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All the cancer we cannot see

Clinical quality indicators of pathways to oncological lung surgery

The impact of COVID-19 on lung cancer detection, diagnosis and treatment for Māori in Aotearoa New Zealand

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Clinical quality indicators of pathways to oncological lung surgery

Sally Harrison, Michelle Kim

One aspect of lung cancer management is surgical resection. Surgical management of lung cancer in the Southern DHB (comprising Otago and Southland patients) does not always meet national and international targets of care. In particular, Māori patients and those with significant socio-economic deprivation are less likely to receive timely care.

The impact of COVID-19 on lung cancer detection, diagnosis and treatment for Māori in Aotearoa New Zealand

Jason K Gurney, Alex Dunn, Michelle Liu, Michelle Mako, Elinor Millar, Myra Ruka, Sue Crengle, Paul Dawkins, Christopher Jackson, George Laking, Diana Sarfati

Te Aho o Te Kahu – Cancer Control Agency has been monitoring the impact of COVID-19 on access to cancer services since the start of the pandemic. New Zealand has largely avoided the substantial impacts on cancer services witnessed in other countries, and there has been little evidence that the pandemic has disproportionately impacted access to cancer services for Māori relative to non-Māori. However, in this Te Aho o Te Kahu-led investigation, we show that rates of lung cancer registration reduced for Māori (but not non-Māori/non-Pacific) New Zealanders in 2020 compared to 2018 and 2019. There was no discernible shift in the distribution of stage at diagnosis over this period. We also found a trend toward a reduction in rates of bronchoscopy for both Māori and non-Māori/non-Pacific patients, with the largest reduction observed for Māori.

Early diagnosis of surgically curable lung cancer is commonly serendipitous

Damian Gimpel, Andrew Pan, Venughanan Manikavasagar, Chunuan Lao, Leonie Brown, David J McCormack, Zaw Lin, Felicity Meikle, Paul Conaglen, Doug Stephenson, Ross Lawrenson, Adam El-Gamel

Lung cancer is the largest cause of cancer death in New Zealand, accounting for 18.3% of cancer-related deaths.There is limited literature on how patients with lung cancer clinically present in New Zealand. The aim of this cohort study was to identify the rate of incidentally diagnosed lung cancer in the Midland Region, the common symptomatology and route of diagnosis. This retrospective cohort study included patients with lung cancer who underwent potentially curative thoracic surgery between January 2011 to June 2018 at Waikato Hospital, New Zealand. Symptoms or signs recorded were cough, dyspnoea, haemoptysis, lymphadenopathy, chest pain, hoarseness, fatigue, weight loss and finger clubbing. The lung cancer cases were grouped into incidental finding, symptomatic general practitioner, symptomatic emergency department and surveillance.

Acute respiratory infection risk associated with exposure to outdoor PM_{10} emissions from domestic heating

Vanessa Hammond, Sierra Alef-Defoe

This study investigated whether Winter woodsmoke pollution at levels encountered in a mid-size Otago town was associated with GP visits for acute respiratory infection during May through August 2014–2018. An analysis of 812 GP visits found that acute respiratory infection risk increased with increasing woodsmoke pollution, accounting for air temperature effects. Further, areas with a higher density of woodburners per hectare had higher rates of GP visits for acute respiratory infections. Woodsmoke pollution can be reduced by residents burning only dry wood and keeping their fire hot (not smouldering).

"There is a huge need, and it's growing endlessly": perspectives of mental health service providers to ethnicChinese in Aotearoa New Zealand

Denzel W K Chung, Katherine H Hall, Jing-Bao Nie, Chrystal Jaye

Mental health providers were interviewed about their experiences providing mental health care to ethnic Chinese in Aotearoa, their opinions about their patients' experiences and their suggestions to improve the system. They highlighted stigmatisation and a lack of appropriate services as key reasons behind ethnic Chinese delaying help-seeking, often until a late-stage "breaking point". Providers often said they felt "ignored," with long-standing concerns around ethnic Chinese mental health, workload concerns and the financial sustainability of service providers not taken seriously. Decisive Government leadership and deeper collaboration between non-Government organisations will be key to improving mental health service accessibility and outcomes.

Expansion and consolidation of fracture liaison service in New Zealand public healthcare setting – Waitematā District Health Board Experience

David D W Kim, Michelle Cowley, Julia Spinley, Min Yee Seow, Rick Cutfield

Fracture liaison service is an effective systematic programme to identify patients who has broken a bone and is at high risk of breaking more bones in the future. Waitematā District Health Board's Fracture Liaison Service was able to grow and mature its service over the past several years to a level where the majority of the Region's patients who suffer a broken bone as a result of low/no trauma will be identified, assessed and treated appropriately to minimise the risk of future broken bones.

Barriers to optimal stroke service care and solutions: a qualitative study engaging people with stroke and their whānau

Matire Harwood, Anna Ranta, Stephanie Thompson, Syrah Ranta, Karen Brewer, John Gommans, Alan Davis, P Alan Barber, Marine Corbin, John Fink, Harry McNaughton, Virginia Abernethy, Jackie Girvan, Valery Feigin, Andrew Wilson, Dominique Cadilhac, Hayley Dennison, Joosup Kim, William Levack, Jeroen Douwes.

The aim of this study was to explore the perspectives of people with stroke and their whānau on barriers to accessing best practice care across Aotearoa, and to brainstorm potential solutions. We conducted ten focus groups nationwide with people of different ages, gender and ethnicities. There were five themes: (1) inconsistencies in stroke care; (2) importance of effective communication; (3) the role of whānau support; (4) the need for more sperson-centered processes; and (5) experienced inequities. Participants also identified potential solutions to these issues. We will advocate for and support the implementation of these solutions.

Hospital based specialists' perspectives of teleconsultation use during the COVID-19 pandemic

Eunice Chou, Andrew McCombie, Tim Eglinton

The purpose of this study is to investigate the safety and limitations of teleconsultations (Telehealth) in different specialties and the possibility of incorporating this into future practice. Teleconsultation is used widely across many specialties during the COVID-19 pandemic. This study found that despite the shortcomings found in teleconsultations and preference for physical consultations, doctors are prepared to provide teleconsultations in the future beyond the pandemic. In appropriately selected patients, especially in specialties that do not involved procedures, teleconsultation will have an increasing role in healthcare.

Delayed diagnosis of HIV infection in women in the Auckland and Northland regions

Judy Gilmour, Rebecca Henley, Michele Lowe, Simon Briggs

We looked back at women diagnosed with HIV infection between 2011 and 2021 under the care of the Infectious Disease Unit at Auckland City Hospital. Fifty-six women were diagnosed during this period. The diagnosis was often made late when the woman presented with complications of an impaired immune system. A third of the women who were living in New Zealand before their diagnosis had opportunities to be diagnosed earlier that were missed. This demonstrates that there are inadequate levels of HIV testing for women in the Auckland and Northland regions.

All the cancer you cannot see

Lutz Beckert, George Laking

Lung cancer is the leading cause of cancer death in New Zealand with 1,700 deaths each year. More New Zealanders die of lung cancer than of breast cancer, prostate cancer and melanoma combined. Between 2008–2017, lung cancer was diagnosed in 43:100,000 Māori and 13:100,000 non-Māori/non-Pacific New Zealanders; a number we need to keep in mind as we look at the information on lung cancer in this edition of the journal.[1] Since 2019, New Zealand has Te Aho o Te Kahu, the Cancer Control Agency, working with partners to prevent as many cancers as possible, ensure early detection and diagnosis, provide high-quality treatment and care, and identify and address inequities in cancer care and treatments.

Information, defined as data in context, is the engine of any decision. This edition of the *New Zealand Medical Journal* coincides with the start of Hauora Aotearoa, Health New Zealand. Hauora Aotearoa is poised to create a more equitable, accessible, cohesive and whānau-centred system, which will improve the health and wellbeing of all New Zealanders. Here we highlight data of four articles that illuminate different aspects of lung cancer—a cancer particularly difficult to see before it is too late.

Surgeons from Dunedin evaluate their multidisciplinary team meetings across seven years.[2] Sally Harrison and Michelle Kim review the 108 patients who received surgery with curative intent for lung cancer. They report milestones on the journey from referral to specialist service and cancer resection. They choose the endpoint of a successful operation to cure cancer as the entry criteria for this audit. That is a valid approach, gives unambiguous data, and is easily verifiable. It also excludes all the patients who did not make it to curative surgery. With this approach, we cannot tell whether those patients were excluded due to intrinsically incurable cancer, or due to failure of timely diagnosis.

Still, the authors can be congratulated on using the agreed Clinical Quality Indicators of the New Zealand Ministry of Health Faster Cancer Treatment as their audit tool. Applying the Standards of Service Provision for Lung Cancer Patients in New Zealand to the Dunedin cohort who made it to surgery shows that, across five indicators and seven years of data, the Standards were almost never met. Only in 2015 and 2016 did 95% of patients achieve a time of not more than 31 days from their GP referral to their first respiratory specialist appointment. What this means is that the system has failed to deliver what it set out to do. We value the authors' candour in revealing this information.

A trend of concern is that the number of patients who receive a CT-guided or Endobronchial Ultrasound (EBUS) biopsy has been reducing. A further trend of greater concern is the consistently inferior performance for the disadvantaged. Those who live rurally, have a higher deprivation index, or live outside the tertiary centre all have significant delays, and at times loss of the surgical curative option. These modifiable risk factors affect Māori more often than non-Māori. The authors reveal more delays in the treatment of Māori patients, lower performance against Standards for Māori, and a very low number of Māori receiving therapy with curative intent. The authors note that deficits in secondary care and diagnosis at late stage, due to reduced access to general practitioners, may contribute to the 3.5 times excess lung cancer mortality in Māori.

In summary, the Dunedin audit reveals failure of the lung cancer diagnostic system, even for those who were fortunate enough to have their cancer diagnosed and operated on. We strongly suspect these findings from the Southern DHB hold true across the country. We can only hope that the current health reforms, by shifting the focus of care into the community, are able to improve the performance of cancer diagnosis.

This edition contains a further report from surgeons in Hamilton.[3] Damian Gimpel and colleagues present data on the subset of patients who made it through cardiothoracic surgery with curative intent. Once again, that approach excludes those who never made it to surgery i.e., the cancer patient you cannot see. For the clinician, these data carry intriguing information: haemoptysis was a presenting problem in 20% of patients; almost half those who had an incidentally discovered lesion on CT scanning had a normal CXR; and, a growing number of patients come forward to curative surgery after CT surveillance.

In 39% of patients whose lung cancer was detected early enough to offer curative surgical treatment, the detection was incidental. This high rate of incidentally discovered cancer begs the question: what is the real prevalence of curable lung cancer in the community? How high is the number of patients with curable lung cancer, who we cannot see? The incidental can-

cer was not found through systematic screening. The lesions were found in patients who could afford to go to a GP without lung cancer symptoms, and who were offered a CXR or CT scan for some other indication.

The authors argue their data lends support to lung cancer screening. How can we assure in New Zealand that patients with the highest risk of curable lung cancer are being screened? At this stage in the New Zealand political landscape, the development of Hauora Aotearoa and a Māori Health Authority may provide a huge opportunity. We highlight here the importance of HRC-funded work by Sue Crengle and colleagues, who have taken on the challenge of exploring a screening service for patients and their whānau at the highest risk of lung cancer.[4]

In the context of getting services right for all New Zealanders, the viewpoint article on the impact of COVID-19 is important.[5] Jason Gurney and colleagues explore data on the impact of the COVID-19 protection framework on lung cancer diagnosis, diagnostic procedures and surgeries. As one would predict, all three markers fell during the lockdowns through 2020, taking until 2021 to recover. The authors make the important point that recovery of these services lagged in Māori compared to the non-Māori population. Although the numbers are small, and the confidence intervals overlapping, the message is important: a stressed system unmasks systemic racism, by revealing modifiable risk factors, that are adversely weighted towards Māori compared to non-Māori, non-Pacific.

The last paper on this subject in this edition of the *New Zealand Medical Journal* has a more empowering aspect.[6] Vanessa Hammond and Sierra Alef-Defoe explore the impact of outdoor exposure to emissions from domestic heating from wood burners on respiratory presentations in mid-sized New Zealand towns. They cite a study from Christchurch from the year 2000 that contributed to the council's decision to phase out wood burners. A bizarre aspect of phasing out wood burners in Christchurch was that many of these stoves were sold to residents in mid-sized towns. Ecologically and epidemiologically, such parochial problem solving does not make sense. The authors remind us that domestic heating is responsible for 94% of the town winter PM_{10} emissions i.e., 141kg are omitted on a typical winter night by domestic wood burners, 0.9kg from motor vehicles, and 1.1kg from industrial and commercial sources.

The authors are cautious in that they do not imply causation in their cross sectional study. They also address possible confounding. Even so, the observation that respiratory visits to the GPs are more frequent in the elderly, women and Māori actually reveals another modifiable risk factor. Air quality is a modifiable risk factor additional to the smoke-free aim, one that regional councils can improve together with their residents. Better air quality leads to improved respiratory health and reduced lung cancer risk factors in an equitable way for all air-breathing New Zealanders.

New Zealand has some catching up to do with regard to lung cancer survival. It is pivotal to have local data. We thank the editors of the *New Zealand Medical Journal* for publishing local audits and data relevant to tangata whenua of New Zealand. This information is relevant to the plans of Hauora Aotearoa. It might not have been accepted for publication by an international journal. It is great to see motivation of healthcare providers to get it right for all New Zealanders. Having local data, and the political will to refresh the New Zealand health service gives some optimism for the future.

COMPETING INTERESTS
Nil.

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Clinical quality indicators of pathways to oncological lung surgery

Sally Harrison, Michelle Kim

ABSTRACT

AIMS: Multidisciplinary team (MDT) meetings are a standard of care for lung cancer management in many regions around the world. Clinical quality indicators (CQIs) can be used to assess the proficiency of these multidisciplinary teams and compare their performance against those recommended by local and international guidelines. The effectiveness of the lung cancer MDT meeting at Dunedin Public Hospital has been evaluated using CQIs with a focus on the timeliness of surgical management.

METHODS: Medical records for all 108 patients who underwent curative intent oncological lung surgery at Dunedin Public Hospital between 2014–2020 were obtained. All patients were discussed at the lung cancer MDT meeting. Performance in six CQIs were evaluated as per the results below.

RESULTS: The CQI for timing of referral to first contact with a respiratory medicine specialist was met in all years studied by mean days. In all years bars for 2014 and 2017, the standard for time by mean days from referral date to surgery was met. In 2017, the mean time to surgery exceeded this standard by only one day. The mean time between respiratory specialist review and surgery was less than 56 days in all years except for 2014. By mean days, 2018 was the only year that surgery was performed within 31 days of discussion at the lung cancer MDT. Computed tomography (CT) guided biopsies and endobronchial ultrasound (EBUS) were only performed within a mean of seven days in only two years (2015 and 2017) out of the seven years of data. The target of all patients with curative small or non-small cell lung cancer receiving a positron emission tomography (PET) scan was not achieved in any year. Post-operative upstaging was more frequent than downstaging (19.4% vs 14.8%), and 71.4% of those upstaged received a PET scan pre-operatively. Māori patients and those with significant socio-economic deprivation were less likely to meet standards of lung cancer care.

CONCLUSIONS: Between 2014–2020, the standards for lung cancer management in surgical patients were frequently achieved as measured by mean days. However, a target of ≥95% (90% for CQI 2; 100% for CQI 6) of patients receiving care at the standard was rarely met. Timing of CT biopsy and EBUS was consistently longer than recommended, and pre-operative PET utilisation was less than 100%. Thus, there is still room for improvement in surgical lung cancer management in the Southern Health District.

Multidisciplinary team (MDT) input into cancer treatment aims to provide coordinated care to patients and improve their oncological outcomes as a result.[1] MDT meetings are a standard of care for lung cancer management in many regions around the world.[1] In New Zealand between 2014 and 2017, 9,093 patients were diagnosed with lung and tracheal malignancy.[2] At a regional level, the Southern District Health Board (SDHB) has a catchment of over 350,000 patients, covering the Otago and Southland regions. With the most recent data available, between 2014–2017, the SDHB treated a total of 603 public patients diagnosed with lung cancer.[3–6] Lung cancer MDT meetings are conducted once a week at Dunedin Public Hospital for all patients within the SDHB. Thoracic surgery is one of the key components of multidisciplinary care of lung cancer patients.[7] In the SDHB, Dunedin Public Hospital is the centre that performs thoracic surgery for those with thoracic malignancy. Both diagnostic biopsies and curative treatment of suspected or proven malignancy are offered.

Clinical quality indicators (CQIs) can be used to assess the effectiveness of multidisciplinary teams, and to analyse important outcomes in the oncological management of patients based on recommended standards.[8] CQIs have the capacity to drive quality improvement and can highlight steps in the patient's lung cancer treatment that could be enhanced. In 2012, the New Zealand Ministry of Health Faster Cancer treatment (NZMHFCT) indicators were implemented into the regional district health boards to ensure thorough collection of data pertaining to oncological management.[9] For patients with a confirmed cancer diagnosis, one indicator is whether they have their first cancer treatment within 31 days of the decision to treat.[9] Another recommendation is that those patients with a high suspicion of malignancy should be referred to hospital services and have their first treatment within 62 days

of the referral being received by the hospital.[9] The NZMHFCT indicators are generic guidelines for all cancer treatment.[9]

More specific for lung cancer is the Standards of Service Provision for Lung Cancer Patients in New Zealand (SSPLCPNZ) document.[7] The second edition of SSPLCPNZ (2016) outlines goals for MDT management. These include all patients (target of ≥95% of patients) seeing a respiratory medicine specialist within 14 days of referral from a general practitioner (GP) or other specialist, and all patients (target ≥95% of patients) commencing lung cancer treatment within 62 days of hospitals receiving a referral. The standard states that all patients should have prompt availability of computed tomography (CT) guided biopsy and endobronchial ultrasound (EBUS) services within seven days of referral (both target ≥95% of patients). All patients with suspected or confirmed small cell and non-small cell lung cancer who are potentially curative should undergo positron emission tomography (PET) scanning (target 100% of patients). The SSPLCPNZ references international guidelines including the British Thoracic Society (BTS) and Society for Cardiothoracic Surgery in Great Britain and Ireland Guidelines on the Radical Management of Patients with Lung Cancer 2010.[7]

Although the NZMHFCT and SSPLCPNZ documents give some guidance regarding timeframes for various steps in the lung cancer diagnostic and treatment pathways in New Zealand, they are not comprehensive. As a result, guidelines from the BTS can provide other benchmarks, as these have also been referred to in the SSPLCPNZ document.[7]

The purpose of this study was to use existing CQIs to evaluate lung cancer management in thoracic surgical patients in the Southern Health District.

Methods

Medical records for all patients who underwent curative intent oncological lung surgery consisting of wedge resection, lobectomy and pneumonectomy at Dunedin Public Hospital between 2014–2020 were obtained. Curative intent patients included those patients deemed to have radiologically staged disease of I or II with Eastern Cooperative Oncology Group (ECOG) performance status between 0–2. There were no exclusion criteria. Demographic data collected included age, sex, ethnicity, place of residence and New Zealand Index of Deprivation (NZDep) (reflecting socio-economic disparity).[10] Place of residence was categorised as either Dunedin and Greater Dunedin or outside of Dunedin, which included other large towns such as Invercargill. Oncological data included PET utilisation, CT biopsy and EBUS referral intervals, radiological staging, pathological staging and histology. Patients were discussed at the weekly lung cancer MDT meeting to decide on proposed investigation and treatment. MDT participants included respiratory physicians, cardiothoracic surgeons, radiation and medical oncologists, a radiologist specialising in lung pathology, a pathologist and a respiratory clinical nurse specialist.

The CQIs for this study included time from referral to first specialist appointment, time from referral to surgery, time from first respiratory specialist appointment to surgery, time from discussion at lung cancer MDT to surgery, timing of CT biopsy or EBUS if these were performed, and inclusion of PET staging. Time from referral to surgery included all referrals from both primary care and secondary care medical practitioners who were non-respiratory specialists. Concordance of radiological and pathological stage was also investigated. These CQIs were based on the SSPLCPNZ, NZMHFCT indicators and BTS Lung Cancer Guideline.[7,9,11] Justification for the inclusion of these particular CQIs are included in Table 1.

Statistics

The percentage of patients that met the prescribed timeframes for CQI 1–5 for each year was calculated. Mean days for each timeframe along the lung cancer pathway were also derived from cumulative patient data for each year studied. The rate of PET uptake was described as a percentage of surgical patients undergoing PET scanning in a certain year (CQI 6). IBM SPSS statistical software was used for analysis.

This study was exempt from review by the Southern Health and Disability Ethics Committee.

Results

A total of 108 patients underwent oncological thoracic surgery between 2014–2020 at Dunedin Public Hospital, with a mean age of 70.5 years and a relatively equal proportion of males and females (Table 2). In terms of ethnicity, 91 patients identified as New Zealand European (84.3%); 11 as Māori (10.2%); three as European (2.8%); one as Samoan (0.9%); one as Asian (0.9%); and one as Middle Eastern (0.9%). Seventy-one patients (65.7%) were from outside the greater Dune-

din area (defined as up to one hours' drive away from Dunedin). Eight Māori patients (7.4% of all patients) lived outside Dunedin. Regarding the NZDep Index, indices of 1–2 demonstrate low levels of deprivation and indices of 9–10 the highest levels of deprivation.[10] Fifty-three patients (49.1%) had a NZDep Index of 7–10, highlighting high levels of deprivation in the cohort.

The majority of procedures performed were lobectomies (80.6%). Fifty-eight patients (53.7%) did not have a histological diagnosis before their operation. In terms of final surgical histopathology, 66 patients (61.1%) had adenocarcinoma, 38 patients (35.2%) had squamous cell carcinoma, three patients (2.8%) had mixed adenosquamous histology, and one patient (0.9%) had small cell carcinoma. Final pathological staging showed that most patients who were operated on had carcinoma in situ, Stage I and II disease (n=81, 75%). Māori patients had similar frequencies of certain tumour pathologies as non-Māori. Twenty-six patients (24.1% of all patients) had a final staging of incurable disease (Stage IIIA and greater), with five Māori patients (45.5% of Stage IIIA and greater) with incurable disease.

A further breakdown of demographics is found in Table 2.

One hundred percent of patients in 2015 and 2016 were seen by a respiratory medicine specialist within 14 days of referral (Table 3). Apart from this, no other CQIs in any years reached the target percentage (≥95% for all CQIs except 2 and 6, 90% for CQI 2, 100% for CQI 6) of patients as per SSPLCPNZ, NZMHFCT and/or BTS guidelines. A breakdown of this data can be seen in Table 3.

The clinical quality indicator for timing of referral to first contact with a respiratory medicine specialist was met, in regards to mean days between these two timepoints in all years studied (Figure 1). In all years bars for 2014 and 2017, the standard for time from referral date to surgery was met based on mean days. In 2017, the mean time to surgery was only longer than this standard by one day. The mean days between respiratory specialist review and surgery was less than 56 days in all years, except for 2014. Based on mean days, 2018 was the only year in which patients were operated on within 31 days of discussion at the Lung cancer MDT. CT guided biopsies and EBUS were only performed within a mean of seven days in two years (2015 and 2017) out of the seven years of data. In no years did 100% of patients receive PETs pre-operatively, with the highest percentage of PETs performed being 88.2% in 2019 (Figure 1).

Standard demonstrated on graph is as follows (as per Table 1): referral date to respiratory outpatient department (OPD) – 14 days; referral date to OT – 62 days; respiratory OPD to OT – 56 days; lung cancer MDT to OT – 31 days; request date to EBUS/CT biopsy – seven days; PET performed – 100%.

Māori patients accounted for four out of the 17 patients (23.5%) who were classified as NZDep 9–10. Eight Māori patients (72.7% of Māori patients) lived outside of Dunedin. Forty-five-point-five percent of Māori patients had incurable disease at final staging compared to 24.1% of the total cohort. Regarding the ≥95% (90% for CQI 2, 100% for CQI6) percentage compliance targets, five patients (45.5% of all Māori patients) took more than 14 days from referral to first respiratory specialist appointment. From referral to surgery, six patients (54.5%) exceeded the proposed 62 days' timeframe. Regarding the time from first respiratory specialist appointment to surgery, again six patients (54.5%) were above the proposed 56-day interval. Six patients (54.5%) took longer than 31 days from the time of discussion at the lung cancer MDT to surgery. Thus, no CQI met the standard proposed for Māori patients. However, when Māori patients were excluded from the dataset, non-Māori patients also did not meet CQI targets in any years, except for CQI 1 in 2015 and 2016. For Māori patients, the mean number of days from referral to first respiratory specialist appointment was 30.3 days, from referral to surgery was 79.6 days, from first respiratory specialist appointment to surgery was 78.5 days, from discussion at lung cancer MDT to surgery was 47.6 days and from referral to CT biopsy or EBUS 8.7 days. When comparing to non-Māori patients, Māori patients had longer timeframes for all outcomes except for time from referral to CT biopsy or EBUS. Out of the six patients who had CT biopsies performed, it took four patients (66.7%) over one week for this to occur from referral. Six patients (54.5%) had PET scans performed pre-operatively, with a target of 100%.

In terms of patients with the highest deprivation indices (NZDep 9–10; 20 patients over all years), four patients (10% of all NZDep 9–10) took more than 14 days from referral to first respiratory specialist appointment and eight patients (40%) took longer than 62 days from referral to surgery. Regarding time from first respiratory specialist appointment to surgery, seven patients (35%) exceeded 56 days. Discussion at lung cancer MDT to surgery was longer than 31 days in 13 patients (65%). This is compared to those who

Table 1: Description of clinical quality indicators with justification for their use and recommended standards.

Clinical quality indicator (CQI)	Justification	Recommended standards
1. Time from referral to first respiratory specialist appointment	The probability of disease progression is decreased and there is the ability to expedite investigations if seen by specialists early. Reducing patient anxiety is prioritised with short outpatient review waiting times.[12]	14 days (SSPLCPNZ *[7])—target ≥95% of patients, 7 days—target ≥95% of patients (BTS#[11]). The NZ standard was used in this study.
2. Time from referral to surgery	Prevention of disease progression and potential curability of malignancy means timeliness of treatment is paramount. This can be achieved through prompt entry into the hospital healthcare system and subsequent appropriate referral to thoracic surgeons. For patients without a histological diagnosis pre-operatively, surgery provides important information for further treatment decisions.[12]	62 days—target 90% of patients (NZMHFCT ^[9]), 62 days—target ≥95% of patients (BTS[11]).
3. Time from first respiratory specialist appointment to surgery	This CQI assesses the lung cancer workup pathway from the first point of entry into the hospital system to definitive management.[11]	56 days—target ≥95% of patients (BTS[11]). There is no New Zealand guideline for this treatment interval.
4. Time from discussion at lung cancer MDT to surgery	There should be swift surgical evaluation and scheduling after discussion at the lung cancer MDT. This CQI allows prioritisation of oncological procedures over other cardiothoracic work.[13]	31 days- target ≥95% of patients (NZMHFCT [9])—please note this is a generic decision-to-treat to treatment timeframe, with the lung cancer MDT used as the timepoint for decision-to-treat. 30 days—target ≥95% of patients (BTS[11]).
5. Timing of CT guided biopsy or EBUS	Reduced time between referral and CT guided biopsy or EBUS helps facilitate a faster diagnosis and thus management decision.[14]	7 days from referral—target ≥95% of patients (SSPLCPNZ [7]).
6. Inclusion of PET staging	PET is able to better appraise indeterminate pulmonary lesions compared to CT modality. It can also evaluate the patient's nodal status. PET is an adjunct to CT in demonstrating metastatic spread.[15,16]	All patients (target 100%) who have curative small cell lung cancer or non-small cell lung cancer (SSPLCPNZ [7]).

* SSPLCPNZ = Standards of Service Provision for Lung Cancer Patients in New Zealand.
^ NZMHFCT = New Zealand Ministry of Health Faster Cancer treatment indicators.
#BTS= British Thoracic Society Lung Cancer Guideline

Table 2: Demographics of oncological thoracic surgery patients.

Demographics	
Mean age (years)	**70.5**
	n (%)
Male sex	56 (51.9)
Ethnicity	
NZ European	91 (84.3)
Maori	11 (10.2)
Samoan	1 (0.9)
Other European	3 (2.8)
Asian	1 (0.9)
Middle Eastern	1 (0.9)
Locality	
Dunedin and Greater Dunedin	37 (34.3)
Outside Dunedin	71 (65.7)
NZ Deprivation Score	
1-2	15 (13.9)
3–4	23 (21.3)
5-6	17 (15.7)
7-8	33 (30.6)
9–10	20 (18.5)
Procedure	
Wedge resection	20 (18.5)
Lobectomy	87 (80.6)
Pneumonectomy	1 (9.3)
Tumour pathology	
Adenocarcinoma	66 (61.1)
Squamous cell	38 (35.2)
Mixed adenosquamous	3 (2.8)
Small cell carcinoma	**1 (0.9)**
TNM pathological staging	
Carcinoma in situ	2 (1.9)
IA	32 (29.6)

Table 2 (continued): Demographics of oncological thoracic surgery patients.

Demographics	
Mean age (years)	**70.5**
IB	19 (17.6)
IIA	13 (12.0)
IIB	15 (13.9)
IIIA	18 (16.7)
IIIB	1 (0.9)
IV	7 (6.5)

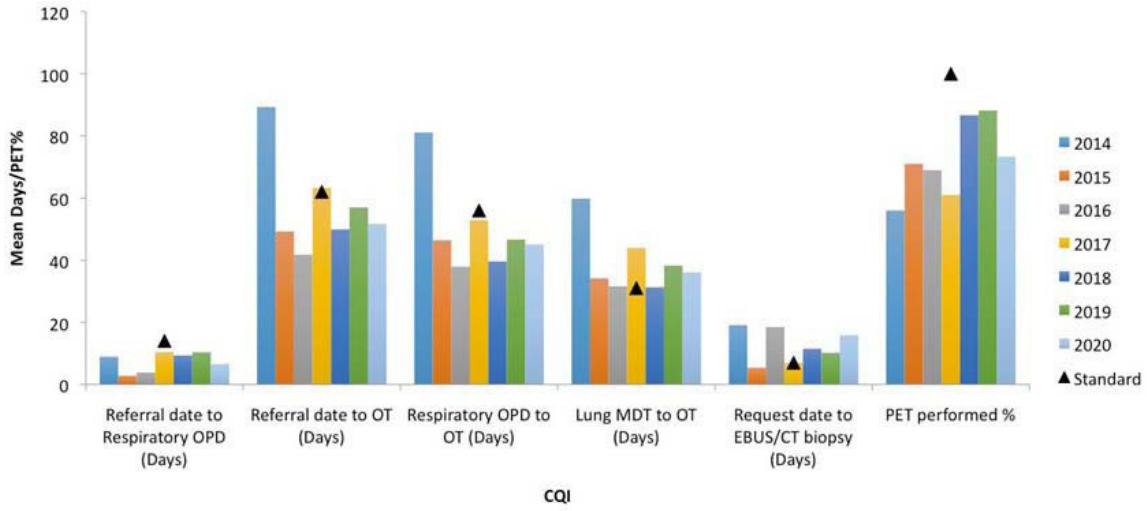
Table 3: Percentage of patients within or outside CQI timeframe per year.

Clinical quality indicator (CQI)	**Year**	**Total number of patients (n)**	**Number of patients within CQI timeframe (%)**	**Number of patients outside CQI timeframe (%)**
1. Time from referral to first respiratory specialist appointment	2014	16	12 (75.0)	4 (25.0)
	2015	14	14 (100)	0
	2016	13	13 (100)	0
	2017	18	11 (61.1)	7 (38.9)
	2018	15	12 (80.0)	3 (20.0)
	2019	17	12 (70.6)	5 (29.4)
	2020	15	12 (80.0)	3 (20.0)
2. Time from referral to surgery	2014	16	7 (43.8)	9 (56.2)
	2015	14	9 (64.3)	5 (35.7)
	2016	13	11 (84.6)	2 (15.4)
	2017	18	13 (72.2)	5 (27.8)
	2018	15	10 (66.7)	5 (33.3)
	2019	17	12 (70.6)	5 (29.4)
	2020	15	11 (73.3)	4 (26.7)
3. Time from first respiratory specialist appointment to surgery	2014	16	6 (37.5)	10 (62.5)
	2015	14	9 (64.3)	5 (35.7)
	2016	13	11 (84.6)	2 (15.4)
	2017	18	13 (72.2)	5 (27.8)
	2018	15	13 (86.7)	2 (13.3)
	2019	17	12 (70.6)	5 (29.4)
	2020	15	10 (66.7)	5 (33.3)

Table 3 (continued): Percentage of patients within or outside CQI timeframe per year.

Clinical quality indicator (CQI)	Year	Total number of patients (n)	Number of patients within CQI timeframe (%)	Number of patients outside CQI timeframe (%)
4. Time from discussion at lung cancer MDT to surgery	2014	16	3 (18.7)	13 (81.3)
	2015	14	6 (42.9)	8 (57.1)
	2016	13	10 (76.9)	3 (23.1)
	2017	18	11 (61.1)	7 (38.9)
	2018	15	9 (60.0)	6 (40.0)
	2019	17	8 (47.1)	9 (52.9)
	2020	15	8 (53.3)	7 (46.7)
5. Timing of CT guided biopsy or EBUS	2014	8	2 (25.0)	6 (75.0)
	2015	5	3 (60.0)	2 (40.0)
	2016	2	0	2 (100)
	2017	7	5 (71.4)	2 (28.6)
	2018	5	1 (20.0)	4 (80.0)
	2019	6	1 (16.7)	5 (83.3)
	2020	4	0	4 (100)

Figure 1: Six CQIs used to assess the surgical lung cancer management in the SDHB.



had the lowest deprivation indices (NZDep 1–2; 15 patients over all years) who had values of 17% (of all NZDep 1–2 patients), 13%, 17% and 47%, respectively, for the same CQIs. Cumulatively over all years, these patients' treatment did not meet the standards for referral date to surgery (mean 67.9 days vs 59.7 days for NZDep 1–2), first respiratory specialist appointment to surgery (mean 61.2 days versus 49.6 days for NZDep 1–2), lung cancer MDT to surgery (mean 45.4 days versus 40.5 days for NZDep 1–2) or request date to EBUS or CT biopsy (mean 11 days versus 4.8 days for NZDep 1–2). However, the mean days from referral to respiratory specialist appointment was 7.3 days (better than for the least deprived patients who had a mean of 10.1 days). Five patients (25%) had longer than one week between referral for CT biopsy and this being performed. The rate of PET scanning pre-operatively was 70% (compared to 80% for NZDep 1–2).

Overall, Māori patients and those with the highest deprivation indices were found to meet CQIs less frequently than the total cohort; however, due to the small number of patients making up these groups, a level of statistical significance cannot be calculated.

Comparison of radiological versus pathological staging in patients who underwent oncological surgery showed upstaging was more frequent than downstaging, with 21 patients (19.4%) over the seven-year study period being upstaged and 16 downstaged (14.8%). Fifteen (71.4%) patients who were upstaged had PETs performed pre-operatively. In hindsight, a total of nine patients (8.3%) with final N2 disease should not have been offered surgery within the seven-year study period. Of the patients who were upstaged, ten patients were upstaged on the basis of nodal status, but only eight patients received preoperative PET staging (80%).

Discussion

The purpose of this study was to determine whether the Southern DHB is meeting national standards for surgical lung cancer management. The six CQIs investigated were primarily derived from the SSPLCPNZ document, NZMHFCT indicators and the BTS Lung Cancer Guideline.[7,9,11] Both the BTS guideline and the SSPLCPNZ document are based on the National Institute for Health and Care Excellence (NICE), Welsh and Scottish National guidelines and the American National Cancer Care Network guideline. Thus, these standards allow comparison to other developed health care systems around the world.[7]

To summarise, except for CQI 1 in 2015 and 2016, no CQIs over any years reached the target of ≥95% (90% for CQI 2, 100% for CQI 6) of patients meeting SSPLCPNZ, NZMHFCT or BTS standards. The CQI for referral to first contact with a respiratory medicine specialist met the SSPLCPNZ standard in all years studied in terms of mean days; however, 31-, 56- and 62-day timeframes were not met in terms of mean days for all years. 2015 and 2017 were the only years in which CT guided biopsy and EBUS were performed within seven days of referral based on mean days. The target of all patients with curative small or non-small cell lung cancer pre-operatively receiving a PET was not reached in any year. Upstaging was more frequent than downstaging post-operatively (19.4% vs 14.8%), with 71.4% who were upstaged receiving a PET scan pre-operatively. Two patients did not have PET scans before their surgery, which may have ultimately changed their clinical course if this had demonstrated N2 disease.

Māori patients and those living outside Dunedin did not regularly meet SSPLCPNZ, NZMHFCT or BTS standards. There is no nationwide standard for provision of lung cancer treatment specific to Māori patients.

Previous research has demonstrated mortality rates up to 3.5 times higher in Māori patients with lung cancer compared to non-Māori patients.[17,18] Deficits in secondary care and diagnosis at late stage due to reduced access to general practitioners may have contributed to this disparity.18 Māori patients accounted for four out of the 17 NZDep indices of 9 and 10 (23.5%), which is disproportionate to their ethnic proportion of 11% in this study. A high proportion (72.7%) of Māori patients in this study lived outside Dunedin which may have also contributed to poor continuity of care and to later referrals to secondary services. Stevens et al found that Māori patients had a significantly longer time from diagnosis to treatment.[17] The current study has confirmed this finding with 54.5% of Māori patients exceeding the 56-day interval, as opposed to 29.4% for all patients over all years. Additionally, 54.5% of Māori patients exceeded the 31-day interval, again compared to 46.7% of all patients over all years.

Most patients were from outside of Dunedin in the current study, so this did not have a significant influence on outcomes. However, 18.5% of patients had the highest levels of deprivation based on NZ Deprivation scoring (9–10) and these patients had the longest waits from referral to surgery with a mean of 67.9 days. For example, 13

patients (65% of NZ Dep 9–10 patients) had more than 31 days between discussion at lung cancer MDT and surgery, showing that deprivation may be a barrier to expedited cancer care.

Clinical quality indicators are tools for local institutions to benchmark their lung cancer management against national and international standards.[8] As this study is the first New Zealand study of this type, the results can only be compared to international research.

Comparable statistics from other sources include those from two large audits. The UK National Lung Cancer Audit (NLCA) 2019/2020 found that for all patients undergoing lung cancer treatment (both surgical and nonsurgical), the median time to treatment was 28 days (2019) and 27 days (2020) nationally.19 The Victorian Lung Cancer Registry Annual Report for 2019 has numerous equivalent clinical quality indicators.20 The mean rate of PET uptake in patients undergoing resection of was 96% in this report, far higher than the current study. The proportion of patients with non-small cell lung cancer who underwent surgical resection and whose clinical stage was in agreement with pathological stage was 83%.20 In the current study, 19.4% of patients were upstaged and 14.8% downstaged (total 34.2%), with agreement of staging in only 65.8% of cases.

Furthermore, the Queensland Lung Quality Index 2011–2016 noted a median time from diagnosis to surgery of 30 days, with 46% of all patients having surgery within this time period.[21] This was benchmarked against a standard of 42 days as per the Cancer Council Australia's Optimal Care Pathway for lung cancer patients.[22] A surrogate marker in this study for diagnosis to surgery could be discussion at the lung cancer MDT to surgery, with a standard of 31 days. In this case, results ranged from 23.1–57.1% of patients reaching this target of the seven years, not dissimilar to the Queensland statistics. In terms of rural patients and those at socio-economic disadvantage, the Queensland data found that patients living outside a major city did not receive different care but those who were socio-economically disadvantaged did.[21] This mirrors the result of the current study. The Danish National Indicator Project has highlighted certain clinical quality indicators for lung cancer management.[23] Comparable to the current study is the time from referral to diagnosis of 28 days with the target of 85% of patients achieving this standard. Similarly, the waiting time for surgery (presumed from referral) should be 14 days, with a target of 85% of patients reaching this. In 2006, 69% of patients met the referral to diagnostic standard and 83% of patients met the waiting time until surgery standard with both results under the 85% standard.[23] This data demonstrates considerably better achievements of standards than the current study.

The West of Scotland Cancer Network Audit Report for Lung Quality Performance Indicators for 2019 included reviewing whether non-small cell lung cancer patients were undergoing pre-treatment PETs, with a target of 95% of patients receiving this.[24] They found that all districts achieved this target and thus far greater rates of PET scanning compared to the Southern DHB.[24] Similarly, other UK studies have mostly achieved critical timeframes along the treatment pathway based on BTS guidelines. A 2007 study from the South Manchester University Hospital had a mean of 3.8 days for GP referral to first respiratory specialist appointment (standard of 14 days).[25] Additionally, a mean of 53.8 days from GP referral to decision to treat (a surrogate for lung cancer MDT; standard of 31 days) and a mean of 75.5 days from GP referral to definitive treatment (standard of 62 days) were demonstrated.[25] A 2002 study, again comparing to BTS guidelines, found that the median days from respiratory review to decision to operate (again a surrogate for lung cancer MDT) was 14 and from lung cancer MDT to operation was 17 days.[26] The median timeframe between first respiratory physician review and surgery was 24 days.[24]

The goal of CQIs is to identify areas that require improvement or further investigation. Apart from time from referral to respiratory physician review, all CQIs have improved since 2014; however, benchmarks were not always met. The time between respiratory specialist review and surgery has been standardised at 56 days in the BTS guideline.[11] This was met in the most recent years of the study (2015–2020). This is interesting considering that this is not part of the New Zealand guideline, but that improvement has occurred despite this.

There have been multiple quality improvement strategies implemented by Southern DHB regarding lung cancer investigation and management.

The first engagement the patient has with the hospital healthcare system is the Fast Track respiratory clinic at Dunedin Hospital, which allows streamlined management for patients with suspected lung cancer. Respiratory physician assessment and bronchoscopy with potential for tissue biopsy is performed on the same day. The clinic relieves some of the responsibility of general prac-

titioners to commence what can be a complex investigatory pathway for lung cancer. It appears that this Fast Track clinic is facilitating timely review of patients as seen in the outcomes from 2014–2020.

The longer than 31-day interval between the lung cancer MDT meeting and surgery was potentially impacted by only having a fortnightly thoracic operating list at Dunedin Hospital. Additionally, the need for patient assessment in the Cardiothoracic Surgery outpatient clinic to quantify surgical risk and optimise the patient's condition prior to surgery may have lengthened this interval. In order to improve this outcome, in the last three years there has been more extensive evaluation via the Fast Track clinic (including full spirometric workup) before the patient's presentation at the lung cancer MDT meeting. Another quality improvement measure has been for patients who are on the surgical waiting list but are likely to breach the 31-day standard to be brought forward for surgery on lists that are usually used for cardiac surgery patients. This clinical reprioritisation had significantly reduced the thoracic oncological waiting list. Reassessment of this CQI should occur with data from 2021 onwards, to ensure that these measures have resulted in an ongoing improvement.

