was therefore not acceptable.

Informed consent

The notion of acquiring informed consent prior to death was considered important by the majority of participants, with discussion focused on two main themes: public education and the importance of personal choice. Opinions around the need for informed consent largely focused on public education or autonomy, and informed consent was discussed more frequently among older age groups, with concern over health literacy regarding informed consent more commonly discussed in the 26–50 age groups.

Participants discussed "opt-in" or "opt-out" systems for individuals to give consent for their records to be included in a national database. Those in favour of opt-out outweighed those in favour of opt-in by a large margin. The two main reasons for this support were that more people would be part of the dataset, and that if people felt strongly about it, they could opt-out. Those in favour of an opt-in system of consent did value PHCD, but wished to make a choice to enter the system themselves.

Family interest

Participants considered some family situations would provide complexity to data collection, storage, and use. Scenarios included the implications of identifying non-biological relatives and issues regarding inheritance of genomic material, the possibility of incidental findings, and the idea of finding out a family secret—such as an abortion. The stigma associated with some health issues, such as sexually transmitted infections, was also raised, as was the possibility of different cultures having different values. The appointment of an external decision-maker/guardian alleviated concerns around respecting the wishes of the dead, given this identity should advocate for the interests of the dead.

Infrastructure

A majority felt PHCD should be stored in Aotearoa New Zealand, expressing concern over storing data overseas, based on differing laws and values in other countries. However, a few participants stated that they did not have a preference where data was stored. The main issues were concerns over hacking, the need for one system to create a streamlined framework for data, and breaches of privacy and trust.

The majority of participants supported keeping data indefinitely. Several participants specifically wanted their data kept indefinitely, citing mainly the usefulness of it, and not caring because they will "not be here". This position was especially marked in older age groups. A small number of participants did not want their data being kept indefinitely; two of these were Māori who cited spiritual reasons.

Governance

The advantages and disadvantages of a centralised system were discussed across age groups. A majority thought that posthumous data should be controlled by the Government. Of these, some thought the Ministry of Health or the National Archives should be responsible for data storage, with medical personnel involved in managing decisions around data use. Responses highlighted the need for posthumous data to have robust infrastructure, noting government departments likely have existing frameworks that may be fit for purpose. Non-governmental control over the data was explored widely but rejected due to lack of consistency in data management versus the extant stability of government systems.

Participants discussed data use and anonymity, with some not caring about being anonymous, while others insisted anonymity was important. Views included there being "no privacy" with electronic data, while others suggested added value or benefit would be seen without anonymity.

Discussion

Globally, awareness about posthumous digital data use is increasing,[11] including discussion around PHCD.[1,12] Findings suggest Aotearoa New

Zealanders provide conditional support for PHCD use, having PHCD stored indefinitely, and used in an ongoing manner. However, there are multiple factors to clarify further including appropriate infrastructure and governance, different consent models, and how Māori or different ethnic and cultural data should be managed.[13,14]

Utilisation

Within Aotearoa New Zealand, the Integrated Data Infrastructure (IDI) research database exists to allow access to a limited range of non-identifiable health information,[15] while similar international databases also exist for this purpose.[16] However, the amount of healthcare data available within these databases is both non-identifiable and limited to specific healthcare data (eg cancer registrations, mortality data). The storage of all posthumous health records in their entirety, potentially being identifiable to facilitate more precise health analyses, could therefore extend the utility of Aotearoa New Zealand's IDI system. Study findings also guide future uses to prevent erosion of trust between the public and data custodians,[17,18] with strong social license[8] for PHCD utilisation, and almost universal support for the information being used to benefit the future generations and global citizens. Participants suggested it is logical for PHCD to be used for research, with general agreement commercial use is acceptable *if* there is benefit, and agreement some commercialisation is necessary to benefit society. The most prominent concern was exploitation of a person's data, which is a common fear around healthcare data use[2,6] including within Aotearoa New Zealand.[19] Clear also was that PHCD should not be for sale, and that it should be a free resource to be used for benefiting others.

Insurance companies were almost exclusively viewed negatively, with a strong indication across all age groups that access to PHCD should not be allowed in this commercial area because of the potential for discrimination, especially for those persons with inheritable diseases. Some participants felt that allowing insurance company access to PHCD was an argument for retaining anonymity of data, so that individuals and families could not be specifically identified.

Māori and Other cultural perspectives

Perspectives indicated recognition and respect around Aotearoa New Zealand's multicultural society and the necessity to acknowledge that different groups may wish to govern their own data.[20] From the small number of Māori participants this view was also clear, with comments generally congruous with the framework of Te Mana Raraunga (Māori Data Sovereignty Network) recognising Māori data should be subject to Māori governance.[7] Broadly, study findings align with the concept of autonomous data rights, and data sovereignty for individuals and communities where control and decisions about the data are overseen by the communities themselves.[21] Local exploration in this space is continuing with the recently funded Genomics Aotearoa Rakeiora programme[22] and the framework of Whakamaua: Māori Health Action Plan 2020–2025.[23]

Consent

Participants considered informed consent important because of the notion of personal agency, though this was also viewed as potentially problematic with people not understanding what they are consenting to. Discussions around consent were driven by participants' wish to have control over the destiny of their "own" data before they died, with this attitude congruent with global trends around perspectives of data "ownership": participants wanted to be able to guide who could access it, and for what purpose. This is in line with global data trends around data control, such as the General Data Protection Regulation in Europe[24] that gives control of personal data to the person who generated it. However, there are suggestions that "co-constructors" of such data are "custodians", and the view of "ownership" of one's own health data need further exploration.[25] Comments around consent align with the strongly upheld value of informed consent within health services in Aotearoa New Zealand,[26] a value that is codified in law with the Code of Health and Disability Services Consumers' Rights (1996)[27] and the Health Information Privacy Code (2020).[28]

While an opt-out system would likely provide a more extensive and useful database, ensuring this has satisfactory social license would be required to ensure the public were sufficiently educated about uses and potential risks. Globally, opt-in systems of "data donation" are being highlighted as a way to increase the size and utility of healthcare datasets.[1,12,29] Yet while this mode of consent presents a greater amount of personal autonomy to potential donors, the likelihood is that data donations will almost certainly be a very small portion of those which an opt-out system would acquire, similar to those issues identified around opt-in systems of organ donation,[30] rendering poorer utility than a larger dataset that opt-out would facilitate.

Family interest

Family interest in PHCD is controversial globally,[31] and there are distinct differences between Māori and European cultures in Aotearoa New Zealand.[26] Family interests are difficult to manage around PHCD interests,[32,33] with discussion regarding the complexities of family indicating there are things that people want to keep private during *and* after their lifetime, and that this is a reasonable expectation which should be upheld. Despite this, there was overwhelming support for allowing families access to PHCD when necessary, but this was not a universally appropriate guideline. This means any system would require clear guidance around health information privacy,[32,33,34] data sharing and use in respect to family access, including discussions about information sharing with subsequent generations of descendants.

Infrastructure and governance

Many responses supported a centralised, secure system of data storage, with PHCD having most utility if they existed in perpetuity. This is problematic in Aotearoa New Zealand, as healthcare records, in general, are legally able to be destroyed ten years after a person's death.[4,34] However, there is provision for PHCD to be lawfully used beyond that point,[28] despite existing law being designed in an era where PHCD were not ubiquitous. If a system of centralised records were established, it would require a law change to assist holding health records in perpetuity to prevent them being destroyed or erased. In addition, further clarity is required about using these data and the level of anonymity that could or should be applied (eg identifiable vs non-identifiable information) as this affects potential uses and impacts descendant healthcare. While some participants did not care about anonymity, some expressly did, and cited data security as a concern, tying the subject in to an issue around trust and potential misuse of data.[6]

While "ownership" of data was not specifically discussed, conversations hinted at data governance being of a custodianship or guardianship role, with persons continually referring to "my" data with the implication that "my data is to be overseen and used by someone else". Many responses favoured this type of data governance being overseen by some type of ethics committee review for access to PHCD, which is congruent with calls within Aotearoa New Zealand to explore how oversight of healthcare data are managed.[35] Most participants thought that the data should be controlled by the Government, mainly the Ministry of Health or National Archives, and include some medical personnel, which highlights the trust in the medical profession that already exists within the community. The main reason for this was preference for a robust infrastructure, and using an existing, stable and enduring administration made the most sense. National storage and governance was suggested, necessitating appropriate data storage and transfer legislation to ensure transparency around data custodianship. Responses by and around Māori interests favoured independent governance of Māori data, discussed earlier.

Aotearoa New Zealand's future posthumous healthcare data utilisation and implications

Findings suggest many Aotearoa New Zealanders conditionally support a centralised system of governed PHCD that was overseen by a government agency, and that included oversight from medical professionals, with data being available for healthcare and research purposes. It was suggested that data should be held in Aotearoa New Zealand, with benefits being foremost for family, then Aotearoa New Zealand citizens, then global benefit. This altruistic perspective also supported the necessity of commercialisation being an obvious downstream effect of data utilisation to extract reasonable benefits; however, selling of the data itself was not supported. A complex array of suggestions around consent concluded with a majority supporting an opt-out system, and Māori data were identified as requiring Māori governance. Implementation of such a system would require alterations to current health data legislation to ensure data are held in perpetuity, a review of how privacy laws (eg the Health Information Privacy Code) may affect inter and intra-generational data sharing,[36] further exploration around how "identified" or "non-identified" data should be defined, and continuing efforts to address ethics frameworks around the utilisation of such data.[7,35] Public consultation to acquire social licence for such changes would be essential to support its development and implementation.[8]

The suggested system is congruous with several positive ideological principles including beneficence, altruism and usefulness; however, there are potential harms associated with the proposed framework should data be misused or outside what is socially or culturally acceptable. These include an erosion of trust in the health-

care system that could lead to possible compromises in healthcare from patients failing to seek treatment or choosing to withhold information,[2,6] and the risk of discrimination and potential for group-based harm.[17,37] This is particularly relevant when research that includes genomic information potentially affects generations, cohorts or communities of individuals and their families,[31,33] while a lack of consensus around consent—both for the individual and future generations—means further investigation is required to identify acceptable solutions. Public consultation and future implementation will need to be transparent about systems, governance, and utilisation in order to establish and maintain public trust while balancing the risks and benefits of data sharing.[2,6]

Limitations

The information may not be representative of Aotearoa New Zealanders in general as the sample size is modest and restricted to one geographic location, which has the potential to affect the generalisability of the findings to other regions of Aotearoa New Zealand. There is also the potential influence of participant selection bias, given participants self-selected for this study, and this may affect the work in regard to the identification of personal attributes, such as altruism or usefulness, or indeed participant attitudes towards PHCD use. Further, there was also a lack of diversity amongst the participant population, with specifically few Māori, Pasifika, Chinese, Indian or other ethnic backgrounds, and their views in ongoing work are important in order to more accurately represent the diverse nature of Aotearoa New Zealand's population. Importantly, Māori participant numbers were low, and while the information provided provides vital insight around how some Māori may wish to manage PHCD, the numbers are not large enough to allow confidence that these views are representative of all Māori.

Conclusions

This study provides the first empirical data on the topic of PHCD utilisation, providing contemporary information around Aotearoa New Zealanders attitudes and perceptions regarding the use of PHCD. It finds conditional support for a centralised database of PHCD, a repository that should be primarily held and managed by the government of Aotearoa New Zealand, for the benefit of family and Aotearoa New Zealanders, and subsequently for global benefit. Given this study establishes the platform for a social license to explore PHCD collection and use, perhaps a logical sequalae is not "Where are the data?" but "How can we utilise the data in a culturally, ethically, and socially responsible and acceptable way?". Further exploration of this topic is required to add perspective on the nuances associated with utilising these precious data in Aotearoa New Zealand, including elements around consent models, data anonymity, and family access. More substantive consultation across a variety of Aotearoa New Zealand locations and ethnicities, in particular Māori and Pasifika, is also necessary to elaborate on these findings, and to consolidate an understanding of what is required to appropriately manage PHCD in this country.

COMPETING INTERESTS
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REFERENCES
1. Sorbie A. Medical Data Donation, Consent and the Public Interest After Death: A Gateway to Posthumous Data Use. In: *The Ethics of Medical Data Donation.* Krutzinna J, Floridi L (eds). Gewerbestrasse: Springer. 2019. Chapter 7.
2. van Staa TP, Goldacre B, Buchan I, Smeeth L. Big health data: The need to earn public trust. BMJ. 2016 Jul 14;354:i3636.
3. Fehringer G, Kraft P, Pharoah PD, et al. Cross-cancer genome-wide analysis of lung, ovary, breast, prostate, and colorectal cancer reveals novel pleiotropic associations. Cancer Res. 2016 Sep 1;76(17):5103-14.
4. Hoeksema K, Wee R, Macdonald A, et al. Where to from here? Posthumous healthcare data, digital e(lectronic)-mortality and New Zealand's healthcare future. N Z Med J. 2017;130(1459):64-70.
5. Gluckman P. Using evidence to inform social policy: The role of citizen-based analytics. Office of the Prime Minister's Chief Science Advisor. 2017.
6. Carnegie UK Trust. Data for public benefit: Balancing the risks and benefits of data sharing. 2018. https://www.carnegieuktrust.org.uk/publications/data-for-public-benefit/.
7. Hudson M, Beaton A, Milne M, et al. Te Mata Ira: Guidelines for genomic research with Māori. Māori and Indigenous Governance Centre, University of Waikato; 2016.
8. Filoche S, Cornwall J. DNA information: Access, use, and implications for healthcare in Aotearoa New Zealand. N Z Med J 2021;134(1528):107-10.
9. Stats NZ Census Data 2018. https://www.stats.govt.nz/2018-census/ Accessed 15 March 2018.
10. Guest G, MacQueen KM, Namey EE. *Applied Thematic Analysis.* 1st Ed. Thousand Oaks, CA: SAGE Publications, Inc. 2012. pp320.
11. Kasket E. *All the Ghosts in the Machine: The Digital Afterlife of your Personal Data.* Robinson, London, UK. 2019. ISBN-13:978-1472141897.
12. Shaw D. Defining Data Donation after Death (DDD): Metadata, Families, Directives, Guardians and the Route to Big Consent. In: *The Ethics of Medical Data Donation*. Krutzinna J, Floridi L (eds). Gewerbestrasse: Springer. 2019. Chapter 10.
13. Cornwall J, Slatter T, Guilford P, et al. Culture, law, ethics, and social implications: Is society ready for advanced genomic medicine? Australas Med J. 2014;7(4):200-2.
14. Hill G. Pharmacogenetics: A Review of the Ethical, Social and Policy Implications of 'Personalised Medicine'. In: *Genes, Society, and the Future. Volume 3.* Henaghan M (ed). 2009.
15. Milne BJ, Atkinson J, Blakely T, et al. Data resource profile: The New Zealand Integrated Data Infrastructure (IDI). Int J Epi 2019;48(3):677-677e.
16. US National Library of Medicine. Clinical Trials Website. https://clinicaltrials.gov/ Accessed 15 July 2021.
17. Carter P, Laurie GT, Dixon-Woods M. The social licence for research: Why care.data ran into trouble. J Med Ethics 2015;41:404-9.

18. Middleton A, Milne R, Almarri MA, et al. Global public perceptions of genomic data sharing: What shapes the willingness to donate DNA and health data? Am J Hum Gen. 2020;107(4):743-52.
19. Privacy Commission. Privacy concerns and sharing data. New Zealand; April 2020.
20. Caron NR, Chongo M, Hudson M, et al. Indigenous genomic databases: Pragmatic considerations and cultural contexts. Front Pub Health. 2020;8:111.
21. Hudson M, Anderson T, Dewes TK, Temara P, Whaanga H, Roa T. "He Matapihi ki te Mana Raraunga" - Conceptualising Big Data Through a Māori Lens. In: *He Whare Hangarau Māori - Language, Culture & Technology* (pp. 64–73). Whaanga H, Keegan TTAG, Apperley M (eds). Hamilton, New Zealand: Te Pua Wānanga ki te Ao / Faculty of Māori and Indigenous Studies, the University of Waikato. 2017.
22. Genomics Aotearoa. Rakeiora Pathfinder Genomic Medicine – Rakeiora announcement. 2020. Available from: https://www.genomics-aotearoa.org.nz/projects/rakeiora-pathfinder-genomic-medicine/rakeiora-announcement Accessed 25 March 2021.
23. Ministry of Health. Whakamaua: Māori Health Action Plan 2020–2025. Wellington: Ministry of Health; 2020.
24. EU General Data Protection Regulation (GDPR): Regulation (EU) 2016/679 of the European Parliament.
25. Ballantyne A. How should we think about clinical data ownership? J Med Ethics. 2020;46:289-94.
26. Menkes DB, Hill CJ, Horsfall M, Jaye C. Perspectives on access to personal health information in New Zealand/Aotearoa. Anthropol Med. 2008;15(3):199-212.
27. New Zealand Government. Code of Health and Disability Services Consumers' Rights (1996).
28. Privacy Commission. Health Information Privacy Code. New Zealand; 2020.
29. Pichler H, Eder J. Supporting the Donation of Health Records to Biobanks for Medical Research. In: *Artificial Intelligence and Machine Learning for Digital Pathology*. Holzinger A, Goebel R, Mengel M, Müller H (eds). Gewerbestrasse: Springer. 2020. pp38-55.
30. Childress JF, Liverman CT (eds). Organ Donation: Opportunities for Action. Committee for increasing rates of organ donation. Washington DC: Board on Health Sciences Policy, Institute of Medicine of the National Academies, National Academies Press. 2006.
31. Abbott A. Icelandic database shelved as court judges privacy in peril. Nature. 2004;429(6988):118.
32. Lucassen AM, Parker M, Wheeler R. Role of next of kin in accessing health records of deceased relatives. BMJ 2004;328:952.
33. Robinson DJ, O'Neill D. Access to health care records after death: Balancing confidentiality with appropriate disclosure. JAMA. 2007;297(6):634-6.
34. New Zealand Government. Health (Retention of Health Information) Regulations; 1996.
35. Ballantyne A, Style R. Health data research in New Zealand: Updating the ethical governance framework. N Z Med J. 2017;130(1464):64-71.
36. Dupras C, Bunnik EM. Toward a framework for assessing privacy risks in multi-omic research and databases. Am J Bioethics. 2021. DOI: 10.1080/15265161.2020.1863516.
37. Crampton P, Parkin C. Warrior genes and risk-taking science. N Z Med J. 2007;120(1250):U2439.

Establishing a database of patients with diabetes and an interest in research participation

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ABSTRACT

AIMS: To establish interest in medical research and student training, based on demographics of those attending public-funded diabetes services and types of research.

METHOD: Patients who attended the Auckland Diabetes Centre (ADC) between July 2018 and July 2019 were invited via text message (SMS) to register their interest in being contacted for future health research projects and medical training. Consenting adults were enrolled in the Auckland Diabetes Centre Volunteer Database (ADCVD) and sent a survey on the acceptability of various types of research and factors influencing participation. Relationships between ADCVD enrolment and other variables were determined using Fisher's exact test. Qualitative data were coded to generate key themes using an inductive approach.

RESULTS: Of 2,884 patients contacted, 527 were enrolled in the ADCVD (response rate: 18.3%); and of these, 176 completed surveys (response rate: 33.3%). Most respondents were NZ European (n=92, 52.3%), male (n=125, 70.6%), and from the least deprived areas (n=35, 19.9%). The type of research did not affect interest. Motivations to participate centred around a hope to improve their own diabetes and that of future generations.

CONCLUSIONS: SMS-based recruitment from a diabetes clinic results in modest interest in participation in teaching and research from predominantly those of NZ European ethnicity and living in areas of least socio-economic deprivation.

Patient involvement in research and medical student training is increasingly recognised as the cornerstone of effective treatment regimens and healthcare service delivery.[1] However, recruiting a large and diverse population sample is challenging. Participation rates may differ based on the recruitment method and the type(s) of research and teaching. Patients are usually invited to participate in research projects and medical student training through advertising or directly through healthcare professionals. In addition, previous research has suggested that the public may be more cautious regarding genetic studies than other types of medical research.[2] However, it is unknown whether these views are representative of the multi-ethnic New Zealand population living with diabetes in Auckland. Furthermore, there is a lack of data on the characteristics of people who participate in research and medical student training.

The Auckland Diabetes Centre Volunteer Database (ADCVD) was conceived to enable patients to register their interest in being contacted for participation in current and future research projects, the training of medical students, or the co-design phase for planned research. The ADCVD was established as a secure internal database, accessed only by centre administrators and Auckland Diabetes Centre (ADC) researchers. The primary intention behind the ADCVD was to streamline patient recruitment for research projects and medical student training. As part of setting up the ADCVD, we also aimed to determine any differences in patient interest based on demographics and types of research, and to investigate what barriers exist and what motivates or enables patient involvement. It was hypothesised that we would see differences based on ethnicity, and that those from higher levels of deprivation would be less likely to express an interest in being involved in research projects and/or training of medical students. Additionally, it was hypothesised that patients would be less willing to participate in genetic studies compared to other types of studies.

Method

This study was conducted following the ethical standards of the Auckland District Health Board (ADHB) and the Health and Disability Ethics Committee (HDEC 18/NTA/36). Scheduling staff members at the ADC who routinely contact patients to arrange clinical appointments also invited patients to enrol in the ADCVD. This approach was deemed less intimidating, and with less obligation than if the healthcare providers were to approach patients directly. All patients who had attended an appointment at the ADC between July 2018 and July 2019 were contacted via text message (SMS). The SMS was written as: "We have diabetes research studies at the Auckland Diabetes Centre. Text YES to be contacted about this. Text NO if you are not interested". Patients who answered "Yes" were contacted by a scheduling staff member either by email, phone call or SMS and were asked to complete a survey.

The survey was written in English and was composed of six questions (Appendix 1). Its purpose was to capture data on the types of research studies in which patients were willing to participate, and qualitative data on factors influencing patients' participation decisions. Patients were also asked if they would be interested in being contacted for medical student training. Qualitative data were coded to generate the main themes using an inductive approach by a single researcher. Patient demographic data such as age, gender, ethnicity, and home address were derived from electronic medical records. Ethnicity, as recorded on clinical records, was then aggregated into the categories listed in Table 1. Deprivation was determined using patients' home addresses and the NZDep Index, an area-based measure of socio-economic deprivation in New Zealand.[3]

Quantitative data were analysed using GraphPad Prism 8.2.1 (California, United States of America). A multivariate logistic regression was performed to assess the relationship between SMS response and the explanatory variables: gender, deprivation index, ethnicity and age. Data were checked for multicollinearity with the Belsley-Kuh-Welsch technique. The heteroskedasticity and normality of residuals were assessed by the White test and the Lilliefors test. The Fisher's exact test was used to assess the relationship between survey responses and demographic variables. A p-value <0.05 was considered statistically significant.

Results

Enrolment

A total of 2,884 patients with diabetes who attended the ADC between July 2018 and July 2019 were sent an SMS by scheduling staff. Of these, 527 (19%) replied "Yes", 618 (21%) answered "No", and the remaining 1,739 (60%) did not respond (NR) (Table 1). Patients who responded "Yes" were entered into the ADCVD and were asked to complete the survey. They were provided with the option of completing the questionnaire by phone, email or an online form provided via an SMS link. The survey was completed by 176 patients (email n=146, phone n=18, SMS n=12), and their answers were entered into the ADCVD (Figure 1).

Demographics

When comparing individual ethnic groups, the proportion of NZ Europeans that both responded to the SMS and completed the survey was significantly greater than for Māori ($p=0.0251$), Pacific ($p<0.0001$), Indian ($p<0.0001$), other Asian ($p<0.0001$), and other ethnicities ($p<0.0001$) (Figure 2).

Age did not influence response rate. The median age of patients who agreed to be contacted about diabetes research and completed the survey was 60.8 years (range of 28–76 years). Women were less likely to respond to the SMS than men [OR=0.69 [0.56, 0.85], $p=0.0004$] and made up only 28% of patients who completed the survey (Figure 3).

As shown in Table 1, individuals from the least deprived quintile (deciles 1 and 2) made up 12.6% (n=363) of those initially contacted, but 19.9% (n=36) of those who completed the survey. Conversely, individuals in the most deprived quintile (deciles 9 and 10) comprised 27.8% (n=803) of those initially contacted, but 20.5% (n=36) of those who completed the survey.

Acceptability of different forms of research

Patient willingness to be involved in specific areas of research was queried, specifically: 1) Genetic studies using blood or saliva, 2) Other studies using blood samples, 3) Questionnaires or surveys, 4) New medication trials, 5) Weight loss studies. There was no difference in the acceptability of the different forms of research studies amongst patients who completed the survey. On average, 86% of patients expressed a willingness to be involved in each area of research. Contrary to our hypothesis, interest in genetic research was similar to that of other research types. Further-

more, willingness to participate in genetic research did not appear to differ by ethnicity (χ^2=8.969, df=5, p=0.11). Overall, 73% of respondents expressed an interest in the design of future studies, whilst 78% of respondents expressed a willingness to be involved in medical student training.

Motivations and challenges

We collected qualitative data about research participation from 92 patients (52% of those surveyed) who provided their views in a free text section of the survey. The key themes and supporting quotes are outlined in Table 2.

Discussion

We created a database of patients attending the ADC who were willing to participate in future research and medical training opportunities. As part of establishing this database, we investigated whether there were demographic differences amongst those interested in taking part, and whether some forms of research were more acceptable than others. We found an overrepresentation of NZ European respondents and an under-representation of patients from Pacific and Asian ethnicities. Based on these results, we cannot conclude that people of non-NZ European descent were less interested in medical research or training; instead, our efforts to engage with these populations may have been insufficient. All study correspondence was in English, giving rise to potential language barriers. Therefore, future attempts to engage with a multi-ethnic cohort of patients should include multilingual correspondence. Involving community leaders may have also helped recruit non-NZ European patients better. However, different ethnic groups may hold different perspectives on the value of research. It has been previously reported overseas that patients who identify as Chinese are less likely to participate in clinical studies, compared to other ethnic groups, due to barriers such as insufficient information provided during recruitment, language, cultural values, and mistrust of research.[4] Further research could explore whether barriers to participation differ by ethnicity amongst our population and how to mitigate these.

We found that patients living in more deprived areas would be less likely to show interest in medical research and training. Again, it is difficult to determine whether the low response rate among

Figure 1: Flow diagram of patient enrolment into the ADCVD.

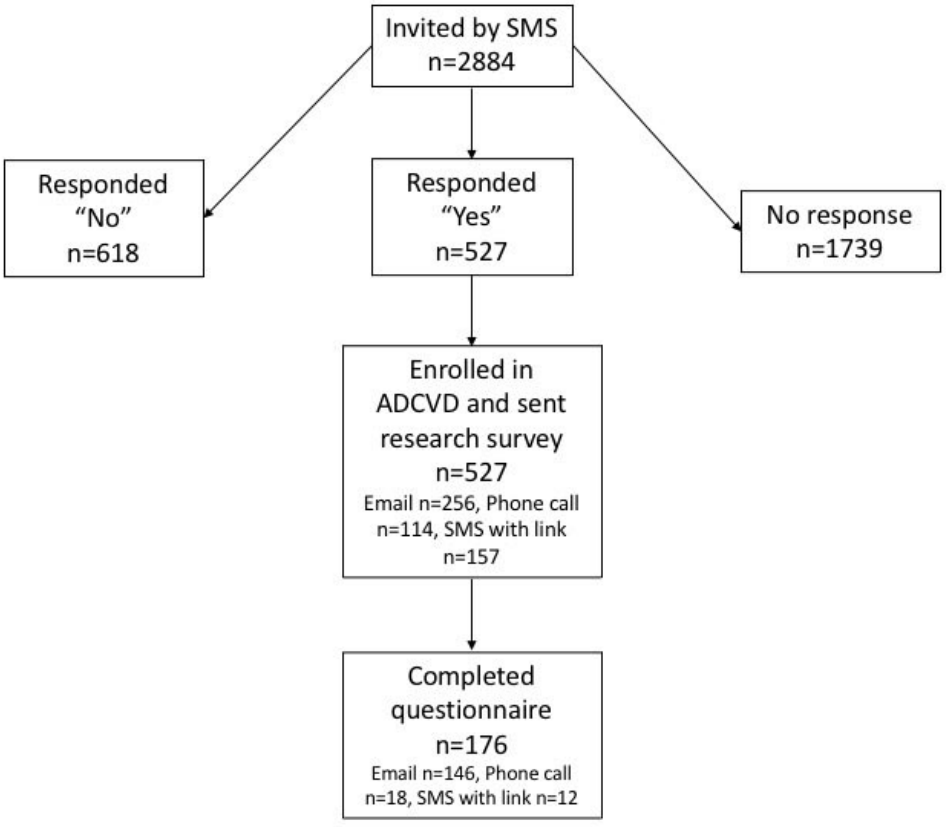


Table 1: Characteristics of patients invited to enrol in the ADCVD categorised by response.

	Invited to enrol in the ADCVD n=2884	**Responded "Yes", was listed on ADCVD and sent questionnaire n=527 (18%)**		**Responded "No" n=618 (21%)**	**Did not reply n=1739 (60%)**
		Completed survey n=176	**Did not complete survey n=351**		
Male n (%)	**1700 (59)**	**125 (70.6)**	231 (65.8)	356 (57.6)	1003 (57.7)
Ethnicity n (%)					
NZ European	540 (18.7)	92 (52.3)	70 (19.9)	141 (22.8)	237 (13.6)
Māori	220 (7.6)	22 (12.5)	23 (6.6)	42 (6.8)	134 (7.7)
Pacific	745 (25.8)	19 (10.8)	93 (26.5)	147 (23.8)	487 (28.0)
Indian	588 (20.4)	23 (13.1)	70 (19.9)	129 (20.9)	365 (21.0)
Other Asian	509 (17.7)	3 (1.7)	58 (16.5)	107 (17.3)	413 (23.8)
Other	282 (9.8)	17 (9.7)	37 (10.5)	52 (8.4)	102 (5.9)
Age, years (SD)	58.4 (12.2)	60.8 (11.5)	58.2 (11.7)	58.6 (12.1)	58.1 (12.3)
NZDep Index					
Least deprived quintile n (%)	363 (12.6)	35 (19.9)	38 (10.8)	88 (14.2)	202 (11.6)
Most deprived quintile n (%)	803 (27.8)	36 (20.5)	80 (22.8)	149 (24.1)	538 (31.0)

Figure 2: The percentage of patients invited to be enrolled in the ADCVD differed from the percentage of patients who agreed and completed the survey by ethnicity.

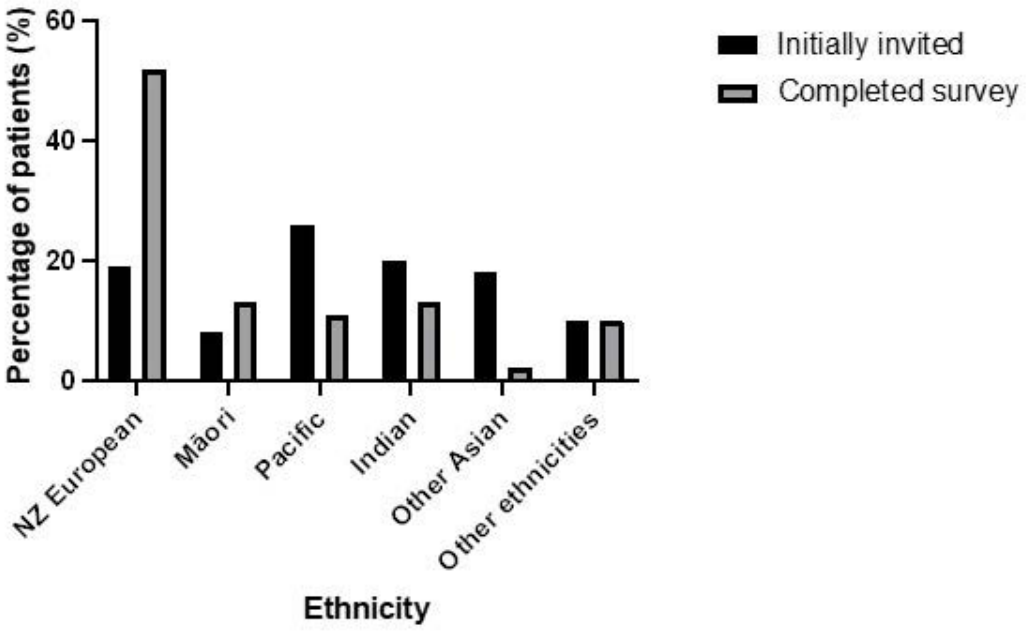
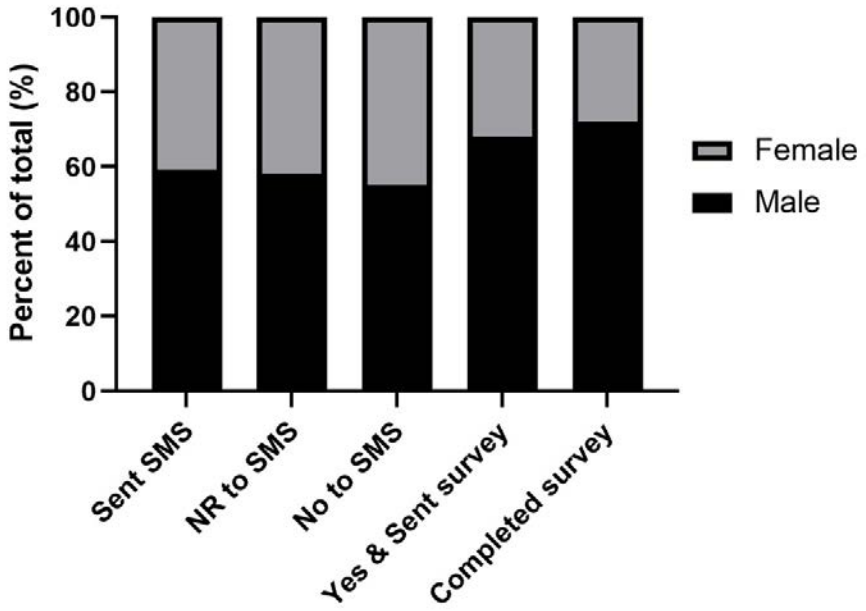


Figure 3: The gender distribution of patients changed across the stages of recruitment.



The proportion of males relative to females increased across the stages of recruitment from the initial invitation to survey completion. NR=no response.

Table 2: Key themes and quotes for the ADCVD patient feedback.

