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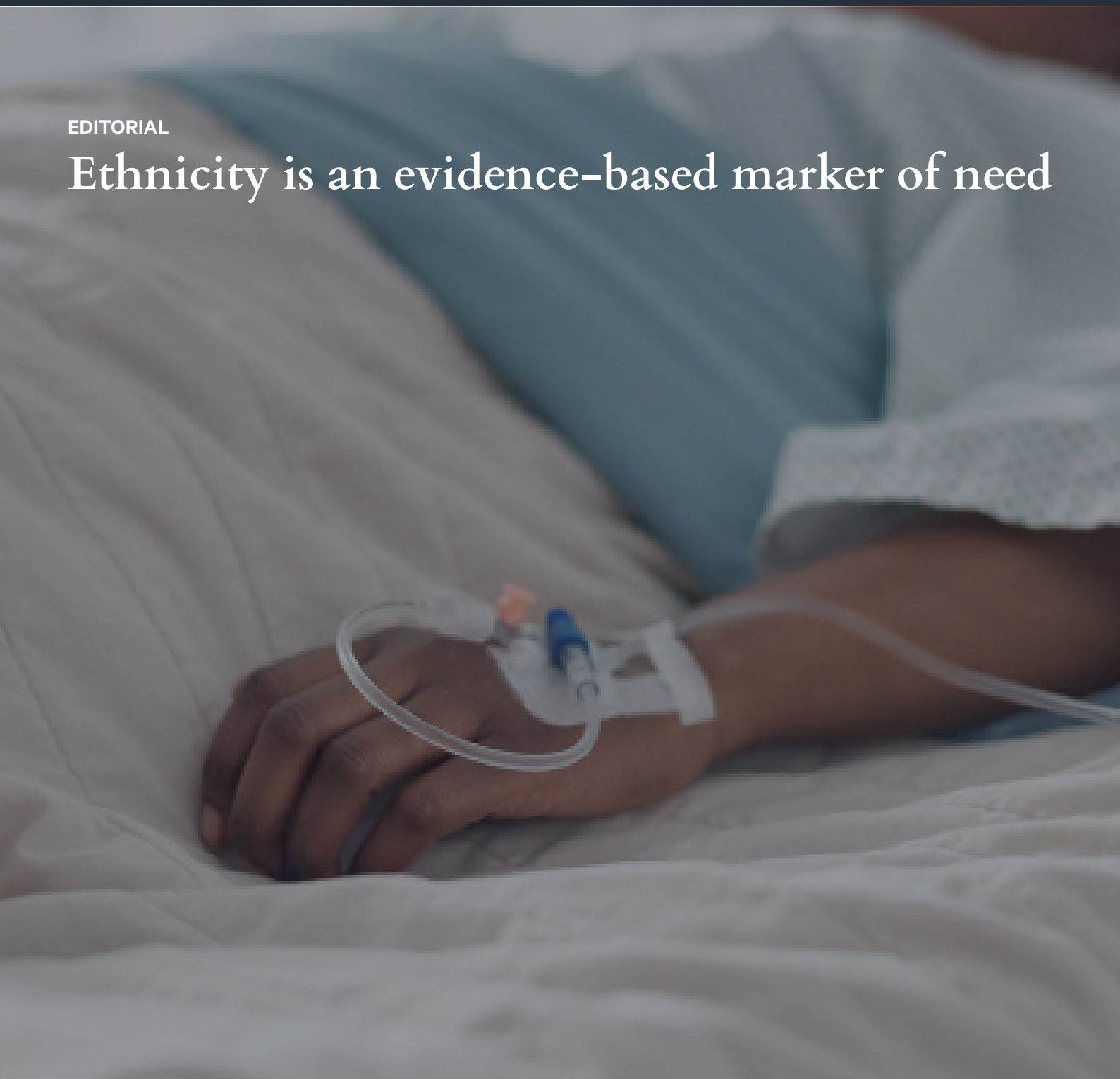

EDITORIAL

Ethnicity is an evidence-based marker of need

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Ethnicity is an evidence-based marker of need (and targeting services is good medical practice)

Belinda Loring, Papaarangi Reid, Elana Curtis, Melissa McLeod, Ricci Harris, Rhys Jones

The Government recently issued a directive to make it harder for government agencies to target services based on ethnicity. The Government is concerned that ethnicity is being used as a proxy for need. We outline why the Government's directive is unscientific and dangerous. Science tells us that ethnicity is actually the strongest marker we have of health need—far better than deprivation or rurality. The directive will undermine efforts to reduce health inequities and will result in wasteful health spending by limiting our ability to target resources at those in greatest need.

Characteristics and outcomes of lung cancer patients presenting through the emergency department: a Waikato District Health Board study

Ross Lawrenson, Chunhuan Lao, Ha Nguyen, Lucia Moosa, Rawiri Keenan, George Laking, Janice Wong, Mark Elwood

About 40% of lung cancer patients attended the emergency department (ED) before their diagnosis, and these patients often had more advanced stages of the disease. In contrast, those who were diagnosed through their general practitioners were found to have earlier-stage lung cancer and consequently had better survival. Māori were more likely than non-Māori to be diagnosed with lung cancer after attending the ED, indicating a disparity in the diagnostic pathway.

Navigating the long journey of heart failure—experiences of Māori and Pacific peoples

Sandra Hanchard, Karen M Brewer, Tua Taueetia-Su'a, Sione Vaka, Shanthi Ameratunga, Taria Tane, Rochelle Newport, Vanessa Selak, Matire Harwood, Corina Grey

This qualitative study aimed to understand the experiences of Māori and Pacific peoples living with heart failure as they navigated care across primary and secondary settings. The two major themes identified related to participants' need for more support to understand and self-manage their heart failure condition, and desire to feel well-connected to the health system in their heart failure journey. Addressing heart failure inequities for Māori and Pacific peoples requires that providers engage in clear and meaningful communication to support patient self-management. Strengthening pathways for Māori and Pacific patients and whānau between primary and secondary services is required to reduce their likelihood of becoming disconnected from care.

National survey of hospital rheumatology service users to inform a statement set describing the minimum service expectations for publicly funded rheumatology secondary care in Aotearoa New Zealand

Rebecca Grainger, Valerie Milne, Rachel Ngan Kee, Nicola Dalbeth

We had a survey open to anyone in Aotearoa New Zealand who has inflammatory or autoimmune rheumatic disease and has used public hospital rheumatology services in the last 5 years where we asked their agreement, or otherwise, with 26 statements describing components of rheumatology services. Over 230 responded and indicated support for most of the statements. We offer a statement set for service components of rheumatology services for Aotearoa New Zealand public (government-founded) hospitals.

Use of puberty-blocking hormones for gender dysphoria in New Zealand: descriptive analysis and international comparisons

Charlotte Paul, Simon Tegg, Sarah Donovan

Health authorities in Europe are moving to restrict the use of puberty-blocking hormones for children with gender dysphoria because of uncertainty whether the dysphoria would persist in the absence of treatment, a lack of evidence about long-term benefits and harms and uncertainty whether children can consent in this situation. (Gender dysphoria or gender-related distress are terms used to describe distress caused by a mismatch between someone's experienced gender and birth sex.) Puberty suppression was first used in the Netherlands in the 1990s for a few children (mainly boys) with life-long extreme gender dysphoria. Nothing was known about use in New Zealand. We used information from Pharmac to estimate use of puberty blockers in New Zealand for those aged 0–11 and 12–17. Most use of these hormones from age 12–17 will be for gender dysphoria. We found that use for gender dysphoria started about 2011 (when the first guidelines were published) and increased slowly to 2014, then much more steeply to 2022. But the incidence of first prescriptions has been declining since 2021. Compared with the Netherlands, England and Wales, and Denmark we have much higher use.

Adherence to New Zealand's Major Trauma Destination Policy: an audit of current practice

Georgia Gibson, Bridget Dicker, Ian Civil, Bridget Kool

This study was an audit conducted to assess whether people who sustained major physical trauma in New Zealand and who were attended by a pre-hospital ambulance provider (land or air) at the time of their injury (between 31 November 2017–30 November 2018) were taken to an appropriate hospital for the level of care required. The "appropriateness of a hospital" for patients of this kind is set out in the New Zealand National Trauma Network's Major Trauma Destination Policy. The study found that 94% of people who met the study criteria were taken to the most appropriate hospital. People were more likely to be taken to the appropriate hospital if the correct destination for that case was the nearest hospital to where the injury took place. In contrast, people were less likely to be transported to the appropriate hospital if the correct destination for that case was not the nearest hospital to where the injury took place. There was lower adherence for patients requiring transport to an advanced-level trauma centre, which may be congruent with being further away from the geographic location of injury. Overall, there was high adherence to the Major Trauma Destination Policy, with scope for improvement in cases where the nearest hospital should be bypassed in favour of a more distant advanced-trauma centre.

Intravitreal therapy in neovascular age-related macular degeneration—adapting to increasing demand and changing times

Brandon Nunns, Vidit Singh, John Ah-Chan

Age-related macular degeneration (AMD) is a leading cause of visual impairment in older adults and is expected to continue increasing in prevalence due to the ageing population. Neovascular AMD (commonly referred to as "wet" AMD) represents a subset of patients with AMD that can develop rapid and irreversible vision loss if not treated with intravitreal injections (i.e., injections administered into the eye) with agents that oppose the molecules responsible for nAMD. Early treatment is important and so guidelines recommend treatment initiation within 14 days, which the Palmerston North Eye Clinic has achieved in this paper through innovations in clinical practice and with the assistance of senior nursing staff in the administration and delivery of the intravitreal injection service. As the demand for injections continues to increase, further resourcing and innovations in practice will be important to keep services compliant with guidelines and achieve the best outcomes for patients.

Dying with and of dementia

Sandy Macleod

With an ageing population, the prevalence of dementia increases. Active medical and behavioural interventions in the early- to mid-stages are commendable. The end-of-life phase is often very challenging for patients, whānau and attending staff. Sensible palliative care can improve symptom burden, prevent under-treatment and over-treatment of symptoms with unnecessary and burdensome interventions, reduce caregiver burden and enhance caregiver quality of life.

End-stage achalasia leading to acute upper airway obstruction and respiratory arrest with successful resuscitation, a case report

Jacob Arahill-Whitham, Ben Thomson, Vishak Surendra, Thomas Haig, Subhaschandra Shetty

Respiratory arrest secondary to megaoesophagus is a rare complication of achalasia. We treated an 85-year-old female with a history of achalasia who presented with sudden respiratory arrest and cardiopulmonary resuscitation in the community. This case provides a rare differential for a patient with acute upper airway obstruction and cardiopulmonary arrest and is the first such case described in the literature in Aotearoa New Zealand.

Ethnicity is an evidence-based marker of need (and targeting services is good medical practice)

Belinda Loring, Papaarangi Reid, Elana Curtis, Melissa McLeod, Ricci Harris, Rhys Jones

Last week, Cabinet released a circular to government organisations, giving effect to the coalition Government agreement commitment to "*issue a Cabinet Office circular to all central government organisations that it is the Government's expectation that public services should be prioritised on the basis of need, not race*."[1] The term "race" originates from a long-discredited presumption of a biological hierarchy of human beings from white to black, and for decades the New Zealand health system has instead used ethnicity. This return to discredited terminology suggests that the foundations of white superiority are still alive and well in New Zealand today. The Government expresses its concern that "*agencies may use ethnic identity or other forms of personal identity as a proxy for need, and therefore a justification in itself for targeted services*."[1] The circular imposes additional requirements for agencies considering targeting services to specific population groups to engage their ministers early, and to provide a strong analytical case for any targeting, recognising that there are "*many variables that can be used to identify and assess need, and that all variables should be considered before ethnic identity is automatically used to determine need*."[1] They must include an assessment of any opportunity costs for all New Zealanders, and "*where culturally specific models are used, eligibility should not be restricted to the specific population group unless there is a strong rationale (e.g. value for money)*."[1]

This directive, and the political discourse surrounding it, is an affront to scientific and public health knowledge, and requires explicit rejection from health professionals and the scientific community.

This directive is one of several recent policy actions from the coalition Government[2] that directly threaten the collective efforts of the health and scientific community to identify and address ethnic health inequities. We revisit the key basic scientific tenets behind ethnic targeting in our health system, and why this practice needs to be strengthened rather than hindered, including enhancing our access to high-quality ethnicity data.

Ethnicity is an evidence-based marker of need

While not forgetting or diminishing that Māori have inalienable rights to health, and right-based arguments for addressing health inequities, there is a strong connection between current Māori health needs and the denial of these rights.[3] The Government's directive is based on a false and unsubstantiated assumption that previous ethnicity-based targeting in health has not been based on robust analysis of need. For those professionals at the frontline of policy development, service commissioning and monitoring, the prevailing problem is the opposite: a mountain of robust analysis demonstrating higher Māori health need, and a trickle of initiatives to specifically target this need.[4] The very presence of continued inequity for Māori in life expectancy,[5] exposure to risk factors,[6] access to care[6–8] and health outcomes[7,8] is evidence that measures to date have not been adequate to meet Māori need. Inequities in health need, access and outcomes persist for Māori at all levels of socio-economic deprivation and rurality.[9]

Ethnicity is superior to many other markers of need

In requesting that other variables be considered before ethnicity, the Government erroneously singles out ethnicity to require a higher standard of proof than allocations based on any other population risk characteristic (e.g., rurality, sex or age). Comprehensive, consistent and long-standing evidence demonstrates that ethnicity is a stronger marker of need than other commonly accessible variables such as rurality and the New Zealand Index of Deprivation (NZDep).[6,9,10,11] Our most widespread

marker for socio-economic deprivation, NZDep, does not assess individual characteristics, but is based on a collective neighbourhood score.[12] By using age-based criteria alone, and ignoring that Māori have a younger population age structure, the bowel cancer screening programme failed to recognise that over half of Māori cancers occurred before the screening threshold of 60 years.[13] Suggesting that these "colour-blind" variables may be better proxies for health need than ethnicity is blatantly untrue and misleading, and encourages weak analytical science and will likely lead to greater waste of public resources due to less effective targeting of resources towards groups with highest need. Racism distributes the determinants of health along ethnic lines and impacts health directly,[14,15] so until racism is eliminated, ethnicity will be a valid marker of need.

Using population patterns to assess risk is at the core of evidence-based medical practice

Using multiple characteristics (of an individual or of a group) to refine clinical hypotheses and assess health risks is a fundamental tool of medicine in clinical fields and population health. Suggesting we ignore some of these characteristics asks us to ignore important analytical tools that are essential for health professionals to efficiently serve our patients and communities and most efficiently target scarce health resources. Similarly, there is no basis for using the individual exception (e.g., "I'm Māori and I don't have high health needs") as a justification for not targeting high-risk populations. This represents a fundamental misunderstanding of individual versus population risk and applies to any population characteristic, not just ethnicity. Most women do not get breast cancer, but at a population level, their higher risk of disease means that we fund breast screening for women over a certain age, based on their risk as a group. Any suggestion that personal or population characteristics should not be used in the design, delivery or monitoring of health services is an attack on evidence-based medicine and must be rejected.

Targeting by ethnicity is evidenced-based and leads to better resource allocation

Like every country, we have a duty to allocate scarce health resources to those most at risk, and to use all available risk characteristics to identify those most in need as sensitively and specifically as possible. New Zealand is in no way unique in seeking to focus extra health system activity on ethnic groups that have been systematically disadvantaged and under-served.[16–18] The Cabinet circular itself notes that New Zealand has a well-established legal and constitutional framework of non-discrimination, and that services targeted or designed for specific population groups are a feature of good government supported by the *New Zealand Bill of Rights Act 1990*, international convention and law.[19] These measures are crucial to address discrimination that already exists in our health system—we must remember that the status quo is not a neutral starting point, but instead has a pre-existing ethnic bias towards our dominant ethnicity.[20] The Government's directive that when culturally specific models are used, "*eligibility should not be restricted to the specific population group unless there is a strong rationale*"[1] completely undermines the whole purpose of targeting resources towards those most at need, and risks irresponsible wastage of scare health resources. For the same reason it would be an irresponsible use of public funds to allow males to receive funded breast cancer screening, it is fiscally and ethically unjustifiable to enable anyone to access services that have been specifically targeted to meet a particular health need for a high-risk group.

Ethnicity data quality and analysis must be strengthened

To support implementation of this directive, the Government has signalled its intention to strengthen the ability for agencies to access timely, high-quality, granular data, and the capability to extract, analyse and present it,[19] although it makes no mention of the need to specifically strengthen the quality of ethnicity data collection and analysis. We need to further strengthen ethnicity data quality to enable better identification and monitoring of need. There is a significant risk that the needed improvements to ethnicity quality and capability[21,22] will not be invested in, and the dismissal of the value of ethnicity will result in changes to ethnicity data collection and reporting that will compromise our ability to identify and monitor ethnic health needs over time.

The Government's directive is not just an attack on Māori, but an attack on science and good

medical practice. Anyone who supports this directive, either actively or complicitly through their silence, is supporting the undermining of our collective scientific knowledge and commitment to evidence-based medical practice. The real risk is in how this message is interpreted and implemented by the sector. Our concern is that this circular will be interpreted as shorthand for "no more ethnicity-based anything" when this is not what the directive actually says, and certainly not what is needed. Moreso than ever, health professionals must remain true to our science/evidence-based principles, which remain unchanged:

- Ethnic health inequities in New Zealand are unjust and avoidable and it is our job as health professionals to use all tools at our disposal to intervene;
- Ethnicity is a strong marker of health need in New Zealand, and is an evidence-based way of targeting healthcare resources; and
- Analyses based on good-quality ethnicity data should be routinely used to identify need, design health interventions and monitor the effectiveness of the health system.