Accessing diagnostic services may have impacted the timeliness of management. This includes EBUS and PET scanning, which is only available at Christchurch Hospital for any public patients in the SDHB catchment. In 2020, the lengthening of time from referral to PET and CT guided biopsy dates was likely affected by the COVID-19 pandemic. Currently, PET scans are also being referred to the private sector to ensure there is adequate staging for all patients with curative potential and until more public PET facilities are available to the SDHB catchment.

As of 2021, a quality assurance committee has finally been established for patients undergoing lung cancer treatment under the Southern DHB. It is aimed at ensuring patients are receiving care in concordance with New Zealand Standards of Service Provision for lung cancer, including reduced timeframes between key points in their management. In order to address the issue of access to timely EBUS services, a business case has been developed to commence EBUS at Dunedin Hospital.

This study has limitations. There are relatively few cases that were analysed in this study—only 108 cases over seven years. Surgical resection is most likely to result in cure for patients with early-stage non-small cell cancer compared to other treatment modalities.[7] The low surgical treatment numbers in this study may be a reflection of cautious patient selection based on lung cancer MDT discussion where patients with higher ECOG scores may have been deemed as not surgically suitable. It has been shown that rates of surgical resection of non-small cell lung cancer in New Zealand is 14.1%, which is lower than other countries, including Australia (for example, the rate of resection in Victoria is 19.1%).[20] Quality of patient records is also likely to have impacted on the accuracy of this study, particularly regarding correct documentation of radiological staging. It must be noted that the clinical quality indicators are developed for all lung cancer patients, many of whom will not undergo surgery. Patients with early-stage lung cancer and those who were referred for surgery but subsequently were not operated on are not included in this study, and thus the results should be interpreted in this context. Finally, analysis of outcomes for Māori patients and those with socio-economic deprivation is challenging due to their small proportion of the studied cohort.

Conclusion

Between 2014–2020, the standards for lung cancer management in SDHB surgical patients was frequently achieved in terms of mean days. However, a target of ≥95% (90% for CQI 2; 100% for CQI 6) of patients receiving care at the standard was rarely met. Timing of CT biopsy and EBUS was consistently longer than recommended and pre-operative PET utilisation was less than 100%. Māori patients and those patients who were the most socio-economically deprived appear to have inequity of care compared to non-Māori patients and those who are not socio-economically deprived. Thus, there is still potential for improvement.

Guaranteeing equity of resource in regards to PET scans and EBUS will be important in the future. This is particularly true in Otago and Southland regions, as these regions have a greater proportion of patients over 60 years of age than the rest of New Zealand.[27] It is hoped that this important step in many patients' lung cancer management can be provided at a local level.

COMPETING INTERESTS
Nil.

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The impact of COVID-19 on lung cancer detection, diagnosis and treatment for Māori in Aotearoa New Zealand

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ABSTRACT

AIM: The purpose of this article is to examine disparities in the impact of the COVID-19 pandemic on access to lung cancer diagnosis and access to clinical services between Māori and non-Māori.

METHODS: Using national-level data, we examined age-standardised lung cancer registrations, diagnostic procedures (bronchoscopy) and lung surgeries separately by ethnic group for the years 2018–2020, as well as patterns of stage of diagnosis.

RESULTS: We found a trend toward a reduction in rates of lung cancer registration in Māori (but not non-Māori/non-Pacific) New Zealanders in 2020 compared to 2018 and 2019, but no apparent shift in the distribution of stage at diagnosis. We found a trend toward a reduction in rates of bronchoscopy for both Māori and non-Māori/non-Pacific patients, with the largest reduction observed for Māori. Rates of lung cancer surgery appeared to have reduced for Māori patients, although this was based on a small number of procedures.

CONCLUSIONS: We observed disparities between Māori and non-Māori/non-Pacific patients in lung cancer registration and bronchoscopy as a result of the COVID-19 pandemic.

Across the world, the impact of the COVID-19 pandemic on access to cancer diagnosis and subsequent clinical services has been profound. In regions with widespread community transmission of the disease, this impact endured throughout 2020 and into 2021, and has resulted in a significant backlog of under-diagnosed and under-treated disease in these regions.[1–6]

In countries like New Zealand that have pursued an elimination approach to COVID-19, the impact has to date been less intense and shorter-lasting, largely concentrated to those times of national or regional lockdown.[7–9] Early in the pandemic, New Zealand's national Cancer Control Agency, Te Aho o Te Kahu, engaged widely with clinicians, researchers and other stakeholders to plan the cancer-related response to the anticipated upheavals to usual healthcare provision caused by COVID-19. As noted elsewhere,[10,11] a focus on preventing exacerbation of inequity was a core element of this response, which included the ongoing monitoring of inequities in access to diagnosis, and partnership with Hei Āhuru Mōwai (National Māori Cancer Leadership Group) and other Māori researchers to develop an Equity Response Framework.[10] This framework aimed to identify the likely impact of the pandemic on existing inequities, and what actions could be taken to mitigate them. These actions, along with strong Māori-focused public health messaging from organisations such as Te Rōpū Whakakaupapa Urutā (the National Māori Pandemic Group), reduced the likelihood that the COVID-19 pandemic would have a differential impact on cancer diagnosis and treatment for Māori.

As part of ongoing monitoring across 2020, Te Aho o Te Kahu provided detailed analysis and reports and engaged with decision-makers to disseminate key findings. These reports outlined changes in cancer registration, diagnostic procedures and treatment (surgery, systemic therapy and radiation therapy).[12–17] These reports compared the occurrence of these events on a month-by-month basis across 2020 against the same period in 2018 and 2019, and presented results separately for the total population and for Māori. While the reduction in these events during the national lockdown of late March and April 2020 was dramatic—for example, cancer registrations dropped by more than 40% over this period compared to previous years[16]—these reports found little evidence of disparities in the magnitude of

these downturns between Māori and non-Māori patients. In other words, it appeared that the pandemic had impacted access to diagnosis and treatment in much the same way for Māori as for the rest of the population.

The sole exception to this absence of disparity was found in the diagnosis and treatment of lung cancer—by far the most common cause of cancer death for Māori.[18] As noted in one of the reports, the number of lung cancer registrations, bronchoscopies and surgeries appeared to have dropped more substantially for Māori patients than the rest of the population.[17] Disparities in the pandemic's impact on lung cancer registrations among Māori compared to the rest of the population is particularly concerning, since it may indicate that Māori patients with symptoms of lung cancer are experiencing greater delays to diagnosis than non-Māori patients, with subsequent ramifications on quality of life and survival.

However, because data were only available up until the end of October for the Te Aho o Te Kahu report,[17] and since that report only presented absolute numbers of cases compared to previous years, two key factors remain unclear: 1) whether disparities in the downturn of registrations (and related procedures) continued for the remainder of 2020, or were "correcting" toward the end of the year; and 2) whether expressing the numbers of events relative to their underlying ethnic-specific population, as well as adjusting rates for differences between Māori and non-Māori in terms of age, will impact our understanding of what happened regarding this disparity. In addition, it remains unclear whether delays to diagnosis during 2020 have resulted in an overall shift in the distribution of disease stage at diagnosis, and whether these changes have inequitably impacted Māori patients.

In this article, we examine age-standardised lung cancer registrations, diagnostic procedures (bronchoscopy) and surgical treatment separately by ethnic group for the years 2018–2020, and we express the number of these events relative to their ethnic-specific underlying population. We also examine patterns of stage of diagnosis by ethnic groups across these years, in order to assess whether the COVID-19 pandemic has resulted in a shift in stage distribution for Māori (and/or non-Māori) patients with lung cancer. We have focussed our comparisons to Māori and non-Māori/non-Pacific populations, to ensure adequate numbers of patients in our month-on-month stratified analyses.

Methods

Participants and data sources

Numerators

This study included three participant cohorts. Firstly, when assessing the impact of COVID-19 on lung cancer registrations, we extracted all those who were diagnosed with lung cancer (ICD code C34) on the New Zealand Cancer Registry (NZCR) between 1 January 2018 to 31 December 2020 (N = 6,679; 1,497 Māori, 5,182 non-Māori/non-Pacific). Secondly, when assessing the impact on access to bronchoscopy, we extracted data for all New Zealanders (irrespective of subsequent lung cancer status) who underwent a bronchoscopy over this same period from the National Non-Admitted Patient Collection (NNPAC; purchase unit code MS02003; N = 7,281; 1,143 Māori, 6,138 non-Māori/non-Pacific). Thirdly, when assessing the impact on lung cancer surgery, we extracted data for all New Zealanders who underwent a publicly-funded lung resection as an inpatient, and who had a diagnosis of cancer on the same admission, from the National Minimum Dataset (NMDS; see Appendix 1 for procedures and ICD codes; N = 1,030; 168 Māori, 862 non-Māori/non-Pacific).

Denominators

When describing rates of lung cancer registration, bronchoscopy and surgery, we used the ethnicity-stratified total estimated residential population of New Zealand for each of 2018, 2019 and 2020 as the denominator, with this data derived from Stats NZ.[19] When describing the distribution of stage of disease at diagnosis, we used the total number of patients diagnosed with lung cancer on the NZCR as the denominator.

Variables

For the purposes of age standardisation, patient *age* at either the time of diagnosis (in the case of lung cancer registration) or procedure (in the case of bronchoscopy and lung surgery) was defined using their date of birth and the data of diagnosis or procedure, respectively. Age was categorised as <50 years, 50–64, 65–74, and 75+. Patient *ethnicity* (Māori, Pacific or non-Māori/non-Pacific) was defined using prioritised ethnicity, as recorded on the NZCR (for registration), NNPAC (for bronchoscopy) or NMDS (for surgery). To prevent misinterpretation of data due to low numbers of diagnoses and procedures, Pacific data were not analysed for this manuscript. *Month and year* of diagnosis or procedure

were derived from the date of diagnosis or procedure from each respective dataset. *Stage of disease* was extracted for each lung cancer registration from the NZCR, and was defined according to the SEER staging system (Local, Regional, Advanced and Unstaged).

Statistical analysis

For our descriptive analysis, we described the number and rate of lung cancer registration, bronchoscopy and lung surgery. Crude and age-standardised rates were described per 100,000 Māori or non-Māori/non-Pacific New Zealanders, using the denominator data derived from Stats NZ. To adjust for differences between Māori and non-Māori/non-Pacific peoples in terms of population age structure, we used direct standardisation techniques to describe age-adjusted rates of diagnosis or procedure, using the 2001 Māori Census population as the standard population.[20, 21] When describing the distribution of stage at diagnosis, we expressed the number of diagnoses within each respective stage (Local, Regional, Advanced, Unstaged) as a proportion (%) of the total number of all combined stages, separately for each year and for Māori and non-Māori/non-Pacific patients. In terms of ensuring the study's responsiveness to Māori, this study was led by a Māori epidemiologist (JG), supported by Māori public servants, academics and clinicians (MM, MR, SC, GL).

Results

Cancer registrations

The cumulative age-standardised rate of lung cancer registrations is shown in Figure 1, stratified by year and ethnicity, with full tabulated data including confidence limits shown in Appendix 2. The rate of lung cancer registrations trended toward being lower in 2020 compared to the previous two years for Māori, but not for non-Māori/non-Pacific peoples. For Māori the cumulative registration rate in 2020 had increased by December to draw close to that observed by the end of 2019, although this may reflect a general downturn between September–December 2019 relative to the same period in 2018. Rates of lung cancer registration for non-Māori/non-Pacific peoples were indiscernible between 2018–2020.

The distribution of stage at diagnosis among lung cancer registrations between 2018–2020 is shown in Figure 2, separately for Māori and non-Māori/non-Pacific patients. For Māori, there was no clear change in stage distribution over the three-year period: the proportion of advanced cancers remained at 47% each year, while the proportion of Unstaged cancers ranged between 29–33% across the three years. Variation between years was somewhat greater for non-Māori/non-Pacific patients, although the stage distribution remained broadly similar across the three-year period.

Figure 1: Cumulative age-standardised rate of lung cancer registrations by month and year (2018–2020) per 100,000 New Zealanders, for Māori (left) and non-Māori/non-Pacific (right).

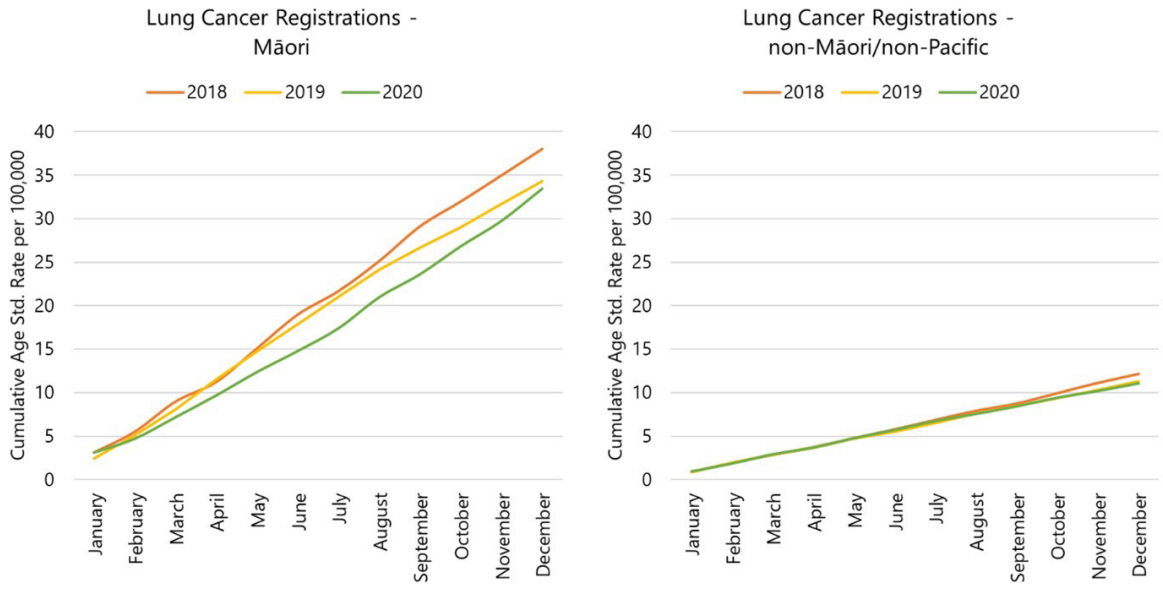


Figure 2: Stacked bar chart showing the crude distribution of local, regional, advanced and unstaged lung cancer on the New Zealand Cancer Registry, by year (2018–2020), separately for Māori and non-Māori/non-Pacific patients.

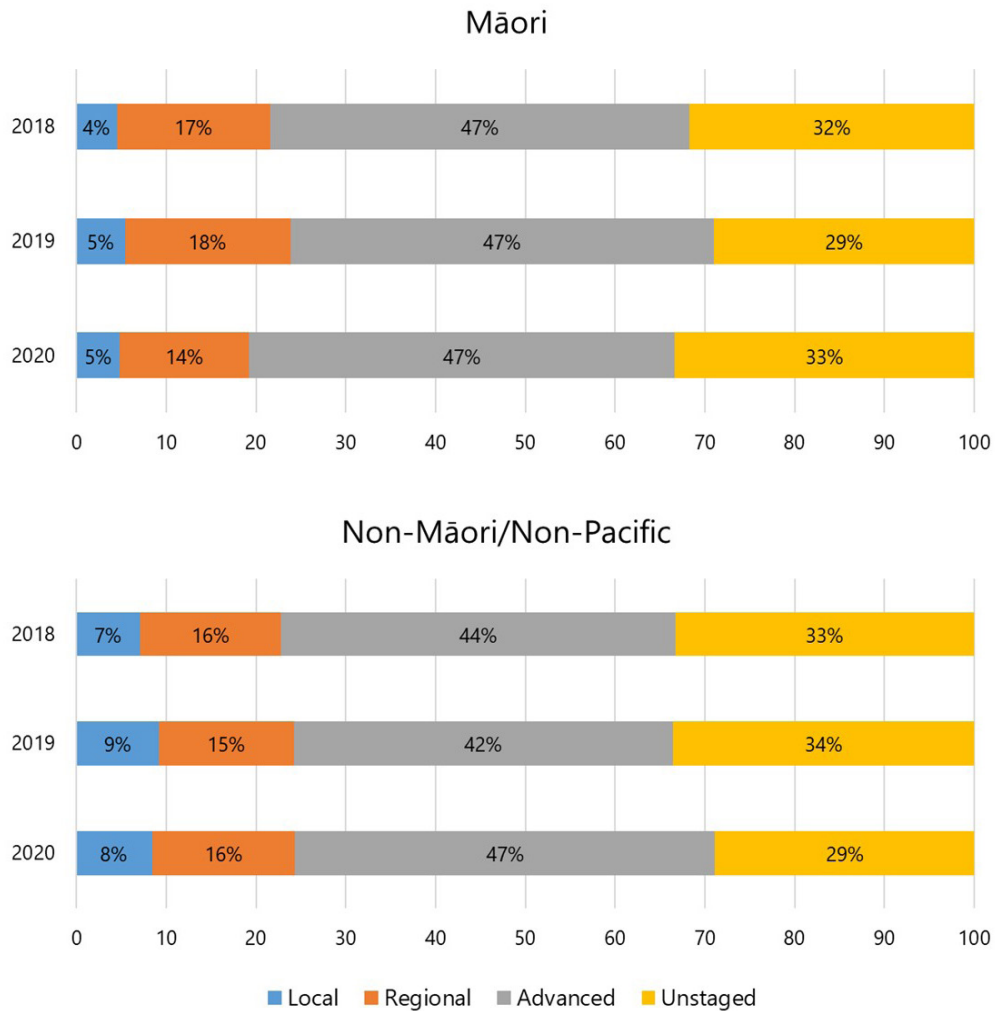


Figure 3: Cumulative age-standardised rate of bronchoscopy by month and year (2018–2020) per 100,000 New Zealanders, for Māori (left) and non-Māori/non-Pacific (right).

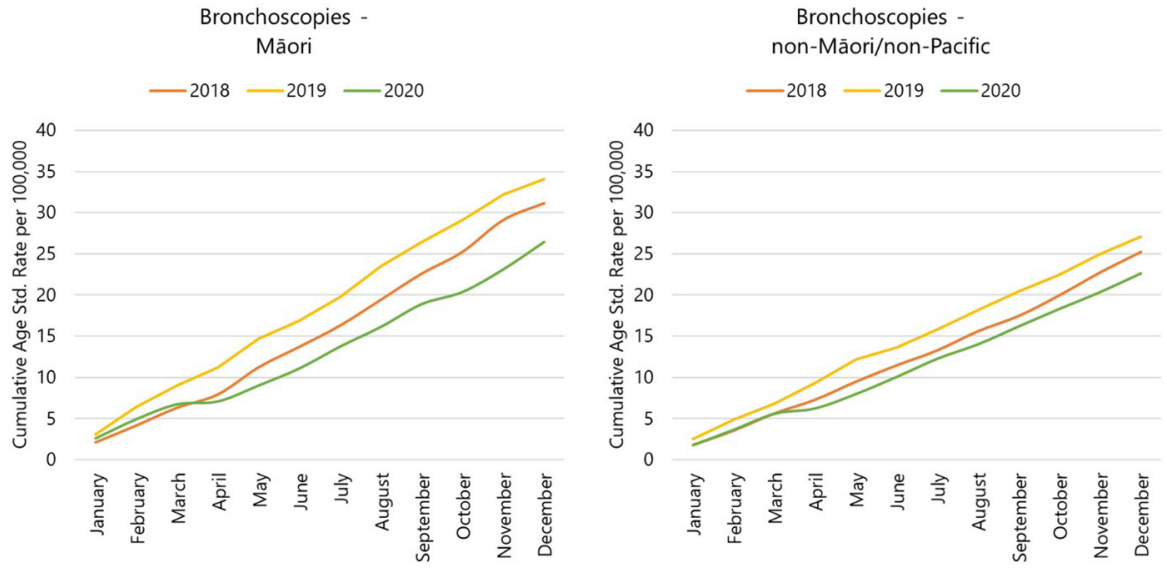
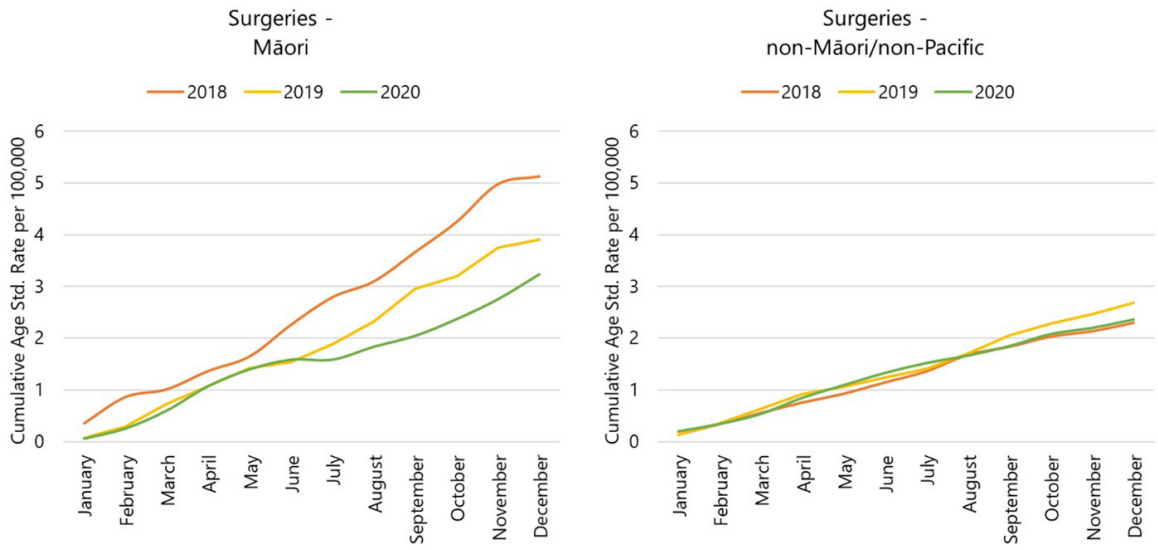


Figure 4: Cumulative age-standardised rate of lung surgery by month and year (2018-2020) per 100,000 New Zealanders, for Māori (left) and non-Māori/non-Pacific (right).



Bronchoscopy

The cumulative age-standardised rate of bronchoscopies is shown in Figure 3, stratified by year and ethnicity, with full tabulated data including confidence limits shown in Appendix 3. The bronchoscopy rate trended toward being lower in 2020 compared to the previous two years for both Māori and non-Māori/non-Pacific peoples, with an abrupt decline occurring between March and April of 2020 (coinciding with the onset of the first national lockdown in New Zealand). The cumulative bronchoscopy rate remained substantially below that observed in previous years by the end of 2020, particularly so for Māori.

Access to lung surgery

The cumulative age-standardised rate of lung surgery is shown in Figure 4, stratified by year and ethnicity, with full tabulated data including confidence limits shown in Appendix 4. For Māori patients, rates of lung surgery trended toward being lower from July of 2020 compared to the same period from previous two years, although this was based on low numbers of procedures and should therefore be interpreted with caution. Rates of lung cancer surgery for non-Māori/non-Pacific peoples were indiscernible between 2018–2020.

Discussion

Beginning in March 2020, there was a trend toward a downturn in the rate of lung cancer registration for Māori (but not non-Māori/non-Pacific) New Zealanders compared to previous years —although the cumulative rate of registration for Māori appeared to be returning to 2019 levels by the end of 2020. There was no apparent shift in the distribution of stage at diagnosis across the three-year period. Rates of bronchoscopy abruptly dropped for both Māori and non-Māori/non-Pacific patients in 2020 relative to previous years (but to a greater extent for Māori), while rates of lung cancer surgery appeared somewhat lower in 2020 for Māori patients, although this was based on a small number of procedures and thus should be interpreted with caution.

What do these findings mean?

Cancer registrations in general decreased during the early phases of the COVID-19 pandemic when there were national lock downs both in New Zealand and internationally. A downturn in lung cancer registrations might be an expected consequence of the COVID-19 pandemic for the following reasons. Firstly, because of the strong public health messaging which advised people to remain home if feeling unwell, it is likely that some patients

who may have otherwise sought care for their symptoms were dissuaded from doing so. Secondly, given the overlap between COVID-19 and lung cancer in common presenting respiratory symptoms, it is plausible that among those who sought care the symptoms of their lung cancer were either not differentiable from symptoms of COVID-19, or a diagnostic bias towards excluding COVID-19 resulted in limited consideration of other causes for their symptoms—with both of these impacting on clinical work-up and subsequent delays to lung cancer diagnosis. Similarly, it is plausible that the reduction in the incidence of seasonal respiratory conditions such as influenza [22] resulted in fewer opportunistic diagnoses of lung cancer among those with respiratory symptoms. Thirdly, the disruptions caused to normal clinical pathways by the pandemic and associated national and regional lockdowns likely impacted access to diagnostic services—including likely difficulties in obtaining community-based tests such as chest x-rays. We noted earlier that there was an abrupt downturn in the rate of bronchoscopy for both Māori and non-Māori/non-Pacific patients from April 2020 compared to previous years, due to a purposeful reduction in bronchoscopy services during the early stages of the COVID-19 pandemic. Unlike lung cancer registrations, we may not expect the cumulative rate of bronchoscopy to "catch-up" with that observed in previous years, since it is possible that in early 2020 other forms of investigation (such as CT-guided biopsy) may have been preferred to bronchoscopy, in order to reduce potential aerosolisation of the SARS-CoV-2 virus.[23–27]

In order to drive the differential impact of COVID-19 on lung cancer diagnosis observed in this study, one or more of the above factors must have acted differently for Māori than they did for non-Māori/non-Pacific peoples. In other words, it is possible that Māori with symptoms of lung cancer were more likely to heed public health advice to remain in-place in spite of symptoms, whether out of hesitancy around the virus and/or a sense of duty to their community; and/or more likely to have their symptoms not differentiable for COVID-19; and/or less likely to gain access to diagnostic services to assist in the diagnosis of their lung cancer. The first two of these factors require further investigation with more granular data than were available for this study: for example, it would be valuable to learn the extent to which patients diagnosed with lung cancer during the national or regional lockdowns of 2020 delayed seeking care, and/or sought care but investigations were delayed, for their early symptoms due to COVID-related barriers;[28, 29] how this compares to patients diagnosed post-lockdowns; and how this experience differs for Māori compared to other ethnic groups.

In terms of access to diagnostic services, it does appear that the cumulative rate of bronchoscopy was somewhat more severely impacted for Māori than it was for non-Māori/non-Pacific peoples (Figure 3), with this reduced access potentially contributing to the differential impact on lung cancer registrations. Such an observation must be interpreted alongside the healthcare access-related factors discussed above. In addition, it is important to bear in mind that the data reported in this study refers to all bronchoscopies performed in the general population, which was likely impacted by reductions in seasonal respiratory illness due to the 2020 lockdowns—which means that it is not straightforward to presume that differential cumulative reductions for Māori correspond to differential access for Māori with symptoms of lung cancer. In terms of future research, it would be useful to view these bronchoscopy data alongside data on CT-guided lung biopsy access during the national and regional lockdowns, and to compare this access between Māori and non-Māori/non-Pacific peoples. Currently these data are not readily available at a national level, but may be reviewed within regions with granular data around lung cancer management (see below).

Related to diagnostic service access is the pathway by which patients enter the cancer care system. We noted in a recent report that the number and proportion of lung cancers referred through the Faster Cancer Treatment (FCT) pathway seemed to be unaffected by the COVID-19 pandemic, for both Māori and non-Māori.[17] The FCT pathway provides monitoring for patients referred with a high risk of cancer, with targets related to timing of first treatment. Around half of Māori lung cancer patients nationwide go through the FCT pathway,[17] although this proportion varies by region.[30] The fact this pathway was unaffected might suggest that Māori patients who were not diagnosed or had their diagnosis delayed due to the pandemic would likely have entered via other pathways such as emergency rooms and incidental findings during hospital admissions.[17] A review of lung cancer registrations between 2015–2018 found that Māori patients were more likely to be diagnosed through emergency presentation than non-Māori patients.[31]

During COVID-related lockdowns, emergency room use was substantially impacted, which may be a factor in creating greater delays to lung cancer registrations for Māori than it would for other ethnic groups.[31] The same rationale exists for inpatient diagnoses: it is plausible that Māori—who are more likely to be hospitalised than non-Māori [32]—are more likely to have their lung cancer diagnosed in an inpatient setting (possibly incidentally when hospitalised for another condition), and if COVID-19 reduced access to inpatient care, then this would differentially impact lung cancer registrations for Māori. The extent of incidental diagnosis (particularly for Māori) remains unknown in New Zealand, but international evidence suggests that 9–40% of lung cancers are diagnosed in this way [33,34]—reinforcing the potential importance of this pathway (particularly for Māori).

There was no apparent shift in the distribution of stage at diagnosis across the three years, for either Māori or non-Māori/non-Pacific patients. Crucially, the proportion of advanced (i.e., metastasised) diagnoses remained relatively stable over this period (particularly for Māori patients), suggesting that, at least by the end of 2020, the downturn in lung cancer registrations for Māori patients does not appear to have led to an increase in the relative proportion of metastasised disease. However, there are two caveats to this observation: firstly, the high proportion of unstaged lung cancer registrations on the NZCR means that the actual proportion of advanced diagnoses is likely to be higher than that observed in this study, although the relative difference between years (and ethnicities) is still likely to be accurate.[35] Future analyses could include datasets such as the Midland and Northern regional registers, which include more granular (and complete) staging information.[36] Secondly, it may be that we do not yet have sufficient data to fully capture the impact of the 2020 downturn in lung cancer registrations on stage distribution for Māori; in other words, such an impact may only become clear once full data are available for multiple years following the onset of the pandemic.

Why just lung cancer?

As noted in the introduction, there has been little evidence that the disturbances to cancer diagnoses caused by the COVID-19 pandemic have differentially impacted Māori, with the exception of lung cancer. As such, it would seem likely that the factors driving the disparity in the downturn of lung cancer registrations for Māori are likely to be unique to lung cancer, rather than applicable to other contexts.

Firstly, it is also important to note that bronchoscopy has the capacity to substantially increase the risk of SARS-CoV-2 spread between patients and clinicians. This, possibly combined with the impact of reductions in bronchoscopy due to reductions in seasonal respiratory illnesses, resulted in stark reductions in its use—reductions which appear to have been at least somewhat worse for Māori. Secondly, as noted above, the pathway toward lung cancer diagnosis is not necessarily the same for Māori patients as it is for non-Māori/non-Pacific patients, and which might have led to fewer Māori registrations over 2020. While the latter factor might also apply to other cancer contexts (e.g., colorectal cancer, where Māori patients are more likely to be diagnosed following emergency presentation than non-Māori patients),[37] perhaps it is the combination of all three factors which ultimately drove the observed differential impact of COVID-19 on lung cancer registrations.

What have we learned?

There are three key lessons to be drawn from our observations of the impact of COVID-19 on lung cancer registrations and treatment. Firstly, the likelihood that the pathway to diagnosis and treatment may differ between Māori and non-Māori/non-Pacific patients means that we need to understand more about the pathways outside of the Faster Cancer Treatment pathway and their associated barriers. The absence of changes in diagnoses through the Faster Cancer Treatment pathway for Māori (and non-Māori) suggests that these other pathways (including emergency presentation and inpatient, incidental diagnoses) may be where the majority of inequities in the lung cancer pathway occur—not just in the context of COVID-19. These inequities reflect implicit bias within the healthcare system, wherein the system is more accessible for non-Māori patients than it is for Māori patients.[38]

Secondly, our observations in all other cancer contexts illustrates that it is not necessarily inevitable that a significant health event such as the COVID-19 pandemic will lead to the exacerbation of health inequities; rather, these can be avoided by deliberate prioritisation of the equitable provision of healthcare within the population, and in particular the preferential allocation of time and resources toward protecting the health of Māori.

Finally, in light of recent evidence suggesting

that primary care communication and national messaging may have diverted attention away from other health conditions,[28,29] there is need for more deliberate focus at a national and regional level on timely access to non-COVID-19 related healthcare. In the context of lung cancer, this focus could be first directed toward high-risk groups (such as Māori smokers and ex-smokers).

Strengths and limitations

The data used in the current study includes all lung cancer registrations reported the New Zealand Cancer Registry (NZCR) over the follow-up period, ensuring national generalisability. We note that we purposefully did not conduct statistical tests on the data, since we note that tests (such as a Cochran-Mantel-Haenszel test for trend) would only tell us if something was different between years, but provide little additional information with which to interpret the data. We also note that, in recent years, there has been renewed emphasis on departing from a reliance on statistical tests and p-values when interpreting differences between groups.[39]

Conclusions

Using national-level data, we observed a downturn in the rate of lung cancer registration for Māori (but not non-Māori/non-Pacific) New Zealanders in 2020 compared to 2018 and 2019. There was no apparent shift in the distribution of stage at diagnosis across the three-year period. Rates of bronchoscopy abruptly dropped for both Māori and non-Māori/non-Pacific patients in 2020 relative to previous years, with this drop appearing to be greatest for Māori. Rates of lung cancer surgery appeared somewhat lower in 2020 for Māori patients, although this was based on a small number of procedures. While other cancer contexts have illustrated that the impact of COVID-19 on access to and through cancer services does not necessarily need to occur inequitably between Māori and non-Māori patients, disparities observed in the lung cancer context suggest that a) we need to ensure that Māori with respiratory symptoms receive best practice care for their symptoms, and b) we need to better quantify and monitor the pathways by which Māori patients with symptoms of lung cancer are entering the healthcare system.

COMPETING INTERESTS
Nil

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Appendix

Appendix 1: Procedures included as lung surgeries.

Procedure name	ICD-10 code
Endoscopic wedge resection of lung	9016900
Lobectomy of lung	3843801
Pneumonectomy	3843802
Radical lobectomy	3844100
Radical pneumonectomy	3844101
Radical wedge resection of lung	3844001
Segmental resection of lung	3843800
Wedge resection of lung	3844000

Appendix 2: Number of lung cancer registrations, crude rate per 100,000 New Zealanders, and age-standardised rate per 100,000 New Zealanders with 95% confidence intervals, by year, separately for Māori and non-Māori/non-Pacific New Zealanders.

		Māori				**non-Māori/non-Pacific**			
		Cases		**Cumulative rate**		**Cases**		**Cumulative rate**	
		Monthly	***Cumulative***	***Crude***	***Age-standardised***	***Monthly***	***Cumulative***	***Crude***	***Age-standardised***
		N	***n***	***n/100,000***	***n/100,000 (95% CI)***	***n***	***n***	***n/100,000***	***n/100,000 (95% CI)***
January	2018	41	41	5.1	3.1 (2.3-4.3)	131	131	3.5	0.9 (0.7-1.1)
	2019	34	34	4.2	2.4 (1.7–3.4)	132	132	3.5	0.9 (0.7–1.1)
	2020	46	46	5.6	3.1 (2.3–4.2)	137	137	3.6	0.9 (0.8–1.2)
February	2018	33	74	9.3	5.5 (4.4–7)	134	265	7.1	1.9 (1.6–2.3)
	2019	38	72	8.8	5.1 (4–6.5)	169	301	8	2 (1.7–2.3)
	2020	24	70	8.5	4.7 (3.7–6)	147	284	7.4	1.9 (1.6–2.2)
March	2018	45	119	14.9	9 (7.5–10.8)	140	405	10.9	2.9 (2.5–3.3)
	2019	42	114	14	8.1 (6.7–9.8)	151	452	12	2.9 (2.5–3.2)
	2020	38	108	13	7.2 (5.9–8.7)	149	433	11.3	2.9 (2.6–3.3)
April	2018	31	150	18.8	11.3 (9.6–13.3)	116	521	14	3.7 (3.3–4.2)
	2019	49	163	20	11.5 (9.9–13.5)	141	593	15.7	3.7 (3.3–4.1)
	2020	39	147	17.8	9.7 (8.2–11.4)	121	554	14.5	3.7 (3.3–4.1)

Appendix 2 (continued): Number of lung cancer registrations, crude rate per 100,000 New Zealanders, and age-standardised rate per 100,000 New Zealanders with 95% confidence intervals, by year, separately for Māori and non-Māori/non-Pacific New Zealanders.

		Māori				non-Māori/non-Pacific			
		Cases		Cumulative rate		Cases		Cumulative rate	
		Monthly	*Cumulative*	*Crude*	*Age-standardised*	*Monthly*	*Cumulative*	*Crude*	*Age-standardised*
		N	*n*	*n/100,000*	*n/100,000 (95% CI)*	*n*	*n*	*n/100,000*	*n/100,000 (95% CI)*
May	2018	51	201	25.1	15.1 (13.1–17.4)	150	671	18	4.8 (4.3–5.3)
	2019	45	208	25.6	14.8 (12.9–17)	141	734	19.4	4.8 (4.3–5.3)
	2020	40	187	22.6	12.4 (10.7–14.3)	157	711	18.6	4.8 (4.3–5.3)
June	2018	54	255	31.9	19 (16.7–21.5)	147	818	22	5.8 (5.3–6.4)
	2019	42	250	30.7	17.9 (15.7–20.3)	115	849	22.5	5.5 (5–6)
	2020	37	224	27.1	14.8 (12.9–16.9)	150	861	22.5	5.7 (5.2–6.3)
July	2018	38	293	36.7	21.7 (19.3–24.4)	155	973	26.1	6.9 (6.3–7.5)
	2019	43	293	36	21 (18.7–23.6)	150	999	26.4	6.6 (6–7.1)
	2020	36	260	31.4	17.4 (15.4–19.7)	147	1,008	26.3	6.8 (6.2–7.3)
August	2018	48	341	42.7	25.1 (22.6–28)	144	1,117	30	7.9 (7.3–8.6)
	2019	45	338	41.5	24.2 (21.7–27)	153	1,152	30.5	7.6 (7–8.2)
	2020	55	315	38	21 (18.7–23.5)	129	1,137	29.7	7.6 (7–8.2)

Appendix 2 (continued): Number of lung cancer registrations, crude rate per 100,000 New Zealanders, and age-standardised rate per 100,000 New Zealanders with 95% confidence intervals, by year, separately for Māori and non-Māori/non-Pacific New Zealanders.

		Māori				non-Māori/non-Pacific			
		Cases		Cumulative rate		Cases		Cumulative rate	
		Monthly	*Cumulative*	*Crude*	*Age-standardised*	*Monthly*	*Cumulative*	*Crude*	*Age-standardised*
		N	*n*	*n/100,000*	*n/100,000 (95% CI)*	*n*	*n*	*n/100,000*	*n/100,000 (95% CI)*
September	2018	52	393	49.2	29.1 (26.3–32.2)	148	1,265	34	8.8 (8.1–9.4)
	2019	36	374	45.9	26.7 (24–29.6)	125	1,277	33.8	8.4 (7.8–9.1)
	2020	41	356	43	23.6 (21.2–26.2)	150	1,287	33.6	8.4 (7.8–9.1)
October	2018	40	433	54.2	32 (29–35.2)	168	1,433	38.5	9.9 (9.3–10.7)
	2019	33	407	50	29 (26.2–32)	144	1,421	37.6	9.4 (8.8–10.1)
	2020	45	401	48.4	26.8 (24.3–29.6)	158	1,445	37.8	9.4 (8.8–10.1)
November	2018	39	472	59.1	35 (31.9–38.4)	172	1,605	43.1	11.1 (10.4–11.9)
	2019	37	444	54.5	31.7 (28.8–34.8)	139	1,560	41.3	10.3 (9.6–11)
	2020	44	445	53.7	29.7 (27–32.7)	120	1,565	40.9	10.2 (9.6–10.9)
December	2018	42	514	64.3	38 (34.8–41.5)	151	1,756	47.2	12.1 (11.4–12.9)
	2019	39	483	59.3	34.3 (31.3–37.6)	151	1,711	45.3	11.3 (10.6–12)
	2020	55	500	60.4	33.4 (30.6–36.6)	150	1,715	44.8	11.1 (10.4–11.8)

Appendix 3: Number of bronchoscopies, crude rate per 100,000 New Zealanders, and age-standardised rate per 100,000 New Zealanders with 95% confidence intervals, by year, separately for Māori and non-Māori/non-Pacific New Zealanders.

		Māori				non-Māori/non-Pacific			
		Cases		Cumulative rate		Cases		Cumulative rate	
		Monthly	*Cumulative*	*Crude*	*Age-standardised*	*Monthly*	*Cumulative*	*Crude*	*Age-standardised*
		n	*n*	*n/100,000*	*n/100,000 (95% CI)*	*n*	*n*	*n/100,000*	*n/100,000*
January	2018	25	25	3.1	2.1 (1.4–3.1)	166	166	4.5	1.8 (1.5–2.2)
	2019	40	40	4.9	3 (2.2–4.2)	178	178	4.7	2.5 (2–3.1)
	2020	34	34	4.1	2.6 (1.8–3.7)	157	157	4.1	1.8 (1.5–2.2)
February	2018	25	50	6.3	4.1 (3.1–5.5)	144	310	8.3	3.6 (3–4.1)
	2019	39	79	9.7	6.4 (5.1–8.1)	174	352	9.3	4.9 (4.2–5.6)
	2020	31	65	7.9	4.9 (3.8–6.4)	155	312	8.2	3.7 (3.2–4.3)
March	2018	28	78	9.8	6.3 (5–7.9)	166	476	12.8	5.6 (5–6.4)
	2019	32	111	13.6	9 (7.4–10.9)	175	527	13.9	6.8 (6.1–7.7)
	2020	24	89	10.7	6.8 (5.4–8.4)	167	479	12.5	5.6 (5–6.4)
April	2018	20	98	12.3	7.9 (6.4–9.7)	137	613	16.5	7.3 (6.5–8.1)
	2019	29	140	17.2	11.2 (9.4–13.3)	198	725	19.2	9.4 (8.5–10.3)
	2020	5	94	11.4	7.1 (5.7–8.8)	52	531	13.9	6.3 (5.6–7.1)
May	2018	43	141	17.6	11.2 (9.5–13.3)	176	789	21.2	9.5 (8.6–10.4)
	2019	43	183	22.5	14.7 (12.6–17.1)	230	955	25.3	12.2 (11.1–13.3)
	2020	24	118	14.3	9 (7.5–10.9)	152	683	17.9	8 (7.2–8.9)

Appendix 3 (continued): Number of bronchoscopies, crude rate per 100,000 New Zealanders, and age-standardised rate per 100,000 New Zealanders with 95% confidence intervals, by year, separately for Māori and non-Māori/non-Pacific New Zealanders.