Themes	Second-order theme	Supporting quotes
Help the diabetes community	Help others Advance knowledge/care Search for a cure	"Even a very small contribution to **improving treatment** of this disease would be rewarding" "I am a diabetic so willing to **help other people** avoid getting diabetes or for those that have it to be able to manage" "I am happy to participate if it will **help with diabetes care"**
Potential personal benefits	Improve own health Better understand own diagnosis	**"**I am diabetic so research is likely to be to **my advantage"** **"**I have type two diabetes and would like to be part of research that may **help educate me better to manage this"** **"**I need to find out **if I can become diabetic free without medication"**
Appreciation for research	Desire to support research/researchers Interest in research Drive to give back	**"**I think it's **important for research studies to happen"** **"**I **support the efforts of medical science**, and in a small way **give back** to the system"
The burden of participation	Time commitment Financial costs Transport issues	"If I need to **travel** places that could be a **problem financially"** **"**I am **not working** so **cannot pay or travel** too often. I dont drive"

patients living in greater deprivation is due to a lack of interest or limited means to respond to our initial contact. The cost to reply to the initial SMS contact, and changes in phone numbers, may have prevented responses. Further, the contact number listed may have been inaccurate or shared with several other family members, making this contact mode unreliable. An opt-out default could have been used instead of the traditional opt-in approach. Previous diabetes research using an opt-out default has reported higher enrolment rates but also higher attrition rates.[6] Therefore, this suggests that the opt-in approach may reach motivated individuals who do not represent the target population but are more likely to follow through in such research or training activities.

Other recruitment strategies may have also proved useful. For example, patients could have been approached while sitting in the ADC waiting room. Although this is labour intensive, face-to-face—*kanohi ki te kanohi*—interactions can foster trust in the researcher and build relationships, thereby facilitating successful recruitment.[7] The Scottish Health Research Register (SHARE) has successfully recruited many volunteers interested in taking part in research. Using the Community Health Index (CHI) number, individuals are identified for potential studies using information held in National Health Service data sets such as those from hospital discharges, hospital outpatient attendances and primary care prescribing. Interestingly, face-to-face recruitment in outpatient departments and general practitioner practices was their most successful recruitment method, with around 90% of those approached agreeing to join.[8] In this way, collaborating with primary care to recruit those who have intimated an interest in participating in health research may better identify potential participants with diabetes.

In line with previous research,[2] we hypothesised that participating in genetic research would be less favourable than other forms of research among our patients. Instead, we observed a similar level of interest across all types of research. Despite these promising results, our study is subject to limitations. Patients chose to complete the survey; thus, our results are susceptible to self-selection bias. The response rate to the SMS invite was low, and the subgroup of respondents in this study may not be equivalent to the entire target population. Also, qualitative data collection consisted mainly of closed questions for brevity. Therefore, the expectations regarding research or medical student training participation may not have been clearly defined, in terms of additional time commitment or other details. Conducting focus groups or conversational interviews can yield more qualitative data and reach saturation of themes; and in doing so, better understand motivations and challenges for patient involvement.

In conclusion, the ADCVD was created to form a primary contact database for future research and medical student training opportunities. SMS-based recruitment did not result in a representative population attending the ADC. Successful patient volunteer database recruitment and maintenance long term will require more funding for the systematic recruitment of volunteers, organisation, administration and interaction with researchers and clinical educators looking for potential volunteers according to various eligibility criteria.

Future engagement should be tailored to suit different contexts and research topics, and to ensure a broad representation of patient demographics and perspectives.

COMPETING INTERESTS
Nil.

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www.nzma.org.nz/journal-articles/establishing-a-database-of-patients-with-diabetes-and-an-interest-in-research-participation

REFERENCES
1. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. A systematic review of the impact of patient and public involvement on service users, researchers and communities. The Patient-Patient-Centered Outcomes Research. 2014;7(4):387-95.
2. Matsui K, Kita Y, Ueshima H. Informed consent, participation in, and withdrawal from a population based cohort study involving genetic analysis. J Med Ethics. 2005;31(7):385-92.
3. Atkinson J, Salmond C, Crampton P. NZDep2013 Index of Deprivation. New Zealand: Ministry of Health; 2014.
4. Limkakeng A, Phadtare A, Shah J, Vaghasia M, Wei DY, Shah A, et al. Willingness to participate in clinical trials among patients of Chinese heritage: a meta-synthesis. PloS one. 2013;8(1):e51328.
5. Yu D, Zhao Z, Osuagwu UL, Pickering K, Baker J, Cutfield R, et al. Ethnic differences in mortality and hospital admission rates between Māori, Pacific, and European New Zealanders with type 2 diabetes between 1994 and 2018: a retrospective, population-based, longitudinal cohort study. The Lancet Global Health. 2021;9(2):e209-e17.
6. Aysola J, Tahirovic E, Troxel AB, Asch DA, Gangemi K, Hodlofski AT, et al. A Randomized Controlled Trial of Opt-In Versus Opt-Out Enrollment Into a Diabetes Behavioral Intervention. American Journal of Health Promotion. 2018;32(3):745-52.
7. Moyle P. A model for Māori research for Māori practitioners. Aotearoa New Zealand Social Work. 2014;1(26):29-38.
8. McKinstry B, Sullivan FM, Vasishta S, Armstrong R, Hanley J, Haughney J, et al. Cohort profile: the Scottish Research register SHARE. A register of people interested in research participation linked to NHS data sets. BMJ Open. 2017;7(2):e013351.

Appendix 1: ADCVD Questionnaire.

1. Have you taken part in health research before? YES/NO

2. Would you be interested in being on our patient volunteer register? This means it would enable researchers to contact you about studies that might interest you to take part in? YES/NO
   a. If no, would you be willing to say why not?
   b. If yes, just need to let you know that being on the register means that our staff will be able to check your medical records (only records that are relative to the study) to make sure you fulfil the criteria for the specific research. All research projects would have to be ethically approved. Do you give this permission? YES/NO
   c. Which types of research would you be NOT be interested in?
      i. Genetic studies using blood or saliva
      ii. Other studies using blood samples
      iii. Questionnaires or surveys
      iv. New Medication trials
      v. Weight loss studies

3. Are there any factors that influence your interest in taking part in research studies? eg money, privacy issues, too time consuming, too many questions.

4. If it was possible to do this in future, would you be happy to give permission for left over blood samples from the blood tests ordered by your doctor to be stored for research? We won't be able to do this straight away, as it is a hypothetical question but if enough people are happy with this, we could look into making this possible in future. YES/NO

5. Would you be interested in providing input into how research projects are designed? eg Phone calls, meetings etc YES/NO

6. Would you be interested in being contacted for medical student training? YES/NO

The Southern Health system's Community Health Council: establishment and processes to engage with communities, whānau and patients

Sarah Derrett, Charlotte Adank, Karen Browne, Kelly Takurua

ABSTRACT

AIMS: This paper aims to: describe steps to establish the Southern Health system's Community Health Council (CHC) and its associated advisors; discuss support for the CHC, advisors and staff; and reflect on engagement activities, what has worked well, and opportunities for development.

METHOD: Prompts for establishing the CHC came from the Health Quality & Safety Commission and previous commissioners of the Southern District Health Board (SDHB). Following support from the Iwi Governance Committee and SDHB and WellSouth Primary Health Organisation (PHO) chief executives and their leadership teams, advertisements called for people interested in joining the CHC. After group interviews, the CHC was established in 2017.

RESULTS: It became evident that an 11 member CHC could not support all requests for engagement throughout the Southern Health system. Consequently, the CHC developed a framework for engagement, a large team of CHC advisors, and a Roadmap to support engagement activities.

CONCLUSIONS: The CHC has supported over 120 CHC members and advisors working on over 95 engagement projects throughout the Southern Health system. It is hoped that the processes described will be useful to the establishment of robust community, whānau and patient forums intended to sit at the centre of Aotearoa New Zealand's restructured health system.

Internationally, the importance of involving patients (often referred to as consumers), families and wider communities in improving healthcare services and planning has been increasing in recognition since the 1970s. Notably, the 1978 Alma Ata Declaration on Primary Health Care specifically declared that: "The people have the right and duty to participate individually and collectively in the planning and implementation of their health care".[1] More recently, the World Health Organization (WHO) emphasised the importance of achieving "people-centred" health systems which requires engagement with, and learning from, patients, service users and communities.[2] The Minister of Health recently announced plans for restructuring Aotearoa New Zealand's publicly funded health system.[3] The restructured system is intended to place people at the "centre of our future health system that is listening and acting on the voices of consumers, whānau, and communities in the design and delivery of health services",[4] including through the use of national, regional and local forums.

In February 2017, the Southern Health system held its inaugural Community Health Council (CHC) meeting. Terms of Reference stated the CHC was to "work collaboratively with the Southern District Health Board (SDHB), WellSouth Primary Health Network (PHO), governance and management teams to develop effective partnerships and communication pathways for its communities, whānau and patients". In 2021, the CHC continues to meet monthly; chaired by Karen Browne since February 2019.

New Zealand's Health Quality & Safety Commission (HQSC) has prepared reports and, recently, indicators of effective engagement.[5,6] Publications focused on consumer/community councils establishment, operation and organisation are currently lacking in New Zealand.[7] Therefore, this paper aims to: describe steps taken to establish both Southern Health system's CHC and a related group of CHC advisors; discuss processes developed to support the CHC, CHC Advisors and staff; and reflect on the engagement activities, what has worked well, and

opportunities for future development. It is hoped this information will be useful to others as New Zealand moves towards expanded roles for consumers, whānau, and communities within a restructured health system.

Method

Preparatory work

Prompts for the CHC's formation were HQSC guidance to DHBs that consumer councils be established,[8] and the (then) SDHB Commissioners expectations that a council be formed in the Southern Health system. In 2016, a steering group formed (including Karen Browne and members of the former Alliance South), and an establishment chair Sarah Derrett was interviewed and appointed (unpaid) to help establish the CHC.

In other regions, the few councils that had formed by late 2016 were usually called "consumer councils" and affiliated with a single DHB. The Southern Health system's council differed because it was to advise the broader Southern Health system, comprising services provided by both the SDHB and WellSouth PHO to a population of 326,280 people (10% Māori) residing over the largest geographical area (>62,356km^2) of any DHB.[9] The council members were needed from throughout the region. In recognition of geographically dispersed "communities" and considering patients as key stakeholders (even as "owners" of New Zealand's taxpayer funded system)—the Community Health Council name was decided.

Importantly, with CEO support the SDHB funded a facilitator Charlotte Adank to help implement and support the CHC. The chair and facilitator met with representatives from the few consumer councils that had already formed, and some kindly shared their Terms of Reference. The CHC's Terms of Reference—ultimately endorsed in early 2017—had input from the SDHB, WellSouth, the Iwi Governance Committee, and detailed the CHC's: purpose, function, membership (and *ex-officio* attendees such as SDHB and WellSouth CEOs); role of the appointed chair; and rotational membership to ensure both continuity of CHC activities and refreshed membership.

The Iwi Governance Committee advised a designated iwi representative should sit on the CHC, and their chair kindly agreed to help interview and select CHC members. Plans for the CHC's establishment were also presented to the SDHB Commissioners and SDHB/WellSouth executive teams ahead of calling for expressions of interest (EoI) for members.

Establishing the CHC

A press release and advertisements calling for EoIs were prepared in late 2016. Advertisements were placed in newspapers, emailed (eg via iwi contacts, Māori health providers, mayoral networks, and MP offices), and placed on SDHB and WellSouth websites. Respondents received an information pack about the CHC and the Southern Health system. Over four weeks, more than 90 EoIs were received by the CHC facilitator.

CHC members were sought with skills in communication, teamwork, decision-making, strategic abilities, strong networks, and with interest/experience in at least one health area (eg Hauora Māori, disability, long-term conditions, mental health, rural health, older people's/men's/women's/youth's/children's health, Pacific people's health, or primary health). Applicants were shortlisted according to their reported health interests, community networks and geographical location. SDHB/WellSouth staff are part of their "communities"; although also likely to be privy to information and potential conflicts of interest arising from their employment. Therefore, CHC members were sought if they were not current SDHB/WellSouth employees, contracted providers or had other conflicts of interest. Eighteen people were shortlisted for interview, for a CHC intended to comprise up to twelve members (including the chair).

The chair and facilitator decided, in discussion with the CEOs and with advice from SDHB Human Resources, that group interviews (4–5 applicants) would be held. Interviewees were informed of this in advance. An interview panel was established, comprising a chair (independent of SDHB/WellSouth), Iwi Governance Committee chair, CHC chair, a member of the SDHB executive, and SDHB patient engagement lead; the CHC facilitator attended. After introductions, and a brief discussion of applicants' interests, a warm-up exercise asking each applicant to discuss three positive personal characteristics and one "more challenging" characteristic with each other. The panel then asked who, from the group, the applicants would prioritise for CHC membership—and why.

The main exercise was a scenario framed as a popular reality TV cooking show. The panel gave the group demographic information (ingredients) about the Southern Health system and asked them to identify (prepare) the top 3 health issues affecting the region, and then to give a two-minute presentation to the panel (taste test) about those issues, and why they were selected. This allowed the panel to see how people worked together and prioritised their top issues. For instance, did all

people have an opportunity to speak, were people open to agreeing collectively, and how were challenges managed? It also provided an opportunity for interviewees to demonstrate that they could avoid focusing solely on "their" health areas of interest. Interviewees were assured there were no right or wrong answers, and that the panel was interested in how they worked as a group.

Reference checks were undertaken for shortlisted potential CHC members. Initially, eight CHC members received letters of offer (two were Māori, including Kelly Takurua), and comprised the inaugural CHC with the chair. Geographic representation was imperfect; two additional members from other areas were interviewed and appointed within six months of the inaugural meeting.

Formative activities

An orientation pack was distributed, staff IDs were issued (emphasising the importance of the CHC), and an induction day was held. Before the first meeting, CHC members' reimbursement for meeting attendance, travel costs, and accommodation (necessary for those travelling long distances) was established. CHC meetings were to be monthly. Therefore, 8–10 hours per month was estimated as the time necessary for "lay" CHC members to attend the four-hour meeting, have time to read materials, and to provide some time for engagement in specific Southern Health system projects.

The first meeting's agenda included: Terms of Reference and a Code of Conduct; the establishment of an Interests Register; an introduction to the Southern Health system's Clinical Council (and how it aligned with, and differed from, the CHC); and an overview of executive leadership teams. CHC members brainstormed, independently of *ex officio* meeting attendees, important early areas to focus on. It was evident the following questions needed to be addressed: who/how should the CHC advise, how do staff engage with the CHC, and how can the CHC ensure its networks are central to the advice provided to the Southern Health system? The ensuing work undertaken by the CHC and facilitator to address these questions is presented below.

Results

A framework for engagement

The CHC established a working sub-group to develop a Community, Whānau and Patient Engagement Framework to guide engagement activities (Figure 1). Te Tiriti o Waitangi was a starting point in considering the strategic goal, informing the guiding principles and continuum of engagement approaches (eg meaningful engagement was desirable at all levels, but especially at collaboration and empowerment, and with specific engagement of Māori).[10] The CHC's engagement approaches followed those outlined by the HQSC;[5] aligned with earlier research.[11–13] Four domains of engagement were identified, beyond only "personal care and hospital services" to wider "community and public health services".

Operationalising engagement

Many requests came forward for engagement on a range of activities or projects. CHC members were rapidly involved in a range of these (eg working with the Executive Director of Strategic Communications to develop a new Southern Health system website; sitting on senior staff recruitment panels). It was soon clear that CHC members could not support all incoming engagement activities. A plan was prepared to invite other community members to form a larger network of CHC advisors. People who had expressed interest in joining the CHC were initially approached. A form was developed to send to these people, as well as future potential CHC advisors, to identify their areas of health interest to help match CHC advisors to incoming engagement activities. The SDHB and WellSouth also supported the reimbursement of CHC advisors for engagement work.

Meetings with staff were held to discuss the Framework and the growing network of CHC advisors. Guidance was required regarding expressing interest in working with CHC advisors; linking staff with interested advisors; supporting both staff and advisors in the process; and assessing the process and outcomes of engagement. One of the CHC's clinical champions advised that it was critical the CHC advisors remain closely linked to the CHC, to avoid risking engagement activities becoming uncoordinated.

The CHC developed a Roadmap outlining the process of engagement (Figure 2).[14] To help match new projects with advisors, staff completed a form describing their proposed project including the purpose of engagement, anticipated duration, other members of the project (eg clinicians, managers, executive leads), and their desired CHC advisor qualities. Following a meeting between staff and potential advisors, if agreement was reached, the advisor(s) would be sent a welcome pack, and engagement would begin. CHC members would then communicate as mentors with advisors, and every second month engagement project reports would be circulated to the CHC

Figure 1: Community Health Council's Community, Whānau and Patient Engagement Framework

Figure 2: Roadmap to guide the Community Health Council's advisor engagement process.

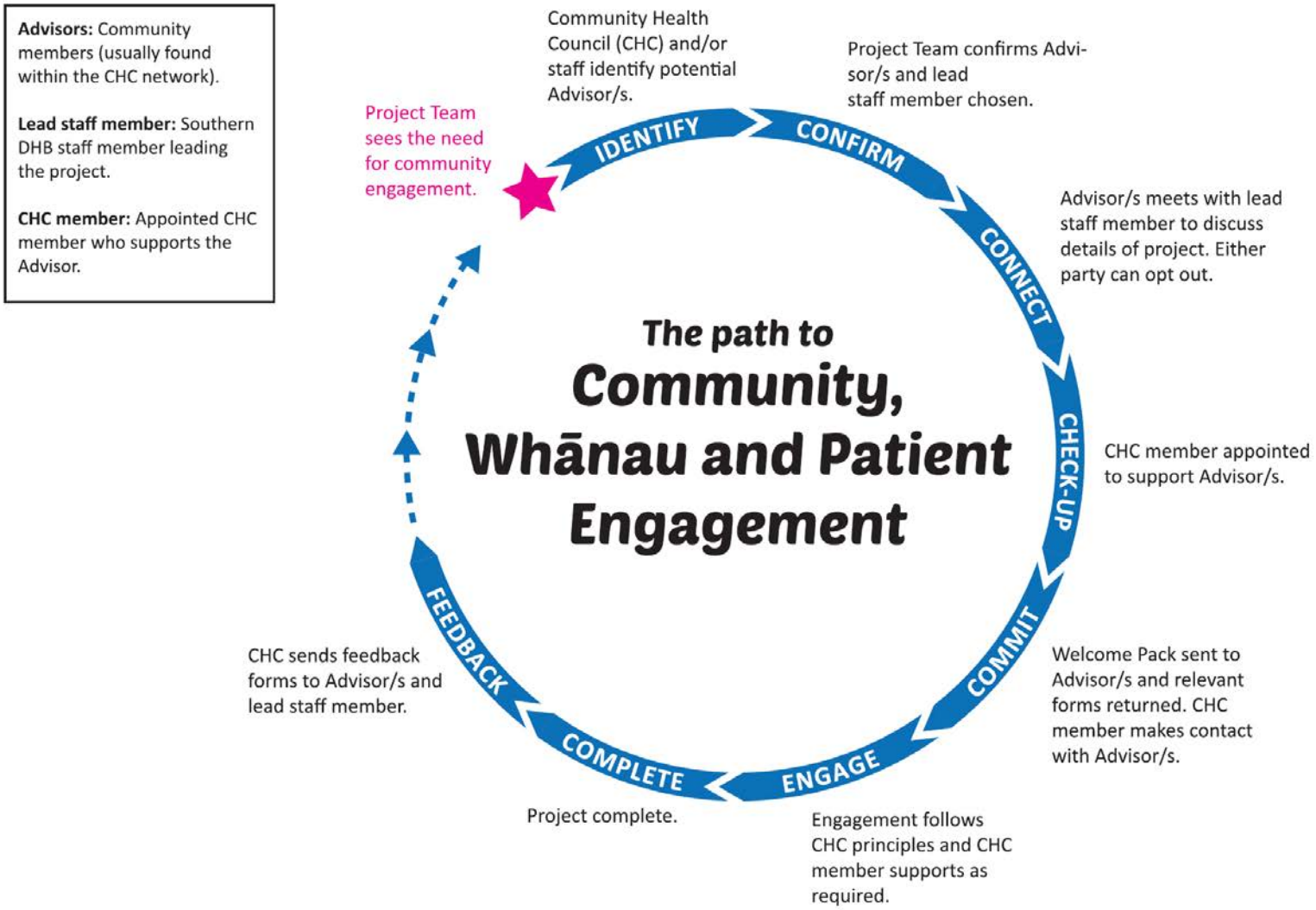
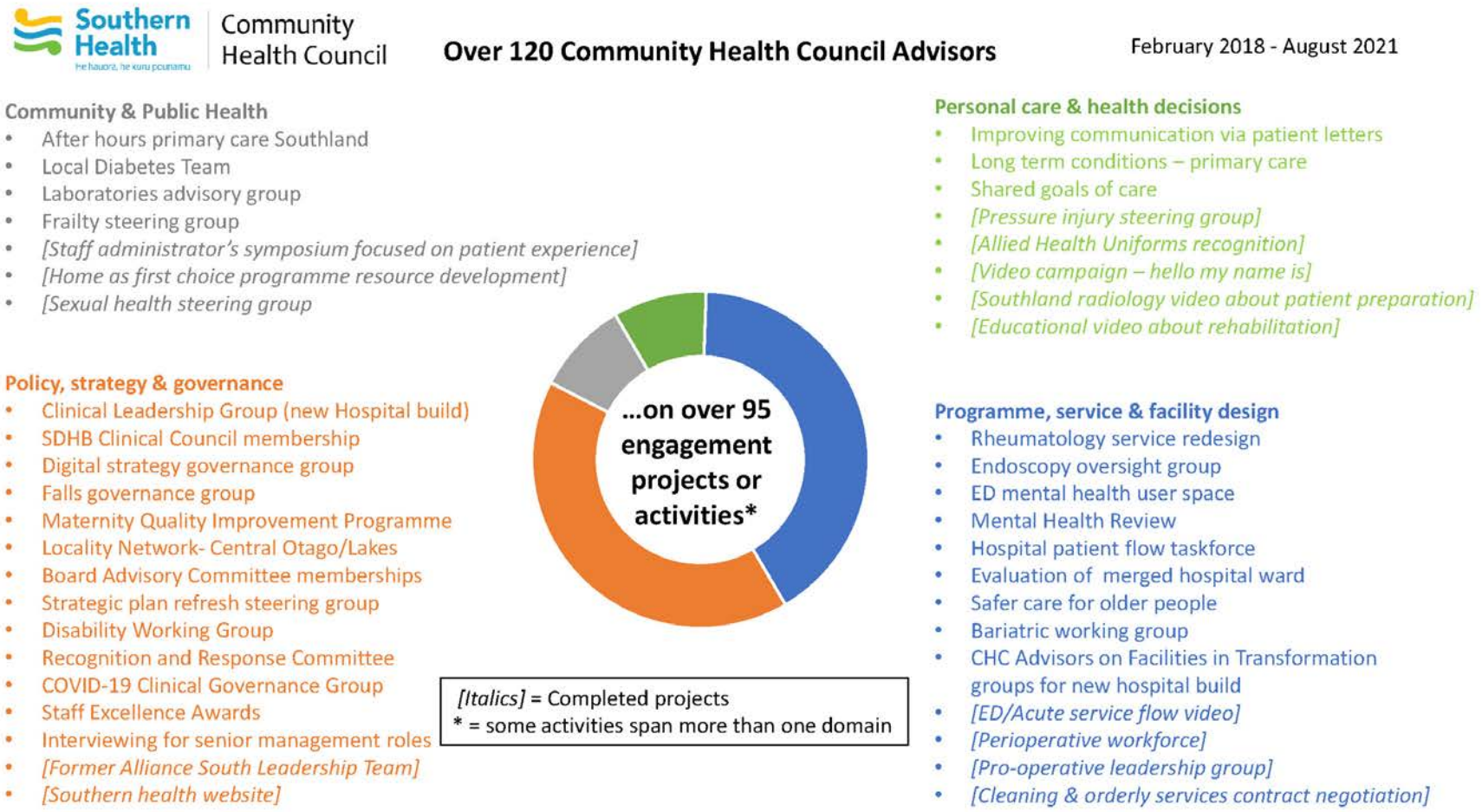


Figure 3: Overview of Southern Health system engagement activities undertaken by CHC advisors.



members with meeting papers to ensure coordination. Upon completion of the engagement project, the CHC facilitator would communicate with both the lead staff member and the CHC advisor to collect information about what worked well and what could be improved.

Outcomes of engagement

Since the Roadmap's launch in 2018, more than 120 CHC advisors have been involved in over 95 engagement projects (Figure 3). Engagement activities have occurred across all four Framework domains, and across the full range of engagement approaches from Informing (eg communication with the CHC about surgical prioritisation approaches) to Empowering (eg CHC members and Advisors sitting on governance groups). Projects had a range of durations (ie from a few hours to years). A number of CHC Advisors have been involved in more than one project, although not simultaneously.

At a symposium organised by the CHC in October 2019 (attended by 70 people, including many advisors, executive teams, and guest speakers from an Australian consumer council), staff and CHC advisors identified key engagement lessons from the Roadmap. Staff and clinical leaders noted the importance of truly integrating advisors into their project teams. Staff commented on the power of CHC advisors talking from their lived experiences, and how such storytelling can be a powerful window into patient experiences, helping to motivate improvement activities. Staff also acknowledged that having CHC advisors involved can sometimes be daunting for staff. CHC advisors noted: the importance of clarifying their role (with them and with others on the project team) when they join new projects; the importance of relationship building; the benefits of having more than one advisor on major projects for mutual support; and the importance of informing advisors of the ultimate outcome of the project. Written feedback from staff and advisors collected at the conclusion of each project is another valuable source of feedback from engagement activities. However, this needs to be formalised, and ethical approval must be sought, for this to be a source of information for future public reporting. Additional insights into how the voice of the community, whānau and patients can make a difference are presented in the publicly available Community Health Council Annual Reports (Table 1).[14]

Discussion

From the outset, the group interview process used in forming the CHC embedded the importance of collaboration, and enabled the CHC to quickly establish group activities for developing the engagement processes (ie Framework and Roadmap). The fact that over 95 engagement activities have been completed, or are ongoing, involving more than 120 CHC advisors, points to the success of the CHC since its formation. CHC's Framework envisaged engagement across the spectrum of domains and approaches. The CHC did not mandate engagement activities. Instead, we developed tools to support and encourage staff and CHC advisors. We believe these strengthened engagement projects, alongside executive team and Iwi Governance support. Prior to the CHC's formation, apart from paid SDHB mental health consumer advisors, engagement in health system improvement activities tended to be intermittent and opportunistic.

Reflecting on the CHC's activities since early 2017, there are aspects to strengthen. Engagement with Māori via the Iwi Governance Committee happened early and was crucial. However, at any one time there have been no more than two Māori CHC members. We recognise many Māori are closely involved in other activities immediately relevant to their iwi, hapū and whānau. However, although equity issues are to the fore of the CHC's agenda (in part because of Māori CHC members), further work is required to ensure the CHC's activities are relevant (and seen to be relevant) to Māori health and wellbeing to increase Māori membership. The CHC continues to focus on how best to increase Māori CHC members and advisors. Ultimately, engagement will be evidenced through an improved health system that is accessible and achieves optimal outcomes for Māori—and all.

The CHC quickly recognised processes were also needed to support staff wanting to engage with communities, whānau and patients. The Framework and Roadmap addressed this need alongside Welcome Packs and Codes of Conduct (emphasising confidentiality) for CHC advisors. However, communication must be ongoing so that newly recruited staff can also learn about engagement processes; genuine engagement can be unfamiliar and daunting for both staff and community advisors. With a restructured system, online learning packages may help orientate staff to the role, practice

Table 1: Examples of feedback about the CHC, CHC advisors & engagement activities.

Person	Role	Feedback*
Ms Odele Stehlin	Previous Chair, Iwi Governance Committee	As we move to reduce the inequities in our health system, the CHC is a critical component of this and ensuring whānau voice, is a voice of change. Thank you for all the work that has taken place so far, it is a journey and a necessary and fundamental one.
Anonymous	CHC Advisor	As an outsider I am freed from following historical and current organisational thinking about particular issues and possible solutions, I can 'think outside the box', challenge the status quo, support novel ideas put forward by individual staff who may initially lack team support.
Mr Mike Hunter	Consultant Surgeon & Intensivist	We've got consumers in the room listening and bringing the different perspective to what we're doing. It's hard to see the full picture when you're inside the frame.
Mr Chris Fleming	CEO, SDHB	Already, they have made a difference to the culture at the DHB, with the comment, 'We need to hear from the Community Health Council' becoming increasingly second nature as issues are proposed and discussed across many forums.
Mr Andrew Swanson-Dobbs	CEO, WellSouth	Council members helped us to interview community representatives for our board of trustees and provided guidance to general practices in our network when they were setting up their own patient engagement groups.
Dr John Adams	Chair, Clinical Leadership Group (CLG) for the new build of Dunedin Hospital	The advisors' input has made significant difference. CHC Advisors are often able to raise basic questions that complement the approach from hospital staff. Several areas have had changes in design and direction as a result of CHC advisor input. In CLG, the CHC Advisors input has been "grounding". There have been clear reminders that this hospital is for the people of the region. The support of our lay advisors to decisions that are having to be made, has also been very important to clinicians. Sometimes clinicians worry when they are having to make compromises, that the public will not understand why something has been done, and the participation of the advisors in those conversations is reassuring. Advisors' opinions also give clinicians strength to stand up for what is needed, when hard conversations are necessary. We would hope that CHC advisor input is not only maintained but increased into the future, and we congratulate the CHC on the quality and capacity for involvement of the people selected for these roles.
Mrs Jo Millar	CHC Advisor, CLG for the new build of Dunedin Hospital (& President, Grey Power Otago)	Due to my interest I was very pleased to be appointed as a Community Health Council Advisor on the CLG of the new build of the hospital. It has been very gratifying to be able to participate as a consumer as the Ministry of Health has a policy of the patient being the focus and priority in all facets of health treatment.

*****Quotes are all from the Community Health Council Annual Reports[14]

and potential of community forums and advisors. Similarly, online learning packages could help ensure that community forum members understand their roles, and the purpose and value of engagement activities. The CHC found it important for projects to have a specified "end", and that advisors be adequately informed of the outcomes of projects, in terms of whether the goals were achieved. Sometimes these loops were not closed, and this will be important in the restructured health system. When establishing new forums, we recommend notifying forum members and staff that feedback will be collected to learn how to improve engagement activities—and that de-identified findings may be published to support improvement. Ethical approval should be sought to support such data collection and reporting from the outset.

A strength of the CHC was in the steering group's and CEOs' conceptualisation of the CHC as a council advising both the SDHB and WellSouth PHO. The Southern Health CHC appears to have been unique in this regard.[7] Silos, and poorly integrated care,[3,15,16] could be lessened if new community forums are not exclusively linked to hospital providers. The CHC was fortunate that the DHB and PHO CEOs, executive teams, commissioners, boards and clinical champions all recognised and supported the opportunities for CHC engagement to improve the Southern Health system. Occasionally, some managers have found the concept of the CHC and advisors difficult to grasp; trusting, respectful and genuine relationships are critical to the sustainability of engagement activities as summarised in the Framework's values. The organisational equivalence of the CHC to the Clinical Council within the Southern Health system helped address such issues. Thinking about how to successfully embed clinical-consumer equivalence within the context of national health system restructuring will be important to avoid new community forums slipping into "tokenistic" tick-box engagement.

Establishing and operating community forums requires adequate resourcing. The CHC would not have succeeded without a paid facilitator role. This role supports the CHC and CHC advisors, manages the Roadmap for engagement, and connections between staff and advisors. Secretarial support is also necessary for minute-taking at monthly meetings and sending out between-meeting resources; the CHC had such support removed after two years which adversely affected the CHC's responsiveness. A significant communications investment is necessary both to ensure calls for new forum members reach Māori communities, disabled people and other marginalised groups, and to support the visibility of engagement activities and outcomes to our wider communities. The CHC has had occasional valuable communications support; strengthening this would undoubtedly have extended the reach and visibility of CHC activities. Lastly, as mentioned, paid reimbursement of members and advisors is necessary in recognition of the expertise "lay" advisors bring—and to ensure new community forums are not biased towards the wealthy and retired.

Conclusion

It is hoped that the CHC's planning, processes, and activities described in this paper may be useful to the establishment of robust community, whānau and patient engagement forums within the restructured health system. The CHC has undoubtedly increased engagement within the Southern Health system. Despite some challenges, the CHC member and advisor activities span all four domains and types of engagement. With adequate recruitment, resourcing, training, and processes in place, the proposed community forums should also succeed. Our experiences point to the clear importance of ensuring strong support from executive and governance leadership within the respective organisations, for the purpose, functioning and scope of future forums. Early attention to appropriate engagement with Māori on such forums, according Te Tiriti, is likely to result in improved health for Māori and all New Zealanders. If Māori are attracted to the new community forums (eg with benefits of engagement being clear and relevant), these have potential to provide a genuine "ground up" compliment to the more "top down" activities of Health NZ and the Māori Health Authority in the restructured national health system.[3]

COMPETING INTERESTS
Nil.

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REFERENCES
1. International Conference on Primary Health Care. Declaration of Alma-Ata. *WHO Chron*. 1978;32(11):428-430.
2. World Health Organization. WHO global strategy on people-centred and integrated health services: Interim Report. Geneva. Available from: https://apps.who.int/iris/bitstream/handle/10665/155002/WHO_HIS_SDS_2015.6_eng.pdf
3. Department of the Prime Minister and Cabinet. The new health system. 2021. Available from: https://dpmc.govt.nz/our-business-units/transition-unit/response-health-and-disability-system-review/information
4. Department of the Prime Minister and Cabinet. Voice of communities and consumers (Factsheet). 2021. Available from: https://dpmc.govt.nz/our-business-units/transition-unit/response-health-and-disability-system-review/information
5. Health Quality & Safety Commission. Engaging with consumers: A guide for district health boards. Wellington: Health Quality & Safety Commission; 2015.
6. Health Quality & Safety Commission. (2021) Consumer engagement quality and safety marker. Health Quality & Safety Commission: Wellington. Available from: https://www.hqsc.govt.nz/our-programmes/partners-in-care/consumer-engagement-qsm/
7. Gurung G, Derrett S, Gauld R. The role and functions of Community Health Councils in New Zealand's health system: A document analysis. N Z Med J. 2020;133(1510): 70-82.
8. Health Quality and Safety Commission. Health Quality and Safety Commission's expectations for 2016/17 Annual and Regional Service Plans. 2016. Health Quality and Safety Commission: Wellington.
9. Southern Health. About us. 2021. Available from: https://www.southernhealth.nz/about-us
10. Te Tiriti o Waitangi, February 6, 1840, http://www.treatyofwaitangi.maori.nz/
11. Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. BMJ Qual Saf. 2016;25(8):626-32.
12. Charles C, DeMaio S. Lay participation in health care decision making: a conceptual framework. J Health Polit Policy Law. 1993;18(4):881-904.
13. Arnstein SR. A ladder of citizen participation. J Am Inst Plann. 1969;35(4):216-24.
14. Community Health Council. CHC engagement framework and roadmap. Available from: https://www.southernhealth.nz/about-us/about-southern-health/community-health-council
15. Cumming J. Integrated care in New Zealand. Int J Integr Care. 2011;11(Spec 10th Anniversary Ed):e138. doi:10.5334/ijic.678.
16. New Zealand Government. He Ara Oranga - Report of the Government Inquiry into Mental Health and Addiction. 2018. New Zealand: New Zealand Government.

Lockdown Level 4 V2.0: different trauma patterns in Auckland in 2021?