COMPETING INTERESTS
Nil.

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Characteristics and outcomes of lung cancer patients presenting through the emergency department: a Waikato District Health Board study

Ross Lawrenson, Chunhuan Lao, Ha Nguyen, Lucia Moosa, Rawiri Keenan, George Laking, Janice Wong, Mark Elwood

ABSTRACT

AIM: This research examines the characteristics and survival outcomes of patients receiving a lung cancer diagnosis after attending the emergency department (ED) of Waikato hospitals in New Zealand.

METHODS: This retrospective study was based on a comprehensive database of Waikato patients recorded on the Midland Lung Cancer Register from 2011 to 2021. We compared the characteristics of patients with and without emergency presentations within 14 days before their lung cancer diagnosis. The survival of patients with and without ED attendance was compared between Māori and non-Māori. This study also analysed the odds ratios (OR) of presenting via ED before diagnosis and surviving 12 months based on logistic regressions.

RESULTS: In total, 2,397 patients were included, with 39.6% attending the ED prior to diagnosis. Māori were 1.27 times more likely than non-Māori to be diagnosed after attending the ED. Other characteristics of patients included being male, being diagnosed with small cell lung cancer and having more advanced-stage disease. Patients attending the ED were less likely to survive 12 months than those without ED visits (OR 0.42), and those with two or more ED visits were even less likely to survive 12 months (OR 0.33).

CONCLUSION: Patients presenting through the ED have more advanced-stage disease, while those presenting through their general practitioners (GPs) have evidence of being diagnosed earlier and having better survival. Barriers to early diagnoses through attendance with a GP, particularly for Māori and for men, need to be explored.

The emergency department (ED) is an important component of the healthcare system, providing immediate access to care. The option of using the emergency route for cancer diagnosis may be appropriate for those with red flag symptoms such as severe pain, bleeding or shortness of breath.[1] However, most lung cancer patients have a history of symptoms prior to diagnosis, and, internationally, an emergency presentation is seen as a marker for delayed diagnosis.[2] Diagnostic delay may be due to early symptoms not being recognised by the patient as important, barriers in access to general practice or an extended diagnostic period before referral to specialist care.[1] Delay may lead to urgent symptoms developing that require immediate assessment and treatment. A review of patient perceptions of the causes of delay reported that system factors, patient factors and disease factors could all contribute.[3] Patients with cancers with a poor outcome, such as pancreatic, oesophageal and lung cancer, are more likely to first present to the ED.[4] In an international study, the proportion of lung cancer patients presenting through ED ranged from 26.7 to 51.1%, with New Zealand performing worst in comparison with eight jurisdictions in Canada, the United Kingdom (UK) and Norway.[4] Patients with more advanced tumour stage are known to be more likely to present to the ED,[5,6] and were associated with lower 12-month survival than those presenting through other diagnostic pathways.[7]

A small Auckland study in 2009 reported 36% of patients were diagnosed after presenting to the ED.[8] There is now a set of New Zealand National Quality Performance Indicators for lung cancer, which state that most patients should be diagnosed through an elective referral pathway from their primary care provider.[9] The national data between 2015 and 2018 demonstrated 45% of lung cancer cases presented through the ED.[9] In the New Zealand system, the general practitioner (GP) clinic is the typical initial step for referrals to secondary care, either for diagnostic imaging

or specialist opinion. There are, however, barriers in New Zealand to access GP service, with patient co-payment and inability to access appointments.[10] Barriers for Māori also include the lack of a relationship with trusted GPs and travel constraints.[11,12] The Waikato District Health Board serves a population of 430,000, with around 23% identifying as Māori and 74% being of European descent. It has a main hospital (in Hamilton) and four rural hospitals with EDs. In cases of suspected lung cancer, free chest X-rays are available through the five Waikato hospitals or through contracted external providers. This study compares the characteristics and outcomes of lung cancer patients diagnosed following presentations through the EDs of Waikato hospitals in New Zealand with patients from the same population diagnosed through GPs in order to identify opportunities for earlier diagnosis and treatment and to improve survival.

Methods

Data source

The population of interest in this retrospective study were all patients diagnosed with lung cancer between 2011 and 2021 who were domiciled in the Waikato District Health Board. The method of presentation was classified as attendance to the ED in the 14 days before diagnosis or referral from another source. While the International Cancer Benchmarking Partnership (ICBP)[4] and Quality Performance Indicator (QPI) framework[13] use attendance in the previous 30 days, it is acknowledged that a number of presentations to the ED may not be for cancer-related symptoms and we believe the shorter period increases the specificity of an emergency lung cancer-related attendance. The referral was most commonly from a GP but could also be from another specialist service or after following up through a lung nodule clinic. ED presentations could be one attendance or two or more attendances in the 14 days prior to diagnosis. The 14-day timeframe of ED attendance was based on the New Zealand Lung Cancer Quality Performance Indicator specifications.[13] The 14-day timeframe is useful when investigating more acute presentations, which require immediate medical attention before lung cancer diagnosis.

The patients were all identified from the Midland Lung Cancer Register database. This register includes data on age, gender, ethnicity (Māori or non-Māori), rurality, smoking status, cancer cell type (small cell lung cancer [SCLC], non-small cell lung cancer [NSCLC], other or unknown), cancer stage, comorbidities and year of diagnosis. Further data on comorbidities were collected from the National Minimum Dataset (NMDS). The Charlson Comorbidity Index (CCI) was calculated according to the research of Glasheen et al.[14] The ED presentation of patients was identified from the database system of Waikato hospitals.

Statistical analysis

We reviewed the characteristics of lung cancer patients with and without ED attendance within 14 days before their diagnosis date. Categorical and continuous variables were compared using Chi-squared tests and Student's *t*-Tests. The Kaplan–Meier method was used to examine all-cause survival of lung cancer patients without and with ED visits by ethnicity (Māori or non-Māori). Multivariate logistic regressions were utilised to examine the adjusted odds ratios (OR) of visiting the ED at least once or twice within 14 days before diagnosis, adjusting for age, gender, ethnicity, rurality, smoking status, cell type, cancer stage, CCI score and year of diagnosis. Then, we analysed the unadjusted and adjusted ORs of surviving 12 months using logistic regressions. All analyses were carried out using Stata 15 (StataCorp LLC, Texas, United States).

Results

We identified 2,397 lung cancer cases. Table 1 shows that 949 (39.6%) lung cancer patients presented through the ED within 14 days before diagnosis. Of those with ED attendances, 75% (714/949) visited the ED once within 14 days, and 25% (235/949) presented to the ED at least twice. Men are more likely than women to attend the ED ($p<0.05$). Approximately 43% (268/618) of Māori patients attended the ED, compared with 38% of non-Māori patients. There were rural and urban differences in ED attendance. While 47.6% (1,140/2,391) of Waikato lung cancer patients lived in rural areas, those rural patients diagnosed through the ED were more likely to attend two or more times than those domiciled in Hamilton, who were more likely only to have one attendance in the prior 14 days. The percentage of patients presenting through the ED at least once within a 14-day period before their diagnosis of SCLC was 50.2% (144/287). Only 36.2% (590/1,629) of patients attended the ED before being diagnosed

with NSCLC. Around 52% (721/1,373) of patients visited the ED before being diagnosed with Stage IV, while the proportion of patients with emergency presentations before being diagnosed with Stage I or II was lower than 20%. There was a high percentage of ED attendances that had no information on smoking status, cell type and stage (more than 45%). This may represent poorly documented patients lacking usual care. The proportion of patients attending the ED decreased over time, from 43.3% for those diagnosed in 2011–2014 to 35.6% in 2019–2021.

Table 2 shows that while age was not a factor, gender was, with men 1.22 times ($p<0.05$) more likely to present through the ED at least once within 14 days before the lung cancer diagnosis date than women, after adjustment for age, ethnicity, rurality, smoking status, cell type, cancer stage, CCI score and year of diagnosis. Māori were more likely to present through the ED than non-Māori (adjusted OR 1.27, 95% confidence interval [CI] 1.03–1.57). Patients were more likely to present via the ED at least once or twice within 14 days before being diagnosed with SCLC than those with NSCLC. Patients were more likely to visit the ED at least once (adjusted OR 2.13, OR 7.06) or twice (adjusted OR 3.27, OR 3.64) within 14 days before being diagnosed with stages III and IV than those with stage I. Lung cancer patients diagnosed during 2019–2021 were less likely to visit the ED than those diagnosed during 2011–2014 (adjusted OR 0.79, 95% CI 0.63–1.00). There was no significant difference in the CCI score or smoking status.

The median survival for those without emergency presentations was 13.6 months, while the median survival for those with one ED visit was 3 months, and for those with at least two ED attendances it was 2.3 months. Figure 1 demonstrates that patients who presented through the ED within 14 days before the lung cancer diagnosis date had a poor prognosis, with a 5-year survival of less than 10%. Māori tended to have poorer survival outcomes than non-Māori in those without ED visits ($p=0.02$). There was an insignificant difference in survival between Māori and non-Māori presenting through the ED ($p>0.05$).

Table 3 illustrates that lung cancer patients presenting through the ED once or at least twice were less likely to survive 12 months than those without ED visits (adjusted OR 0.42 and 0.33, respectively, $p<0.001$). Māori were less likely to survive 12 months than non-Māori (adjusted OR 0.75, 95% CI 0.58–0.96). Older patients, male patients and those with more comorbidities (CCI score 2+ vs 0) were less likely to survive 12 months (respective adjusted OR 0.97, 0.75, 0.61). Patients without a smoking history had a higher chance of surviving 12 months than current smokers (adjusted OR 2.74, 95% CI 1.78–4.23).

Discussion

The ED presentation rate in this study was lower than the national rate (45%) in the *Lung Cancer Quality Improvement Monitoring Report*.[9] This is likely due to the shorter 14-day window used in this analysis. Therefore, we cannot compare directly with results based on the 30-day window.[4] While these indicators are being updated, our analysis addresses two key factors: 1) the route to diagnosis—i.e., the proportion of people with lung cancer who are diagnosed following presentation to the ED, by stage, and 2) overall survival for people with lung cancer at 1 year (2 and 3) from diagnosis, by type (NSCLC/SCLC) and stage.

The finding that men are more likely to be diagnosed after an ED attendance is consistent with evidence from Suhail et al.,[15] but Nilssen et al. found no gender differences.[16] Our finding maybe a reflection that, generally, New Zealand men have a higher use of the ED than women do.[17] Māori lung cancer patients were 27% more likely than non-Māori to visit the ED within 14 days prior to their lung cancer diagnosis. Non-Māori in our region are principally of European ancestry, although our non-Māori comparison group will include a small proportion of Pacific and Asian patients. The concern is that barriers for Māori to primary care are leading to diagnostic delay and thus presentation to the ED with more advanced disease.[5] Multiple barriers have been cited and include longer travel times, since many live in rural areas,[18] socio-economic barriers and racism.[11,19,20] The results of our study, which are adjusted for stage, cell type, smoking and rurality, indicate that there are persistent barriers in the system rather than patient and tumour factors alone that lead to more Māori presenting through ED.

The finding that lung cancer patients presenting through the ED were more likely to be diagnosed with advanced stage is consistent with a Canadian study.[15] In England, the proportion of patients diagnosed with stage IV following ED attendance was 72% during 2015–2016,[21] compared to 76% in our study. UK patients with emergency

presentations were also less likely to have treatment of curative intent or to receive surgery.[22] Patients with advanced diseases presenting through the ED may delay seeking care because they lack understanding of the symptom severity. On the other hand, patients may face barriers to primary care, including financial, geographic, cultural or informational obstacles.[23]

Emergency presentation is associated with a combination of less attention to cancer symptoms and more difficulties in accessing care, contributing to poorer outcomes[7] and higher care and treatment costs. We found that patients with ED attendance tended to have median survival of fewer than 3 months, while patients presenting through other diagnosis routes had longer median survival (around 13.6 months). Emergency presentation is one of the strongest negative predictors of survival in those diagnosed with lung cancer.[24] The likelihood of death within the first month after diagnosis is 4 times greater for patients with ED visits compared to those presenting via other routes.[22] In the UK, the 1-year relative survival of lung cancer patients diagnosed through GP referral was 40% (95% CI 40–41), while the 1-year survival rate in those diagnosed via ED presentation was only 12% (95% CI 11–12).[24] Earlier diagnosis in primary care will reduce emergency presentations.[9] This can be achieved through increased access to primary care services, public awareness campaigns and early diagnosis initiatives. In the UK, a National Awareness and Early Diagnosis Initiative launched in 2008 to raise public awareness of early symptoms of cancers and to promote early diagnosis[25] significantly increased public awareness of lung cancer symptoms and the number of urgent GP referrals for suspected cases, and also decreased the percentage of lung cancer patients diagnosed through the ED.[26] A similar but smaller "cough cough cough" campaign in New Zealand did not seem to have any significant changes. We believe any measures to improve early diagnosis could improve survival rates, including adoption of a national lung cancer screening programme.[27]

There has been a smaller proportion of patients presenting in the ED before lung cancer diagnosis in recent years. A reduction in lung cancer patients' emergency presentation rate was also observed in England (37.9% in 2006 and 34.3% in 2013).[28] Patients with lung cancer are less likely to be diagnosed through the emergency pathway, and are more likely to be diagnosed with early-stage and treatable disease if they have better access to primary care or specialist services where symptoms may be recognised early.[29] Primary healthcare practitioners play a crucial role in reducing delays to cancer diagnosis, as they can encourage patients to participate in cancer screening programmes or to visit their GP practice with symptoms before receiving a diagnosis.[30] With that in mind, the New Zealand government and regional health bodies continue introducing new initiatives to improve patient access to primary healthcare, i.e., Very Low Cost Access (VLCA) fees and the Primary Options for Acute Care programme. These and other initiatives are aimed at making appointments cheaper or accessing the diagnostics otherwise only available via the hospital more quickly. While workforce and capacity issues also need to be addressed, any further development and roll out of these programmes could have a significant impact if they reduce the number of ED presentations prior to a lung cancer diagnosis.

One of the strengths of this study is that we utilised comprehensive information regarding demographic characteristics, smoking status, cell type, cancer stage, comorbidities and emergency presentations of lung cancer patients. We also identified rural–urban areas based on a novel rural–urban classification for New Zealand health research created by Whitehead et al.[31] This research also had some limitations. We could not classify ED presentations by admission method or referral sources such as via accident and emergency services, GP, other emergency admissions to inpatients and emergency referrals to outpatients. While overall numbers give us a target to reduce from given the terrible mortality for those with an ED presentation within 14 days, in our rural hospitals the ED is often the only pathway to some services. There may also be bias in that some groups (men, Māori and Pacific people, and those from low socio-economic communities) may preferentially use the ED for healthcare and may also have reasons other than diagnostic delay for having more advanced disease.

Conclusion

Patients presenting through the ED have more advanced-stage disease, while those presenting through their GPs have evidence of being diagnosed earlier and having better survival. The barriers for Māori and for men that lead to greater reliance on the ED for diagnosis need to be addressed. Without this, the health system will continue its role of perpetuating the stark inequity that exists for Māori.

Table 1: Characteristics of lung cancer patients with and without emergency department visits within 14 days before diagnosis date.

Factors		Without ED visits	With one ED visit	With two or more ED visits	P-value	P-value
		(1)	(2)	(3)	(2) vs (1)	(3) vs (1)
Age group	<50	42 (53.8%)	26 (33.3%)	10 (12.8%)	0.11	0.86
	50–54	62 (58.5%)	35 (33.0%)	9 (8.5%)		
	55–59	122 (63.9%)	48 (25.1%)	21 (11.0%)		
	60–64	183 (61.4%)	91 (30.5%)	24 (8.1%)		
	65–69	240 (62.7%)	108 (28.2%)	35 (9.1%)		
	70–74	287 (63.1%)	118 (25.9%)	50 (11.0%)		
	75–79	216 (59.7%)	107 (29.6%)	39 (10.8%)		
	>80	296 (56.5%)	181 (34.5%)	47 (9.0%)		
Gender	Female	740 (63.3%)	323 (27.6%)	106 (9.1%)	0.01	0.09
	Male	708 (57.7%)	391 (31.8%)	129 (10.5%)		
Ethnicity	Māori	350 (56.6%)	195 (31.6%)	73 (11.8%)	0.11	0.02
	Non-Māori	1,098 (61.7%)	519 (29.2%)	162 (9.1%)		
Rural/urban	Urban	747 (59.7%)	441 (35.3%)	63 (5.0%)	<0.01	<0.01
	Rural	696 (61.1%)	272 (23.9%)	172 (15.1%)		
	Unknown	5 (83.3%)	1 (16.7%)	0		
Smoking status	Current smoker	444 (59.8%)	229 (30.9%)	69 (9.3%)	<0.01	0.02
	Ex-smoker	769 (63.1%)	333 (27.3%)	116 (9.5%)		
	Never smoked	120 (61.9%)	57 (29.4%)	17 (8.8%)		
	Unknown	115 (47.3%)	95 (39.1%)	33 (13.6%)		
Cell type	NSCLC	1,039 (63.8%)	449 (27.6%)	141 (8.7%)	<0.01	<0.01
	SCLC	143 (49.8%)	95 (33.1%)	49 (17.1%)		
	Others	14 (82.4%)	2 (11.8%)	1 (5.9%)		
	Unknown	252 (54.3%)	168 (36.2%)	44 (9.5%)		
Cancer stage	I	282 (86.8%)	39 (12.0%)	4 (1.2%)	<0.01	<0.01
	II	113 (81.9%)	19 (13.8%)	6 (4.3%)		
	III	348 (75.5%)	87 (18.9%)	26 (5.6%)		
	IV	652 (47.5%)	534 (38.9%)	187 (13.6%)		
	Unknown	53 (53.0%)	35 (35.0%)	12 (12.0%)		

Table 1 (continued): Characteristics of lung cancer patients with and without emergency department visits within 14 days before diagnosis date.