		Māori				non-Māori/non-Pacific			
		Cases		Cumulative rate		Cases		Cumulative rate	
		Monthly	*Cumulative*	*Crude*	*Age-standardised*	*Monthly*	*Cumulative*	*Crude*	*Age-standardised*
		n	*n*	*n/100,000*	*n/100,000 (95% CI)*	*n*	*n*	*n/100,000*	*n/100,000*
June	2018	32	173	21.6	13.7 (11.8–16)	171	960	25.8	11.5 (10.5–12.5)
	2019	25	208	25.6	16.8 (14.6–19.4)	137	1,092	28.9	13.6 (12.6–14.8)
	2020	25	143	17.3	11.1 (9.3–13.2)	170	853	22.3	10.1 (9.2–11.1)
July	2018	31	204	25.5	16.3 (14.1–18.8)	167	1,127	30.3	13.3 (12.2–14.4)
	2019	34	242	29.7	19.8 (17.4–22.6)	174	1,266	33.5	15.8 (14.7–17.1)
	2020	32	175	21.1	13.8 (11.8–16.1)	181	1,034	27	12.3 (11.3–13.4)
August	2018	38	242	30.3	19.4 (17.1–22.1)	184	1,311	35.2	15.6 (14.5–16.8)
	2019	45	287	35.3	23.5 (20.8–26.5)	168	1,434	38	18.2 (17–19.6)
	2020	31	206	24.9	16.1 (14–18.7)	156	1,190	31.1	14 (13–15.2)
September	2018	37	279	34.9	22.6 (20–25.5)	155	1,466	39.4	17.5 (16.3–18.7)
	2019	33	320	39.3	26.4 (23.5–29.6)	182	1,616	42.8	20.5 (19.1–21.9)
	2020	37	243	29.3	18.9 (16.6–21.6)	191	1,381	36.1	16.2 (15.1–17.4)

Appendix 3 (continued): Number of bronchoscopies, crude rate per 100,000 New Zealanders, and age-standardised rate per 100,000 New Zealanders with 95% confidence intervals, by year, separately for Māori and non-Māori/non-Pacific New Zealanders.

		Māori				non-Māori/non-Pacific			
		Cases		Cumulative rate		Cases		Cumulative rate	
		Monthly	*Cumulative*	*Crude*	*Age-standardised*	*Monthly*	*Cumulative*	*Crude*	*Age-standardised*
		n	*n*	*n/100,000*	*n/100,000 (95% CI)*	*n*	*n*	*n/100,000*	*n/100,000*
October	2018	33	312	39	25.3 (22.5–28.3)	182	1,648	44.3	20 (18.7–21.3)
	2019	35	355	43.6	29.1 (26.1–32.5)	200	1,816	48.1	22.5 (21.1–24)
	2020	20	263	31.8	20.4 (17.9–23.2)	167	1,548	40.5	18.3 (17.1–19.7)
November	2018	43	355	44.4	29.1 (26.1–32.5)	214	1,862	50	22.7 (21.4–24.2)
	2019	40	395	48.5	32.2 (29–35.7)	175	1,991	52.7	24.9 (23.5–26.5)
	2020	35	298	36	23.1 (20.5–26.1)	181	1,729	45.2	20.4 (19.1–21.8)
December	2018	28	383	47.9	31.2 (28.1–34.6)	188	2,050	55.1	25.2 (23.7–26.8)
	2019	23	418	51.4	34.1 (30.8–37.7)	175	2,166	57.3	27.1 (25.6–28.7)
	2020	44	342	41.3	26.4 (23.6–29.6)	193	1,922	50.2	22.6 (21.3–24.1)

Appendix 4: Number of lung surgeries among those with a lung cancer diagnosis, crude rate per 100,000 New Zealanders, and age-standardised rate per 100,000 New Zealanders with 95% confidence intervals, by year, separately for Māori and non-Māori/non-Pacific New Zealanders.

		Māori				**non-Māori/non-Pacific**			
		Cases		**Cumulative rate**		**Cases**		**Cumulative rate**	
		Monthly	*Cumulative*	*Crude*	*Age-standardised*	*Monthly*	*Cumulative*	*Crude*	*Age-standardised*
		n	*n*	*n/100,000*	*n/100,000 (95% CI)*	*n*	*n*	*n/100,000*	*n/100,000 (95% CI)*
January	2018	5	5	0.6	0.4 (0.1–0.9)	16	16	0.4	0.1 (0.1–0.3)
	2019	1	1	0.1	0.1 (0–0.5)	17	17	0.4	0.1 (0.1–0.3)
	2020	1	1	0.1	0.1 (0–0.5)	20	20	0.5	0.2 (0.1–0.4)
February	2018	6	11	1.4	0.9 (0.5–1.6)	23	39	1	0.3 (0.2–0.5)
	2019	3	4	0.5	0.3 (0.1–0.8)	27	44	1.2	0.4 (0.2–0.5)
	2020	3	4	0.5	0.3 (0.1–0.7)	19	39	1	0.3 (0.2–0.5)
March	2018	2	13	1.6	1 (0.6–1.8)	24	63	1.7	0.6 (0.4–0.8)
	2019	6	10	1.2	0.7 (0.4–1.3)	33	77	2	0.6 (0.5–0.8)
	2020	5	9	1.1	0.6 (0.3–1.2)	30	69	1.8	0.5 (0.4–0.8)
April	2018	5	18	2.3	1.4 (0.9–2.2)	16	79	2.1	0.8 (0.6–1)
	2019	4	14	1.7	1.1 (0.6–1.8)	26	103	2.7	0.9 (0.7–1.2)
	2020	7	16	1.9	1.1 (0.7–1.8)	33	102	2.7	0.8 (0.6–1.1)
May	2018	4	22	2.8	1.6 (1.1–2.5)	24	103	2.8	0.9 (0.7–1.2)
	2019	5	19	2.3	1.4 (0.9–2.3)	17	120	3.2	1.1 (0.8–1.4)
	2020	5	21	2.5	1.4 (0.9–2.2)	32	134	3.5	1.1 (0.9–1.4)

Appendix 4 (continued): Number of lung surgeries among those with a lung cancer diagnosis, crude rate per 100,000 New Zealanders, and age-standardised rate per 100,000 New Zealanders with 95% confidence intervals, by year, separately for Māori and non-Māori/non-Pacific New Zealanders.

		Māori				**non-Māori/non-Pacific**			
		Cases		**Cumulative rate**		**Cases**		**Cumulative rate**	
		Monthly	*Cumulative*	*Crude*	*Age-standardised*	*Monthly*	*Cumulative*	*Crude*	*Age-standardised*
		n	*n*	*n/100,000*	*n/100,000 (95% CI)*	*n*	*n*	*n/100,000*	*n/100,000 (95% CI)*
June	2018	8	30	3.8	2.3 (1.6–3.2)	17	120	3.2	1.2 (0.9–1.5)
	2019	2	21	2.6	1.5 (1–2.4)	23	143	3.8	1.2 (1–1.6)
	2020	3	24	2.9	1.6 (1.1–2.4)	23	157	4.1	1.3 (1.1–1.7)
July	2018	7	37	4.6	2.8 (2–3.9)	23	143	3.8	1.4 (1.1–1.7)
	2019	4	25	3.1	1.9 (1.3–2.8)	23	166	4.4	1.4 (1.1–1.7)
	2020	0	24	2.9	1.6 (1.1–2.4)	22	179	4.7	1.5 (1.2–1.9)
August	2018	4	41	5.1	3.1 (2.3–4.2)	32	175	4.7	1.7 (1.4–2.1)
	2019	6	31	3.8	2.3 (1.6–3.3)	39	205	5.4	1.7 (1.4–2.1)
	2020	4	28	3.4	1.8 (1.3–2.7)	18	197	5.1	1.7 (1.4–2)
September	2018	8	49	6.1	3.7 (2.8–4.9)	18	193	5.2	1.8 (1.5–2.2)
	2019	9	40	4.9	3 (2.2–4.1)	31	236	6.2	2.1 (1.7–2.5)
	2020	3	31	3.7	2.1 (1.4–2.9)	25	222	5.8	1.9 (1.5–2.2)
October	2018	8	57	7.1	4.2 (3.3–5.5)	23	216	5.8	2 (1.7–2.4)
	2019	4	44	5.4	3.2 (2.4–4.3)	31	267	7.1	2.3 (1.9–2.7)
	2020	5	36	4.3	2.4 (1.7–3.3)	28	250	6.5	2.1 (1.8–2.5)

Appendix 4 (continued): Number of lung surgeries among those with a lung cancer diagnosis, crude rate per 100,000 New Zealanders, and age-standardised rate per 100,000 New Zealanders with 95% confidence intervals, by year, separately for Māori and non-Māori/non-Pacific New Zealanders.

		Māori				**non-Māori/non-Pacific**			
		Cases		**Cumulative rate**		**Cases**		**Cumulative rate**	
		Monthly	*Cumulative*	*Crude*	*Age-standardised*	*Monthly*	*Cumulative*	*Crude*	*Age-standardised*
		n	*n*	*n/100,000*	*n/100,000 (95% CI)*	*n*	*n*	*n/100,000*	*n/100,000 (95% CI)*
November	2018	8	65	8.1	5 (3.9–6.4)	15	231	6.2	2.1 (1.8–2.6)
	2019	8	52	6.4	3.8 (2.8–5)	19	286	7.6	2.5 (2.1–2.9)
	2020	5	41	5	2.8 (2–3.8)	17	267	7	2.2 (1.9–2.6)
December	2018	2	67	8.4	5.1 (4–6.5)	23	254	6.8	2.3 (2–2.7)
	2019	2	54	6.6	3.9 (3–5.1)	25	311	8.2	2.7 (2.3–3.1)
	2020	6	47	5.7	3.2 (2.4–4.3)	30	297	7.8	2.4 (2–2.8)

Early diagnosis of surgically curable lung cancer is commonly serendipitous

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ABSTRACT

AIMS: Lung cancer is the largest cause of cancer death in New Zealand, accounting for 18.3% of cancer-related deaths.[1,2] There is limited literature on how patients with lung cancer clinically present in New Zealand. The aim of this cohort study was to identify the rate of incidentally diagnosed lung cancer in the Midland Region, the common symptomatology and route of diagnosis.

METHODS: This retrospective cohort study included patients with lung cancer who underwent potentially curative thoracic surgery between January 2011 to June 2018 at Waikato Hospital, New Zealand. Symptoms or signs recorded were cough, dyspnoea, haemoptysis, lymphadenopathy, chest pain, hoarseness, fatigue, weight loss and finger clubbing. The lung cancer cases were grouped into incidental finding, symptomatic general practitioner, symptomatic emergency department and surveillance.

RESULTS: Three hundred and ten patients with lung cancer had thoracic surgery with curative intent at Waikato Hospital. Two hundred and fourteen (69%) patients had symptoms which prompted presentation to a treating physician and 96 (31%) patients were asymptomatic. Incidental diagnosis was demonstrated in 121 (39.4%) patients. Of the patients diagnosed incidentally, 36.4% (n=44) had symptoms of lung cancer with the main symptoms including 45% with cough (n=20), 28% with dyspnoea (n=12) and 28% chest pain (n=12).

CONCLUSIONS: In New Zealand, a large amount of lung cancer is still diagnosed incidentally with symptoms of cough, dyspnoea and chest pain. Further research into the development of a lung cancer screening program in New Zealand for a high-risk population is warranted.

Lung cancer is the largest cause of cancer death in New Zealand, accounting for 18.3% of cancer-related deaths.[1,2] It is also the leading cause of cancer death in patients of Māori descent.[1,2] A study by Gurney et al that analysed cases of cancer in New Zealand from 2007–2016 highlighted that Māori patients with lung cancer were 30% more likely to die than non-Māori with lung cancer.[27] Most patients with lung cancer present with advanced disease and are offered palliative treatment. Approximately 20% of New Zealand patients with newly diagnosed lung cancer are treated surgically.[2] There is limited literature on how patients with lung cancer clinically present in New Zealand. Part of the recognised conundrum with accurately diagnosing lung cancer is the nonspecific symptoms.[8] Furthermore, the first step in imaging has traditionally been a chest radiograph which in turn has a high false negative rate for diagnosing lung cancer.[20] An incidental detection of lung cancer has been associated with improved survival.[21]

The Waikato Cardiothoracic Surgical Unit provides a lung cancer resection service to the Midland Region, with a population of 880,000 and with approximately 490 new cases of lung cancer diagnosed per year. Using a cohort of patients with lung cancer receiving curative surgery in Waikato Hospital, we aimed to review the presenting symptoms, the first diagnostic method of imaging and whether the diagnosis was incidental or non-incidental. The hypothesis for this study is that a number of cases of early-stage disease are diagnosed incidentally and subsequently offered curative surgery in the Midland Region. The aim of this cohort study was to identify the rate of incidentally diagnosed lung cancer in the Midland Region, the common symptomatology and route of diagnosis.

Methods

This retrospective cohort study included patients with lung cancer who underwent potentially cura-

tive thoracic surgery between January 2011 to June 2018 at Waikato Hospital, New Zealand. This time frame was utilised as full medical records were available. Baseline characteristics included pre-operative patient variables as well as the tumour characteristics including date of cancer diagnosis, cancer stage (grouped into I, II, III and IV) and cancer cell type. We categorised the cell types into 6 groups: non-small cell lung cancer (NSCLC), NSCLC-others, small cell, carcinoid (including typical and malignant carcinoid), low grade mucoepidermoid carcinoma, and others.

Symptoms and signs at time of diagnosis were confirmed by cross referencing the original handwritten and electronic patients files. Two authors reviewed all these notes and achieved concordance to ensure correct data collection. Symptoms or signs recorded as directly caused by lung cancer were cough, dyspnoea, haemoptysis, lymphadenopathy, chest pain, hoarseness, fatigue, weight loss and finger clubbing. Based on the subsequent patient management by treating physician (not symptoms), the lung cancer cases were grouped into incidental finding, symptomatic general practitioner, symptomatic emergency department and surveillance. Regardless, if the patients had symptoms at diagnosis or not, if patients were not under surveillance (regular surveillance of previously identified lung nodules) and were detected because of an incidental investigation of another presenting health issue, they were recorded as incidentally detected lung cancers.

The mode of clinical imaging included chest radiograph (CXR), computed tomography (CT), positron emission tomography (PET), or magnetic resonance imaging (MRI). Statistical analysis between incidental and non-incidental patient cohorts for patient characteristics, mode of detection and symptomatology was undertaken with chi-square tests and a p-value of less than 0.05 was used to define whether the difference was significant or not.

Institutional approval was given for this project and classed as an audit and ethics approval was not required as deemed negligible risk.

Results

Between January 2010 and June 2018, 310 patients with lung cancer had thoracic surgery with curative intent at Waikato Hospital, including 78 (25.2%) Māori patients and 232 (74.8%) non-Māori patients (Table 1).

Mean age was 66 years, and 55.5% were female. Two hundred and sixty-one (84.2%) patients were either current or ex-smokers. The predominant lung cancer was NSCLC with two hundred and ninety cases (93.5%). There was no significant difference between Māori and non-Māori patients whether the diagnosis was incidental or not (Table 1). Our study, however, only has 78 Māori patients and a nationwide study would be more powered in order to highlight any disparities to diagnosis for a Māori patient population. Two hundred and fourteen (69%) patients had symptoms which prompted presentation to a treating physician, and 96 (31%) patients were asymptomatic. These asymptomatic patients were diagnosed on either routine check-up imaging via a chest radiograph or diagnosed upon imaging investigating an unrelated disease process. Patients were determined as an incidental diagnosis if the detection occurred because of an investigation of another presenting health issue. Incidental diagnosis was demonstrated in 121 (39.4%) patients and 189 (60.6%) accurately investigated for lung cancer (Table 2).

The use of CXR was still the most common form of imaging modality utilised to diagnosis lung cancer (Table 3). However, the rate of detection with CT was higher in the incidental diagnosis cohort with 38% of patients identified incidentally with lung cancer via CT compared with only a rate of 11.1% non-incidental patients diagnosed via CT. Of the 46 patients who had an incidental diagnosis via CT, 22 patients (47%) had a normal chest radiograph prior.

Of the patients diagnosed incidentally, 36.4% (n=44) had symptoms of lung cancer with the main symptoms including 45% with cough (n=20), 28% with dyspnoea (n=12), and 28% chest pain (n=12) (Table 4). Although these patients presented with symptoms, they are identified as incidental diagnoses, as the investigations were not undertaken with the intent of diagnosing lung cancer. There were 18 patients who had no symptoms and classed as non-incidental (Table 4). Fourteen of these patients were under surveillance imaging for malignancy. Although the remaining four patients did not have primary symptoms, the request for imaging directly queried lung cancer due to their risk factors from clinical history as determined by the treating physician. Patients were determined as an incidental diagnosis if the detection occurred because of an investigation of another presenting health issue. Of those diagnosed incidentally despite symptomatology of lung cancer, 35 patients (79.6%) were diagnosed

Table 1: Baseline characteristics of incidentally identified patients and non-incidentally identified patients.

	Incidental		Non-incidental		Total	p-value
Year of diagnosis						**0.172**
2011	19	50.0%	19	50.0%	38	
2012	7	23.3%	23	76.7%	30	
2013	18	47.4%	20	52.6%	38	
2014	17	47.2%	19	52.8%	36	
2015	15	35.7%	27	64.3%	42	
2016	18	38.3%	29	61.7%	47	
2017	17	29.3%	41	70.7%	58	
2018	10	47.6%	11	52.4%	21	
DHB						**0.299**
Bay of Plenty	48	45.7%	57	54.3%	105	
Lakes	16	42.1%	22	57.9%	38	
Tairawhiti	9	36.0%	16	64.0%	25	
Taranaki	5	23.8%	16	76.2%	21	
Waikato	43	35.5%	78	64.5%	121	
Gender						**0.617**
Female	65	37.8%	107	62.2%	172	
Male	56	40.6%	82	59.4%	138	
Ethnicity						**0.355**
Māori	27	34.6%	51	65.4%	78	
non-Māori	94	40.5%	138	59.5%	232	
Age group						**0.159**
<60	24	35.8%	43	64.2%	67	
60–69	42	38.2%	68	61.8%	110	
70–79	45	38.1%	73	61.9%	118	
80+	10	66.7%	5	33.3%	15	
Smoking status						**0.44**
Current smoker	35	41.2%	50	58.8%	85	
Ex-smoker	64	36.4%	112	63.6%	176	
Never smoked	22	44.9%	27	55.1%	49	

Table 1 (continued): Baseline characteristics of incidentally identified patients and non-incidentally identified patients.

	Incidental		Non-incidental		Total	p-value
COPD						**0.938**
No	84	39.3%	130	60.7%	214	
Yes	34	39.1%	53	60.9%	87	
Unknown	3	33.3%	6	66.7%	9	
Stage						**0.153**
I	78	41.7%	109	58.3%	187	
II	32	40.5%	47	59.5%	79	
III	9	23.1%	30	76.9%	39	
IV	1	100.0%		0.0%	1	
Unknown	1	25.0%	3	75.0%	4	
Cell type						**0.353**
NSCLC	115	39.7%	175	60.3%	290	
Carcinoid	3	23.1%	10	76.9%	13	
Small cell	2	100.0%	0	0.0%	2	
Low grade mucoepidermoid carcinoma	0	0.0%	1	100.0%	1	
Others	1	25.0%	3	75.0%	4	
Total	**121**		**189**		**310**	

Abbreviations: DHB – district health board, COPD – chronic obstructive pulmonary disease, NSCLC – non small cell lung cancer

Table 2: Mode of detection and symptoms of incidentally identified patients and non-incidentally identified patients.

Results	Incidental	Non-incidental
Detection of Lung Cancer	121	189

Table 3: Modality of detection of lung cancer either incidental or non-incidental.

	Incidental		Non-incidental		Total	
Imaging						
CXR	69	57.0%	156	82.5%	225	72.6%
Chest CT	46	38.0%	21	11.1%	67	21.6%
PET	2	1.7%	3	1.6%	5	1.6%
MRI	1	0.8%	1	0.5%	2	0.6%
Unknown	3	2.5%	8	4.2%	11	3.5%

CT – computed tomography, PET – positron-emission tomography, MRI – magnetic resonance imaging

on an acute admission to hospital, whereas only nine patients (20.4%) were diagnosed in a primary care community setting. Of those 35 patients diagnosed in the hospital, we did not have access to primary care community case notes to determine whether these symptoms had been present but not highlighted to be linked to lung cancer.

Discussion

The five-year survival within New Zealand and Australia is extremely poor at 11 and 17%, respectively.[23] Furthermore, surgical resection of lung cancer is associated with improved survival.[28] The most recent 2021 New Zealand lung cancer quality improvement report, however, does not ascertain survival differences between surgical and non-surgical patients.[29] This study has shown that of patients undergoing curative resection for lung cancer at Waikato Hospital, 121 (39%) patients were discovered because of incidental findings on imaging for other reasons. The remainder were diagnosed following the investigations of symptoms, or because of ongoing surveillance of patients with lung nodules. A population control study from the United Kingdom on lung cancer symptoms demonstrated that often lung cancer diagnosis is not the primary differential when investigating patients.[8] A population study from Australia identified that only a small proportion of patients recognise the signs and symptoms of lung cancer, even if a current smoker.[9] In our study, 69.4% of patients had symptoms that could be attributable to lung cancer at the time of diagnosis. Of these, cough, dyspnoea and chest pain were the most common presenting symptoms with 44.2%, 20% and 18.1% of patients, respectively. This is consistent with other literature available on the presenting symptoms on diagnosis of lung cancer.[10–12]

The difficulty that is faced when cough or dyspnoea are the main presenting symptoms is that other differential diagnoses, such as a respiratory tract infection or cardiovascular disease, are explored as the first diagnosis. A large retrospective study of 2,293 patients by Kocher et al identified that cardiovascular disease and COPD were present in 62.1 and 62% of patients, respectively.[14] Furthermore, it has been hypothesised that co-morbidities and suspicion of more benign disease can be isolated as one of the reasons between initial onset of symptoms and a lack of urgency to undertake medical investigation.[13] Other literature reports constitutional symptoms as being a main presenting symptom, particularly in an aging population.[9] This difference between our cohort could be contributed, by splitting constitutional symptoms into weight loss and fatigue in order to get a more specific representation of presenting symptoms. In terms of the association of a particular symptom and lung cancer, a systematic review of lung cancer diagnosis symptoms by Shim et al demonstrated that haemoptysis had the highest positive predictive value of 2.4–7.5%.[18]

In our single centre cohort, the incidental rate of lung cancer was 39%. It has been reported that up to 30–54% of a unit's thoracic surgical patients are diagnosed incidentally. [3-5] Another large retrospective cohort study of 1,279 patients only found an incidental diagnosis in 9.1%.[6] This discrepancy between our cohort and other literature could be due to how Kocher et al only included asymptomatic patients as an incidental diagnosis.[6] In our analysis, if the intention for diagno-

Table 4: Primary symptoms for incidental and non-incidental patients at time of diagnosis.

Results	Incidental		Non-incidental		Total		p-value
Symptoms							
Cough							**<0.001**
No	101	83.5%	72	38.1%	173	55.8%	
Yes	20	16.5%	117	61.9%	137	44.2%	
Dyspnoea							**<0.001**
No	109	90.1%	139	73.5%	248	80.0%	
Yes	12	9.9%	50	26.5%	62	20.0%	
Haemoptysis							**<0.001**
No	118	97.5%	152	80.4%	270	87.1%	
Yes	3	2.5%	37	19.6%	40	12.9%	
Lymphadenopathy							**–**
No	121	100.0%	189	100.0%	310	100.0%	
Yes	0	0.0%	0	0.0%	0	0.0%	
Chest pain							**0.003**
No	109	90.1%	145	76.7%	254	81.9%	
Yes	12	9.9%	44	23.3%	56	18.1%	
Hoarseness							**0.563**
No	120	99.2%	186	98.4%	306	98.7%	
Yes	1	0.8%	3	1.6%	4	1.3%	
Fatigue							**<0.001**
No	120	99.2%	166	87.8%	286	92.3%	
Yes	1	0.8%	23	12.2%	24	7.7%	
Weight loss							**0.002**
No	115	95.0%	158	83.6%	273	88.1%	
Yes	6	5.0%	31	16.4%	37	11.9%	
Finger clubbing							**0.379**
No	120	99.2%	185	97.9%	305	98.4%	
Yes	1	0.8%	4	2.1%	5	1.6%	
Overall							**<0.001**
No primary symptoms	77	63.6%	18	9.5%	95	30.6%	
Had primary symptoms	44	36.4%	171	90.5%	215	69.4%	
Total	**121**		**189**		**310**		

sis was not related to lung cancer, then this was classified as an incidental finding. Therefore, in our cohort there are patients who are symptomatic, but an incidental diagnosis of lung cancer has been made. For example, a patient with chest pain has been investigated but lung cancer was not suspected. It has been observed that those patients with lung cancer who are diagnosed incidentally have an improved survival rate.[3,5,6] Furthermore, those patients who have been diagnosed incidentally with the imaging modality of CT, have a prognostic survival benefit.[3,7] In our cohort, of the 46 patients who had an incidental diagnosis via CT, 22 patients (47%) had a normal chest radiograph prior.

The significant disparity in survival for Māori patients with lung cancer when compared to non-Māori population should warrant investigation into the feasibility of a targeted screening program for at high-risk Māori patients. The New Zealand national lung cancer working group has stated that more research is required on screening for lung cancer.[24] A study undertaken to examine the cost-effectiveness of a low-dose CT screening program in New Zealand stated that it is likely to be cost-effective in the high-risk group of Māori patients.[26] In comparison, the Australian Government have stated that a lung cancer screening program, regardless of whether a patient population is at high-risk for lung cancer, is not currently supported.[25] Overseas, the current European position on lung cancer promotes the use of low-dose CT for lung cancer screening,[17] and the American National Lung Screening Trial also demonstrates a survival benefit for those diagnosed with low-dose CT.[18] The NELSON trial has demonstrated that in high-risk patients, mortality from lung cancer was significantly lower among those who were detected on CT screening.[22] However, there have been concerns over the extrapolation of these results into an Indigenous population.[16]

The majority of patients diagnosed with lung cancer will initially be detected following general practitioner-initiated investigations.[19] However, access to primary healthcare in New Zealand is an ongoing challenge. A low-dose CT screening program is likely to improve outcomes from lung cancer in New Zealand, but patient participation is vital for success. In a small cohort study in the USA by Raz et al, of 185 current smokers deemed high-risk, only 18.9% of the cohort had accessed lung cancer screening services, with the remaining 81.1% completely unaware of the available program.[15]

Conclusion

This is the first local experience from the Midland Region documenting the symptomatology and route of diagnosis for lung cancer. Furthermore, this cohort study has demonstrated that in a New Zealand population, a large amount of lung cancer is still diagnosed incidentally. The common symptoms are cough, dyspnoea and chest pain. Despite patients presenting with symptoms, lung cancer is still not one of the initial differential diagnoses that are investigated despite having symptoms consistent with lung cancer. A number of patients are diagnosed with lung cancer despite having a normal chest radiograph. Further research into the development of a lung cancer screening program in New Zealand for a high-risk population is warranted.

COMPETING INTERESTS
Nil.

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Acute respiratory infection risk associated with exposure to outdoor PM_{10} emissions from domestic heating

Vanessa Hammond, Sierra Alef-Defoe

ABSTRACT

AIM: Woodsmoke exposure has known adverse respiratory health effects. However, most studies are based on exposure in developing countries or developed cities. Woodburners are commonly used for domestic heating in New Zealand, and in some areas they impact air quality. We investigated whether woodsmoke exposure at levels encountered in a mid-size township has health effects.

METHOD: We performed a time-stratified case crossover analysis of 1,870 general practitioner (GP) visits for acute respiratory infections (ARI) over five consecutive winters (May–August 2014–2018). Daily air concentrations of particulate matter less than 10 µm (PM_{10}) were obtained from a fixed-site monitoring station. Conditional logistic regression was used to estimate OR and 95%- CI after adjusting for the effects of temperature.

RESULTS: A 10 µg/m^3 increase in PM_{10} concentration was associated with 8% (95% CI 1%–15%) and 20% (95% CI 4%–38%) increases in the odds of a GP visit for an ARI within 24 hours for women and girls, and Māori of both sexes, respectively.

CONCLUSION: Woodsmoke pollution may negatively affect the respiratory health of residents in mid-size towns. However, those most affected by woodsmoke are also likely to be most affected by woodburner phase-out policies. Air quality and housing policies must be integrated to meet a mutual goal of improved health.

Woodburning stoves and fireplaces emit known health-damaging pollutants, including carcinogenic compounds.[1] In New Zealand's South Island, where the coldest winters are experienced, 47% of the population uses woodburners for home heating.[2] Wood has some advantages over electricity, including higher heat output, the ability to scavenge or barter for material, and independence from the power grid. However, in some towns, domestic woodsmoke is the primary driver of winter outdoor air pollution, with daily average concentrations of particulate matter less than 10 µm (PM_{10}) frequently exceeding the 50 µm/m^3 National Environmental Standard for Air Quality.[2,3] Depending on the weather, breaches can occur up to 50 days per winter.[2]

People who routinely experience short-term exposure to high woodsmoke concentrations in winter are potentially at increased risk of adverse health outcomes. Because woodsmoke particles are generally smaller than 1 µm they can be inhaled deep into the respiratory system.[4] Toxicology studies show that short-term woodsmoke inhalation can compromise the respiratory tract's defence systems.[1] Epidemiological studies linking solid fuel combustion exposure to respiratory issues have been carried out for many years, with most evidence coming from developing countries. In these settings, where fuels typically include wood, charcoal, dried animal dung, and agricultural waste, exposure has been linked to acute respiratory infections in children, and chronic bronchitis, tuberculosis, and chronic obstructive pulmonary disease in women.[1,5] Questions remain for exposure in developed countries, where wood is the predominant fuel and better housing conditions and combustion appliances are typically observed.[6] A recent meta-analysis of data from Europe, North America, Australia and New Zealand indicated that exposure to indoor wood burning is associated with an increased risk of respiratory infections.[7] There was insufficient data to draw conclusions about outdoor exposure to woodsmoke from indoor sources.

Within New Zealand, there have been woodsmoke health effects studies in Christchurch, Auckland, and nationally based on modelled data.[3,8–11] In Christchurch, where woodsmoke makes up 90% of ambient outdoor PM_{10},[3] increases in PM_{10} were associated with increased mortality,[10] cardio-respiratory hospital admissions,[3] and respiratory symptoms and medication usage among people with chronic obstructive pulmonary dis-

ease.[9] In Auckland, exposure to neighbourhoods with higher densities of wood or coal-burning households was associated with increased odds of emergency department visits during early childhood.[8] Limitations of these studies include difficulties in generalising beyond the city environment and their focus on relatively severe outcomes or susceptible populations. It is unclear whether winter woodsmoke pollution in smaller New Zealand towns is associated with respiratory illness to the degree observed in cities, or whether woodsmoke exposure has a potential role in milder health conditions.

Small to medium sized towns in developed countries are ideal for studying woodsmoke health impacts as they are largely free of industrial pollution and road traffic emissions. Acute respiratory infections (ARIs) are common conditions that are better suited for small-population analysis than more severe but less frequent causes of morbidity. We aimed to describe the association between woodsmoke exposure and local general practitioner (GP) visits for ARIs in a mid-sized town with known woodsmoke pollution issues.

Methods

Study location and population

We compared GP ARI coding among four similarly sized towns in Otago with known woodsmoke pollution issues and selected one as the study location (population < 6000) based on its high number of coded visits and consistency across years. A 2019 Emissions Inventory identified that domestic heating is responsible for 94% of the town's daily winter PM_{10} emissions.[12] The inventory used a household survey to collect information on local domestic heating methods and fuel types. Emission factors were applied to these data to estimate emissions for the area. According to the inventory, 56% of the town's households use woodburners to heat their main living area, burning an estimated 26 tonnes of wood and discharging around 141 kg of PM_{10} on a typical winter's night. Less than 1% of households used coal. Outdoor burning is prohibited within the town during winter months. There is no area that could be considered metropolitan, and the nearest highway is at least 200 m beyond the town's residential boundaries. There is no local power station. Agricultural burning in rural land surrounding the town is not considered to be a significant contributor to air pollution experienced within the urban centre due to distance and prevailing weather conditions. For reference, the town's estimated daily winter PM_{10} emissions were 0.9 kg from motor vehicles and 1.1 kg from industrial and commercial sources.

The study population were residents of all ages who presented to their local GP and were diagnosed with an ARI between 1 May–31 August 2014–2018 (Table 1). Excluded were individuals with a home address outside of the town (i.e., visitors) as their exposure during control periods could not be estimated. Anonymised patient data were provided by the local Primary Health Organisation. ARI visits were identified by Read codes. These are a standardised system of recording patient findings and proceedings across primary care. Of interest were visits coded H00 (acute nasopharyngitis), H01 (acute sinusitis), H02 (acute pharyngitis), H03 (acute tonsilitis), H04 (acute laryngitis and tracheitis), H05 (other acute upper respiratory tract infections) and H06 (acute bronchitis and bronchiolitis). Patient age, sex, ethnicity, geographic unit of home address, consultation date and time, and encrypted National Health Index (NHI) number were obtained. Only the first GP visit per day per person was included in the analysis. Individual consent (at patient level) was not required because patient information was not being requested in a form that could identify the individuals concerned. The University of Otago Human Ethics Committee (HD19/027) approved this study.

Woodsmoke exposure and air temperature

The Otago Regional Council monitors winter PM_{10} and air temperature at a fixed site in the study town and agreed to provide study data. Mean 24-hr PM_{10} concentrations and mean 24-hr air temperature was based on the time frame of an air pollution event—3:00 pm to 2:59 pm the next day.

Woodsmoke exposure in the home neighbourhood was assessed by the number of households per hectare using woodburners as their main heat source based on 2018 Census Statistical Area 1 data, replicating the method of Lai et al.[8] The national interim coverage rate for the 2018 Census was 98.6%, the heat and fuel type questions each had a response rate of 92.3% and a quality rating of "moderate".[13] Geographic unit of home address was converted from 2013 Census Meshblock to 2018 Statistical Area 1 using the 2021 Geographic Areas Table.[14]

Study design

Case crossover study

In the case crossover design statistical inference is based on a comparison of each subject's exposure during a period relevant for the causation of the outcome (the hazard period) and during one or more control periods. We tested three hazard periods: 1) exposure during a 24-hour window from 3:00 pm the day before a GP visit to 2:59 pm on the day of visit ("same day"); 2) exposure during a 24-hour window between 3:00 pm two days before, and 2:59 pm the day before a GP visit (one-day lag); and 3) exposure during a 72-hr window from 3:00 pm three days before a GP visit to 2:59 pm on the day of visit (three-day average). Control periods were seven and 14 days before and seven days after the hazard period, to control for time-varying co-factors that may be associated with the day of the week. Control period length was matched to hazard period length. To reduce potential exposure misclassification, we restricted the case crossover analysis to GP visits made by persons residing in a Census Meshblock that fell wholly or partially within a one km radius of the PM_{10} monitoring station.

Ecological study

We also investigated group-level associations between neighbourhood woodburner density, as a proxy for woodsmoke exposure, and ARI GP visitation rates. Unlike the case crossover approach, the ecological study did not assume equal exposure around the PM_{10} monitoring station. However, causality cannot be implied due to the cross-sectional design.

Statistical methods

The Dupont method was used to calculate sample size requirements for the case crossover analysis.[15] Based on type I and type II error rates of 0.05 and 0.8, respectively; a 0.12 probability that a case will be exposed to high PM_{10} in the control periods, and a correlation coefficient of 0.2 between hazard and control periods, 599 cases were required to detect an odds ratio (OR) of 1.5. Assuming a higher probability of exposure on control days (0.18) reduces the sample size requirement to 440 for an OR of 1.5. Conditional logistic regression with robust standard errors was used in a complete case analysis to produce risk estimates presented as OR with mean temperature as a covariate. Stratified analyses were conducted by age, sex, and prioritised ethnicity (European, Māori, and all other ethnicities combined). Further stratification into individual disease categories or by year would have resulted in numbers too small for analysis. Goodness-of-fit was tested by plotting the change in Pearson's Chi-squared against predicted probabilities, the link function was tested using a Stata's linktest command, and potential multicollinearity between PM_{10} and mean daily temperature by examining variance inflation factors.

ARI visitation rates were calculated as the number of ARI GP visits divided by the estimated population for the corresponding Statistical Area, multiplied by 1000. The rates were age-standardised using the direct method, with New Zealand's 2018 population as the reference. Multilevel Poisson and negative binomial models were used to identify potential associations between group-level woodsmoke exposure and ARI GP visitation rates at Statistical Area 1 level. Goodness-of-fit was tested using a Chi-squared statistic and Stata's linktest command. All analyses were conducted using Stata 17.0 (StataCorp, Texas).

Results

During the winters of 2014 to 2018, 1,870 ARI GP visits were made by 1,142 individuals. Slightly over half (54.7%) were made by children aged 14 years or younger. More visits were made by women and girls (55.4%) than by men and boys (44.6%). During the same period, mean daily PM_{10} was 34.84 μg/m^3 (range 7.6–97.0 μg/m^3) and mean daily air temperature was 6.5 °C (range -4–17.6°C). The difference between PM_{10} during the same day hazard period and the average concentrations during the three corresponding control periods (the exposure term[16]) had a median of 3.65 μg/m^3 and IQR of 35.87 μg/m^3. The current 24-hr PM_{10} National Environmental Standard for Air Quality[17] of 50 μg/m^3 was exceeded multiple times each year (Table 1).

According to 2018 Census data, the mean number of woodburning dwellings per hectare was 3.4 (range 0.2–7.5). Overall, 546 (28.7%) households were renters, with marked variance in this proportion by Statistical Area (range 3%–50%). Only area-level deprivation quintiles 1 (least deprived) to 3 were represented in the study township. There were no significant differences in woodburner density between the represented deprivation quintiles.

Table 1: Mean PM_{10}, number of National Environmental Standard for Air Quality exceedances*, mean temperature, and number of general practitioner visits for acute respiratory infections by condition, age group, sex, ethnicity, and year for whole study town.

	Winter season (1 May – 31 Aug)					
	2014	**2015**	**2016**	**2017**	**2018**	**Total**
Mean daily PM_{10} (µg/m^3), (SD, range)	40.3 (21.3, 10.6–94.2)	32.7 (21.0, 7.6–91.7)	32.3 (23.0, 8.7–94.3)	39.3 (22.5, 9.9–97)	26.9 (16.1, 7.7–80)	34.8 (21.7, 7.6–97.0)
PM_{10} exceedances, n	42	18	29	43	12	144
Mean daily air temp (°C)	5.8 (3.6, -1.3–16.6)	5.5 (4.2, -4.0–15.7)	7.0 (4.4, -1.9–17.6)	6.0 (3.9, -1.5–16.8)	8.3 (3.0, 1.7–15.0)	6.5 (4.0, -4.0–17.6)
GP visits, n (%)						
Total	288	438	396	417	331	1870
Condition						
Nasopharyngitis (H00)	0 (0.0)	9 (2.1)	1 (0.3)	1 (0.2)	2 (0.6)	13 (0.7)
Sinusitis (H01)	31 (10.8)	40 (9.1)	41 (10.4)	44 (10.6)	33 (10.0)	189 (10.1)
Pharyngitis (H02)	19 (6.6)	15 (3.4)	23 (5.8)	28 (6.7)	29 (8.8)	114 (6.1)
Tonsilitis (H03)	30 (10.4)	31 (7.1)	43 (10.9)	16 (3.8)	17 (5.1)	137 (7.3)
Laryngitis & tracheitis (H04)	18 (6.3)	33 (7.5)	20 (5.1)	27 (6.5)	18 (5.4)	116 (6.2)
Other ARI (H05)	158 (54.9)	264 (60.3)	221 (55.8)	226 (54.2)	180 (54.4)	1049 (56.1)
Bronchitis & bronchiolitis (H06)	32 (11.1)	46 (10.5)	47 (11.9)	75 (18.0)	52 (15.7)	252 (13.5)
Sex						
Male	123 (42.7)	198 (45.2)	177 (44.7)	170 (40.8)	166 (50.2)	834 (44.6)
Female	165 (57.3)	240 (54.8)	219 (55.3)	247 (59.2)	165 (49.8)	1036 (55.4)
Age group, years, n (%)						
≤ 14	154 (53.5)	257 (58.7)	198 (50.0)	234 (56.1)	179 (54.1)	1022 (54.7)
15-24	34 (11.8)	29 (6.6)	22 (5.6)	25 (6.0)	24 (7.3)	134 (7.17)
25-44	43 (14.9)	63 (14.4)	78 (19.7)	54 (13.0)	53 (16.0)	291 (15.6)
45-64	38 (13.2)	50 (11.4)	60 (15.2)	67 (16.1)	42 (12.7)	257 (13.7)
≥ 65	19 (6.6)	39 (8.9)	38 (9.6)	37 (8.9)	33 (10.0)	166 (8.9)
Ethnicity, n (%)						
European	259 (89.9)	371 (85.5)	347 (88.1)	335 (80.5)	267 (81.4)	1579 (84.9)
Māori	24 (8.3)	51 (11.7)	38 (9.6)	54 (13.0)	39 (12.0)	206 (11.1)
Pacific Peoples	3 (1.0)	5 (1.2)	4 (1.0)	6 (1.4)	5 (1.5)	23 (1.2)
Asian	2 (0.7)	8 (1.8)	5 (1.3)	21 (5.0)	15 (4.6)	51 (2.7)
MELAA	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.6)	2 (0.1)

MELAA: Middle Eastern, Latin American and African ethnicities. *Exceedances based on current 24-hr average National Environmental Standard for Air Quality[17] of 50 µg/m^3. Note that the World Health Organisation 24-hr guideline was reduced to 45 µg/m^3 in 2021.[18]

Table 2: Stratified results of case crossover analysis of PM_{10} by general practitioner visits for acute respiratory infection based on patients residing in a 2013 Census Meshblock within or partially within a 1 km radius of the PM_{10} monitoring station (n = 812).