Keith Teo, Sunder Balasubramaniam, Ian Civil

ABSTRACT

AIMS: Coronavirus disease 2019 (COVID-19) resulted in the implementation of public health restrictions to reduce transmission. These restrictions have reduced trauma-related admissions to hospitals. Auckland, New Zealand, had two periods of Level 4 lockdowns, in 2020 and 2021. In the 2021 lockdown, Aucklanders were generally less compliant with the restrictions. Therefore, we hypothesised that trauma-related activity would be greater in the 2021 lockdown compared to 2020.

METHODS: A retrospective descriptive study of trauma admissions to Auckland City Hospital (ACH) during 2020 (26 March to 27 April 2020—33 days) and 2021 (18 August to 21 September 2021—35 days) lockdown periods was performed.

RESULTS: Trauma admissions and trauma call activations increased from 97 to 105 (8.2%) and from 35 to 46, respectively, in the 2021 lockdown compared to 2020. The numbers of males and road related injuries requiring admission were increased from 49 to 66 ($p = 0.08$) and from 21 to 28 ($p = 0.44$), respectively, in 2021 compared to 2020. Major trauma admissions increased from 13 to 23 in the 2021 lockdown compared to 2020.

CONCLUSIONS: Trauma-related presentations to hospital were higher in the 2021 Auckland lockdown compared to 2020. Lockdown fatigue and reduced compliance in 2021 may have contributed to this finding, suggesting that future lockdowns may be less effective.

Coronavirus disease 2019 (COVID-19) has spread globally at an unprecedented rate, prompting governments to implement temporary restrictive public health measures to reduce the transmission of the disease. New Zealand developed a four level alert system representing increasingly restrictive public health interventions with the aim of eradicating COVID-19. The most restrictive Alert Level, Level 4, also known as "lockdown", mandated that the New Zealand population isolate at home, except when accessing essential services. Alert Level 4 was implemented in 2020, from 26 March to 27 April 2020 (33 days) across New Zealand, following several weeks of less restrictive measures that started after the first verified case of COVID-19 on 28 February 2020.[1]

A decline in trauma admissions during the 2020 lockdown has been reported in several studies in New Zealand and internationally. The Midland region of New Zealand had a 36.5% reduction in injury admissions during the 2020 lockdown compared to similar periods from 2017–2019.[2] Similarly, Christchurch Hospital reported a 42% reduction in major trauma during the 2020 lockdown compared to the preceding 33-day period before lockdown.[3] The Northern Region of New Zealand also reported a 25% decrease in major trauma admissions during the 2020 lockdown compared to the same period in 2019.[4] In Ireland, a 40% decrease in trauma admissions was reported during their 2020 lockdown compared to the previous year.[5]

In 2021, the Delta variant of COVID-19 increased the disease burden globally due to its higher virulence and increased risk of hospitalisations and severe disease.[6–8] As COVID-19 vaccination rates in New Zealand were approximately 20% when the Delta variant was detected in Auckland, the Government implemented another lockdown to reduce transmission and allow vaccination rates to increase.[9] While most of the country stepped down to Alert Level 3 after two weeks, Auckland remained in Alert Level 4 from 18 August to 21 September 2021 (35 days).

Reports in the media have suggested that the 2021 lockdown, specifically in Auckland, was not conscientiously adhered to, compared to the 2020 lockdown. An article reported that lockdown breaches in Auckland during the Alert Level 4 lockdown in 2021 were 28% higher compared to the lockdown in 2020.[10] Multiple reports of lockdown breaches have led to arrests and subsequent charges filed against the offenders by police.[11] Many of these cases received significant media attention and public backlash for their actions, especially people who utilised essential workers' permits to

breach the public health restrictions. Traffic counts during the Alert Level 4 lockdown in 2021 were also higher compared to the lockdown in 2020, as reported by the New Zealand Transport Agency.[12,13]

We anticipated that poorer public compliance with Alert Level 4 lockdown in Auckland in 2021, compared to 2020, would be reflected in the pattern of trauma admissions over this period. We hypothesised that the number of trauma calls and trauma admissions would be greater in 2021 compared to 2020 (and comparable to pre-pandemic times), and that injury patterns might reflect behaviour not consistent with being in lockdown.

Methods

A retrospective descriptive study of trauma admissions to Auckland City Hospital (ACH) was performed during the 2020 (26 March to 27 April 2020—33 days) and 2021 (18 August to 21 September 2021—35 days) lockdown periods. The ACH Trauma Registry database, established in 1994, collects prospective data on all trauma admissions to ACH.[14] Data were extracted on patients admitted for trauma-related presentations over the two lockdown periods and corresponding periods in 2019—to provide a context of trauma admissions during non-lockdown conditions. An injury severity score (ISS) of 13 or more, using the 2005/2008 version of the Abbreviated Injury Scale (AIS), was considered major trauma based on the New Zealand Major Trauma National Minimum Dataset.[15] In 2019, the ACH Trauma Registry database used the 1998 version of the AIS and using this version and equivalent definition of major trauma is an ISS of 16 or more.[16]

Specific data collected included patients' demographics, number of trauma call activations, number of trauma admissions, type of injury (blunt or penetrating), mechanism of injury, intention (self-inflicted, unintentional, inflicted by others, unknown), date of injury, type of admission (transfer, direct, unknown), ISS and mortality. The SPSS statistics version 28 (IBM, New York) was used to analyse the data. Descriptive statistics were used for patient demographics. Continuous variables were analysed with the student t-test. Categorical data was analysed with either the Pearson's chi-square test or Fisher's exact test. The null hypothesis was rejected for p-values <0.05.

This study was deemed not to require formal ethics review by the Health and Disability Ethics Committee (HDEC).

Results

There were increases in trauma admissions from 97 to 105, and trauma call activations from 35 to 46, when comparing the 2020 and 2021 Level 4 lockdown periods. Statistical analysis was not performed for these differences. Table 1 shows the trauma-related admissions to ACH during the two lockdown periods in 2020 and 2021. Trauma admission numbers in the 2020 and 2021 lockdown periods were reduced, compared to the corresponding non-COVID periods in 2019 (March–April; 174, August–September; 143).

In the 2021 lockdown, 34.7% (49 vs 66) more males were admitted for trauma presentations compared to 2020, which corresponded to a 12% increase in the male-to-female ratio. Despite the trend in more males, this difference did not reach statistical significance (p = 0.08). The preponderance of male involvement in trauma in 2021 is comparable to the non-COVID 2019 time periods (63% [2021] vs 69% and 59% [2019]). The median age of the trauma patients during the 2021 lockdown period was similar to the 2020 lockdown period (52.5 vs 53.8; p = 0.63).

Road-related injuries leading to trauma admissions were higher in 2021 compared to 2020 lockdown periods (21 vs 28). Comparing the mechanisms of injury between both lockdowns, the differences were not statistically significant (p = 0.44). Of note, the number of road-related injuries in the 2021 lockdown was more similar to the two 2019 periods (35 and 31) in Table 1. Falls are still the most common mechanism of injury in both lockdown and non-lockdown periods, as shown in Table 1.

The absolute number of trauma admissions with major trauma (ISS ≥13) was increased in the 2021 lockdown compared to 2020 (13 vs 23). Statistical analysis was not performed for this difference. The number of major traumas during the 2021 lockdown was similar to the numbers in 2019 (22 and 20).

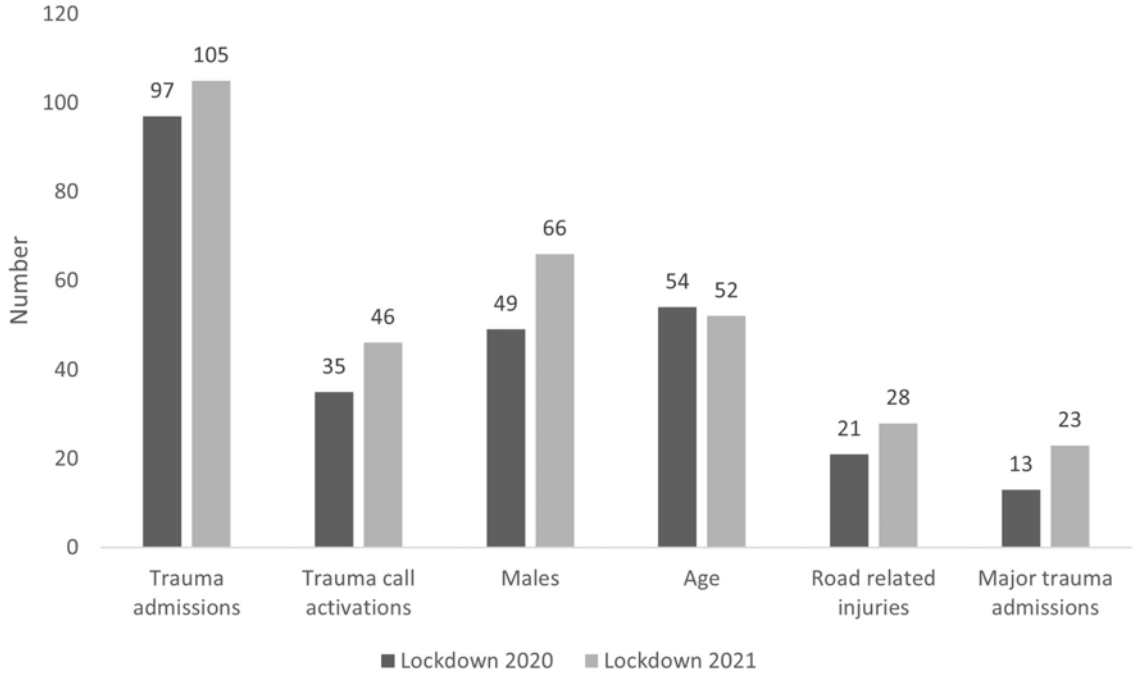
Figure 1 shows key comparisons between Level 4 lockdowns in 2020 and 2021. Overall, there is an increase in trauma admissions, trauma call activations, males involved in trauma, road-related injuries and number of major trauma admissions. The median age of the trauma patients was similar.

Table 1: Trauma-related admissions to Auckland City Hospital (ACH) during the two lockdown periods in 2020 and 2021 and their corresponding periods in 2019.

	2019, n (%) (26 March to 27 April)	**2019, n (%) (18 August to 21 September)**	**2020, n (%) (26 March to 27 April)**	**2021, *n* (%) (18 August to 21 September)**	**Absolute % change (2020 to 2021)**	**p-value (between 2020 to 2021)**
Trauma admissions	174	143	97	105	+ 8.2	-
Trauma calls	52	65	35	46	+ 31.4	-
Sex						
Male	120 (69)	85 (59)	49 (51)	66 (63)	+ 34.7	0.08
Female	54 (31)	56 (39)	48 (49)	39 (37)	- 24.6	
Age						
Median (IQR)	39.5 (36–59)	47 (31–61)	54 (40-67)	52 (34-68)	- 3.5	0.63
Type of injury						
Blunt	160 (92)	136 (95)	86 (89)	92 (87)	+ 5.9	0.82
Penetrating	14 (8)	7 (5)	11 (11)	13 (13)	+ 18.2	
Mechanism of injury						
Road-related	35 (20)	31 (22)	21 (22)	28 (27)	+ 33.3	0.44
Gunshot	2 (1)	2 (1)	1 (1)	0 (0)	- 100.0	
Stabbing	10 (6)	4 (3)	7 (7)	9 (9)	+ 28.6	
Fall	88 (51)	79 (56)	59 (61)	53 (50)	- 10.2	
Other*	39 (22)	26 (18)	9 (9)	15 (14)	+ 66.7	
Injury Severity Score (ISS)						
Non-major trauma (ISS ≤12)	152 (87)	123 (86)	84 (87)	82 (78)	- 2.4	-
Major trauma (ISS ≥13)	22 (13)	20 (14)	13 (13)	23 (22)	+ 76.9	

*Other: mechanisms that do not fit into the defined categories—quad bike accidents, blunt assaults, off road bicycle, skateboard, e-scooter accidents, animal attacks etc.
IQR: interquartile range.

Figure 1: Key comparisons between lockdown in 2020 and 2021.



Discussion

This comparison of Level 4 lockdowns has shown increased trauma-related hospital admissions and trauma call activations in 2021 compared to 2020, despite similar public health restrictions in place during both periods. Of note, more males were involved in the trauma admissions in the 2021 lockdown, and road-related injuries leading to trauma admissions were increased in 2021, although both trends did not reach significance. The number of trauma admissions with major trauma in the 2021 lockdown was higher than in the 2020 lockdown.

The poorer compliance with public health restrictions in the 2021 lockdown reported in the media, compared to the 2020 lockdown is potentially reflected in the greater number of trauma-related admissions and trauma call activations in ACH. Studies have suggested the concept of "lockdown fatigue" from extended and repeated lockdowns from the literature.[17–19] This can manifest as physical exhaustion, headaches, increased worry,[19] and increased symptoms of anxiety and depression.[18] As reported by Goldstein et al,[17] the effect of a 120-day lockdown waned overtime, likely from non-compliance resulting in diminished effect on COVID-19 death rates and population mobility. Like prolonged lockdowns, the second lockdown in Auckland in 2021 may have contributed to "lockdown fatigue", resulting in reduced compliance to restrictions and increased numbers of trauma admissions and trauma calls. Of note, the Goldstein paper did not compare two different lockdowns like our study. However, the conclusion that prolonged or repeated lockdowns have diminishing effects on the population is comparable. Although public health messaging has been consistent in promoting compliance with the public health restrictions to reduce the spread of the virus, this had likely been less successful in 2021. Future public health restrictions for COVID-19 may not be well tolerated by the population, and may result in more trauma-related admissions compared to previous lockdowns.

A male predominance in trauma activity is often reported in the literature[20–22] and has also been reported in New Zealand.[23,24] The 2020 lockdown in Auckland had approximately equal numbers of male and female trauma patients, while the 2021 lockdown reverted back to higher males involved in trauma. This decrease in male trauma patients in the 2020 lockdown was also reported in the Midland region (50% reduction), and in Christchurch hospital (47% reduction).[3,25] This decrease may be attributed to the effect of the 2020 lockdown in reducing high-risk activity, both recreational and occupational, that have higher

participation of males compared to females. As compliance to the 2021 Auckland lockdown may have been reduced compared to the 2020 lockdown, the number of males involved in trauma has increased to non-lockdown levels.

The number of road-related injuries leading to trauma admissions increased in the 2021 lockdown compared to the 2020 lockdown. As reported in the media, the 2021 lockdown had higher traffic counts compared to the 2020 lockdown.[12,13] A review reported that a decrease in traffic count during COVID-19 lockdowns in many countries resulted in reduced road traffic crashes and associated deaths but increased injury severity.[26] This review by Yasin et al was a narrative review without stringent inclusion criteria. Therefore, the conclusions reached may be influenced by selection bias, and may not be generalisable. However, the decrease in traffic count during lockdown that was expected in the 2021 lockdown did not occur, which most likely led to the increase in road-related injuries. This increased population mobility may be due to more widespread COVID-19 testing and vaccination, and increase in delivery services. Future lockdowns may need more directed public health messaging regarding safe driving to help reduce the burden of road-related injuries.

The number of trauma admissions with major trauma has increased in the 2021 lockdown compared to 2020. This increase may also be the result of reduced compliance to restrictions and more risky behaviour undertaken by Aucklanders during the 2021 lockdown, as discussed above. However, it is noteworthy that the sample size is small, and potential bias is possible, making the results less generalisable. In addition, lockdowns were rare before COVID-19, hence literature published on trauma behaviour during lockdown is limited.

Due to the increase in trauma activity in the 2021 lockdown compared to the 2020 lockdown, it is likely that trauma resources in future lockdowns will need to be maintained at non-lockdown levels. Other hospital services like non-urgent elective surgery, clinics or investigations have been scaled down during Alert Level 4 lockdowns, with concomitant re-distribution of resources. For trauma services, our study supports maintaining similar resources during lockdowns due to a comparable workload to non-lockdown periods.

Limitations

Limitations of this study are found in that it includes data from a single institution. However, this is an internal comparison of trauma-related activity, and there was no change of any destination protocols between the two time periods. In addition, the sample size is small, and the study population is limited to ACH catchment, which may not be generalisable. The small sample size also limits statistical analysis between both periods. However, the lockdowns in both periods are a rare occurrence in the context of a global pandemic that will be difficult to replicate. A second limitation is the slight difference in time periods between the two lockdown periods, with the second being two days longer than the first. This might have had a small effect in exaggerating the differences between the two periods. A third limitation is that this is a retrospective descriptive study with no formal statistical analysis performed. In addition, confounding variables like availability of the vaccine and the better understanding of the COVID-19 virus are key differences between the two lockdowns. However, these variables are not easily quantifiable compared with increased lockdown breaches and traffic flow. There may be other reasons other than lockdown fatigue contributing to increased trauma activity. More research is needed to determine the cause of the increase in trauma activity.

Conclusion

Trauma calls and trauma admissions were higher in the 2021 Alert Level 4 lockdown period compared to the similar lockdown in 2020. This suggests that societal behaviour in 2021 was more similar to pre-COVID behaviour than was the case in 2020. Lockdown fatigue and indifference to COVID-19 regulations may exist to a greater level in 2021. This raises the possibility that future lockdowns may prove progressively less effective, and that trauma service resources should be maintained at non-lockdown levels to ensure adequate care of trauma patients.

COMPETING INTERESTS
Nil.

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REFERENCES
1. Ministry of Health NZ. Single case of COVID-19 confirmed in New Zealand. https://www.health.govt.nz/news-media/media-releases/single-case-covid-19-confirmed-new-zealand. Updated 28 February 2020. Accessed 19 October 2021.
2. Christey G, Amey J, Singh N, Denize B, Campbell A. Admission to hospital for injury during COVID-19 alert level restrictions. *N Z Med J.* 2021;134(1531):50-58.
3. Fan D, Scowcroft H, McCombie A, Duncan R, Wakeman C. A comparison of major trauma admissions to Christchurch Hospital during and after COVID-19 lockdown in New Zealand. *N Z Med J.* 2021;134(1540):46-55.
4. McGuinness MJ, Harmston C. Association between COVID-19 public health interventions and major trauma presentation in the northern region of New Zealand. *ANZ J Surg.* 2021;91(4):633-638.
5. Fahy S, Moore J, Kelly M, Flannery O, Kenny P. Analysing the variation in volume and nature of trauma presentations during COVID-19 lockdown in Ireland. *Bone Jt Open.* 2020;1(6):261-266.
6. England PH. SARS-CoV-2 variants of concern and variants under investigation in England. Technical briefing 14.
7. Sheikh A, McMenamin J, Taylor B, Robertson C. SARS-CoV-2 Delta VOC in Scotland: demographics, risk of hospital admission, and vaccine effectiveness. *Lancet.* 2021;397(10293):2461-2462.
8. Twohig KA, Nyberg T, Zaidi A, et al. Hospital admission and emergency care attendance risk for SARS-CoV-2 delta (B.1.617.2) compared with alpha (B.1.1.7) variants of concern: a cohort study. *Lancet Infect Dis.* 2021.
9. Plank M. After its first suspected Delta variant community case, New Zealand goes into short, sharp nationwide lockdown. https://theconversation.com/after-its-first-suspected-delta-variant-community-case-new-zealand-goes-into-short-sharp-nationwide-lockdown-166276. Updated 17 August 2021. Accessed 19 October 2021.
10. Clent D. Covid-19: More Aucklanders caught breaking rules in latest lockdown. https://www.stuff.co.nz/national/health/coronavirus/126448392/covid19-more-aucklanders-caught-breaking-rules-in-latest-lockdown. Published 24 September 2021. Accessed 19 October 2021.
11. Daly M. A holiday in Wānaka and boot-full of KFC: All of the Covid lockdown breaches. https://www.stuff.co.nz/national/health/coronavirus/126451677/a-holiday-in-wnaka-and-bootfull-of-kfc-all-of-the-covid-lockdown-breaches?rm=a. Published 22 September 2021. Accessed 19 October 2021.
12. Guildford J. Covid-19: Lockdown traffic higher than last year as tests and jabs drive motorists to the roads. https://www.stuff.co.nz/national/health/coronavirus/126224384/covid19-lockdown-traffic-higher-than-last-year-as-tests-and-jabs-drive-motorists-to-the-roads?rm=a. Published 30 August 2021. Accessed 19 October 2021.
13. Agency WKNT. Waka Kotahi COVID-19 transport impact. https://www.nzta.govt.nz/assets/resources/covid-19-impacts-on-transport/waka-kotahi-nzta-covid-19-tracking-core-report-waves-1-26-20210914.pdf. Published 2021. Accessed 16 March 2022.
14. King M, Paice R, Civil I. Trauma data collection using a customised trauma registry: a New Zealand experience. *N Z Med J.* 1996;109(1023):207-209.
15. New Zealand Major Trauma National Minimum Dataset. https://www.majortrauma.nz/assets/New-Zealand-Major-Trauma-Minimum-Dataset-August-2021.pdf. Published August 2021. Accessed 21 October 2021.
16. Van Ditshuizen JC, Sewalt CA, Palmer CS, Van Lieshout EMM, Verhofstad MHJ, Den Hartog D. The definition of major trauma using different revisions

of the abbreviated injury scale. *Scand J Trauma Resusc Emerg Med.* 2021;29(1):71.
17. Goldstein P, Levy Yeyati E, Sartorio L. *Lockdown fatigue: The diminishing effects of quarantines on the spread of COVID-19.* Red Nacional de Investigadores en Economía (RedNIE);2021.
18. Mack DL, DaSilva AW, Rogers C, et al. Mental Health and Behavior of College Students During the COVID-19 Pandemic: Longitudinal Mobile Smartphone and Ecological Momentary Assessment Study, Part II. *J Med Internet Res.* 2021;23(6):e28892.
19. Labrague LJ, Ballad CA. Lockdown fatigue among college students during the COVID-19 pandemic: Predictive role of personal resilience, coping behaviors, and health. *Perspect Psychiatr Care.* 2021;57(4):1905-1912.
20. Roberts Z, Collins JA, James D, et al. Epidemiology of adolescent trauma in England: a review of TARN data 2008-2017. *Emerg Med J.* 2020;37(1):25-30.
21. Cameron PA, Fitzgerald MC, Curtis K, et al. Over view of major traumatic injury in Australia--Implications for trauma system design. *Injury.* 2020;51(1):114-121.
22. Mekkodathil A, El-Menyar A, Kanbar A, et al. Epidemiological and clinical characteristics of fall-related injuries: a retrospective study. *BMC Public Health.* 2020;20(1):1186.
23. Services ADHBT. *Auckland City Hospital Trauma Registry Report.* 2019.
24. Network. NZMTRaNT. Annual report 2019-2020. https://www.majortrauma.nz/assets/Publication-Resources/Annual-reports/NZMT2019-20V2-FINAL.pdf. Accessed 3 December 2021.
25. Christey G, Amey J, Campbell A, Smith A. Variation in volumes and characteristics of trauma patients admitted to a level one trauma centre during national level 4 lockdown for COVID-19 in New Zealand. *N Z Med J.* 2020;133(1513):81-88.
26. Yasin YJ, Grivna M, Abu-Zidan FM. Global impact of COVID-19 pandemic on road traffic collisions. *World Journal of Emergency Surgery.* 2021;16(1):51.

Effectiveness of a preschool asthma education programme, compared to usual care, on the frequency of acute asthma events: a community-based cluster randomised trial

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ABSTRACT

AIM: To determine whether an asthma intervention delivered within preschools can improve asthma outcomes in children aged 2–5 years with asthma or a high probability of asthma.

METHODS: Between 2011 and 2013, we undertook a pragmatic, single-blind, cluster randomised trial in Auckland, New Zealand. We randomly assigned (1:1 ratio) preschools, and their children aged 2–5 years with asthma or a high probability of asthma, to receive an asthma intervention (a 12-month respiratory nurse-led asthma assessment using an evidence-based, web-based tool and a class-based asthma education programme for four months), or a control intervention (a class-based science education programme for four months). Both groups received standard asthma management by their primary care physician. The primary outcome was the proportion of children that had at least one unscheduled ("urgent") medical or ED attendance for asthma over 12 months.

RESULTS: We randomised 171 preschools, 85 to the intervention (341 children) and 86 to the control (334 children). We found no difference in the primary outcome (intervention: 216/341, 63% vs control: 181/334, 54%: adjusted Odds Ratio=1.36, 95% Confidence Interval=0.95-1.94, p=0.095). However, compared with the control group, the intervention group had improved and sustained asthma control and fewer asthma symptoms over 12 months.

CONCLUSIONS: Combining asthma education with a nurse-led, evidence-based asthma assessment and education intervention led to sustained improvements in asthma control in this preschool population, but its effect on acute events remains unclear.

In 2001 and 2003, the International Study of Asthma and Allergies in Children (ISAAC) found that young children in New Zealand had some of the world's highest prevalence of asthma symptoms,[1] with reported asthma in 30% of children aged 6–7 years and current wheeze in 22%.[2] More recent data from ISAAC is not available for NZ. The 2020/21 New Zealand Health Survey reported that 6% of children aged 2–4 years had asthma (defined as the child's parents/caregivers had been told by a doctor that the child had asthma, and the child currently used asthma treatments).[3]

A 2002 report noted that asthma was a leading cause of childhood hospital admissions in New Zealand, and the third-ranked cause of years-lost-to-disability.[4] Between 2010–2019 there was a 62% reduction in hospital admissions with an asthma diagnosis for New Zealand children aged under 5-years.[5] However, clear ethnic differences exist, with Māori children under 5 years two to three times more likely to be admitted to hospital for asthma than non-Māori children of the same age.[5]

Most medicines recommended by guidelines for the management of childhood asthma are fully subsidised by the New Zealand Government. Despite this, suboptimal use of these medicines is likely to contribute to asthma-related morbidity. For example, in 2004, inhaled corticosteroids (ICS) were underused, and there was an over-reliance on short-acting beta$_2$-adrenoceptor agonists

(SABA) in children aged 0–4 years.[6] Contributing factors include the difficulty of diagnosing asthma in young children (eg wheeze vs asthma),[7–9] challenges in determining the age to start asthma medication,[10] limited asthma education for children and their families, low adherence to recommended treatment regimens amongst children,[6, 11] low health literacy levels particularly among Māori,[12] and low provision of written asthma action plans to children/guardians/caregivers,[13–14] despite evidence-based asthma guidelines recommending their use.[15]

Two asthma interventions were independently developed in 2008 in New Zealand to improve asthma education and management. The first intervention was a web-based asthma assessment and education tool called Giving Asthma Support to Patients (GASP), developed by a primary healthcare organisation (Comprehensive Care Ltd.) in Auckland, New Zealand. GASP was designed to link with primary care patient management software, and assist general practitioners (GPs) and GASP-trained nurses with the differential diagnosis of asthma and its management, underpinned by evidence-based asthma treatment guidelines.[16–18] GASP includes an asthma assessment, spirometry (in adults only), provision of a personalised self-management action plan and trigger advice. GASP-trained nurses initiate changes to the action plan over time, after consultation with the patient's GP, who also approves clinically indicated medication changes. Audit data from 2008–2011, from 761 people aged 5–64 years with uncontrolled asthma seen in primary care in the Waitematā region of Auckland, indicated GASP had a positive impact on asthma control, and reduced hospital admissions and emergency department (ED) presentations.[19] The second intervention was developed by the Pharmaceutical Management Agency of New Zealand (PHARMAC) and consisted of an asthma-specific, curriculum-based preschool education programme. In 2017, 64% of New Zealand children under five years attended some form of preschool (up from 54% in 2009).[20] Delivering an asthma intervention within a preschool enables greater reach to the child, their peers, teachers, and guardians/caregivers. In 2009, the intervention was piloted in 20 New Zealand preschools and, although only delivered once, was successful in increasing awareness, knowledge, confidence and asthma self-management in guardians/caregivers of children with asthma.[21] However, the intervention had no impact on ICS, SABA use or asthma-related hospitalisations (most likely due to limitations of the clinical outcome analyses).

In 2011, we designed a pragmatic trial to assess the effectiveness of the GASP tool and the PHARMAC asthma education programme[21] on asthma control in New Zealand children aged 2–5 years. We hypothesised that the combined intervention would significantly reduce the frequency of acute asthma events over 12 months through better asthma control (by increasing ICS use and decreasing SABA use), compared with a control intervention.

Methods

We undertook a single-blind, parallel-group, cluster randomised trial within the Kaipara and Rodney Districts, North Shore City and Waitakere City. The protocol was approved by the Upper South A Regional Ethics Committee and the Auckland and Northern Kindergarten Associations (trial registration number: ACTRN12611001143910).

Participants

Using data from the Ministry of Education register of Early Childhood Services (as of 1 July 2010), we identified preschools located within selected census areas (ie those of low socio-economic status and a high proportion of Māori and Pacific people, regular smokers aged ≥15 years, and household crowding, based on 2006 NZ census data) within the study region. We excluded preschools providing home-based care. We invited the lead teacher in identified preschools to participate and obtained their written consent. The teacher distributed a newsletter to guardians/caregivers of all children enrolled at the preschool. This explained the study, eligibility criteria for the children and how guardians/caregivers could register their interest. Interested guardians/caregivers were contacted by a researcher, the study further explained, inclusion/exclusion criteria assessed, and verbal consent sought (for those who met eligibility criteria) prior to randomisation of the preschool. We obtained written consent from guardians/caregivers at the baseline data collection day, after randomisation of the preschool.

Children were eligible if they were aged between two and four years eight months at enrolment, had received a diagnosis of asthma from a GP or other medical practitioner, and were enrolled at a participating preschool. Eligibility was broadened two months into recruitment (see Appendix for rationale) to include children with a high probability of asthma, defined as currently using an asthma inhaler (any type) and at least one of the following: recurrent wheeze episodes in the last year that responded to treatment with a SABA; and/or a dry

cough in the last year (especially at night and/or on exertion); and/or a personal history or family history of atopy. Children were excluded if they had a medically diagnosed respiratory illness other than asthma, had previously received a GASP assessment, were enrolled at another participating preschool, and/or were currently enrolled in another respiratory-related study.

Randomisation and masking

We digitally randomised preschools to the intervention or control in a 1:1 ratio, using block randomisation stratified by preschool license size (40, 75 children) and centre age group (2–5, 0–5 years). Researchers searching medical records for primary outcome data, and trial clinicians reviewing these data, were masked to treatment allocation. Participants and researchers collecting secondary outcome data were aware of treatment allocation.

Procedures

The study intervention was an asthma intervention comprising asthma education plus GASP, and the control intervention was science education (See Appendix). In brief, intervention preschools received a four-month, asthma-specific, curriculum-linked learning and activity unit (consisting of nine 30-minute lessons), with associated resources for teachers and children, and a staff professional development programme; an asthma accreditation programme; identification bracelets for children with asthma/high probability of asthma; and cessation support for staff who smoked. Resources were delivered by the research team (face-to-face) at baseline and four months, although the lessons could be delivered by teachers at any time. Participating children with asthma/high probability of asthma attending the intervention preschools received standard asthma management by their GP. Additional asthma-specific support was delivered by a GASP-trained nurse (face-to-face) to the children and their guardian/caregiver at baseline, one, four, eight and 12 months. This support included: a GASP assessment (no spirometry); education on asthma medication use and symptom management; a GASP action plan for each child's guardian/caregiver/preschool (a copy of the associated decision support was sent to the child's usual GP. If the GASP assessment identified a required change to the child's asthma medication, the guardian/caregiver was referred to the child's usual GP); strategies to improve medication adherence (eg text reminders, charts), with a focus on the child taking the required medication twice daily; and cessation support for family members that smoked.

Preschools randomised to the control group received a four-month, science-specific, curriculum-linked learning and activity unit (consisting of nine 30-minute lessons), with associated resources for teachers and children, and staff professional development. These resources were delivered to the children by the research team (face-to-face) at baseline and four months, although the lessons could be delivered by teachers at any time. Participating children with asthma/high probability of asthma received standard asthma management by their GP (ie no GASP assessment was undertaken, and no related asthma education was given). After the trial was completed, we offered guardians/caregivers in the control group a free GASP assessment for their child.

Outcomes

Baseline data for the children included age, gender, ethnicity, social class (NZ Deprivation Index 2006,[22] using the preschool's street address as a proxy), age at asthma diagnosis, family history of asthma (immediate blood relatives), asthma triggers, atopic reaction, vaccination history and current asthma medication.

The primary outcome was the proportion of children that had at least one acute asthma event, defined as an unscheduled ("urgent") medical or ED attendance (including hospital admission) for asthma in the last 12 months. Events were self-reported by guardians/caregivers at baseline, and at one, four, eight and 12 months, then verified against medical records via data linkage, using the child's National Health Index number—a unique number allocated to all New Zealanders at birth. A researcher electronically searched GP records (regional) and hospital records (national) for any acute asthma events, and provided the data to a clinician to review and confirm.

Secondary outcomes for children, assessed face-to-face at baseline, one, four, eight (phone interview) and 12 months, included: time to first acute asthma event; frequency of SABA use; asthma symptoms (daytime symptoms, nocturnal awakenings); asthma medication changes; inhaler technique and frequency of preventer inhaler use (defined as good, medium, or poor) for the guardians/caregiver giving the child their inhaler; degree of asthma control[18] as measured by the GASP tool (intervention group only, defined as controlled, partially controlled, or uncontrolled); and absenteeism from preschool/other activities due to asthma.

Additional outcomes assessed face-to-face at baseline and 12 months included: frequency of corticosteroid use for asthma (oral, inhaled); guardians/caregivers absenteeism from work/other activities due to their child's asthma; child's quality of life;[23] second-hand smoke exposure; household crowding; and acceptability of the intervention to guardians/caregivers. See the Appendix for a full description of all secondary outcomes.

Secondary outcomes and characteristics for preschools, assessed in a face-to-face interview with the lead teacher at baseline and 12 months, included: age and gender of children attending; number of staff and their smoking status; number of years the lead teacher had been employed at the preschool; number of asthma-related events at the preschool in the last year; and the "healthy building" status of the preschool. Additional information collected at baseline, one and 12 months included: whether all children with asthma were known to the lead teacher; the current smoke-free and asthma management policies at the preschool and adherence to these policies; knowledge of asthma triggers; confidence in recognising asthma symptoms and how to administer first aid in the event of an asthma attack; and the asthma accreditation status for the preschool. At 12 months we asked the lead teachers about the acceptability of the intervention.