CCI score	0	338 (60.4%)	166 (29.6%)	56 (10.0%)	0.13	0.39
	1	354 (64.4%)	148 (26.9%)	48 (8.7%)		
	2+	756 (58.7%)	400 (31.1%)	131 (10.2%)		
Year of diagnosis	2011–2014	416 (56.7%)	248 (33.8%)	70 (9.5%)	<0.01	0.93
	2015–2018	564 (60.3%)	283 (30.2%)	89 (9.5%)		
	2019–2021	468 (64.4%)	183 (25.2%)	76 (10.5%)		
Total		1,448 (60.4%)	714 (29.8%)	235 (9.8%)		

ED = emergency department; NSCLC = non-small cell lung cancer; SCLC = small cell lung cancer; CCI = Charlson Comorbidity Index.

Figure 1: Kaplan–Meier survival curves by ethnicity and emergency department visits.

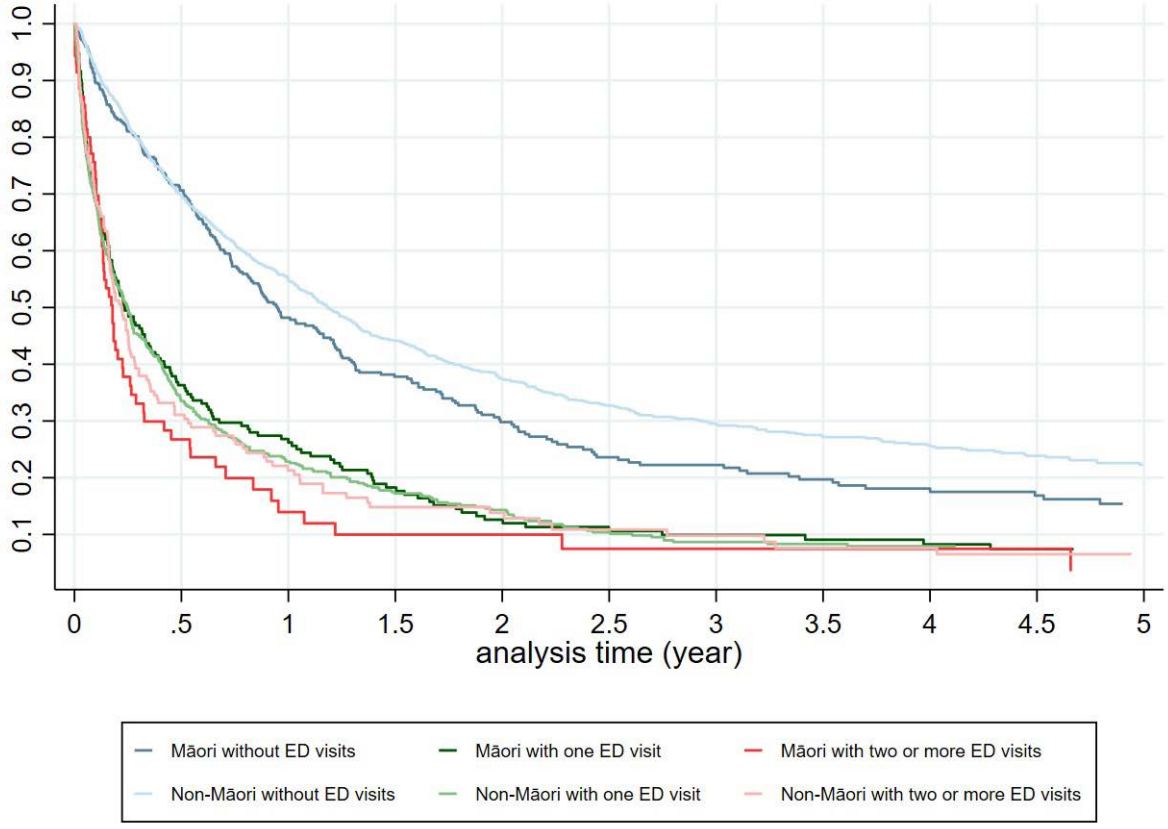

Table 2: Adjusted odds ratios of emergency department visits.

Variables	With ED visits vs without (95% CI)	With two or more ED visits vs with one ED visit (95% CI)
Age (years, continuous)	1.00 (0.99–1.01)	0.99 (0.97–1.00)
Gender		
Female	Reference	Reference
Male	1.22 (1.02–1.47)*	1.03 (0.74–1.41)
Ethnicity		
Non-Māori	Reference	Reference
Māori	1.27 (1.03–1.57)*	1.03 (0.71–1.50)
Rural/urban		
Urban	Reference	Reference
Rural	0.94 (0.78–1.12)	4.65 (3.33–6.49)***
Smoking status		
Current smoker	Reference	Reference
Ex-smoker	0.86 (0.70–1.07)	1.46 (0.99–2.17)
Never smoked	1.08 (0.75–1.56)	1.41 (0.71–2.78)
Unknown	1.26 (0.88–1.79)	1.54 (0.85–2.80)
Cell type		
NSCLC	Reference	Reference
SCLC	1.45 (1.11–1.90)**	1.74 (1.12–2.69)*
Others	0.49 (0.13–1.86)	2.38 (0.18–31.95)
Unknown	1.59 (1.25–2.04)***	0.87 (0.56–1.35)
Cancer stage		
I	Reference	Reference
II	1.43 (0.83–2.46)	3.39 (0.80–14.31)
III	2.13 (1.43–3.15)***	3.27 (1.01–10.60)*
IV	7.06 (4.99–9.98)***	3.64 (1.23–10.82)*
Unknown	4.26 (2.43–7.49)***	3.60 (0.94–13.73)
CCI score		
0	Reference	Reference

Table 2 (continued): Adjusted odds ratios of emergency department visits.

1	0.93 (0.71–1.21)	1.18 (0.73–1.91)
2+	1.20 (0.96–1.51)	1.15 (0.76–1.72)
Year of diagnosis		
2011–2014	Reference	Reference
2015–2018	0.92 (0.74–1.14)	0.92 (0.62–1.35)
2019–2021	0.79 (0.63–1.00)*	1.46 (0.97–2.21)

***p<0.001, **p<0.01, *p<0.05.
ED = emergency department; CI = confidence interval; NSCLC = non-small cell lung cancer; SCLC = small cell lung cancer; CCI = Charlson Comorbidity Index.

Table 3: Odds ratios of 1-year survival.

Variables	Unadjusted odds ratios (95% CI)	Adjusted odds ratios (95% CI)
ED visits		
Without	Reference	Reference
With one ED visit	0.25 (0.21–0.32)***	0.42 (0.32–0.54)***
With two or more ED visits	0.18 (0.12–0.27)***	0.33 (0.21–0.50)***
Age (years, continuous)	0.98 (0.97–0.98)***	0.97 (0.96–0.98)***
Gender		
Female	Reference	Reference
Male	0.65 (0.55–0.78)***	0.75 (0.60–0.92)**
Ethnicity		
Non-Māori	Reference	Reference
Māori	0.78 (0.64–0.96)*	0.75 (0.58–0.96)*
Rural/urban		
Urban	Reference	Reference
Rural	0.96 (0.80–1.13)	0.96 (0.77–1.18)
Smoking status		
Current smoker	Reference	Reference
Ex-smoker	1.10 (0.90–1.34)	1.39 (1.08–1.79)*
Never smoked	2.20 (1.57–3.08)***	2.74 (1.78–4.23)***
Unknown	0.33 (0.23–0.49)***	0.58 (0.35–0.96)*
Cell type		

Table 3 (continued): Odds ratios of 1-year survival.

NSCLC	Reference	Reference
SCLC	0.61 (0.46–0.81)***	1.08 (0.78–1.49)
Others	4.76 (1.31–17.38)*	2.51 (0.44–14.26)
Unknown	0.67 (0.53–0.84)***	0.67 (0.49–0.93)*
Cancer stage		
I	Reference	Reference
II	0.35 (0.20–0.59)***	0.35 (0.20–0.60)***
III	0.13 (0.08–0.19)***	0.12 (0.08–0.18)***
IV	0.03 (0.02–0.05)***	0.03 (0.02–0.05)***
Unknown	0.04 (0.02–0.07)***	0.09 (0.04–0.19)***
CCI score		
0	Reference	Reference
1	0.88 (0.68–1.12)	0.76 (0.56–1.03)
2+	0.69 (0.56–0.85)***	0.61 (0.46–0.80)***
Year of diagnosis		
2011–2014	Reference	Reference
2015–2018	1.08 (0.88–1.32)	1.02 (0.80–1.31)
2019–2021	1.37 (1.09–1.72)**	1.16 (0.87–1.55)

***p<0.001, **p<0.01, *p<0.05.
CI = confidence interval; ED = emergency department; NSCLC = non-small cell lung cancer; SCLC = small cell lung cancer; CCI = Charlson Comorbidity Index.

COMPETING INTERESTS
All authors disclose no competing interests.
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DATA AVAILABILITY
The data supporting this study cannot be publicly shared for ethical or privacy reasons.

ETHICS APPROVAL
The study was approved by the Health and Disability Ethics Committee, Ministry of Health, New Zealand (ref. no. 2022 AM 5900).

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Navigating the long journey of heart failure—experiences of Māori and Pacific peoples

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ABSTRACT

AIMS: Māori and Pacific peoples in Aotearoa New Zealand experience significant inequities in heart failure rates, treatment and outcomes compared to NZ Europeans. We aimed to understand the experiences of Māori and Pacific people living with heart failure as they navigated care across primary and secondary settings.

METHODS: This research involved a secondary analysis of data collected in a wider qualitative study investigating evidence–practice gaps of cardiovascular care experienced by Māori and Pacific people. From the wider pool of semi-structured interviews, we identified 24 people (seven Māori and 17 Pacific peoples, 23 from the North Island) living with heart failure, and applied template and framework analysis to explore their distinct experiences.

RESULTS: Two major themes identified related to participants: 1) Condition—need for more support to understand and self-manage their heart failure condition, and 2) Journey—desire to feel well-connected to the health system in their heart failure journey.

CONCLUSIONS: Addressing heart failure inequities for Māori and Pacific peoples requires that providers engage in clear and meaningful communication to support patient self-management. Strengthening pathways for Māori and Pacific patients and whānau (families) between primary and secondary services is required to reduce their likelihood of becoming disconnected from care.

There are significant and long-standing inequities in heart failure (HF) rates, management and outcomes for Māori and Pacific peoples in Aotearoa New Zealand. In fact, inequities are widening, with HF hospitalisation rates in older Europeans declining and no corresponding improvement for Māori and Pacific peoples.[1] HF prevalence and hospitalisation rates are much higher for Māori and Pacific peoples than for non-Māori non-Pacific people, particularly in younger age groups where HF is generally less common.[2–4] Māori with a primary diagnosis of HF have higher hospital readmission rates compared with non-Māori.[5] After adjusting for age, Pacific peoples are more than twice as likely as the total Aotearoa New Zealand population to be discharged from hospital with a diagnosis of HF.[6] A study by Hikaka et al.[7] illustrated persistent inequities in medication uptake among Māori with HF; the authors called for culturally revamped approaches to health literacy. Māori are more likely to die younger from HF[5] even after controlling for socio-economic deprivation.[8] These are imperatives to better understand and address contributors to inequities in the HF care pathway.

HF is a long-term, progressive condition that is managed in hospital and community health settings.[9] Continuity of care for HF is associated with improved survival, fewer unplanned readmissions, better medication management and clinic attendance, positive engagement with providers and increased quality of life.[10,11] Specialist-managed programmes that centre cultural safety, including nurse-led cardiac services, have been shown to have high acceptance by Māori HF patients.[12,13] Considering chronic disease management more generally, a programme with education materials provided by Pacific staff in Pacific languages was found to improve understandings of HF and medications among Pacific patients with HF.[14] Whānau (family) centric models of care have also been demonstrated to work for Māori and Pacific peoples with chronic conditions such as type 2 diabetes,[15] suggesting useful parallels for HF management.

Despite increasing attention to inequities, few studies have investigated Māori and Pacific peoples' experiences of HF and their preferences for care. A Māori- and Pacific-led programme of research—Manawataki Fatu Fatu (MFF) for ACCESS , which means Māori and Pacific Hearts in Unison for Achieving Cardiovascular Care in Equity StudieS

—is investigating how to improve heart healthcare for Māori and Pacific peoples.[16] There are three streams of the programme: i) cardiovascular risk assessment and management in primary care, ii) pre-hospital care for a cardiac event in the community, and iii) HF long-term management. The present paper follows on from a wider qualitative study[17] that examined the reasons for evidence–practice gaps in heart healthcare based on the experiences and perspectives of Māori and Pacific peoples. The analysis here explores how Māori and Pacific patients and whānau experience HF as a fluctuating condition requiring coordination of care across primary and secondary settings. The findings will contribute to one of the overarching goals of the MFF programme—to identify models of heart healthcare that are responsive to the needs and aspirations of Māori and Pacific peoples.

Method

In this study we applied qualitative Kaupapa Māori methodologies and Pacific research frameworks to interview Māori and Pacific peoples across Aotearoa New Zealand with personal, or whānau, experience of HF. This research involved a secondary analysis of data collected in a wider qualitative study investigating evidence–practice gaps of cardiovascular care experienced by Māori and Pacific peoples.

Methodology

The guiding principles of the MFF programme[16] are inspired by a navigational framework, te kapehu whetū (the Māori star compass), offering a metaphor for examining the journey of HF. In our relational approach to qualitative research, we value Māori and Pacific knowledge (Kāinga), apply a strengths-based lens to our analysis (Ngoi), aim to collaborate with providers and stakeholders in the health system (Ngā Rangi), and centre and elevate the voices of whānau (Ngā Reo). The translational goal of our programme (Manu) reminds us to centre the aspirations of communities and where they see the destination of living well with HF. For Māori and Pacific peoples, the health journey is as much a spiritual endeavour as a physical one. For example, Tongans at the start of each year (Uike Ha'amo) will spiritually prepare their vaka (Kavenga mafasia) for what highs and lows may come their way (O'e hala fononga) during a long journey ahead. Our own vaka (vessel) is led by senior researchers (MH, CG) with expertise in Kaupapa Māori and Pacific methodologies[18,19] and is carried forwards by a team comprised mostly of Māori and Pacific researchers.[20]

Participants

The participants in the wider qualitative study had a personal or whānau experience of acute coronary syndromes and/or HF or were eligible for cardiovascular risk assessment. We drew on professional networks in the health sector and our own communities for recruitment. Participants self-identified with Māori and/or a Pacific ethnicity, were aged over 18 years and provided informed consent. For this paper, we report a focussed analysis of the subset of participants with experience of HF. From a total of 61 patients and whānau interviewed in the wider study, 24 participants (seven Māori, 17 Pacific peoples) had lived experience of HF. Pacific ethnicities represented were Samoan, Tongan, Cook Islands Māori and Tokelauan. We had a higher proportion of Pacific participants in large part due to co-author TTS's strong community relationships in the Capital, Coast and Hutt Valley. HF participants comprised 16 males and eight females (no other genders), with five aged 25–44, 11 aged 45–64 and eight aged 65+ years. Most participants (23) were from the North Island, encompassing rural and urban areas (the rural/urban split was not recorded). One participant was interviewed as a whānau member. Each participant was asked to choose a pseudonym.

Data collection

We conducted semi-structured interviews between November 2021 and August 2022 in English, Samoan and Tongan. Cultural protocols and language choice, guided by the participants, were incorporated into interviews, including opening and closing karakia or lotu (incantation or prayer), whakawhanaungatanga (making introductions and connections), and allowing space and time for talanoa (free-flow dialogue). Interviews, lasting up to 60 minutes, invited participants to discuss their heart condition experience and journey in care management, what made them comfortable or uncomfortable in their interactions with healthcare professionals and services, what was important to them for heart health and their ideas for improving heart health services in Aotearoa New Zealand.

Analysis

All interviews were analysed using template analysis, a type of thematic analysis,[21] through

which we developed five themes. The five main themes identified in the wider study were:

- Context—social, whānau, cultural and spiritual contexts and values of patients and whānau.
- Mana—desire by patients and whānau for mana (dignity) in their experiences of healthcare.
- Condition—the role of good and reciprocal communication with providers to support self-management of heart health.
- People—influence of important people in heart healthcare.
- Journey—the heart healthcare journey—from getting in to staying in.