	Number of GP visits	Same day			24 h lag			3-day average		
		OR*	(95%CI)	p	OR	(95%CI)	p	OR	(95%CI)	p
All (n = 812)	812	1.05	(1.00–1.11)	0.052	1.03	(0.98-1.08)	0.245	1.00	(0.96–1.03)	0.782
Sex										
Male (n = 340/812)	340/812	1.01	(0.93–1.09)	0.838	0.99	(0.92–1.07)	0.793	0.96	(0.91–1.01)	0.116
Female (n = 472/812)	472/812	1.08	(1.01–1.15)	0.016	1.06	(0.95–1.03)	0.064	1.02	(0.98–1.07)	0.306
Ethnicity										
European (n = 646/806)	646/806	1.02	(0.97–1.08)	0.409	1.03	(0.97–1.09)	0.305	0.99	(0.95–1.03)	0.631
Maori (n = 106/806)	106/806	1.20	(1.04–1.38)	0.013	1.10	(0.97–1.25)	0.143	1.03	(0.92–1.15)	0.602
Other (n = 54/806)	54/806	1.11	(0.90–1.36)	0.320	0.93	(0.77–1.12)	0.425	1.00	(0.83–1.20)	0.998
Age										
0-14 (n = 414/812)	414/812	1.06	(0.98–1.13)	0.137	1.04	(0.97–1.11)	0.292	1.01	(0.96–1.06)	0.643
15 + (n = 398/812)	398/812	1.05	(0.97–1.12)	0.211	1.03	(0.95–1.10)	0.500	0.98	(0.93–1.03)	0.425

*OR: Odds ratio based on 10 µg/m^3 increase in PM_{10} concentrations, adjusted for air temperature over the same time periods.GP: General practitioner. Lower denominators indicate missing data.

Case crossover analysis

A subset of 812 visits made by residents living within a 1 km radius of the PM_{10} monitoring station with complete PM_{10} and air temperature data was used for the case crossover analysis. For women and girls, a 10 µg/m^3 increase in PM_{10} concentration was associated with an 8% increase in the odds of an ARI GP visit within 24 hours (OR 1.08, 95% CI 1.01–1.15, Table 2). For Māori of both sexes, a 20% increase in odds was observed for the same concentration increase and period, but with a wide confidence interval (OR 1.20, 95% CI 1.04–1.38, Table 2). Although a 5% increase in odds was observed for all GP visits, the 95% confidence interval included 1.0 so we cannot rule out a type I error (OR 1.05, 95% CI 1.00–1.11, Table 2). These associations were not sustained across different exposure lag periods. The age-stratified analysis did not indicate any age-related risk differences.

Ecological analysis

The ecological analysis was based on 1,870 visits made by residents of the whole study township. The estimated ARI GP visitation rate per 1,000

people per year was 131.3 (95% CI 126.7–136.1). The lowest rates were observed in the least deprived areas, at 47 per 1,000 people per year. ARI GP visitation rates were significantly higher in deprivation quintiles 2 (145.3 per 1000 people per year, relative risk [RR] 3.1, 95% CI 1.58–6.07) and 3 (171.6 per 1,000 people per year, RR 3.66; 95% CI 1.28–10.49) compared with quintile 1 (least deprived). We found a group level association between woodburner density and ARI GP visitation rate. With each additional woodburning household per hectare, the risk of an ARI GP visit increased by 17% (RR 1.17, 95% CI 1.06–1.30) for people living in that area. The association between deprivation and ARI GP visits was no longer significant after adjustment for woodburner density. Further, there was no evidence of effect modification by deprivation quintile.

Discussion

Woodsmoke exposure may increase ARI risk in the study town. The most affected populations appear to be women and girls, and Māori of both sexes. The magnitude of any woodsmoke effect on these groups is uncertain due to wide confidence intervals around our estimates. Stronger effect sizes for women than men and Māori than non-Māori have been previously reported in air pollution studies.[11,19] It is unlikely that either group has an inherent vulnerability to woodsmoke. Although not directly investigated here, any increased susceptibility of Māori is almost certainly due to underlying imbalances in the social determinants of health and burden of diseases caused and perpetuated by systemic factors. We know that racism in the healthcare system affects access, experience, and outcomes for Māori.[20] Similarly, gender inequality and restrictive norms shape women and girls' environmental exposures and access to care.[21] However, reported sex-based risk differences could be partly due to residence-based exposure estimates being more accurate for women.[19] Potential sex-linked biological differences in risk (such as lung size) are unconfirmed.[19]

Our findings support those reported for other health outcomes in New Zealand. A PM_{10} increase of 10 μg/m^3 was associated with a 4% (95% CI 2%–6%) increase in respiratory mortality in Christchurch,[10] and 7% (95% CI 3%–10%) and 20% (95% CI 7%–33%) increases in the odds of all-cause mortality in adults aged 30–74 years and for Māori nationally.[11] Also in Christchurch, an interquartile rise in PM_{10} of 14.8 μg/m^3 was associated with a 3% (95% CI 2%–4%) increase in respiratory-related hospital admissions.[3] For woodburner density, a 7% (95% CI 3%–12%) increase in the odds of non-accidental emergency department (ED) visit before age three years per wood or coal-burning household per hectare was reported in Auckland.[8] We found a much larger effect size of 17% (RR 1.17, 95% CI 1.06–1.30) increased risk of GP visit for ARI per wood or coal-burning household per hectare. This could be due to our inclusion of people of all ages, or to our health outcome of interest being considerably milder than an ED visit. Our linkage of outdoor woodsmoke pollution from indoor sources with respiratory infections somewhat fills the research gap identified by Guercio et al.[7]

Winter woodsmoke pollution could be reduced by strategic intervention. An Australian intervention subsidised woodburner replacement with electric heating, ran education campaigns to improve woodburner use, and fined homeowners who repeatedly emitted excessive woodsmoke.[22] Post intervention, woodburning prevalence fell from 66% to 30% of all households. Mean daily wintertime PM_{10} fell from 44 μg/m^3 during 1994–2000 to 27 μg/m^3 during 2001–2007, and wintertime cardiovascular and respiratory mortality fell significantly. An American intervention exchanged older woodburners with lower emission models.[23] Wintertime mean $PM_{2.5}$ concentrations fell from 27.2 μg/m^3 in the two winters before the intervention to 19.7 μg/m^3 for two winters after. A reduction of 5 μg/m^3 in $PM_{2.5}$ was associated with large reductions in respiratory infections in children, including influenza (52%) and throat infections (45%). Another American intervention included a mandatory no-burn programme when air quality was forecast to be poor, retrofitting with lower-emitting appliances before the transfer and sale of a property, and a limit on the number of woodburning devices allowed in new developments.[24] $PM_{2.5}$ reduced by 3.79 μg/m^3 post intervention. Among people aged 65 years or older, cardiovascular disease hospitalisation rates decreased from 152.2 to 81.1 per 1,000 population, and ischemic heart disease rates from 60.7 to 31.6 per 1,000 population. Although all three studies reported improved air quality and reduced adverse health impacts following an intervention, none addressed the potential issue of cold homes and their associated health impacts.

It is important that in our efforts to reduce woodsmoke pollution, we do not compromise people's ability to heat their homes. Living in a cold house was recently associated with poorer mental wellbeing and higher rates of sick days, asthma, mould, colds, and flu among New Zealanders.[25] Some interventions can potentially raise home temperatures as well as improve outdoor air quality and reduce health inequity. For example, retrofitting insulation has been shown to increase home warmth and improve health.[26] A home insulation intervention was recently associated with reduced hospital admissions, with the greatest benefits observed for Māori and Pacific Peoples.[27] Critically, from a woodsmoke perspective, insulated houses need less energy to heat.[28] Retrofitting insulation may contribute to improved air quality through lesser woodburning or greater capacity to rely on clean heat devices, which typically have lower heat outputs and higher running costs. Although an association between increased insulation and improved air quality is speculative, due to the demonstrated health benefits it seems reasonable to argue that the first step in improving air quality is improving the thermal efficiency of homes. Homes inhabited by groups already disadvantaged by unjust systems, policies, and practices should be targeted first.

As the most deprived quintile areas were not represented in our study township, we cannot draw firm conclusions about differential susceptibility to woodsmoke exposure by deprivation status. The association between deprivation quintiles 1–3, and ARI rates was no longer significant after adjustment for woodburner density—despite density not differing between deprivation quintiles. It is possible that more deprived areas have older, less efficient woodburners, or that residents are using lower quality wood. We know from previous work in this community that more deprived households often buy smaller quantities of wood at a time, which tends to have a higher moisture content as winter progresses. Poor combustion efficiency results in higher PM_{10} emissions.[1] It is also possible that poorer housing quality in more deprived areas is facilitating greater infiltration of outdoor air pollution into the indoor home environment or other causes of respiratory illness, such as mould. Due to these potentially confounding factors, woodburner density may not be an appropriate measure when trying to understand whether woodsmoke moderates a pathway between deprivation and ARI or other health outcomes. Other likely effect modifiers include co-morbidities and household crowding. A further issue with our deprivation approach is that we do not know if individual-level socio-economic attributes of Māori or women and children in the study area were aligned with the area-based deprivation measure used. Some individuals may be experiencing significant hardship within a relatively less deprived area.

Like most epidemiological studies of woodsmoke exposure, we do not have personal exposure information. Personal exposure will vary according to individual time and activity patterns and housing characteristics. Using the same day of the week on control days and restricting the analysis to those who live near the PM_{10} monitoring station will attenuate exposure measurement error somewhat. Confounding by fixed factors such as housing conditions and smoking status is controlled for in the case crossover study design. However, within-person confounding is still possible for transient factors that change over time within a participant. The aggregation of ARI GP visits to the statistical area level in our woodburner density analysis may have reduced the effects of intra-individual variance, enabling detection of a stronger association between woodsmoke and ARI.

Unknown completeness of the GP data also affects the internal validity of our study. We do not have information on the proportion of visits coded. More deprived individuals may be less likely to visit their GP due to accessibility and cost. It is possible that adults with ARI are underestimated in our study. The high proportion of children under 14 years in our study may be partly due to GP visits being free for this group.

Relatively few studies have examined the health impacts of woodsmoke in developed countries. Ours adds to this underdeveloped research area, and further indicates that residential wood burning may be associated with adverse respiratory health effects and disproportionately affect women and girls, as well as Māori. The norms, systems, policies, and services supporting inequity must be addressed. Reducing woodsmoke exposure may reduce inequities in ARI risk, but urgent action is required to remove the role of systemic influences. The potential impact of retrofitting home insulation on heating practices and air quality should be investigated in future work. For the sake of our health and the environment, we need to move away from burning wood in high-emissions devices for domestic heating. However, we cannot rapidly do so until our houses have considerably improved thermal efficiency.

COMPETING INTERESTS
Nil

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"There is a huge need, and it's growing endlessly": perspectives of mental health service providers to ethnic Chinese in Aotearoa New Zealand

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ABSTRACT

AIM: Little is known about the experiences of ethnic Chinese accessing mental health services in Aotearoa New Zealand, resulting in uncertainty around their service preferences, and facilitators or barriers to their mental health help-seeking. This paper investigated the experiences of providers of specific mental health services for ethnic Chinese in Aotearoa, their opinions regarding their patients' experience, and their suggestions to improve the system.

METHOD: Sixteen health professionals with experience and expertise delivering mental health services for ethnic Chinese were interviewed at 12 organisations across Aotearoa. Interviews were recorded, transcribed and analysed using general inductive methods and thematic analysis.

RESULTS: Practitioners' experiences revolved heavily around cultural brokerage, which is vital for culturally appropriate care, but this is time-consuming and receives little formal support. Practitioners thought the patient experience was inadequate, with a lack of language and culturally appropriate services leading to delays in help-seeking. Practitioners' suggestions for system improvement included increasing resourcing for research, and for expanding the availability of language and culturally appropriate services.

CONCLUSION: Current mental health service provision is inadequate for ethnic Chinese seeking help in Aotearoa, and is causing harm by delaying mental health help-seeking. Decisive Government leadership and deeper collaboration between non-Government organisations (NGOs) will be key to improving mental health service accessibility and outcomes.

Despite being Aotearoa New Zealand's fourth-largest ethnic group (270,100; almost 6% of the population[1]), little is currently known about the experiences of ethnic Chinese patients accessing mental health services in Aotearoa. Ethnic Chinese in Aotearoa form a diverse, culturally-heterogenous group, with these differences driven by distinct waves in migration from differing parts of Asia over the last 150 years.[2] Around three quarters are overseas-born, and approximately 50% are recent immigrants who have been in Aotearoa less than 10 years.[3]

There is evidence suggesting under-utilisation of mental health services among ethnic Chinese relative to the non-Chinese population in Aotearoa,[4] which aligns with findings from ethnic Chinese migrants internationally.[5,6] In addition, recent reviews into Aotearoa's mental health system have found that it does not provide enough culturally-specific, holistic options for treatment.[7,8] More recently, challenges have been presented by the COVID-19 pandemic, which has further negatively impacted ethnic Chinese mental health.[9]

In situations where linguistic and cultural barriers exist between patients and health practitioners, cultural brokerage plays an important role in health service provision both within Aotearoa[10] and internationally.[11,12] Cultural brokers are described as being both "liaisons between patients/consumers within their cultural group or community and the providers in their health care agency", as well as being cultural guides who "not only understand the strengths and needs of the community, but also are cognisant of the structures and functions of the healthcare setting".[13] Culturally-specific factors, such as traditional Chinese conceptualisations of mental health and the influence of wider family networks, also impact upon the course of mental illness, as well as the timing and willingness of ethnic Chinese to access mental health services.[5,14]

While there is increasing research internationally focused on mental health service access among East Asian immigrant populations (including ethnic Chinese), current knowledge is largely focused on North

America.[15–17] In 2021, a scoping review found health research related to Asian and other ethnic minority communities in Aotearoa was "limited in quantity and research areas covered", with research focusing on the "use and impact of health and community care" particularly lacking.[18]

In light of this, along with the significant healthcare reforms being introduced by the Government, it is timely to seek further understanding of the experiences of ethnic Chinese patients and their whānau. This study seeks to guide and improve the future provision of such services, by exploring the perspectives of health professionals who have particular experience and expertise in delivering mental health services to ethnic Chinese.

Method

Recruitment and participants

Recruitment was undertaken using purposive sampling. We contacted organisations who advertised mental health related services specifically for Asian populations in general, and/or for the ethnic Chinese population in particular. Twelve organisations agreed to participate, all based in one island of Aotearoa. Five were non-Government organisations (NGOs), four were services provided by District Health Boards (DHBs), two were alternative medicine practices and one was a general practice.

A total of 16 individuals participated: seven managerial staff, four social workers, three health professionals (one GP, one clinical psychologist, one nurse specialist), and two alternative medicine practitioners (one acupuncturist, and one acupuncturist/herbalist). Particularly for the staff from NGOs, there was substantial overlap between roles, with many managerial staff also involved in frontline social work. Recruitment for interviewing continued until data saturation occurred. Interviews were all between 50–65 minutes in duration.

Data collection

Fully informed, written consent was obtained from all participants. Twelve semi-structured interviews were carried out by DWKC; eight occurred face-to-face and four were conducted via Zoom. Some interviews were group interviews with more than one participant involved. All interviews were audio-recorded and, upon completion, the audio-file was transcribed by a professional transcription service under a confidentiality agreement. Transcript anonymisation and insertion of pseudonyms was performed by DWKC, and explanatory notes were added where necessary. Member checking occurred, with only one participant requesting substantive changes to the transcript to remove material which they "preferred not to be recorded". The audio recordings were then deleted.

Data analysis

NVivo was used for thematic data analysis. A general inductive approach, which uses "detailed readings of raw data to derive concepts, themes or a model… from the frequent, dominant or significant themes inherent in raw data",[19] was used as its exploratory and open-ended nature makes it particularly suitable for studies where little information is available prior to the study. A codebook, initially constructed by DWKC, was agreed upon by all authors. Subsequent coding underwent several iterative cycles negotiating shared agreement between all four authors. The combined backgrounds of the authors allowed for various lenses to be brought to the analysis, including Chinese medicine, bioethics, medical anthropology, medical education and Western clinical medicine.

Ethical approval

Ethics approval was received from the University of Otago Human Ethics Committee (reference number D21/012). Appropriate locality approvals were applied for, and received, for research done with DHB participants. Consultation with Te Komiti Rakahau ki Kāi Tahu/the Ngāi Tahu Research Consultation Committee was also undertaken.

Results

Interview data were grouped into three domains reflecting the interview structure: practitioners' experiences, practitioners' views of the patient experience, and practitioners' suggestions for system improvement. Within these domains, six themes and 29 sub-themes were identified, as shown in Table 1. All quotes below are published under pseudonyms.

Practitioners' experiences

The practitioners' experiences were particularly defined by the sub-theme of cultural brokerage:

> If you come to see the psychiatrist, they will ask you, 'Oh, how do you translate this into Chinese?' Zing san beng ji sang [CANTONESE: 精神病醫生]. A 'mental illness doctor,' literally. And they feel offended. But if you say you are coming to see a 'psychological doctor,' sam lei ji sang [CANTONESE: 心理醫生], it will be better accepted. Because a 'mental health

> doctor' means I have a mental health disorder. But then a 'psychological' problem, people say, 'Ah yes, this can be easily fixed.' (Roman, DHB staff member)

Respect and cultural sensitivity is vital, especially when interacting with patients whose viewpoints can vary significantly from the mainstream. Practitioners often linked these views to external, sociocultural factors, and emphasised the importance of a holistic assessment taking these into account:

> We always have to go back to the time before the migration. Some literature actually says, 'Why now? This is a problem you have been dealing with for some time, but how come suddenly your GP wants to refer you to us? Why now? And it was not a problem in the past, why is it now?' (Roman, DHB staff member).

Often, a degree of flexibility around conventional first-line therapies was necessary:

> Most of the Westernised counselling models, they think people have the capability to explore it on their own, so they are supporting them to keep exploring, to get a solution on their own. But when those people come to a new country, and new setting, who don't know about information and systems, they're not capable. (Andy, NGO social worker)

Cultural brokerage's adaptability makes it important for building trust and rapport, especially for patients who often have little familiarity with the health system in Aotearoa and may hold differing views regarding mental health and mental illness. Good relationships often encourage and maintain help-seeking behaviours, with skilled cultural brokers trusted more than mainstream health professionals in some instances:

> They [patients] only trusted [Anita and Sandy, DHB staff members]. So, when they do postvention, they tried to engage with the family, but they don't engage with the new people… There is a number of cases, they don't trust mainstream key workers, but come back to them. (Faye, DHB manager)

Maintaining this sensitivity to differing cultural nuances was seen as important, especially considering the diversity of the "ethnic Chinese" group. Although aspects of culture may be shared, participants were keen to emphasise that the term "ethnic Chinese" encompasses vastly differing individuals:

> Not every Chinese is a migrant… some Chinese consider themselves Kiwis. Others may consider themselves as integrated into the host culture, while still maintaining some traditional Chinese values and beliefs, and are able to navigate Chinese, Kiwi and other ethnic minority cultures comfortably. (Vivian, DHB manager)

While the cultural broker role is valuable for patient interactions, it is often an informal and ad hoc one, with little in the way of formal support structures or resourcing to assist practitioners performing this role. This can result in a considerable workload:

> For a European social worker, their cases average 10 hours… For all my cases average is 40. My max is 70. Why? Because they don't speak the language. I need to be the person going to different organisations, talking to different parties and all come back to me. (Sam, NGO social worker)

In addition, bureaucratic and financial struggles were common concerns, especially for participants in the NGO sector. One directly asked the interviewer for help navigating the system (a request which was politely declined due to conflict of interest concerns):

> We want to become so very good. We want to involve more [health] professionals, but we need funding to support their salary. We need to prepare heaps of documentation, we don't know who can help us to do this kind of professional documentation... So, if you do have any resources or you have some students who can help, please let me know. (Teresa, NGO manager)

Cumulatively, these concerns led to a widespread feeling of cynicism, with many believing ethnic Chinese health in particular, or even Asian health in general, was being ignored by the Government:

> I think there is a brain and heart difference. Maybe Government and DHB leader-

Table 1: Domains, themes, and sub-themes from this study.

Domain	Theme	Sub-themes
Practitioners' experiences		
	Patient interactions	Cultural brokerage *A process of mediating different cultural views, in which respect and cultural sensitivity is vital.*
		Cultural sensitivity in assessment and treatment *Being careful to take sociocultural factors into account when assessing and treating patients.*
		Diversity of ethnic Chinese *The term "ethnic Chinese" encompasses a wide range of individuals with differing health needs.*
	External factors	Organisational challenges *Practitioners often face significant administrative workloads and financial constraints.*
		Feeling ignored *There is a perception that the Government has largely not taken practitioners' long-standing concerns seriously.*
		Role of alternative medicine *Practitioners of alternative medicine felt they could provide a complementary, potentially more culturally-comfortable service.*
Practitioners' views of patient experiences		
	Pre-service	
		Low awareness of mental health *The perception of mental health as something to "get over", rather than receive treatment for is still reasonably widespread.*
		Stigma & shame *Mental illness is still seen as shameful, often conflated with psychosis or insanity.*

Table 1 (continued): Domains, themes, and sub-themes from this study.

Domain	Theme	Sub-themes
		Effects on wider family *The stigma of mental illness can affect family members too, discouraging help-seeking.*
		Isolation from support systems *Having fewer family or social supports can make help-seeking particularly challenging.*
		Lack of language, culturally appropriate services *Even individuals who are willing to seek help struggle to find suitable mental health services.*
	Within service	Trustworthiness of Government services *Government mental health services are seen as more credible, and are appreciated for their affordability.*
		Language & cultural barriers *Some patients struggle to adjust to language barriers and differing cultural expectations within mainstream mental health services.*
		Delayed in help-seeking *Anecdotal evidence indicates that patients generally don't seek help until a late-stage "breaking point".*
Suggestions for system improvement		
	Frontline changes	Someone like them *Seen as the ideal: practitioners with a similar cultural background and fluent in the patient's mother tongue.*
	Systemic changes	Resourcing for research *More clarity on the needs within the community were seen as vital foundational work for any further action.*
		Improving mental health awareness *Further psychoeducation to encourage increased awareness of mental health and mental illness among ethnic Chinese.*
		Giving patients choice *Expanding the availability of language and culturally appropriate services, and allowing patients more freedom to choose what works for them.*
		Increased representation *Seen as important to ensure ethnic Chinese and Asian viewpoints on mental health are given sufficient attention.*

> ship, they recognise in their brain, and they judge that, 'Right, Asian populations are quickly growing, so we need to prepare and provide some service'. But their heart is still very cold and frozen, not willing to fund or allocate. (Sandy, DHB manager)

Outside of the conventional medical sphere, alternative medicine practitioners felt they could play an important complementary role in mental health treatment, particularly for patients who find accessing and utilising mainstream services challenging:

> People more often open up to their close friends and family members. So if there's something, they rarely say it. 'Why am I going to tell you? You can do nothing. But you can help me with acupuncture and herbs, because I know I'm going to feel better.' It's a different approach, but it's seen as an antidepressant, anti-anxiety medication, Chinese medicine. And talking is always seen as superficial. (Leon, acupuncturist/Chinese herbalist)

Practitioners' views of patient experiences

Although acknowledging this could vary depending on patient background, practitioners thought ethnic Chinese had low awareness about mental health:

> We ran a couple of focus groups. You can feel the differences in generation. They feel that if you are just minor depressed, you should just get over it by yourself... Don't rely on society. They still have that mindset. (Cass, NGO social worker)

This is particularly manifest through stigmatisation of mental health issues. Practitioners pointed out the common use of the term *jing shen bing* [MANDARIN: 精神病], which literally translates to "mental illness" but is commonly used as a lay-term for psychosis or insanity. They noted the two are often conflated:

> They think that people have mental health issues, it means that they are crazy, and they will do something to hurt people. (Sally, NGO manager)

The traditionally more collectivist, family-centric nature of Chinese culture also means an individual's stigma can affect their wider family, further discouraging help-seeking behaviours:

> Our Chinese, we have a saying: gaa chaau bat ho ngoi joeng [CANTONESE: 家醜不可外揚; 'household shame cannot be made public']. When there's a conflict in the family, they don't want to talk to anyone because of the face, because of the stigma or maybe they don't want to tell people about the bad thing about their family. There's a lot of cases being hidden. (Sam, NGO manager)

Isolation from support systems was cited as another major barrier, as well as being a common factor in exacerbating mental illness:

> The isolation, the cultural barriers, not understanding how things work and being dependent so much on their children, whereas in China, they could just get about. They have a social network, whereas here, it's very difficult. (George, GP)

Even for ethnic Chinese willing and able to seek help, the mental health system is currently seen as inadequate. The availability of language and culturally appropriate mental health services for the ethnic Chinese population, or even the Asian population in general, is severely lacking:

> Some of the clients we met, their mental illness is serious enough to access mental health services under their DHB's mental health unit. But they still cannot get culturally and linguistically appropriate services. They will help their language by using interpreters, [to] go through the process. When you're doing the assessment, it's still OK, but when you go through a therapeutic intervention, it just doesn't work. (Sally, NGO manager)

Additionally, there is little promotion of the language and culturally appropriate services that do exist, leading to low awareness of them among ethnic Chinese communities. In at least one case, this was by design, due to financial constraints preventing their NGO from effectively meeting expected demand:

> We didn't do too much promotion. Because we don't have enough staff on the ground is the first thing, all my staff are part time. When you open the floodgates, we are the one in the front treating all the cases… You can't see the numbers, but there is a

> huge need, and it's growing endlessly. (Sam, NGO social worker)

Within mental health services, the patient experience seems to be mixed. One participant said Government services, in particular, were seen as trustworthy and affordable, and that the issue was primarily a lack of awareness and promotion:

> They have many Asians in the mainstream services. And they're really happy because they trust: this is a Government service, and this is free… Government has credibility. I guess it's only how well the Western colleagues translate those good things about Government services to the people here. (Priscilla, DHB psychologist)

Others said language barriers and cultural barriers (e.g., differing conceptualisations of mental health and mental illness) presented significant issues for ethnic Chinese who are seeking mental health support:

> I think they [patients] need more time to get into it. And they got language problems and the culture problem. That they have to understand it, but it takes time. They're not confident to use it. When people get into trouble, they need the confidence. (Teresa, NGO manager)

Overall, delays in help-seeking seem to be very common, with presentations generally late-stage and more severe, and only occurring after a "breaking point" at which activities of daily living become severely affected:

> Under-reported, lack of access. Definitely. But we can see the increase in the suicide rate, lay presentation… [ethnic Chinese access mental health services] too late. So what they are dealing is very significant, serious cases. So mainstream always say, 'Why Asian cases are always dramatic?' (Faye, DHB manager)

Suggestions for system improvement

Having a patient seen by "someone like them" —a health professional from a similar cultural background, and fluent in the patient's mother tongue— was seen as the ideal for individual clinical practice, particularly from a mental health context:

> I think the best way is using those people who have similar or same cultural background, and understand the language. Because with counselling, you need to be very focused on—even small language that the clients use, you need to be sensitive and pick up what it means. But those people who do not understand the language, it's not possible. (Andy, NGO social worker)

In light of the diversity of Aotearoa's ethnic Chinese population, though, it was emphasised that having practitioners from a similar cultural background, and sharing the same language, was not a replacement for cultural sensitivity:

> There are assumptions that just because a person is from a certain Asian background, they fully understand the cultural values, customs, practices, beliefs, and norms held by clients from a variety of Asian backgrounds… there is still a need to be mindful not to impose their own value or norms on their Chinese clients. (Vivian, DHB manager)

Many suggestions for systemic changes revolved around the theme of increased resourcing. Participants pointed out further research, to better detail the needs within the ethnic Chinese community, was a necessary precursor to any future actions:

> If you don't understand the population and the community, then how can you provide the service? How can you design a service that you say is more culturally appropriate? That's why I think that there's more research needed to know where we're at currently and what are the needs and why people not coming forward in the early stage. (Jenny, NGO manager)

Resourcing to improve mental health awareness among ethnic Chinese was advocated:

> I'd like to see more psychoeducation on anxiety and depression, domestic violence. Parent-child relationship, as opposed to high-achiever kind of parenting style. They are the seeds for anxiety. Suicide prevention, mood dysregulation. This is the main problem at the moment. Lots of Asians without knowing, they've got huge problems

around mood dysregulation. (Priscilla, DHB psychologist)

In addition, there were suggestions to "give patients choice". Expanding the availability of language and culturally appropriate services, and allowing patients to choose the service that suits them best, was seen as key to driving greater acceptability, and utilisation, of mental health services:

> They could have made their workforce representative of the population, and make a team for culturally and linguistically appropriate services… People still have a choice. Second generation of Asian, they see themselves as Kiwi, they can use mainstream services, that's fine. For someone who have a problem with the language barrier or cultural issues, then they can choose to use that particular service. (Jenny, NGO manager)

NGOs currently provide the majority of these services, and while they benefit from being seen as less stigmatising and more community-focused than larger Government-linked organisations, they are currently restricted by fragmentation and competition for scarce resources:

> Funding issues become one of the factors that create competition rather than collaboration. From a community perspective, we hope to see better cooperation to improve the Chinese community's psychological health, but these sometimes run into difficulties for various reasons. (Cass, NGO social worker; translated from Mandarin)

Some felt representation in mental health governance was vital to ensure the ethnic Chinese, or even Asian, viewpoint on mental health was given sufficient attention:

> We need enough people up at government level who are representative of the groups they're trying to represent… It's good that we have a few Asian doctors, for example, who are part of the Labour Party. Where we want them to be is at ministerial level. If the Minister of Health was a Chinese person, they'll make a huge difference to the funding Asian people get. I wouldn't doubt that. (George, GP)

Ultimately, most said that the primary issue was one of recognition, and that the provision of language and culturally appropriate services was being constrained primarily by the Ministry of Health and local DHBs not recognising the needs of ethnic Chinese in their strategic planning. These reflected a central, long-standing concern for many interviewees:

> My highlight comment, the Government really needs to look into the policy to establish a specific funding for the Asian. Because they do have special funding for the Māori, Pacific, but not for the Asian. That one shoe fits all policy is not really working here. (Sam, NGO manager)

Discussion

The three primary themes that emerged from our interviews with practitioners were: that mental health service provision in Aotearoa is inadequate for ethnic Chinese seeking help; that these inadequacies are causing harm by delaying mental health help-seeking for ethnic Chinese; and that these inadequacies largely arise from Government neglect and inaction regarding Asian mental health in general, and ethnic Chinese mental health in particular.

Firstly, practitioners felt mental health service provision in Aotearoa was inadequate for ethnic Chinese seeking help, with low utilisation of mental health services. This aligns with results from the last major study of Asian mental health help-seeking patterns in Aotearoa.[4] Whilst that report hypothesised that this was likely due to a lower underlying prevalence of mental illness among the ethnic Chinese population, practitioners we spoke to largely disagreed with this view. Instead, they saw the problem as being a lack of mental health awareness within the ethnic Chinese community; a lack of awareness among practitioners regarding the needs of ethnic Chinese patients; and a lack of policy and funding support for language and culturally appropriate services. These findings almost exactly paralleled concerns raised in a 2013 study of health professionals in Ōtautahi/Christchurch,[20] indicating little progress has been made since then. A more recent (2021) study echoed these concerns: over half of Chinese still reported difficulties in receiving language and culturally appropriate support when accessing health services.[21]

The sparse progress made since 2013 shows much work remains to be done around the resourcing and promotion of language and culturally appropriate mental health services for ethnic Chinese in

Aotearoa. The urgency of this is emphasised as our study found the current system could be causing harm to ethnic Chinese in Aotearoa, mainly by delaying their help-seeking. There were strong concerns that ethnic Chinese were not seeking help for mild-to-moderate mental illness, but either delaying treatment until it had significant adverse effects on daily functioning; or, prior to COVID-19 border restrictions, until they could seek language and culturally appropriate care in their home countries.

The primary concerns raised by practitioners included financial constraints and heavy workloads, which are long-standing and not unusual in Aotearoa New Zealand's health system.[22–24] This study, however, provides a novel perspective on the particular challenges these raise for cross-cultural practitioners working in mental health care in Aotearoa. The time consuming nature of effective cultural brokerage, combined with its lack of formal support in the wider health system, means that language and culturally appropriate mental health services for ethnic Chinese often cannot be delivered in a consistent and sustainable way. A previous study from 2013 raised the prospect of a reinforced "negative cycle" for ethnic Chinese mental health in Aotearoa, where widespread under-utilisation of mental health services leads to low awareness of ethnic Chinese mental health needs and concerns, resulting in neglect from policy-makers, and little funding and policy support as a result.[20] Our findings support these concerns, and show that they have not been adequately addressed in the last eight years.

Most practitioners believed that the ability to break this negative cycle was largely in the Government's hands. In recent years, increasing research within Aotearoa,[4,18,20,21] as well as mainstream media coverage[25–27] largely driven by NGOs, has brought more attention to the issue of Asian mental health. Despite this, no Government action seems to be forthcoming. Recent reviews into the mental health system[7,8] and the major reforms announced for the health system at large[28] have made little mention of initiatives to improve accessibility for ethnic Chinese, Asians or even the migrant population as a whole.

It is clear that a renewed focus must be placed upon ethnic Chinese mental health provision in Aotearoa, to adequately meet the needs of the rapidly growing ethnic Chinese community. More resourcing for research—in particular, better quality data around mental health prevalence, utilisation and key barriers and facilitators to mental health service access—is an urgent foundational need, vital for informing any future actions around the mental health system. In addition, the provision of language and culturally appropriate mental health services also needs to be a higher priority for the Ministry of Health, to ensure subordinate agencies are adequately empowered to establish, resource and promote these services, whether directly or through NGOs. Further collaboration between NGOs, such as charitable organisations and community associations, needs to be encouraged, to ensure these services can be reliably and sustainably provided. Although these changes would benefit the ethnic Chinese community, there is significant potential for these changes to improve mental health service provision for other ethnic minority groups in Aotearoa as well.

While a previous study has explored the opinions of health professionals regarding mental health service provision for ethnic Chinese in Aotearoa,[20] this study is unique in also exploring practitioners' experiences when providing these services. It is also the first to explore the role of cultural brokerage in mental healthcare for ethnic Chinese in Aotearoa, including the costs and burdens it can impose on practitioners.

A key strength of this study was its ability to cover a broad range of health professional perspectives, from frontline practitioners to managers and the alternative medicine sphere. Combined with the qualitative nature of this study, based on semi-structured interviews, this allowed for a broad-based view encompassing both "frontline" experiences interacting with patients, and "behind the scenes" financial and administrative issues.

The primary limitations of this study were its limited generalisability, due to its small sample size and the fact that all participants were based in one island of Aotearoa. In addition, the experiences and opinions of ethnic Chinese patients were related by health practitioners and managers, not obtained directly: as an extension to this study, we are investigating this further.

COMPETING INTERESTS
Nil.

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Expansion and consolidation of fracture liaison service in New Zealand public healthcare setting – Waitematā District Health Board Experience

David D W Kim, Michelle Cowley, Julia Spinley, Min Yee Seow, Rick Cutfield

ABSTRACT

aim: To describe the service delivery of the Fracture Liaison Service (FLS) at Waitematā District Health Board (WDHB) for the year 2020, and to outline how the service evolved in recent years.

method: We reviewed and analysed the WDHB FLS database as well as 4-month and 12-month patient follow-up records from the calendar year 2020.

results: In 2020, we identified and assessed 1,225 patients. We either directly initiated anti-osteoporosis medication (AOM) (256), recommended to start AOM with patient's GP (477), or recommended to continue or switch to a different AOM (441) in the vast majority (1174 = 95.8%). In remaining 51 patients, AOM was either deemed unnecessary (owing to relatively young age and good DEXA indices) or patient refused it. Three hundred and thirty dual energy X-ray absorptiometry (DEXA) scans were arranged by FLS, and 79.5% were found to be either osteoporotic (32.9%) or osteopenic (46.6%). At 4-month and 12-month follow-up, 85.1% and 74.4%, respectively, of those expected to be on treatment were on treatment.

conclusion: The WDHB FLS has expanded and consolidated considerably in recent years. Nationwide implementation of effective FLSs should significantly reduce the burden of fragility fractures.

The fracture liaison service (FLS) is a comprehensive secondary fracture prevention programme that has been adopted and implemented internationally, where fragility fracture patients are systematically identified, assessed and managed with the intention of minimising the risk of future fractures.[1,2] FLSs have been shown to be cost-effective,[3,4] and FLSs around the globe are supported and evaluated by the International Osteoporosis Foundation (IOF) under their Capture the Fracture® (CTF) initiative on the basis of 13 key performance indicators.[5,6] In New Zealand, FLSs have been established in nearly all district health boards (DHBs) since the Ministry of Health mandated implementation of FLS in 2015. A facility survey of FLSs in New Zealand in 2020,[7] and a more recent in-depth national survey of FLSs (unpublished work) conducted by the Accident and Compensation Corporation (ACC) and Osteoporosis New Zealand (ONZ) illustrated a large regional heterogeneity in the quality and breadth of service delivery, with the majority of the FLSs unable to deliver broad and comprehensive secondary fracture prevention for their local population. The ACC recently confirmed their continued commitment to provide funding support of FLSs that are willing and able to deliver secondary fracture prevention in accordance with IOF CTF's Best Practice Framework.[6] ONZ, in partnership with ACC, has also committed to provide practical and strategic support to those FLSs that are willing to participate in service improvement to attain CTF Best Practice recognition.

Waitematā District Health Board (WDHB) is the largest DHB in New Zealand, serving over 630,000 residents in the greater Northern and Western Auckland. The WDHB FLS was established in late 2012 and was the first FLS in the country. The FLS had attained Bronze Star recognition from IOF CTF programme[8] in 2014, and had reported our service establishment and early achievements to this *journal*.[9] Since 2014, with additional funding support from ACC and WDHB, the we were able to significantly grow and refine our service. We are now identifying substantially larger number of fragility fracture patients by having adopted several additional methods of patient identification. We are also providing more streamlined and comprehensive management for identified patients. More recently we started to perform follow-up to ensure treatment initiation and adherence in those needing to be treated. In late 2020, on the basis of our 2019–2020 work, we attained Gold Star recognition from the IOF CTF programme.[8]

In this report we detail our service delivery in the

calendar year 2020, and we discuss factors that have allowed us to expand and achieve current status. We hope that sharing our experience will help other FLSs to deliver more effective secondary fracture prevention. Additionally, we hope to inform other New Zealand healthcare professionals, particularly our primary care colleagues, about FLS in New Zealand; successful secondary fracture prevention relies on good coordination and communication between primary and secondary care.

Methods

Prospectively maintained WDHB FLS database records, as well as 4- and 12-month follow-up data, of patients who were identified and assessed by WDHB FLS in the calendar year 2020 that were reviewed and analysed.

FLS case identification

The WDHB FLS eligible population consists of those over the age of 50 years residing in WDHB area who suffered a new fragility fracture, defined as a fracture sustained from no identifiable trauma or from a low impact trauma such as falling from a standing height or less. Those patients with fractures of any bone in the head, neck, hands, feet, ankle, ribs, sternum and clavicle were excluded.

FLS personnel

The service had two dedicated FLS coordinators with total full-time equivalent (FTE) of 1.6, and both were clinical nurse specialist level. FLS co-ordinators actively identified patients who met our service case identification criteria, and implemented care according to our protocol. The service had two clinicians, both endocrinologists (total FTE 0.1), providing clinical leadership and oversight for the FLS. Any cases that the FLS coordinators needed advice on management were discussed with the clinician. The service also had clerical support worker (0.2 FTE) aiding with data handling and entry, and clinical records management. WDHB FLS worked closely with an orthogeriatrician who provided dedicated medical care of hip fracture patients over the age of 65 years presenting to WDHB. The orthogeriatrician was responsible for reporting to the Australia and New Zealand Hip Fracture Registry.

Case detection

FLS co-ordinators identified cases from a number of avenues. We continued to use daily orthopaedic inpatient lists and outpatient fracture clinic lists. We are now routinely identifying patients from emergency department (ED) trauma list. Since 2017, we started utilising ACC-generated fracture claims list identifying those who likely had a "FLS relevant fracture" (i.e., over 50 years with a fragility fracture) not already identified by FLS, and send communication letters to those patients and their respective general practitioners (GP), encouraging them to be assessed. Those patients who make contact with FLS, either directly or via their GP, were then assessed. With the intention to detect more vertebral fractures, we started identifying patients with symptomatic or asymptomatic vertebral compression fractures through screening radiology reports. WDHB Radiology Services provided FLS with a pre-selected list of patients whose radiology report (x-ray, computed tomography [CT] and magnetic resonance imaging [MRI] that included thoraco-lumbar spine as region of interest) contained prespecified keywords such as "fracture", "compression" and "wedge". FLS co-ordinators then reviewed these patients' radiology reports and correlated with a clinical history from electronic records to determine if they may have suffered either non-traumatic or low-impact trauma induced vertebral compression fracture. Letters were sent to these patients and their GPs with a recommendation to start treatment and/or have dual exergy x-ray absorptiometry (DEXA) scan, where appropriate. Additional cases were also identified through inpatient (mostly general medical and orthopaedic) electronic referrals, GP electronic referrals, and those referred to WDHB for DHB funded DEXA scans with fragility fracture that were not yet detected by FLS.

Assessment

Patients identified and confirmed to be a FLS case, as described above in "*FLS case identification*", had their medical history reviewed with relevant clinical information prospectively collected and recorded. This included current fracture mechanism and location, past fracture history, previous DEXA scan result(s), and past and current anti-osteoporosis medication (AOM) history. AOM was considered to be one or more of the following: current bisphosphonate treatment or on bisphosphonate "drug holiday", denosumab, teriparatide, hormone replacement therapy (HRT), and raloxifene. Other relevant clinical information including past medical history, family history, current medications, smoking and alcohol consumption, mobility and exercise, propensity to fall and its risk factors, dietary intake, body weight/ body mass index were routinely sought. For all patients assessed, either face-to-face or via a phone call, falls risk was routinely evaluated using three questionnaires from Health Quality & Safety Commission New Zealand.[10]

Investigation

A DEXA scan was routinely performed in those under 75 years of age and in some patients over 75 where the scan result could alter management decision. DEXA scans were at no cost to the patient and were performed by a private DEXA provider, Auckland Bone Density (ABD), contracted by WDHB. All DEXA scans were performed on General Electric Lunar Prodigy densitometers. Management recommendations were provided by the reporting specialist from ABD. Laboratory test results were routinely reviewed for significant abnormalities, and in patients who have significantly low bone density for their age (i.e., DEXA Z-score <-2.0) relevant secondary screening laboratory tests were recommended.

Intervention

Identified patients were either seen on the ward or in fracture clinic, or contacted by a phone call. A clinical history was taken and rationale for further investigation and/or treatment was discussed. Those over the age of 75 were routinely recommended to initiate pharmacotherapy if they were not already on an AOM. Those with hip fractures (<65 years, as those over 65 were managed by our orthogeriatrician) were initiated on treatment as inpatients. For those being referred for a DEXA scan (most patients under 75) AOM treatment decision was made after the DEXA scan has been completed, with pharmacotherapy initiated or recommended to be initiated in appropriate cases. Vitamin D was recommended in appropriate cases (e.g., elderly and those receiving intravenous (IV) zoledronic acid infusion). Procollagen-1 N-terminal peptide (P1NP) was recommended to be checked six months after treatment initiation in those starting oral bisphosphonates. Those deemed to be at high risk of falls were referred to the WDHB falls prevention programme; a community group or in-home strength and balance programme. For all patients assessed by WDHB FLS, a letter with information on assessment, investigation, and relevant treatment plan/recommendation was sent to the patient's GP, with copy of the letter to the patient.