Sample size

We sought to include 188 preschools (94 preschools per arm, 400 children per arm) to provide at least 90% power (p=0.05) for detecting a 50% reduction in the proportion of children who had at least one acute asthma event in the last 12 months in the intervention group compared with the control group. These figures were based on an expected proportion of acute asthma events of 9% in the intervention group compared with 17% in the control group. In the absence of feasibility data, the control event rate, and likely effect size, was estimated from individual participant data collected previously using the GASP tool (self-report, all ages, those with 12-month follow-up data, n=152). Recruitment aimed for at least 25% of participating children to be Māori, and 15% to be Pacific. A cluster inflation factor was applied assuming a moderate intra-cluster correlation coefficient of 0.02.[24] A cluster size of five was selected. The sample size assumed a 15% loss to follow-up—midway between the loss observed in the few other asthma trials involving children (which ranged from 11.5% to 22%).[25–27]

Statistical analysis

Analyses using SAS v9.3 were guided by a pre-specified plan, and undertaken on an intention-to-treat basis using individual (child) data. All tests of significance were two-tailed. Continuous variables were compared with t-tests or Mann–Whitney tests, and categorical data with Chi-squared tests as appropriate. A generalised Linear Mixed Model with a logit link was used to analyse binary child/guardian outcomes, and a Linear Mixed Model was used to analyse continuous child/guardian outcomes, with a preschool fitted as a random effect. The main analyses were unadjusted and sensitivity analyses were conducted adjusting for potential covariates measured at baseline. Time-to-first acute asthma event between the treatment groups was analysed using Kaplan–Meier curves and the log-rank test.

Funding

PHARMAC funded the trial but had no role in the data collection or analyses.

Results

Participant flow and baseline characteristics

The first preschool randomisation was on 30 September 2011, and the last follow-up was on 10 August 2013. Of 179 preschools assessed, 171 were eligible and randomised, 85 in the intervention group (341 children) and 86 in the control (334 children) (Figure 1).

Loss to follow-up at 12 months was 0.6% for preschools and 10% for children (Figure 1). Significantly fewer children were lost to follow-up at 12 months in the intervention group, compared with the control group (12 vs 29 children, respectively; p=0.008). Baseline characteristics were balanced, except for asthma diagnosis, inhaler technique, wheeze and atopy (Table 1), and preschool cleaning and asthma triggers (see Appendix). These variables were subsequently adjusted for in the primary analyses.

Primary outcome

Based on medical record data, a total of 216 (63%) children in the intervention group were found to have had 577 acute asthma events over 12 months, compared with 181 (54%) children, and 466 events in the control group. Unadjusted analyses indicated a significantly higher proportion of acute asthma events in the intervention group compared with the control group (Odds

Figure 1: Recruitment and retention of participants throughout the trial.

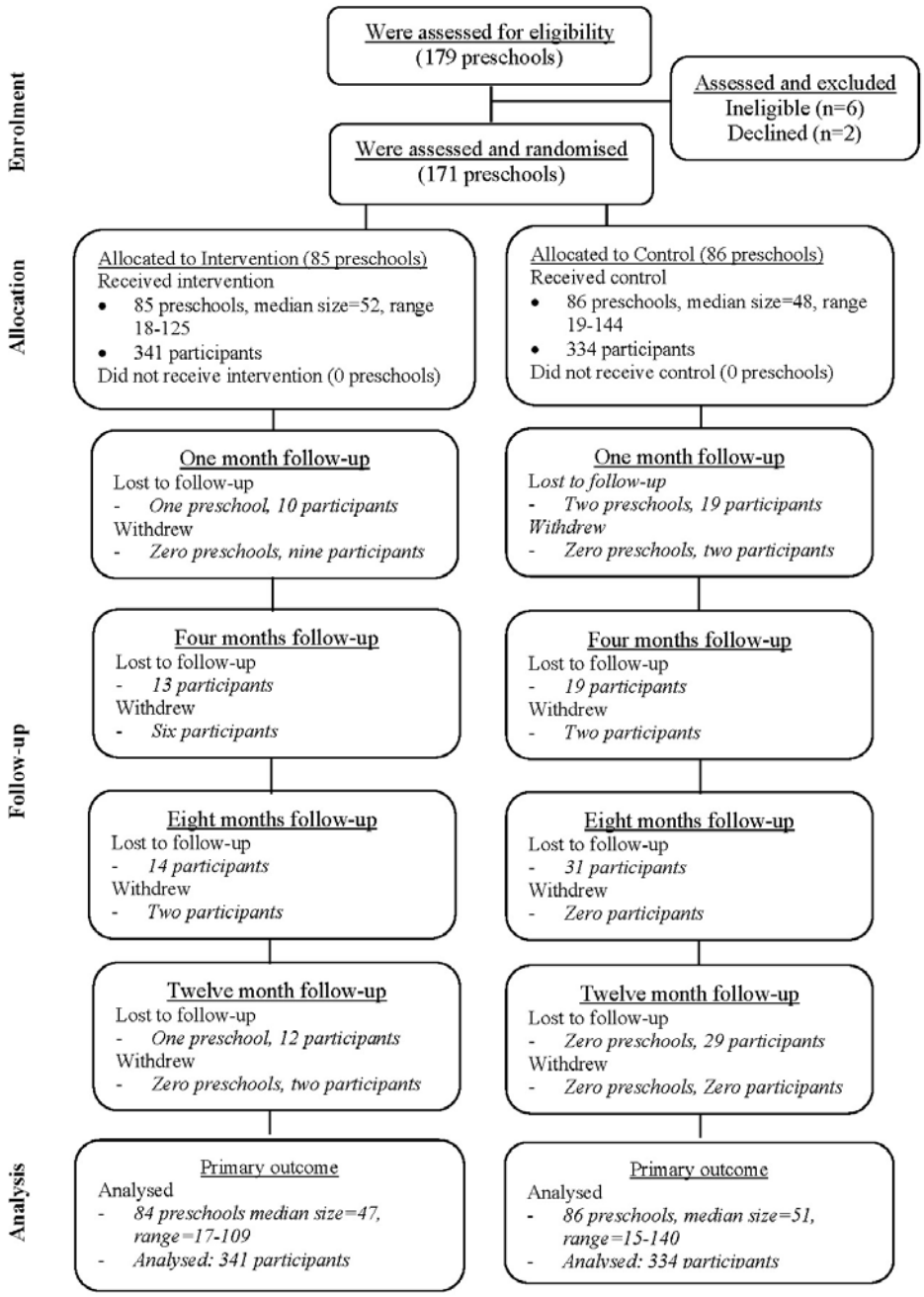

Table 1: Baseline characteristics.

Preschool characteristics	**Intervention N=85 (n, %)**	**Control N=86 (n, %)**
Number of children preschool licenced for:		
40	48 (57)	47 (55)
75	37 (43)	39 (45)
Age group preschool licenced for:		
0–5 years	43 (51)	44 (51)
2–5 years	42 (49)	42 (49)
Number of children aged 2-5 years		
Total	4,599	4,855
Mean per preschool (SD)	54 (21)	57 (26)
Number of asthma related events at the preschool in the last year Mean (SD)	6.4 (11.9)	5.5 (11.2)
All asthmatic children were known to lead teacher	55 (65)	63 (73)
Preschool had asthma-specific guidelines	11 (13)	9 (11)
Characteristics of children	**Intervention N=341 (n, %)**	**Control N=334 (n, %)**
Female	133 (39)	142 (43)
Age (years)		
Mean (SD)	3.2 (0.8)	3.1 (0.8)
Ethnicity		
Māori	87 (26)	66 (20)
Pacific	56 (16)	48 (14)
Other (non-Māori, non-Pacific)	198 (58)	220 (66)
Deprivation index[a]		
By census area unit (Mean, SD)	5.9 (2.5)	5.8 (2.2)
Diagnosed with asthma	**203 (60)**	**163 (49)**
Māori	55 (63)	33 (50)
Pacific	36 (64)	26 (54)
Other (non-Māori, non-Pacific)	112 (57)	104 (47)

Table 1 (continued): Baseline characteristics.

Preschool characteristics	Intervention N=85 (n, %)	Control N=86 (n, %)
High probability of asthma*	**138 (40)**	**171 (51)**
Used an asthma inhaler AND	123 (36)	157 (47)
Had a recurrent wheeze	126 (37)	126 (38)
Had a dry cough	117 (34)	153 (46)
Had a history of atopy		
Age diagnosed with asthma (years)		
Mean (SD)	1.8 (0.8)	1.8 (0.8)
Family history of asthma	292 (86)	282 (84)

SD: Standard deviation.
[a] For preschool location, where 1 is least deprived and 10 is most deprived area of New Zealand by NZDep2006.[22]
* None of these children went on to get a medical diagnosis of asthma during the study.

Table 2: Acute asthma events in children over the last 12 months.

	Intervention N=341 (n, %)	Control N=334 (n, %)	Adjusted Odds Ratio (95% CI)	P-value
Number of children with at least one event in the last 12 months	216 (63)	181 (54)	1.35 (0.95–1.92)[a] 1.22 (0.85–1.74)[b] 1.36 (0.95–1.94)[c] 1.27 (0.77–2.10)[d]	0.095 0.286 0.095 0.352
Subgroup analyses				
- Asthma diagnosis	133 (66)	97 (60)	1.29 (0.84–1.99)	0.247
- High probability of asthma	83 (60)	84 (49)	1.49 (0.90–2.47)	0.117
Hospitalisations in the last 12 months	6 children* (8 events, 1.4% of all 577 events)	2 children (2 events, 0.4% of all 466 events)	–	–

[a] Adjusted for stratification factors (preschool licence size, preschool age group) and asthma inclusion criteria (asthma diagnosis, high probability of asthma).
[b] Adjusted for same factors as in [a], but also asthma inhaler technique (good, medium, poor) and deprivation index.[22]
[c] Adjusted for same factors as in [b], but also ethnicity (Māori, Pacific, Other).
[d] Adjusted for same factors as in [c], but also age group (<3 years, ≥3 years), medication use (defined as "using an inhaled corticosteroid twice a day every day") and symptoms (defined as "waking ≥3 times per week or every night").
*One child died.
CI=Confidence Interval.

Ratio=1.43; 95% Confidence interval [CI]=1.10-2.01; p=0.042). After adjusting for asthma diagnosis, inhaler technique, stratification factors, social class, ethnicity, age group, medication use and night time waking, no significant difference in the primary outcome was observed between the groups (Table 2).

Post-hoc subgroup analysis found no difference in the proportion of acute asthma events between those children with a medical diagnosis of asthma compared to those with a high probability of asthma (Table 2). When considering only those children hospitalised with asthma (as an indicator of severity), more children in the intervention group were hospitalised than those in the control group, but this difference was not significant (p=0.286) (Table 2).

Comparison of self-reported data on acute asthma events with medical records revealed under-reporting of these events over the 12-month study period by guardians/caregivers, particularly in the intervention group. Hospitalisations were over-reported in both groups, whilst GP and ED visits were under-reported (See Appendix). We investigated whether the children who had under-reported events were any different to those that did not, but found no difference according to asthma severity, age, and Deprivation Index.

Secondary outcomes

Based on medical record data, the median time to first acute asthma event was significantly shorter in the intervention group compared to the control group

Table 3: Frequency of asthma medication use by children over time.

	Intervention N=341 (n, %)		**Control N=334 (n, %)**	
SABA use	**Baseline**	**12 months**	**Baseline**	**12 months**
Never	120 (35)	184 (60)	134 (40)	135 (45)
≤2 times per week	137 (40)	103 (33)	105 (31)	35 (12)
≥3 times per week	49 (14)	12 (4)	60 (18)	16 (5)
Less than 6 puffs daily	29 (9)	9 (3)	24 (7)	62 (21)
More than 6 puffs per day	6 (2)	1 (0.3)	11 (3)	46 (15)
OCS use (Number of courses in last 12 months)				
0	132 (43)	224 (73)	132 (44)	187 (62)
1–5	158 (52)	81 (27)	158 (53)	107 (36)
≥6	15 (5)	0 (0)	10 (3)	6 (2)
ICS use				
One puff, once a day	10 (3)	3 (1)	30 (9)	22 (7)
Two puffs, once a day	5 (2)	4 (1)	42 (13)	32 (11)
One puff, twice a day	71 (21)	97 (31)	8 (2)	46 (16)
Two puffs, twice a day	68 (20)	128 (41)	36 (11)	49 (16)
One puff, three times a day	0	3 (1)	21 (6)	0
Two puffs, three times a day	0	0	13 (4)	2 (1)
Not using	162 (48)	73 (24)	173 (52)	131 (44)
Missing data	25 (7)	1	11 (3)	18 (6)

SABA: short-acting beta$_2$-adrenoceptor agonists.
OCS: oral corticosteroids.
ICS: inhaled corticosteroids.

(159 vs 255 days, respectively; Hazard ratio=1.33; 95% CI 1.09–1.62; log-rank test p=0.005). Note that the log-rank test does not enable adjustment for cluster.

No differences in asthma medication use were noted by treatment group at baseline, or by ethnicity. Almost two thirds of children (421/675) were using a SABA at baseline. SABA use in the intervention group significantly decreased over 12 months, compared to the control group (p<0.0001) (Table 3). At baseline, OCS use varied between 0–13 courses in the last 12 months, with just over 50% of children having had between 1–5 courses. A greater mean change from baseline to 12 months in OCS use was observed in the intervention group (0.97, Standard error [SE]=0.07), compared to the control group (0.44; SE=0·07; mean change 0.53, 95%; CI 0.34–0.72; p<0.0001). At baseline, 50% (335/675) of children did not use an ICS. A greater reduction in the proportion not using an ICS from baseline to 12 months was observed in the intervention group (from 48% to 24%), compared to the control group (from 52% to 44%; p<0.0001) (Table 3).

Children in the intervention group were significantly more likely to have medication changes, a better inhaler technique, more frequent use of their preventer inhaler, have fewer daytime asthma symptoms, less night time waking, and improved quality of life (in some domains) over 12 months, than children in the control group (see Appendix). Asthma control, although only measured in the intervention group children using the GASP tool, also improved over time (see Appendix). Despite these findings, no significant differences in absenteeism rates due to asthma (preschool, the child's usual activities, and the guardians/caregivers work and usual activities) were found between the two groups after 12 months (see Appendix).

Over 12 months, 84% of preschools in the intervention group had more than one asthma-specific lesson plan delivered (number of lessons delivered in addition to the introductory lesson: mean=3.4; SD=2.1; median=3) (see Appendix). Teachers in the intervention group were significantly more likely to feel confident in their asthma understanding after 12 months than control group teachers (see Appendix). Both the teachers and the guardians/caregivers of the children involved found the study helpful and were satisfied with its conduct, with those in the intervention group reporting more positive views than those in the control group for all outcomes, except the effectiveness of the curriculum material (see Appendix).

Discussion

We found significant underuse of ICS and over-reliance on SABA in the trial population at baseline, justifying the need for an intervention. The trial intervention had no significant impact on acute asthma events, even after adjusting for baseline differences or when comparing children diagnosed with asthma to those with a high probability of asthma. However, time to first acute asthma event was significantly shorter in the intervention group, possibly due to increased awareness of early symptoms because of the asthma-specific education delivered to this group. Compared to the control group, the trial intervention resulted in less frequent use of SABA and OCS by the children, and increased use of ICS, resulting in improved and sustained control of asthma and fewer asthma symptoms.

This trial is one of the first to investigate the effectiveness of an asthma education programme in a preschool environment. Our study had several strengths. First, rather than merely educating immediate family members about how to manage asthma (including acute events), our more holistic approach included reaching out to all the child's caregivers (ie the child and their peers, teachers and guardians). It is often assumed that asthma education can only be delivered by health professionals, but understanding asthma triggers and early recognition and management of an acute asthma event is relevant to all who interact with children. Second, the pragmatic study design helped ensure greater generalisability to the population of interest. Third, the trial was rigorous, with blinded assessment of the primary outcome, a large sample size, high participant retention, intention-to-treat analysis, and randomisation to ensure a balance in baseline characteristics (the few observed differences were likely due to chance and subsequently adjusted for in analyses). Given the above strengths, the observed impact of the intervention on non-acute asthma outcomes, and the fact that medication management via the GASP tool was appropriate for this age group (and based on current evidence-based best practice guidelines at that time),[16–18] it is unclear why the intervention had no impact on the primary outcome.

Several limitations should be noted. First, the study was under-powered; the estimate used to calculate the sample size was based on a small GASP dataset and the recruitment target of 94 preschools (and 400 children) per arm was not met. Second, inconsistencies between self-reported

and medical record data of the primary outcome indicate that recall and/or social desirability bias may have been at play. Third, the multiple statistical comparisons increased the chances of a type I error. Fourth, guardians/caregivers may have changed their behaviour due to being part of a trial (Hawthorne effect). Fifth, researchers collecting secondary outcome data were not blinded to group allocation. Sixth, it is possible that teachers and guardians/caregivers attending preschools nearby, but randomised to different arms, may have shared intervention information. Seventh, differential loss to follow-up was observed; however, the availability of primary outcome data for all randomised children via electronic health records minimised this bias. Eighth, international evidence suggests both an under- and over-diagnosis of asthma in primary care,[28] so it is possible we may have missed some children with asthma and included some children without asthma. However, the final eligibility criteria for the trial were broad, including both children with a medical diagnosis of asthma or a high probability of asthma, and was in line with current New Zealand treatment guidelines for this age group at the time the trial started recruitment.[29] Ninth, we were unable to follow-up patients for as long as we would have liked, due to funding constraints. Tenth, asthma definitions change over time[30] and there are overlaps of asthma phenotypes.[31] Finally, while the trial was designed in conjunction with asthma specialists, based on the asthma treatment guidelines in 2011,[16–18] new asthma treatment guidelines post-trial completion may impact how the trial findings are interpreted, and how preschool children with asthma-related symptoms are managed.[7,29]

Our findings contrast with those of three Cochrane reviews examining the impact of self-management asthma programmes for children and adolescents.[32–34] These reviews reported that asthma education reduced absenteeism from school and usual activities, improved self-efficacy and physiological measures of lung function,[32] and reduced asthma-related ED visits and hospitalisations.[32–34] One review highlighted the need to investigate the effectiveness of the individual components of asthma education programmes.[32] Our trial had many different components and, although it is not possible to say which of these had the greatest impact, evidence indicates them to be individually effective.[35,36] Furthermore, the 2008–2011 GASP audit suggested its use resulted in a reduction in acute asthma events.[19] Our findings for preschool staff are consistent with those reported by a Cochrane review (five trials, 111 primary/secondary schools) reporting asthma education provided to staff working within school environments can increase both asthma knowledge and confidence.[37]

The trial has signalled that significant and sustained changes in the personalised management of asthma symptoms in young children is possible through regular reviews of asthma medication, clear explanations about medication use, recognising and addressing key triggers, and use of asthma action plans by children with asthma (or a high probability of asthma) and their guardians/caregivers/teachers. Screening programmes for early identification of 1) wheeze and other asthma-related symptoms in children, and 2) children at higher risk of asthma, have been effective in other countries (eg the Head Start Program in the USA),[38] and it seems prudent to establish them in New Zealand. This screening could involve incorporation of a GASP-trained nurse within general practices, after-hours medical centres, and hospital emergency rooms (supported by Government funding). Delivery of the programme to schools of all levels could also be worth exploring, prioritising to areas of greatest need and incorporating interactive computerised asthma patient education programmes.[39] Evaluations of the intervention within these environments, over a long period, would be important to determine sustainability. Finally, the trial has highlighted the limitations of using self-reported data related to acute asthma events. Future research focusing on such outcomes should use medically verified data wherever possible.

Appendix:
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COMPETING INTERESTS
Janet Mackay, Scott Metcalfe and Marama Parore are, or were, employees of PHARMAC, which funded the study. The Ministry of Done is the name of a company specialising in project deployment and development of educational resources and is not a government agency. We declare no competing interests.

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All requests for de-identified individual participant data or programme documents will be considered where the proposed use aligns with public good purposes, does not conflict with other requests, or by planned use of the Trial Steering Committee, and the requestor is willing to sign a data access agreement. Contact regarding data sharing should be via the corresponding author.

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REFERENCES
1. Pearce N, Ait-Khaled N, Beasley R, et al. Worldwide trends in the prevalence of asthma symptoms: Phase III of the International Study of Asthma and Allergies in Childhood (ISAAC). Thorax 2007;62:758-66.
2. Asher M, Stewart A, Clayton T, et al. Has the prevalence and severity of symptoms of asthma changed among children in New Zealand? ISAAC Phase Three. NZ Med J 2008;121(1284):52-63.
3. Ministry of Health. Annual Update of Key Results 2020/21: New Zealand Health Survey. Ministry of Health, Wellington. Retrieved from: https://www.health.govt.nz/publication/annual-update-key-results-2020-21-new-zealand-health-survey
4. Holt S, Beasley R. The Burden of Asthma in New Zealand Wellington: Asthma and Respiratory Foundation of New Zealand (Inc.) and Medical Research Institute of New Zealand, 2002.
5. Schlichting D, Fadason T, Grant CC, et al. Childhood asthma in New Zealand: the impact of on-going socioeconomic disadvantage (2010-2019). NZ Med J

2021;134(1533):80-95.
6. Metcalfe S. Asthma medicines (SABAs, LABAs and ICSs) and hospitalisations by age and by ethnicity over time. Board Paper, Wellington: Pharmaceutical Management Agency, 2004.
7. Pavord ID, Beasley R, Agusti A, et al. After asthma: redefining airways diseases. Lancet 2018;391(10118):350-400.
8. Galant S, Morphew T, Amaro S, et al. Current asthma guidelines may not identify young children who have experienced significant morbidity. Pediatrics 2006;117:1038-45.
9. Kuehni C, Frey U. Age-related differences in perceived asthma control in childhood: guidelines and reality. Eur Respir J 2002;20:880-89.
10. Castro-Rodriguez J, Rodrigo G. Efficacy of inhaled corticosterids in infants and preschoolers with recurrent wheezing and asthma: a systematic review with meta-analysis. Pediatrics 2009;123:e519-25.
11. Burgess S, Sly P, Devadason S. Adherence with Preventive Medication in Childhood Asthma. Pulm Med 2011;2011:973849.
12. Ministry of Health. Kōrero Mārama: Health Literacy and Māori. Wellington: Ministry of Health, 2010
13. Crengle S. The management of children's asthma in primary care: are there ethnic differences in care? Auckland: PhD Thesis. The University of Auckland; 2008. Retrieved from: https://researchspace.auckland.ac.nz/handle/2292/4957
14. Novak C, Dodd J. Childhood Asthma in New Zealand: a healthtracker research survey. Market research report commissioned by Pharmaceutical Management Agency. Wellington: Pharmaceutical Management Agency, 2006.
15. National Heart Lung and Blood Institute. National Heart, Lung and Blood Institute/National Asthma Education and Prevention Program. Expert Panel Report 3: Guidelines for the Diagnosis and Management of Asthma, Full Report. Bethesda: US Department of Health and Human Services. http://www.nhlbi.nih.gov/guidelines/asthma/asthgdln.htm, 2007.
16. New Zealand Guidelines Group. Diagnosis and Treatment of Adult Asthma. Wellington: New Zealand Guidelines Group, 2002.
17. British Thoracic Society / Scottish Intercollegiate Guidelines Network. British Guideline on the Management of Asthma: a national clinical guideline: revised. London, Edinburgh: British Thoracic Society / Scottish Intercollegiate Guidelines Network, 2009.
18. Global Initiative for Asthma. Global Strategy for Asthma Management and Prevention: Update. South Africa: Global Initiative for Asthma, 2010.
19. Ram F, McNaughton W. Giving Asthma Support to Patients (GASP): a novel online asthma education, monitoring, assessment and management tool. J Prim Health Care 2014;6(3):238-44.
20. Statistics New Zealand. New Zealand Childcare Survey: 2017. Wellington: Statistics New Zealand, 2017.
21. Hohaia T, Hammond K. He Tapu Te Ha: Space to Breathe Early Childhood Education Programme. Evaluation Report of the pilot delivered in kohanga reo and early childhood centres in Taranaki, Whanganui and Taumaranui communities in April-July 2009. A report prepared for the Pharmaceutical Management Agency and Tui Ora Ltd. Hawera, Taranaki: Aatea Solutions, 2010.
22. Salmond C, Crampton P, Atkinson J. NZDep2006 Index of Deprivation Wellington: Department of Public Health, University of Otago, 2007.
23. Fekkes M, Theunissen N, Brugman E, et al. Development and psychometric evaluation of the TAPQOL: a health-related quality of life instrument for 1–5 year old children. Qual Life Res 2000;9:961-72.
24. Donner A, Klar N. Design and Analysis of Cluster Randomization Trials in Health Research London: Arnold 2000.
25. McWhirter J, McCann D, Coleman H, et al. Can schools promote the health of children with asthma? Health Educ Res 2008; 23(6):917-30.
26. Warschburger P, von Schwerin A-D, Buchholz H, et al. An educational program for parents of asthmatic preschool children: short- and medium-term effects. Patient Educ Counsel 2003;51:83-91.
27. Stevens C, Wesseldine L, Couriel J, et al. Parental education and guided self-management of asthma and wheezing in the pre-school child: a randomised controlled trial. Thorax 2002;57:38-44.
28. Aaron SD, Boulet LP, Reddel HK, Gershon AS. Underdiagnosis and overdiagnosis of asthma. Amer J Resp Crit Care Med 2018;198 (8):1012-1020.
29. McNamara D, Asher I, Davies C, et al. New Zealand Child Asthma Guidelines 2020. Asthma and Respiratory Foundation.
30. Asher I, Pearce N, Strachan D, et al. Chapter 2: What is asthma? The Global Asthma Report 2018. Auckland, New Zealand: Global Asthma Network, 2018.
31. Brand PLP, Schultz A. To track or not to track: wheeze phenotypes in preschool children. Eur Respir J 2018;51:1800042.
32. Wolf F, Guevara J, Clark N, et al. Educational interventions for asthma in children. Cochrane Database Syst Rev 2002(4): doi: 10.1002/14651858.

CD000326.
33. Harris K, Kneale D, Lasserson TJ, McDonald VM, Grigg J, Thomas J. School-based self-management interventions for asthma in children and adolescents: a mixed methods systematic review. Cochrane Database of Systematic Reviews 2019, Issue 1. Art. No.: CD011651.
34. Boyd M, Lasserson T, McKean M, et al. Interventions for educating children who are at risk of asthma-related emergency department attendance. Cochrane Database Syst Rev 2009(2): doi: 10.1002/14651858.CD001290.pub2.
35. Levy M, Hardwell A, McKnight E, et al. Asthma patients' inability to use a pressurised metered-dose inhaler (pMDI) correctly correlates with poor asthma control as defined by the Global Initiative for Asthma (GINA) strategy: a retrospective analysis. Prim Care Respir J 2013;22:406-11.
36. Bhogal S, Zemek R, Ducharme F. Written action plans for asthma in children. Cochrane Database Syst Rev 2006;3:doi: 10.1002/14651858.CD005306.pub2.
37. Kew KM, Carr R, Donovan T, Gordon M. Asthma education for school staff. Cochrane Database of Systematic Reviews 2017, Issue 4. Art. No.: CD012255. DOI: 10.1002/14651858.CD012255.pub2.
38. Eakin MN, Zaeh S, Eckmann T, et al. Effectiveness of a home- and school-based asthma educational program for head start children with asthma: a randomized clinical trial. *JAMA Pediatr.* 2020;174(12):1191-1198.
39. Bussey-Smith K, Rossen R. A systematic review of randomized control trials evaluating the effectiveness of interactive computerized asthma patient education programs. Ann Allergy Asthma Immunol 2007;98:507-16.

Measuring drug harm in New Zealand: a stocktake of current data sources

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ABSTRACT

AIMS: The availability of legal and illegal drugs is widespread across New Zealand. All drugs have the potential to cause harm to those who use them, and to others. Understanding the nature and extent of these harms depends upon the ongoing and systematic collection of relevant data, which is crucial in achieving the current national policy goal of minimising drug harm. Thus, we aim to describe how information on drug harm is currently collected and measured in New Zealand.

METHODS: This article maps and evaluates harm data within New Zealand, explores data collection methods and timing, and identifies the drugs and types of harm assessed to date. We review large and predominantly administrative datasets that provide a measure of harm, which are collected more than once and/or are updated periodically.

RESULTS: We highlight a number of key gaps and limitations that exist within the current data landscape, and outline barriers to ensuring greater utilisation. We recommend more frequent data collection, including improved data on harms to others, and inclusion of a wider range of drugs.

CONCLUSIONS: Implementation of these recommendations will improve the understanding of comprehensive drug harm in New Zealand, to guide effective local harm reduction policies and interventions.

A wide range of legal and illegal psychoactive substances ("drugs"; includes alcohol) are available in New Zealand, all of which have the potential to cause harm. Nationwide, the annual cost of harm arising from the use of illegal psychoactive drugs, excluding alcohol and tobacco, has been estimated at $1.9 billion.[1] Harm from alcohol has further been estimated at $7 billion,[2] while the tangible costs of tobacco were most recently estimated at $2.5 billion.[3] The harm resulting from a drug is complex, can be acute or chronic, and depends upon factors including pharmacological properties, purity, the population who use it, consumption patterns, context of use and administration practices, and policy/regulatory settings.[4, 5] Minimising this harm forms the current overarching goal for New Zealand drug policy; to minimise alcohol and other drug (AOD)-related harm and promote and protect health and wellbeing.[6]

The systematic collection of data on drug harm in New Zealand is important to achieve the goal of harm minimisation and measure progress towards achieving this policy objective. Timely data are needed to inform evidence-based policies, and can further aid the Government in prioritising resources and making policy decisions. Adequately measuring harm can help to ensure that health promotion campaigns are both effective and appropriate for the communities in which they are implemented.[7, 8] Furthermore, relevant data can influence public education and discourse, which may help to destigmatise particular drugs and the people who use them.[9] Lastly, when gathered regularly and consistently, this data can provide the means for evaluating policy and harm minimisation initiatives.

Despite its importance, the measurement of drug harm may be overlooked, or is equated with prevalence of use. While "use" is a simpler metric than "harm", the policy implications of focussing on measuring use are problematic, in that it perpetuates a view that all drug use is implicitly harmful. Different methods exist for quantifying drug harms—both harms to self and harms to others. In New Zealand, a Drug Harms Index (NZDHI) has been updated and published three times, which has quantified harms arising from use of the most widely used illegal drugs.[1, 10, 11] The multi-criteria decision analysis (MCDA) method has also been used to compare and rank harms from different drugs.[12] Using these methods, data on use and harm can further be combined to develop a more comprehensive picture of harm prevalence within a given population.[12] Importantly, both the NZDHI and MCDA methods are strengthened by having appropriate New Zealand-specific data available.

Within New Zealand, a number of data sources exist for specific types of harm and substances,

including administrative datasets and individual research projects. We aim to describe how information on drug harm (including legal drugs such as alcohol and tobacco) is currently collected and measured in New Zealand, and to highlight relevant gaps and challenges of measuring drug harms. Robust policy should be developed based upon a combination of many different kinds of data; thus, this stocktake provides a resource for understanding the current data landscape for measuring drug harm in New Zealand.

Mapping the harm data available in New Zealand

Table 1 provides an overview of the current drug harm data in New Zealand. For each data source, it includes information on the type of data available, the frequency and timing of data collection, and some of the types of harm it addresses, using previous harm classifications.[12] Information was extracted from previous reports and publications on the dataset, and protocols or data dictionaries, but did not include information gained directly from project teams or researchers that was not readily available. We have highlighted key strengths and limitations of each individual dataset. However, we note that the main strength lies in the capacity to triangulate using multiple data sources to build a more reliable picture of drug harm, rather than relying on a single data source; our aim was to focus on the overall data landscape rather than details of individual datasets. We focussed on large and predominantly administrative datasets that are collected more than once and/or are updated periodically. Datasets that estimate use only (eg wastewater testing) have not been included, though those that measure both use and harm are included. This data landscape has been assessed, paying particular attention to scope, coverage and representativeness. Based upon the datasets identified, there are areas in which the available data are not sufficient for contemporary understandings of drug harm within New Zealand. A number of gaps and limitations are discussed below, themed into key issues.

Gaps and limitations in the available drug harm data

Missing or sparse data

Relevant data are sparse or unavailable for some forms of drug related harm, particularly in the case of harm to others. For instance, there are little data on family adversities that may arise from drug use, such as divorces, child neglect, or the loss of child custody. In addition, there is no routinely reported information on injury, such as acts of physical or sexual violence, that are related to drug use beyond alcohol. Aside from the Methadone in Pregnancy study, there is inadequate information surrounding fetal exposure to different substances within New Zealand, which limits the extent to which outcomes such as fetal alcohol spectrum disorder can be targeted.[13] Finally, there does not appear to be regularly collected data on the extent of community harms, such as a decline in social cohesion.

Novel substances and routes of administration

There is little insight into some newer substances and routes of administration, with one example the increased prevalence of vaping. While the harms of tobacco containing cigarettes are well defined, there are comparatively less data in New Zealand, or even internationally, on the consequences of nicotine vaping.[14] This is partly due to the relative novelty of vaping, which also limits the extent to which longer-term harms can be identified at this point in time. Data pertaining to new psychoactive substances (NPS) are also sparse or otherwise poorly defined in many local datasets, or may be inconsistently collected such that it hinders interpretation of harm.[15] In part, this is due to the wide range of such substances, in addition to the rapid pace at which new synthetic drugs have historically been developed and introduced.[16] While this lag in information is inevitable for such substances, it does increase the likelihood of overestimating or underestimating their harm.

Dated or irregularly collected data

Some of the available data on use and harm are outdated or has been collected in an irregular manner. Because harm measurement is generally intended to inform contemporary interventions, older information could pose a threat to the validity of studies in this area. For example, one of the country's largest datasets that evaluated substance use disorder, Te Rau Hinengaro,[17] is over 14 years old, limiting its relevance. Some regular studies of drug harm among frequent drug users and police arrestees have had their funding discontinued (eg IDMS, NZ-ADUM).

Non-representative data

Insights gathered from at-risk groups of people who use drugs cannot always be generalised to the wider population, or to specific demographic groups. Firstly, in many cases the only available data are collected from a subsection of people who use drugs, such as those who have been convicted of drug-related crimes or who are receiving

Table 1: Currently available data on drug-related harm within New Zealand.

Data source	Method of collection	Substance categories	When collected	Type of drug harm	Limitations & Strengths
The Mortality Collection (MORT) **Ministry of Health**	Aggregated from cause of death certificates.	Reports on ICD classification of cause of death for all deaths registered in New Zealand.	Annually from 1988 onwards. Data from 1970–1987 also available upon request.	Harm to person using drug: drug-specific mortality, drug-related mortality.	Limitation: Based on ICD coding–substances are grouped and must have been deemed contributory to mortality (not always simple to determine). Strengths: updated regularly. Integrates information from multiple sources.
Global drug survey (GDS) **Research company**	Anonymous online surveys.	Reports on 20 most commonly used psychoactive drugs over the 12 months prior.	Annually from 2014–2021 (2020 missing).	Harm to person using drug: drug-specific morbidity.	Limitations: self-reported and self-selected. Limited to those with internet access. Strengths: detailed breakdown of drug types.
Programme for the Integration of Mental Health Data (PRIMHD) **Ministry of Health**	Clinical data (including treatment episodes) from district health boards and non-government organisations.	Alcohol, cannabis, amphetamine-type stimulants, opioids, and sedatives/tranquilisers.	Annually from 2008, more services reporting from 2011.	Harm to person using drug: drug-specific morbidity, plus lifestyle and wellbeing questions related to social and psychological harm.	Limitations: only treatment episodes (known barriers to treatment exist). Only includes a limited number of substance types. Strengths: integrates harm data from a wide range of sources across NZ.
University of Otago data on blood borne viruses in needle exchange programmes	Blood serology.	Injected psychoactive substances.	Period of two weeks in 2009.	Harm to person using drug: drug-related morbidity.	Limitations: data is out of date and may not reflect current trends. Strengths: data across a large number of different NZ locations.