We found many similarities across Māori and Pacific groups regarding heart healthcare in the wider study. For example, there were commonalities in the contexts of patients and whānau ("Context"), a desire for reciprocal communication with providers ("Condition"), participants' expectations for mana-enhancing heart care ("Mana"), aspirations for a health workforce with greater representation of Māori and Pacific providers ("People") and gaps in accessible, connected healthcare pathways ("Journey"). However, we noted that participants living with HF had distinct experiences with self-managing their condition over the long term, compounded by episodic needs to access care across primary and secondary settings. To bring these experiences to the fore, we conducted a secondary analysis using two original themes in the wider study where the distinctions were most apparent: "Condition" and "Journey". We used the framework method developed by Gale et al.[22] to elaborate on the experiences of HF participants by tabling key insights into a matrix of cases and codes across the five themes identified in the wider study. Analytical memos were written up to deepen our understanding of issues captured by the themes.

Ethics approval

This study was approved by the Auckland Health Research Ethics Committee (AHREC), ref. 22609.

Results

Condition

This theme relates to the ability of participants to understand their condition and be partners in self-management.

Participants expressed a desire to recognise their HF symptoms, to understand when it was important to seek care and to feel confident in doing so: "*Our people need to be aware of the signs and when to call for help.*" – Penny. Resources to monitor daily symptoms, such as weight and fluid intake, were actively taken up by participants and, for some, formed part of their new identity of living with their condition. Participants who were confident on their journey of self-management also wanted "*somebody* [clinical] *still monitoring me.*" – Jason.

Opportunities to improve communication and health literacy efforts by providers were apparent in participants' confusion about their HF treatments: "*There are seven tablets in a pack for me to take. I cannot remember what each tablet is good for.*" – Isaac. Participants found that explanations from providers were insufficient, *"They* [doctors] *don't really explain what the pill's for."* – KB1. However, they valued resources such as the *"yellow card, which has the name of the tablets and what they do.*" – Sela.

Relationships with providers could hinder or facilitate participants' understanding and acceptance of therapies. Tina asked for explanations about medication but said, *"They look at you and they think that you are dumb … I threw the tablets away because I did not know what they were for."* Through facilitation by a Samoan nurse, Tina was later happy with another provider, who *"would sit with me and break things down for me to understand."* Participants valued two-way communication and partnership with their provider: *"I always check in with* [my nurse] *to say, oh yeah, that actually worked. I mean, I'm still doing my journey, but it's been great having her just in the background."* – KB1.

Provision of health advice in the participants' first language was preferred but uncommon. If provided, it may have better supported informed choices for participants in managing their HF condition over the long term. For example, Pita kept working against medical advice, because he needed to support his family. Later, he felt certain that if he had been seen by a Tongan doctor from the beginning and had the consequences of continuing to work explained in the Tongan language, he "*would have listened more closely."*

Journey

This theme relates to the participants' desire to feel well-connected to the health system in their HF journey, from diagnosis to discharge, from hospital

to care in the community.

Participants reported that receiving a HF diagnosis was delayed in both primary and secondary care, despite seeking care for symptoms such as breathlessness: "*I was admitted to the hospital yearly for my pneumonia attack, they should have checked me thoroughly to see if I had HF; instead I was told it was pneumonia.*" – Maka. Eva similarly expressed disappointment: "*If my doctor did his part thoroughly, address my problem properly, organised for me to see the specialist early, maybe I would have had the surgery much earlier.*" Participants also experienced difficulties in being taken seriously. Sione described his wife taking him to the hospital ED after he tried to make an urgent appointment with his GP and was only offered a booking for 5 days later: "*I tell my wife if she didn't take me to hospital maybe I die at home with the* [GP] *receptionist booking me for next Tuesday. But I told her* [receptionist] *this is an emergency you know, but she thought I was kidding.*" Once participants could access in-hospital care, positive experiences were reported: "*Everyone at the hospital, down to the cleaners, interact with you really well.*" – Tom.

Problems with the discharge process were raised by participants: "*We were never given discharge notes about his conditions and what to do or any follow up.*" – Tim. Feeling abandoned in community care was another concern: "*They see you for like a year and then if you're doing well, you know, you're put back out in the world by yourself, and sometimes that's the hardest thing.*" – Jason. In comparing diabetes to HF services, Maka observed: "*My wife suffered from diabetes, their team from health service are always in touch with her. The HF patients are not well contacted compared to my wife.*"

Regular appointments with GPs could be difficult to obtain for participants, affecting ongoing management of their HF condition. Participants enrolled in a tertiary service reported strong relationships with cardiac nurses, which in turn could elicit better support from their GP: "*Now the GP's seeing what* [name] *the nurse has been doing for the cardio thing in* [hospital outpatient clinic], *she's there and my GP looked at all the records and he goes, 'oh, you're doing really good,' and I said 'yeah'. Now he's following up with me how things are going. Whereas before I never had that follow-up.*" – KB1.

Participants sought political solutions to address the high demand for HF services. Maka explained, "*There are a lot of patients died, it is as though the Government do not want to know, to understand the big picture, it is like a river that claims the lives of HF patients.*" Pat similarly commented, "*I think they should make it more political so that we can get more results. It's the only way it's going to happen. That Treaty's* [Treaty of Waitangi] *not been followed and we're disappearing in the crowds.*"

Discussion

This study explored experiences of seven Māori and 17 Pacific patients and whānau with HF as they navigated care across primary and secondary settings. Guided by Kaupapa Māori theory and Pacific frameworks, we undertook semi-structured interviews and used both template and framework analysis to explore HF experiences. Poor communication from providers and a lack of continuity of care from diagnosis of HF to hospital discharge and community management were common. Even as patients and whānau adopted resources for self-management, it was reciprocal relationships with providers, often through nurse-led services, that notably contributed to positive experiences in the HF care journey.

Despite the availability of guideline-directed therapies for HF management, Māori and Pacific peoples have not shared equitably in the benefit of treatments and services.[23] Participants struggled to understand their treatment regimen when there was poor relationship-building by providers. This is a reminder that the onus is on providers to ensure the delivery of information meets patients' and whānau needs and expectations, and to take time to understand what barriers might exist in their social contexts.[24] The Aotearoa New Zealand Ministry of Health's health literacy framework[25] is premised on a health system where consumers have the capacity to understand health advice, make informed decisions and navigate services. Despite widespread dissemination of these health literacy principles, findings of this research suggest that they have not been consistently translated into practice in the heart health space. Our findings align with an international study by Lambert et al.[26] demonstrating that health professionals had a limited understanding of the health literacy needs of Indigenous patients on a cardiovascular disease (CVD) pathway. As asserted by Carlson et al.,[27] the responsibility for CVD health literacy sits with front-line providers, but requires systems changes to meet the needs of marginalised communities.

Many participants struggled throughout their HF care journey, from getting a timely diagnosis in both primary and secondary care settings, receiving regular care from a GP and being given a clear picture of the management strategy post-discharge for both medical care and social support. While inconsistent diagnosis and management for HF has been documented,[28] Māori and Pacific patients and whānau also face compounding barriers to care, particularly institutional racism, and inequitable access to the social determinants of health.[29] Given the detrimental physical, emotional and spiritual impacts of a HF condition, there was a strong desire by participants to remain closely connected to the health system, even after being deemed medically stable. Participants understood they had a lifelong condition and reasonably expected regular and proactive monitoring; they were concerned that they would not be able to access heart health expertise when they needed it. The findings of this study emphasise the need to address inconsistencies in the implementation of HF care pathways in Aotearoa New Zealand, particularly in relation to communication practices by providers, and re-examine discharge planning to meet the needs of Māori and Pacific peoples. This is the focus of a research plan that has been initiated by the MFF programme.

A key strength of this study has been the elevation of the voices of Māori and Pacific whānau, overcoming power differentials that typically privilege provider perspectives. A limitation of our research is Māori representation of participants being predominantly from Auckland. We were not able to further investigate inequities that might be experienced by whānau in rural settings. A more in-depth analysis with more regional data may have revealed different experiences by participants of HF management approaches across localities.

Te Pae Tata, the interim New Zealand health plan mandated by the *Pae Ora Act (2022)* sets out two key actions in their strategy for people living with chronic health conditions: 1) ensuring nationally consistent clinical pathways for integration of care between primary and secondary settings, and 2) supporting Māori and Pacific community providers to work alongside whānau for self-management. This provides a framework to address the gaps identified in our study. The success of a "walk alongside" approach where Kai Manaaki (case managers in primary care settings) help Māori and Pacific peoples living with type 2 diabetes to manage their clinical and social support needs[15] suggests opportunities to boost community-driven services for HF management.

There are considerable pressures in the Aotearoa New Zealand health system that affect optimal HF management and patient-centred care; some include affordable and timely access to primary care, adequate funding for nurse-led services to meet the increasing demand for care in the community[30] and routine screening with echocardiograms. Despite these system constraints, healthcare workers are obligated to provide culturally safe care. To meet our obligations to Te Tiriti o Waitangi and the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP), the Aotearoa New Zealand health system urgently needs to address the significant burden of HF on Māori and Pacific whānau and communities.

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Non-financial interests: SH is a member of the Whānau, Consumer and Clinician Digital Council and National Cardiac Clinical Network – Te Whatu Ora Health New Zealand. VS is a member of the Data Safety Monitoring Board for the Cess@Tion clinical trial and a board member and deputy chair of the medical assessment committee for the Auckland Medical Research Foundation. KB is co-director of Pūtahi Manawa.
All other authors declare no relevant financial or non-financial interests.

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National survey of hospital rheumatology service users to inform a statement set describing the minimum service expectations for publicly funded rheumatology secondary care in Aotearoa New Zealand

Rebecca Grainger, Valerie Milne, Rachel Ngan Kee, Nicola Dalbeth

ABSTRACT

AIMS: The essential components of a rheumatology service for public hospital rheumatology services in Aotearoa New Zealand are not yet defined. We aimed to seek the views of users of public hospital rheumatology services on potential components of a rheumatology service.

METHODS: Online survey of adults in Aotearoa New Zealand who self-reported as having used district health board rheumatology services in the past 5 years. Participants indicated their level of agreement (7-point Likert scale) on whether service statements should be a component of public hospital rheumatology services and provided free-text comments. Analysis used descriptive statistics and inductive content analysis.

RESULTS: Over 80% of participants (n=237) agreed or strongly agreed with 23 of the 26 statements about rheumatology care. The three statements that did not reach 80% agree or strongly agreed addressed infusion services for biologic disease modifying anti-rheumatic drugs, offering outpatient assessment for non-inflammatory musculoskeletal conditions and discharge back to primary care when an inflammatory disease is stable. The free-text comments were 1) expression of support of the statement, 2) reconfirming how or why particular services were valued or valuable, 3) caveats about statements, and 4) suggesting other services not mentioned in the statement.

CONCLUSION: People with inflammatory rheumatic diseases who have used rheumatology services agreed with the majority of the statements of service components, with some caveats. A statement set describing the minimum service expectations for publicly funded rheumatology secondary care in Aotearoa New Zealand has been developed and endorsed by Arthritis New Zealand and the New Zealand Rheumatology Association.

People with inflammatory rheumatic diseases (IRDs) need healthcare from specialist rheumatology teams to achieve the best possible rheumatic disease outcomes. In Aotearoa New Zealand, there is currently no national service model for what should be provided in a rheumatology service and how care should be organised and delivered. The views of rheumatologists and users of rheumatology services—people with rheumatic diseases—are critical in informing potential rheumatology service models. We aim to develop a national rheumatology service model for public hospitals in Aotearoa New Zealand, informed by key stakeholders.

In 2022, we described the consensus among rheumatologists in Aotearoa New Zealand as to what components of best-practice rheumatology services identified in the international literature should be included in rheumatology services in the Aotearoa New Zealand public health system.[1] Of 22 considered statements of service components, there was consensus among rheumatologists that 16 be included in both small and large hospitals in Aotearoa New Zealand, and one statement with consensus to include in larger hospitals only. There were five statements, including addressing

discharge of people with well-controlled IRD to primary care and telemedicine, for which consensus was not reached. These findings outlined rheumatologists' views of the minimal components of public health system rheumatology services in hospitals in Aotearoa New Zealand.

Service users' views are essential to inform service models.[2] To address this need, we undertook a qualitative study with people from across Aotearoa New Zealand with IRDs who had used public health system rheumatology services.[3] We explored their views of these rheumatology services, specifically considering staffing, ways of working and what health services were able to be accessed via these services. We then evaluated if the best practice statements from the literature captured these needs. Patient-participant feedback led to a refining of statements from the rheumatologist consensus exercise and the development of three new principles and three new statements.[3]

In this study we aimed to seek views on all the statements considered to date from a wider group of people with IRDs who have used rheumatology services. We undertook a nation-wide survey of people who have used district health board (DHB, now Health New Zealand – Te Whatu Ora) rheumatology services in hospitals in Aotearoa New Zealand in the last 5 years. Our research question was *How do people using public rheumatology services view the potential service components of public hospital rheumatology services?* We describe the findings of this survey, which informed a statement set describing the minimum components (staffing, services, ways of working) for publicly funded rheumatology secondary care in Aotearoa New Zealand. These statements have since been endorsed by Arthritis New Zealand and the New Zealand Rheumatology Association.

Methods

Service user views on the statements of care in DHB rheumatology services from the rheumatologist consensus exercise and patient focus group were sought via an electronic survey. Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Otago.[4,5] This bespoke survey was developed by the research team. The survey was open to all persons over 18 years in Aotearoa New Zealand who self-reported as having used DHB rheumatology services in the past 5 years, where "used" was not further defined.

The survey was disseminated via Arthritis New Zealand social media channels (Twitter, Facebook) and communication streams, via a short-URL link to the page on the Arthritis New Zealand website.[6] The advertisement materials are provided in Appendix 1. These websites are all open to the public, and, in addition, the social media sites will have "followers". Recruitment was through convenience sampling. Demographic and self-reported clinical data were collected without identification. After careful consideration and to reduce potential for harm, iwi affiliation data were not collected, as results were unlikely to yield benefits to specific iwi. Participants were asked to indicate their level of agreement, using a 7-point Likert scale, on whether each service statement should be a component of future public hospital (secondary or specialist care) rheumatology services in Aotearoa New Zealand. Response options were "strongly agree", "agree", "somewhat agree", "neither agree or disagree", "somewhat disagree", "disagree" and "strongly disagree". The survey questions included the three principles of care and 23 of the 25 statements of care (Appendix 2). All statements considered in the rheumatologist consensus exercise were included, including those on which rheumatologists had not reached consensus; (Statements #4 [Survey question number (Q) Q20], #17 [Q22], #18 [Q23], #20 [Q10] and #22 [Q23]). Survey questions 1, 11 and 12 were the three new principles, and questions 2, 9 and 10 were the three new statements from the service-user qualitative study. The principles and statements were re-ordered to be grouped in similar ideas or care areas.

Two statements addressing Te Tiriti o Waitangi obligations and use of health equity assessment tools (Statements #18 and #19) were not included in the survey. The *Pae Ora (Healthy Futures) Act 2022* embeds these expectations in all care delivered by Health New Zealand – Te Whatu Ora. Therefore, we considered that these statements, which were developed before the *Pae Ora Act* was passed, no longer needed to be included in rheumatology-specific service standards.

To allow participants to provide additional views and suggestions, free-text comments were invited (but optional) for each statement, and at the survey conclusion. REDCap and pilot testing by the research team, which includes a person with an IRD who has used both public hospital and private rheumatology services, indicated the

survey would take less than 10 minutes to complete and that all functionality worked as expected. The survey instrument has 30 screens/pages with the statements having a screen each. The demographics, service use and consent screens/pages had 3–6 responses each. The order of the standards was fixed. It was not mandatory for a participant to answer every question and participants could more forward and backwards through the survey. No specific steps were taken to actively prevent multiple entries from an individual. The survey instrument is provided in Appendix 2.

The survey was open for 4 weeks, from 17 June 2022 until 15 July 2022. A reminder was posted on the Arthritis New Zealand social media channels on 1 July 2022. A responder was considered a "study participant" if at least one response to any statement was provided. Data were downloaded from REDCap and summarised using descriptive statistics. Consensus about a principle or statement was defined as >80% of participants giving ratings of "strongly agree" or "agree". The free-text comments were analysed using inductive content analysis to describe the additional information provided about the statements.[7] Comments were read several times and views were categorised according to key content overall or by particular service statement. Views or ideas were coded and categorised independently by two team members (VM, RG), then discussed and refined until an agreed categorisation reached. These were summarised narratively.

Ethical approval was obtained from the University of Otago Human Ethics Committee, approval number D22/140. The study was funded by Arthritis New Zealand, with Arthritis New Zealand also disseminating the study URL; however, the authors undertook the study independently.

The reporting of this study is guided by the CHERRIES checklist for web-based surveys.[8]

Results

The survey link was opened 278 times, with 253 people giving consent for data collection and 246 people then providing complete demographic data. Of these, 237 people gave a response to at

Table 1: Survey participants' demographics and diagnoses.

Participant demographic characteristic n=237		**N/N (%)**
Sex	Female	213 (90)
	Male	17 (7)
	Non-binary	6 (3)
	Prefer not to say	1 (0)
Age group	18–39 years	58 (24)
	40–59 years	122 (51)
	>60 years	57 (24)
Ethnicity, n=259*	Pākehā/NZ European	216 (83)
	Māori	22 (9)
	Pacific peoples	5 (2)
	Other	16 (62)
Duration of care in DHB rheumatology service	Less than 1 year	14 (6)
	1–5 years	87 (37)
	More than 5 years	136 (57)

Table 1 (continued): Survey participants' demographics and diagnoses.