Record keeping and follow-up

Relevant demographic and clinical details of all patients assessed by FLS were recorded using local FLS database spreadsheet. Follow-ups were performed at 4 and 12 months post index fracture for those patients who were expected to be on treatment (i.e., already on treatment prior to index fracture, initiated on treatment by FLS, or recommended GP to initiate treatment). The main aim of the 4-month follow-up was to check treatment initiation in those where AOM was recommended, and involved reviewing electronic records (TestSafe pharmacy dispensing records system). If AOM dispensing was not apparent, then the patient or the GP practice was contacted by letter or phone call to confirm or reinforce treatment initiation. 12-month follow-up was, again, conducted for those patients who were expected to be on treatment, with the main intention of checking if those expected to be on AOM are adhering to treatment. Additionally, re-fracture events were ascertained.

Ethical approval

Ethical approval was not sought as identifying and intervening on patients with fragility fracture for secondary fracture prevention is expected best clinical care in New Zealand.

Results

Between 1 January and 31 December 2020, WDHB FLS has assessed 1,225 patients meeting our case identification criteria. Patient demographics and general characteristics are as summarised in Table 1. Mean age of the entire cohort was 75.6 years, with those 75 and older comprising 56%. Nine hundred and twenty-eight (75.8%) were female. NZ European comprised 832 (67.9%) patients, and Other European 208 (17.0%). One hundred and eighty-one (14.8%) had history of at least one fragility fracture preceding the index fracture. Four hundred and forty-four (36.0%) were already receiving AOM, the majority (92%) being oral or IV bisphosphonate treatment. Five hundred and fifty-nine (45.6%) patients were identified from radiology report, 305 (24.9%) from inpatient fracture list, 60 (4.9%) from ACC generated list, 156 (12.7%) from ED trauma list, 116 (9.5%) from fracture clinic list, 25 (2.0%) from ward consult referral, and 4 (0.3%) from GP referral. Forty-one (3.4%) patients had a hip fracture, 482 (42.3%) vertebral compression fracture, 154 (13.6%) humerus, 375 (32.9%) wrist/forearm, and 85 (7.5%) had pelvic fracture.

Three hundred and thirty (26.9%) were offered to have a DEXA scan. Thirty-two (9.7%) have either declined this at the time of FLS assessment, or have declined the DEXA appointment or did not attend. Of 298 patients who had DEXA scan performed, 98 (32.9%) were found to be osteoporotic, 139 (46.6%) osteopenic and 61 (20.5%), normal.

Four hundred and forty-one (36.0%) were already on AOM prior to the index fracture, with the majority on either an oral (198 = 44.9%) or IV (201 = 45.6%) bisphosphonates. Eleven (2.5%) were on denosumab, 6 (1.4%) on teriparatide, and 25 (5.7%) were on a "drug holiday". Of 784 who were not on AOM at the

Table 1: Patient demographics and characteristics.

Total no. of patients identified and assessed by FLS	**1,225**
Mean age (range)	**75.6 (50–102)**
Gender – female (%)	**928 (75.8%)**
Ethnicity (%)	
NZ European	832 (67.9%)
Other European	208 (17.0%)
Maori	31 (2.5%)
Pacific	23 (1.9%)
Chinese	58 (4.7%)
Indian	29 (2.4%)
South-East Asian	7 (0.6%)
Other Asian	21 (1.7%)
Middle Eastern	11 (0.9%)
Other	5 (0.4%)
Prior fragility fracture history (%)	**181 (14.8%)**
Source of patient identification (%)	
Fracture clinic list	116 (9.5%)
Inpatient fracture list	305 (24.9%)
ED trauma list	156 (12.7%)
Ward consult referral	25 (2.0%)
Radiology report	559 (45.6%)
ACC fracture data	60 (4.9%)
GP referral	4 (0.3%)
Location of index fracture (%)	
Hip	41 (3.4%)
Vertebrae	530 (43.3%)
Humerus	158 (12.9%)
Wrist/forearm	403 (32.9%)
Pelvis	93 (7.6%)

time of index fracture, AOM was either not recommended (younger patients with robust DEXA indices) or declined by patient in 51. Of the remaining 733 who were deemed to require AOM, 256 were initiated on treatment directly by FLS; 62 (24.2%) on oral bisphosphonate, 176 (68.8%) IV zoledronic acid, 16 (6.3%) denosumab, and two (0.01%) teriparatide. The other 477 were recommended by FLS to start treatment with their GP, or by a hospital subspecialist in rare instances. Therefore, of 1,225 FLS patients assessed, treatment for 1,174 (95.8%) were either directly or indirectly initiated by FLS, or recommended to be continued or changed.

Referrals to falls prevention programme, either in-home strength and balance programme or community group strength and balance programme, were made in 63 (5.1%) patients.

Follow up at four months revealed that 955 of 1,122 patients (85.1%) who were expected or recommended to have started on treatment, and were alive, were on AOM. Twelve-month follow-up data was analysed for patients from January to June 2020 and revealed treatment continuation rate of 74.4%. Re-fracture rate at the 12-month point was 2.0%.

In addition to 1,225 FLS patients, including 41 patients with hip fractures under the age of 65, 358 patients 65 and older (55 and older for Māori and Pacific Islanders) with a hip fracture were admitted to the orthopaedic ward at North Shore Hospital in 2020. An orthogeriatrician, who works closely with FLS, provided both falls risk assessment and initiation of AOM for these patients. Approximately 75% of them left the hospital on AOM, and 62% of them were reported to be receiving treatment at 120-day follow-up.[11] For the same cohort, falls risk assessment was performed in 95% while inpatient.[111]

Discussion

Our data illustrate that establishing and implementing an efficient and effective FLS in a New Zealand public healthcare setting is feasible. Over the years, we refined our service delivery model focusing on increased case detection, improved patient evaluation process and improved treatment initiation and adherence rates. Changes we have implemented are largely in accordance with the recent position paper by the IOF CTF working group, National Osteoporosis Foundation and Fragility Fracture Network,[12] and the second edition of Clinical Standards for Fracture Liaison Services in New Zealand.[13] We have identified and assessed approximately 80% of expected fragility fracture cases in WDHB during the calendar year. Robust treatment initiation/continuation rates of 85.1% and 74.4% at 4 and 12 months, respectively, are also encouraging. On the basis of our work during the period from mid-2019 to mid-2020, we attained Gold Star Rating on the IOF CTF Map-of-Best-Practice.[8]

Compared to our previously published work,[9] the service has greatly expanded not only in terms of the number of FLS patients identified and intervened on, but also in having more avenues for patient identification. There has been a significant increase in detecting vertebral fracture and community fracture

Table 2: Patient assessment and management.

DEXA scan referred (%)	**330 (26.9%)**
DEXA scan performed (%)	**298 (24.3%)**
DEXA scan result (%)	
Osteoporosis	98 (32.9%)
Osteopenia	139 (46.6%)
Normal	61 (20.5%)
Treatment continued, recommended or initiated total (%)	1,174 (95.8%)
Already on treatment, continued	441 (36.0%)
Treatment initiated by FLS	256 (20.9%)
Treatment recommended by FLS for GP to start	477 (38.9%)
Treatment not recommended/ patient declined	51 (4.2%)
Referral (>65) for strength and balance programme (%)	**63 (5.1%)**

cases. Vertebral fracture patients, akin to hip fracture patients, are known to have very high-risk for future fractures, therefore it was our intention to increase identification of them. We worked with our radiology department and have developed a semi-automated system to identify these patients, as described in the methods above. Identification of fragility fracture patients who never come in contact with WDHB hospitals or clinics has been challenging. We have, at least partially, got around this issue by utilising ACC-generated monthly fracture claims report.

We started conducting 4-month follow-up in late 2019. While this has been resource intensive, we believe that it is a key element of a mature FLS; ensuring administration of AOM where indicated is a core FLS activity. The other important function of the 4-month follow-up is to review DEXA scan results where scans were delayed, and providing treatment recommendations to GPs and patients accordingly. In instances where appropriate AOM was not started or those with delayed DEXA with report recommending AOM, further written communication is sent to the patient and their GP at this 4-month follow-up. More recently, we have started to conduct 12-month follow-up. Intentions of the 12-month follow-up are, again, to ensure treatment adherence in those who are expected to be on treatment, and also to identify re-fracture. AOM adherence has been reported to be poor in the literature.[14–15] Increasing the proportion of patients treated with IV zoledronic acid has helped with our relatively high treatment adherence rate. Ensuring administration of repeat IV zoledronic acid doses at appropriate time intervals remains a challenge.

Our prior fracture rate of 14.8% at the time of patient identification seems lower than anticipated. This is likely due to a number of reasons including relying on patient self-reporting in some cases, and in other cases, available WDBH electronic medical records where some past fragility fractures (e.g., distant past, managed outside of WDHB or in the private sector) would have been missed.

Referral of high-risk cases to a falls prevention programme has been another important addition to our service delivery in recent years. However, we acknowledge that our referral rate is low, and that there is a room for improvement. Some of the reasons for this low referral rate is due to exclusion of those under 65 years of age (no funding for falls prevention programme in this group), as well as all hip fracture cases over 65 years who were managed by the orthogeriatric service with an independent and comprehensive falls prevention pathway. A number of our patients were already enrolled in a falls prevention programme.

WDHB FLS continued delivering our service through 2020 despite inherent challenges from COVID-19 related disruptions. Our FLS co-ordinators were able to carry on performing their clinical tasks during and after the COVID lockdowns, often working remotely from home and finding alternative ways to do business. Improvisation in certain aspects of our service delivery was inevitable, including utilisation of more phone calls and letter communications instead of face-to-face consultations of patients. This does not seem to have compromised patients' perception of the service we provided; however, a patient satisfaction survey conducted in late 2020, with 79 respondents out of 250 randomly selected FLS patients, showed overwhelmingly positive results with a weighted average of 4.85 out of 5 of patients either "satisfied" or "very satisfied" with the service.

We recognised that accurate and up-to-date record keeping of clinical information gathered on FLS patients is crucial. We have dedicated administration staff who assist with data entry and other administrative duties. We would like to stress the importance of clearly defining the terms entered into the database to ensure accurate, consistent and complete data entry.

There are several key factors that enabled the successful expansion and consolidation of WDHB's FLS. We believe that having dedicated FLS co-ordinators, with regular discussion with clinician(s) with expertise in osteoporosis medicine remains a core element of a successful FLS. Ongoing funding support from the WDHB and ACC was essential in sustaining and expanding the service with recruitment of appropriate FLS personnel. It has been also invaluable to work in close liaison with our orthogeriatrician who cares for the older acute hip fracture patients. Keeping close ties and regular dialogue with orthopaedic, radiology and bone density provider colleagues allowed refinement of our service delivery. Regular monthly service meetings with a supportive service manager have been very helpful in resolving service-level issues. Regular FLS clinical meetings to discuss challenging cases and recent published literature, as well as having opportunities to attend professional development events for the clinical staff enabled us to keep abreast with the latest developments in osteoporosis and secondary fracture prevention. Strategic support and guidance from ONZ have given us a sense of direction in driving service improvement over the years.

There are numerous challenges for FLS locally

at WDHB and nationally. WDHB FLS's biggest challenge has been insufficient FTE to perform all key aspects of FLS work—especially so since implementation of 4- and 12-month follow-ups. Our FLS coordinators often had to go above and beyond allocated hours to complete all tasks. Accurate data capture and entry into database, and well as getting timely DEXA scans have been challenging at times. ACC and ONZ's recent initiatives to fiscally and strategically support FLSs for the next few years will not only help our service address our issues, but also enable other FLSs throughout the country to deliver better secondary fracture prevention. Similarly, a forthcoming national fragility fracture registry (FFR)[16] will enable individual FLS's performances to be gauged against the Clinical Standards for Fracture Liaison Services in New Zealand.[13] FFR will identify variations in FLSs throughout the country, and allow respective FLSs to use the data to drive improvement. It will also provide huge opportunities for clinical research.

In conclusion, WDHB FLS has expanded and consolidated over the years to deliver better and broader secondary fracture prevention. Nationwide implementation of effective and efficient FLS will minimise the burden of fragility fractures for our aging population.

COMPETING INTERESTS
Nil.

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Barriers to optimal stroke service care and solutions: a qualitative study engaging people with stroke and their whānau

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ABSTRACT

AIM: The aim of this study was to explore the perspectives of people with stroke and their whānau on barriers to accessing best practice care across Aotearoa, and to brainstorm potential solutions.

METHOD: We conducted ten focus groups nationwide and completed a thematic analysis.

RESULTS: Analysis of the data collected from the focus groups identified five themes: (1) inconsistencies in stroke care; (2) importance of effective communication; (3) the role of whānau support; (4) the need for more person- rather than stroke-centred processes; and (5) experienced inequities. Participants also identified potential solutions.

CONCLUSION: Key recommendations include the need for improved access to stroke unit care for rural residents, improved post-discharge support and care coordination involving the whānau, improved communication across the patient journey, and a concerted effort to improve culturally safe care. Next step is to implement and monitor these recommendations.

Stroke is a leading cause of death and disability globally.[1] In Aotearoa New Zealand, hereafter referred to as Aotearoa, stroke incidence has been estimated at up to 9,000 strokes per year and is expected to increase by 40% in the next decade.[2] In Aotearoa, inequities in access to hospital-based stroke care occur by ethnicity and geography. Our recent research shows that patients presenting to non-urban hospitals and Māori experience major access barriers and worst patient outcomes.[3,4] Although this research identified several of the issues in stroke care that need to be addressed, patient perspectives and self-determined solutions of people with lived stroke experience is required to inform next steps.

Several Aotearoa-based evaluations of patient healthcare experiences, including stroke care, report varying levels of satisfaction.[5] Experiences also differ between ethnic groups, with unique issues such as structural racism and lack of cultural safety being described by Māori and Pacific peoples, and travel and distance from family support reported by people living rurally.[6–8]

To date there has, however, been no systematic attempt to gather information on the patient's overall experience (from pre-hospital to post-rehabilitation) of stroke care across the country. Perceptions from patients and their whānau and caregivers (referred to collectively as whānau in this paper) about access to and the quality of healthcare through stroke services would provide meaningful information. Such information would be further enriched by including a diverse range of voices, including people of different ethnicities, ages, cultures and locations. There is also opportunity to explore potential solutions to improve service access for all New Zealanders.

We have previously reported on results from patient, whānau, and health provider surveys.[9] Here we report additional data obtained from patient focus groups. These groups can add particular value, as ideas are communicated in an open, supportive environment with mutual encouragement from the participants who share a lived experience.

The aim of this study was to explore patient and whānau perspectives on accessing best practice care across Aotearoa, and to brainstorm potential person-centred solutions.

Method

This is a qualitative sub-study of the wider REGIONS Care project; a multi-part nationwide observational study that investigated geographic and ethnic inequities in stroke care access and post-stroke outcomes.[10]

This sub-study specifically explored access barriers using qualitative data obtained from focus groups involving persons with stroke and whānau. This approach has previously been shown to add value,[11] and builds on prior work consisting of small focus group interviews of Māori with stroke, their whānau, and health providers and managers.[12] It offers the additional opportunity to engage with stakeholders to determine what other decision criteria might be important when deciding on service priorities (e.g., acceptability to the community and feasibility).[13] Focus groups were utilised in order to allow participants to encourage each other to comment. In addition, the focus group method of data collection is preferred when investigating cultural perspectives and diverse views.[14]

Patient recruitment

While obtaining consent for the REGIONS care project, participants were asked to indicate whether they were interested in taking part in a survey[8] and/or a qualitative focus group interview. Those who agreed to participate in a focus group underwent purposeful sampling according to age (<65 and >65), residence (urban versus non-urban), gender and ethnicity (Asian, Māori, Pacific, and NZ European). In total, we aimed to conduct ten focus groups; five at urban and five at non-urban hospitals.

Data collection

Consumer group sessions were facilitated by research staff, experienced in facilitating focus groups and impartial to the reported findings, and with little to no affiliation with the hospital services discussed. Research questions were open-ended but focused on the following themes: overall experience of care, description of difficulties in accessing services, perceived barriers to accessing services, and any suggestions to reduce access barriers. Interviews were digitally recorded and transcribed.

Analysis

Focus group interviews underwent data-driven thematic analysis. This was intended to provide flexibility and ensure data that were important to participants was captured and interpreted as intended. Key themes were named according to scope, and defined and described incorporating participant quotes for illustration purposes. Triangulation of results occurred with four researchers (MH, KB, AR and ST) to ensure robust and valid conclusions. We present participant quotes by the hospital they attended grouped into "urban" versus "non-urban" as geographic differences in hospitals was a main focus of the overarching REGIONS Care project. Urban setting was defined as hospital <25km from a city of >100,000 population.[10] We do not present quotes by individual hospital or individual patient characteristics such as ethnicity, in order to preserve participant anonymity in the setting of a small sample size.

Study consent, funding, and ethics

Focus group participants were sent information sheets prior to the meeting and given an opportunity to ask questions at the beginning of the session before providing written consent. The study was funded by the Health Research Council of New Zealand (HRC 2017/037) and received ethics approval from the Health and Disability Central Ethics Committee (17/CEN/164).

Results

We conducted ten focus groups at five urban and five non-urban hospitals. There were two to seven people in each focus group, with a diverse range of ages, ethnicities, genders and other factors, such as the inclusion of some caregivers. See Table 1 for group characteristics and Table 2 for participant characteristics.

Analysis of the data collected from the focus groups identified five themes: (1) inconsistencies in stroke care; (2) communication; (3) family/whānau support; (4) stroke-centred processes; and (5) inequities. Participants also identified potential solutions to issues.

Theme 1: inconsistencies in stroke care

Participants described the services they received and the people involved along their stroke journey, and grouped these across the timeline from diagnosis and acute care, to inpatient rehabilitation, and through to "life with stroke" in the community, as presented in Table 2.

Diagnosis and acute care

Overall, participants offered many positive reviews of the diagnostic process and acute care phase. However, some inconsistencies were highlighted, especially for young people for whom stroke was not considered in the initial differential diagnosis. This is described in detail in the Equity section below. Participants also raised some negative experiences e.g., that the stroke care workforce appeared to be "run off their feet" and not always experts in the stroke field, as these two people at opposite ends of the country pointed out:

Table 1: Characteristics of groups.

FG	Date	No. of participants	DHB – Hospital	Setting
1	28.11.2018	7	Counties Manukau DHB – Middlemore	urban
2	12.12.2018	5	Capital & Coast DHB – Kenepuru	urban
3	23.01.2019	5	Canterbury DHB – Christchurch	urban
4	25.03.2019	4	Waitemata DHB – Waitakere	urban
5	09.04.2019	4	Northland DHB – Whangarei	non-urban
6	15.04.2019	3	Waikato DHB – Hamilton	urban
7	20.05.2019	7	Southern DHB – Invercargill	non-urban
8	10.06.2019	6	Hawke' Bay DHB – Napier	non-urban
9	17.06.2019	2	Lakes DHB – Rotorua	non-urban
10	30.07.2019	3	Bay of Plenty DHB – Whakatane	non-urban

Table 2: Characteristics of patients.

Demographic information of all participants	
People with stroke	34 (72.3%)
Whānau/family	13 (27.7%)
Age range, years	32–94
Age >50	31 (91.2%)
Sex, female (%)	23 (48.9%)
Ethnicity, n (%)	
NZ European	19 (55.9%)
Māori	9 (26.5%)
Pacific	3 (8.8%)
Asian	2 (5.9%)

*Demographics data exclude whānau as data for these were not available.

Table 3: Various services involved in stroke care, as named by participants.

Acute care and diagnosis	Hospital inpatient care	Community care
Public Ambulance including helicopter General Practice staff Emergency Department staff Radiology (called the "Scanners") Hospital orderlies Hospital doctors Hospital nurses Therapists Family/whānau	Hospital doctors Hospital nurses Hospital therapists Rongoā (traditional healers) Family/whānau	Stroke Foundation Accident Compensation Corporation Work and Income Aotearoa staff Social workers Needs assessors Employers Inland Revenue Department New Zealand Transport agency (for drivers' licences) Sports and hobby groups Therapists General Practice staff Whānau

Five subthemes emerged: diagnosis, stroke rehabilitation, community, stroke units, and hidden costs.

"They were simply run off their feet. Good people trying to do a good job, but they just couldn't manage everything" – urban hospital

"They can do their best, and that's it, if they don't specialise in one thing. At the hospital you get three or four doctors coming around, and different ones come and see you … and you don't know whether they're on the button or not." – non-urban hospital

Many also described not receiving enough information, particularly to understand why they had had a stroke. This question, "why did I have a stroke?" was asked at all focus groups. When participants attempted to request further investigations to understand "why", they felt that their concerns were often dismissed or mis-labelled:

"Then something would change in you, actually, if you knew why [you had a stroke]. Because you can't see anything happening you can't understand it." – non-urban hospital

"Or I wanted to know how …. How does it heal? How long does it take? How is it going basically? Then I got told I was paranoid and suffered from post-traumatic stress and depression …. I said, 'It's not depression. It's about being active about your health. It's about wanting to know'". – non-urban hospital

Stroke rehabilitation

Descriptions of stroke rehabilitation were mostly positive, often highlighting the comprehensive care received from several different therapists:

"Great, every hour I had someone different, like a physio for one hour, and then they'd tell me to go back to my bed and have a sleep. Then I'd have a speech therapist, have lunch and I'd have another sleep, and then I'd have a psychologist in the afternoon, and all these people getting you well again. It was amazing." – non-urban hospital

Community care

Unsurprisingly, when considering the number and variety of agencies that engage with people after stroke (Table 2), there were major inconsistencies in community care, including waiting times and access to types of therapy, especially speech and language therapy. Most waited one to two weeks, but others waited two to five months for follow-up care. Consequently, people felt that their recovery had not reached full potential, or they had to improvise at their own cost:

"Seven and a half weeks before they came round home to see whether I needed a shower stool and raisers and that sort of thing. That was a bit; I was a bit peeved about that because I had to buy them. I'd had to adapt to do things myself anyway." – non-urban hospital

Some described feeling they had been lost in the system, and once "found" they were then overwhelmed by stroke service visits:

"Heard from nobody for months, and then next minute you're inundated with everybody. They all want to see you, all in that week, and 'How's this been, and how's that been?' Almost as if they're trying to catch up on what they've done … Yes, or what they haven't done." – non-urban hospital

Stroke units

When available, stroke units were generally praised for the multi-disciplinary approach, their stroke expertise, and coordination. Even those who could not access a stroke unit wished they had been able to, confirming a desire for stroke-focused, coordinated care:

"I think being in a stroke ward I think would be great for everybody, to talk about what's happened to their bodies, and how they're managing it and everything." – non-urban hospital

"I thought the cardiologists had organised it. But, I now know it wasn't; it was general medicine. So, there was a problem in the system. I found that people were operating in silos. There was no sharing of information." – urban hospital

Hidden costs

Stroke care is publicly funded in Aotearoa yet there were multiple hidden costs affecting timely and efficient access to stroke services such as:

Transport and carparks

"And especially if you've got to go to places, like they say, catch a taxi or catch a bus and everything. Sometimes with the bloody buses I go at different times, and I catch another one that misses it altogether. So, my appointments have been missed because of different times. And taxis … 30 bucks to come from there to here." – Non-urban hospital

Primary care visits, laboratory tests and prescriptions

"Coming from an earning $1,200 bucks a week right down to … $300 a week now. It's really hard. You often think 'it's not pay week this week, I can't go to the doctor this week. I'll go to the doctor next week when I've got some money'." – non-urban hospital

"Now he has to have a blood thinner – a tablet he takes now every day. His medications basically doubled since the stroke." – non-urban hospital

The impact on wider whānau, requiring time off work or spent organising assessments and care

"So we really pushed for it, emailing back and forth to [DHB] staff and the Social Worker that we really need a needs assessor before mum goes home. Me and my sister we had to take turns looking after our mum. So we, you know, one of us have to stay home with while not working and one of us will be working." – urban hospital

Theme 2: communication

Many participants acknowledged that the "FAST" message was very effectively communicated enabling the early identification of stroke, resulting in timely access to acute care:

"I was looking at his face because I automatically thought stroke, face. So at his face and nose, [and] I thought 'oh my god they all add up'. So just keep on advertising all that information to everybody." – non-urban hospital

"I was sitting down on the seat, I was falling over. And there was a girl right beside me and she's going, 'He's having a stroke.' Somebody said, 'How do you know?' She goes, 'Well, I watch bloody TV.'… And she called the ambulance" – non-urban hospital

Regarding pre-hospital general practice encounters, face-to-face was preferred as many described misdiagnoses over the phone, leading to delays in stroke diagnosis and care:

"I rang the doctor, and they said, 'Oh look, we don't have any space today.' This was a Friday, 'We have space available on Tuesday, so come in then.' I went, 'Okay.' Then Saturday

morning … I was driving, and then I veered right to the side and hit the curb, and it wasn't until then that I stopped and thought, 'hey, something really is wrong', but they said I don't need to go until Tuesday. So on that I didn't ring an ambulance, or anyone, I waited until Tuesday" – urban hospital

Communication in hospital was variable. Many commented that with satisfactory communication they felt assured and empowered:

"Everything that happened there was comforting. I felt I was being given information I needed, about what was gonna happen, what they were doing, the scan, things like that. And that was really good. It was the atmosphere that I had never experienced before … caring and support … made me feel much, much more secure." – urban hospital

However, unsatisfactory communication occurred when participants were spoken "at" or about, or when there were delays. Consequently, participants felt abandoned:

"I feel that some of the people kind of think they are so far above you … some people came into the room and they would have their own conversations with other people about you, in front of you, using terminology that I didn't understand and stuff like that, and then they'd go 'you alright?' and then they'd leave." – urban hospital

"He said, 'No you should be fine because you've got your wife to look after you. No driving for three months'. He went away and he left us to go. He said, 'We'll be in touch to put you under your own GP. Then we'll be in touch'. I still haven't heard from anybody." – non-urban hospital

As a result, people felt that they, or whānau, had to fight to be heard, and acknowledged that the required effort may be impossible for some:

"It was just little niggly fights that I had to do for myself … nobody … looking after you … I had my kids to back me up … they could go fight for me. But there's other people who come in that can't do that and wouldn't know where to start." – non-urban hospital

Some noted differences in communication styles between acute and community services. One man reported good communication from the hospital team following discharge, but a negative comment made by an acute assessment unit (AAU) nurse when he initially presented to hospital had stuck with him one year later:

"I found it was quite personal and felt like they were talking to you and not just a group of people as such and concerned about your health rather than anything else. I found that very helpful actually and quite good. It was quite nice, a nice fuzzy feeling if that's a word to use … when I got into AAU, the nurse said, 'Well, don't take your shoes off, you're not gonna stay here long'. And I thought I wasn't. That's alright … it was just one of those funny things that sticks in your mind which is weird." – non-urban hospital

Participants made a specific request for stroke services to acknowledge that good communication works best when both parties are participants. Instead, they felt an expectation to just "sit and listen" and be available when it suited the service:

"I had people come to my house. They … say to my daughter, 'Your father's never here'. She goes, 'Well, if you want to catch him, you come here at seven o'clock in the morning and catch him because he wants to up and he wants to be gone because he goes for walks. He doesn't sit at home like people do'. And they go, 'Oh well, we need to talk to him'. [She said], 'Well, that's what I mean. Here's his phone number, ring him up'." – Non-urban hospital

Theme 3: whānau wellbeing

Families were involved across the entire stroke care journey. People relied on whānau for acute assessment, medical and nursing type care, therapy, childcare, income, information and aroha (love). Aroha was expressed in different ways, with one man saying it was wonderful to have family "beside me" at every step, with benefits on his wellbeing:

"The attitude at home was good. My health at home was good. I've got some step grandchildren and man-alive they were fantastic. They were right by my side the whole time. They would eat with me even though I wasn't eating. I was doing this pump thing. They were right beside me." – non-urban hospital

People described how whānau members gave up their lives/work to support them. This first quote from a young woman talking about her mother; the second from a man about his wife:

> *"Yeah, she even quit her job, because I couldn't drive for two months either… she flew down and came to the hospital with me, and went to [rehabilitation in another city] with me, in rehab, and then lived with me, to drive me and the kids around." – non-urban hospital*

> *"I've got my wife, and I have asked her to stop working … So, my case is different. If my wife can look after me, it's better than if the government gives somebody else; because she knows in and out and she will be every time with me." – urban hospital*

Family meetings with stroke services were described as important to clarify information and ensure that everyone was on one page, as was the case for this woman talking about her husband with stroke and their daughters:

> *"We had a family meeting, and that's when it was decided about [his] licence, and because they're family, the girls came as well. They had questions to ask, and it was just about what he would be doing, was that in place, and they were very good weren't they, very helpful? That was a good meeting and it sort of set us right on what he should do, and the girls too, because they knew him and so forth, and they could sort of hear all of this too." – non-urban hospital*

Theme 4: stroke-centred versus person-centred care

Participants felt that stroke services were stroke- and not person-centred. People described having multiple tests and assessments, and felt that these were a process or box-ticking exercise rather than being focused on improving one's outcomes:

> *"I'd never had to sit and eat a meal with someone watching me eating and hearing me crunching or watching me walk, they wouldn't let me leave until they got their boxes ticked" – Non-urban hospital*

Person-centred stroke care was preferred because it was driven by the person and their whānau. For example, having rehabilitation in their own home enabled whānau involvement, allowed the therapist to understand the person better and was considered more effective and efficient:

> *"I said, 'But, he's not familiar with these [hospital] surroundings. We need to get him back home in his own environment'. I said, "Give me a week at home, you come and visit him, and I bet you he can make a cup of tea straight away'. We did that." – non-urban hospital*

Person-centred care was considered to be strengths-based, building on current personal assets to achieve personal goals, yet recognising both the good in, and burden of, having a stroke:

> *"This stroke was a bit of a blessing in disguise. I found out about my health issues and I managed to get where I wanted to be in work. But, it came at a bit of a price at the time with all the emotional stress for myself and the family." – urban hospital*

Members of every focus group said that the little things counted. For example, people wanting to go to the toilet were often directed to wait for assistance. It upset many and people described going despite, or in spite of, these orders, to maintain dignity and independence:

> *"Sometimes they don't come for ages. Sometimes they do. Mum she couldn't press the button herself, so we had to press the button for her. Eventually my mum she just started going to the toilet by herself, even though she wasn't supposed to because she was waiting there for a long time." – urban hospital*

Person-centred stroke services would also support people's "return to my life but now with stroke". A key issue for many, which reflects the "car culture" of Aotearoa, was a return to driving:

> *"Thank goodness it's only for a short period. I feel so sorry for people in the predicament that lose their licence and lose their mean of getting round. That's probably one of the worst parts, lack of transportation, independent transportation. Yeah, that's a big thing. That's it, eh? When you lose your licence, you lose your whole way where you're gonna go. That's right, you lose your independence don't you?" – non-urban hospital*

Getting back to work was also critical for maintaining a sense of the old self, and adjusting to the new. Stroke services did not feature in these narratives. Rather it seemed that this was largely left to the employers, with one describing his relief when his employer found new work:

> *"When I had a stroke my truck licence is gone. So, that was again another bit of uncertainty about whether I would return back to what was my current role. But, work were quite accommodating and they said, 'No, we can fit you into other avenues in the business'." – urban hospital*

Many worried about returning to work, based on others' or personal experiences, and would have appreciated timely advice from stroke services:

> *"I thought, 'I'll be alright, I'll be alright to go back to work.' Well, I tell you, it wasn't long. I just wore myself out. I was not ready for it. My brain was not ready for the input … I wish I had have had that information." – non-urban hospital*

All enjoyed the focus group as an opportunity to hear others' personal experiences and share their own. As one person said, it helped put their stroke in perspective and they wished the local stroke service would provide similar programmes for them:

> *"I think the reason I came here today is to hear what's happened to other people mainly to put it in perspective with what's happening to me" – Non-urban hospital*

Theme 5: equity

Participants expressed concerns about what were perceived as often unfair differences in the provision of stroke care due to rurality, age, body habitus and ethnicity. There were issues with travel to hospital on rural roads. Two people said the ambulance got lost in transit and the roads were in a bad state:

> *"I kept saying to her, 'You're going the wrong way, you're going the wrong way'. I could tell by the way she was going. So, it took an hour and a half to get from our place to Hospital." – non-urban hospital*

> *"We had a terrible drive in the ambulance I remember now, boneshaking drive." – non-urban hospital*

Some were transferred to urban centres because rehabilitation could not be adequately provided at the local, rural centre:

> *"Yeah, I was in hospital here for a week because I had to wait for a bed to come available in [the city]. I lay here for a week until I got rehab in [city] because there was just not enough beds." – non-urban hospital*

Transfers were especially hard for people whose whānau would also be isolated, or could not travel due to other commitments:

> *"I couldn't just suddenly drop everything and head up to [other centre] … the last thing I think you need to be is isolated. We've got no family in [city] of any description." – non-urban hospital*

There were also extra costs for people who lived rurally, and these weren't considered by stroke services:

> *"Yeah, mum drove my kids up to visit me, and then we had to pay for accommodation for both the kids … The kids stayed with us, with me [in hospital]. Yeah, and that's more money in accommodation, and then your petrol. It was crazy but you can't not see your children for [weeks]." – non-urban hospital*

Though not many made comments on body habitus, one man did express his feeling of discrimination about his weight while in the hospital:

> *"I felt a little bit of discrimination, while I was in the hospital to do with my stroke, about my weight … at one space there was a comment made in front of me along the lines of 'what do you expect? Based on your weight'. Also there was a conversation right outside my door, about my weight that I overheard – I was a little taken aback about that." – urban hospital*

Age specific issues included problems getting a timely diagnosis when young, as stroke is considered a condition for older peoples. One man had his stroke in his 30s and described how the first responders initially thought his symptoms were due to alcohol intoxication:

> *"I remember them asking my wife, 'Did he get on the piss last night? Is he drunk? Is he taking anything?' No. I don't do that. We're fit people." – urban hospital*

He eventually had a CT of his head and stated that:

> *"12 hours after it had started. They said, 'We've got some bad news. You've actually had a stroke'." – urban hospital*

There were also issues for some younger people to access rehabilitation:

> *"The hospital was fantastic and everything like that, but they said to him, 'You have to go to [another centre] for rehab because you're under 65'." – non-urban hospital*

At the other end of the age spectrum were descriptions of ageism:

> *"Yes, particularly me because I think most doctors immediately think that's his age. Yeah. That's what I heard. That's the first thing they say. That's what they say, because I remember they stand at the bed and they have the whole gang of doctors and. I heard him … talking to his cohort saying, 'What do you expect at his age?', those things I think, oh, yeah." – non-urban hospital*

Māori participants described the lack of Māori staff and services within current stroke services, and accessed cultural support elsewhere:

> *"I went to Māori healing, Māori rongoā, and karakia. I believed they were all those things that helped me, because there was nothing else." – non-urban hospital*

> *"Because Māori are very high up in the people that get strokes – Māori and Pacific Island – I wondered why there was not one brown face at all that I saw anywhere. So, then if they were the top end of the clientele, so to speak, where is their role model? Where is their person that would make them feel comfortable culturally perhaps." – Non-urban hospital*

Solutions

As well as sharing their experiences, participants also put forward their suggestions of solutions for these issues:

Navigators to help communication and break down silos

> *"In the end somebody said, 'You need an advocate', then once the advocate became involved, she did have trouble too, but it wasn't as bad and it got sorted out eventually. Advocates are really important." – urban hospital*

Coordinated care

> *"A stroke is not something that you bring on yourself; it is an accident. So, hearing these stories, why isn't it covered by ACC? [Stroke care could be] a bit more structured as far as your payments go, as far as your rehabilitation goes, and the constant check ups and things like that. That's what I would like to see going forward. I didn't actually realise at the time that it wasn't normally covered by the ACC. When I heard that, I just didn't understand it." – urban hospital*

More Māori and Pacific staff and services

> *"The needs assessor. Um having that more available and especially Māori and Pacific staff." – urban hospital*

> *"For me, Māori rongoā, karakia, mirimiri. Those are all things that I really believe in. I had my first lot up at the hospital actually." – non-urban hospital*

Shared experiences

> *"The very month that I had a stroke there was an article, and it was written by a chappie who's surviving a stroke. It was an American one, and it was just an extract from the book, and I got more information from that than what I did from anything else really." – urban hospital*

> *"We'd been to a stroke meeting once … and we're definitely going to go back. You got so much out of that day didn't you? It was only for about an hour, or an hour or two, just talking to other stroke patients." – non-urban hospital*

Discussion

In this study we gathered information about the views of people with lived experience of stroke about stroke care, what barriers need to be overcome and some proposed solutions.

Inconsistency in stroke care across different regions in Aotearoa was highlighted as an important issue. Participants felt that staff managing their

stroke at smaller non-urban hospitals were not always qualified to make accurate decisions and questions appeared to be not always effectively answered. People wanted to be in a stroke unit to feel more confident in their diagnosis and treatment, regardless of where they live. Communication was challenging in both urban and non-urban settings, and some people felt talked down to by health providers; something that should be addressed through raising awareness and training.

Some participants felt abandoned. They wanted their specialist doctors to continue working with them after discharge instead of giving them a list of instructions and sending them on their way. They reminded us that when someone has a stroke, it can change their entire life. Awareness about this aspect of life with stroke and ways to cope psychologically in daily life seem to be important gaps within stroke care, which should be addressed. Consumers very much valued their whānau and the support they provided. The help provided by whānau members throughout the stroke journey made people with stroke feel more supported and less alone. It is important that these voluntary services provided by whānau are acknowledged and valued as a vital part of coordinated stroke care.

Other inequities were highlighted. Driving from rural areas to hospitals made people feel unsafe and some had to drive themselves to other hospitals, which was very expensive. People experiencing strokes at younger ages often felt dismissed. Māori felt they had to seek desired Māori services outside of the public health sector. These barriers to optimal stroke care can be mitigated by providing consumers in rural areas with funding for travel and/or relocation, ensuring that stroke care is accessible for younger people, and improving availability of health services aligned with Māori values, including traditional healing.

In terms of cultural safety, several Māori and Pacific participants mentioned that they were perplexed by the limited number of Māori and Pacific hospital staff working in stroke services. When Māori doctors and other clinicians are available, Māori patients reported feeling safer and at ease; that there is already a connection between patient and clinician because of their shared culture. Especially te reo Māori speaking clinicians, as they would help address cultural and also language barriers.

Four key recommendations emerge from the outcome of this study. Firstly, there is a need for improved access to early specialist decision-making, management, and prognostication in non-urban areas. To adequately address this, centralisation will probably be required for some services, but much could be achieved through the implementation of adequately funded telemedicine coverage in rural areas. This would also reduce barriers imposed by long travel distances offering care closer to home. "Telestroke" in the hyperacute setting is already available in some parts of the country and should expand. There is, however, little, if any, remote expert support offered to generalist teams at smaller hospitals beyond the first few hours of hospital presentation, and this should be explored in earnest. Secondly, there is a clear need for shared goal setting. Some study participants did not perceive that the therapy that was delivered was of practical value to them as individuals. We know that it is important to include patients and whānau when designing and, ideally collaboratively, delivering a tailored rehabilitation programme, but we need to ensure this happens consistently and effectively throughout stroke services in Aotearoa. Thirdly, there is a need for early targeted support on discharge with ongoing specialist care provided after discharge from hospital, and a smooth coordinated transition to available non-specialist community services. The Ministry of Health has set targets around optimising the first transition (i.e., community team contact within seven days of discharge), but services struggle to meet this target largely due to resource constraints. Follow-up with specialist doctors is almost non-existent again largely due to resource limitations. Both require increased sector investment. The transition from specialist community rehabilitation support to living with stroke long-term relies largely on non-government organisations such as stroke foundations and volunteer services. Implementing "Take Charge"; a community-based self-directed rehabilitation programme to allow the person with stroke to take charge of their own recovery, is another option.[15,16] More information about available services, expanding on what is currently available, and finding effective ways to connect people with stroke with the services they want and need should be priorities moving forward. Stroke is a major life changing event, and post-stroke psychological support services are lacking entirely representing another area that requires investment. Finally, clinicians need to reflect on their communication styles, own personal biases and cultural competence. More training opportunities should be made available, and services should actively consider including course completion/demonstration of communication skills and cultural safety as part of their appraisal and certification models. The need for more Māori and Pacific doctors, nurses, and allied health professionals in Aotearoa is pressing, and needs to be a national priority.

A strength of this study is that the focus groups were diverse, including a wide range of people from different locations across Aotearoa, and of different ethnicities, ages and genders. Another strength is that these focus groups allowed people to bounce ideas off each other and to feel supported by one another when speaking about their experience with stroke. Participants expressed a feeling of consolidation when hearing about people's different experiences with stroke and the focus groups allowed for open discussions that were free of judgement, encouraging people to really speak their mind.

A limitation was that some of the focus groups were very small and lacked the diversity of perspectives that can spur more interesting discussions. It raises the question of whether we missed important perspectives. There is a possibility that if there was only one person of a certain ethnicity, age or gender in a focus group, they may have felt hesitant to speak up.

Conclusion

Much work has gone into improving stroke care processes and outcomes, but efforts have mainly focused on what clinicians, funders, and planners think people need. In this study, we have identified what is important to people with stroke and their whānau in Aotearoa. Key recommendations include improved access to stroke unit care for rural residents, improved post-discharge support and care coordination involving whānau, improved communication across the patient journey, and a concerted effort to improve culturally safe care. The next step is to implement and monitor these recommendations.

COMPETING INTERESTS
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Hospital based specialists' perspectives of teleconsultation use during the COVID-19 pandemic

Eunice Chou, Andrew McCombie, Tim Eglinton

ABSTRACT

AIMS: Teleconsultation has been widely utilised during the COVID-19 pandemic. It allows clinicians to provide healthcare social distance restrictions. This study investigates its safety and limitations in different specialties and the possibility of incorporating telemedicine into future practice.

METHODS: This was a qualitative study of 151 hospital-based specialists in New Zealand. An electronic questionnaire was sent via email addresses. These included participants' demography and their experience of using teleconsultation during the pandemic. The safety and suitability of teleconsultation were assessed with time efficiency, data security concerns, missed clinical information and specialist's ability to examine patients.

RESULTS: This study found that 92.7% of hospital-based specialists used teleconsultation during the pandemic. More specialists reported the efficiency was similar or greater with teleconsultation and most patients could be seen via teleconsultation appointments. Limitations of these were due to poor physical examination and poor non-verbal cues sensing. There isa general preference for physical consultation.