Table 1 (continued): Currently available data on drug-related harm within New Zealand.

Data source	Method of collection	Substance categories	When collected	Type of drug harm	Limitations & Strengths
The Institute of Environmental Science and Research (ESR) publication **New Zealand Crown Research Institute**	Toxicology profile (blood, urine, hair, surface of the skin, intimate swabs) from toxicology assessments of sexual assault survivors.	Psychoactive drugs present in toxicology assessments.	Between 2015–2018.	Harm to person using drug: drug-related morbidity.	Limitations: many sexual assaults not reported immediately (or at all), limiting the utility of toxicology. Strengths: provides information on drug-facilitated sexual assault.
National Minimum Dataset (NMDS) **Ministry of Health**	Public and private hospital discharge information. Includes drug-related morbidity data.	Alcohol, opioids, cannabis, sedatives, hypnotics, anxiolytics, cocaine, amphetamines, other stimulants, hallucinogens, inhalants, mixed.	Annually from 1993.	Harm to person using drug: drug-specific morbidity, drug-related morbidity.	Limitations: requires some assessment that drug use contributed to patient presentation. Strengths: enables examination of change over time.
New Zealand National Poisons Centre (NZNPC) **University of Otago**	Data on enquiries to call centre.	Includes data on calls made due to drugs such as methamphetamine, LSD, GHB, cannabis, and synthetic cannabinoids.	Helpline service commenced in 1964.	Harm to users: drug-specific morbidity.	Limitations: NZNPC contacted on a voluntary basis. Self-report increases likelihood of inaccuracies. Strengths: data on harm which may not be captured elsewhere, as may not require medical treatment.
New Zealand Transport Agency (NZTA) reports **Ministry of Transport**	New Zealand Police reports to NZTA on motor vehicle accidents involving drugs, includes resulting fatalities, injury, and charges.	Alcohol and "other drugs"'.	Annually from 1990–2019.	Harm to person using drug: drug-related mortality, drug-related morbidity, loss of tangibles (criminal record).	Limitations: drug types are broadly grouped. Strengths: extensive data on the impact of alcohol in particular.
Te Rau Hinengaro: The New Zealand Mental Health Survey	Survey and interviews.	Alcohol, "other drugs", cannabis.	Between 2001–2004.	Harm to person using drug: dependence (substance use disorders).	Limitations: data becoming out of date. Drug types are broadly grouped. Strengths: very large sample. Oversampling for Māori and Pacific populations.

Table 1 (continued): Currently available data on drug-related harm within New Zealand.

Data source	Method of collection	Substance categories	When collected	Type of drug harm	Limitations & Strengths
Christchurch Health and Development Study **University of Otago**	Interviews of longitudinal birth cohort members. Examines drug use disorders and drug related harm.	Alcohol, tobacco, vaping, synthetic cannabis, solvents, sedatives, methamphetamines, heroin or homebake, morphine/MSTs, cocaine/crack, ecstasy or MDMA, BZP/legal highs, hallucinogens, prescription medications for psychoactive properties.	Relevant data collected regularly for period 1991–2017.	Harm to person using drug: loss of relationships, loss of tangibles, impaired mental function, dependence (substance use disorders).	Limitations: self-reported. Single age cohort born in 1977 (now aged 44–45). Strengths: longitudinal. Data on drug use collected regularly.
Dunedin Multidisciplinary Health and Development Study **University of Otago**	Interviews of longitudinal birth cohort members. Examines drug use disorders and drug related harm.	Cannabis, alcohol, tobacco, "hard drugs".	Relevant data collected regularly for period between 1991–2019	Harm to person using drug: dependence (substance use disorders).	Limitations: self-reported. Cohort members born in 1972–1973 (now aged 49–50). Strengths: longitudinal. Data on drug use collected regularly.
Alcohol Harm to Others Survey	Computer assisted telephone interviewing about harm experienced due to others' alcohol use.	Alcohol.	Between 2008–2009.	Harm to others: Physical, social, economic, psychological.	Limitations: self-reported. Out of date. Strengths: Rich data on harm to others.
Methadone in Pregnancy Study **University of Canterbury**	Interviews and a large range of other testing for longitudinal groups of children and mothers.	Methadone.	Relevant data collected regularly from 2003–2021.	Harm to others: fetal exposure.	Limitations: random sampling for non-exposure group, but not for exposure group (social disadvantage for the latter). Strengths: fills key data gap regarding outcomes of fetal methadone exposure.

Table 1 (continued): Currently available data on drug-related harm within New Zealand.

Data source	Method of collection	Substance categories	When collected	Type of drug harm	Limitations & Strengths
Youth 2000 Survey Series **Multiple New Zealand universities**	Surveys of secondary school students.	Tobacco, vaping, alcohol, cannabis, other drugs.	Collected 2001, 2007, 2012, and 2019.	Harm to person using drug: alcohol-related morbidity, misuse.	Limitations: schools only, therefore, may exclude high-risk youth. Difficult to assess harm from different substances within "other drugs" category. Self-reported. Strength: data on specific cohort of interest.
Ministry of Justice Data on drug offences **Ministry of Justice**	Government report of drug-related charges and convictions.	BZP, cannabis, cocaine, ecstasy, fantasy, heroin, LSD, methamphetamine, morphine, opium, other opiates, stimulants, and depressants.	Annually from 2010.	Harm to person using drug: loss of tangibles (criminal record).	Limitations: unable to separate harm to those using drug and others. Strengths: demographic breakdown. Data on type of drug offence (eg possession).
Illicit Drug Monitoring System (IDMS) **Massey University**	Interviews of frequent drug users.	Methamphetamine, crystal methamphetamine, opiates, cannabis, LSD, and ecstasy (MDMA).	Annually from 2006–2016 (discontinued).	Harm to person using drug: loss of tangibles (criminal record). Harm to others: crime (property crime, violent crime).	Limitations: data not representative of lower risk use groups. Only includes people from three main centres (Auckland, Wellington, Christchurch). Strengths: data provided from a hard-to-reach population.
New Zealand Drug Trends Survey (NZDTS) **Massey University**	Online survey.	Methamphetamine, cannabis, LSD, ecstasy, cocaine, heroin, morphine, alcohol, tobacco.	Annual and ongoing from 2017.	Harm to person using drug: dependence.	Limitations: self-selected sample. Limited to people with access to internet Strengths: very large sample of frequent drug users from all NZ regions.

Table 1 (continued): Currently available data on drug-related harm within New Zealand.

Data source	Method of collection	Substance categories	When collected	Type of drug harm	Limitations & Strengths
New Zealand Alcohol and Drug Use Survey (NZADUS) **Ministry of Health**	Self-report, survey.	Alcohol, tobacco, cannabis, ecstasy, stimulants, amphetamines, hallucinogens, sedatives, opiates, BZP, other drugs.	2007, 2008.	Harm to person using drug: loss of relationships, loss of tangibles (employment, criminal record). Harm to others: family adversities.	Limitations: data becoming out of date. Strengths: large number of respondents from Māori and Pacific populations.
Alcohol Use in New Zealand Survey (AUiNZ) **Te Hiringa Hauora**	Survey.	Alcohol.	2019–2020.	Harm to person using drug: dependence, drug-related morbidity (physical health, mental health), loss of tangibles, loss of relationships. Harm to others: crime, community, family adversities, economic cost.	Limitations: no time series data available yet, as only recent. Strengths: very detailed survey with broad harm types.
New Zealand Health Survey (NZHS) **Ministry of Health**	Self-report, survey, interview.	Alcohol, tobacco, cannabis, ecstasy, amphetamines, stimulants, codeine, sedatives, hallucinogens, cocaine, heroin, opium.	1992/93, 1996/97, 2002/03, 2006/07, and annually from 2011.	Changes each year–examples as follows. Harm to person using drug: dependence. Harm to others: exposure to second-hand smoke	Limitations: completed in person at respondent's home, potentially leading to underreporting. Measures not consistently assessed. Strengths: representative population data.
The Centre for Adverse Reactions Monitoring (CARM) **New Zealand Pharmacovigilance Centre**	Reporting by New Zealand health professionals and pharmaceutical companies on adverse drug reactions.	Pharmaceutical drugs, including psychoactive drugs.	2000 till present.	Harm to person using drug: drug-specific morbidity.	Limitations: only pharmaceutical drugs. Not designed for extra-medical drug use, which limits reporting. Strengths: Information is reported by those with considerable knowledge of adverse drug reactions. Previous data collection included "legal high" products, including synthetic cannabinoids.

Table 1 (continued): Currently available data on drug-related harm within New Zealand.

Data source	Method of collection	Substance categories	When collected	Type of drug harm	Limitations & Strengths
Alcohol burden of disease studies	Summarises wide range of data (both national and international) on alcohol use and associated harm.	Alcohol.	2000/2002, updated in 2004/2007.	Harm to person using drug: drug related morbidity.	Limitations: lack of New Zealand data in some cases. Strengths: allows comparison with other countries.
Estimates from the New Zealand Drug Harm Index **Ministry of Health**	Summarises wide range of data (both national and international) to estimate economic costs of different psychoactive substances.	From 2022 update: methamphetamine, heroin, cocaine, synthetic cannabinoids, GHB/GBL, cannabis, MDMA.	Three releases, most recently 2022.	Harm to person using drug: premature death and reduced quality of life. Harm to others: economic cost, crime.	Limitations: narrow description of harm. Scope only a limited number of illegal drugs. Strengths: cost estimates of drug harm. Includes harm to both self and others.
New Zealand Crime and Safety Survey (NZCASS) **Ministry of Justice**	Questionnaires and interviews of randomly selected people in NZ. Includes questions about suspected perpetrator drug use.	Alcohol, other drugs do not appear to be separated into different categories.	2006, 2009, 2014.	Harm to others: crime.	Limitations: Does not include victimless crimes (drug offences). Not always evidence that perpetrator was under the influence of drugs. Strengths: Indication of harm to others.
New Zealand's Arrestee Drug Abuse Monitoring research programme (NZ-ADAM) (Now ADUM) **New Zealand Police, Massey University**	Interviews of police detainees.	Methamphetamine, cannabis, opioids, pharmaceutical medicines and new psychoactive substances.	Pilot 2004, 2005-2009, annually 2010–2016 (complete).	Harm to person using drug: loss of tangibles. Harm to others: crime.	Limitations: sample not representative of arrestee population in NZ. Strengths: drug harms from high-risk population. Measure of harm to others.

treatment for drug dependence. In reality, most people who use drugs do not develop substance use disorders and are therefore unlikely to experience drug-related harm in the same way.[18] As such, this information says little about drug harm in the wider New Zealand population.

General challenges for harm measurement

Measuring patterns of use and consumption

An initial challenge is estimating drug use or consumption, which needs to be combined with harm data in order to understand the distribution of harm. Challenges exist in measuring drug use; self-reported data are prone to recall bias and people may modify their responses based on social acceptability,[19] and population-level monitoring such as wastewater detection can only quantify how much of a drug is being consumed by a particular population utilising a wastewater treatment plant.[20] Consumption estimates are known to be particularly difficult to make, partially due to large variances in how a drug is used.[11] For example, while a large proportion of the population use alcohol, drinking motives and behaviours vary from person to person;[21] these motivations and behaviours then affect harm.[22,23]

Heterogeneity of drug use

Another key issue is the large degree of heterogeneity in factors such as potency, purity, and route of administration, all of which can have a considerable influence on the overall harm attributed to a particular drug. This is true in the case of factors including lethality, medical consequences and potential for abuse.

Unintentional drug use

It can often be difficult to make estimates about drugs which tend to be ingested unwittingly. For instance, drugs sold as MDMA in New Zealand are routinely cut with substances such as creatine, which may alter their overall risk and also limits the utility of self-reported drug use by substance.[24] More harmful substances, such as synthetic cathinones, are also known to be sold as MDMA in some cases.[24] In addition, the fact that substances such as GHB can be unknowingly ingested, and not subsequently reported, means that their harm is difficult to accurately quantify.

Poly-drug use

Many substances are not used in isolation within a given period of time; poly-drug use is not always detailed in the available datasets, but is an important factor to account for when measuring harm. For example, concurrent use of two or more drugs such as benzodiazepines, opiates and alcohol can increase the risk of death by overdose when compared to the use of just one of these substances.[25,26]

International examples of measuring harm

The issue of measuring harm is not confined to New Zealand, though each jurisdiction would need to target its data collection based on the systems available and overarching policy goals. In Australia, it was identified that significant health-related drug harm was occurring in the community, often in parallel with acute mental health issues, which was not being detected in emergency department or admitted patient data. This led to the National Ambulance Surveillance System (NASS), which codes ambulance attendance data where drugs have played a role in the ambulance callout.[27] In Europe, the recently established ESCAPE project has led to improved understanding of harms arising from injecting drug use, by analysing residues from used syringes, which provides an understanding of potential overdose risk through polysubstance use.[28] The utility and practicality of such approaches should be considered in a New Zealand context.

Recommendations for improving local harm data

Within New Zealand, there are data measuring drug use (including wastewater testing and surveys); however, a relative lack of data exists surrounding associated harms. This presents a barrier to meeting the policy goal of harm minimisation,[6] thereby necessitating efforts toward collection of both use and harm data. Our review identified a large number of useful information sources; however, it also highlighted substantial gaps. In seeking to improve the data landscape for New Zealand, we make the following recommendations for Government departments responsible for drug policy, policy makers, health boards and other relevant organisations who collect drug harm data.

Harm to others data

Within New Zealand, the available information provides little insight into how drugs impact others, such as family, partners and communities. Although there are recent data on alcohol-

related harm to others (Alcohol Use in New Zealand Survey), relevant data on harm to others are scarce for other drugs. This issue has also been identified internationally, with data tending to focus more heavily upon how those who use drugs are affected.[29] To facilitate the development of policies which target broad categories of harm, surveys and other forms of data should be reviewed and amended to incorporate "harm to others" criteria, based upon established frameworks with inclusion of all harms arising from drug supply and use.[12,30] This is particularly relevant for agencies that deal directly with families and communities affected by drugs, such as Oranga Tamariki and the New Zealand Police.

Routine data collection

Policy development, evaluation and revision necessitates regularly updated information on drug harm. At present, the collection of data covering all harm categories is not routine and has resulted in many sources of information becoming dated. To avoid this issue in future, surveys such as the Te Rau Hinengaro: The New Zealand Mental Health Survey should be repeated more frequently to provide a current picture of substance use disorders within New Zealand, and resourcing of data collection methods that have faster reporting times (eg monitoring of online drug use forums, or High Alert)[31] should be increased by the responsible Government departments. This will enable swift and appropriately targeted policy amendments.

Establishing protocols for harm data

To enable consistent and systematic measurement of drug harm going forward, New Zealand Government departments responsible for drug policy should establish protocols that guide the collection, coding and storage of relevant data in a centralised location. At a minimum, it would be beneficial for links to all the currently available data sources (along with a description of that data) to be collated and made publicly available. Agencies and organisations responsible for data collection should also ensure that future data are collected in a way that allows for separate analysis of information for groups including Māori and youth, and by geographic region where possible. We acknowledge that establishing and maintaining such resources can be costly. However, ultimately, investment in improved data will facilitate more effective and targeted harm reduction policies and interventions.

Limitations

This stocktake aimed to consider measurement of drug harms, and does not consider the motivations of individuals for drug use—or any perceived benefits of drug use—by the individuals who use them. While it is acknowledged that this represents a one-sided view of drug use, drug policy is currently framed in a way that is focussed on harm minimisation and, therefore, it is the measurement of harm that should be most influential to current drug policy. In addition, this review also focussed on publicly available data, and it is acknowledged that organisations such as the National Drug Intelligence Bureau, and others, may have access to harms data that are not in the public domain.

Implications and conclusions

This study provides a stocktake of the current drug harm data available in New Zealand, which can be used by researchers and policy makers as a resource, when looking for harms data. In addition, recommendations have been made to improve the current data landscape at a systems level. Measuring harm accurately in New Zealand can contribute to a health-based approach to drugs and better inform drug policy. In particular, it will allow resources to be focussed more effectively on those that are experiencing harm, rather than all those who use drugs. This approach would acknowledge that not all those who use drugs are experiencing harm or perpetuating harm on others; therefore, it is not efficient or necessary for those individuals to receive a policy response. While use and harm cannot be equated, it is important for both to be measured effectively and combined, to guide policy responses that are health-based, proportionate and appropriately targeted. This is particularly important to consider in the context of specific populations, for example, more frequent use of a drug may be associated with greater harm in youth populations than in adults. While there are many challenges to measuring drug harm within New Zealand, the current review has identified a number of ways in which measurement can be improved.

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REFERENCES
1. McFadden M, Bellamore L, MacDonald B. The New Zealand Illicit Drug Harm Index 2020: Research report. Wellington: Ministry of Health; 2022.
2. New Zealand Law Commission. Alcohol in our lives: curbing the harm. Wellington: New Zealand Law Commission,2010.
3. New Zealand Ministry of Health. Background Information: New Zealand's Tobacco Control Programme. In: New Zealand Ministry of Health, editor. Wellington, New Zealand2016. p. 3.
4. MacCoun RJ. Drug war heresies learning from other vices, times, and places. Reuter P, editor. Cambridge, U.K. New York: Cambridge University Press; 2001.
5. Nutt D, King LA, Saulsbury W, Blakemore C. Development of a rational scale to assess the harm of drugs of potential misuse. Lancet. 2007;369(9566):1047-53.
6. New Zealand Inter-Agency Committee on Drugs. National drug policy 2015 to 2020: Minimise alcohol and other drug-related harm and promote and protect health and wellbeing. In: New Zealand Ministry of Health, editor. Wellington, New Zealand: Ministry of Health; 2015.
7. Van Der Sterren AE, Anderson IP, Thorpe LG. 'Individual'harms, Community 'harms': reconciling Indigenous values with drug harm minimisation policy. Drug Alcohol Rev. 2006;25(3):219-25.
8. Bonomo Y, Bowes G. Putting harm reduction into an adolescent context. J Paediatr Child Health. 2001;37(1):5-8.
9. Livingston JD, Milne T, Fang ML, Amari E. The effectiveness of interventions for reducing stigma related to substance use disorders: a systematic review. Addiction. 2012;107(1):39-50.
10. Slack A, O'Dea D, Sheerin I, Norman D, Wu J, Nana G. New Zealand drug harm index. Wellington: Business and Economic Research Limited; 2008.
11. McFadden Consultancy. The New Zealand Drug Harm Index 2016. Wellington: Ministry of Health; 2016.
12. Nutt DJP, King LAP, Phillips LDP. Drug harms in the UK: a multicriteria decision analysis. Lancet. 2010;376(9752):1558-65.
13. New Zealand Ministry of Health. Taking action on fetal alcohol spectrum disorder: 2016-2019 an action plan: Wellington, New Zealand: Ministry of Health; 2016.
14. Gravely S, ezen P, Ouimet J, Quah ACK, Cummings KM, Thompson ME, et al. Prevalence of awareness, ever-use and current use of nicotine vaping products (NVPs) among adult current smokers and ex-smokers in 14 countries with differing regulations on sales and marketing of NVPs: cross-sectional findings from the ITC Project. Addiction. 2019;114(6):1060-73.
15. Rychert M, Wilkins C, Witten K. Issues with monitoring the safety of psychoactive products under a legal regulated market for new psychoactive substances ('legal highs') in New Zealand. Drug Alcohol Rev. 2017;36(5):589-96.
16. Zawilska JB, Andrzejczak D. Next generation of novel psychoactive substances on the horizon – A complex problem to face. Drug Alcohol Depend. 2015;157:1-17.
17. Wells JE, Oakley Browne MA, Scott KM, McGee MA, Baxter J, Kokaua J. Prevalence, interference with life and severity of 12 month DSM-IV disorders in Te Rau Hinengaro: The New Zealand Mental Health Survey. Aust N Z J Psychiatry. 2006;40(10):845-54.
18. Wells J, Baxter J, Schaaf D. Substance use disorders in Te Rau Hinengaro: the New Zealand mental health survey. Wellington, Alcohol Advisory Council of New Zealand. 2007.

19. Johnson T, Fendrich M. Modeling sources of self-report bias in a survey of drug use epidemiology. Ann Epidemiol. 2005;15(5):381-9.
20. Lancaster K, Ritter A, Rhodes T. "A more accurate understanding of drug use": A critical analysis of wastewater analysis technology for drug policy. Int J Drug Policy. 2019;63:47-55.
21. Kuntsche E, Knibbe R, Gmel G, Engels R. Who drinks and why? A review of socio-demographic, personality, and contextual issues behind the drinking motives in young people. Addict behav. 2006;31(10):1844-57.
22. Wall M, Casswell S. Drinker types, harm, and policy-related variables: results from the 2011 International alcohol control study in New Zealand. J Drug Issues. 2017;41(5):1044-53.
23. Martin C, Wyllie A, Casswell S. Types of New Zealand drinkers and their associated alcohol-related problems. J Drug Issues. 1992;22(3):773-96.
24. Johnson CS, Stansfield CR, Hassan VR. Festival testing: A survey of suspected drugs seized from New Zealand music festivals, December 2018 to March 2019. Forensic Sci Int. 2020;313:110367.
25. Coffin PO, Galea S, Ahern J, Leon AC, Vlahov D, Tardiff K. Opiates, cocaine and alcohol combinations in accidental drug overdose deaths in New York City, 1990–98. Addiction. 2003;98(6):739-47.
26. Darke S, Hall W. Heroin overdose: research and evidence-based intervention. J Urban Health. 2003;80(2):189-200.
27. Lubman DI, Matthews S, Heilbronn C, Killian JJ, Ogeil RP, Lloyd B, et al. The National Ambulance Surveillance System: A novel method for monitoring acute alcohol, illicit and pharmaceutical drug related-harms using coded Australian ambulance clinical records. PloS one. 2020;15(1):e0228316.
28. European Monitoring Centre for Drugs and Drug Addiction. An analysis of drugs in used syringes from sentinel European cities: Results from the ESCAPE project, 2018 and 2019, Technical report. Luxembourg; 2021.
29. Room R, Laslett A-M, Jiang H. Conceptual and methodological issues in studying alcohol's harm to others. Nord Stud Alcohol Drugs. 2016;33(5):455-78.
30. Wilkinson C, Ritter A. Applying a 'harm to others' research framework to illicit drugs: political discourses and ambiguous policy implications. Addiction. 2021;116(8):1941-6.
31. Drug Information and Alerts Aotearoa New Zealand (DIANZ). About Us Website2021 [Available from: https://www.highalert.org.nz/about-us/.

Re-imagining anti-racist theory for the health sector

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ABSTRACT

Ethnic health inequities between Māori and other New Zealanders continue to manifest systemically across the health sector. They are unjust, unfair, and are a breach of Te Tiriti o Waitangi. Institutional racism is a key modifiable driver of these disparities. Historically, health sector responses to racism could be characterised as *ad hoc* or in-action.

Efforts have included investment in Māori health providers, Māori representation in governance, equity initiatives, kawa whakaruruhau—cultural safety and Te Tiriti training. Most anti-racist interventions have been educational and focused on individual change—especially for operational staff and students, rather than decision-makers. These historic contributions have been insufficient to address entrenched problems of systemic and societal racism.

This paper examines three anti-racism initiatives currently occurring across Aotearoa; i) the Matike Mai Constitutional Transformation report/movement, ii) the development of the National Action Plan Against Racism, and iii) Ao Mai Te Rā currently being developed within the health sector.

Drawing on long-time involvement in anti-racism praxis and scholarship, the Māori and non-Māori authors of this paper are making the case to re-imagine anti-racism theory. Such re-imagining needs to centre engagement with Te Tiriti. In addition, we argue it needs to involve both tangata whenua and Tauiwi.

Racism is a modifiable determinant of health outcomes that, particularly at the institutional level, impacts the quality and availability of health services, thereby fuelling health inequities.[1] It is the lived experience of Māori that Tauiwi—mainly Pākehā—have unjustly established in this country:

> *Everyday racism [that] attacks our rangatiratanga and prevents us from living our lives in the ways we want to, both as individuals and as groups.*[2]

In a reciprocal manner, racism is also the mechanism by which Pākehā actively and passively benefit from the established social order. Racism in the health sector has been linked to increased health risk factors, poorer mental and physical health outcomes, increased co-morbidities and premature death.[3] The existence of institutional racism within the health sector is a breach of Te Tiriti o Waitangi[4] the Declaration on the Rights of Indigenous Peoples[5] and the Convention on the Elimination of All Forms of Racial Discrimination.[6]

The landmark report *Pūao Te Ata Tū*[7] brought institutional racism to the attention of the public sector. The report inspired bicultural reforms, such as incorporating Māori values into policy and attempting to address cultural and historic racism by the transfer of resources to Māori. However, the neo-liberal ideologies that transformed Aotearoa into a market economy from the mid-1980s[8] ignored the recommendations of *Pūao Te Ata Tū*, claiming deregulation would resolve inequities. This hands-off approach has allowed institutional racism to flourish, with measurable negative impacts on health inequities.[9] It is literally a matter of Māori life and death.

While there is a growing acknowledgement of racism and some improvement in individual practice in Aotearoa, few initiatives have attempted to enact change at an institutional or societal level.[10] For example, there have been decades of kawa whakaruruhau and Te Tiriti training in the health sector.[11,12] Health workers are encouraged and even required, for a number of professions, to undertake competency training to be culturally safe practitioners.[13,14] There have also been various efforts to decolonise and indigenise health curricula, but they have not had adequate financial or political support to ensure their sustainability.[15] There have also been social marketing and education-orientated anti-racism interventions targeting civil society.[16]

While all these initiatives have had beneficial impacts, there is little evidence that existing anti-racism interventions have led to a reduction in institutional racism or improved Māori

health outcomes.[17] Crown witnesses in the Wai 2575 hearings conceded that institutional racism and subsequent health inequities continue to be a significant problem.[4]

Despite the lack of success in disrupting racism to date, there is currently unprecedented interest in anti-racism work. The Ministry of Justice and the Human Rights Commission are currently developing a National Action Plan on Racism, the Ministry of Health have commissioned major work, and the Teaching Council is also undertaking a significant programme of work. In addition, scholars from Auckland University of Technology, and the universities of Waikato and Otago have all secured major research grants to work in this area, and we are also aware of ongoing unfunded or non-funded community-led initiatives.

Meanwhile, Matike Mai Aotearoa[18] released a landmark report on constitutional transformation, as a pathway to just and sustainable futures for Aotearoa. Led by Margaret Mutu and Moana Jackson, this engagement process involved expansive discussions through hundreds of hui (gatherings), with thousands of participants. Hui were complemented by written submissions, focus groups and interviews that were gathered throughout the motu (land). From this deeply grounded process came a set of values and the suggestions for new constitutional arrangements that could honour Indigenous and treaty rights.

This paper provides an overview of i) the Matike Mai Constitutional Transformation movement, ii) examines the proposed National Action Plan Against Racism, and iii) Ao Mai Te Rā, the major health sector project. Finally, we outline contributions we hope our Marsden study, 'Re-imagining anti-racism for the health sector' can offer.

Matike Mai—Constitutional Transformation

Matike Mai incorporates understandings of the independence of hapū (sub-tribes) alongside their interdependence through whakapapa (genealogy), within the wider Māori polity, as the basis for constitutional authority. It proposes a dynamic relationship between Māori and the Crown, where just constitutional relations require independence for hapū to make decisions while acknowledging interdependence embedded in Te Tiriti. Matike Mai proposes distinct but interconnected spheres or domains:

> *We call those spheres of influence the "rangatiratanga [Māori unfettered authority] sphere", where Māori make decisions for Māori and the "kāwanatanga [governance] sphere" where the Crown will make decisions for its people. The sphere where they will work together as equals we call the "relational sphere" because it is where the Tiriti relationship will operate.*[18]

The Matike Mai vision requires authentic engagement, collaboration and commitment that recognises the realities and tensions of colonial history, its unresolved injustices and inequities. As experts, knowledge-holders and leaders within the rangatiratanga sphere, as well as drawing on intergenerational lived experiences of racism, Māori are able to guide and advise Tauiwi in theories, approaches and interventions to eliminate it. Within the kāwanatanga sphere, the Crown needs to be able to match the radical generosity Māori frequently bring to the table, with a mighty commitment to addressing racism and transforming monocultural practice. It is here that Tauiwi must prepare themselves to work respectfully in upholding Te Tiriti and halting racism. It is important to reiterate that the kāwanatanga sphere is inhabited by Tauiwi but Māori also occupy this sphere with rights and responsibilities, both within and outside the Crown.[19]

Matike Mai provides a useful mechanism for challenging structural racism that could help the health sector re-focus and transform the unjust Crown structures and practices that featured so prominently in the Wai 2575 Waitangi Tribunal report.[4] The forthcoming establishment of the Māori Health Authority may address some of the aspirations of Matike Mai, but it remains to be seen whether their scope of practice and investment levels will enable the full expression of tino rangatiratanga.[20]

National Action Plan Against Racism

Across the globe, countries have developed national action plans on racism as part of their active implementation of the Convention on the Elimination of All Forms of Racial Discrimination.[6] Our government has been slow to commence work after it appeared as a recommendation from a United Nations Human Rights Committee,[22] and

the next reporting round was due December 2021.

The Ministry of Justice is leading the whole-of-Government engagement and the Human Rights Commission are leading civil society engagement. At the time of writing, there was limited information available in the public domain about how the plan will be developed and what it might address. We understand the Human Rights Commission have established an advisory think tank to inform its work made up of 50% Māori and 50% ethnic communities—focusing on those with lived experience of racism. This proposed national plan it is of enormous importance to both those targeted by racism and those working in anti-racism.

In response to the lack of progress on the proposed plan in March 2021, a gathering of anti-racism practitioners (approximately 75 from around the country) was called to collectively articulate what we wanted to see in a national action plan on racism. A unique comprehensive briefing paper[23] was developed and signed off by the group which presented the views of tangata whenua, tangata Tiriti—Pākehā (white settlers)—and tangata Tiriti—Tauiwi of colour. The briefing paper centred on Māori aspirations and values, and articulated what Te Tiriti-based anti-racism praxis looks like currently in Aotearoa. It emphasised the need for constitutional transformation, Te Tiriti compliance, and decolonisation of narratives and spaces. It advocated for the establishment of an anti-racism clearing house to strengthen the evidence base, co-ordinate anti-racism work and build an anti-racism workforce. It concluded with distinctive priorities from each caucus.

The briefing paper showed diverse viewpoints of the dynamics of racism and idiosyncratic framing about what is anti-racism. The briefing paper[23] defined anti-racism as:

> *... the art and science of naming, reducing, disrupting, preventing, dismantling and eliminating racism. It takes a multiplicity of forms but centres around solidarity with those targeted by racism, an analysis of power and a commitment to reflective, transformative practice (p.9).*

In the context of Aotearoa, this also involves tino rangatiratanga, decolonisation and upholding Te Tiriti.

Ao Mai Te Rā—health sector

The Wai 2575 Waitangi Tribunal[4] stage one report was damning of the normalisation of racism within the health sector. The evidence presented to the Tribunal exposed racism within legislation, policy, funding and contracting practices; within governance structures; and critically in the quality and accessibility of care provided. Politically, it was impossible for the Ministry of Health to not respond as they engage in stages two and three of the hearings.

In July 2020, the Ministry of Health[24] released Whakamaua, their new Māori health action plan, which was buttressed in August 2020 by a new Te Tiriti framework.[25] Whakamaua identifies that addressing racism and discrimination is one of four high level priorities over the next five years. This positioning of racism has the (unintended) result of reinforcing the idea that the responsibility to address racism sits with Māori. Our experience, and analysis, is that eliminating racism is the responsibility of the Crown and Pākehā in alliance with Māori and Tauiwi of colour who wish to work in this space.

With little consultation with long-standing anti-racism groups, the Ministry has initiated Ao Mai Te Rā, an anti-racism programme which aims to support the health sector with insights and tools to understand and address racism. The brief is to address racism against Māori, Pacific and other ethnic minorities as the groups most impacted by racism. During the initial stage of the project, the contracted Māori and Pacific research team are undertaking a review of international literature to determine best practice, and a local environmental scan. The project leads are planning on engaging widely with the sector to build collective ownership, and they are working towards developing an anti-racism maturity model[26] to determine where to invest.

The authors respectfully suggest that as well as the approach outlined above it is critical to address racism at its source. Pākehā are the main instigators (and beneficiaries) of racism within the health sector, and as the party most in need of change it would therefore be useful to involve Pākehā in identifying solutions. Pākehā have cultural insider insights into racism and Te Tiriti responsibilities within the kāwanatanga sphere, and need to be responsible for working constructively with their people, in alliance with Māori, to eliminate racism.

Racism has a geographic specificity[27] so solutions imported from other countries may not have relevance or effectiveness in the context of this land. There is no magic bullet to anti-racism rather it is an iterative art and science of having a go, reflecting, and having another go. Most anti-racism work that has occurred in this country has

been unfunded and remains unpublished. Much of the mātauranga (knowledge) around anti-racist praxis lies with elders of the Māori sovereignty and anti-racism movements rather than in books and academic papers. It has always been relational work.

Re-imagining anti-racism

Racism and anti-racism are multifaceted and complex phenomena that require an innovative and actively transformative approach to produce meaningful changes in the health sector. The health system, with its ideological denial of racism, is profoundly resistant to change from without, which has contributed to a lack of cohesion and sustainability among the approaches highlighted in the introduction. We have embarked on a project, funded by a Marsden grant, to develop an action-focused theory of anti-racism that is relevant to all levels of the health sector, from education to policy and practice.

Drawing particularly on the work of Matike Mai, our focus is on the nexus of Māori and Tauiwi health aspirations and knowledges that, if fully articulated, can inspire individual and systems change. We see the tricameral nature of Matike Mai as the overarching organising structure for our study. This includes the organisation of the project (eg constitution of the research team, recruitment of participants, choice of methods etc), and also the understanding of the project aims. Here, we conceptualise the health sector as a relational sphere in which Māori and Tauiwi could work together as equals. At present this is not a reality in the health sector, although the forthcoming health reforms have the potential to realise greater equity.

The project incorporates the development of a draft theory using wānanga with health professionals engaged in anti-racism or Te Tiriti honouring practices. The draft theory will be tested in the healthcare sector, with attention to ensuring its practical application and capacity for drawing together the anti-racism initiatives being developed across the disciplinary and population boundaries in Aotearoa. Inquiries about the project can be directed to the corresponding author.

Conclusion

Active resistance, inaction and *ad hoc* approaches mean anti-racism initiatives have not significantly disrupted racism within our health system. Matike Mai offers an articulate vision for Te Tiriti—honouring decision-making processes which embrace tino rangatiratanga and create a setting to produce respectful relational engagement between tangata whenua and tangata Tiriti. To successfully address racism we need a planned, systemic approach that is congruent with the holistic, relational constitutional transformations envisaged by Matike Mai. This paper has introduced a research project that aims to develop and test such an approach.