Inflammatory rheumatic disease[#]	Rheumatoid arthritis	132 (56)
	Psoriatic arthritis	48 (20)
	Autoimmune connective tissue/autoimmune diseases (including systemic lupus erythematosus, Sjögren's disease, systemic sclerosis, myositis, undifferentiated)	48 (20)
	Axial spondyloarthritis (including ankylosing spondylitis)	32 (14)
	Peripheral spondyloarthritis (including reactive arthritis and inflammatory bowel disease associated arthritis)	12 (5)
	Osteoarthritis	10 (4)
	Juvenile idiopathic arthritis	7 (3)
	Crystal arthritis	4 (2)
	Polymyalgia rheumatica	3 (1)
	Vasculitis	2 (1)

*Participants were able to nominate more than one ethnicity.
[#]Participants could nominate more than one inflammatory rheumatic disease, so percentages add up to more than 100.

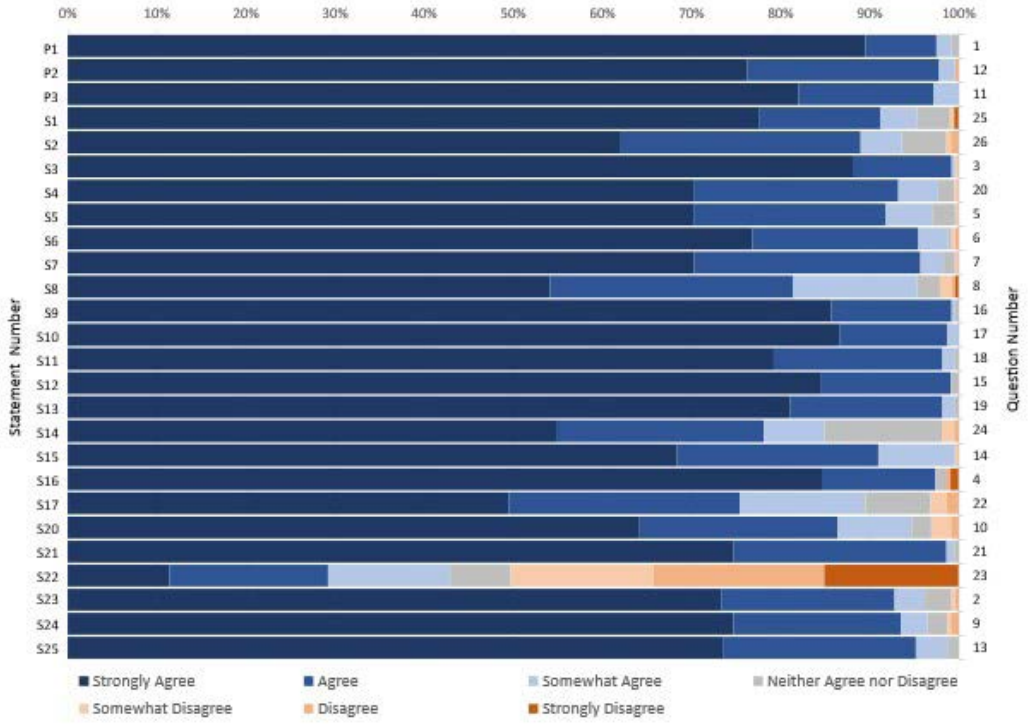
least one statement and 219 people provided complete survey responses (completion rate 219/253, 86.5%). Data from incomplete survey responses were included in analysis. Most participants were female (213/237, 90%), three-quarters were older than 40 years of age, and the most frequently reported ethnicity was New Zealand European (83.4%) (Table 1). Most participants reported their diagnosis leading to use of DHB rheumatology services as an inflammatory arthritis, most often rheumatoid arthritis (56%), psoriatic arthritis (20%), and spondyloarthropathies (19%) and connective tissue disease/autoimmune disease (20%). More than half of the participants had been in the rheumatology care of their current DHB for more than 5 years. More than half of participants reported using one of four DHB's rheumatology services, namely Capital, Coast and Hutt Valley (19%), Southern (13%), Waikato (11%) and Canterbury (11%) (Appendix Table 1).

Consensus was reached for 23 of the 26 principles and statements of care, with >80% participants giving ratings of "strongly agree" or "agree" (Figure 1, data provided in Appendix 3). The range for respondent selection of "strongly agree" for these 23 items was 54.1% to 89.5%. Statement 8 (Q8 in survey), "*Within an outpatient rheumatology clinic, a specialised rheumatology nurse should have their own consultations with chronic rheumatic disease patients*" had the lowest "strongly agree" response at 54.1%.

Three statements did not receive at least 80% "strongly agree" or "agree" responses from survey participants. These statements addressed provision of an infusion service for biologic disease modifying anti-rheumatic drugs (Statement 14 [Q24 in the survey]); offering outpatient assessment for non-inflammatory musculoskeletal conditions like osteoarthritis and fibromyalgia (Statement 17 [Q22]); and discharge back to primary care when an inflammatory disease is stable (Statement 22 [Q23]). Statement 22, "discharge to primary care when stable", had highest participant disagreement with only 29% of respondents rating "strongly agree" or "agree", 37% rating "somewhat agree", "neither agree or disagree" or "somewhat disagree" and 34% rating "disagree" or "strongly disagree".

Free-text comments about statements (n=634) were provided by 135 participants. The minimum number of comments for a statement was 13 and

Figure 1: Survey participant responses to statements on components of public hospital rheumatology services.



the mean number of comments per statement was 24. Statement 22, "discharge to primary care when stable", had the highest number of comments at 53. There were 145 free-text comments provided at the end of the survey. Content analysis showed comments were 1) expression of support of the statement, 2) reconfirming how or why particular services were valued or valuable, 3) caveats about statements, and 4) suggesting other services not mentioned in the statement. Overall, the majority of free-text responses were in support of service component statements. However, these were of two types: direct positive endorsement, and indirect endorsement by contrasting with current (poor) care experiences that would be improved or addressed if rheumatology services had the care component described. Other free-text responses were about the value of nursing, allied health, or support or education services. Comments in response to statements (Questions 5, 6, 7, 8, 9) about nurse care strongly and consistently expressed the high value that participants placed on nurse care, emphasising how helpful and important this care was to them. There were also caveat statements about nurse-led care or services, including that while nurse-led care was valued, it should not be a substitute for rheumatologist specialist care, it should be in appropriate clinical circumstances only, and that nurses should have suitable and adequate training in rheumatology. Other caveats about the statements included the following: that telehealth should be used only if clinically appropriate, and also if patient choice/agreement had occurred; that service users/patients did not have the knowledge or experience to comment on appropriateness or otherwise of staff full-time equivalent requirements or dedicated infusion services; and that shared specialty clinics would not be necessary if there was improved communication between specialist services and/or specialists. Suggestions of other valued healthcare services that were currently either hard to access from rheumatology services or should be provided included physiotherapy, occupational therapy, pharmacy, podiatry, mental health support and health literacy services. Content analysis of free-text comments to Statement 22 "discharge to primary care when stable" showed reasons participants did not agree with this statement to include the unpredictable nature of IRDs, including flares and features that required rheumatologist expertise to interpret and treat, the difficulties in accessing primary care or re-accessing rheumatologist care if discharged, that

general practitioners are specialist generalists while rheumatologists are specialists in their IRDs, and also, offering the preferred option of staying under rheumatology service care with less frequent routine visits but easy access when needed.

Discussion

In this survey of people who have used DHB rheumatology services in the last 5 years, consensus was reached for 23/26 of the statements of care components for public health system rheumatology services. Statements that did not achieve consensus included provision of infusion services, assessment of non-inflammatory musculoskeletal conditions, and discharge back (transfer of care) to primary care when inflammation is controlled. Free-text comments included further support of the statements, framed either positively or by contrasting with current care experiences, caveats about statements and suggesting other services. These data provide further guidance from service users about what should be included in publicly funded secondary care rheumatology services in Aotearoa New Zealand.

Since most of these statements were from best practice recommendations for rheumatology services in the international literature, have achieved consensus in a survey of rheumatologists in Aotearoa New Zealand and have already been refined by people with IRD, these data are not surprising. However, it remains important to seek the views of service-users to inform service recommendations.[9] This work also allows comparison of views of rheumatologists and service users, particularly around statements that did not reach agreement in one or both groups.

There were two statements that did not reach 80% agreement/consensus for both rheumatologists[1] and service users, namely Statement 17 (offering outpatient assessment for non-inflammatory musculoskeletal conditions like osteoarthritis and fibromyalgia) and Statement 22 (discharge back to primary care when inflammatory disease stable). Rheumatologists were not asked why they rated statements as they did. Importantly, neither of the statements were derived from the literature and were generated, as is appropriate, in the first round of the rheumatologist consensus exercise.[1] Assessment and management of non-inflammatory conditions is within scope of rheumatology training;[10] however, rheumatologists in secondary care rheumatology services accept referrals for non-inflammatory conditions far less frequently than private practice rheumatologists (43% versus 97%).[10] Since rheumatologist staffing levels in publicly funded rheumatology services in Aotearoa New Zealand are well below recommended levels,[11,12] rheumatology services may be making triage decisions to match demand with service capacity. Importantly, best practice recommended care for non-inflammatory conditions may not require a rheumatologist. For example, the best practice management for knee osteoarthritis includes education, exercise and weight loss,[13] which can be provided by a variety of healthcare professionals and may be best coordinated in appropriately resourced primary care.[14] Statement 22 (discharge back to primary care when stable) was not derived from the literature but generated during the first round of consensus exercise.[1,15] Given this, it is perhaps less surprising that rheumatologists had varying views on this statement, and that service user participants in this survey did not support this statement. Transfer of care back to primary care from a rheumatology service has been framed as a mechanism of managing high demand for rheumatology services or to reduce costs through care in primary care. However, evidence suggests that costs are not reduced and quality of care for patients is lower when chronic inflammatory conditions are not managed in secondary care.[16] Regardless of reasons behind these statements, given lack of consensus by rheumatologists and rheumatology service users these statements were not included in a statement set describing the minimum service expectations. These issues can be further considered at a health system level, or perhaps at a local level where services can be configured to suit community requirements and expectations, with meaningful consideration made as to adequate resourcing venues in order to best meet community health needs.

There were two statements that reached 80% agreement/consensus from one of rheumatologists[1] or service users, namely Statement 14 (provision of an infusion service, rheumatologists only) and telemedicine, or virtual visits by telephone or video, as a care option (Statement 21, service users only). Rheumatologists agreed that an infusion service for biologic medications was needed in both large and small DHB rheumatology services.[1] Some participants in the service users survey provided free-text comments indicating that they were not aware that such a service would be needed. In Aotearoa New Zealand there

are three approved and funded intravenous biologic medicines for IRD (infliximab, rituximab and tocilizumab). These, as well as other intravenous agents such as cyclophosphamide, require a day-stay infusion service. People receiving these medications for IRD can attend an infusion service that also provides care to people referred from other medical specialist services. On balance, despite lack of consensus from service users, we suggest an infusion service should be part of publicly funded rheumatology secondary care, and this statement was included in the statement set. Free-text comments suggesting that nurse-led care is from nurses with sufficient training would suggest nursing staff in infusion centres should have some working knowledge of IRD. Telemedicine, or virtual visits by telephone or video, as a care option (Statement 21) did not gain consensus for inclusion by rheumatologists[1] but over 80% of service users agreed this should be available. Rheumatologists may have concerns about telemedicine direct to patients approaches due to unresolved issues around technology use, and evidence base about how to implement and maintain optimal patient outcomes.[17,18] Patients using telemedicine services report finding this satisfactory in some clinical settings such as when disease well controlled, education or medication review are the main focus and when the patient knows their rheumatologist.[19,20] While the clinically appropriate circumstances for telemedicine in rheumatology care requires further clarification, based on consensus from service users, this statement was included in the statement set.

The survey results confirm the findings of our previous study,[3] that nurses are a highly valued part of specialist rheumatology services. The free-text comments provided some more nuanced insights into the views of service users, specifically that nurses should not replace specialist rheumatologist care. This would be consistent with recommendations of how nurses can work in rheumatology.[21] Te Kaunihera Tapuhi o Aotearoa, the Nursing Council of New Zealand has clear guidelines about assessing scope of practice for nursing at the level of enrolled nurse, registered nurse and nurse practitioner. Health New Zealand – Te Whatu Ora may wish to provide national-level guidance about the role and scope of rheumatology nursing practice in Aotearoa New Zealand, as, to date, this does not seem to have been clearly defined. Examples could include that nurse consultations are used only alternately with rheumatologist consultations, or that a rheumatologist consults on all nurse-led visits, or that nurse visits only occur during specific care periods (when stable/remission/low disease activity), or for specific care needs (teaching self-injections for medication administration). Importantly, people with IRD highly value rheumatology nursing care and this should be accessible, in some way, in all publicly funded rheumatology secondary care services in Aotearoa New Zealand.

This study must be interpreted in context of its strengths and limitations. The authors who are rheumatologists confirm that the survey participants had a range and frequency of IRD similar to that seen in rheumatology practice and the majority had been using rheumatology services for more than 5 years. This seems representative of most clinic profiles. Additionally, responses were received from throughout the country. Other strengths include a national scope and dissemination via a non-governmental organisation. These are also potential limitations, as an open recruitment strategy means we cannot report a response rate, and the dissemination via Arthritis New Zealand and social media may lead to responses only from people with prior association with Arthritis New Zealand and those active in social media. We also note that the survey sample is only a very small number of potentially eligible participants, which must number in the thousands. Our study could be criticised for not inviting service users to equal participation in a service development initiative and rather asked service user opinion on previously identified statements of care. This work extends previous work with people with IRD and the service statements from literature were from international evidence-based recommendations. Anonymous survey participation meant service users could report their views without any risk; however, we cannot verify or further explore the comments provided in free text. In seeking service user views, we asked about services that some participants may not have encountered or considered (such as rheumatologist and rheumatology nurse FTE required per head of population). Another limitation is that service "use" was not defined and therefore we do not know what extent of services participants engaged with—this could vary from one appointment with a rheumatologist to many visits with rheumatologists, nurses and other healthcare professionals over many years. A final limitation of our study is that the views of another key stakeholder in secondary specialist rheumatology services have not been included:

the views of general practitioners, a key referrer to rheumatology services. Future service development research could focus on the needs of general practitioners in providing and co-ordinating care for people with IRDs.

In conclusion, we report that people in Aotearoa New Zealand with IRD who use rheumatology services agreed with the majority of the statements of service components, with some caveats. A statement set describing the minimum service expectations for publicly funded rheumatology secondary care in Aotearoa New Zealand has been developed (Appendix 4). The statement set includes three principles of care and 21 statements organised into 1) staffing (3 statements), 2) nursing care (4 statements), 3) care processes, delivery and services (9 statements), 4) allied health services (3 statements), and 5) rheumatoid arthritis care (2 statements). This proposal has been endorsed by Arthritis New Zealand. The New Zealand Rheumatology Association also provided endorsement of these statements, however, they requested an addendum suggesting more pragmatic rheumatologist staffing ratios, which are more achievable in the short to medium term. This service proposal has been used as a basis for a stocktake of rheumatology services across Aotearoa New Zealand. These data can then be used by individual rheumatology services or by Health New Zealand – Te Whatu Ora to inform priorities for rheumatology service improvement and direct training priorities for the national rheumatology workforce.

COMPETING INTERESTS
ND is a board member of Auckland Medical Research Foundation and was president for the New Zealand Rheumatology Association 2020–2022.
RG was NZRA executive 2017–2023 and has been on the RACP Finance and Risk committee since 2023, and is a board member of Wellington Medical Research Foundation.

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Authors contributions per ICMJE: RG, RNK, ND designed the overall study and contributed to practical aspects of study design. RG, RNK, ND acquired the data. RG, VM, RNK, and ND all contributed to data analysis. RG wrote the first draft of the manuscript. RG, VM, RNK, and ND all revised providing critical revision for intellectual content. RG, VM, RNK, and ND all approved the final manuscript for publication, and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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URL
https://nzmj.org.nz/journal/vol-137-no-1603/national-survey-of-hospital-rheumatology-service-users-to-inform-a-statement-set-describing-the-minimum-service-expectations-for

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Appendices

Appendix Table 1: DHB rheumatology service used by participants (n=246).

District health board	Count (%)*
Auckland	26 (10.6)
Bay of Plenty	16 (6.5)
Capital, Coast and Hutt Valley	48 (19.5)
Counties Manukau	9 (3.7)
Hawke's Bay	14 (5.7)
Lakes	0 (0)
MidCentral	15 (6.1)
Northland	7 (2.8)
Tairāwhiti	2 (0.8)
Taranaki	8 (3.3)
Waikato	27 (11.0)
Wairarapa	3 (1.2)
Waitematā	8 (3.3)
Whanganui	7 (2.8)
Canterbury	27 (11.0)
Nelson Marlborough	3 (1.2)
South Canterbury	2 (0.8)
Southern	32 (13.0)
West Coast	1 (0.4)

*Percentages add to up greater than 100 as participants could nominate more than one DHB.