CONCLUSION: Teleconsultation is used widely across many specialties during the pandemic. Despite limitations identified with teleconsultations and preference for physical consultation, doctors are prepared to provide teleconsultations in the future beyond the pandemic. In appropriately selected patients, especially in non-procedural specialties, teleconsultation will have an increasing role in healthcare.

During the COVID-19 pandemic, social distancing has been mandated to prevent and reduce the transmission of COVID-19. Thus, traditional person-to-person outpatient appointments were highly restricted to ensure patient and clinician safety. Consequently, the pandemic became a catalyst to the rapid expansion of telecommunication, including the use of teleconsultation in medicine. Teleconsultation is often known as telehealth, telemedicine or remote consultation. It involves the clinician using an electronic device to interact with patients. These include phone calls and video conferencing via various platforms like Zoom or Skype. Zoom statistics has demonstrated a 2900% increase in meeting participants daily since the start of the pandemic.[1] This trend has been evident in the use of telemedicine with a journal article demonstrating that teleconsultation use has increased substantially during the pandemic in many countries.[2] In Europe, the number of teleconsultations via phone call and video conferencing nearly tripled over three months during the pandemic.[3]

There have been studies investigating the role of teleconsultation during the COVID-19 pandemic. Among strategies that reduce infection transmission including wearing face masks, sneezing/coughing into elbow and hand hygiene, researchers have reported teleconsultation to be an effective way of minimising virus transmission via avoiding person-to-person contact while still providing care to patients.[4]

Heavily burdened countries have used teleconsultations to diagnose and monitor COVID-19 infected patients. A systematic review[5] suggests that teleconsultation was most useful in providing non-urgent care and follow-up appointments for patients with chronic conditions during the pandemic. These specialties include immunology and allergy,[6] oncology,[7] diabetes[8] and mental health services.[9] These reports suggested that these specialties were well suited for teleconsultation that could be integrated into future practice.

No studies have investigated doctor's views of teleconsultation use during the COVID-19 pandemic in New Zealand. Most international studies have focused on the immediate benefits of remote consultations in reducing the morbidity and mortality of COVID-19 in this pandemic rather than the perceived safety and efficiency of this novel delivery of medical care and where its limitations may lie.

This study investigates the perspectives of Canterbury's hospital-based specialists on teleconsultation appointments during the COVID-19 pandemic. The aim of this study was to investigate the amount of teleconsultation used across specialties and to assess the acceptability and safety of these appointments. It also sought viewpoints concerning the possibility of continuing teleconsultations after the pandemic and incorporating these into normal practice. This study was approved by the University of Otago Human Ethics Committee, 20/057.

Material and methods

Participants

Participants were included in the study if they were hospital-based specialists working in the Canterbury District Health Board (CDHB). All specialists were invited via their email addresses to complete an electronic questionnaire on Research Electronic Data Capture (REDCap) electronic data capture tools hosted at University of Otago.[10,11] Participants provided informed consent by agreeing to complete the survey. Surveys were distributed firstly on 10 August 2020 and then on 4 September 2020, to those who did not respond to the initial survey.

Questionnaire

The questionnaire consisted of multiple-choice questions and options for qualitative comments. The first set of three questions asked of the demographics of participants; age, gender and specialty. The next set of questions asked about specialists' teleconsultation experience prior to and during COVID-19. The last set of questions asked to describe the suitability of telephone and video consultation for follow-up appointments within the specialty. These asked the ability of patients to be seen, time efficiency, concerns around data security and if any clinical information was missed due to the use of teleconsultation. Questions were also included about specialists' preferences for teleconsultation compared with person-to-person consultations and their willingness to continue with teleconsultation after the pandemic. Respondents were given the option to write comments around why they did not perform teleconsultation during COVID-19, examples of clinical information missed in patients due to teleconsultation and suggestions to improve teleconsultation.

Statistics

Microsoft® Excel® 2013 was used for data analysis, including calculations of frequencies and percentages and the subsequent pie and bar charts that were produced.

Results

Demographics

The demographics of the respondents are shown in Table 1. Fifty-one percent of hospital-based specialists who responded were female. There were 588 invitations sent out, and 151 responses were received (25.7% response rate). The highest response rate was from medicine without procedure (29.7%) and the lowest was from Anaesthetics (12.5%). Specialties that did not need to consult patients in high volumes were excluded in this study as teleconsultation was not applicable to their services.

Percentages for all variables are column percentages except for "Specialty summarised" which contains response rates within each specialty.

Specialties included under Surgery are Cardiothoracic, ENT, General Surgery, Orthopaedics, Obstetrics and Gynaecology, Paediatric surgery, Plastics, Urology and Vascular.

Specialties included under medicine with procedures are: Cardiology, Dermatology, Emergency medicine, Gastroenterology, Opthalmology, Pain medicine, Respiratory.

Specialties included under medicine without procedures are Endocrinology, General medicine, Haematology, Infectious Disease, Immunology, Nephrology, Neurology, Olders Persons Health, Oncology, Paediatrics, Paediatric oncology, Paediatric endocrinologist, Palliative care, Rehab medicine and Rheumatology.

Prior experience with teleconsultation

Overall, 20.5% of hospital-based specialists had no prior experience with teleconsultation, in the form of either telephone call or video call consultation. More than half (61.6%) had not had any experience with video call consultations prior to COVID-19 pandemic.

Teleconsultation use during COVID-19 pandemic

During the COVID-19 pandemic, 11 (7.3% of respondents) specialists did not use either form of teleconsultation. Of these, five (45.5%) stated they did not use teleconsultation as it was not suitable for their specialty. The top three specialties that utilised teleconsultation were surgery, psychiatry and medicine without procedures. Anaesthetics did not use video call consultations at all during this time. Figure 1 demonstrates teleconsultation use by specialty during the pandemic.

Safety, efficacy and efficiency

Figure 2 and Figure 3 demonstrates that all hospital-based specialists thought that most patients could be seen with either form of teleconsultation. This was

Table 1: Demographics of respondents.

Variable	n (%)1
Age	
30–35	4 (2.6%)
36–40	20 (13.2%)
41–45	21 (13.9%)
46–50	36 (23.8%)
51–55	22 (14.6%)
56–60	17 (11.3%)
61–65	13 (8.6%)
66–70	6 (4.0%)
Gender	
Female	76 (50.7%)
Male	74 (49.3%)
Specialty summarised	
Anaesthetics	10 (12.5%)
Surgery2	36 (26.3%)
Medicine with procedures3	29 (27.1%)
Medicine without procedures4	49 (29.7%)
Psychiatry	27 (27.3%)
Total response rate	151 (25.7%)
Amount of teleconsultation experience prior to COVID-19 pandemic	
No experience	31 (20.5%)
Telephone consultation only	63 (41.7%)
Video consultation only	4 (2.7%)
Both telephone and video consultation	53 (35.1%)

Figure 1: Teleconsulting use during the COVID-19 pandemic, categorised by specialty.

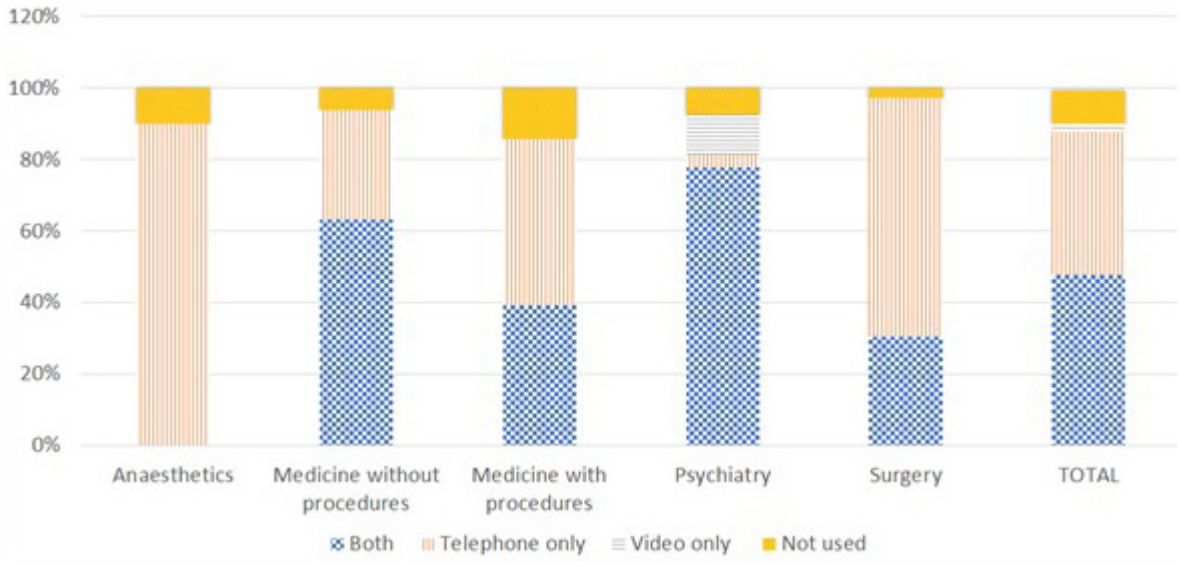


Figure 2: Pie chart demonstrating aspects of consultation missed due to not seeing patients in person.

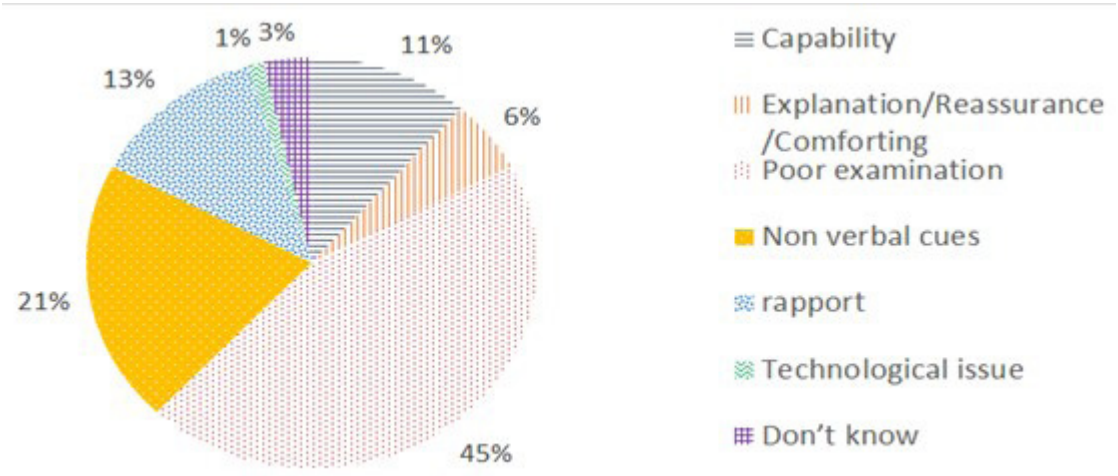
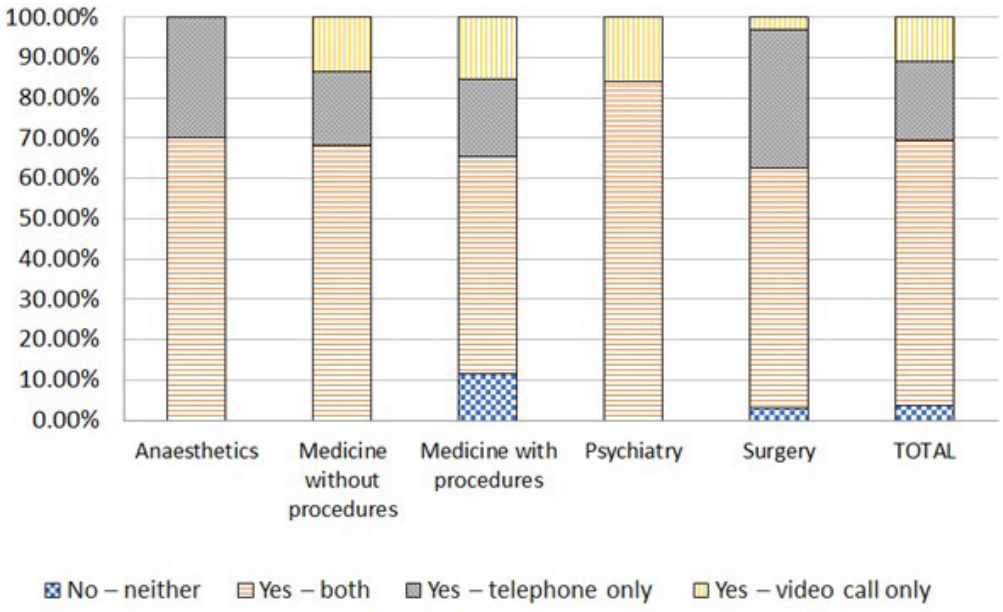


Figure 3: Providing teleconsultation in the future.



most applicable to specialties without procedures. Specialties that did not involve procedures, for example, psychiatry, thought that more patients could be seen through video consultations (88.5%) compared to specialties with procedures like surgery (63.5%) and medicine with procedures (39.1%) during the pandemic.

Appendices 1 and 2 demonstrate the number of patients seen with telephone and video consultation.

Overall, more hospital-based specialists (57.6%) believed the time efficiency was similar or greater with teleconsultation use compared with person-to-person consultations. Medicine without procedures and psychiatry were the specialties that reported the highest rates of reduced efficiency, up to 40%. Appendix 3 shows hospital-based specialists' perspectives of the time efficiency with teleconsultation use.

Despite general perceived time efficiency in this form of communication, most specialties had at least some concerns regarding internet security with video call consultations. Around 3% of surgeons and psychiatrists had great concerns.

Fifty-two-point-five percent of specialists believed they missed some aspect or information while using teleconsultation and not seeing patients physically. Out of these, 62.2% of specialists working in medicine without procedures had missed some aspect. Not having the ability for physical examination and assessment of non-verbal cues were the main restrictions from using teleconsultation as opposed to seeing patients in person-to-person consultations as demonstrated in Figure 2.

Traditional person-to-person consultation was preferred over telephone consultations in all specialties. There was slightly more support for video consultations, but still the majority preferred physical consultation over this modality if possible. Appendices 4 and 5 show hospital-based specialists' preferences for physical or telephone and video consultations overall.

Future use of teleconsultation

Figure 3 shows that after the COVID-19 pandemic is over, almost all hospital-based specialists would be happy to provide teleconsultations to patients in routine clinical practice.

Discussion

This study found that the majority of hospital-based specialists had used teleconsultations during the pandemic fitting with international literature. Despite some minor disadvantages identified with teleconsultations and a general preference for physical consultations, the majority were also prepared to continue to use teleconsultations going forward in regular clinical practice. This is relevant in a New Zealand context with many patients living rurally and so not always having local access to specialist care.

Uptake of teleconsultations was high across all clinical specialties and highest in non-procedural specialties. There are existing individual case studies that look at how teleconsultations suit their service and specialty of interest. They have shown that telemedicine is becoming increasingly popular in psychiatry, immunology and allergy, oncology, and diabetic patients.[8,12,13] Non-procedural specialists in these areas can look to replicate similar benefits in New Zealand.

There were no previous studies that used standardised measurements to compare all specialties' perspectives of providing teleconsultation during the pandemic. One study looked at personality types and their associations to provider's satisfaction rates.[14]

In this study, more than half of hospital-based specialists reported potentially missing clinical information due to not seeing patients in person physically. Forty-five percent reported this was contributed by poor physical examination ability and difficulty interpreting non-verbal cues. Two specialists have reported missed physical exam findings. They also missed relationship and building rapport with patients. The obvious limitation of teleconsultation in specialties involving procedures requires them to be performed in person. This reflects the lower uptake of teleconsultation in surgery and medicine with procedures. While these shortcomings were identified, qualitative reports from this study suggest that they were not major safety issues. Almost all hospital-based specialists were happy to provide teleconsultation to patients after the end of this pandemic.

These shortcomings could be mitigated with the addition of tools to use alongside teleconsultation. For example, some devices to aid examination (oximeters and blood pressure cuffs) could be used with teleconsultation. China has diagnosed and triaged patients with respiratory symptoms with the measures above during the pandemic with proven success.[4]

Literature suggests that initial consultations for patients with complex medical and social backgrounds should be in person to build rapport and trust.[15] This will facilitate a smoother transition to subsequent follow-up appointments via teleconsultation as a pre-existing doctor–patient relationship has been established. Relatedly, a study reported that patients in surgical specialties preferred teleconsultation for follow up appointments relative to first consultations.[16]

This is likely explained by high patient satisfaction rates reported with teleconsultations which had shorter appointment times. In this study, more than

half of hospital-based specialists found that teleconsultation was at least just as efficient than physical consultation. Patients that were determined to be suitable for teleconsultation appointments were based on SMO's discretions.

It is also important to also consider equitable access to teleconsultation given the need of internet access and suitable devices.[2] In the future, appropriate patient selection for teleconsultation will be important, utilising it in situations where physical examination is not mandatory or able to be replaced with video-based inspection or adjuncts mentioned above.

Teleconsulting could be particularly attractive to improve access to healthcare for patients who struggle to attend physical appointments due to poor mobility, poor access to transport, or loss of time at work. Teleconsultation also benefits medical staff in rural hospitals as they are able to access specialists' opinions through this platform without travelling the physical distance. There are several documented cases in New Zealand where unwell patients averted tertiary hospital admissions as the management plan was made in conjunction with specialists' advice through teleconsultation.[17]

Limitations

A limitation of this study is the response rate from hospital-based specialists. This sample population number is made up of the total number of CDHB hospital-based specialists that provided a response to the survey. As some specialists are dual-trained or are assigned under more than one specialty, the response rate may be underestimated due to some invitations being duplicated (we did not access the email addresses). In addition, it was not studied what percentage of consultations were face-to-face or via teleconsulting nor whether implementing teleconsultation increased the number of consultations overall.

Due to the nature of the study being a questionnaire, there is a lack of depth in these questions and the ability to investigate answers deeper is restricted. This study, in particular, did not investigate whether teleconsultation appointments were first specialist assessments or follow up consults. It also did not look at patients' perspectives of teleconsultation during the COVID-19 pandemic. Studies show that teleconsultation is well received by the public. This holds true, especially during the pandemic.[18] A cohort study of orthopaedic and spinal patients in Christchurch concluded that there is a high patient satisfaction rate with teleconsultations in selected surgical specialties.[19] Most public concerns were around technical challenges and poor examination.[20]

Conclusion

The COVID-19 pandemic has been a catalyst for change in many areas of healthcare. This study confirms that teleconsulting has been widely used in multiple specialties in this region during the pandemic and was generally acceptable to the hospital-based specialists, especially in non-procedural specialties. In appropriately selected patients, teleconsultation will have an increasing role in healthcare systems. With increasing specialisation and centralisation of health services, teleconsultation provides a vehicle for improved access to tertiary and quaternary specialist services whilst saving costs to patients and healthcare systems.

COMPETING INTERESTS
Nil.

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Data statement: The data that support the findings of this study are available from the corresponding author, upon reasonable request. The data will not be publicly published to maintain research participants' confidentiality.

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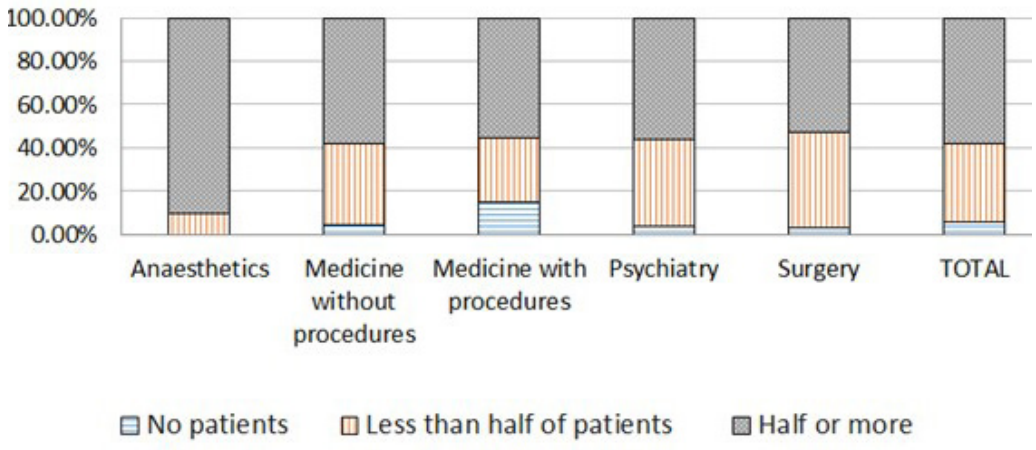
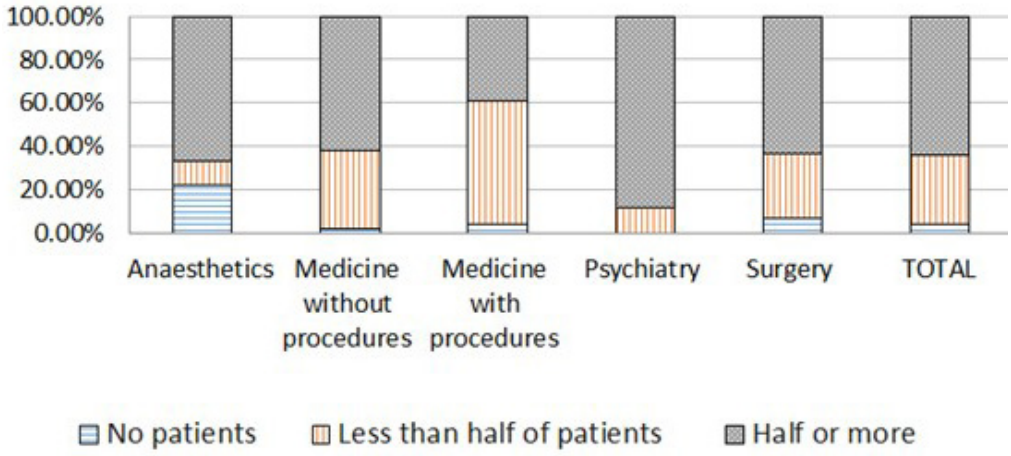
Appendices

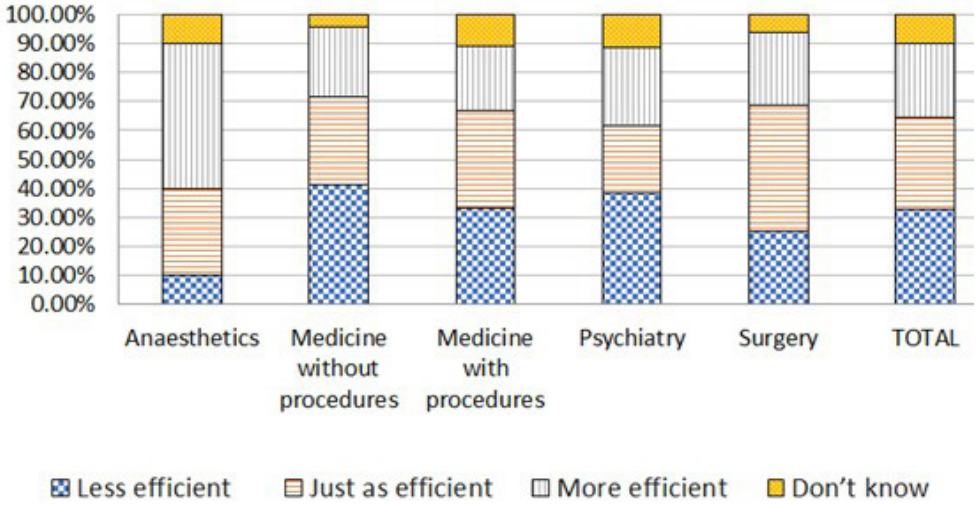
Appendix 1: The proportion of patients seen with telephone consultation if that needed to happen.



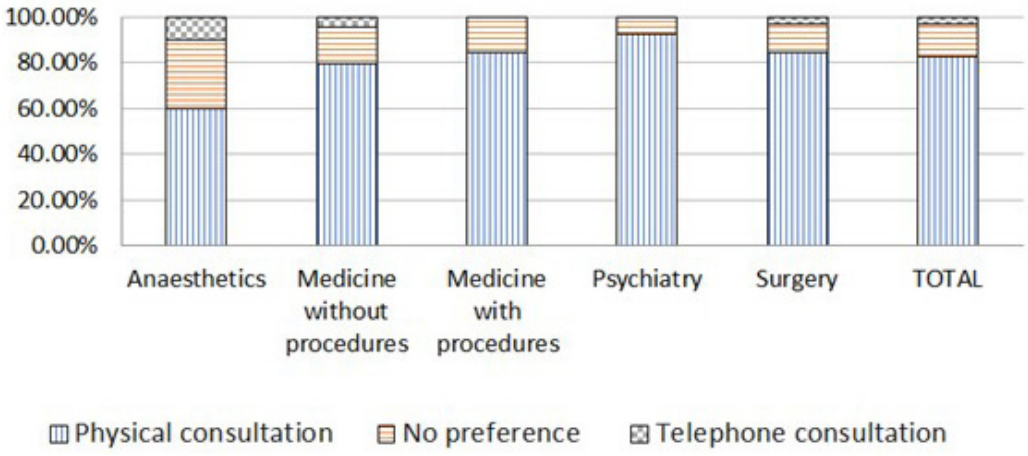
Appendix 2: The proportion of patients that were able to be seen with video consultation.



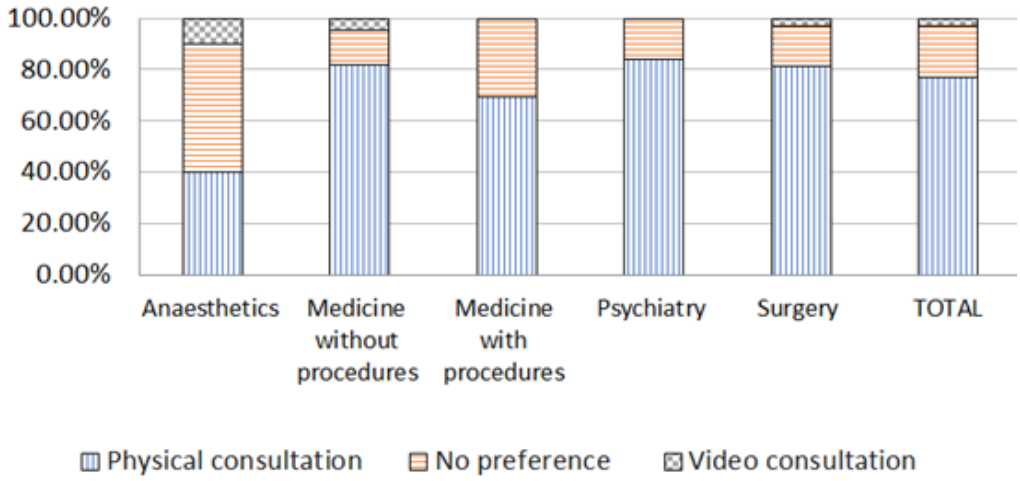
Appendix 3: Hospital based specialists' perspective of time efficiency with teleconsultation use.



Appendix 4: Hospital based specialists' preference for physical and telephone consultations.



Appendix 5: Hospital based specialists' preference for physical and video consultations.



Delayed diagnosis of HIV infection in women in the Auckland and Northland regions

Judy Gilmour, Rebecca Henley, Michele Lowe, Simon Briggs

ABSTRACT

aims: We aimed to describe the epidemiology of women with HIV infection in the Auckland and Northland regions, and to assess whether there were missed opportunities for an earlier diagnosis of HIV infection.

methods: We undertook a retrospective cohort analysis of women diagnosed with HIV infection between July 2011 and June 2021 under the care of the Infectious Disease Unit, Auckland City Hospital.

results: Fifty-six women (54 cis and 2 trans) were diagnosed during the period. Eleven (20%) were diagnosed following a presentation with one or more AIDS-defining illnesses. Three (6%) died within six months of diagnosis. Fifteen of 44 (34%) women residing in New Zealand prior to their diagnosis of HIV infection had identifiable healthcare interactions that could have resulted in an earlier diagnosis of this infection.

conclusions: Women account for one in eight of the total population of people diagnosed with HIV infection in the Auckland and Northland regions. There are currently inadequate levels of HIV testing for women in the Auckland and Northland regions. There is a need for targeted HIV screening efforts for women. HIV screening needs to be optimised to maximise coverage, normalise testing and reduce the stigmatisation associated with testing.

Anti-retroviral therapy (ART) has dramatically improved the life expectancy for people with HIV (PWH).[1] The early diagnosis of HIV infection and subsequent early initiation of ART is associated with significant health benefits and the prevention of HIV transmission.[2,3] Unfortunately, many PWH in New Zealand are diagnosed late, when their CD4 count has fallen to a level that places them at risk of, or when they present with, an AIDS-defining illness.[4] In the Auckland and Northland regions, we continue to see women whose HIV infection is diagnosed late.

The aims of this study were to describe the epidemiology of the cohort of women diagnosed with HIV infection in the Auckland and Northland regions during the 10-year period of 2011 to 2021 who received care from the Infectious Disease Unit at Auckland City Hospital; to compare these women to the cohort of men who were diagnosed during the same period and who received care from the same unit; and to assess whether there were missed opportunities where these women's HIV infection could have been diagnosed earlier.

Methods

This study was a retrospective cohort analysis.

The Infectious Disease Unit at Auckland City Hospital provides inpatient and outpatient care for adults with HIV infection residing in the Northland, Waitematā, Auckland and Counties Manukau district health board (DHB) regions.

Eligible patients were women aged 15 years and over, who were diagnosed with HIV infection during the 10-year period of July 2011 to June 2021, and who subsequently received care from the Infectious Disease Unit at Auckland City Hospital.

Demographic and clinical data were collected from each woman's medical record. These data were compared with those of the men who were diagnosed with HIV infection during the same period.

For the subset of women who resided in New Zealand prior to the diagnosis of their HIV infection, and who were not diagnosed with HIV infection at the time of the acute retroviral syndrome, we estimated the number of years since the acquisition of their HIV infection based on their CD4 count at diagnosis and data from the CASCADE study (Table 1).[5]

If a woman had a previous negative HIV test within the estimated period since her acquisition of HIV infection, then this period was reduced appropriately. We assessed whether there were potential missed opportunities for an earlier diagnosis of HIV infection for each woman during this period.

A woman met the definition of "certain or very

likely to have been infected outside of New Zealand" if she was diagnosed with HIV infection at the time of arrival to New Zealand; if she was diagnosed after arrival to New Zealand but had no sexual partners in New Zealand; or had sexual partners in New Zealand who were known to be HIV negative; or if she had an overseas sexual partner who was the definite or the very likely source of HIV infection. This decision was made by the HIV clinician and the woman at the time of the diagnosis of her HIV infection.

The Fisher's exact test, Chi-squared test and Mann–Whitney U-test were used to compare characteristics of the cohorts.

Ethical approval was granted by the Southern Health and Disability Committee (21/STH/180).

Results

During the 10-year study period, 451 adults in the Auckland and Northland regions were diagnosed with HIV infection, and subsequently received care from the Infectious Disease Unit at Auckland City Hospital; 56 (12%) women (54 cis and 2 trans women) and 395 (88%) men.

The baseline characteristics of the newly diagnosed women are shown in Table 2. Their median age at diagnosis was 37.5 (interquartile range (IQR) 29.5–45.5) years. Their DHB of domicile was Counties Manukau (n=25), Auckland (n=16), Waitematā (n=12) or Northland (n=3). The baseline characteristics of the women compared with the men who were diagnosed during the same period are shown in Table 2. There was a difference in the proportion of diagnoses made over time, with women continuing to be diagnosed in similar numbers during the study period compared with men whose diagnoses peaked in the middle years of the study period. There was a difference in the self-reported ethnicity of the women compared with the men (Table 2) or with the Auckland Region population obtained from the 2018 New Zealand Census (Table 3).[6] This showed that women more likely to be of sub-Saharan African and Pacific ethnicity, and less likely to be of NZ European/Other European/Other ethnicity; and more likely to be of sub-Saharan African and Pacific ethnicity and less likely to be of European and Asian ethnicity, respectively. Twenty-four women were certain (n=18) or very likely (n=6) to have been infected with HIV outside of New Zealand. The self-reported ethnicity of the women who were certain or very likely to have been infected within New Zealand compared with those certain or very likely to have been infected outside of New Zealand is shown in Table 4. The women who were certain or very likely to have been infected within New Zealand were more likely to self-report their ethnicity as Māori, Pacific or NZ European, and less likely to self-report this as Asian.

At the time of diagnosis, 27 (49%) women had a CD4 count less than 350 cells/mm^3 and 15 (27%) women had a CD4 count less than 200 cells/mm^3. There was no difference in the CD4 count at diagnosis of the newly diagnosed women compared with the newly diagnosed men (Table 2) or with a New Zealand wide study looking at the CD4 count at diagnosis in the cohort of people diagnosed with HIV infection from 2005 to 2010.[4]

The possible risk factors for acquisition of the 56 women were sexual transmission (n=49), sexual transmission and injecting drug use (IDU) (n=6), and perinatal transmission that occurred outside of New Zealand (n=1).

The reason for performing the HIV test that resulted in the women's diagnosis was presentation with one or more AIDS-defining illnesses (n=11), presentation with the acute retroviral syndrome (n=3), presentation with symptoms or an illness that highlighted the need for HIV testing (n=4), patient request (n=5), testing once the woman's partner or child was diagnosed with HIV infection (n=10) or HIV screening (n=23) (antenatal screening (n=8), Immigration Service screening (n=7), Community Alcohol and Drug Service screening (n=2), Prison Service screening (n=2), Refugee Service screening (n=2), Hospital screening (n=1) or Psychiatry Service screening (n=1)).

Eleven of the 56 (20%) women were initially diagnosed with one or more AIDS-defining illnesses that resulted in their HIV infection being diagnosed; *Pneumocystis jirovecii* pneumonia (n=3); *Pneumocystis jirovecii* pneumonia, disseminated *Mycobacterium avium-intracellulare* complex infection and oesophageal candidiasis (n=1); *Pneumocystis jirovecii* pneumonia and oesophageal candidiasis (n=1); lymphoma (n=2); tuberculosis (n=2); cerebral toxoplasmosis (n=1); or oesophageal candidiasis (n=1). During the same period, 34 of the 395 (9%) men were diagnosed with one or more AIDS-defining illnesses that resulted in their HIV infection being diagnosed (p=0.02).

Three of the 56 (6%) women died within six months of their diagnosis of HIV infection. All deaths were due to the AIDS-defining illness they presented with. An additional woman, who presented with cerebral toxoplasmosis, remained severely incapacitated 12 months after her presentation. During the same period, three of the 395 (1%) men died within six months of their diagnosis of HIV infection due to the AIDS-defining illness they presented with (p=0.03).

Twelve women were either not residing in New Zealand prior to their diagnosis of HIV infection

Table 1: Estimated years since acquisition of HIV infection based on the CD4 count at diagnosis.[5]

CD4 count range at diagnosis (cells/mm³)	Estimated years since acquisition of HIV infection
≤ 199	7
200–349	5
350–499	3
≥ 500	1

Table 2: Baseline characteristics of the women and men diagnosed with HIV infection in the Auckland and Northland regions July 2011 to June 2021.

Baseline characteristic		Women, n=56 (%)	Men, n=395 (%)	p value
Date of diagnosis	July 2011–June 2013	9 (16)	77 (19)	0.049*
	July 2013–June 2015	15 (27)	100 (25)	
	July 2015–June 2017	9 (16)	106 (27)	
	July 2017–June 2019	9 (16)	67 (17)	
	July 2019–June 2021	14 (25)	45 (12)	
Age at diagnosis, n (IQR) (years)		37.5 (29.5–45.5)	38 (30–49)	0.48†
Self-reported ethnicity	Māori	5 (9)	28 (7)	<0.001*
	Asian	13 (23)	76 (19)	
	sub-Saharan African	13 (23)	7 (2)	
	Pacific peoples	12 (21)	33 (8)	
	NZ European	11 (20)	172 (44)	
	Other European/Other/NA	2 (4)	79 (20)	
CD4 count at diagnosis (cells/mm³)#	<200	15 (27)	99 (25)	0.71*
	200–349	12 (22)	66 (17)	
	350–499	12 (22)	89 (23)	
	≥500	16 (29)	140 (35)	

Note. NA: not available.
*Chi-squared test, †Mann–Whitney U-test (two tailed), # CD4 count result not available for one woman and one man.

Table 3: Self-reported ethnicity of women diagnosed with HIV infection in the Auckland and Northland regions July 2011 to June 2021 compared with the Auckland population self-reported ethnicity.

Self-reported ethnicity	Women n=56 (%)	Auckland population (%)*†	p value
Māori	5 (9)	11.5	<0.001#
European	13 (23)	53.5	
Asian	13 (23)	28.2	
Middle Eastern/Latin American/African	13 (23) ‡	2.3	
Pacific peoples	12 (22)	15.5	
Other	0 (0)	1.1	

*From 2018 NZ Census data (all ages and genders).[6]
†Where a person reported more than one ethnic group, they were counted in each applicable group.
#Chi-squared test.
‡All 13 women self-reported their ethnicity as sub-Saharan African.

Table 4: Self-reported ethnicity of women diagnosed with HIV infection in the Auckland and Northland regions July 2011 to June 2021 who were certain or very likely to have been infected within New Zealand, compared with those who were certain or very likely to have been infected outside of New Zealand.

Self-reported ethnicity	Women certain or very likely to be infected within New Zealand (n=32) (%)	Women certain or very likely to be infected outside of New Zealand (n=24) (%)	p value
Māori	5 (16)	0 (0)	<0.001#
NZ European	10 (31)	1 (4)	
Pacific peoples	9 (28)	3 (13)	
sub-Saharan African	5 (16)	8 (33)	
Asian	2 (6)	11 (46)	
Other European/Other	1 (3)	1 (4)	

#Chi-squared test.

(n=8), or presented with the acute retroviral syndrome (n=4). There were therefore 44 women whose HIV infection could have potentially been diagnosed earlier if they had received HIV testing during the period that they were estimated to have had HIV infection. The median estimated duration of infection prior to HIV diagnosis for these 44 women was three (IQR 1–7) years. Fifteen of the 44 (34%) women had identifiable healthcare interactions that could have resulted in HIV testing being performed prior to their diagnosis of HIV infection (Table 5). If these 15 women had been offered an HIV test at the earliest of these interactions, it is very likely that their HIV infection would have been diagnosed a median of 14 (IQR 6.5 to 33) months earlier. Assuming that this earlier diagnosis was made, it is almost certain that three episodes of *Pneumocystis jirovecii* pneumonia, one of which resulted in a woman's death, would have been prevented as the diagnosis of HIV infection for these three women would have been made 27, 38 and 74 months prior to their presentation with this AIDS-defining illness.

Discussion

During the 10-year study period, one in eight (12%) adults newly diagnosed with HIV infection who received care from the Infectious Disease Unit at Auckland City Hospital were women. This demonstrates that women make up a significant minority of the total population of people diagnosed with HIV infection in the Auckland and Northland regions. This proportion of 12% is similar to, or somewhat lower than, recently reported proportions of 12, 19, 24 and 26% from Australia, the United States of America, Europe and the United Kingdom respectively.[7–10]

Women resided in all four DHBs in our region at the time of diagnosis of their HIV infection. There was no difference in age or CD4 count at diagnosis comparing the newly diagnosed women with the newly diagnosed men. This would suggest that as a cohort, these women were infected with HIV at a similar age and were diagnosed with this infection after a similar duration of infection when compared with the newly diagnosed men. There was a difference in the proportion of diagnoses made over time with women continuing to be diagnosed in similar numbers during the study period compared with men whose diagnoses peaked in the middle years of the study period. The causes of this difference are uncertain but include the possibility that recent HIV prevention strategies in New Zealand, such as pre-exposure prophylaxis, are more targeted at men who have sex with men, or men in general. There were differences in self-reported ethnicity when comparing the newly diagnosed women, with the newly diagnosed men or with the total Auckland population, with sub-Saharan African and Pacific women being over-represented and NZ European/European and Asian women being under-represented. These differences may have been the result of a higher rate of undiagnosed and/or untreated HIV infection in the men that some of the sub-Saharan African and Pacific women had as sexual partners. Some of the women contracted HIV infection before arriving in New Zealand, complicating any further analysis of the self-reported ethnicity differences.

Half of the women in this cohort had a CD4 count at diagnosis that met the definition of a "late presentation" (<350 cells/mm^3); this reflects current inadequate levels of HIV testing for women in the Auckland and Northland regions. This proportion is the same as that found in an earlier New Zealand wide study from 2005 to 2010.[4]

One fifth of the women in this cohort were diagnosed with HIV infection after they presented with one or more AIDS-defining illnesses. These AIDS-defining illnesses had an associated six-month mortality of 6%. These presentations illustrate an absence of HIV testing in this subset of the cohort; the higher proportion of presentations with AIDS-defining illnesses, and the higher associated six-month mortality when compared with the newly diagnosed men, demonstrates that at least a subset of the newly diagnosed women were diagnosed later than the newly diagnosed men.

The Ministry of Health recommends HIV testing for the following groups: persons with a history of unprotected sexual exposure that could result in HIV transmission; persons with a history of injecting drug use that involves the sharing of drug injecting equipment; persons seeking assessment for sexually transmitted infections; pregnant women; persons with recently diagnosed tuberculosis infection; persons with sexual contacts from countries where transmission of HIV infection is common; prospective partners in a new sexual relationship and any person whose blood or body fluids is the source of an occupational exposure for a healthcare provider.[11] Some of these groups are not clearly defined and for some of them, the healthcare provider is required to perform a relatively detailed risk-based assessment. Previous antenatal HIV testing in New Zealand following a risk-based assessment has been shown to result in the missed diagnosis of maternal HIV infection resulting in the subsequent transmission of HIV infection to the woman's new-born child.[12] The Ministry of Health's recommendations include only two indicator

Table 5: Identifiable healthcare interactions during the estimated period of HIV infection that could have resulted in HIV testing being performed.

Patient	Age at diagnosis (years)	CD4 count at diagnosis (cells/mm3)	Potential undiagnosed period (years)	Sexual health screen (n)	Earliest interaction (months prior to diagnosis)	Chlamydia or gonorrhoea from sexual health screen	Earliest interaction (months prior to diagnosis)	Abnormal cervical smear (n, grade)	Earliest interaction (months prior to diagnosis)	Colposcopy (n, grade)	Earliest interaction (months prior to diagnosis)	Other	Earliest interaction (months prior to diagnosis)	Cumulative earliest interaction (months prior to diagnosis)
1	40	4	7	8	74	C	54	1, LG	22	1, CIN1/HPV	21	ED review: viral illness, thrombocytopenia & lymphopenia	55	74
2	39	18	7	4	27									27
3	31	20	7	1	10	C	10							10
4	48	29	7					6, LG	79	2, CIN1/HPV 1, LSIL/HPV	51			79
5	29	60	7					2, LG	6					6
6	48	106	7	1	38							ORL review: asymmetric tonsils, biopsy showed reactive hyperplasia	6	38
7	30	131	7			G	12							12
8	53	156	7									SHS review: perineal discomfort	36	36
9	16	187	7									ED review: pneumonia, thrombocytopenia, lymphopenia & variant lymphocytes	3	3
10	37	319	5	1	14									14
11	26	395	3	6	29									29

Table 5 (continued): Identifiable healthcare interactions during the estimated period of HIV infection that could have resulted in HIV testing being performed.