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REFERENCES

1. Harris RB, Cormack DM, Stanley J. Experience of racism and associations with unmet need and healthcare satisfaction: the 2011/12 adult New Zealand Health Survey. Australian & New Zealand Journal of Public Health. 2019;43(1):75-80.
2. Smith, C., Tinirau, R., Rattray-Te Mana, H., Tawaroa, M., Moewaka Barnes, H., Cormack, D. and Fitzgerald, E. (2021) Whakatika: A survey of Maori experiences of racism. Whanganui: Te Atawhai o Te Ao Charitable Trust p.9
3. Harris R, Cormack D, Tobias M, Yeh L-C, Talamaivao N, Minister J, et al. The pervasive effects of racism: Experiences of racial discrimination in New Zealand over time and associations with multiple health domains. Social Science and Medicine. 2012;74(3):408-15.
4. Waitangi Tribunal. Hauora report on stage one of the health services and outcomes inquiry. Wellington, New Zealand: Author; 2019.
5. United Nations. (2007). Declaration on the Rights of Indigenous Peoples. New York, NY: Author
6. United Nations. International Convention on the Elimination of all Forms of Racial Discrimination. New York, NY: Author; 1966.
7. Ministerial Advisory Committee on a Māori Perspective for the Department of Social Welfare. Puao te ata tu (Day break). Wellington, New Zealand: Department of Social Welfare; 1988.
8. Kelsey J. The New Zealand experiment: A world model for structural adjustment? Auckland, New Zealand: Auckland University Press with Bridget Williams Books; 1995.
9. Reid P, Robson B. Understanding health inequities. In: Robson B, Harris R, editors. Hauora Māori standards of health IV: A study of the years 2000-2005. Wellington, New Zealand: Te Rōpū Rangahau Hauora a Eru Pōmare; 2007. p. 3-11.
10. Came, Griffith D. Tackling racism as a "wicked" public health problem: Enabling allies in anti-racism praxis. Social Science & Medicine. 2017;199:181-8.
11. Wepa D. Cultural safety in Aotearoa New Zealand. 2nd ed. Auckland New Zealand: Cambridge University Press; 2015.
12. Ramsden I. Teaching cultural safety. New Zealand Nursing Journal. 1992;85(5):21-3.
13. Heke D, Wilson D, Came H. Shades of competence? A critical analysis of the cultural competencies of the regulated-health workforce in Aotearoa New Zealand. International Journal for Quality in Health Care. 2018:mzy227-mzy.
14. Medical Council of New Zealand. Statement on cultural safety 2019.
15. Ahuriri-Driscoll A, Lee V, Came H. Amplifying Indigenous voice and curriculum within the public health academy – the emergence of Indigenous sovereign leadership in public health education. Higher Education Research & Development. 2021;40(1):146-61.
16. Human Rights Commission. Give nothing to racism: Human Rights Commission; 2017 [cited 2017 15 August]. Available from: http://www.givenothing.co.nz/.
17. Curtis E, Jones R, Tipene-Leach D, Walker C, Loring B, Paine S-J, et al. Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. International Journal for Equity in Health. 2019;18(1):174.
18. Matike Mai Aotearoa. He whakaaro here whakaumu mō Aotearoa: the report of Matike Mai Aotearoa. New Zealand: Matike Mai Aotearoa; 2016.
19. O'Sullivan D. The Treaty of Waitangi in Contemporary New Zealand Politics. Australian Journal of Political Science. 2008;43(2):317-31.
20. Came H, Baker M, McCreanor T. Structural racism, constitutional transformation and the New Zealand health sector: Learnings from the Matike Mai Aotearoa report. Journal of Bioethical Inquiry. 2021;18(1):59-70.
21. O'Sullivan D, Came H. New Authority could transform Māori health, but only if it's a leader, not a partner. The Conversation [Internet]. 2021. Available from: https://theconversation.com/new-authority-could-transform-maori-health-but-

only-if-its-a-leader-not-a-partner-15942522.CERD. Concluding observations of the CERD on the New Zealand government (CERD/C/NZL/CO/21-22). Geneva, Switzerland: United Nations; 2017.
22. STIR, NZ Public Health Association. Briefing paper on the forthcoming National Action Plan Against Racism. Auckland, NZ: STIR: Stop Institutional Racism and NZ Public Health Association; 2021.
23. Ministry of Health. Whakamaua: Māori Health Action Plan 2020-2025. Wellington, New Zealand: Author; 2020.
24. Ministry of Health. Te Tiriti o Waitangi and the health and disability system: Ministry of Health; 2020 [Available from: https://www.health.govt.nz/system/files/documents/pages/whakamaua-tiriti-o-waitangi-framework-a3-aug20.pdf.
25. Storm I, Harting J, Stronks K, Schuit AJ. Measuring stages of health in all policies on a local level: The applicability of a maturity model. HEALTH POLICY. 2014;114(2-3):183-91.
26. Dunn K, Geeraert P. The geography of 'race' and 'racism'. GeoDate. 2003;16(3):1-6.

Epidemiology of dog-related injuries within New Zealand

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ABSTRACT

BACKGROUND: Understanding the epidemiology of injury caused by dogs is crucial for targeting injury prevention efforts and monitoring their effectiveness. There are no contemporary published New Zealand studies describing the epidemiology of dog-related injuries (DRIs). This study aims to address this gap.

AIM: To describe the epidemiology of DRIs in New Zealand.

METHODS: A review of Accident Compensation Corporation (ACC) new claims for DRIs that required medical attention, and publicly funded hospital discharges identified from the National Minimum Dataset (NMDS) for the period of 1 July 2014 to 30 June 2019. ACC cases were identified using the TE60 READ code and relevant diagnosis or external agency descriptions; NMDS cases with an ICD-10-AM external cause of injury code of W540, W541, or W548 were included.

RESULTS: There were 108,324 new ACC claims for DRIs and 3,456 hospitalisations during the five-year review period. The majority of injuries were dog bites (51%, n=54,754 ACC claims; 89%, n=3,084 hospitalisations). The all-age incidence of ACC claims for all DRIs significantly increased by 1.75% per year ($p<0.001$) during the period reviewed, with a significant increase in claims for dog bite injuries of 1.64% per year ($p<0.001$), a significant increase in DRI hospitalisations (2.43% per year, $p=0.046$), and a non-significant annual increase ($p=0.217$) in dog bite injury hospitalisations. Children aged 0–9 years had similar rates to adults of ACC claims for dog bite injuries; however, children 0–9 years were more likely to be hospitalised. Māori had a higher incidence of ACC claims and hospitalisations for dog bite injuries than non-Māori. ACC claims and hospitalisations for dog bite injuries were more likely to occur in areas of greater deprivation, with substantial regional variation across the country.

CONCLUSION: The incidence of injury from dogs in New Zealand is increasing. Inequity exists with substantial regional variation, in higher rates among those living in areas of greater deprivation, and with Māori in the setting of the ongoing effects of colonisation. Children aged 0–9 years are no more likely than other age groups to present for medical attention but are more likely to be hospitalised. Reasons for these disparities require further investigation.

Dog bites and other dog-related injuries (DRIs) are an ongoing cause of morbidity internationally and in New Zealand, with subsequent serious physical and psychological consequences for the victims. Injuries include wounds or crush injuries, with or without damage to other structures, fractures, head injuries, localised or systemic bacterial infections, rabies, or tetanus. Many hospitalisations for dog bites are severe, with two thirds of people admitted requiring a general anaesthetic.[1] There can also be serious non-bite injuries,[2,3] for example a cyclist who sustained a fatal head injury in 2011 after colliding with a dog.[4]

Psychological trauma for victims or caregivers can also have long-term consequences,[5–12] including the development of post-traumatic stress disorder,[5,8] a reduction in physical activity, or avoidance of public spaces,[13] and may result as much from the fear of being threatened by a dog as the injury.[12] A New Zealand study found that 72% of adult dog bite victims with a claim from Accident Compensation Corporation (ACC) reported psychological effects, with 36% of these being moderate or severe.[7] There may also be intangible costs from dog attacks such as concerns about neighbourhood safety.[14]

Despite ongoing attempts at prevention through policy and education, this is an increasing public health issue, with numbers shown to rise in multiple studies worldwide.[1,15–19] For example, hospitalisations for dog bite injuries in New Zealand have increased almost seven-fold from 1.74 per 100,000 in 1979 [17] to 12.3 in 2014.[1]

Children are particularly at risk of hospitalisation from dog bites, and also receive more serious bites to the head and neck.[1,15,20–24] Physical scarring in these areas are often highly visible, and can require multiple scar revisions.[25] Frequently, lacerations in children are deep, may require amputation or loss of tissue substance, and have been shown to have an average healing time of nearly

11 months.[10] Non-bite injuries including mid-shaft femur fractures, head injuries, or skull/facial fractures, can also be a cause of considerable injury in children and are frequently overlooked.[2] Injuries to children from dogs are particularly unacceptable, and differ from other causes of unintentional injury in children, in that the incident may involve an attack or aggression. The need for further investigation into this area within New Zealand has been further highlighted following the recent tragic death of an infant from a dog mauling.

Further at-risk groups are Indigenous cultures and those from areas of greater deprivation.[26–29] A New Zealand study demonstrated how Māori (New Zealand's Indigenous population) are overrepresented in the incidence of hospitalisations for dog bite injuries.[1] The same study found that as socio-economic deprivation increases, so does the incidence of hospitalisations for dog bite injuries.[1] While the reasons for this are unclear, this needs to be interpreted within the context of colonisation, and current systems existing within New Zealand that create an inequitable environment for Māori.[30]

A range of information sources are available in New Zealand, including ACC claims, emergency department presentations, animal management reported dog attacks, and hospitalisation rates. Non-bite injuries are rarely studied, and dog bite injuries are commonly investigated using data from hospitalisations. However, this likely only reflects a small proportion of dog bites that occur, and broader measures of dog bites are required.[31] For example, rates of dog bites measured predominantly from household surveys range from 1.80% to 7.95% in studies internationally.[22,32–36] The lifetime incidence of dog bites from cross-sectional studies is reported to be between 25% and 45%.[36–38]

Understanding the epidemiology of injury caused by dogs is crucial for investigating disparities in prevention strategies and policies, targeting injury prevention efforts, and monitoring their effectiveness. There are no contemporary published New Zealand studies describing the epidemiology of DRIs. Therefore, this study aims to address this gap.

Methods

This retrospective, observational, descriptive study reviewed new ACC claims for DRIs where medical attention was sought, and DRI hospitalisation data from the New Zealand Ministry of Health's National Minimum Dataset (NMDS) for the five-year period 1 July 2014 to 30 June 2019.

ACC data

Individuals with a new claim registered for a DRI were identified using the following search:

- Dog Bite A: Read Code TE60;
- Dog Bite B: [External agency 1="Live Dog"] AND [Contact 1="Kicked/Butted/Bitten by Animal"] AND [free text within the injury description contains the following non-case sensitive words "bite", "bit", "bitten", "biten"] AND [read code does not equal "TE60"];
- Other Dog Related Injuries: [External agency 1="Live Dog"] AND [Not Dog Bite A or Dog Bite B].

Secondary claims were excluded. Variables of interest included: fiscal year, age, prioritised ethnicity, read code, diagnosis description, location of injury on the body, contact type, external agency, event location by Territorial Authority (TA), residential location by TA (and if the residential location was within Auckland, further defined by the six regional areas that existed pre-2010), meshblock of residential address (decile), and provider type. For injury locations within Auckland, further information was given on provider board area and meshblock. Ethnicity (Stats NZ Level 1 or 2) was prioritised and classified as Māori or non-Māori.

NMDS data

Individuals who had a publicly funded hospital discharge (from public or private hospitals) with an external cause of injury ICD-10-AM code W54 (W540: Bitten by dog, W541: Struck by dog, W548: Other contact with dog) were included. To maintain consistency with previous research in the field,[1] and to align with Ministry of Health recommendations,[39] short stay events (where length of stay is zero or one midnight spent in hospital) were removed.[39] For cases in which there was more than one DRI during the review period, only the first event was considered. Variables of interest included: ethnicity, age, domicile area level deprivation, hospital, date of presentation to hospital, diagnosis including location of injury on the body, procedure codes, and length of stay. Ethnicity (Stats NZ Level 1 or 2) was classified as Māori or non-Māori. Patient domiciles were assigned an area level deprivation score based on the 2018 NZ Deprivation (NZDep18) score.[40]

Statistical analysis

Age was grouped into three categories: 0–9 years was used due to the higher incidence of DRIs previously found in this group,[1] and was compared with older children (10–14 years) and adults (15 years and over). Māori was compared to non-Māori. For each geographical region (TA), the proportion of people living in decile 9 and 10 (most deprived) was used as an area measure of deprivation.

Data on the geographical location of injury was collated by each of the 67 TAs of New Zealand, which are the second tier of locally governed areas in New Zealand. The TA of the hospital was used for hospitalisations. Given that Auckland Council comprises 29% of the New Zealand population, data were also grouped into four main areas of Auckland Central, North, South East and West, closely matching the four current areas serviced by Auckland animal management services (Table 1). ACC data were provided by the six sub-Council regions, which existed prior to the 2010 formation of the Auckland "Supercity". For claims identified as occurring in "Auckland City", it was unclear if the location of injury was "Auckland City Central" area or "Auckland City" as a whole region. In these cases, the Local Board of the provider was used. If there was no provider location, they were not included in the analysis of geographical area to reduce bias.

Denominator data for 2014 to 2017 were calculated using the interpolation method, using 2013 and 2018 census data.[41] Numerator data for the calculation of local area incidence rates used annual estimates derived from the total numbers of injury in a specific area over the five-year period of interest. Of note, areas were defined slightly differently in each census. Population estimates of the pre-2010 Auckland areas were not available; however, a close estimate of these was available by local board.

Data were analysed using a generalised linear model, modelling the observed categorical data as having a Poisson distribution. A p-value of <0.05 was considered to be statistically significant. Statistical analyses were carried out using SAS 9.4,[42] Open-Epi version 3.01[43] and "R" version 4.1.1.[44] Maps were created with ArcGIS Pro version 2.7.1.

Results

ACC claims

Between 2014 to 2018 there were a total of 108,324 ACC claims nationally for DRIs where medical attention was sought (Table 3), with over half of these dog bites (51%, n=54,754).

ACC claims for DRIs significantly increased by 1.75% per year ($p<0.001$) during the period reviewed. The average annualised rate was 479.7 per 100,000 people (95% CI 476.8, 482.5), (Table 2), with the lowest rate in 2014/15 (459.9 per 100,000; 95% CI 453.6, 466.3), and highest in 2017/18 (497.8 per 100,000; 95% CI 491.4, 504.3), (Figure 1).

ACC claims for dog bite injuries alone significantly increased by 1.64% per year ($p<0.001$). The average annualised rate was 242.5 per 100,000 (95% CI 240.4, 244.5), (Table 2), with the lowest rate in 2014/15 (234.4 per 100,000; 95% CI 229.9, 239) and highest in 2017/18 (249.7 per 100,000; 95% CI 245.1, 254.3), (Figure 2).

Hospitalisations

Across the five-year study period there were 3,456 hospitalisations nationally for DRIs (Table 3), which were predominantly dog bites (89%, n=3,084).

Hospitalisations for DRIs significantly increased by 2.43% per year ($p=0.046$) during the period reviewed, with an average annual incidence of 15.3 per 100,000 (95% CI 14.8, 15.8), (Table 2), with the lowest rate in 2014/15, (14.0 per 100,000; 95% CI 12.9, 15.1), and highest in 2017/18 (16.3 per 100,000; 95% CI 15.2, 17.5), (Figure 3).

There was a non-significant annual increase in hospitalisations for dog bite injuries of 1.59% ($p=0.217$), with an average annual incidence of 13.7 per 100,000 (95% CI 13.2, 14.1), (Table 2). This was lowest in 2014/15 (12.6 per 100,000; 95% CI 11.5, 13.7), and highest in 2017/18 (14.6 per 100,000; 95% CI 13.5, 15.8), (Figure 4).

Age

Children aged 0–14 years had a total of 14,346 DRIs over the five years, of which 75% were dog bites (n=10,801). There were 857 DRI hospitalisations in this age group, which were predominantly dog bites (95%, n=813), (Table 3).

In children aged 0–9 years, both ACC claims and hospitalisations had a non-significant decrease across the five years for both dog-related injuries (ACC by 0.94%, $p=0.242$; hospitalisations by 2.46%, $p=0.364$) and dog bite injuries (ACC by 2.12%, $p=0.422$; hospitalisations by 1.26%, $p=0.075$), (Figures 1–4).

In contrast, adults had a significant increase in both ACC claims and hospitalisations for both DRIs (ACC by 4.16%, $p<0.001$, hospitalisations by 6.16%, $p<0.001$) and dog bite injuries (ACC by 4.74%, $p<0.001$, hospitalisations by 5.20%, $p<0.001$).

ACC claims for dog bite injuries among young children (0–9 years of age) (255.8 per 100,000; 95% CI 250.1, 261.5) were similar to adults (260.4 per

100,000; 95% CI 257.9, 262.8, p=0.155). However, hospitalisations among children aged 0–9 years (22.0 per 100,000; 95% CI 20.3, 23.7) were significantly higher than the 10–14-year age group (10.1 per 100,000; 95% CI 8.4, 11.7, p<0.001), and adults (13.5 per 100,000; 95% CI 12.9, 14.0, p<0.001), (Table 2).

Adults had significantly higher ACC claim rates for all DRIs (556.7 per 100,000; 95% CI 553.1, 560.2), compared to children aged 0–9 years and 0–14 years (328.7 per 100,000; 95% CI 322.2, 335.2, p<0.001; and 298.5 per 100,000; 95% CI 289.7, 307.3, p<0.001, respectively), (Table 2). However, hospitalisation rates were significantly higher among children aged 0–9 years (23.2 per 100,000; 95% CI 21.5, 24.9) than other age groups, (Table 2).

Ethnicity

Tamariki (children) Māori of both younger and older age groups (0–9 and 10–14 years) had significantly higher rates of both ACC claims and hospitalisations for dog-related and dog bite injuries compared to non-Māori children (p<0.001 for all comparisons), with tamariki Māori being 2.47 (0–9 years) and 2.17 (10–14 years) times more likely to be hospitalised for a dog bite injury (Table 2).

Likewise, Māori adults had higher rates of ACC claims and hospitalisations for dog bite injuries than non-Māori adults (p<0.001 for all comparisons), being 2.50 times more likely to be hospitalised for a dog bite injury. However, Māori adults had significantly lower rates of DRI ACC claims compared to non-Māori (p<0.001), (Table 2).

Deprivation

ACC claims and hospitalisations for dog bite injuries were higher in areas of greater deprivation (Figures 5 and 6), with ACC claims 3.38 times higher in areas of greatest deprivation (decile 10) than in the least deprived areas (decile 1). Similarly, hospitalisations were 3.97 times greater in areas of greatest deprivation (decile 10) compared to the least deprived areas (decile 1)

Regional variation

The maps displayed in Figures 7–9 illustrate the geographical distribution of ACC claims for dog-related and dog bite injuries, relative to deprivation within each TA. In the North Island, TAs with the highest incidence of ACC claims for all dog-related and dog bite injuries (>550 per 100,000; and >350 per 100,000, respectively) were spatially clustered around the Northern, Eastern and Central areas, and aligned with having >25% of the population living in areas of higher deprivation (decile 9/10 areas), (Figure 9).

This pattern was not as evident for the South Island, where several TAs with a low level of deprivation (<10% living in decile 9/10 areas) had high rates of DRIs and dog bites (>550 per 100,000; and >250 per 100,000, respectively).

Within the Auckland Region dog bite injury ACC claims were highest in South East Auckland (276.1 per 100,000; 95% CI 269.7, 282.6), and lowest in Central Auckland (145.6 per 100,000; 95% CI 140.8, 150.5), and hospitalisations over five times higher in South East Auckland (31.64 per 100,000; 95% CI 29.5, 33.89) compared to Central Auckland (5.72 per 100,000; 95% CI 4.81, 6.64, p<0.001), (Table 4).

Within the seven most heavily populated areas of New Zealand (Auckland, Christchurch, Wellington, Hamilton, Tauranga, Lower Hutt and Dunedin), both ACC claims and hospitalisations for dog bite injury within each age group largely remained stable (no significant change) or had a significant increase. An exception to this was in Dunedin, where there was a significant decrease in the 0–9-year age group only (18.7%, p=0.001).

Figure 1: Annual incidence of DRI ACC claims.

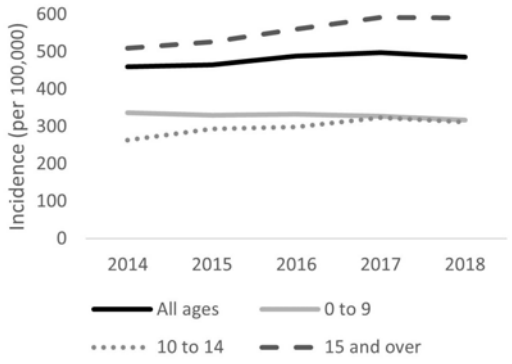
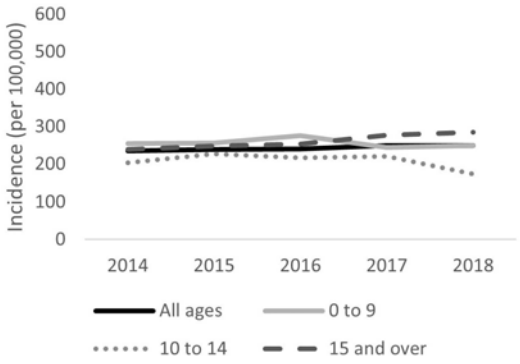


Figure 2: Annual Incidence of dog bite injury ACC claims.



Severity

Almost three quarters (72%, 2,220/3,084) of people hospitalised for a dog bite injury required at least two procedures while in hospital, with a further 7% (n=216) requiring only one procedure. The average length of stay in hospital was 2.3 days.

Only one third (33%, n=18,296/54,754) of ACC claims for dog bite injury had the location of injury recorded. Injury to the head/neck region was more common among children (0–9 years) (54%, n=1,428/2,664). Children aged 10–14 years and adults were more commonly bitten on the limbs/torso (72%, n=698/969; and 87%, n=12,807/14,663, respectively, p<0.001).

Similar results were found for hospitalisations of dog bite injury, where the majority (95.9%, n=2,957) had the location of injury recorded. Children aged 0–9 years who were hospitalised received a far greater proportion of injury to the head/neck region (75%, n=488/653, p<0.001), with the 10–14-year age group and adults more likely to be bitten on the limbs/torso (53%, n=78/147, p<0.001 and 89%, n=1,926/2,157, p<0.001, respectively).

Injury descriptions were provided for hospitalisation data only. Dog bite injuries (coded W540) were consistently described as lacerations or open wounds. Detailed information regarding depth or size of wound, wound location, injury to important structures, or development of complications (eg local or systemic infection) were not reliably reported in the datasets reviewed.

Non-bite DRIs that were hospitalised were predominantly fractures (52%, n=195/372) or wound lacerations or infections (30%, n=111/372), with a small number of head injuries (4%, n=14/346) or other injuries (15%, n=52/346). Fractures included tibial plateau (28% 55/195), femoral neck or shaft (20%, 39/195), with seven pelvic, seven humeral shaft, 16 bi/tri-malleolar, 51 other distal limb, and 19 "other" fractures.

Figure 3: Annual incidence of DRI hospitalisations.

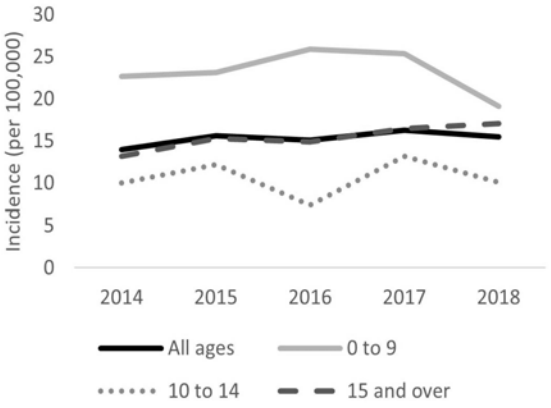


Figure 4: Annual incidence of dog bite injury hospitalisations.

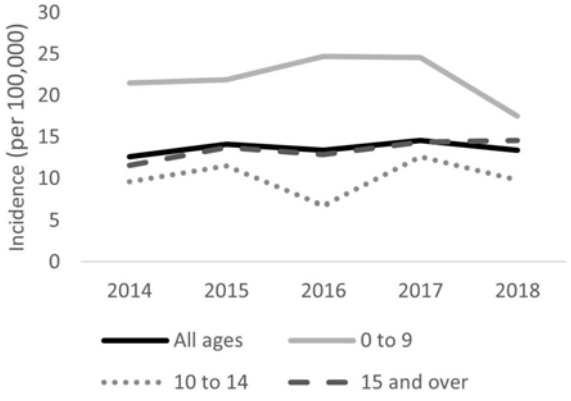


Figure 5: Incidence of hospitalisations for dog bite injuries by NZDep2018 (per 100,000 people).

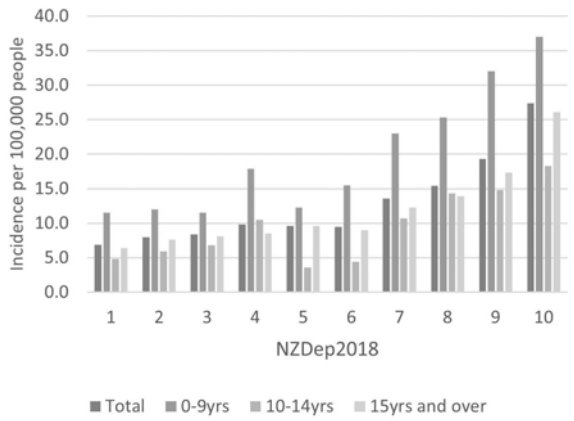
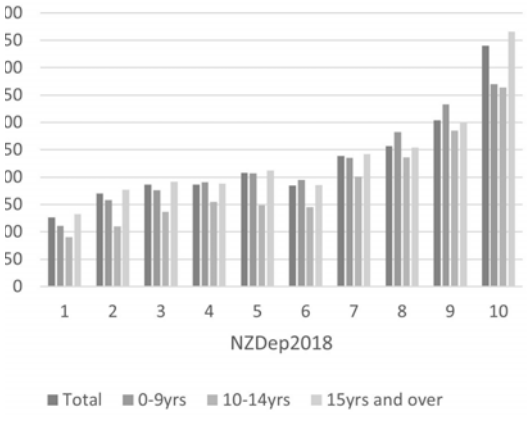


Figure 6: Incidence of ACC claims for dog bite injuries by NZDep2018 (per 100,000 people).



Discussion

The high incidence of DRIs in New Zealand is cause for concern, particularly given the apparent inequities and increasing injuries over time. There is a nearly eight-fold increase in the risk of hospitalisation from a dog bite injury compared to forty years ago, with an incidence of 1.7 per 100,000 in 1979[17] rising to 13.4 per 100,000 in 2018/19. The reliability of this finding is strengthened by other New Zealand studies demonstrating increasing rates over time,[1,15,17,45] with similar results found in a recent UK study.[19] This increase has come about despite regional attempts by each TA at addressing this worsening problem.

This study also revealed an increasing incidence of ACC claims for all DRIs at a rate of 1.75% per year ($p<0.001$), and for dog bite injury specifically at a rate of 1.64% per year ($p<0.001$). While a broader definition for DRIs was used in this study, the incidence of 485.7 claims per 100,000 in 2018/19 (95% CI 479.4, 492.0) is nearly three times that stated in a Governmental report with an approximate incidence of 164 per 100,000 people (n=6,300) in the 1999/2000 year.[45] Similar results in both the review of ACC and NMDS datasets provide strong evidence that DRIs are increasing.

It is uncertain whether rates are increasing due to an increase in injuries or in an increase in presenting for medical attention, either due to severity of injuries or for other reasons. However, given that the number of dog bites that present for medical attention in other countries represent only a small proportion of all dog bites,[22,32–36,46] ACC claims and hospitalisations are already indicators of the more severe end of the spectrum of injuries.

A finding that contrasts to previous studies both nationally[1] and internationally[47] is that in the current study children were *equally* as likely as adults to present for medical attention due to a dog bite. This finding only became evident when analysing ACC claim data, rather than hospitalisation data alone. However, children were more likely to be hospitalised, consistent with previous studies.[1,15,45] This is likely a reflection of the greater severity of the injuries in children, which occur more frequently on the head or neck regions.[1,48–51]

Almost half (49%) of ACC claims for injuries caused by dogs were non-bite related. This may have implications for policy or other prevention strategies. A previous US study highlighted non-bite injuries as an overlooked injury in children, caused either through direct contact with a dog, or adults holding a child tripping over a dog.[2]

The present study found higher rates of injury occurred in individuals living in areas of higher deprivation. This finding is consistent with many other health conditions, independent of factors such as income, education or car access.[52,53] Regional variation in injury rates was evident, with a nearly seven-fold difference in the incidence of dog bites between TAs with the highest and lowest rates of dog-bite injury. The relationship between low socio-economic area and dog bite injuries has also been described in studies in the US,[29] Canada[28,54] and the UK.[55]

Higher rates of injury among Māori must be interpreted within the historical and current context of the ongoing effects of colonisation, including discrimination and institutional racism.[30,56] Māori continue to live within a dominant non-Māori culture, and also have lesser levels of socio-economic security than non-Māori.[57] Further research is needed in New Zealand to investigate additional systemic factors behind the inequities, including regional differences in dog ownership, funding, or culturally appropriate prevention strategies and policies that empower Māori.

The circumstances surrounding dog bites and other DRIs needs further investigation to guide both in-home and public policies and interventions. Differences in injury rates between public and private, urban and rural, or higher and lower density areas were difficult to determine in the current study, due to how geographical location of injury is recorded by ACC. Likewise, because injuries frequently occur in public or on a property not owned by the victim,[1,7] using the victims address would not be an appropriate way to investigate this. A New Zealand survey of 535 adults with an ACC claim for a dog bite injury found that over one third (36%) occurred in public places, with only 21% occurring in the victim's home, and 43% on other private property. Of note, 56% were reported as occurring in urban areas.[7]

Dog aggression may be influenced by intrinsic factors such as breed, size, jaw-size, gender; or environmental factors such as training, exercise, weaning time, early socialisation, medication, or food.[58,59] There is an absence of appropriately designed epidemiological dog bite studies exploring risk factors for DRIs. Injury studies commonly make claims regarding risky breeds or dog gender which can be unfounded due to the absence of a control/comparison group. In addition, more commonly owned breeds are more likely to be involved in injury statistics.[59,60] Furthermore, breed is frequently poorly identified.[59,61] A recent

large Finnish study (n=9,270) investigating risk factors for dog aggression comparing household pure-bred dogs with or without aggressive behaviour found a relationship with breed; however, not with the breeds often considered dangerous.[62] For example, miniature poodles were more aggressive, and Staffordshire bull terriers, less so. Older age, and being male, of small body size, lacking the company of other dogs, and being the owners' first dog, were all associated with dog aggression. There was no difference in weaning age, daily exercise, time spent alone, sterilisation, family size, or living in an urban area. Of note, dog aggressiveness is also not the only factor involved in whether an injury will occur, as environmental barriers such as fencing, leashes or in-home gates or kennels also likely prevent injury.[63]

The strengths of this study are its novel nature as it is the first published, in-depth study of the epidemiology of DRIs in New Zealand. However, findings need to be considered in light of some limitations. While some indices of severity were included in this study, further measures were not investigated such as: wound depth, size, or type;[64] injury to tendons, arteries, nerves or other important functional structures such as eyes, ears, lips, nose or genitals; amputations; fractures;[65,66] head injuries; spinal cord injury;[67] infections including cellulitis, necrotising fasciitis or sepsis; loss of function; development of arthritis; cosmetic consequences; circumstances surrounding the injury; "bite style" the dog used;[68]or the psychological impact.[7] Wake et al reported only 12% of adults with an ACC claim for a dog bite had a minor injury (drawing little/no blood),[7] with an Austrian study also describing a predominance of severe injuries with 85% of paediatric dog bites presenting to hospital being deep wounds.[50] This has not been studied in children in New Zealand.

Additional limitations include the accuracy of clinical diagnoses in hospital and ACC data. Injury rates only represent those presenting for medical attention (ACC claims), and rates are likely higher.[9,32,36,37] ACC changed their coding processes in September 2018, which may result in differences in incidence from that year. Hospitalisation rates require careful interpretation by area, as they used population data from the TA in which the hospital was located rather than DHB data. They have also assumed little migration between areas over time, and patients can be referred to plastic surgical centres within larger hospitals. The hospitalisation rates used in this study are also exclusive of short stay events and therefore not representative of presentations to hospital, as many injuries are treated within the emergency department and discharged. A further limitation of this study was the use of an ecological area-based measure of deprivation (NZDep18),[40] producing a deficit framing of results.[69] The use of subjective wellbeing and other capability-based approaches[70,71] would offer a strengths-based narrative exploring protective rather than risk factors.[72] This preliminary research has created a foundation from which further research areas can be explored, and intervention strategies can be trialled with clear injury outcome measures specific to New Zealand. Future researchers or organisations can monitor their progress by using the described search strategy for dog bites and all DRIs, within ACC (new claims) and NMDS (hospitalisation) datasets.

Conclusion

The incidences of injury from dogs in New Zealand is increasing. Inequity exists with substantial regional variation, and higher rates among those living in areas of greater deprivation and Māori in the setting of the ongoing effects of colonisation. Children aged 0–9 years are no more likely than other age groups to present for medical attention but are more likely to be hospitalised. Reasons for these disparities require further investigation.

Figure 7: Distribution of ACC claims for DRIs, by TA.

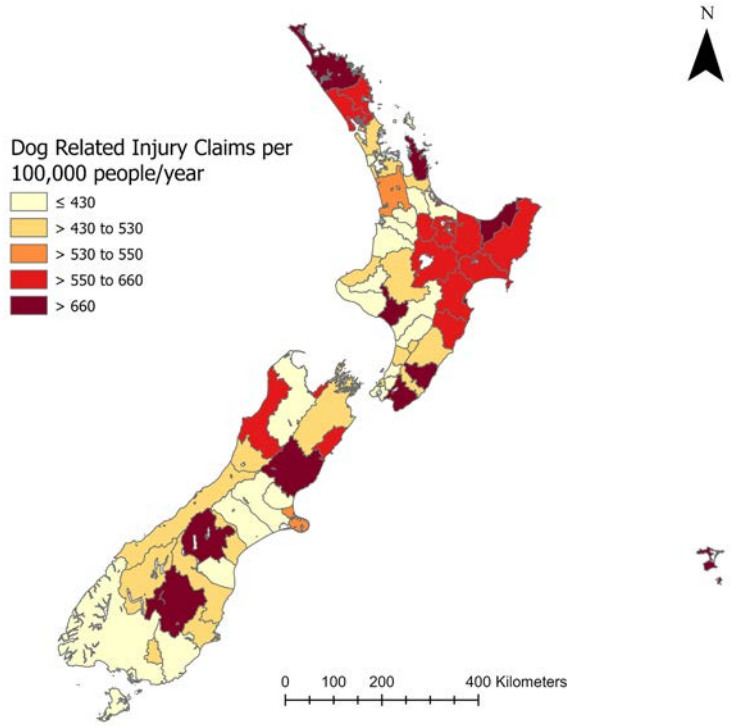


Figure 8: Distribution of ACC claims for dog bite injuries, by TA.