Appendix 1: Advertising material for Arthritis New Zealand channels

Take Part in Research page

Have you used DHB rheumatology services in the last 5 years? Do you want to share your opinion on future services? Survey respondents are required.

https://redcap.link/publicrheumsurvey

For more information, please contact Professor Rebecca Grainger (University of Otago, Department of Medicine).

Email: rebecca.grainger@otago.ac.nz

Phone: 04-385 5541

This study has been approved by the University of Otago Human Ethics Committee reference D22/XXX (TBC)

Please click on the button below to find out more about the study.

More Information

Appendix 1 (continued): Advertising material for Arthritis New Zealand channels

Facebook post

Have you used DHB rheumatology services in the last 5 years? Do you want to share your opinion on future services? Survey respondents are required.

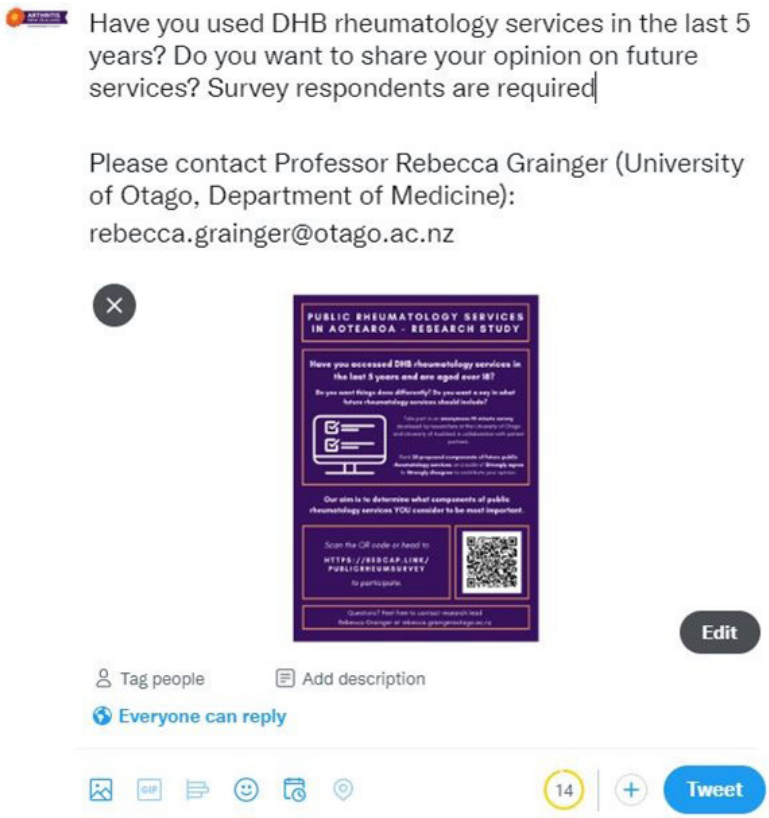
Please click on the study flyer below to find out more about the survey.

For more information, please contact Professor Rebecca Grainger (University of Otago, Department of Medicine):

Email: rebecca.grainger@otago.ac.nz

This study has been approved by the University of Otago Human Ethics Committee reference D22/XXX (TBC)

Twitter post



Have you used DHB rheumatology services in the last 5 years? Do you want to share your opinion on future services? Survey respondents are required.

Please contact Professor Rebecca Grainger (University of Otago, Department of Medicine): rebecca.grainger@otago.ac.nz

Appendix 2: A survey for people who have used public rheumatology services in Aotearoa New Zealand

A survey for people who have used Public rheumatology services in Aotearoa New Zealand

Informed consent	
Information sheet to be inserted here following ethics approval.	
I am over 18	◯ Yes ◯ No
I have accessed DHB rheumatology services in the last 5 years	◯ Yes ◯ No
I have read the above information concerning this project and understand what it is about. I agree to participate in this project.	◯ Yes ◯ No

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Background Information

This information is collected for data analysis purposes only, and will not be shared publicly. All survey responses will remain anonymous.

Age (please type)

Gender

Ethnicity (please select all that apply)

In the last five years I have used rheumatology services in the following DHB(s) (please select all that apply):

North Island

South Island

In total, I have been accessing the above selected DHB(s) for: ◯ Less than 1 year ◯ 1-5 years ◯ More than 5 years

I am accessing DHB rheumatology services for the following condition(s) (please select all that apply):

How many years ago were you diagnosed by a rheumatologist with the condition selected above? If multiple conditions selected, please given the time since your first/earliest diagnosis. ◯ Less than 1 year ◯ 1 to 5 years ◯ 6 to 10 years ◯ Over 10 years

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Overview

You will be presented with 26 statements describing a variety of components of a rheumatology service or service delivery. You are asked to score each one on a scale of Strongly agree to Strongly disagree with your view on whether that component should be part of public rheumatology services.

These statements have been derived from international best-practice standards for rheumatology service delivery, rheumatologist opinion in Aotearoa/New Zealand, and people with arthritis conditions currently accessing DHB rheumatology services in Aotearoa/New Zealand.

We anticipate this survey will take ~10mins to complete.

Space will be provided at the end of each statement for additional comments, these are optional.

When reading the statements, please note:

The word 'patients' means 'people living with rheumatic disease'. This is to maintain consistency with the statements previously reviewed by Aotearoa/New Zealand rheumatologists. The word 'chronic' means 'long-term'

The words 'rheumatic disease' means 'condition for which you are accessing rheumatology servces' e.g. rheumatoid arthritis, or gout

Referral to 'primary care' means your GP

Referral to 'rheumatology service' includes any part of specialist rheumatology care, usually rheumatologists and the rheumatology nurses

Some statements are self-explanatory, others require greater explanation of context or definitions. These are provided in italics where necessary.

Some of these may seem obvious - "of course DHBs should have that!". The purpose of this survey is to document YOUR VIEWS. We need to know what you, the users, want, even if it may seem obvious!

At the end of the survey, there is opportunity to offer any other services you think are important that we have not asked about. This is also optional.

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 1

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
A rheumatology service should value individuals and their experiences through positive interpersonal interactions, supportive relationships and within a health system organised with the patient's needs at the centre.	○	○	○	○	○	○	○

Other comments [optional]:

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 2

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients should have (a) specific rheumatologist(s) responsible for their care and be provided with the names and roles of other medical, nursing, allied health and administrative staff who may be involved in their care.	○	○	○	○	○	○	○

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 3

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with chronic rheumatic disease should have access to a rheumatology service to support coordinating their care (e.g., with a rheumatology nurse specialist or rheumatologist).	○	○	○	○	○	○	○

Background: The rheumatology service would be staffed by rheumatologists and rheumatology nurses, not general physicians or GPs.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 4

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
A public rheumatology service should involve at least one full time equivalent (FTE) rheumatologist per 80,000 people within the served population.	○	○	○	○	○	○	○

Background: The following recommendation is from British Rheumatology Society best-practice guidelines. With Aotearoa/New Zealand's population of ~5.1million, this recommendation would mean about 64 full-time equivalent (FTE) rheumatologists across the country.

There are currently ~30 FTE rheumatologists working in Aotearoa/New Zealand. To meet this recommendation, DHBs would need to double the number of rheumatologists working in DHB rheumatology services. Having more rheumatologists would mean shorter wait-times, and greater ability for patients to get urgent appointments.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 5

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with chronic rheumatic disease should have access to a nurse-led telephone service for education.	○	○	○	○	○	○	○

Background: Nurse-based education may be available soon after diagnosis, and ongoing throughout care.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 6

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with chronic rheumatic disease should have access to a nurse-led telephone service for ongoing support.	○	○	○	○	○	○	○

Background: A nurse-led telephone would be for between-appointment support, urgent queries (for example, about symptoms or medication side effects), and management that does not require direct input from the rheumatologist.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 7

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Specialist rheumatology nurses should participate in comprehensive disease management of chronic rheumatic disease.	○	○	○	○	○	○	○

Background: "Comprehensive" in this statement means addressing all relevant health care needs i.e. referrals to other allied health professionals, emotional support, appropriate medication advice.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 8

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Within an outpatient rheumatology clinic, a specialised rheumatology nurse should have their own consultations with chronic rheumatic disease patients.	○	○	○	○	○	○	○

Background: Sometimes it may be appropriate for patients to see rheumatologist nurses, who are under appropriate supervision by a rheumatologist. For example, for clinical review when you are fairly well, assessment and work-up for new medications, education about new diagnoses and medications.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 9

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
A public rheumatology service should involve at least one full time equivalent (FTE) rheumatologist nurse per FTE rheumatologist.	○	○	○	○	○	○	○

Background: This would mean that for every rheumatologist, there would be a rheumatology nurse who could provide quicker appointment support, a nursing-phone line and care co-ordination.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 10

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients under the care of a rheumatology service should be offered telephone or video follow-up consultations, providing it is clinically appropriate to do so.	○	○	○	○	○	○	○

Background: Telephone or video follow-up consultations would be with a specialist from the rheumatology service (nurse or rheumatologist). This would only occur if you and the rheumatologist/nurse agree this is suitable for you (safe and would help you manage your condition), given clinical and personal factors (such as travel).

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 11

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Healthcare professionals in a rheumatology service should ensure patients have the understanding that they need about their rheumatic condition; including appropriate communication, content, and framed to support patients' active involvement in shared decision-making.	○	○	○	○	○	○	○

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 12

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Healthcare professionals in a rheumatology service should actively support patients to participate in decision-making and self-management.	○	○	○	○	○	○	○

Background: Self-management support is the education and support given by healthcare providers to enable people with a long-term condition to increase their skills and confidence in managing their health problems.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 13

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Rheumatology services should actively provide information to patients with rheumatic diseases about outside services or providers that provide social, emotional, or practical support.	○	○	○	○	○	○	○

Background: "Outside services or providers" may include support groups, and other specialist and non-specialist disciplines outside of the DHB rheumatology service itself. This could include, for example, services from Arthritis New Zealand, Health Navigator website, community-based exercise providers.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 14

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
A rheumatology service should aim to involve other specialists in "combined clinics", where the management of chronic disease spans across different specialties (e.g., combined clinics with dermatology or ophthalmology).	○	○	○	○	○	○	○

Some people with rheumatic diseases may have multiple parts of their body affected and would benefit from seeing different specialists. A combined clinic would mean a patient goes to one appointment and sees multiple specialists, rather than seeing a rheumatologist and being referred on to other specialties in a separate appointment. This would only apply to some specific health problems in some people with rheumatic disease.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 15

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
A rheumatology service should have timely access to musculoskeletal imaging, including ultrasound and magnetic resonance imaging (MRI), to aid in the diagnosis and management of inflammatory arthritis.	○	○	○	○	○	○	○

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 16

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with chronic rheumatic disease, and difficulties with activities of daily living (ADLs), or hand function, should have access to specialist occupational therapy, and/or hand therapy.	○	○	○	○	○	○	○

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 17

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with chronic rheumatic disease and active foot problems should have access to podiatry assessment and ongoing review.	○	○	○	○	○	○	○

Background: A podiatrist is a health professional with expertise in assessment and management of feet/feet problems/walking problems.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 18

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with chronic rheumatic disease should have access to specialist physiotherapy, with periodic review.	○	○	○	○	○	○	○

Background: Periodic review means follow-up appointments at appropriate intervals.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 19

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with chronic rheumatic disease who suffer from pain issues, should have access to a qualified health professional who specialises in chronic pain management (e.g., specialist pain management physician or psychologist).	○	○	○	○	○	○	○

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 20

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with chronic rheumatic disease and disease flares, or possible treatment-related side effects, should receive advice within 1-working day of contacting a rheumatology service.	○	○	○	○	○	○	○

If you think a time period that differs from 1-working day is more appropriate, please comment below.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 21

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Healthcare professionals providing care to patients with chronic rheumatic disease, admitted to a public (DHB) hospital, should be able to access inpatient review by a member of the rheumatology service that the patient's care falls under, if requested and clinically appropriate.	○	○	○	○	○	○	○

Background: If you are in hospital and your treating doctors need rheumatology advice, they should be able to arrange for you to be seen or get advice by phone, whichever they think is needed.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 22

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
A rheumatology service should provide outpatient assessment for patients with non-inflammatory musculoskeletal conditions, such as fibromyalgia and osteoarthritis, when specialist input is sought by primary care.	○	○	○	○	○	○	○

Background: Non-inflammatory musculoskeletal conditions are not treated with immunosuppressive or disease-modifying anti-rheumatic medications.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 23

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with chronic rheumatic disease who are clinically stable, and have a clear treatment plan, should be considered for discharge to primary care for ongoing follow-up without ongoing need for rheumatology service input (apart from administrative responsibilities, such as endorsement for methotrexate).	○	○	○	○	○	○	○

Background: This statement means your rheumatologist would discharge you from the rheumatology clinic to GP care, with advice about expected management. You can be referred BACK to rheumatology care if you and your GP think that is needed.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 24	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
A rheumatology service should include an infusion unit for the delivery of specialist-prescribed intravenous medications (e.g., infliximab, tocilizumab, rituximab), which is supervised (directly, or at a distance) by a member of the rheumatology service.	○	○	○	○	○	○	○

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 25

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with active rheumatoid arthritis should be offered the opportunity to commence conventional disease-modifying anti-rheumatic drug (DMARD) therapy (e.g., methotrexate, sulfasalazine, hydroxychloroquine), within six weeks of referral to a rheumatology service.	○	○	○	○	○	○	○

Background: DMARDs are medications that aim to slow or stop disease. People with rheumatoid arthritis have a higher chance of good outcome (less active rheumatoid arthritis, or better control) if DMARDs are started early, within 12 weeks of the start of symptoms of rheumatoid arthritis.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Statement 26

	Strongly agree	Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Disagree	Strongly disagree
Patients with active rheumatoid arthritis should be monitored 3-monthly, using a composite score such as DAS-28 CRP/ESR, until their treatment target is met.	○	○	○	○	○	○	○

Background: DAS-28 CRP/ESR stands for 'disease activity score' and is a score of rheumatoid arthritis activity, used to monitor disease progression. The DAS takes into consideration the number of swollen and tender joints, the patient's report of how their rheumatoid arthritis is affecting them, and blood test results. It is the gold standard for monitoring rheumatoid arthritis activity.

Other comments (optional):

Appendix 2 (continued): A survey for people who have used public rheumatology services in Aotearoa New Zealand

Other comments and suggestions

Finally, is there anything else you would like to see in future public rheumatology services in Aotearoa/New Zealand? Please note that these suggestions should be within the scope of public rheumatology service delivery i.e. not a whole system recommendation.

Appendix 3: Survey participant responses to Statements on components of public hospital rheumatology services

Question No.	Statement No.	Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree	Total
1	P1	89.5	8.0	1.7	0.8	0.0	0.0	0.0	100.0
12	P2	76.3	21.5	1.8	0.0	0.0	0.4	0.0	100.0
11	P3	83.0	15.3	2.9	0.0	0.0	0.0	0.0	101.2
25	S1	77.6	13.7	4.1	3.7	0.5	0.0	0.5	100.1
26	S2	62.1	26.9	4.6	5.0	0.5	0.9	0.0	100.0
3	S3	88.0	11.1	0.4	0.0	0.4	0.0	0.0	99.9
20	S4	70.3	23.0	4.5	1.8	0.5	0.0	0.0	100.1
5	S5	70.3	21.6	5.2	2.6	0.4	0.0	0.0	100.1
6	S6	76.7	18.5	3.4	0.4	0.4	0.4	0.0	99.8
7	S7	70.3	25.4	2.6	1.3	0.4	0.0	0.0	100.0
8	S8	54.1	27.3	13.9	2.6	1.3	0.4	0.4	100.0
16	S9	85.7	13.5	0.4	0.4	0.0	0.0	0.0	100.0
17	S10	86.5	12.1	1.3	0.0	0.0	0.0	0.0	99.9
18	S11	79.3	18.9	1.4	0.5	0.0	0.0	0.0	100.1
15	S12	82.6	14.3	0.0	0.9	0.0	0.0	0.0	97.8
19	S13	81.1	17.1	1.4	0.5	0.0	0.0	0.0	100.1
24	S14	54.8	23.3	6.8	13.2	1.4	0.5	0.0	100.0
14	S15	67.4	22.3	8.5	0.0	0.4	0.0	0.0	98.6
4	S16	83.2	12.5	0.0	1.3	0.0	0.4	0.9	98.3
22	S17	49.5	25.9	14.1	7.3	1.8	1.4	0.0	100.0
10	S20	64.3	22.3	8.3	2.2	2.2	0.9	0.0	100.2
21	S21	74.8	23.9	0.9	0.5	0.0	0.0	0.0	100.1
23	S22	11.4	17.8	13.7	6.8	16.0	19.2	15.1	100.0
2	S23	73.3	19.5	3.4	3.0	0.4	0.4	0.0	100.0
9	S24	74.4	18.7	3.0	2.2	0.4	0.9	0.0	99.6
13	S25	73.5	21.7	3.5	1.3	0.0	0.0	0.0	100.0

Appendix 4: Statement set endorsed by the New Zealand Rheumatology Association and Arthritis New Zealand

This list of principles and statements of care is the recommended minimum service expectations for a publicly funded rheumatology secondary care service in Aotearoa New Zealand.