Patient	Age at diagnosis (years)	CD4 count at diagnosis (cells/mm3)	Potential undiagnosed period (years)	Sexual health screen (n)	Earliest interaction (months prior to diagnosis)	Chlamydia or gonorrhoea from sexual health screen	Earliest interaction (months prior to diagnosis)	Abnormal cervical smear (n, grade)	Earliest interaction (months prior to diagnosis)	Colposcopy (n, grade)	Earliest interaction (months prior to diagnosis)	Other	Earliest interaction (months prior to diagnosis)	Cumulative earliest interaction (months prior to diagnosis)
12	41	453	3	5	30	C	30					Pregnancy, no HIV testing with standard antenatal screen	24	30
13	42	638	1					1, LG	1					1
14	18	650	1	1	7									7
15	38	931	1	1	1									1

Note. C: *Chlamydia trachomatis*, G: *Neisseria gonorrhoeae,* LG: low grade cervical smear change, CIN1: cervical intraepithelial neoplasia grade 1, LSIL: low-grade squamous intraepithelial lesion, HPV: human papillomavirus, ED: Emergency Department, ORL: Otorhinolaryngology, SHS: Sexual Health Service.

conditions that can be used to highlight where HIV testing should be performed. The British HIV Association's (BHIVA) recent Adult HIV Testing Guidelines recommend among their HIV testing groups, all people presenting with symptoms and/or signs consistent with an HIV indicator condition.[13] Their list of indicator conditions includes, in addition to the standard AIDS-defining illnesses, sexually transmitted infections, cervical dysplasia, herpes zoster, acute or chronic hepatitis B or C, unexplained lymphadenopathy, a mononucleosis-like illness, unexplained thrombocytopenia or leukopenia lasting greater than four weeks, unexplained weight loss, unexplained oral candidiasis and unexplained fever. The Australasian Society for HIV Medicine (ASHM) includes a very similar list of indicator conditions in their Indications for HIV testing document.[14] Using a combination of the Ministry of Health and the BHIVA/ASHM guidelines, a third of women in this cohort who were residing in New Zealand prior to their diagnosis of HIV infection had healthcare interactions where there were one or more missed opportunities for an earlier diagnosis of this infection. If HIV testing had been performed at the earliest of these interactions, these women's HIV infection would very likely have been diagnosed a median of 14 months earlier with the associated prevention of three episodes of *Pneumocystis jirovecii* pneumonia and one death. These missed opportunities demonstrate an area where a significant improvement in HIV testing needs to occur.

Almost half the women in this cohort had their HIV infection diagnosed following testing from an established screening programme. These screening programmes need to ensure that the approach they take to HIV testing results in the maximum coverage and the normalisation of this testing. Regular audits of these programmes should be undertaken to highlight areas where improvements can be made. For most screening settings, universal offer opt-out HIV testing, where people are informed that they will automatically receive an HIV test unless they actively decline, is felt to be the most effective method to increase testing coverage, normalise testing and reduce the stigmatisation associated with testing.[13,15] The different ways in which various HIV screening programmes in New Zealand offer HIV testing may result in a higher or lower proportion of women receiving an HIV test.

Current antenatal HIV screening in New Zealand illustrates how an HIV screening programme may miss some women with undiagnosed HIV infection. It was removed from the National Screening Unit's oversight in 2015, resulting in less available data demonstrating the proportion of pregnant woman who have HIV testing performed. The Ministry of Health's 'Pregnancy and Breastfeeding with HIV' website[16] states that antenatal HIV screening is a universal offer opt-in process which is likely to be less effective when compared with universal offer opt-out screening. The New Zealand College of Midwives Consensus Statement[17] takes a risk-based approach which is less effective when compared with universal offer opt-out screening: "the pregnant woman determines her risk factors following this discussion and decides whether to undertake HIV screening". There is a further hurdle to antenatal HIV screening with the Auckland and Northland community laboratory testing form including two separate tick boxes in the antenatal section; one for "1st Antenatal screen & HIV" and the other for "1st Antenatal screen no HIV"; this approach is very likely to result in a lower proportion of pregnant women receiving HIV testing and does not contribute to normalising testing or reducing stigma. In order to maximise and normalise antenatal HIV screening, we believe this test should be reinstated to the National Screening Unit's oversight, that it should be a universal offer opt-out process and that an HIV test should be included as one of the standard tests in the initial antenatal screen on the community laboratory testing form.

Consideration should also be given as to whether there are other areas where HIV screening for women would be beneficial. In this cohort, women were not diagnosed following routine General Practitioner (GP) screening which would provide a significant opportunity to diagnose women with HIV infection earlier; an HIV test should be considered as part of a GPs standard well women's check.

Healthcare providers should be aware that almost all women in New Zealand contract HIV infection from sexual transmission, with only one in eight women in this cohort having a further possible risk factor for the acquisition of HIV infection. Basing HIV testing decisions for women on the requirement of further risk factors, in addition to sexual transmission, will result in missed diagnoses.

Trans women have a higher prevalence of HIV infection when compared with other adults with HIV.[18] This higher prevalence is contributed to by a number of factors including challenges in accessing HIV prevention interventions, and high rates of sex work, substance misuse and mental health disorders.[19] There is also evidence from the UK that trans adults with HIV are diagnosed later than other adults with HIV.[19] Trans women attending sexual health clinics in Australia were more likely to be diagnosed with a sexually transmissible infection

(STI) when compared with cis women,[20] and cisgenderism and transphobia were found to be associated with a lower likelihood of recent HIV/STI testing.[21] These factors highlight that trans women in the Auckland and Northland regions need access to supportive environments where they can obtain regular HIV/STI testing.

Although the number of women in this cohort is relatively small, the Infectious Disease Unit at Auckland City Hospital is very likely to provide care for more women with HIV than any other Infectious Disease or Sexual Health Unit in New Zealand. It is possible that women who may have a higher risk of HIV infection, such as trans women and sex workers, may be more likely to receive their care from a Sexual Health Unit and so may be under-represented in this study. This study is limited by its retrospective design; there will have been other healthcare interactions that we are unaware of that should have highlighted the need for HIV testing during the period that women in this cohort were estimated to have had undiagnosed HIV infection. It is possible that some women may have been offered HIV testing during the time that they were estimated to have had undiagnosed HIV infection but declined this offer.

Women make up a significant minority of the total population of people recently diagnosed with HIV infection in the Auckland and Northland regions. This study shows that there are currently inadequate levels of HIV testing for women in the Auckland and Northland regions. This finding is further supported by the higher proportion of women who presented with one or more AIDS-defining illnesses and the higher six-month mortality when compared with newly diagnosed men. There is a need for targeted HIV screening efforts for women in the Auckland and Northland regions. The Ministry of Health's HIV testing guideline needs updating and HIV screening in New Zealand needs to be optimised to maximise coverage, normalise testing and reduce the stigmatisation associated with testing. We expect the Ministry of Health's HIV testing guideline will be updated as part of the upcoming Ministry of Health's HIV Elimination Action Plan.

COMPETING INTERESTS
Nil.

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Digital solutions for providing patients access to hospital-held health information: what are the design issues that need to be addressed?

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ABSTRACT

A patient and whānau centred healthcare system includes patients having easy access to their health records when and where they need it. Accessible digital solutions providing patients with access to their health information, including hospital-held healthcare records, will support patients and whānau to be active and informed participants in their health. A Northern Region proof-of-concept, providing patients with electronic access to their hospital-held health information, identified several challenges in the design of such "portals". The purpose of this paper is to present a discussion of these challenges, and to present a review of the literature on how other countries and health settings have managed them. The review has led to recommendations around how delegated access, auditing access, adding and correcting of information, the timing of test result availability, and retrospective records should be handled. However, more investigation is required into the challenges surrounding how various types of more sensitive information should be handled. There is still considerable work to be done on how to technically and operationally transform these "default design principles" into reality within the complexity of New Zealand hospitals' electronic health information systems.

With the increased digitisation of hospital health records across Aotearoa New Zealand, providing patients with access to their hospital-held health information should become easier. It is well known that patients want access to the health information stored by health services as well as the ability to correct any inaccuracies in the information.[1,2] The Privacy Act 2020 and Health Information Privacy Code stipulate the right for individuals to access and request corrections to their health information stored by a health service.[3]

Online patient portals have been implemented in around 70% of primary care practices, with one in five of these practices offering patient access to clinical notes.[4] However, there are no similar secondary care (hospital) patient access portals in New Zealand. There has been an incremental "best of breed" approach to building electronic health record systems in hospitals to date, resulting in an array of different systems which makes providing consumer access to their hospital-held health information difficult, and the ability to make patient corrections across multiple systems even more challenging. The New Zealand Ministry of Health recently launched Hira (National health information platform), creating an ecosystem of data and digital services. Hira is intended to provide patients with better access to and control over their health information.[5]

Several countries, such as Sweden and Estonia have a longer history of providing patient accessible electronic health records (PAEHRs) than New Zealand.[6] PAEHRs are purported to benefit patients, health services and the wider health system.[7] The benefits of patient access have included the opportunity to empower patients, inform patients about their health, increase patient health literacy, and involve patients in their own care.[8,9] Furthermore, a key benefit is quick and easy access to health information whenever it is needed, including when accessing care with a different provider/service. This convenient access is also particularly advantageous in emergency situations.[8] Being able to give family/whānau or caregivers access to patient health information has also been regularly noted as a benefit.[8] Although the benefits to patients seem vast, it is important to consider that the use of electronic platforms to provide patients access to health information could potentially contribute to increasing inequities resulting from the digital divide. Access is not equal, despite the widespread availability of the internet and personal digital devices, with those already experiencing poorer health outcomes having lower access.[10,11] Internationally, those from

ethnic minority groups, those with lower income levels or those from lower levels of education have been found to be less likely to adopt PAEHRs.[12] Implementation of PAEHRs should occur alongside strategies to address the digital divide and ensure all can benefit.

There is some evidence of clinician resistance to providing patients with digital access to their health records. Much of this appears to stem from resistance to change or to learn new systems, concerns about time management and impact on workload, potential impact on patient rapport, and concerns about patient anxiety and confusion.[7,13–15] Some resistance from clinicians has been linked to concerns about how transparent records may interfere with the clinician–patient relationship. This was particularly so for mental health clinicians, who reported changing the way that they wrote if they knew the patient was going to be able to see their notes.[8]

As part of continuous quality improvement processes the Northern Region Health Systems Design Council and healthAlliance recently set up a platform with Waitematā District Health Board to give a selected group of patients access to some of their hospital healthcare information for six weeks. This proof-of-concept was designed to identify the issues that would need to be addressed in the design of a future consumer hospital-held information portal. The online portal, named Mabel, enabled the small group of consumers access to view their hospital letters, test results and medication records from Northern Region DHB datasets. Users were given a web link to use to log on to Mabel from an internet-enabled device at any time during the period it was available. Access to Mabel was view only with no ability to edit or add information. After having access to Mabel users could provide optional anonymous feedback on the service. Users reported Mabel to have high usability and found several benefits from having access to hospital-held their health information. The main benefits identified by users were around being able to access the information they did not otherwise have easy access to, having the information all in one place, being able to track information over time, being able to access it whenever they wanted, and feeling more informed and involved in their care.

> *"Having a comprehensive overview of all results from blood tests, etc, compiled in one place. I would not usually have access to all of the information unless I went through a (somewhat convoluted) process to obtain it from my GP. Only the most significant results are normally provided, so it was helpful to see them all."*

Although Mabel received positive user reports, the proof-of-concept encountered many data-related challenges due to the complexity of the many data systems and difficulties related to integrating data seamlessly for the user. The project took longer than expected due to the exploration of clinical concerns, privacy, and security risk clearance.

Making available and supporting a portal for consumers to access their hospital data is mired in governance challenges, such as who can take what action, upon what data, in what situations, and using what methods. Moreover, there was a lack of common terminologies, coding of information or data standards across the various clinical systems as well as operational standards to reduce errors in classification. It was recommended that future projects invest resources in finding national or international guidelines and evidence on governance and system design in a number of areas. These areas included:

1. What should be the age of personal access, and how should the transition from parental access be managed?
2. How should delegated access to the portal be managed?
3. How should sensitive information be managed?
4. Should patients have access to information, such as test results, before their clinician has had an opportunity to discuss their implications with them?
5. How should patients be able to audit who has accessed their health records?
6. Should patients be able to add their own data, and how should patients be able to correct any incorrect information in their record?
7. How far back in time should patient access to retrospective records go?

This paper discusses these challenges and presents a review of the literature on how other countries and health settings have managed them, as well as how they have been managed in the New Zealand primary care context. Finally, it provides recommendations for potential solutions for the New Zealand secondary care (hospital) context.

Age of access

The question of when a child or adolescent should gain access to their personal health record, and furthermore when parental access should cease, is complex. As a child grows and develops into a young adult,

they become better able to comprehend their personal health information and make decisions about their care. This progression to independence comes with an expectation that health professionals and the health system will respect their autonomy over their health information. When it comes to the personal health record, adolescents should be encouraged to have access if requested.

In New Zealand, when a child turns 16 they are entitled to full access to their health records and parental access can cease. Due to the complexity of this issue, the Royal New Zealand College of General Practitioners published a guidance on patient portals which included access for young people.[15] Their guidance on portal access for young people aged under 16 includes the options of:

- access for the young person only (if there are determined to have sufficient maturity and understanding),
- shared portal access for both the young person and their parent(s) or guardian(s), or
- access only for the parent(s) or guardian(s).

Contrary to this, portals in New Zealand primary care such as ManageMyHealth™, ConnectMed, and myindici, state in their terms and conditions that access is limited to those 16 or older,[17–19] and that parental access should cease at 16.[18] This highlights the discrepancies between national guidance and what vendors offer.

Internationally, countries vary in the age of access to PAEHRs. Some countries allow individual access from ages as young as 12, with shared access for parents and children until ages 16 or 18, at which point the record becomes restricted for parents and entirely owned by the child.[6,20] In some cases, the parent is required to request access and the adolescent to either grant it or be notified when a parent has accessed their record.[6,21]

It has been recommended that differential access should be provided for adolescents and parents, allowing parents to view non-confidential information in the child's record, and giving the child the ability to hide information from the parent (e.g., sexual health information). Similarly, parents should be able to restrict their child's access to specific sensitive family information that the parent contributed to their record (e.g., family history of genetic diseases, substance abuse).[21] Importantly there cannot be a one size fits all model as there needs to be exemptions to allow full parental access for unusual or complex situations (e.g., intellectual disability). In all situations, however, the privacy settings would ideally be customisable by the adolescent to protect their confidentiality.

Delegated access

Beyond the complexity of the age of access to PAEHRs, there are challenges of providing delegated access for whānau or caregivers involved in a person's care. Many patients have whānau, friends or caregivers who help them navigate the health system, and who play an active role in supporting them to manage their health. To do this effectively having access to the patient's health record is essential, but without a delegated access functionality they will require the patient to share their login information presenting privacy and security concerns.[22,23] Proxy access to primary care portals in New Zealand is available with patient permission but, anecdotally, informal sharing more often takes place.

International studies indicate that a high proportion of patients want a delegated person, a care partner, to be able to access their health records.[24,25] In our proof-of-concept, 58% of users who provided feedback reported that they would like the option to give someone they choose (e.g., a whānau member) access to view their health information in the portal. Estonia is an example of where delegated access is an option, and patients can delegate access to an individual who can then view the patient's personal information and purchase prescribed medication on their behalf.[20] Similarly in Australia, delegated access is available where carers can register and then view and add to their family member or clients' records.[20]

A qualitative study in Germany highlighted that, although patients find it helpful to be able to share their health records with care partners, they want the option to withhold some information and prefer proxy access.[26] Proxy access should allow the delegated person to access the patient's information through their own login and password, to prevent sharing of that patient's login details. This helps to ensure that providers can tell who they are exchanging messages with (i.e., patient or their care partner) and protects the patient's privacy.[27] These preferences have been echoed by a number of papers and commentaries reviewing the personal health record system in the US.[27–29] The US literature recommends that the service should allow the patient granular control over what their care partner can access and action; for example, choosing what information their care partner can see, whether they have the authority to book appointments on the patient's behalf, order prescription refills or communicate with providers. In summary, it is clear that PAEHRs need to have the

option of delegating access, but this needs to be made as user-friendly as possible and reduce the need for sharing of passwords or for care partners to log in as the patient.

Sensitive information

Allowing patients the ability to hide some information from their care partners, parents or children, raises the question of what is considered sensitive health information and how this should be managed. Generally, sensitive information includes information pertaining to domestic violence, genetic information, mental health information, reproductive and sexual health, and substance abuse.[30] Evidence shows that patients prefer granular control over what information their health care providers can access, and this is true for both sensitive information and their health record in general.[31]

In a US study, patients indicated they would not want to share their entire health record with any healthcare professional, and preferred to be able to control what they could access. This preference was stronger when the patient had sensitive information in their record, or for clinicians who were not their primary care provider.[31] Many countries, such as Switzerland, Australia, Denmark and Estonia, have already allowed patient control over what information their health care professional can access. In some cases, there are "break the glass" protocols, allowing clinicians to access restricted patient information in case of need/emergency, or if the patient is not able to communicate their preference.[20,32] Concerns have been expressed by both patients and clinicians about the restriction of clinician access to information impacting the quality of care. A study of US clinicians showed that while providers respected patients privacy, they felt that patient restriction of data could harm clinician–patient relations and quality of care.[33] A patient sample in Belgium also believed that restricting information from clinicians could impair their quality of care, and felt it was the patients' responsibility for any negative consequences that may occur from hiding information from their clinician.[34] These studies highlight the balancing act between patient preferences and health care provider needs when it comes to privacy and restricted access.

"Break the glass" protocols are already used in some contexts in New Zealand hospital systems, such as for access to full mental health service notes where these are held in separate systems from the rest of the hospital record. The use of these protocols is generally audited to ensure that use was appropriate.

Automatic visibility of health information

One of the most frequently used and most liked part of Mabel was access to test results. Patients reported that it allowed them the ability to track changes over time and take a more active role in their health.

> *"I could easily take an interest in my own health data; I didn't have to wait to see someone to get a test result or notes."*

> *"In the past, I wouldn't be informed if my test results were normal or slightly off. with Mabel I can check this myself, so I don't have to wonder."*

Although access to test results has clear benefits, the use of patient portals for accessing electronic health records can result in patients having access to health information—such as new test results—before a clinician has had the opportunity to discuss the results with them. A mixed-methods study from the US indicated that patients highly valued rapid access to test results before they have been reviewed by their clinician, or before they had met to discuss them. However, it also suggested that such access may lead to increased anxiety and increased rates of patient contacting/visiting their clinicians due to confusion, and therefore add to clinician workload. It was proposed that adding clinical interpretation notes in the record would help to mitigate these negative consequences,[35] and is commonplace in primary care portals.[23]

In contrast, a recent study in the Netherlands showed that accessing test results before reviewing them with a clinician did not result in significant negative consequences. Any anxiety experienced by the patients was not thought to exceed that caused by the alternative—delay in the test results to allow for clinician review—or the anxiety when delivered abnormal results in person by their clinician. Confusion was more prevalent than anxiety but considered to be less concerning, and it was suggested this could be alleviated by improving communication within the health record, such as clinician notes and minimising time between results being released and a follow-up appointment.[36]

A final notable study showed similar results indicating insignificant changes in anxiety and confusion in most participants. Of the few who did experience negative consequences, the results released were considered sensitive or highly emotive, such as relat-

ing to suspicion of cancer or incurable genetic conditions. A patient group in a recent study in Belgium preferred concerning test results to be delivered in a consult setting face-to-face with their clinician.[37] This highlights the potential benefit of being able to categorise sensitive test results for clinician approval before release. This would allow clinicians to withhold any distressing or confusing results until they were able to speak with the patient or, similarly, not release such results at times when the patient cannot ask questions; for example, just before the weekend.[37]

There are identified benefits to automatic loading of test results into PAEHRs without clinician moderation.[38] A study with cancer patients illustrated the benefits of patients accessing test results prior to their appointments, as it allowed patients to be more prepared and have questions ready for their clinician prior to the appointment.[39] The results showed that accessing results prior to review by their clinician was not associated with increased anxiety, which is similar to the results of another study in cancer patients.[40] Further, it is thought that automatic access may mean that patients pick up important results in the rare cases that these fall through the cracks between various clinicians/services in the hospital setting.

These studies highlight that there are clear benefits to the automatic loading of test results, but that there may be a degree of heterogeneity between different patient samples and contexts. In summary, the evidence recommends that within patient portal systems: there is the ability to categorise sensitive test results for clinician approval before release; that there is space for clinician interpretation notes in the record; that if not immediate there is a time cut-off for automatic loading of results if not actioned by a clinician; and that if possible individual patients should have the ability to choose whether they are able to access their results automatically in their health record or only through a clinician.

Auditing

A variety of access and auditing of access protocols exist across different countries and electronic health record systems. A key characteristic of access control is whether health provider access to the record requires explicit consent from the patient, or whether it is implied. Most countries require the patient to give explicit consent for their information to be shared with healthcare providers, although there are some situations where consent is implied if the patient has a therapeutic relationship with the clinician. Even when patient consent is given, there can still be other guidelines in place, such as in Switzerland, where healthcare providers have further defined safety and access levels.[32] Other countries, however, such as France, have implied consent whereby the creation of the electronic health record requires explicit consent but from then on consent for sharing information is implied.[41] In France, patients are sent a text message when a new physician accesses their information, so that they are aware of who is accessing their information. This is similar to a process in Denmark, whereby patients are sent a letter if a clinician with no known therapeutic relationship to the patient accesses their record.[20,42]

As mentioned earlier, many countries allow patients to control what information their clinicians can access, particularly access to sensitive information.[20,32] Where countries have a "break the glass" protocol allowing clinicians to access restricted patient information in the case of emergency,[20,32] the patient is informed of this exceptional access later. However, Australia differs in that if a patient has hidden information, a clinician cannot access it even in an emergency.

Auditing, and the ability for patients to view the audit results on who has accessed their record, varies between countries, with some countries requiring audits to be done internally, others independently. For example, in Estonia electronic patient record systems are independently audited every two years, while in Sweden access logs to patient records are required to be verified regularly and systematically by healthcare providers and documented or stored for 10 years.[41] In many countries, including Australia, Denmark and Estonia, all patient record access activity is logged, and these log files are accessible by the patient, and they can report irregularities.[20] In New Zealand, primary care patients are not able to easily audit who has access to their primary care records.

Patient additions or edits to the health record

Previous work has highlighted that many patients want the ability to edit incorrect information when they identify this in their records.[2] Furthermore, the Privacy Act 2020 and Health Information Privacy Code stipulate the right for people to access and request corrections to their personal health information stored by the health service.[3] Current processes for requesting and handling corrections to their information are time- and resource-intensive on both sides. PAEHRs could potentially allow people to directly edit certain information (such as changes to address or phone number) or to make additions of information to the record.

Although there is consensus that patients should

have the ability to request corrections to information in their records, there is little published on the actual use and impact of patient requested amendments.[43] Generally, patient additions to electronic health records are limited to personal information such as demographics, current medications and allergies, and do not allow patients to edit information that has been entered by others.[44] This allows patients to ensure their information is correct, while protecting the integrity of clinician's input. Where patient portals do not allow patients edit access, if a patient would like information to be edited or amended they can request this through their healthcare provider.[45] This is the case in the New Zealand primary care portals, where patients are generally advised to contact their general practice through their portal regarding errors and for corrections, and do not have the ability to add to or edit their health record directly.[22] In our proof-of-concept, the ability to identify errors and correct them (by contacting their clinician) was seen as a benefit of the use of the portal.

> *"There were a few discrepancies I noticed regarding medical equipment I use which I was able to address with my healthcare provider."*

Further to correcting health information through patient portals, there is benefit to patients adding to the record with their own information (e.g., symptom reporting, treatment outcomes, activity logs). Like patients' corrections of their records, there is little published on the processes and benefits of patient additions to their electronic records. Allowing patients to add to their electronic health records allows patients to provide their clinicians with up-to-date information, supports better clinician understanding of the patient's health,[46] and also improves the accuracy of the records.[47] It is recommended that digital solutions for providing patients with their health information should allow patients to enter their own information, supporting easy and convenient data collection and improving the accuracy of the records.[48]

How far back in time should records be made available

Many health records preceded the rise of technology in healthcare or the concept of sharing notes with patients. Therefore, at the time of documentation many clinicians would not have considered this a possibility. Questions arise as to whether it is appropriate for all available records to be available to patients in digital form, or if this should be limited to only those from a specific time point onwards.

Internationally, there is variation in the extent to which historical data is included in digital solutions providing patients access to their records. When rolling out their electronic health record, Estonia made a national standard that all information from 2009 must be included.[6] In contrast, in most other countries it was up to the regional government or healthcare provider to decide to what extent historical data was to be displayed (Sweden, Norway, Denmark, Finland, France, Netherlands, Australia, New Zealand, US). When implemented in Denmark, there was an overview of personal medical history included from as far back as 1977 (which includes information such as a list of contacts with hospitals), whereas the overview of contacts with general practitioners only went back as far as 2003 (the year the electronic health record was implemented).[20] While there was variation among the different countries, most countries only give patients access to records from the date at which the electronic system was implemented—anything older had to be requested as a paper copy. As most health systems have been guided by what is feasible, there is no answer to the question around what leads to a better experience for patients.

Discussion and recommendations

A patient and whānau centred healthcare system includes patients having easy access to their hospital-held health information when and where they need it. Accessible digital solutions providing patients with access to their hospital-held healthcare records will support patients and whānau to be active and informed participants in their health. Our proof-of-concept raised many design questions that will need to be answered in any future digital consumer access to hospital-held electronic health records.

As other countries have more experience of large scale secondary care PAEHRs, there is much we can learn from them. This review of the available evidence has shown that there is variation in PAEHRs around the world and that the design challenges we identified are not always easy to solve. From this review, it appears that there are some areas where the design will be relatively easy to agree, based on the evidence and the New Zealand context. Some will require investigation of technical solutions, and some may require legal/privacy considerations and potentially national mandates (e.g., how far back records should go).

In summary, this paper discussed a number of challenges that need to be addressed in the design of PAEHRs. Based on how other countries and New

Zealand primary care have managed these, we recommend that digital solutions for consumer access to hospital-held health information include the following:

- The option of different access levels where the primary user can provide their delegated whānau or caregiver proxy access to their record with selected functionalities. This will allow support people to be actively involved in supporting a patient;
- The ability for adolescents to have access with the ability to restrict parental/caregiver access for sensitive information. Adolescents taking an active role in managing their health should be encouraged, and therefore access should be available if and when they want it;
- Along with the automatic and immediate loading of test results, the ability for patients to hide the visibility of non-clinician reviewed results if they prefer. This will minimise anxiety associated with delays in test results, but allow choice for those that would prefer to wait;
- A patient-facing log of all users, and accesses to their electronic health records, so patients have the ability to know who is accessing their record and when;
- The ability for patients to add to and comment on information in their record, and the assurance that existing pathways for correcting information should continue. This will ensure patients can actively participate in their care but will also ensure the integrity of the health professional's judgement is not compromised.
- Transparency by healthcare providers about the date from which records will be made available through electronic solutions (with the principle of 'as far back as makes sense to consumers and clinicians'), and assurance that other processes for accessing records earlier than this date continue. This may vary due to digital information systems, and technical and clinical processes within each provider.

The above could be seen as the ideal default settings for the New Zealand health system across both primary and secondary care. There will no doubt be some variation across the system, but we suggest this should be transparent and justified for the public.

Other areas still require further investigation before default settings could be agreed, including how to manage sensitive health information. It is recommended that further work with consumers in Aotearoa New Zealand is undertaken to better understand their expectations on these issues.

Conclusion

A Northern Region proof-of-concept providing patients with electronic access to their hospital healthcare information identified several challenges in the design of such "portals". International and New Zealand primary care portal examples and evidence have led us to make several recommendations around delegated access, auditing access, adding and correcting information, the timing of test result availability, and retrospective records. However, more investigation is required into some challenges around how various types of more sensitive information should be handled. There is also considerable work to be done on how to technically and operationally turn these "default design principles" into reality within the complexity of New Zealand hospitals' electronic health information systems. This will no doubt lead to some variation in their implementation. Still, shared aims and principles would undoubtedly be a good start to empowering patients to be more involved in their hospital-based healthcare.

COMPETING INTERESTS
Nil.

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Symptomatic hypercalcaemia following the use of calcium sulfate beads in periprosthetic joint infections

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ABSTRACT

Calcium sulfate beads (CSBs) are used as a method of delivery of antibiotics in periprosthetic joint infections, non-union and chronic osteomyelitis.[1–3] Symptomatic hypercalcaemia can occur as a complication following the insertion of CSBs however it is rare and few cases have been reported.[4–7] The cause of hypercalcaemia is poorly understood.

We present the case of a 76-year-old woman who developed symptomatic hypercalcaemia following the insertion of CSBs for a periprosthetic joint infection.

A 76-year-old woman was admitted with a right periprosthetic hip fracture and underwent revision arthroplasty the following day. One week later she developed a complicated infected right hip wound. Corynebacterium tuberculostearicum, Enterococcus faecalis and Staphylococcus epidermidis were isolated. She underwent a washout of her hip and placement of 20mls of CSBs impregnated with vancomycin and gentamicin. She was commenced on intravenous vancomycin two days following her operation.

Six days following the placement of CSBs she developed a delirium with poor oral intake, polyuria and hypovolaemia.

Laboratory analysis determined that she was hypercalcaemic with a calcium level of 3.1 mmol/L, a corrected calcium of 3.3mmol/L and an albumin of 20g/L. Of note prior to the insertion of CSBs her corrected calcium was 2.4mmol/L. Her creatinine preoperatively was 56umol/L and eGFR 85 mL/min, but subsequently deteriorated with a creatinine of 137umol/L and eGFR 32 mL/min. Plasma parathyroid hormone was suppressed at 1.2pmol/L (1.6–7.0 pmol/L). Thyroid function tests demonstrated a T4(free) of 13pmol/L (8–16pmol/L), and a TSH which was slightly elevated at 6.7mIU/L (0.4–5.3 mIU/L). Serum vitamin D was normal at 97nmol/L (50–150nmol/L). Serum immunoglobulins, serum free light chains and serum protein electrophoresis did not show any evidence to suggest multiple myeloma. A CAT scan of her chest, abdomen and pelvis did not show any evidence of malignancy or granulomatous disease.

She had no prior history of hypercalcaemia, calcium disorders, parathyroid disease or kidney disease. She was not on any medications known to induce hypercalcaemia. She was receiving annual zoledronic acid for osteoporosis, her last dose having been given 11 months prior to her hip fracture.

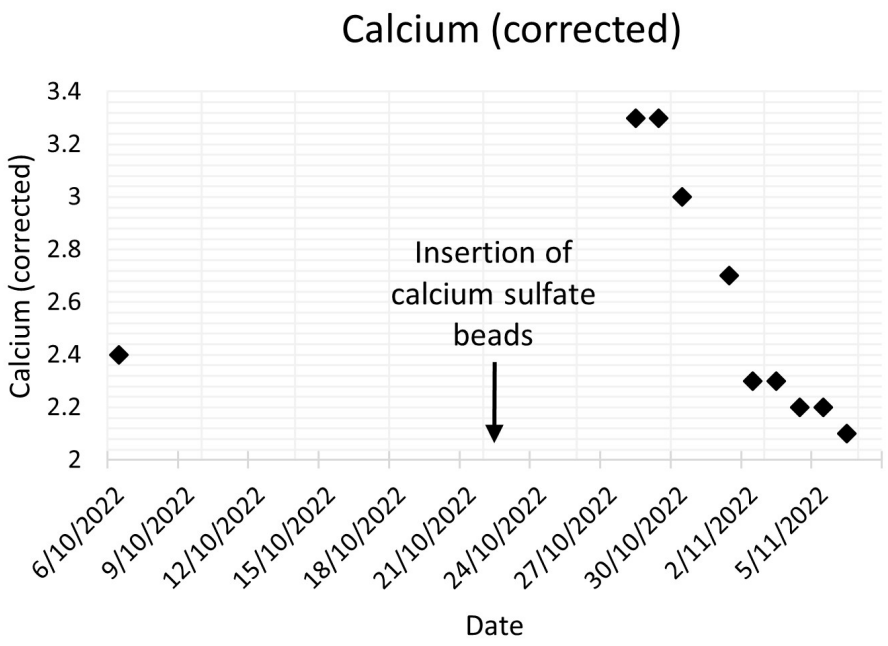
Her acute kidney injury was thought due to hypovolaemia and hypercalcaemia. Intravenous vancomycin was started four days prior to the diagnosis of hypercalcaemia. Daily vancomycin levels were at the lower end or below the target vancomycin concentration range. Vancomycin was not thought to have contributed to her kidney injury. She was not on any other nephrotoxins. She had an indwelling catheter throughout her post-operative period. Her CT abdomen did not show any significant renal tract lesion nor obstruction.

She was initially managed with large volume intravenous normal saline. Her hypercalcaemia improved only slightly and she was therefore given intravenous zoledronic acid. Her calcium subsequently normalised over several days (see Figure 1). Her renal function returned to normal.

Discussion

The use of CSBs is increasing, particularly as a method for delivery of high doses of antibiotics locally in orthopaedic surgery.[2] In our centre (serving a population of 550,000), CSBs are used in operations 25–30 times per year. They are advantageous in that they do not need subsequent removal as they are completely resorbed.[3] Symptomatic hypercalcaemia has been reported as a rare complication of CSBs. A recent literature review in 2021 by Tarar et al[8] identified a total of 1,049 patients who underwent CSBs implantation, of which 44 patients

Figure 1: Changes in corrected calcium levels pre- and post-surgery.



developed hypercalcemia. Of those, three patients developed symptomatic hypercalcaemia requiring management. Our patient developed symptomatic hypercalcaemia following the insertion of antibiotic impregnated CSBs, requiring treatment with aggressive fluid replacement and zoledronic acid.

There is very limited data to fully elucidate the cause of hypercalcemia following the placement of CSBs. Possibilities include premature breakdown of the CSBs, location of the bead placement near increased vasculature, or more rapid absorption of calcium from the beads.[9] A 2018 study by Kallala et al[6] indicates a possible dose dependent relationship between CSBs and the development of hypercalcaemia, and recommended a maximum dose of 40mls per operation. Our patient received only 20mls being half this recommended maximum dose for CSBs.

In conclusion, hypercalcaemia following placement of antibiotic eluting CSBs is a rare and poorly understood complication of this treatment. In a very few cases such as ours, symptomatic hypercalcaemia requiring treatment can occur. For best practice, patients should be informed of the possible complication of hypercalcaemia following the placement of CSBs, and serum calcium and renal function should be monitored pre and post-operatively. In patients at high risk for hypercalcaemia, such as those with primary hyperparathyroidism, kidney disease, critical illness, or prolonged periods of immobilisation, other methods should be considered for treatment of orthopaedic infections. Given the increasing use of CSBs in orthopaedic practice and increased potential for complications following their use, further investigation and studies are required.

COMPETING INTERESTS
Nil.

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Management dilemma in metastatic papillary thyroid carcinoma

Cheerag Bharatbhai Patel, Omid Ahmadi, Charles de Groot, James Sanders

ABSTRACT

Papillary thyroid cancer is the most common type of well-differentiated thyroid cancer. It is associated with a survival rate greater than 95% with appropriate treatment, particularly in younger patients. We present the unique case of a 25-year-old male with severe Autistic spectrum disorder (ASD) with a right level V neck mass of several months. Due to his severe ASD, his first assessment was conducted in the hospital foyer, and every subsequent clinical assessment and blood test required a general anaesthetic (GA). He was subsequently diagnosed with T2 N1b M0 (Stage I) papillary thyroid cancer. He required extensive multidisciplinary team (MDT) input to determine the goal for his treatment whilst taking into consideration perioperative care, wound management, compliance with exam and blood tests, radioactive iodine administration and lifelong medication requirements if total thyroidectomy was considered. Following multiple MDT and family meetings, the decision was made to proceed with right hemi-thyroidectomy, right level I-V and central neck dissection. He required one-week stay in the intensive care unit under sedation post-operatively, and was discharged from hospital a further six days later with no complications. He is currently being followed-up every six months which presents its own challenges.

This case highlights the extraordinary challenges and considerations that need to be made when dealing with surgical pathology in a patient with severe intellectual disability, even in the setting of a relatively common surgical pathology.

Papillary thyroid cancer (PTC) is the most common type of well differentiated thyroid cancer. Thyroid cancer affects over 300 individuals in New Zealand every year with an incidence of 5.2 per 100,000 population.1 Papillary thyroid cancer is staged according to the American Joint Committee on Cancer, which will classify the extent of disease at diagnosis, guides treatment, and which informs prognosis.[2] With appropriate treatment, five-year survival for localised PTC or PTC with only regional nodal spread is around 99%.[3] The American Thyroid Association recommends total thyroidectomy and adjuvant radioactive iodine in the setting of bulky nodal metastatic disease and the British Thyroid Association also similarly advocates for a total thyroidectomy.[4–5] However, it may not always be possible to follow these treatment guidelines.

We present the unique case of a young man with severe Autistic Spectrum Disorder (ASD) who presented with Stage I PTC with bulky nodal disease. While generally, advanced papillary thyroid cancer with nodal metastases can be effectively treated and cured—particularly in young patients—cases that are compounded by co-morbid severe intellectual disability can require departure from gold standard treatment. There is little published on this subject to date.

We explore the multiple challenges around managing this unique case and the inventive, flexible approaches that were required to provide the best outcome for the patient. This case provides several useful learning points to help inform future clinical management of young cancer patients with co-morbid severe intellectual impairment.

A 25-year-old male with severe ASD was referred to the Department of Otolaryngology, Head and Neck surgery at Waikato Hospital for a right-sided level V neck mass. This mass had been noted by carers for approximately six months prior to presentation and it was felt that it was increasing in size. There were no obvious associated aerodigestive, systemic or constitutional symptoms.

His medical background included severe ASD, which meant that he was non-verbal and employed only very basic communication techniques. He lived in a permanently staffed residential care facility. Functionally, he mobilised independently in the care facility and generally was directable in following commands. He was non-compliant with medical examination. His weight and height were 86kg and 188cm, respectively, meaning that patient transfer and restraint if necessary was considerably more challenging.

Due to the severity of his ASD, his first clinical assessment had to be performed at the entrance of the hospital due to his reluctance to come inside the hospital. Physical examination was a very

brief palpation of the neck mass which felt solid, measuring approximately 3cm by 4cm and corresponded to the right level V region. The complete history, although limited, was obtained from his main carer. A decision was made to complete further comprehensive assessment under general anaesthesia (GA). This required considerable coordination with the surgical and the anaesthetic team, and to ensure the availability of an ultrasound (US) machine, radiologist, and pathologist. Under GA, an US scan of the neck by the surgical team revealed multiple abnormally enlarged right sided lymph nodes in levels III–V and a suspicious, hyperechoic ill-defined right thyroid nodule with microcalcifications. A comprehensive oral and panendoscopic examination was unremarkable. A fine needle aspirate (FNA) of the thyroid nodule and a core biopsy of the abnormal lymph nodes was completed, which was examined in theatre and reported as abnormal cells consistent with a neoplastic process. The patient was then taken intubated to the radiology department for a computed tomography (CT) scan under GA.

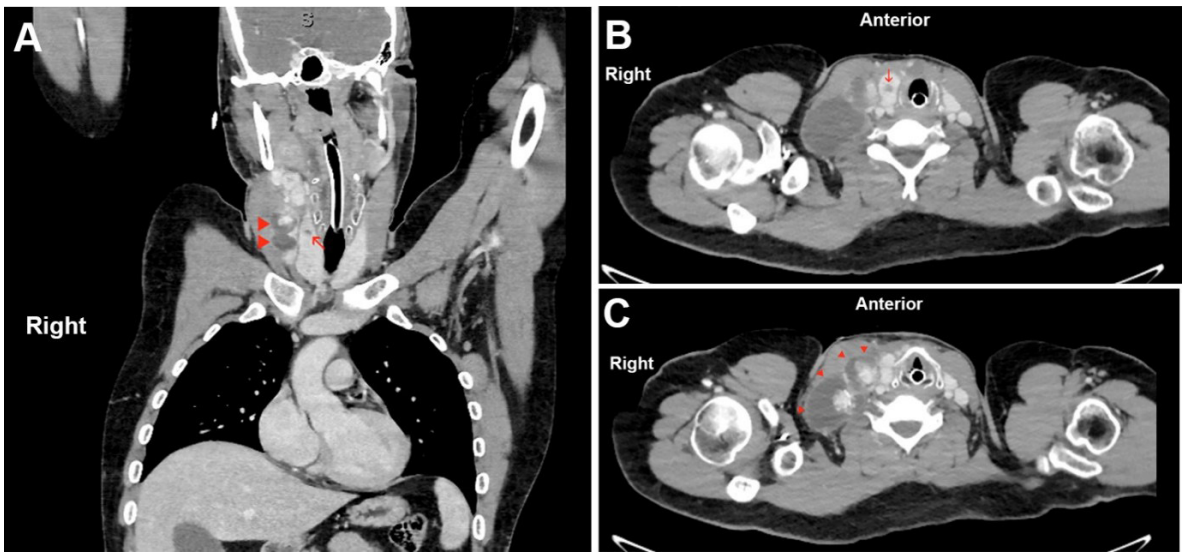
This confirmed multiple right sided pathologic lymph nodes—many of which were cystic—involving levels II–V and level VI, complete internal jugular vein effacement, and sparing of the common carotid artery and trachea. He also had a number of blood tests while under GA, which revealed normal thyroid function tests.

Histological analysis was consistent with metastatic papillary thyroid carcinoma (PTC), radiologically staged as T1b N1b M0.

Extensive multidisciplinary team (MDT) discussions included the family; carers; local head and neck cancer MDT; members of the surgical, anaesthetic, palliative care, radiation oncology, and intensive care teams; a medical physicist; and a clinical nurse specialist. The challenges with radioactive iodine (RAI / I^{131}) included a lack of confidence that the patient would swallow the capsule or liquid I^{131}. Spitting of the I^{131} if swallow was attempted or with endoscopic placement of I^{131} would lead to likely exposure of staff members. The challenges of isolation for radiation protection in the immediate days after consumption were considered. Ultimately the risks of radiation exposure to public or staff were deemed too high. In addition, it became clear that the patient was likely to interfere with the surgical wound, dressings and drains, and there was a serious concern with the ability to nurse him in the immediate post-operative period. Non-compliance with blood tests and need for lifelong medication, especially in the setting of total thyroidectomy, were also explored.