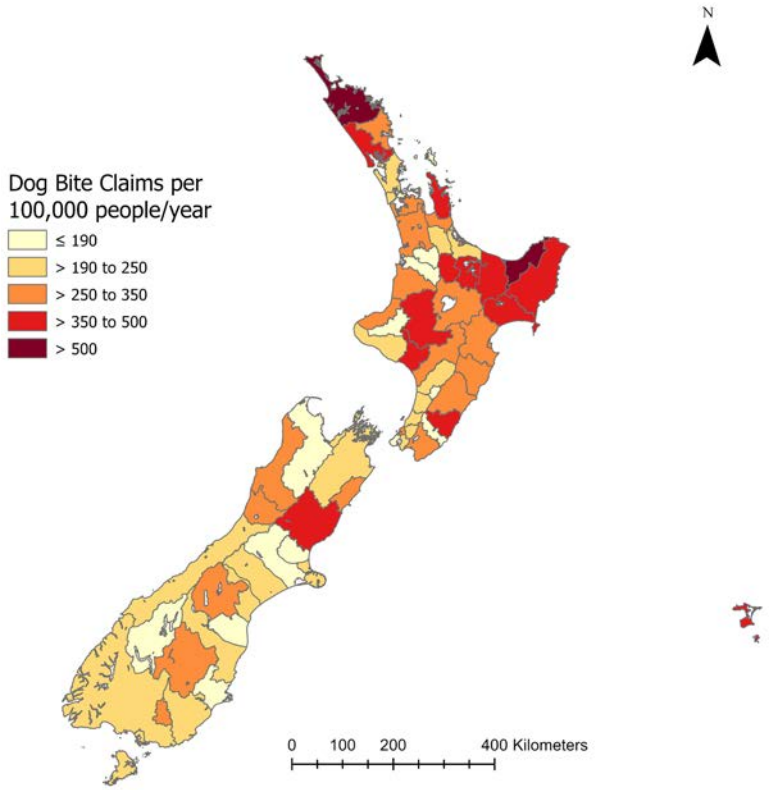
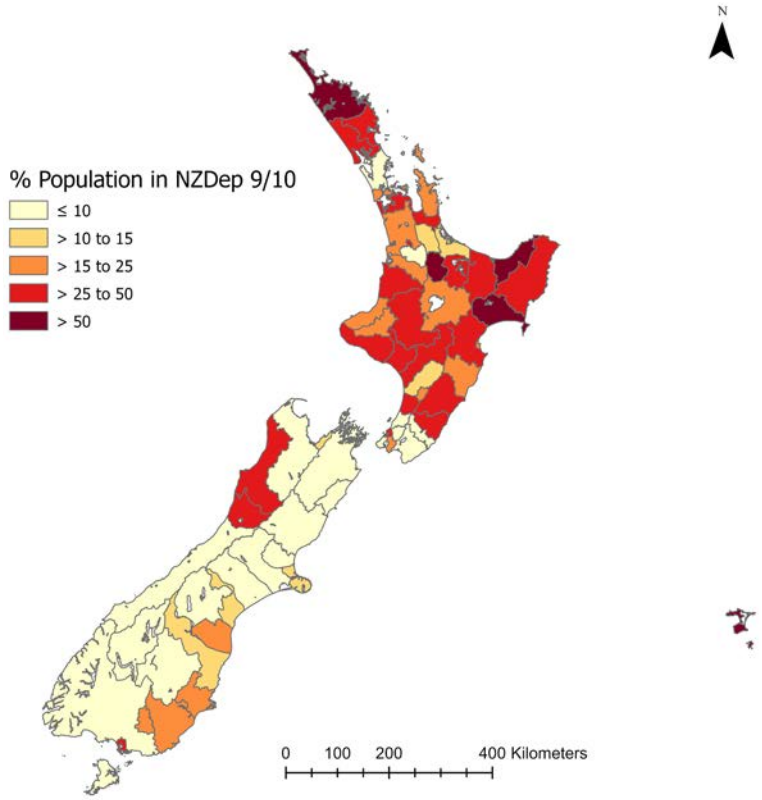


Figure 9: Proportion of people living in areas with NZDep2018 scores 9–10, by TA.



COMPETING INTERESTS
Nil.

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REFERENCES.
1. Mair J, Duncan-Sutherland N, Moaveni Z. The incidence and risk factors of dog bite injuries requiring hospitalisation in New Zealand. N Z Med J. 2019 May 3;132(1494):8-14.
2. Juang D, Sippey M, Zuckerbraun N et al. "Non-bite dog-related" injuries: an overlooked injury mechanism in the pediatric population. J Trauma. 2011;71(5):S531-3.
3. Kreisfeld R, Harrison J. Dog-Related Injuries. 2005.
4. New Zealand Coroners Court. Cater [2011] NZCorC 70 (27 June 2011). Recommendations made by the coroner to the Auckland Council [Internet]. 2011. Available from: URL: http://www.nzlii.org/nz/cases/NZCorC/2011/70.html.
5. Ji L, Xiaowei Z, Chuanlin W, Wei L. Investigation of posttraumatic stress disorder in children after animal-induced injury in China. Pediatrics. 2010 Aug;126(2):e320-324.
6. Westgarth C, Watkins F. Chapter 23: Impact of dog aggression on victims. In: Mills D, editor. Dog bites: a multidisciplinary perspective. Sheffield: 5M Publishing; 2017.
7. Wake A, Minot E, Stafford K, Perry P. A survey of adult victims of dog bites in New Zealand. N Z Vet J. 2009 Dec;57(6):364-9.
8. Peters V, Sottiaux M, Appelboom J, Kahn A. Posttraumatic stress disorder after dog bites in children. J Pediatr. 2004 Jan;144(1):121-2.
9. Keuster TD, Lamoureux J, Kahn A. Epidemiology of dog bites: A Belgian experience of canine behaviour and public health concerns. Vet J. 2006 Nov;172(3):482-7.
10. Hersant B, Cassier S, Constantinescu G, et al. Facial dog bite injuries in children: retrospective study of 77 cases. Ann Chir Plast Esthét. 2012 Jun;57(3):230-9.
11. Rusch MD, Grunert BK, Sanger JR, et al. Psychological Adjustment in Children after Traumatic Disfiguring Injuries: A 12-Month Follow-Up: Plast Reconstr Surg. 2000 Dec;106(7):1451-8.
12. Boyd CM, Fotheringham B, Litchfield C, et al. Fear of dogs in a community sample: Effects of age, gender and prior experience of canine aggression. Anthrozoös. 2004 Jun;17(2):146-66.
13. Vargo D, DePasquale JM, Vargo AM. Incidence of dog bite injuries in American Samoa and their impact on society. Hawaii J Med Public Health J Asia Pac Med Public Health. 2012 Jan;71(1):6-12.
14. American Veterinary Medical Association Task Force on Canine Aggression and Human-Canine

Interactions. A community approach to dog bite prevention. J Am Vet Med Assoc. 2001 Jun 1;218(11):173249.
15. Marsh L, Langley J, Gauld R. Dog bite injuries. N Z Med J. 2004 Sep 10;117(1201):U1043.
16. Australian Veterinary Association. Dangerous dogs - a sensible solution [Internet]. 2012. Available from: https://www.parliament.vic.gov.au/images/stories/committees/SCEI/Dogs_Inquiry/Subs/Submission_187c_-_Marcia_Balzer_-_Australian_Veterinary_Association_-_Attached_to_email.pdf
17. Langley J. The Incidence of Dog Bite Injuries in New Zealand. N Z Med J. 1992;5.
18. Park J, Kim DK, Jung J, et al. Dog-bite injuries in Korea and risk factors for significant dog-bite injuries: A 6-year cross-sectional study. PLOS ONE. 2019 Feb 21;14:e0210541.
19. Tullock J, Owczarczak-Garstecka S, Fleming K, et al. English hospital episode data analysis (1998–2018) reveal that the rise in dog bite hospital admissions is driven by adult cases. Sci Rep. 2021;11:1767.
20. Horisberger U, Stärk KDC, Rüfenacht J, et al. The epidemiology of dog bite injuries in Switzerland – characteristics of victims, biting dogs and circumstances. Anthrozoös. 2004 Dec 1;17(4):320–39.
21. Lang ME, Klassen T. Dog bites in Canadian children: a five-year review of severity and emergency department management. CJEM. 2005 Sep;7(5):309-14.
22. Kahn A, Robert E, Piette D, et al. Prevalence of dog bites in children: a telephone survey. Eur J Pediatr. 2004;163(7):424.
23. Daniels DM, Ritzi RBS, O'Neil J, "Tres Scherer LR. Analysis of Nonfatal Dog Bites in Children. J Trauma Inj Infect Crit Care. 2009 Mar;66(3):S17-22.
24. Weiss HB. Incidence of Dog Bite Injuries Treated in Emergency Departments. JAMA. 1998 Jan 7;279(1):51.
25. Eppley BL, Schleich AR. Facial Dog Bite Injuries in Children: Treatment and Outcome Assessment. J Craniofac Surg. 2013 Mar;24(2):384-6.
26. Bjork A, Holman RC, Callinan LS, et al. Dog bite injuries among American Indian and Alaska Native children. J Pediatr. 2013 Jun;162(6):1270-5.
27. West C, Rouen C. Incidence and characteristics of dog bites in three remote Indigenous communities in Far North Queensland, Australia, 2006-2011. J Vet Behav. 2019 May 1;31:17-21.
28. Raghavan M, Martens PJ, Burchill C. Exploring the relationship between socioeconomic status and dog-bite injuries through spatial analysis. Rural Remote Health. 2014;14(3):2846.
29. Ponce M, Piron J, Smith L, et al. Burden of Dog Bites Higher in Low SES Cities of Los Angeles County, 2009. 2011.
30. Reid J, Rout M, Tau TM, Smith CW-R, Ngai Tahu Research Centre. The colonising environment: an aetiology of the trauma of settler colonisation and land alienation on Ngai Tahu Whanau [Internet]. 2017 [cited 2021 Dec 15]. Available from: http://ndhadeliver.natlib.govt.nz/delivery/DeliveryManagerServlet?dps_pid=IE28489676
31. Oxley J, Christley R, Westgarth C. Contexts and consequences of dog bite incidents. J Vet Behav Clin Appl Res. 2017 Oct 23;23:33-9.
32. Sacks JJ, Kresnow M, Houston B. Dog bites: how big a problem? Inj Prev J Int Soc Child Adolesc Inj Prev. 1996 Mar;2(1):52-4.
33. Masthi NRR, Narayana DHA, Kulkarni P, et al. Epidemiology and prevention of animal bite and human rabies in a rural community-One health experiment. Asian Pac J Trop Dis. 2014 Jan 1;4:S486-90.
34. Häsler B, Hiby E, Gilbert W, et al. A One Health Framework for the Evaluation of Rabies Control Programmes: A Case Study from Colombo City, Sri Lanka. PLoS Negl Trop Dis. 2014 Oct 23;8(10):e3270.
35. Deray R, Rivera C, Gripon S, et al. Protecting children from rabies with education and pre-exposure prophylaxis: A school-based campaign in El Nido, Palawan, Philippines. PloS One. 2018;13(1):e0189596.
36. Westgarth C, Brooke M, Christley RM. How many people have been bitten by dogs? A cross-sectional survey of prevalence, incidence and factors associated with dog bites in a UK community. J Epidemiol Community Health. 2018 Apr 1;72(4):331-6.
37. Wake A, Stafford K, Minot E. The experience of dog bites: a survey of veterinary science and veterinary nursing students. N Z Vet J. 2006 Jun;54(3):141-6.
38. Beck AM, Jones BA. Unreported dog bites in children. Public Health Rep Wash DC 1974. 1985;100(3):315-21.
39. Ministry of Health. Factsheet: Short stay emergency department events. 2015.
40. Stats NZ. NZDep 2018 Area Codes. 2018.
41. Stats NZ. Subnational population estimates (DHB, DHB constituency), by age and sex, at 30 June 1996-2020 (2020 boundaries). Statistics New Zealand.
42. SAS Institute Inc., Cary, NC, USA. SAS.
43. Dean A, Sullivan K, Soe M. OpenEpi: Open Source Epidemiologic Statistics for Public Health, Version 3.01 [Internet]. [cited 2021 Oct 22]. Available from: www.OpenEpi.com, updated 2013/04/06
44. R Core Team. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL https://www.R-project.org/). 2019.
45. Department Of Internal Affairs – Te Tari Taiwhenua. Survey of Territorial Authorities on Dog Control

Issues - Final Report [Internet]. 2001. Available from: ISBN 0478092830.
46. Duncan-Sutherland N, Cunningham C, Cooper S, et al. An Audit of Dog Related Injury Notification Practices in a New Zealand Public Hospital. N Z Med J 2022;135.
47. Jakeman M, Oxley JA, Owczarczak-Garstecka SC, et al. Pet dog bites in children: management and prevention. BMJ Paediatr Open. 2020 Aug 1;4(1):e000726.
48. Chen HH, Neumeier AT, Davies BW, et al. Analysis of Pediatric Facial Dog Bites. Craniomaxillofacial Trauma Reconstr. 2013 Dec;6(4):225-32.
49. Mannion CJ, Graham A, Shepherd K, et al. Dog bites and maxillofacial surgery: what can we do? Br J Oral Maxillofac Surg. 2015 Jul;53(6):522-5.
50. Schalamon J. Analysis of Dog Bites in Children Who Are Younger Than 17 Years. PEDIATRICS. 2006 Mar 1;117(3):e374-9.
51. Abraham JT, Czerwinski M. Pediatric Dog Bite Injuries in Central Texas. J Pediatr Surg. 2019 Jul;54(7):1416-20.
52. Blakely T, Atkinson J, Kiro C, et al. Child mortality, socioeconomic position, and one-parent families: independent associations and variation by age and cause of death. Int J Epidemiol. 2003 Jun;32(3):410-8.
53. Blakely T, New Zealand, Ministry of Health. Tracking disparity: trends in ethnic and socioeconomic inequalities in mortality, 1981-2004. Wellington, N.Z.: Ministry of Health; 2007.
54. Clarke NM, Fraser D. Animal control measures and their relationship to the reported incidence of dog bites in urban Canadian municipalities. Can Vet J. 2013 Feb;54(2):145–9.
55. Murray GE. Examining evidence on dog bite injuries and their management in children. Nurse Child Young People. 2017 Apr 11;29(3):35-9.
56. Robson B, Harris R, Te Ropu Rangahau Hauora a Eru Pomare. Hauora, Māori standards of health. a study of the years, 2000-2005 IV IV. Wellington, N.Z.: Te Ropu Rangahau Hauora a Eru Pomare; 2007.
57. Neighbourhood Deprivation [Internet]. Ministry of Health, NZ; 2018 [cited 2021 Dec 15]. Available from: https://www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-awe-o-te-hauora-socioeconomic-determinants-health/neighbourhood-deprivation
58. Haug LI. Canine Aggression Toward Unfamiliar People and Dogs. Vet Clin North Am Small Anim Pract. 2008 Sep;38(5):1023-41.
59. Newman J. Human directed dog aggression; a systematic review [Internet]. University of Liverpool; 2012. Available from: https://livrepository.liverpool.ac.uk/7753/1/NewmanJen_June2012_7753.pdf
60. Clarke T. Public Perceptions of Breed Related Risk - Fact or Fiction? In: Dog Bites A Multidisciplinary Perspective. Sheffield, UK: 5M Publishing.
61. Patronek GJ, Sacks JJ, Delise KM, et al. Co-occurrence of potentially preventable factors in 256 dog bite–related fatalities in the United States (2000–2009). J Am Vet Med Assoc. 2013 Dec 15;243(12):1726-36.
62. Mikkola S, Salonen M, Puurunen J, et al. Aggressive behaviour is affected by demographic, environmental and behavioural factors in purebred dogs. Sci Rep. 2021 Dec;11(1):9433.
63. Lissamen A, Duncan-Sutherland N, Shepherd M, Kool B. Systematic Review of Dog Bite Prevention Strategies. Unpubl Data. 2021.
64. World Health Organisation. Rabies Fact Sheet [Internet]. 2021. Available from: https://www.who.int/news-room/fact-sheets/detail/rabies
65. Lackmann G-M, Draf W, Isselstein G, Töllner U. Surgical treatment of facial dog bite injuries in children. J Cranio-Maxillofac Surg. 1992 Feb;20(2):81-6.
66. Nygaard M, Dahlin LB. Dog bite injuries to the hand. J Plast Surg Hand Surg. 2011 Apr;45(2):96-101.
67. Kumar R, Deleyiannis FWB, Wilkinson C, O'Neill BR. Neurosurgical sequelae of domestic dog attacks in children. J Neurosurg Pediatr. 2017 Jan;19(1):24-31.
68. Shannon C. Bite Heirarchy Charts [Internet]. Available from: https://www.raisingcanine.com/education/bad-to-the-bone-analyzing-assessing-dog-bites/bite-hierarchies/
69. Exeter DJ, Zhao J, Crengle S, et al. The New Zealand Indices of Multiple Deprivation (IMD): A new suite of indicators for social and health research in Aotearoa, New Zealand. Ergin I, editor. PLOS ONE. 2017 Aug 3;12(8):e0181260.
70. Fu M, Exeter DJ, Anderson A. "So, is that your 'relative' or mine?" A political-ecological critique of census-based area deprivation indices. Soc Sci Med. 2015 Oct;142:27-36.
71. Fu M, Exeter DJ, Anderson A. The politics of relative deprivation: A transdisciplinary social justice perspective. Soc Sci Med. 2015 May;133:223-32.
72. Thurber KA, Thandrayen J, Banks E, et al. Strengths-based approaches for quantitative data analysis: A case study using the australian Longitudinal Study of Indigenous Children. SSM - Popul Health. 2020 Dec;12:100637.

Table 1: Geographical divisions of the Regional Auckland area.

	Auckland Central	West Auckland	South East Auckland	North Auckland
Regional areas (pre-2010)	Auckland City	Waitākere City	Manukau City Franklin District Papakura District	Rodney District North Shore City
Local board (post-2010)	Whau Puketāpapa Albert–Eden Waitematā Ōrākei Maungakeikei–Tāmaki Waiheke Great Barrier	Henderson–Massey Waitākere Ranges	Otara–Papatoetoe Māngere–Ōtāhuhu Franklin Manurewa Papakura Howick	Upper Harbour Kaipatiki Devonport–Takapuna Hibiscus and Bays Rodney
Public Hospital	Auckland	Waitākere	Middlemore	North Shore
District Health Board (approximate)	Auckland	Waitematā	Counties Manukau	Waitematā

Table 2: Annualised national incidence (per 100,000 people) of DRIs and dog bite injuries during 2014 to 2018 by age and ethnicity.

	Dog-related injuries per 100,000 people (95% CI)						Dog bite injuries per 100,000 people (95% CI)					
	ACC claims			Hospitalisations			ACC claims			Hospitalisations		
	Total	Māori	non-Māori	Total	Māori	non-Māori	Total	Māori	non-Māori	Total	Māori	non-Māori
All ages	479.7 (476.8,482.5)	468.7 (461.6,475.9)	481.7 (478.6,484.8)	15.3 (14.8, 15.8)	30.5 (28.6,32.3)	12.5 (12.0,13.0)	242.5 (240.4,244.5)	340.9 (334.8,347.0)	224.2 (222.1,226.4)	13.7 (13.2,14.1)	29.1 (27.4, 30.9)	10.8 (10.3,11.3)
0– 9	328.7 (322.2,335.2)	426.4 (412.0,440.9)	294.3 (287.2,301.5)	23.2 (21.5, 24.9)	41.6 (37.1,46.1)	16.8 (15.1,18.5)	255.8 (250.1,261.5)	359.2 (345.9,372.4)	219.5 (213.3,225.6)	22.0 (20.3,23.7)	39.3 (34.9, 43.7)	15.9 (14.3, 17.6)
10–14	298.5 (289.7,307.3)	372.3 (352.5,392.0)	274.4 (264.7,284.0)	10.6 (8.9, 12.2)	17.1 (12.9, 21.4)	8.5 (6.8, 10.2)	207.9 (200.6,215.2)	309.7 (291.7,327.7)	174.6 (166.9,182.3)	10.1 (8.4, 11.7)	16.9 (12.7, 21.1)	7.8 (6.2, 9.5)
≥15	556.7 (553.1,560.2)	497.7 (488.7,506.6)	566.3 (562.5,570.2)	15.4 (14.8, 16.0)	28.9 (26.7, 31.0)	13.2 (12.6, 13.8)	260.4 (257.9,262.8)	339.7 (332.3,347.1)	247.4 (244.8,249.9)	13.5 (12.9,14.0)	27.7 (25.6,29.8)	11.1 (10.6,11.7)

Table 3: Total national number of DRIs and dog bite injury during 2014 to 2018 by age and ethnicity.

	Dog-related injuries						Dog bite injuries					
	ACC claims			Hospitalisations			ACC claims			Hospitalisations		
	Total	Māori	non-Māori	Total	Māori	non-Māori	Total	Māori	non-Māori	Total	Māori	non-Māori
All ages	108,324	16,522	91,802	3,456	1,074	2,382	54,754	12,016	42,738	3,084	1,027	2,057
0–9	9,895	3,341	6,554	699	326	373	7,701	2,814	4,487	663	308	355
10–14	4,451	1,368	3,083	158	63	95	3,100	1,138	1,962	150	62	88
≥15	93,977	11,813	82,164	2,599	685	1,914	43,953	8,064	35,889	2,271	657	1,614

Table 4: Estimated annual incidence per 100,000 people dog bite injuries by Territorial Authority (ordered from highest to lowest all-age incidence of ACC claims).

	Dog bite injury ACC claims per 100,000 people (95% CI)			Hospitalisations (95% CI)	
Territorial Authority	**0–9 years**	**10–14 years**	**15 and over**	**All-ages**	**All-ages**
Ōpōtiki	561.2 (402.8–762.4)	713.0 (467.4–1045.0)	720.5 (635.1–814.2)	695.7 (621.6–776.4)	
Kawerau	546.4 (377.8–766.1)	726.2 (456–1102.0)	652.5 (559.2–756.9)	641 (560.3–730.3)	
Far North	541.3 (475.7–613.4)	329.9 (261.8–410.7)	505.8 (478–534.9)	497.7 (473.2–523.1)	5.85 (3.58–9.08)
Thames–Coromandel	484.6 (380–609.6)	540.5 (394.6–723.8)	389.8 (355.7–426.4)	407.6 (375.4–441.9)	
Rotorua	385.5 (334.9–441.7)	320.9 (258.0–394.9)	410.0 (386.3–434.8)	399.5 (378.9–421)	25.71 (20.77–31.49)
Whakatāne	323.6 (259.4–399.1)	493.9 (385.8–623.3)	396.2 (363.4–431.1)	393.1 (364.3–423.5)	38.84 (30.34–49.02)
South Waikato	459.5 (368.8–566.0)		378.6 (339.8–420.6)	380.2 (345.9–416.9)	
Whanganui	408.9 (340.0–487.9)	320.4 (238.9–421.3)	378.2 (350.3–407.7)	378.2 (353.2–404.6)	15.89 (11.24–21.86)
Gisborne	356.5 (299.2–421.6)	258.6 (192.8–340.0)	388.4 (360–418.5)	372.8 (348.5–398.4)	13.49 (9.33–18.91)
Wairoa	481.8 (335.2–672.0)		350.5 (289.2–421.1)	369.4 (313.9–431.9)	
Masterton	328.3 (247.8–427.2)	356.6 (245–502.7)	369.2 (332.8–408.5)	363.1 (330.6–397.9)	20.26 (13.40–29.47)
Kaipara	425.7 (328–545.3)	214.1 (124.4–345.3)	354.9 (316.7–396.5)	354.8 (320.4–392)	
Ruapehu	417.8 (302.6–563.4)	146.2 (59.26–304.1)	353.7 (302.9–410.6)	349.7 (305–399.3)	
Hurunui	369.2 (252–523.4)		359.6 (309.4–415.8)	347.4 (302.9–396.7)	
Taupo	357.2 (288.5–437.4)	279.8 (196.9–386.6)	349.1 (319.2–381)	345.5 (319–373.7)	
Whangārei	361.1 (315.6–411.3)	298.4 (241–365.4)	328.8 (309.8–348.6)	331.2 (314.3–348.9)	24.60 (20.22–29.65)
Central Otago	286.8 (200.7–398.1)	351.8 (223.6–528.5)	332.5 (295–373.6)	328.5 (294.4–365.4)	
Waitomo	360.6 (238.5–524.5)		345.0 (286.9–411.7)	325.9 (276.6–381.5)	
Mackenzie	403.7 (229.8–661.3)		275.8 (208.1–358.9)	318.6 (251.5–398.3)	

Table 4 (continued): Estimated annual incidence per 100,000 people dog bite injuries by Territorial Authority (ordered from highest to lowest all-age incidence of ACC claims).

	Dog bite injury ACC claims per 100,000 people (95% CI)			Hospitalisations (95% CI)	
Territorial Authority	**0–9 years**	**10–14 years**	**15 and over**	**All-ages**	**All-ages**
Buller	295.4 (177.9–463.4)	374.1 (196.7–650.3)	309.5 (259.1–367.0)	311.8 (265.5–363.8)	
Hastings	350.0 (304.0–401.2)	291.7 (234.8–358.5)	299.5 (280.5–319.4)	306.3 (289.3–324.0)	25.82 (21.14–31.25)
Central Hawke's Bay	335.1 (233.1–467.4)	284.2 (158.0–473.7)	290.2 (247.3–338.6)	296.2 (257.3–339.3)	
Napier City	336.5 (283.0–397.2)	212.7 (155.8–283.8)	294.4 (273.3–316.7)	294.5 (275.6–314.3)	
Porirua City	304.2 (256.2–358.6)	267.1 (203.7–344.3)	288.3 (265.9–312.1)	289.3 (269.6–310.0)	
South Wairarapa	331.0 (210.3–497.3)	161.3 (59.1–357.6)	288.0 (239.6–343.3)	285.5 (241.8–335.0)	
Auckland South East	333.0 (315.5–351.2)	301.2 (277.4–326.5)	261.9 (254.7–269.1)	276.1 (269.7–282.6)	31.64 (29.5–33.89)
Waikato	304.5 (260.7–353.5)	168.6 (126.1–221.0)	270.0 (250.9–290.1)	267.0 (250.3–284.4)	
Rangitīkei	243.5 (161.0–354.1)		276.8 (236.4–322.3)	265.3 (229.9–304.7)	
Hamilton City	286.1 (256.2–318.6)	223.1 (184.9–267.0)	256.3 (243.8–269.4)	258.5 (247.3–270.1)	50.66 (45.80–55.89)
Tauranga City	273.6 (240.4–310.2)	173.1 (137.1–215.8)	263.1 (249.3–277.4)	258.4 (246.2–271.1)	13.13 (10.54–16.17)
New Plymouth	276.9 (234.8–324.5)	215.8 (164.9–277.5)	257 (239.6–275.3)	256.9 (241.4–273.2)	12.81 (9.61–16.75)
Gore	246.8 (153.0–378.3)		267.6 (224.8–316.3)	256.3 (218.5–298.8)	
Grey	239.5 (152.2–359.8)		265.9 (224.9–312.3)	256.1 (219.8–296.7)	
Tararua	285.0 (202.7–390.3)	326.6 (207.6–490.8)	239.4 (204.8–278.3)	252.5 (220.8–287.4)	
Hauraki	201.9 (132.3–295.8)	285.3 (174.4–442.2)	256.8 (222.9–294.4)	251.9 (221.6–285.2)	
South Taranaki	240.7 (180.6–314.8)	149.3 (86.8–240.8)	257.3 (227.9–289.4)	246.8 (221.4–274.3)	
Westland	221.8 (116.6–385.5)		250.5 (202.1–307.1)	242.2 (198.7–292.5)	
Christchurch City	230.3 (210.5–251.6)	178.4 (154–205.7)	241.8 (233.9–249.8)	236.8 (229.7–244)	19.94 (17.95–22.10)

Table 4 (continued): Estimated annual incidence per 100,000 people dog bite injuries by Territorial Authority (ordered from highest to lowest all-age incidence of ACC claims).

	Dog bite injury ACC claims per 100,000 people (95% CI)			Hospitalisations (95% CI)	
Territorial Authority	**0–9 years**	**10–14 years**	**15 and over**	**All-ages**	**All-ages**
Nelson City Council	211.6 (163.6–269.5)	170.2 (113.6–245.9)	243.9 (223–266.2)	235.4 (216.8–255.2)	10.59 (7.07–15.30)
Marlborough	195.6 (148–253.8)	182.3 (119.5–267.1)	243.9 (222.4–267)	234.6 (215.4–255.1)	
Horowhenua	231.6 (170.9–307.1)	154.6 (91.54–245.8)	233.5 (208.3–260.9)	228.2 (205.6–252.5)	
Matamata–Piako	269.5 (208.4–343.2)	225.6 (150.5–325.8)	220.9 (196.6–247.3)	227.9 (205.8–251.8)	
Kāpiti Coast	237.5 (186.9–297.9)	155.5 (102.9–226.2)	224.6 (205.2–245.4)	221.8 (204.2–240.5)	
Southland	173.4 (124.5–235.5)	139.6 (81.13–225.1)	227.4 (201.5–255.8)	213.4 (191.1–237.6)	
Waitaki	216.1 (146.5–308.2)	101.1 (44.24–200.1)	221.0 (191.6–253.6)	212.7 (186.6–241.5)	
Auckland total	239.7 (230.4–249.2)	216.4 (203.7–229.6)	206.2 (202.6–209.8)	211.4 (208.2–214.7)	15.17 (14.31–16.07)
Auckland West	160.3 (139.5–183.2)	158.6 (128.3–194.1)	216.5 (205.3–228.2)	203.7 (194.1–213.6)	1.58 (0.88–2.63)
Timaru	195.7 (147.7–254.6)	126.7 (77.48–196.4)	211.9 (191.7–233.6)	203.7 (185.8–223)	
Auckland North	186.2 (169.1–204.5)	97.0 (83.86–116.6)	218.6 (211.2–226.3)	202.2 (195.9–208.7)	10.32 (8.95–11.85)
Western Bay of Plen	111.5 (80.95–158.9)	108.6 (66.39–168.3)	249.6 (226.9–274)	200.5 (183.3–219)	
Lower Hutt City	183.1 (153.7–216.5)	195.0 (152.0–246.5)	203.9 (190.3–218.1)	200.4 (188.4–212.9)	50.19 (44.3–56.63)
Clutha	204.4 (132.7–301.9)	133.5 (62.02–253.6)	218.0 (183.9–256.6)	195.9 (168.1–227.1)	
Ashburton	198.0 (146.2–262.6)	123.2 (68.51–205.3)	199.9 (176.6–225.4)	194.6 (174.1–217)	
Invercargill City	232.6 (185.9–287.6)	97.84 (58.9–153.5)	194.1 (176.1–213.4)	192.9 (176.7–210.1	13.91 (9.94–18.97)
Upper Hutt City	182.2 (137.1–237.7)	164.3 (106.7–242.6)	193.2 (173.1–214.9)	189.8 (172–209.1)	
Dunedin City	201.4 (168.9–238.3)	138.1 (102.6–182.1)	185.5 (174.1–197.5)	184.6 (174.1–195.5)	12.6 (10.02–15.64)

Table 4 (continued): Estimated annual incidence per 100,000 people dog bite injuries by Territorial Authority (ordered from highest to lowest all-age incidence of ACC claims).

	Dog bite injury ACC claims per 100,000 people (95% CI)			Hospitalisations (95% CI)	
Territorial Authority	**0–9 years**	**10–14 years**	**15 and over**	**All-ages**	**All-ages**
Waimate			198.4 (153.7–252.1)	184.3 (145–231.1)	
Carterton	125.6 (54.9–248.4)	102.4 (26.04–278.6)	194.0 (152.1–244.0)	179.3 (142.9–222.3)	
Tasman	149.0 (109.6–198.2)	78.0 (44.42–127.8)	181.4 (163.6–200.6)	170.2 (154.5–186.9)	
Queenstown–Lakes	204.1 (149.6–272.4)	169.0 (98.2–272.4)	156.3 (136.9–177.7)	162.7 (144.6–182.5)	
Ōtorohanga	157.9 (85.6–268.5)		154.7 (118.6–198.6)	162.6 (129.6–201.5)	
Stratford	162.5 (85.5–282.5)		192.7 (151.4–242.0)	153.0 (120.4–191.9)	
Waipa	136.5 (101.5–180.0)	81.2 (47.2–130.9)	153.4 (136.9–171.3)	145.8 (131.5–161.3)	
Auckland Central	185.9 (170.3–202.4)	164.4 (143.7–187.3)	138.7 (133.5–144)	145.6 (140.8–150.5)	5.72 (4.81–6.64)
Waimakariri	103.8 (73.8–142.1)	115.3 (74.86–170.3)	143.4 (128.3–159.7)	136.5 (123.2–150.7)	
Wellington City	115.6 (96.7–137.0)	80.1 (64.0–113.5)	118.1 (110.9–125.7)	116.0 (109.5–122.9)	7.37 (5.82–9.22)
Palmerston Nth City	75.6 (55.2–101.2)	75.3 (47.28–114.2)	111.8 (100.8–123.6)	104.6 (95.06–114.8)	16.91 (13.28–21.23)
Selwyn	86.3 (60.7–119.2)		96.8 (84.22–110.8)	94.5 (79.65–102.3)	

Note: Areas with populations of ≤5,000, and any categories with ≤10 dog bite injuries over the five years were not included.

Not the cause, for the cause: inflammatory bowel disease caused by etanercept

Lily Wu, Ricardo Jurawan

Anti-tumour necrosis factor-α (anti-TNF-α) therapy are effective treatments for various immune-driven conditions. Etanercept, an anti-TNF-α commonly used to treat rheumatoid arthritis, as well as other rheumatology and dermatology conditions, may be associated with an increased risk of new-onset inflammatory bowel disease (IBD).

A 68-year-old woman presented with a three-month history of diarrhoea, abdominal pain and weight loss. She has a background of rheumatoid arthritis treated with methotrexate, and etanercept was introduced six years ago. She also had a history of hypertension, and previous total abdominal hysterectomy and bilateral salpingo-oophorectomy were performed at another centre three years previously for presumed ovarian malignancy. The histology was benign.

She underwent ileocolonoscopy, which showed ulcerated mucosa in the terminal ileum and caecum. Her faecal calprotectin was elevated at 224mcg/g. Faecal pathogen testing was negative. She had not taken any non-steroidal anti-inflammatory medications within the past six months.