Principles
1. A rheumatology service should value individuals and their experiences through positive interpersonal interactions, supportive relationships and within a health system organised with the patient's needs at the centre.
2. Healthcare professionals in a rheumatology service should actively support patients to participate in decision-making and self-management.
3. Healthcare professionals in a rheumatology service should ensure patients' education requirements about their rheumatic condition are met, including appropriate communication, content, and framed to support patients' active involvement in shared decision-making.
Statements
Staffing
S1. Patients should have specific rheumatologist(s) responsible for their care and be provided with the names and roles of other medical, nursing, allied health and administrative staff who may be involved in their care.
S2. A public rheumatology service should involve at least one full-time equivalent (FTE) rheumatologist per 80,000 people within the served population.*
S3. A public rheumatology service should involve at least one full-time equivalent (FTE) rheumatologist nurse per FTE rheumatologist.
Nursing care
N1. Patients with chronic rheumatic disease should have access to a nurse for education.
N2. Patients with chronic rheumatic disease should have access to a nurse-led telephone service for ongoing support.
N3. Specialist rheumatology nurses should participate in comprehensive disease management of chronic rheumatic disease.
N4. Within an outpatient rheumatology clinic, a specialised rheumatology nurse should have their own consultations with chronic rheumatic disease patients, supervised by a rheumatologist as needed.
Care processes, delivery and services
C1. Patients with chronic rheumatic disease should have access to a rheumatology service to support coordinating their care (e.g., with a rheumatology nurse specialist or rheumatologist).
C2. Patients with chronic rheumatic disease and disease flares, or possible treatment-related side effects, should receive advice within 1-working day of contacting a rheumatology service.
C3. Patients under the care of a rheumatology service should be offered telephone or video follow-up consultations, providing it is clinically appropriate to do so.

Appendix 4 (continued): Statement set endorsed by the New Zealand Rheumatology Association and Arthritis New Zealand

C4. Healthcare professionals providing care to patients with chronic rheumatic disease, admitted to a public (DHB) hospital, should be able to access inpatient review by a member of the rheumatology service that the patient's care falls under, if requested and clinically appropriate.
C5. Patients with chronic rheumatic disease who suffer from pain issues should have access to a qualified health professional who specialises in chronic pain management (e.g., specialist pain management physician or psychologist).
C6. A rheumatology service should aim to involve other specialists in "combined clinics", where the management of chronic disease spans across different specialties (e.g., combined clinics with dermatology or ophthalmology).
C7. Rheumatology services should actively provide information to patients with rheumatic diseases about outside services or providers that provide social, emotional or practical support.
C8. A rheumatology service should have timely access to musculoskeletal imaging, including ultrasound and magnetic resonance imaging (MRI), to aid in the diagnosis and management of inflammatory arthritis.
C9. A rheumatology service should include an infusion unit for the delivery of specialist-prescribed intravenous medications (e.g., infliximab, tocilizumab, rituximab), which is supervised (directly, or at a distance) by a member of the rheumatology service.
Allied health services
A1. Patients with chronic rheumatic disease, and difficulties with activities of daily living (ADLs), or hand function, should have access to specialist occupational therapy, and/or hand therapy.
A2. Patients with chronic rheumatic disease and active foot problems should have access to podiatry assessment and ongoing review.
A3. Patients with chronic rheumatic disease should have access to specialist physiotherapy, with periodic review.
Rheumatoid arthritis
RA1. Patients with active rheumatoid arthritis should be offered the opportunity to commence conventional disease-modifying anti-rheumatic drug (DMARD) therapy (e.g., methotrexate, sulfasalazine, hydroxychloroquine), within 6 weeks of referral to a rheumatology service.
RA2. Patients with active rheumatoid arthritis should be monitored 3-monthly, using a composite score such as DAS-28 CRP/ESR, until their treatment target is met.

European Alliance of Associations for Rheumatology = EULAR; National Institute of Health and Care Excellence = NICE; Royal College of Physicians = RCP.
Researcher generated is from Gibbs and Grainger,[1] Rheumatologist generated is from first round of Delphi.[1]
*The New Zealand Rheumatology Association notes that "*The staffing ratio of 1:80,000 is aspirational and the NZRA has suggested that a pragmatic target of 1:100,000 is more achievable and adequate for the short to medium term.*"

Use of puberty-blocking hormones for gender dysphoria in New Zealand: descriptive analysis and international comparisons

Charlotte Paul, Simon Tegg, Sarah Donovan

ABSTRACT

AIM: To investigate use of puberty-blocking hormones (gonadotropin-releasing hormone analogues [GnRHa]) for gender dysphoria in New Zealand. Specifically, to describe demographic characteristics and time trends in the prevalence and incidence of prescribing, and to calculate cumulative incidence (proportion) of first prescribing of GnRHa for gender dysphoria in order to make valid international comparisons.

METHOD: The national Pharmaceutical Collection was used to identify all dispensing from 2006 to 2023 to those aged <18, by sex/gender and age. Cumulative incidence of first prescriptions between ages 12 and 17 (which largely excludes prescribing for other indications) was calculated and compared with the Netherlands and England and Wales.

RESULTS: In New Zealand, prescription of GnRHa for gender dysphoria started around 2011; prevalence of use increased to 2014, then more steeply to 2022, followed by a decline. Incidence data show the decline started from 2021. New Zealand, compared to the Netherlands (which started prescribing in the 1990s), had 1.7 times the cumulative incidence of first prescriptions by 2018. Compared to England and Wales up to 2020, New Zealand had 3.5–6.9 times the cumulative incidence.

CONCLUSION: The high rate of prescribing for probable gender dysphoria in New Zealand, and the decline after 2021, require further investigation.

There is medical and public interest internationally in understanding the extent of use of puberty-blocking hormones (gonadotropin-releasing hormone analogues [GnRHa]) by children and young people with gender dysphoria. In New Zealand, puberty blockers are reported to have become "*more accessible here than in many countries.*"[1] But no information has been published to support that claim.

Internationally, there has been a dramatic increase in children and young people referred with gender dysphoria (distress caused by a mismatch between their experienced gender and birth sex—gender here referring to an inner sense of being male, female or non-binary).[2] Puberty blockers are being increasingly prescribed for this indication.

These hormones were first used in the 1980s to delay central precocious puberty (before age 8 for girls and 9 for boys) primarily to improve final height;[3] this remains the approved indication by Medsafe, the FDA and other regulators. They are also used to treat idiopathic short stature.[4] The first use for gender dysphoria was reported in 1998,[5] and the "Dutch Protocol" was formalised in 2006.[6] According to this protocol, a small group of children (predominately natal boys) who had "*lifelong extreme gender dysphoria*", were psychologically stable and who had supportive families were eligible for treatment. The reasons for treatment were to reduce suffering from gender dysphoria, to suppress the development of secondary sex characteristics so it would be easier to pass in the adult gender role and to buy time to allow exploration of gender identity. In the last decade, international guidelines have widened eligibility for treatment away from the original strict Dutch Protocol.[7,8]

There are polarised views of the appropriate care for children with gender dysphoria. New Zealand guidelines follow the World Professional Association for Transgender Health (WPATH),[9,8] and recommend GnRHa for children with "*persistent and well documented gender dysphoria,*"[10] though no details are given of the diagnostic process. There has been a further widening of eligibility in 2023.[11]

In contrast, a growing number of European countries, including Sweden, Finland, France, England and Wales, and Denmark have signalled moves to restrict access to puberty-blocking hormones for gender dysphoria because of uncertainty about the natural course of gender dysphoria, a paucity of evidence about long-term benefits and harms and uncertainty that children can consent in this situation.[12–17] The National Health Service (NHS) England has recently banned the routine use of puberty-blocking hormones for gender dysphoria on the basis that there is "*not enough evidence to support* [their] s*afety or clinical effectiveness*."[18] In the United States (US), 22 states have banned use for this indication for anyone under age 18.[19]

Despite the dramatic increase internationally in children being referred to specialist services,[2,20,21] no countries have reported national figures for use of GnRHa for gender dysphoria in a way that makes for easy comparison across countries. Nevertheless, numerator data are available from published sources, which can be used to calculate cumulative incidence of first prescriptions.

New Zealand has an excellent source of national data on publicly funded dispensed medicines—the Pharmaceutical Collection. In New Zealand, GnRHa are funded by the national drug-buying agency Pharmac, despite not being approved by the regulator, Medsafe, for use for gender dysphoria.

The aims of this investigation are: 1) to describe demographic characteristics and time trends in the prevalence and incidence of prescribing GnRHa to people under age 18 in New Zealand, and 2) to calculate the cumulative incidence (proportion) of first prescribing of GnRHa for gender dysphoria from age 12 in order to make valid international comparisons.

Method

The number of individuals prescribed GnRHa, for age groups 0–11 and 12–17 by sex/gender (as recorded on the National Health Index [NHI]) each year from 2006 to 2023 (prevalence of use), was obtained from the Pharmaceutical Collection through *Official Information Act* requests to Pharmac.[22] Numbers of individuals *first* prescribed GnRHa in each year (incidence) were also obtained. (Pharmac data do not include exact numbers for cells <6 to prevent deductive identification; hence, 3 was used for these cells.) Until 2013, natal sex was recorded on the NHI; from May 2013 gender was recorded. The data include all publicly funded, community-dispensed pharmaceuticals. Excluded are bulk and hospital dispensings and those without a match to the NHI. Data in the Pharmaceutical Collection do not include information on specific indications for use. Hence, data on use of GnRHa include prescribing for central precocious puberty and short stature. Note: the data for New Zealand are for dispensing but "prescribing" has been used for ease of understanding and comparison with other countries that report prescribing data. They are likely to be very similar.

Information on total prescribing of GnRHa for gender dysphoria in England and Wales for those aged 9–17, 2008–2021, was obtained from published sources. These are based on people referred to the Gender Identity Development Service (GIDS) who were referred to the two English paediatric endocrine liaison clinics (at University College London Hospital and Leeds Children's Hospital) and who had been discharged from GIDS.[23] The Cass Review also includes an audit of patients referred to the same endocrine clinics and discharged from GIDS from April 2018 to 2022.[15] Both data sources include only those *discharged* from GIDS after receiving GnRHa in overlapping periods. Using the age distribution of first receiving GnRHa from the Cass Review, and assuming patients were discharged at age 18, we estimated the total number of first prescriptions from 2008 to 2020. Information from the Netherlands was also obtained from published sources.[24–26] The main clinic in the Netherlands is estimated to treat 95% of such children.

Cumulative incidence of starting GnRHa aged 12–17 for New Zealand was calculated to compare with the overseas data—from 2009 to 2015, 2009 to 2018 and from 2008 to 2020 (using 2010 as estimated first use for gender dysphoria). Cumulative incidence (or proportion) is the number of people starting GnRHa over a certain period divided by the population at risk at the start of the period.[27] Users younger than 12 years were excluded to remove the great majority of use for other indications.

For England and Wales and the Netherlands, cumulative incidence was calculated as the total number of first prescriptions in the time period divided by the population aged 12–17 at the beginning of the time period from census data.[28,29] For England and Wales, seven children were excluded because they were referred for

endocrine assessment before age 12.[23] For the Netherlands, an uncertain number of children under age 12 will be included because, though initially use was only from age 12, later *"the protocol was adapted so that adolescents could start GnRHa before age 12 if puberty had started."*[24]

Results

From 2006 to 2009, the prevalence of prescribing GnRHa up to 17 years was stable (a mean of 74 per year) in New Zealand, representing use for other indications, as shown in Figure 1. From 2010, use increased slowly to 2014, then more steeply to 2022, followed by a decline. Among those aged 12–17, the increase was steeper from 2016; among those aged under 12, a steep increase was not seen until after 2018. The decline was similar in those 12 and older and those younger than 12.

The pattern of all prescribing according to age and sex/gender is shown in Figure 2. Up to 2011, the highest prescribing was in the 0–11 age group, and was much higher for females than males. From 2012 to 2016, and again from 2018 to 2022, there were substantial increases for females ages 0–11, such that the highest prescribing for females was in this age group. In contrast, there was only a small increase for males, from 2018. The number of females and males aged 12–17 prescribed GnRHa increased from 2012 to 2016, then, with similar numbers of males and females, more steeply to 2022. Since 2022, prescribing has fallen for both genders.

Figure 3 shows that the number of people aged 0–11 receiving a *first* prescription of GnRHa (incidence) was stable until around 2012, then increased slowly until 2018, when use increased markedly to 2021 and has subsequently dropped steeply. For those aged 12–17 receiving a first prescription of GnRHa—expected to be almost all for gender dysphoria—was less than six each year from 2006 to 2008, started to increase in 2009 then more steeply from 2016 to 2021 (148) before declining.

Table 1 presents estimates of cumulative incidence of people aged 12–17 prescribed GnRHa for gender dysphoria comparing New Zealand, England and Wales, and the Netherlands for

Figure 1: Total number of people aged <18 prescribed GnRHa each year and according to age group, in New Zealand, 2006–2023.

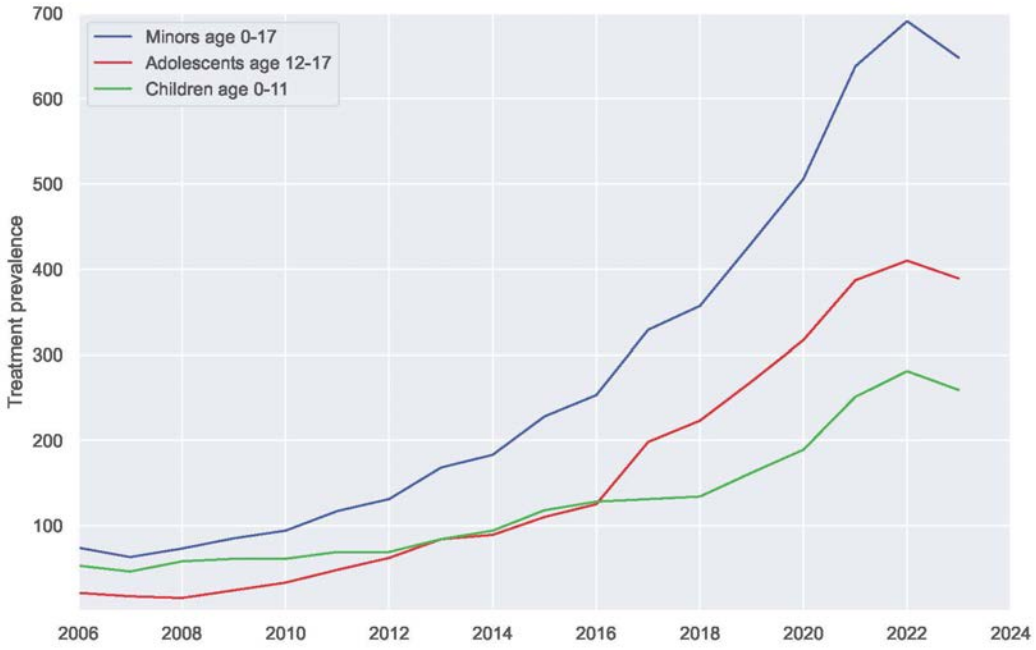


Figure 2: Number of people aged <18 prescribed GnRHa each year by age group and recorded sex/gender, in New Zealand, 2006–2023.

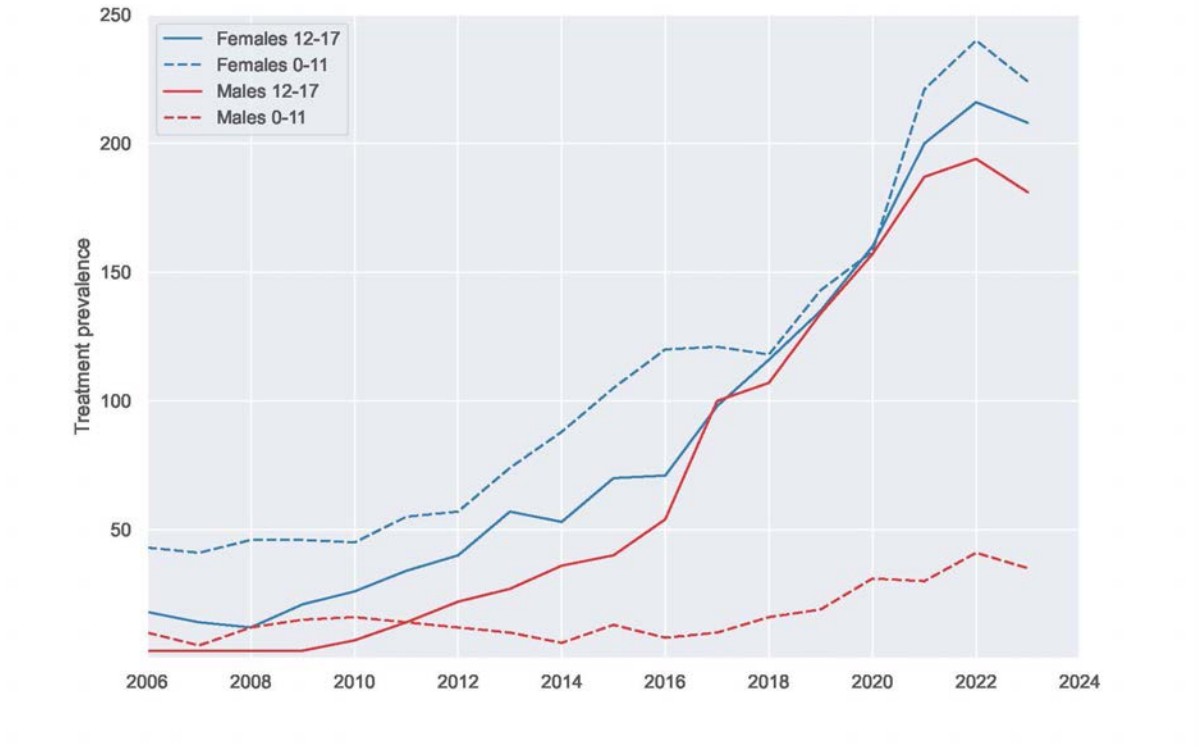


Figure 3: Number of people aged <18 newly prescribed GnRHa each year in New Zealand, 2006–2023.