Eventually, it was decided that a right hemithyroidectomy and right lateral (I–V) and central (VI–VII) neck dissection would be completed, level VII representing paratracheal fibro-adipose tissue below the level of the suprasternal notch. To manage the perioperative period a plan was devised, with collaboration of the intensive care unit (ICU), to keep him intubated for approximately seven

Figure 1: A) Coronal CT slice demonstrating right neck lymphadenopathy with cystic component (u) and thyroid nodule (→) in the superior aspect of the right thyroid lobe. **B)** Axial CT slice of the right thyroid lobe nodule (→). **C)** Axial CT slice demonstrating right neck lymphadenopathy with evidence of central necrosis and scattered calcification (u) .



days until his surgical drains could be removed and his wound had largely healed. An anaesthetic plan was also devised to minimise preoperative distress with a considered medication regiment with specific dosing. He received 40mg of Diazepam at home pre-operatively, and 800mg of Ketamine in the hospital transit lounge 25 minutes prior to the first observation in the operating theatre. He was then transferred from his car seat to a pink evacuation sheet to the operating theatre with monitoring on and gas induction was initiated once he arrived in theatre. The operation took place three weeks after this discussion, he remained in the ICU for eight days and for a further four days in the ward before being discharged home without complication. His surgical drain was removed while he was still intubated in ICU.

The main tumour was 23mm in maximum diameter with extension into but not beyond the extra-thyroid fat pad and there was 0.02mm clearance at the closest resection margin; however, adjacent level VI tissue was excised as a separate specimen. Ten of 47 lymph nodes were positive for PTC, and the largest lymph node was 45mm in size. The final histological diagnosis confirmed pT2 N1b metastatic papillary thyroid carcinoma. His case was re-discussed post-operatively in the local head and neck cancer multidisciplinary meeting, with a consensus for him to undergo surveillance neck US assessment under GA every six months. The total duration of surveillance is still to be decided.

It has now been 12 months since his surgery, and he has remained well without any evidence of disease recurrence on post-operative follow-up, with clinical and ultrasonographic examination and blood tests including thyroglobulin tumour markers under GA.

Discussion

This case highlights the unique challenges of managing cancer in individuals with severe intellectual impairment such as with severe ASD. While the gold standard therapy in this case would have been total thyroidectomy, neck dissection, and RAI,[6] multiple issues beyond oncological standard of care had to be considered.

Verbal communication can be a significant problem for patients with severe ASD, with nearly 80% being unable to express their needs verbally.[7] Interacting with the healthcare setting can predictably provoke anxiety for an individual with ASD, and this can often be severe.[8] The combination of anxiety, difficulty with communication, and not being able to understand and fully participate in their own health problems necessitate extensive multidisciplinary team input. The unique challenges in this case demanded an inventive approach to manage the post-operative period. This ultimately led to the joint decision to keep him intubated in the ICU until the initial wound healing was complete and drains were removed.

Some of the challenges in this case, such as non-compliance with RAI and radiation risk to others, were unavoidable and have been previously documented in similar cases.[9–10] In this case, challenges that were explored included whether RAI therapy would be completed in hospital or in residential care; the risk of chewing and spitting out the RAI tablet; and exposing healthcare workers, carers or co-residents to radiation. Involvement of the medical physicists helped guide decision making in this area. Patient self-care while isolating such as feeding, washing and dressing were important issues that also had to be explored, as well as the psychological distress of change to routine and isolation.

However, other issues can be managed and optimised. A systematic review of perioperative management of paediatric surgery patients with comorbid ASD identified three important themes. These were:

- collaborating with the caregiver;
- establishing a system to communicate to the perioperative staff the information gathered from the caregivers;
- adopting an individualised approach to managing the perioperative environment based on the information gathered from the caregivers.[11]

These recommendations should be considered for all patients with ASD presenting to the hospital for surgical pathology. Additionally, we would advocate for institutions to establish guidelines to help manage surgical patients with ASD with attention to the unique demographic needs of their patient population. In New Zealand, for example, additional effort should be made to deliver culturally appropriate care to Māori, as well as the multitude of other cultures within New Zealand.

While conventional gold standard treatment guidelines should be considered and adhered to where possible, these should be customised in light of the unique challenges that some patients with ASD present with. In this case, these included concerns regarding ability to adhere to lifelong

requirement for medication, non-compliance with regular blood tests, and risk of radioactive harm to both patient and others. Risk of radioactive harm due to non-adherence to strict self-isolation during RAI treatment is a unique consideration for thyroid cancer management.[9–10] This further necessitated deviation from conventional treatment in this case. The key lessons learned from this case are the importance of being patient- and caregiver-centric, being inventive, and having regular MDT involvement and a willingness to deviate from conventional treatment guidelines when managing surgical pathology in patients with ASD.

COMPETING INTERESTS
Nil.

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A short review of bone surgery: fractures and their treatment

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In the last decade of last century and in the first of this the great development of operative surgery drew the surgeon's attention from the treatment of fractures. Arbuthnot Lane is the man who aroused the surgeons of Britain from their lethargy in this direction, by his insistence on the desirability of treating fractures by open operation.

A commission of British Medical Association was set up in 1910 to investigate the late results of fractures treated by the old method of setting and immobilisation by splints, and of the newer methods of massage and mobilisation and open operation. The verdict of this committee, given in 1912, was a revelation to surgeons for so high was the percentage of ultimate bad results of the conservative methods that confidence in them was rudely shaken. Cases treated by Lane's operative method gave the best result. A strong fillip was thus given to the method, and it was largely used by surgeons in all parts of the world. On the other hand, the Liverpool school, with Robert Jones at its head, continued to follow and develop the principles laid down by Owen Thomas for treatment of fractures by means of careful "setting" under deep anæsthesia, and the maintenance of fragments in true alignment by means of extension and immobilisation of the limb in the special splints with the name of Thomas is associated.

Both methods of treatment have a common aim, that of the replacement and maintenance of the broken fragments in accurate apposition, perfect anatomical restoration. The Fracture Committee stated that "there is a clear interdependence in fractures between the anatomical and the functional result. If the anatomical result is bad, the functional is bad in more than 50 per cent of cases. If the anatomical result is good the functional is good in 90 per cent." Therefore, the most certain way to attain a good method, whether operative or non-operative, which does not definitely provide a good anatomical result, should be accepted as a method of choice.

The war did more than anything else could have done to bring about the developments in the treatment of fractures. The conventional methods of putting up fractures were soon shown to be thorough ineffectual, and many ingenious forms of apparatus were devised, some simple, and some most complicated. From the contest for superiority, the Thomas splints and their modifications emerged easily first on account of their simplicity, the comfort which they gave the patient in transport, the ready access for the dressing of wounds, and the good control which could be exercised over the broken fragments. These splints were adapted to the upper limbs as well as lower, and were fitted with attachments for the suspension to overhead bars. The lessons learnt in the war hospitals are only slowly being applied to civil practice. Particularly is this the case with regard to the Thomas splint, which should be the standard splint supplied in ambulance outfit, and its methods of application routine teaching in first-aid classes.

We may consider our general treatment of fractures under three main headings:—(1) Massage and mobilisation; (2) splint and extension; (3) operation. They cannot be looked upon as independent methods, for any two, or the whole three, may be used in combination.

(1) **MASSAGE AND MOBILISATION**.—Massage owes its effectiveness largely to a reflex action. When a bone is broken the ends lacerate the surrounding tissues and cause painful stimuli to pass to the spinal cord. In response powerful efferent stimuli are sent to the muscles which pass into a condition of spasm which is the principal factor in producing and maintaining displacement of the site of fracture. By light rhythmical stroking movements applied to the skin over the site of injury countering influences are sent to diminution in displacement. Besides this action massage and early mobilisation of the limb both passively and actively have most beneficial effect is promoting the absorption of effusions from the tissues generally and from the joints and tendon sheaths specially. The nutrition of the limb is thereby promoted and the reparative process has-

tened. Muscular atrophy, painful neuritic symptoms, impairment of movements of joints and tendons are all avoided, and the limb is ready for full function immediately that union is sound. In many fractures of the upper limb excellent results are obtained by the use of this method and a simple arm sling. The type of fracture to which the method is most applicable is that where there is little original displacement, or where reduction is easy and redisplacement is unlikely, e.g., Colles' fracture. The disadvantage attending its use alone is the amount of personal attention and time which it requires. Of its immense value as an adjunct to other methods of treatment there can be no doubt.

(2) **SPLINTS AND EXTENSION**.—This must be the most general method of treatment. It is essential that as accurate as possible primary reduction of the fracture shall be secured, and for this powerful extension under deep anæthesia is often required. As I have said before, the Thomas splint and its modifications have the widest field of usefulness. It facilitates the moving and the nursing of the patient, and by its means effective extension and counter-extension can be applied. Robert Jones considers that there are a few fractures which will not yield to a patient and skilful use of this method. Lateral and over-riding displacement can usually be readily overcome, but more difficulty is experienced with axial displacement, especially of short fragments, and to meet these difficulties new splints have been devised, with the object of bring these distal fragments into line with the proximal, i.e., frames for carrying the upper limb in a position of abduction or abduction and outward rotation in fractures of the upper end of the humerus; for the maintenance of supination in fractures near the proximal end of the radius, and for wide abduction of both lower limbs in fracture of the neck of the femur. Plaster of Paris cases are of great service for similar purposes. Extension is, of course, most commonly applied by means of adhesive strapping, but in certain cases other devices are useful. In a fracture of the leg bones where the condition of the skin precludes the use of strapping, the Sinclair foot piece, which is attached to the foot by a special glue, may be applied. In other cases, such, for example, as the supracondylar fracture of the femur, greater extension may be required for reduction than can be attained by means of strapping. Various forms of direct extension to the bone may be used. Stenimann's pins may be driven into the femoral condyles, or the condyles or the tuberosities of the tibia may be drilled, and a metal rod put through, or an apparatus known as the ice tongs may be made to grip the femur. I have used Stenimann's method on several occasions in difficult cases with good results, weights of between twenty and thirty pounds being put on. The pins generally work loose in about three weeks, and in future I shall adopt the transfixion method in such cases. The disadvantage is the liability to a slight bone necrosis and persistence of a sinus for some time after removal of the pin. Hey Groves describes a double transfixion apparatus for use in fractures of long bones. The upper and lower rods are connected by a pair of vertical rods which can be elongated by means of a screw tube.

(3) **OPERATION**.—On the indications for operative interference there has been much debate. Important factors are the facilities for securing a perfect aseptic technique and the familiarity of the surgeon with this particular class of work. The main indication for operation is the failure to restore the bones to a correct anatomical position by extension methods applied for ten days. Operation should, I think, be the routine treatment in fractures of the patella and olecranon, and it is very often called for in the case of detachment of a process from the bone as in fracture of a condyle, trochanter of malleolus. There is a great variety in operative methods to select from:—(1) *Operative reduction and retention by external splinting*.—This is often all that is required in a spinal fracture of the tibia where the fragments can be made to dovetail. (2) *Suturing*.—This may be used especially in patella and olecranon fractures, wire being the commonest substance used. In fracture of the patella I pass a wire round the circumference of the bone and draw in the fragments. In some patella cases, catgut suture of the ligaments is sufficient to maintain position. Encircling wire may be used to hold together long oblique fractures, but it is apt to interfere with the blood supply, and so delay osteogenesis. (3) *Screwing and Pegging*.—Pegs or screws of metal, ivory, or bone, are used to fasten on detached pieces of bone such as malleolus or condyle. (4) *Plating*.—The use of metal plates such as internal splints is too well known to require discussion. The main objection raised to their use is that their presence has an inhibitory influence on callus formation. It has happened in my own practice on several occasions that no repair in a fracture tibia took place until the plate was removed, when it rapidly occurred. Rutherford Morrison figures a striking case in which callus formation in a plated femur was present only on the side of the bone distant from

the plate. Another objection raised against the presence of plates is their tendency to loosen from the bone, to cause irritation and a serous outpouring into the tissues with sinus formation, necessitating removal of the plate. I have recently seen a case in which, two years ago, I plated a mal-united fracture of the radius. The result was satisfactory until a month ago. The patient was carrying a heavy piece of furniture when she felt the bone snap. X-ray examination showed a transverse fracture through the lowest screw hole, the bone having been partially absorbed around the screw. To overcome their objections fixation with plates made form boiled beef bone has been introduced. These are fixed in place with bone screws and both plate and screws become incorporated with the living one. This appears to be an ideal method. Gallie and Robertson report 100 successful cases so treated. (5) *Bone Grafting*.—The great exponent of this method in treatment of ordinary fractures is Albee. He deprecates the use on any non-absorbable foreign material. He favours the use of a sliding inlay graft cut with the twin saw of his motor outfit.

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Interweaving diabetes care – wellbeing of the Tongan people with Type 2 diabetes mellitus in New Zealand

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AIMS: Quality standards for diabetes care and a range of initiatives have not improved outcomes for Pacific People with Type 2 Diabetes Mellitus (T2DM) in New Zealand. This research examined the meaning of being Tongan with T2DM in New Zealand, Tongan people's food practices, and strategies and services that are needed to improve diabetes management for Tongan people with T2DM.

METHODS: This study used a combined talanoa and hermeneutic phenomenology approach undertaken by a Tongan researcher for, and with, Tongan leaders to explore their lived experiences. This approach built upon Tongan values of listening to stories and seeking to find the meaning through interpretation of those stories.

RESULTS: Diabetes services for Tongan people with T2DM require a Tongan worldview and holistic approach that encompass mo'ui lōtolu, wellbeing of sino (body), 'atamai (mind), and laumālie (spirit/soul) to fulfil fatongia (duty/obligations). Participants acknowledged the importance of receiving practical and meaningful information that involves family, church, and community. Food practices and diabetes management is never about an individual. It is always about wellbeing within collective communal living. This approach is symbolised by a Tongan food basket, *Kato Polopola,* interweaving talanoa and the holistic approach that is fundamental to mo'ui lōtolu. *Kato Polopola* recognises the critical role of the loto (heart), the centre of authority in deciding what to accept and reject. The importance of loto'i Tonga (Tongan heart), willingness to transform knowledge into action and maintaining an authentic relationship (vā). It is about no one thing, it is about all the strands (factors) woven together, held by 'ofa (love/heart), 'ilo (knowledge/mind) and lotu (prayers/spirit).

CONCLUSIONS: Tongans with T2DM need meaningful information and appropriate support to enable commitment for sustainable behavioural changes. There are possibilities for modifying practice to enhance the ability of service providers and the Tongan community to get the benefit of talanoa and contextualised services.

Increasing insulin pump uptake at Counties Manukau DHB by enhancing clinician expertise

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Whitiora Diabetes Service at CMDHB had the opportunity to improve service delivery, and address long standing issues with equity following seed funding from the Ministry of Health (MOH) under "Improved Planned Care". Since September 2012, when pump therapy became a funded option, patient update has been low, with Māori and Pacific underrepresented. In 2021, the service began revising support for patients with diabetes, including professional development for clinicians.

AIMS: To improve clinician expertise to support patients using pump therapy within Whitiora Diabetes Service. With an increase in clinician expertise, we hypothesised that referrals for pump would increase, particularly for Māori and Pacific.

METHODS: The diabetes multidisciplinary team (MDT) completed an online survey using SurveyMonkey regarding pump expertise, and professional development needs. This was used to develop a staff education programme. The programme was developed and delivered by the pump project team and industry representatives. Fourteen staff education workshops were held over nine months in 2021. The survey was completed again at cessation of the programme to evaluate its effectiveness, and gaps in the education programme. Pump referral rates at the end of the staff education programme were compared to the year prior to the programme.

RESULTS: Twenty-five specialist diabetes clinicians from the MDT completed the pre-workshop survey. Fif-

teen have completed the post-workshop survey to date. Preliminary results indicate that staff report increased knowledge and confidence to support patients using pump therapy. Referrals for pump therapy have increased by 700% over the last 12 months.

CONCLUSIONS: A significant clinical and service benefit has been achieved through the implementation of a MDT training programme. Enhancing clinician expertise has an important contribution to CMDHB's goal to increase uptake, and successful use of pump by people with diabetes who have had lower rates of use to this technology, particularly Māori and Pacific.

Diabetic foot interventions to improve outcomes for Indigenous populations in high-income countries: a scoping review

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AIMS: Indigenous peoples represent 5% of the world's population.[1] They experience higher rates of diabetes and associated complications than non-indigenous people, including poorer outcomes for diabetes foot disease (DFD).[2,3] Providing equitable care through well-organized diabetes foot interventions can improve outcomes.[4] This scoping review provides an overview of the literature on diabetes foot interventions that incorporated a focus on equity for Indigenous peoples.

METHODS: This review followed the PRISMA-ScR guidance for scoping reviews.[5] MEDLINE, Informit indigenous collection, CINAHL, PsychINFO, SCOPUS, and Embase were searched to the 17 June 2021 using search terms relating to the diabetic foot, interventions, and Indigenous peoples. All publications were eligible if they described a diabetes foot intervention that included Indigenous peoples from high-income countries. Two reviewers independently screened titles, abstracts, and full-text publications, and contributed to data charting. Key study characteristics included country, Indigenous population, intervention description, any foot-related outcomes, and alignment with the CONSIDER statement.[6]

RESULTS: We screened 730 publications and 30 met the eligibility criteria. Interventions focused on indigenous peoples from Australia (n=12), Canada (n=6), USA (n=6), New Zealand (n=2), Greenland (n=2) and Nauru (n=2). Primary prevention interventions were predominant (n=20) with a focus on increasing foot screening rates (n=16). Other interventions included health promotion and education (n=4), comprehensive foot interventions (n=4), a diabetic foot ulcer management protocol, and a service brokerage model. Only one study of the 27 evaluated met all the CONSIDER checklist requirements; 55% (n=15) met fewer than 9 items; few (n=3) met both items in the participation domain.

CONCLUSION: A limited number of diabetes foot interventions in the literature described diabetes-related foot outcomes for Indigenous peoples. Specific cultural approaches to foot interventions were not evident. To inform future DFD policies and programs and help guarantee equitable outcomes, research led by non-indigenous researchers needs to be conducted in partnership with Indigenous communities.

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The Australian and New Zealand Diabetic and Ischaemic Foot Outcomes Study (ANZ-DIFOS): preliminary findings

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AIMS: Diabetic foot disease (DFD) is a common and debilitating condition. In New Zealand, there is a high incidence of lower limb amputation during hospitalisation for DFD and an over-representation within New Zealand Māori populations.[1,2] The Australia and New Zealand Diabetic and Ischaemic Foot Outcomes Study (ANZ-DIFOS) is a binational prospective study with an aim to report the presentation, management, and outcomes of DFD.[3]

METHODS: This multicentre study includes Waikato Hospital, New Zealand; Sir Charles Gairdner Hospital, Perth; the Royal Adelaide Hospital and Queen Elizabeth Hospitals, SA; and Prince of Wales Hospital, Sydney. Participants with DFD that meet inclusion criteria will be reviewed at baseline, 1, 3, 6 and 12 months. Service and referral details, demographic, and clinical history, wound and perfusion data, outcomes and discharge information will be collected. The primary outcomes are time to wound healing, major amputation, overall mortality, and amputation-free survival at 12 months. Recruitment began in August 2020 in New Zealand, February 2021 in Perth, March 2021 in Adelaide, and July 2021 Sydney.

RESULTS: Only NZ data are discussed. One hundred and twenty participants were included, with a median age of 69 years (range 30–91 years), 39 were females and 49 (41%) identified as New Zealand Māori. Major limb amputation at 30 days was 7.5%, with 25 (21%) and 28 (23%) participants overall having undergone a major limb amputation and a minor limb amputation respectively. Furthermore, 68% of major limb amputations occurred in Māori participants. The 30-day mortality is 1.7%. Overall, 20 (17%) New Zealand participants have died, with 50% of these deaths occurring in Māori participants.

CONCLUSIONS: This preliminary data from ANZ-DIFOS highlights the burden of DFD. Whilst recruitment and follow up are ongoing, this study may show emerging evidence of the risk of lower limb amputation, variations in treatment and outcomes in DFD.

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Is it feasible to use first antenatal HBA1C to target Northland pregnant women at high risk for gestational diabetes mellitus for earlier intervention?

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AIMS: HbA1c levels fall by approximately 10% in early pregnancy so first antenatal Hba1c 36–49 mmol/mol may indicate pre-diabetes. National guidelines recommend referral to diabetes services only if HbA1c is in the diabetes range of 50 or greater; screening for gestational diabetes mellitus (GDM) at 24–28 weeks' gestation for all others. In Northland, GDM screening and treatment is often delayed or difficult due to geographical spread and low socio-economic status. We therefore sought to establish whether referral based on first antenatal HbA1c would capture women with GDM earlier and allow better intervention. We also audited whether national guidelines are being followed.

METHODS: We captured all women who had a first antenatal HbA1c at any Northland laboratory between 1 January to 31 December 2020. We focused on women with HbA1c 36–49 and completed pregnancy. We collected basic demographic data, GDM screening results and subsequent outcomes.

RESULTS: There were 240 women, 67.9% Māori, of 1,593 completed pregnancies, who had a first antenatal HbA1c of 36–49 mmol/mol. Of these, 21.6% were not subsequently screened for GDM (40% in subgroup

First antenatal HbA1c	GDM (number of women)	No GDM: polycose only	No GDM: OGTT	Not screened
36–40	31	74	63	42
41–44	10	2	3	8
45–49	4	0	1	2

HbA1c 41–49 including two women who had polycose test only). Of those who were screened, only 23.9% had GDM. Of the 30 women with HbA1c 41–49, five required emergency caesarean section (two treated for GDM); four newborn were macrosomic (two GDM pregnancies), and eight had hypoglycaemia (four GDM pregnancies). None of these outcomes were statistically significant.

CONCLUSION: We did not find that first antenatal HbA1c 36–49 mmol/mol predicted subsequent GDM. Our high non-screening rate, especially for women with HbA1c 41–49 mmol/mol, likely influenced this result.

Effect of divergent continuous glucose monitoring technologies on glycaemic control in Type 1 diabetes mellitus: a systematic review and meta-analysis of randomised controlled trials

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AIMS: We aimed to conduct a systematic review and meta-analysis of randomised controlled clinical trials (RCT) assessing separately and together the effect of the three distinct categories of continuous glucose monitoring (CGM) systems (adjunctive, non-adjunctive and intermittently scanned CGM [isCGM]), compared to traditional capillary glucose monitoring, on HbA1c and CGM metrics.

METHODS: PubMed, Web of Science, Scopus and Cochrane Central register of clinical trials were searched. Inclusion criteria were randomised controlled trials; participants with Type 1 diabetes of any age and insulin regimen; investigating CGM and isCGM compared to traditional capillary glucose monitoring; and reporting glycaemic outcomes of HbA1c and/or time-in-range (TIR). Glycaemic outcomes were extracted post-intervention and expressed as mean differences and 95%CIs between treatment and comparator groups. Results were pooled using a random-effects meta-analysis. Risk of bias was assessed using the Cochrane Rob2 tool.

RESULTS: This systematic review was conducted between January to April 2021; it included 22 RCTs (15 adjunctive, five non-adjunctive, and two isCGM)). The overall analysis of the pooled three categories showed a statistically significant absolute improvement in HbA1c percentage points (mean difference (95% CI): -0.22% [-0.31 to -0.14], I^2=79%) for intervention compared to comparator and was strongest for adjunctive CGM (-0.26% [-0.36, -0.16]). Overall TIR (absolute change) increased by 5.4% (3.5 to 7.2), I^2=71% for CGM intervention compared to comparator and was strongest with non-adjunctive CGM (6.0% [2.3, 9.7]).

CONCLUSIONS: For individuals with T1D, use of CGM was beneficial for impacting glycaemic outcomes including HbA1c, TIR, and time-below-range (TBR). Glycaemic improvement appeared greater for TIR for newer non-adjunctive CGM technology.

Diabetes in pregnancy: using the sFLT-1/PLGF ratio to predict preeclampsia

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Placental growth factor (PlGF) based tests are used internationally as prognostic markers in suspected preeclampsia. The Ministry of Health are yet to endorse these tests in New Zealand. A recent Christchurch study confirmed the effectiveness of the sFlt-1/PlGF ratio in predicting preeclampsia in a New Zealand population.

AIMS: To investigate the utility of the sFlt-1/PlGF ratio in pregnancies complicated by pre-existing diabetes (DM) and prediabetes (pre-DM).

METHODS: A subgroup analysis of a prospective cohort study of 240 singleton pregnancies with suspected preeclampsia at 20+0 to 36+6 weeks' gestation. Participants and clinicians were blinded to the sFlt-1/PlGF ratio results.

RESULTS: Included were 27 pregnancies (10 Type 1 DM, 8 Type 2 DM, 9 pre-DM), 11 participants were Māori, six Pasifika, six NZ European, one Filipino, one Indian. In the 11 (40.7%) pregnancies with elevated sFlt-1/PlGF ratios, seven had a clinical diagnosis of preeclampsia, two cases of preeclampsia were misdiagnosed, and two cases of placental insufficiency complicated by abruption were missed. In the 16 pregnancies with normal sFlt-1/PlGF ratios, disclosing the blood results may have prevented hospitalisation and/or reduced the frequency of day unit assessments in four participants. The sFlt-1/PlGF ratio was not raised in cases of chronic proteinuria, chronic hypertension, or worsening renal failure, however subsequent elevations indicated the onset of superimposed preeclampsia. In one pregnancy, renal dialysis caused transient mild elevations in the sFlt-1/PlGF ratio.

CONCLUSIONS: In pregnancies complicated by pre-existing DM or pre-DM, the sFlt-1/PlGF ratio performed better than clinical assessment and routine tests at identifying placental insufficiency, including preeclampsia. The sFlt-1/PlGF ratio differentiated between placental-mediated disease and chronic conditions such as hypertension and chronic kidney disease. Further study could assess the utility of a routine sFlt-1/PlGF ratio at 32 weeks' gestation in women with pre-existing DM to identify those at high risk of preterm placental insufficiency.

The metabolic effects of a CREBRF gene variant in NZ Women – assessment of satiety and incretins

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A variant of the *CREBRF* gene (rs373863828-A; p.Arg457Gln) is associated with an increase in BMI but a decrease in the risk for Type 2 diabetes and gestational diabetes. This variant is found almost exclusively in people of Māori and Pacific ancestry. Although the exact function of *CREBRF* is unknown, this variant has been found to be associated with an increase in postprandial insulin release in men. Glucagon-like peptide 1 (GLP-1) and gastric inhibitory peptide (GIP) are incretin hormones which mediate insulin release following a meal and regulate satiety.

AIMS: The primary objective of this study was to investigate the effect of the rs373863828-A *CREBRF* variant on postprandial incretin release in Māori and Pacific women, and to assess whether this effect is associated with a concordant difference in experiences of satiety.

METHODS: Fifty participants (14 homo- or heterozygous for rs373863828-A (AX), 35 reference genotype (GG), one excluded) were recruited to take part in a study where plasma samples and satiety scores were taken at baseline and 30, 60, 90, 120, and 150 minutes following a standardised mixed-meal test. Hormone quantification by ELISA and magnetic immunoassay was undertaken for a matched cohort of 28 participants (14 GG and 14 AX; matched for BMI, age and Polynesian ancestry). Postprandial GLP-1 and GIP concentration and satiety were analysed using a baseline-adjusted area-under-the-curve (AUC) and suddenness score.

results: No significant differences were found between the matched AX/GG pairs for AUC measurements and suddenness scores for both incretin release and satiety reports.

CONCLUSIONS: Preliminary evidence in women suggests that differential incretin or satiety responses do not appear to mediate the reduced risk of Type 2 diabetes associated with the rs373863828-A allele. A larger sample size may be necessary to reveal any potential differences based on the rs373863828-A variant.

First clinical test results for a low-cost light-based glucose sensor

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AIMS: Measuring blood glucose (BG) is central to diabetes management. However, glucometer BG measurements are infrequent, invasive, and painful, semi-invasive interstitial continuous glucose monitors (CGMs) are prohibitively expensive, and no non-invasive methods are currently available. This study presents first clinical validation test results for a low-cost (<NZ$250) light-based, non-invasive glucose sensor using discrete wavelength LEDs in the near infra-red (1400–1700nm) range.

METHODS: Heathy adults (ethics approval from University of Canterbury Human Ethics Committee) and

neonatal ICU infants (ethics approval from NZ HDEC South) were tested. Adult subjects drank 330ml of Coca Cola (17.5g glucose). At 9 measurement intervals (t =0–60mins every 10mins, 90mins and 120mins) glucometer measurements and 3 light-based measurements (carotid artery, palm, and finger) were made, yielding 33 comparison pairs per test. For NICU subjects light-based glucose measurements were taken at 3 sites (foot, wrist, chest) every time a standard clinical BG measurement was made. Reference and light-based BG values are compared using a modified Clarke Error Grid (CEG).

RESULTS: N=27 subjects (22 neonates; five adults) with 290 measurements, yielded 163 pairs, where 117 did not record a pulse for light-based data analysis. The glucose range was 1.9–7.9mmol/L. The CEG contains 62%, 31%, 6% and 1% in zones' A, B, C and D respectively. Outliers in the C and D ranges had poor pulsatile signals for analysis, yielding larger error. Bland Altman analysis demonstrated slight overestimation of BG for neonates, and slight underestimation for adults using a joint overall calibration.

CONCLUSIONS: Results show good performance for a first prototype non-invasive light-based blood glucose monitor. There is a need to test a wider glucose range into hyperglycemia and to improve test use and/or light intensity to ensure a good pulse waveform is captured for analysis.

Results from a national survey on diabetes inpatient management using the quality standards for diabetes care 2020

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Following a keynote address at NZSSD in 2015 many clinicians were interested to investigate what was happening in New Zealand Diabetes inpatient care. We designed and administered an online survey using the Standards for Diabetes Care 2020, to get a snapshot of diabetes clinical care nationally.

AIMS: The aim of this survey was to investigate aspects of inpatient clinical care for people with diabetes in New Zealand in relation to the Quality Standards for Diabetes Care across 20 DHBs. The information could be used for Quality improvement initiatives, both locally and nationally. The objective was to design and survey all 20 DHBs on aspects of inpatient Diabetes care in relation to Standards 13–15, in the Quality Standards for Diabetes Care Toolkit 2014.

METHODS: The Quality Standards for Diabetes Care were reviewed. A survey of 20 questions was designed using SurveyMonkey, which was then emailed to Diabetes Nurses and Pharmacists across all DHBs, through the national professional organizations. The anonymised feedback was collated and analysed.

RESULTS: Feedback was received from 32 participants. Results demonstrated disparities across the DHBs for many aspects of Diabetes Clinical Care in relation to the Quality Standards for Diabetes Care 2020. The findings could be a useful basis for Quality Improvement initiatives both locally and nationally.

Collaboration to improve diabetes service delivery, equity, and technology uptake

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Whitiora Diabetes Service at CMDHB historically has low patient uptake of PHARMAC-funded insulin pump therapy. Approximately 2% of the eligible population with Type 1 diabetes (T1DM) use this treatment option, with Māori and Pacific, approximately 37% of the T1DM population, making up only 5% of pump patients.

AIMS: Use of targeted funding to develop a model of care (MOC) for pump therapy to improve and upscale service delivery, co-designed with our CMDHB patients. The focus was on equity and quality, with the ability to share tools and resources nationally.

METHODS: Development of a successful funding bid, with clear aims, objectives, and project deliverables to improve planned care. A governance group of stakeholders, and a project working group of multidisciplinary diabetes clinicians, and diabetes technology researcher, Hamish Crocket, were formed. The project working group collaborated with other DHBs, undertook pump user focus groups, and telephone reviews to inform the development of resources to support patients and staff. A staff pump training programme was developed and implemented in 2021.

RESULTS: A patient centric MOC is being developed. This includes a pump start pathway that all patients with Type 1 diabetes at CMDHB will be offered, and a broad range of patient resources: hardcopy, electronic, and video. Staff knowledge and confidence was enhanced following the pump training programme. Referrals for pump therapy have increased.

CONCLUSIONS: Ministry of Health resourcing for the project has enabled CMDHB to address historic challenges with service delivery, and technology uptake,

particularly for Māori and Pacific peoples. With an equity and quality focus, the MOC has been developed in collaboration with our patients and other DHBs, particularly Waikato DHB that have a much larger pump service. Resources will be shared nationally, ensuring access for all which should serve those with diabetes well as we move towards the Health NZ transition.

Collaborative development of a real-time diabetes dashboard to improve outcomes in Waikato patients with Type 2 diabetes

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BACKGROUND: Implementation of clinical guidance to manage Type 2 diabetes (T2D) is typically problematic resulting in marked inequities in care. Data analysis, education, and benchmarking all independently improve diabetes management and outcomes, and reduce the "post-code" variation and inequities in care. Consequently, we describe the collaborative development of a regional diabetes dashboard to provide real-time data to enable benchmarking, education, identification of people with T2D (PWT2D) and research to improve diabetes outcomes.

METHODS AND DESCRIPTION: Lead diabetes clinicians and data analysts from the DHB diabetes service and all three Waikato primary healthcare organisations worked collaboratively to develop a "live" dashboard for the 25,000 PWT2D in the region. Consensus was reached for practice-level data to be presented by ethnicity for key targets and appropriate prescribing as outlined by the NZSSD national T2D guidance including: 1) % with HbA1c <53 mmol/mol; 2) % on metformin with eGFR >30 mL/min; 3) % on ACEi/ARB with renal disease; 4) % on empagliflozin or dulaglutide; and 5) % with LDLc <1.8 mmol/L) with renal or cardiovascular disease (CVD), or a five-year CVD risk >15%; 6) % with HbA1c >90 mmol/mol on insulin etc. Practices receive a benchmarking report identifying inequities and potential areas to improve care. Education is provided on ideal management and staff can easily identify PWT2D not meeting each target, enabling proactive care. Studies using the dashboard data are planned to investigate the relationship between system- and practice-level factors and outcomes.

RESULTS AND CONCLUSIONS: No data are currently available on the effects of the dashboard on diabetes outcomes. But we believe the collaborative approach and demonstration of the dashboard "in action" will be of particular interest to the NZSSD audience, as the dashboard will likely be a useful tool in improving regional diabetes outcomes.

The impact of multimorbidity on the ability to make lifestyle changes in those with prediabetes and excess weight – a qualitative study

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AIMS: Multimorbidity, where an individual is living with two or more conditions, is increasing worldwide. It is common among those with prediabetes, a risk factor for Type 2 diabetes (T2D) and cardiovascular disease. The aim of this study was to qualitatively examine the impact of multimorbidity on the ability to make lifestyle changes among adults with prediabetes and overweight/obesity.

METHODS: In the primary care-based Prediabetes Intervention Package study, 58 participants were interviewed on completion of the six-month intervention. They were asked about the impact of other health conditions on making lifestyle changes for their prediabetes. Interviews were transcribed and data analysed thematically. The socio-ecological model of personal, interpersonal, organisational, community and policy guided interpretation as to how multimorbidity impacted on ability to make lifestyle changes, how different conditions created challenges, and the ways these challenges were able to be overcome.

RESULTS: Of the 58 participants, almost half (48%) were Māori. Participants ranged in age from 28–69 years. At six months, 45% had regressed to normoglycaemia, and 55% had persisted with prediabetes or progressed to T2D. Fifty-five (95%) participants reported living with at least one other condition. More than half (53.4%) described how specific conditions were a barrier or challenge to making lifestyle changes. Joint pain reducing mobility, and mental health or stress, including weight stigma were the most frequently described difficulties. Health professional and community support such as free supportive pool access helped to overcome challenges. While there were challenges, many participants recognised their lifestyle changes not only positively impacted glycaemia and weight, but also other conditions e.g., hypertension, and dyslipidaemia.

CONCLUSIONS: This study confirmed multimorbidity is common among those with prediabetes and overweight/obesity, and this influenced their ability to implement lifestyle changes. The external environment presented challenges which often required interpersonal and community support to facilitate healthy lifestyle changes.

IEC standard test results for an open-source, ultra-low-cost insulin pump

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AIMS: Insulin pumps are the most consistent and accurate means of regulating blood glucose levels in T1 and T2 diabetes. However, insulin pump technology is underutilised due to high costs of NZ$7,000–10,000 and limited reimbursement. An ultra-low-cost insulin pump made widely available with an open-source design would significantly improve equity of access to the best care and outcomes. This study presents results validating the accuracy of an open-source ultra-low-cost (<NZ$150) insulin pump.

METHODS: The low-cost insulin pump was tested in-vitro to the IEC 60601-2-24 standard and set at a basal rate of 1U/h, delivering a 0.25U dose every 15 minutes. over a 25-hour period following a 24-hour stabilisation period. Insulin delivery was measured by total displaced fluid mass with a microscale. Data was processed into trumpet curves per the unit standard. Data were also processed to calculate accuracy over individual one-hour windows, and compared to published literature for the Medtronic 640G, Medtronic 670G, and Tandem t:Slim pumps.

RESULTS: N=5 tests, with a total of 500 individual doses administered. Overall percentage error in each of the five tests was 0.60%, 0.54%, 2.35%, -0.90%, 0.30%. Accuracy across one-hour windows was ±15% for 99% of doses, ±10% for 96.8% of doses and ±5% for 88.8% of doses. Comparable published data on commercial systems are shown in Table 1.

CONCLUSIONS: We demonstrate highly accurate insulin dosing using a prototype ultra-low-cost insulin pump. Our data compares favourably with commercially available systems. Clinical testing and further validation are required to ensure the design is robust and meets or exceeds all IEC standard requirements.

Table 1: Accuracy of Insulin pump dosing across one-hour windows.[1]

Insulin pump	Doses delivered to accuracy of within		
	±15%	±10%	±5%
Medtronic 640G	95.6%	93.1%	84%
Medtronic 670G	99.4%	97.8%	90.3%
Tandem t:Slim	99.8%	98.9%	91.4%

Insulin pump special eligibility criteria in New Zealand: a survey of prescriber opinion and practice

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AIMS: Funding for insulin pump therapy (CSII) in New Zealand for people with type 1 diabetes is determined by meeting PHARMAC special authority (SA) criteria. We aimed to survey the opinion and practice of CSII prescribers with respect to the current SA criteria and contextualise the results with respect to contemporary literature and best practice.

METHODS: Quantitative and semi-qualitative survey of CSII prescribers in New Zealand. Mixed qualitative and quantitative analyses were used.

RESULTS: Of the 94 survey respondents, 88% stated the criteria needed updating. However, 75% maintained CSII funding by PHARMAC should remain under updated SA criteria. Most (60%) of respondents thought the current criteria did not promote health equity for Māori and Pasifika. Only 33% of respondents strictly adhered to the criteria. Thematic analyses of free text responses indicated that the criteria did not reflect quality of life benefits offered by CSII, changes in life course, clinician or patient autonomy, and beneficence of CSII not otherwise stated in the current criteria.

CONCLUSIONS: The majority of CSII prescribers in New Zealand disagreed with the SA criteria, resulting in most not strictly adhering to them. Updated criteria are required to improve health equity and reflect best evidence.

The OPTIMISE study protocol: a multicentre optimisation trial comparing continuous glucose monitoring, snacking habits, sleep extension and values-guided self-care interventions to improve glucose time-in-range in youth in Type 1 diabetes

Many young people with Type 1 diabetes (T1D) experience higher than recommended glucose levels, increasing their risk for short- and long-term diabetes complications. Multicomponent interventions to improve glycaemic control, psychosocial and/or behavioural functioning may be more effective than single-component interventions in young people with Type 1 diabetes, but may be more burdensome, and it is unknown which combination of components is most effective.

AIM: The OPTIMISE study uses a Multiphase Optimisation Strategy (MOST) to identify the best combination of four interventions targeting key diabetes self-care behaviours for use in clinical practice to improve short term glycaemic outcomes.

METHODS: This six-week trial will recruit 80 young people (aged 13–20 years) with T1D (≥6 months duration), and pre-enrolment HbA1c ≥58 mmol/mol [7.5%] in the prior six months. Both main and interaction effects will be estimated using a linear regression model with change in glucose time-in-range (TIR: 3.9–10.0 mmol/L) as the primary outcome. Participants will be randomised to one of 16 conditions in a factorial design using four intervention components: 1) real-time continuous glucose monitoring; 2) targeted snacking education; 3) individualised sleep extension; and 4) values-guided self-care goal setting. Baseline and post-intervention glucose TIR will be assessed with blinded continuous glucose monitoring. Changes in self-care (snacking habits, sleep timing and duration, and psychosocial outcomes) will be assessed at baseline and post-intervention to determine if these interventions impacted behaviour change.

CONCLUSION: The study outcomes will enable selection of effective and efficient intervention components that increase glucose TIR in young people who struggle to achieve targets for glycaemic control. The optimised intervention will be evaluated to inform a future randomised controlled trial and guide planning of effective clinical interventions in adolescents and young adults living with Type 1 diabetes. Trial registration: Australian New Zealand Clinical Trials Registry ID: ACTRN12620001017910.

Metabolic effects of a CREBRF gene variant in New Zealand women

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AIMS: An Arg457Gln missense variant in the CREBRF gene (rs373863828) is prevalent in New Zealand Māori and Pacific people, but rare in other ethnic groups. The A allele of this variant is associated with increased BMI, but paradoxically reduced risk of Type 2 diabetes mellitus (T2DM) and gestational diabetes (GDM). rs373863828-A is associated with increased glucose-stimulated insulin release in men.[1] Here we present preliminary data on the metabolic effects of rs373863828-A in New Zealand women.

METHODS: Plasma insulin and glucose were measured at 30-minute intervals for 150 minutes during a mixed meal tolerance test (MMTT) in 50 New Zealand Māori and Pacific women (A allele, n=14). Body composition and resting metabolic rate (RMR) were measured using DXA (Hologic, USA) and indirect calorimetry (Promethion, Sable Systems USA). The associations between insulin and glucose measurements over time after the MMTT and allele type were estimated by mixed linear models. ANCOVA estimated associations between allele type and other variables, with age, ancestry and BMI as covariates.

RESULTS: Rs373863828-A was associated with increased total lean mass of 4.9kg (95% CI 1.5–8.3), p=0.005 and increased RMR of 116.8 kcal/day (95%CI 13.4–1414.7), p=0.03 after adjusting for BMI and other covariates. There was no effect of rs373863828 on either plasma insulin or glucose response to a meal. There were no statistically significant differences in other outcome measures, including HOMA2-IR and HOMA2-%B.

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