Whilst awaiting outpatient follow-up, she presented acutely with abdominal pain and ongoing diarrhoea. A CT abdomen showed extensive small bowel mural thickening. She was treated for inflammatory enteritis with intravenous hydrocortisone. Her symptoms of abdominal pain and chronic diarrhoea resolved within 24 hours. She was discharged on prednisone, and etanercept was stopped.

Four days later, she re-presented with epigastric pain and vomiting. CT abdomen showed small bowel obstruction. She proceeded to urgent laparotomy following failure of conservative management. Intraoperative findings were unexpectedly of extensive peritoneal nodules suspicious for malignancy, especially at the site of her previous gynaecological surgery, where small bowel was adhered. A small bowel to transverse colon bypass was performed. Histology of peritoneal nodules confirmed metastatic high-grade serous carcinoma of the ovary. She is being considered for palliative chemotherapy.

Discussion

This case serves to raise awareness of the increasingly recognised association of etanercept and new-onset IBD.

Etanercept is a TNF-receptor fusion protein, which unlike the monoclonal IgG1 antibodies, infliximab and adalimumab, does not fix complement or have antibody-dependent cytotoxicity on TNF-α bearing cells.[1] This has been postulated to contribute to its inefficacy in the treatment of Crohn's disease,[2] and furthermore, an increased risk of IBD.[3]

The onset of gastrointestinal symptoms can be days to many years after starting etanercept.[3] In a population-based Denmark study of 17,018 patients with autoimmune diseases other than IBD—with over 50% having rheumatoid arthritis—etanercept-exposed patients had a significantly increased risk of de novo IBD. No increased risk was observed in the infliximab or adalimumab groups.[4]

In an American study, 443 cases of etanercept-related IBD were reported to an adverse event system, where the reporting physician felt there was a direct relationship between the initiation of etanercept and the development of IBD.[5]

In a systematic review, 53 cases of new-onset IBD on etanercept therapy were found. The average time from etanercept introduction to IBD onset was 27 (+/- 24) months. Gastrointestinal (GI) symptoms improved in most patients after discontinuation of etanercept, the time to symptom relief ranged from days to 10 months.[6]

Individuals with IBD have an increased risk of autoimmune diseases,[7] and ankylosing spondylitis is known to be associated with IBD with an incidence of 5–10%.[8] Recurrence of IBD after etanercept reintroduction has also been observed.[9–10]

Physicians who prescribe etanercept therapy to patients who subsequently develop IBD should be aware of this association. Withdrawal of etanercept should be considered in addition to best practice management of new-onset IBD, and reporting to the national formulary for adverse reactions.

Figure 1: Endoscopic image of terminal ileitis with aphthous ulceration, erythema, granularity, friability.

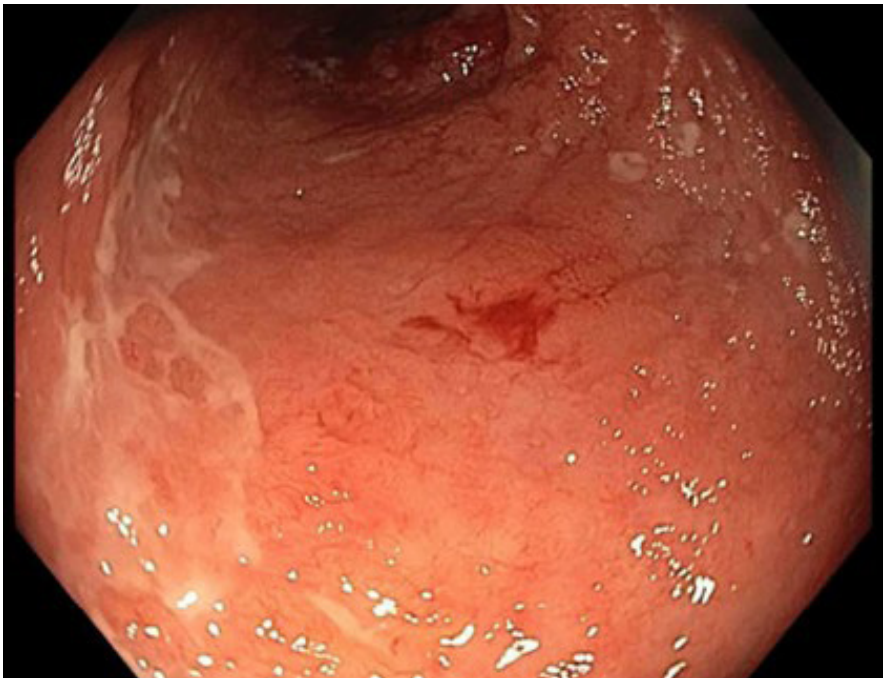
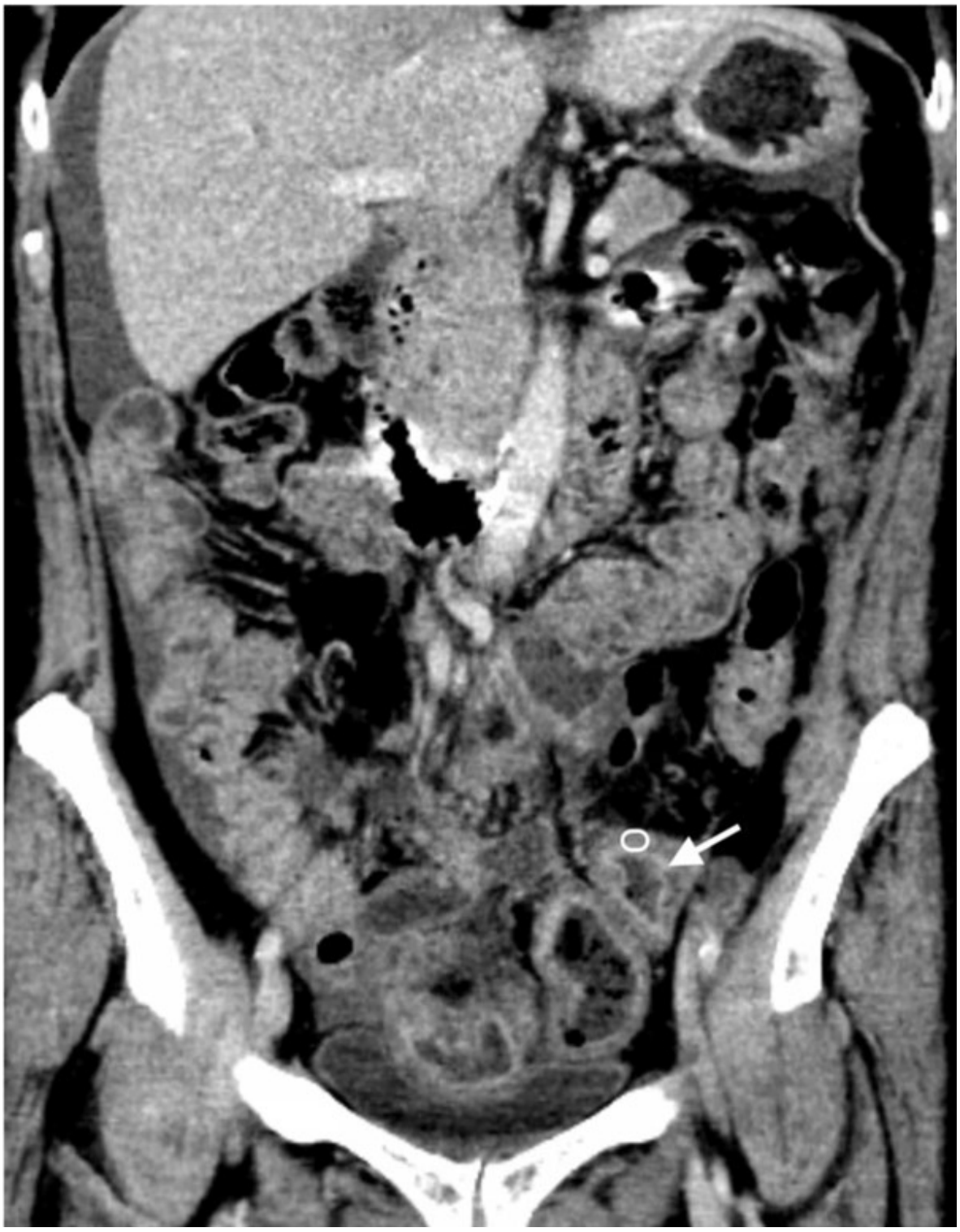


Figure 2: CT coronal image demonstrating mucosal hyperenhancement (arrow) and oedematous wall thickening (circle) of distal small bowel loop.



COMPETING INTERESTS
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REFERENCES
1. Haraoui B, Krelenbaum M. Emergence of Crohn's disease during treatment with the anti-tumor necrosis factor agent etanercept for ankylosing spondylitis: possible mechanisms of action. Semin Arthritis Rheum. 2009;39:176-181.
2. Sandborn WJ, Hanauer SB, Katz S, et al. Etanercept for active Crohn's disease: a randomized, double-blind, placebo-controlled trial. Gastroenterology. 2001;121:1088-1094.
3. Zou J, Rudwaleit M, Brandt J, et al. Up regulation of the production of tumour necrosis factor alpha and interferon gamma by T cells in ankylosing spondylitis during treatment with etanercept. Ann Rheum Dis. 2003;62:561-564.
4. Korzenik J, Larsen MD, Nielsen J, et al. Increased risk of developing Crohn's disease or ulcerative colitis in 17 018 patients while under treatment with anti-TNFα agents, particularly etanercept, for autoimmune diseases other than inflammatory bowel disease. Aliment Pharmacol Ther. 2019 Aug;50(3):289-294.
5. O'Toole A, Lucci M, Korzenik J. Inflammatory Bowel Disease Provoked by Etanercept: Report of 443 Possible Cases Combined from an IBD Referral Center and the FDA. Dig Dis Sci. 2016 Jun;61(6):1772-4.
6. Bieber A, Fawaz A, Novofastovski I, Mader R. Antitumor Necrosis Factor-α Therapy Associated with Inflammatory Bowel Disease: Three Cases and a Systematic Literature Review. J Rheumatol. 2017 Jul;44(7):1088-1095.
7. Wilson JC, Furlano RI, Jick SS, Meier CR. Inflammatory Bowel Disease and the Risk of Autoimmune Diseases. J Crohns Colitis. 2016 Feb;10(2):186-93.
8. Rudwaleit M, Baeten D. Ankylosing spondylitis and bowel disease. Best Pract Res Clin Rheumatol. 2006;20:451-471.
9. Song IH, Appel H, Haibel H, et al. New onset of Crohn's disease during treatment of active ankylosing spondylitis with etanercept. J Rheumatol. 2008;35:532-536. 132.
10. Ruemmele FM, Prieur AM, Talbotec C, et al. Development of Crohn disease during anti-TNF-alpha therapy in a child with juvenile idiopathic arthritis. J Pediatr Gastroenterol Nutr. 2004;39:203-206.

Establishing an acute admission unit for older people at a New Zealand hospital

Brent Hyslop, Nicky Baxter, Tori Booth, Minh Ha Nguyen

For older adults admitted acutely to hospital, it has been shown that admission to a dedicated unit for older people improves outcomes.[1–3] These outcomes include reduced inpatient complications (such as falls and delirium); better functional outcomes; and reductions in length of stay, residential care admission and cost. The role of these units, also called ACE (Acute Care of Elders) or acute geriatric units, is being increasingly recognised in Australasia.[4–6] This research letter describes the introduction and initial outcomes of such a unit at Dunedin Hospital. This may be of interest to other hospitals considering similar units and provides some New Zealand data for comparison.

A four-bed admission unit for older people was introduced at Dunedin Hospital in June 2019, named OPAL (Older Person's Assessment & Liaison). This number of beds was chosen for practical reasons, rather than modelling of demand. The unit used existing beds and resources from the Older People's Health (OPH) inpatient service. The unit was co-located on a 24-bed ward with an existing geriatric Assessment, Treatment and Rehabilitation (ATR) unit. The ATR unit reduced from 24 to 20 beds to provide four beds and staffing for OPAL. Historically, the ATR unit has admitted patients directly from the emergency department (ED), but for various reason this function had declined. The OPAL unit aimed to enhance this direct admission function for the OPH service, and to establish best practice acute hospital care for frail older people, within a dedicated physical space. OPAL staff were those with interest and skill in this area. OPAL medical and allied health staff also worked in the ATR unit, the co-location of which made this straightforward.

The overall approach taken was for patients admitted to OPAL to be either discharged home within about 48 hours or otherwise shifted to an ATR unit bed, under the care of the same medical team and allied health staff where possible. OPAL admission criteria were patients aged 75 years or older who were physiologically stable, and had either: fragility fracture for conservative management; functional impairment necessitating admission (after review by a supported discharge team where possible); or geriatrician recommendation. Patients were admitted to OPAL from ED or directly from a community setting.

One aim was to transfer patients from ED to OPAL as soon as they were identified as being for OPAL admission, and to then complete the medical admission process (clerking) in the OPAL unit rather than in ED. As clerking can take about an hour, and as patients can sometimes spend several hours in ED before being seen by the admitting team, transferring patients to OPAL for the admission process there would significantly reduce time spent in ED. A flow chart was developed to inform staff of the admission process. When beds were available in OPAL during working hours, prospective patients were proactively identified in ED by a geriatrician or geriatric medicine registrar.

Once in OPAL, an aim was for patients to have a comprehensive geriatric assessment as soon as practicable,[7] with early allied health input and care planning. An interdisciplinary admission document was developed. During initial weeks, allied health staff routinely attended OPAL during weekends; however, this was not able to be sustained due to employment contractual issues.

For quality assurance, an audit and outcome analysis were conducted in two phases; first for an 18-day trial period, then for the first 100 patients. An electronic data collection template was designed and used, with a focus on the admission process and length of stay. Over the trial period, relevant data were collected from paper and electronic clinical records following patient discharge. For the remainder of the first 100 patients, data were collected from the electronic clinical record retrospectively. Despite an attempt, a reliable figure on the number of patients fitting the inclusion criteria but not admitted to OPAL due to no occupancy was not collected. This audit was conducted

in line with the National Ethics Advisory Committee's National Ethical Standards for health and disability quality improvement, and data used were considered minimal risk by the University of Otago Human Ethics Committee (Health).

During the initial 18-days, 18 patients were admitted to OPAL. Seventeen out of eighteen patients came through ED; one came directly from their home. Fourteen out of seventeen admissions from ED had their medical admission (clerking) on OPAL (rather than in ED), thereby reducing the amount of time they spent in ED. A majority of patients had collaborative physiotherapy and occupational therapy reviews within four hours of OPAL admission (11/13 where time clearly documented). Nine patients in this trial period were seen by a geriatrician on the day of admission.

Demographic, admission and outcome data for the first 100 patients admitted to OPAL (including those from the trial period) are shown in Table 1. This covers a period between June and October 2019 (128 days).

These outcomes were considered promising and in keeping with the known benefit of ACE units. Almost half of patients admitted (47/100) were discharged directly from the OPAL unit, with mean LOS 3.6 days and all but one returning to their home. Given the high levels of comorbidity and the fact that OPAL patients generally had functional impairment preventing them being at home at the time they were admitted, this was considered a pleasing result (without having a clear comparison group). In addition, all patients received comprehensive geriatric assessment, a well-established and effective intervention not being widely delivered in acute settings at Dunedin Hospital.[7]

The other main group of patients, those admitted first to OPAL and then shifted to the ATR unit, had a total mean length of stay (LOS) of 13 days. This was compared to an approximated total mean LOS of 28 days for patients admitted first to another ward in the hospital and then transferred to ATR for "Reconditioning" (as per Australasian Rehabilitation Outcomes Centre (AROC) coding) (pre-ATR 12 days + ATR 16 days—based on Dunedin Hospital AROC 2018 and ATR May 2019 data). This comparison suggests significant efficiencies in LOS when older people requiring longer admissions with rehabilitation were initially admitted to OPAL rather than to other wards. While there are possible confounders, a similar magnitude of reduced LOS has been shown elsewhere in New Zealand and Australia, in particular at Middlemore Hospital (ACE unit + ATR = 17 days; other medical ward + ATR = 25 days).[6,9] Of note, this group of OPAL patients received early interdisciplinary input, minimising deconditioning and optimising functional recovery. They were also generally able to maintain continuity of care with the same team on the same ward throughout their hospital stay, thereby reducing intra-hospital transfers and associated delays.

Dedicated acute admission units with comprehensive geriatric assessment have been shown to improve outcomes for older people. Without additional resource, establishing a small unit at a New Zealand hospital was feasible, supporting the delivery of early comprehensive geriatric assessment and efficiencies in inpatient care. By facilitating direct admissions from the community (avoiding ED completely) and by clerking patients on OPAL rather than ED (allowing earlier transfer out of ED in many cases), the unit also reduced time spent by older people in ED, thereby improving patient flow and reducing risks related to being in emergency departments.[10] The unit continues to operate (following disruption due to the COVID-19 pandemic). Downsides included the unit's relatively small bed number, which anecdotally often precluded the admission of suitable patients. Reduced ATR capacity was also a concern, but it was justified by expected overall improvements in LOS and by recognition that a significant proportion of patients admitted to OPAL would, if initially admitted elsewhere, have later been transferred to ATR anyway. Expansion of the unit is considered, with a view to the New Dunedin Hospital.

Table 1: Demographic and admission data for the first 100 patients admitted to the OPAL unit, Dunedin Hospital.

Median age (years) [range]	**86 [69–100]**
Female gender	74%
Aged residential care resident	8%
Number of comorbidities listed ǂ	
Less than 5	17%
5–9	66%
Ten or more	17%
Documented cognitive impairment ǂ	47%
Admission source	
Direct from community	12%
From Emergency Department	88%
Time of admission ǂ	
Working hours	64%
Weekends	22%
Weekdays after hours	14%
Primary reason for hospital admission	
Fracture	15%
Functional impairment	68%
Medical problem	16%
Pre-procedural care	1%

ǂ As listed on the discharge summary for the OPAL admission.
ǂ Working hours are Monday–Friday, 8am to 4.29pm, Weekends are Friday 4.30pm to Monday 7.59am.
Outcomes for these 100 admissions to the OPAL unit were as follows:
47/100 patients discharged directly from OPAL, with a median length of stay (LOS) of three days (mean 3.6 days, range 1–13 days). 46/47 returned to their previous place of residence; one discharged to a more supported place of residence. For these patients discharged directly from OPAL, the 30-day unplanned readmission rate was 17% (8/47). Applying a general classification process,[8] four of these readmissions were considered "potentially preventable", while the other four were considered "anticipated but unpredictable hospital care" due to chronic health and care needs.
7/100 patients admitted to OPAL were transferred from OPAL to another ward or regional hospital for ongoing care.
The remainder (46/100) were transferred from OPAL to the adjacent ATR unit. These patients had a total mean LOS of 13 days (OPAL stay 3.3 days + ATR stay 9.7 days), range 4–28 days (one patient died as an inpatient). These patients generally remained under the care of the same medical team.

COMPETING INTERESTS
Nil.

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REFERENCES
1. Flood K, Booth K, Vickers J et al. Acute care for elders (ACE) team model of care: a clinical overview. Geriatrics. 2018;3(50). https://doi:10.3390/geriatrics3030050
2. Fox MT, Persaud MP, Maimets I et al. Effectiveness of acute geriatric unit care using acute care for elders components: a systematic review and meta-analysis. J Am Geriatr Soc. 2012;60:2237-2245.
3. Baztán JJ, Suárez-García FM, López-Arrieta J et al. Effectiveness of acute geriatric units on functional decline, living at home, and case fatality among older patients admitted to hospital for acute medical disorders: meta-analysis. BMJ. 2009;338:b50.
4. Mudge AM, Hubbard RE. Management of frail older people with acute illness. Intern Med J. 2019;49:28-33.
5. Australian and New Zealand Society for Geriatric Medicine. Position Statement 3: Geriatric Medicine services in and around general hospitals. Revised 2019.
6. Ko Awatea, Counties Manukau Health. Health System Improvement Guide: Acute Care for the Elderly (Version 7). 2015 [cited 2022 Mar 15]. Available from: https://koawatea.countiesmanukau.health.nz/assets/Ko-Awatea/Resources/Acute_Care_for_elderly.pdf
7. Ellis G, Garner M, Tsiachristas A et al. Comprehensive geriatric assessment for older adults admitted to hospital. Cochrane Database Syst Rev. 2017;9:CD006211.
8. Blunt I, Bardsley M, Grove A, Clarke A. Classifying emergency 30-day readmissions in England using routine hospital data 2004-2010: what is the scope for reduction? Emerg Med J. 2015;32(1):44-50.
9. Waitematā District Health Board, The National Institute for Health Innovation. Frail Elderly – Innovative Models of Care. [cited 2022 Mar 15]. Available from: https://i3.waitematadhb.govt.nz/assets/documents/our-work/research-innovation/innovation-library/Frail-Elderly-Innovative-Models-of-Care.pdf
10. McCabe JJ, Kennelly SP. Acute care of older patients in the emergency department: strategies to improve patient outcomes. Open Access Emerg Med. 2015;7:45-54.

Symptoms associated with colorectal cancer in patients referred to secondary care

Malgorzata Hirsz, Lyn Hunt, Michael Mayo, Lynne Chepulis

The recent introduction of population-based screening for colorectal cancer (CRC) in New Zealand has placed an additional demand on already scarce colonoscopy resources, in some circumstances leading to delays in investigation for the presence/absence of CRC.[1] Prioritisation for colonoscopy is therefore becoming increasingly important. One way to help secondary care specialists to select patients for colonoscopy is to identify symptoms (and other predictors such as demographics, co-morbidities and test results) associated with CRC within the referred population.

The importance of investigating the association between symptoms and CRC, based on data from the referred population, was emphasised by Hsiang and colleagues.[2] Until now, two such studies have been conducted in New Zealand; a cohort study based on data from Christchurch Hospital collected in 2010,[3] and a case-control study based on data from patients diagnosed with CRC in 2018 at Middlemore Hospital in Auckland which used referrals and consultation documents along with diagnosis information.[4] Both studies found iron deficiency anaemia and rectal bleeding to be independent predictors of CRC, while the Auckland study additionally reported palpable mass to be associated with CRC. However, both studies reviewed only small populations (38 and 177 CRC patients, respectively) and they were single-centre studies, hence there is a need to review these associations in patient cohorts from other New Zealand locations.

Here, we provide results of a retrospective cohort study for the association between CRC diagnosis and symptoms, using information stated in electronic referrals (e-referrals) made to the Gastroenterology and General Surgery departments of Waikato DHB between 1 January 2015 and 31 December 2017. Patients were included if the e-referral was followed by a full colonoscopy with visualisation of the caecum, and each patient referral had to specify at least one of the following: a symptom or test result associated with CRC; co-morbidities related to gastrointestinal tract; or a family history of CRC. Patients who had a history of pre-existing CRC or polyps stated in e-referrals were excluded. Registration with CRC in the New Zealand Cancer Registry (NZCR), ICD-10-AM codes C18-C20, from 1 January 2015 to 31 December 2017 was used to confirm/exclude CRC diagnosis.

An automated procedure made purposely for this study was used to extract relevant information from the free-text notes included in the e-referrals. Symptom selection was based on Jellema et al.[5] A detailed explanation of the methods for sample selection and symptom extraction is available elsewhere.[6]

We carried out multivariable logistic regression analysis to investigate which predictors, among all extracted variables, along with patients' gender and ethnicity (prioritised ethnicity categorised as Māori/non-Māori/unknown) were independent predictors of CRC in our cohort. The model was controlled for age (modelled as a continuous variable on a logarithmic scale). Backwards elimination based on the likelihood ratio test was implemented for the selection of statistically significant variables at the significance level of 5%. To assess if the model-predicted CRC risk was consistent with the observed frequencies of CRC, the models fit to the data was assessed using the Hosmer–Lemeshow test, where a p-value <0.05 would imply that model did not fit data well.[7] Data were analysed using R version 3.2.2.

The study was carried out under the approval by the New Zealand Health and Disability Ethics Committee number 17/417.

Data from 3,315 patients undergoing a colonoscopy with a median age of 64 years (IQR 52; 72) were analysed; 42% were male and 10% were Māori. Overall, 203 patients (6.1% of the study cohort) were diagnosed with CRC. The median age of those CRC patients was 70 years (IQR: 63.5; 79); 54% were male, 10.8% were Māori. The following predictors were included in the analysis: abdominal pain, perianal symptoms, bloating, change in bowel habits, constipation, diarrhoea, lack of

appetite, palpable mass (abdominal or rectal), rectal mucous, rectal bleeding, tiredness, weight loss, occult blood, anaemia, haemorrhoids, IBD, abnormal liver function and family history of CRC. The most often reported symptoms in patients diagnosed with CRC were anaemia (39.9%), rectal bleeding (36.0%), change in bowel habit (28.1%), and weight loss (13.8%), while in the non-CRC patients the prevalence of those symptoms were 16.3%, 29.4%, 33.6% and 9.3%, respectively.

The odds ratios (ORs) with 95% CIs from the final age-adjusted model are presented in Figure 1. There was no statistically significant disagreement between the observed and fitted values (p=0.35).

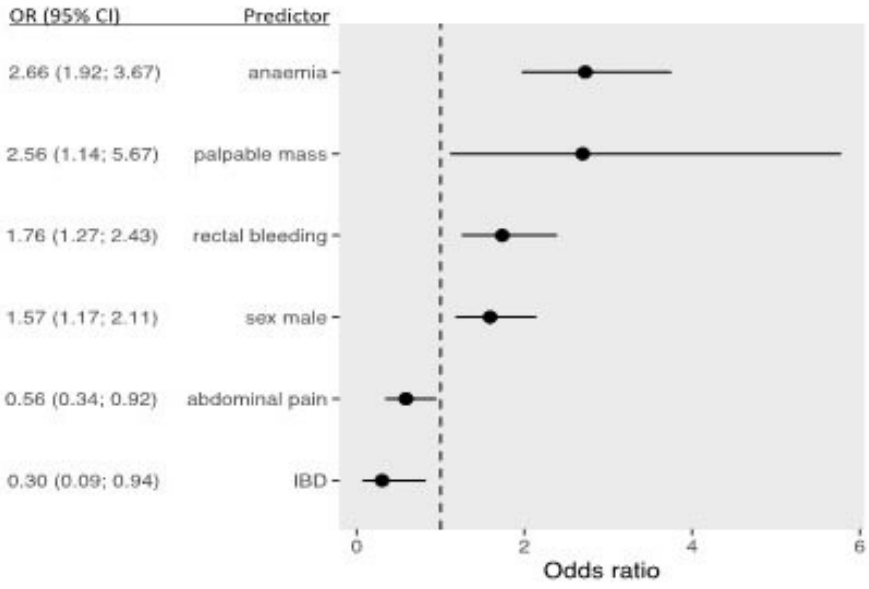
In our study, similarly to Sanders et al,[3] and Schauer et al,[4] anaemia and rectal bleeding were associated with CRC, despite the fact that we used different methodology to collect symptoms data compared to Schauer et al. With respect to palpable mass, Sanders et al did not find a statistically significant association, while our results differed from Schauer et al's result. In our study, the OR was much lower than the OR reported by Schauer et al [OR=6.71 (95% CI: 2.31, 19.54)]. However, due to the very wide confidence interval, the true association in both populations studied could in fact be very similar. Also, Schauer et al and Sanders et al both investigated specifically iron deficiency anaemia, while our data did not provide the distinction between different types of anaemia. This is a limitation of our study, caused by the use of e-referrals.

We did not have enough data to investigate interactions between symptoms and ethnicity; however, ethnicity itself was not associated with CRC in our cohort. Additionally, our results show that even after controlling for symptoms and age, males have much higher risk of CRC than females; yet in our study population, males were less likely than females to undergo colonoscopy.

The restriction of the sample used in the statistical analysis to patients with full colonoscopy affected the representativeness of the sample with respect to age. Younger patients were underrepresented in the study cohort, compared to those who satisfied inclusion criteria but did not get colonoscopy (median age 64 and 57 years, respectively). Additionally, our study may have inadvertently included patients who had pre-existing CRC or polyps. We cannot say what impact, if any, this could have on the estimated ORs.

The symptoms found in our study, as associated with CRC, agree with the findings by Schauer et al. This gives confidence in the appropriateness of using anaemia and rectal bleeding as factors for prioritisation of patients for urgent colonoscopy in New Zealand. Interestingly, in our study population, males were found to under-utilise the colonoscopy resources despite their high risk of CRC not only in the primary care population,[8] but also, as shown in this study, in the population referred to secondary care.

Figure 1: Age-adjusted ORs with 95% CIs based on the final model.



COMPETING INTERESTS
Nil.

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URL
www.nzma.org.nz/journal-articles/symptoms-associated-with-colorectal-cancer-in-patients-referred-to-secondary-care

REFERENCES
1. Bagshaw P, Cox B. Adequacy of publicly funded colonoscopy services in New Zealand. NZ Med J. 2020;133:7-11.
2. Hsiang JC, Bai W, Lal D. Symptom presentations and other characteristics of colorectal cancer patients and the diagnostic performance of the Auckland Regional Grading Criteria for Suspected Colorectal Cancer in the South Auckland population. NZ Med J. 2013;126:95-107.
3. Sanders AD, Stevenson C, Pearson J, Burt M, McGeoch G, Hudson B, Eglinton TW. A novel pathway for investigation of colorectal symptoms with colonoscopy or computed tomography colonography. The NZ Med J. (Online). 2013;126(1382).
4. Schauer C, Wijesinghe U, Wang M, et al. Improving efficiency of current diagnostic pathways for investigation of colorectal cancer in symptomatic patients. NZ Med J. 2021;134:123-125.
5. Jellema P, Van der Windt DA, Bruinvels DJ, et al. Value of symptoms and additional diagnostic tests for colorectal cancer in primary care: systematic review and meta-analysis. Bmj. 2010;340.
6. Hirsz, M. Epidemiological evidence that can help to improve timely diagnosis of colorectal cancer in New Zealand. Doctoral dissertation, The University of Waikato. 2021. Retrieved from https://hdl.handle.net/10289/14593
7. Hosmer Jr DW, Lemeshow S, Sturdivant RX. Applied logistic regression. John Wiley & Sons; 2013.
8. Lawrenson R, Logie J, Marks C. Risk of colorectal cancer in general practice patients presenting with rectal bleeding, change in bowel habit or anaemia. Eur J Cancer Care. 2006;15:267-271.

General Practitioners in leadership and governance

Ben Gray

Stolarek et al's editorial on leadership and governance[1] applies the Cynefin framework of complex systems to health provision and governance. I think they rightly identify that "most clinical specialty-level work functions predominantly in the complicated domain, whereas organisational and national system-level challenges… sit in complexity." They go on to argue that these clinicians, used to working in the complicated domain, may not be well suited to managing these system-level complexities. What this comment ignores is the "specialty" of General Practice. As argued in my paper on the Cynefin Framework,[2] General Practitioners work predominantly in complexity. There is a strong argument that if we are looking for clinicians to take roles in system level governance, General Practitioners may be well suited to contribute to this challenge.

COMPETING INTERESTS
Nil.

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URL
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REFERENCES
1. Stolarek I, McHardy K, McCann L, et al. Leadership and governance—what is needed to deliver the Aotearoa New Zealand health reforms. New Zealand Medical Journal. 2022;135(1553): 7-9.
2. Gray B. The Cynefin framework: applying an understanding of complexity to medicine. Journal of Primary Health Care. 2017;9(4):258-61.

Response to Letter: General Practitioners in leadership and governance

Iwona Stolarek, Karina McHardy, Lloyd McCann, Andrew Simpson, Grant Howard, John Robson

The authors would like to thank Dr Gray for his response to our editorial, and we acknowledge that leaders and governors may come forward from all specialties. What is important is that as they transition to system-level roles we support, and ensure that they have, or attain, the appropriate skills and expertise.

COMPETING INTERESTS
Nil.

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An Adequate Medical Service *[extract]*

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The General Practitioner is the foundation of the medical service of a country. It is he who can best help the progress of preventive medicine by the early diagnosis and treatment of disease. His work is all the better for healthy rivalry with his neighbours. Any form of compulsory national service, whether it is of the nature of the insurance scheme adopted in Great Britain, or like that proposed by a former Minister of Public Health, who wished to bring the whole profession under his control, would give satisfaction neither to the public nor to the doctor.

Sir John Tweedy wrote: "Any change, whether effected form within or imposed from without, that restrains the liberty or lessens the responsibility of a medical man or hampers the free play of his intellectual activities, will be detrimental to the authority and usefulness of medicine, and prejudicial to the interests of public health and national welfare."

It is generally recognised that the standard of medical practitioners and of nurses in New Zealand is a high one. This standard is likely maintained by the Registration Acts administered by the Medical Board. In the future, with the great increase of medical students at the Otago Medical School, this Dominion is likely to rely for its supply of doctors mainly on this school. Supervision of medical education should be in the hands of the Medical Board. It would probably be of great advantage to the Medical School if the State took over the Dunedin Hospital for teaching purposes, appointed a Director of the School to control the clinical teaching, and to have a seat in the University Council. Although the cost of medical education is already heavy, it is impossible to carry on the school by the fees paid by students, for these fees amounted last year to only one-fourth of the expenditure of the school. Accommodation is inadequate, facilities for clinical teaching are inadequate, and so are some of the salaries. Let the State take over the school and rectify these defects.

Unfortunately, it was recently decided to add a sixth year to the medical course. But unless this is made a clinical year, the students' time will, to a certain extent, be wasted. There is a great tendency to teach medical, as well as other students, too much. "It is far better," says Sir James Mackenzie, "to be trained to understand a few matters thoroughly than to have a superficial knowledge of a great many things."

Sir Charters Symonds, in his recent Hungarian Oration, says that Astley Cooper recognised the evil effects of too much teaching, and inculcated, in his students, personal observation of the processes of nature. Discussing modern medical education, he says that it is clear to everyone that the curriculum is overloaded. He proposes to reduce the time spent on the preliminary sciences, and to cut out at least one-third of anatomy, which he thinks might be done without the omission of anything essential and without diminishing the educative value of the subject. There is no doubt the Otago Medical curriculum should be revised, and that could be done by nobody better than the Medical Board which comprises general practitioners well qualified to judge the education from the clinical and practical standpoints.

Why should not the students in their sixth year be distributed amongst the other three large hospitals in New Zealand, each one of which has more clinical material than Dunedin? Would this arrangement not be of benefit both to the students and to the hospitals? Moreover, it would help to relieve the congestion of students at the Dunedin Hospital. It would, of course, be necessary to appoint clinical teachers in each of the other hospitals.

To keep up the standard after registration every opportunity must be given to the general practitioner to keep abreast of the times. The public hospitals should be freely opened to him, and he should be encouraged to attend clinics such as those instituted during the past winter by the energetic secretary of the local branch of the British Medical Association.

To get the best results there must be co-operation and harmony between the general practitioner and the departmental officers. The appointment on the Medical Board of representative members of the British Medical Association, which comprises most of the general practitioners, was the first official recognition ere of the British Medical Association, and was a favourable omen for the future good relations between its members and the Health Department.

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