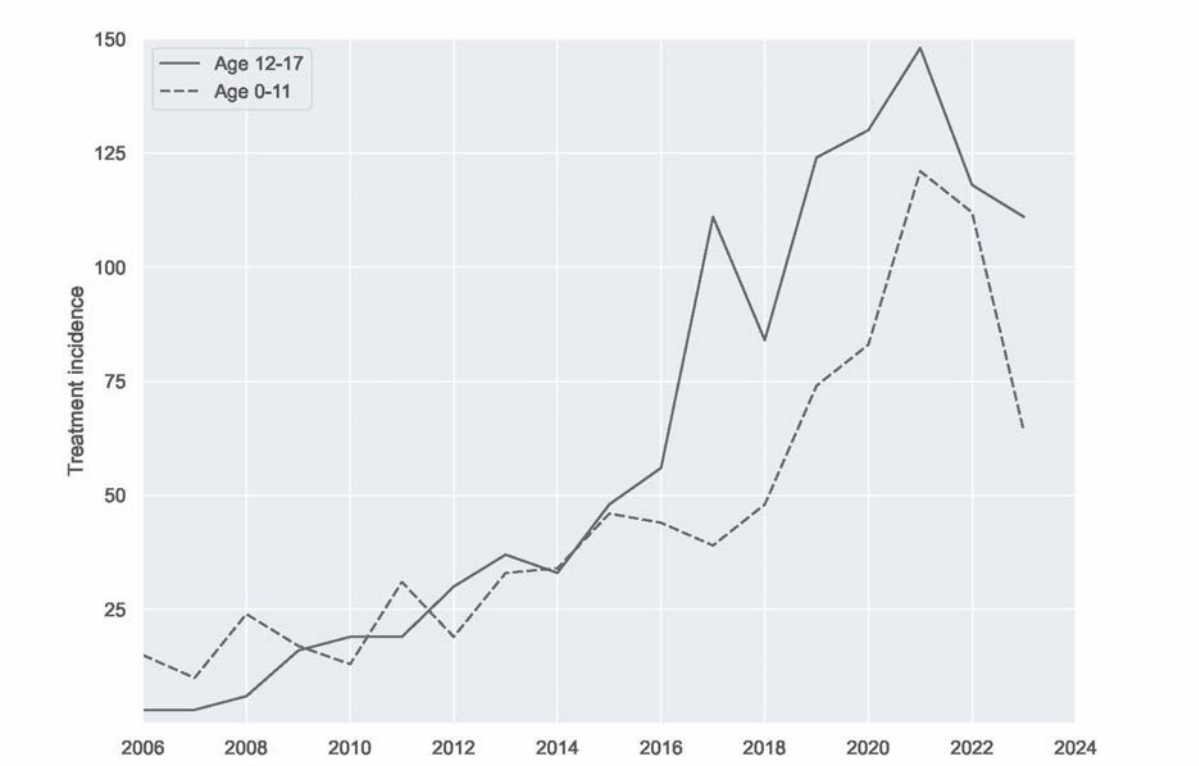


Table 1: Cumulative incidence of starting on GnRHa for gender dysphoria per 100,000 adolescents aged 12–17* (total number of individuals). Dates determined by comparison data availability.

	New Zealand	England and Wales	Netherlands
2009–2015	50.0 (186)		36.6 (436)
2009–2018	117.5 (437)		69.8 (831)
2008–2020	183.0 (691)	26.6 (1100)	

*For the Netherlands, this will include a small number starting before age 12.

comparable time periods. From 2009 to 2015, New Zealand had a higher cumulative incidence than the Netherlands, even though the Netherlands was the first country in the world to use GnRHa for gender dysphoria, starting much earlier than New Zealand in the 1990s. Over the whole duration from 2009 to 2018, use was 1.7 times higher in New Zealand, reflecting a much steeper increase in prescribing in New Zealand from 2015 to 2018. Compared to England and Wales from 2008 to 2020, the estimated cumulative incidence was 6.9 times higher in New Zealand.

Discussion

The prevalence of prescribing puberty-blocking hormones in New Zealand increased from 2011 (when the first New Zealand guidelines were published)[30] to 2016 and then more steeply from 2016 to 2022, before declining. The increase in the latter period had been most marked among those aged 12–17 (a more than threefold increase) that must be very largely attributable to use for gender dysphoria. Incidence data show the decline among those aged 12–17 started from 2021; use also declined steeply among those under age 12 at the same time.

For those younger than 12, use has been mainly among females, as expected for precocious puberty.[31] But in this age group, use has increased markedly among females, especially since 2018, when New Zealand guidelines recommending GnRHa for gender dysphoria from Tanner 2 were published.[10] Thus, some of this use is likely to be for gender dysphoria as Tanner 2 (puberty onset) is before age 12 for the majority of girls.[32] A small increase in prescribing for central precocious puberty might be expected from 2010 to 2023 because of a decline in age at puberty.[33] For similar reasons, there is likely to have been an increase in prescribing for short stature. Nevertheless, the size of the recent increase as shown in the incidence data implies some prescribing for gender dysphoria before age 12, though the extent is unknown.

Comparisons of cumulative incidence among countries demonstrate that New Zealand started out and quickly attained a similar pattern of prescribing to the Netherlands, which first started the so-called "Dutch Protocol" for gender dysphoria in the 1990s, then overtook it to 1.7 times the cumulative incidence by 2018. The difference was even more marked compared to England and Wales up to 2020, such that New Zealand had 6.9 times the cumulative incidence of prescribing. Note: the latter comparison included prescribing only up to the end of 2020, when restrictions were introduced following the High Court judgement "Bell v Tavistock" in the United Kingdom.[15]

There are a number of limitations. First, the New Zealand data do not include indication for prescribing. For that reason, to make a conservative comparison with other countries, the New Zealand data on cumulative incidence have been restricted to age 12 and over, past the age of *first* prescription for precocious puberty or for short stature. On the other hand, the restriction to children aged 12 and over will fail to account for some prescribing for gender dysphoria at younger ages; hence, the comparison across countries of use for gender dysphoria will be conservative.

In the New Zealand prevalence data (but not the incidence data), those aged 12 and over may include a few children who were prescribed GnRHa for precocious puberty or short stature and have continued to age 12 or 13. Nevertheless, use will be largely for gender dysphoria.

Second, because gender (not sex) has been recorded on the NHI since May 2013 and can be changed at the request of the patient and natal

sex is not retained, (personal communication, Joel Brown, Te Whatu Ora) there are great uncertainties about how this information is related to natal sex. Hence, overall usage, and use by age group, are more reliable than use by sex/gender.

Third, though data available for New Zealand allow for a relatively complete picture of prescribing, there might be an under-estimate, as hospital dispensing is not included. But it is likely to be small, because dispensings are generally from the hospital outpatient pharmacy and thus are captured in the Pharmaceutical Collection.

Finally, the England and Wales incidence of GnRHa use of 1,100 was estimated from published sources for people discharged from the service, with assumptions about age at first prescription and age at discharge. As an alternative, we used journalist Hannah Barnes' estimate of 2,000 children referred for puberty blockers.[34] As this included data to 2023, though not all of those will have been prescribed GnRHa, we used 1,800 children to 2020. This reduced the comparative incidence from 6.9 to 4.2 times. A further source of uncertainty is possible use outside the two NHS clinics that GIDS referred to. GIDS has been the only provider of specialist services for children in England and Wales,[35] but there have been private gender clinics that treat children—though they are expensive. We have estimated a further 20 percent of children received GnRHa privately. This reduces the comparative incidence from 6.9 to 5.7, or from 4.2 to 3.5 using the Barnes' estimate. In the Netherlands, a further 5% of prescribing was estimated. This reduced the comparative incidence only slightly from 1.7 to 1.6. These considerations show that the finding of much higher prescribing in New Zealand is robust—though there are uncertainties about the exact figure. Confirmation of the size of the comparative difference with England and Wales comes from data on the prevalence of prescribing of GnRHa for gender dysphoria there of "approximately 378" or 9.2/100,000[36] compared to 410 or 104/100,000 in New Zealand, in 2022, among those aged 12–17. Current prevalence of use in New Zealand is 11 times higher, reflecting a sharp decline in use in England and Wales following the judicial review of treatment practices in 2020.[15]

It is unclear whether any other countries have such high prescribing rates as New Zealand. Australia has no national data. In the US, national insurance claims show 4,780 children aged 6–17 started GnRHa for gender dysphoria from 2017 to 2021, among 40 million children.[37] The estimated cumulative incidence is 12 per 100,000 (compared to 162 per 100,000 aged 12–17 in New Zealand over the same time period). Nevertheless, the US data will be underestimated as they don't include patients not covered by insurance or those without a recorded gender dysphoria diagnosis, and includes a wider age range. In Denmark, a centralised gender service for young people was established in 2016, prescribing GnRHa to 219 people up to January 2023.[38] The cumulative incidence for 2016–2022 was 52 per 100,000 aged 12–17, compared to 210 per 100,000 for New Zealand over the same period; cumulative incidence was 3.9 times higher in New Zealand.

Why is prescribing so high in New Zealand and why has it increased so rapidly? One possibility could be a steeper rise in the prevalence of adolescent gender dysphoria or transgender identity in New Zealand. But, surprisingly, there is no evidence for a rise in transgender identity from 2012 to 2019 in the Youth Health 2000 surveys.[39,40] Nevertheless, a strikingly high proportion of girls in the Growing Up in New Zealand study, aged 12 in 2021/2022, reported a non-binary or transgender identity (8.2% of natal girls and 1.5% of natal boys).[41] This suggests a very recent increase among children. Because of a lack of standard survey methods across countries, it is impossible to make reliable cross-country comparisons.

The main reasons for higher prescribing are likely to be found in our health system. These could be: a) easier access to assessment, b) a lower threshold for diagnosis of gender dysphoria, or c) greater likelihood of recommending treatment with GnRHa than other treatment options. In England and Wales there have been long wait lists for specialist services and these have served to restrict access. Moreover, in both England and Wales and the Netherlands, specialist services have developed detailed protocols for the diagnosis of gender dysphoria and for psychological assessment[42,43] that are lacking in New Zealand. Indeed, the direction has been to prioritise access over assessment and psychological support.[44] Nevertheless, it is unknown whether there is a greater likelihood of recommending GnRHa treatment versus psychological approaches in New Zealand.

The decline in prescribing from 2021 is surprising. It could be a chance occurrence, but incidence data show it has continued to decline over 2 years. If it is real, it is not explained by a decline in gender dysphoria/incongruence in recent cohorts[41] nor,

so far as we can tell, by any recent restriction on accessing services. We tentatively suggest that clinicians and parents may be becoming aware of more cautious approaches overseas to prescribing GnRHa for gender dysphoria, leading to a decline.

The Ministry of Health should investigate the very high rates of prescribing GnRHa in New Zealand and the much higher cumulative incidence of use compared to other countries. Differences in health service factors across countries require special consideration. The Ministry of Health is undertaking an evidence review.[45] An essential first part of any review is to establish the facts.

The findings are robust but have unavoidable limitations. Most important is the lack of available information about indications for prescribing GnRHa. Nevertheless, by confining the comparative analysis to those commencing GnRHa at age 12 and over, this limitation is largely overcome. It remains a limitation to interpreting the striking increase in the prescribing of GnRHa to children under age 12. Estimating cumulative incidence of first prescriptions is a feasible way of making comparisons among countries across time.

COMPETING INTERESTS
No conflicts or competing interests.

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Adherence to New Zealand's Major Trauma Destination Policy: an audit of current practice

Georgia Gibson, Bridget Dicker, Ian Civil, Bridget Kool

ABSTRACT

AIM: To evaluate adherence to the New Zealand Major Trauma Destination Policy (MTDP). This audit assessed if, based on their injuries, Emergency Medical Services (EMS) attended major trauma cases were taken to the MTDP determined appropriate hospital. Findings will guide and further improve pre-hospital trauma care and associated patient outcomes.

METHODS: A retrospective evaluation of adherence to the New Zealand MTDP for a random sample of 100 cases (ISS >12) injured between 31 November 2017–30 November 2018 who survived to hospital. The EMS electronic patient record (ePRF) was reviewed for each case. Adherence was indicated by the transport of injured patients from the scene to the appropriate initial destination based on meeting the respective regional MTDPs.

RESULTS: Overall, there was a 94% adherence rate to the MTDP. For patients that were not classified as requiring transport to an advanced-level trauma centre, there was a 98.9% (n=86/87) adherence compared to 61.5% (n=8/13) adherence in those that did require transport to an advanced-level trauma centre.

CONCLUSION: There was high adherence to the MTDP, with 94% of cases being taken to the appropriate destination directly from the incident scene. There is scope for improvement in cases whereby the nearest hospital should be bypassed in favour of a more distant advanced-level trauma centre.

Globally, more than two-thirds (70%) of injury deaths occur in the pre-hospital setting.[1] In New Zealand, 54% of injury deaths occur pre-hospital and 45% of those deaths are estimated to be survivable or potentially survivable.[2] These data suggest that the health burden of major trauma in New Zealand may, in part, be reduced by optimising pre-hospital trauma care, in particular optimising the systems that determine the most appropriate destination for patients in the acute phase of care.[3] International evidence confirms that cases severe enough to be classified as major trauma are likely to have better outcomes if the patient is transported directly to an advanced-level trauma centre, even if this means bypassing the nearest medical facility.[4] With major trauma destinations taking priority over closer, non-trauma centres for transport from the incident site, appropriate resources and hospital personnel are more readily available to patients with severe injury. This model of trauma care was accredited by the American College of Surgeons in 1987 to reduce delayed secondary transfer to trauma centres and reduce pre-hospital injury deaths.[2–4]

Equivalent models of major trauma response protocols have been implemented and audited internationally.[5–7] Findings from these studies reveal that destination protocols are not optimally adhered to and that certain groups experience different rates of adherence. Fitzharris et al.[5] found a major trauma protocol adherence rate of 74% for P4 (most severe) cases by Emergency Medical Service (EMS) providers in Australia.[5] MacKenzie et al.[6] reported 56% of major trauma patients in a US study were transported directly to a major trauma hospital, and that compliance reduced with increasing age and with the type of criteria met in each case. The three types of criteria that could be met included injury, physiology and mechanism criteria (all including parameters/specific incident or injury characteristics used to include or exclude major trauma). Compliance was highest when the injury criteria was met either with or without another criteria (86.0–94.0%). Cases meeting mechanism and physiology criteria together had the next highest compliance rate (68.7%), and the third highest rate of compliance was seen when mechanism criteria alone was met (45.8%). The lowest level of adherence was in cases meeting physiology criteria alone (34%).[6] A 2020 study from the Netherlands by Van

Rein et al. reported a major trauma destination policy adherence rate of 72%, with a lower adherence rate of 42% in rural regions where there was an increased distance to advanced trauma centres.[7] In addition, this study found reduced adherence for older patients, but increased adherence for paediatric patients.

New Zealand's trauma system is divided into four regional trauma networks based on population.[8] Each of these regions has at least one advanced-level trauma centre (seven in total), which are operational 24 hours a day, providing intensive care and advanced resources similar to a Level 1 or Level 2 American College of Surgeons Verified Trauma Centre.[9] In addition to the seven advanced-level trauma centres, the New Zealand trauma system includes 15 mid-level trauma hospitals that are also appropriate for the direct transport of many patients with major trauma based on the criteria they meet at the scene. This makes a total of 22 trauma hospitals across the country. In 2017, New Zealand's National Trauma Network (Te Hononga Whētuki ā-Motu, formerly known as the Major Trauma National Clinical Network) introduced a Major Trauma Destination Policy (MTDP) with the overall aim to improve major trauma survival rates in the pre-hospital trauma response phase.[10] The policy requires EMS providers at the scene to assess if patients meet eligibility criteria for transport to a trauma hospital directly from the scene (Table 1).[3] The New Zealand National Trauma Network uses a threshold for major trauma of an Injury Severity Score (ISS) of greater than 12.[11] Note, ISS is an anatomical injury scoring system.[12]

Despite the establishment of MTDPs, there is evidence world-wide that they are not strictly adhered to, causing preventable fatalities and morbidity post-major trauma.[5–7,13,14] An audit of adherence to the MTDP was undertaken in 2018 by the New Zealand National Trauma Network, Hato Hone St John and Wellington Free Ambulance (WFA) when the MTDP was first introduced (in an email from B. Dicker in January 2022). The audit found that in 91% of cases, transport to the right hospital or staging as per the destination policies was adhered to. The aim of this study was to build on the findings of the 2018 audit to further explore adherence to New Zealand's MTDP.

Materials and methods

This study was part of a larger Health Research Council of New Zealand study exploring predictors of survival among major trauma cases.[2] In the larger study, EMS data from New Zealand's two EMS providers, Hato Hone St John and WFA, were probabilistically linked to NZTR data. To be included in the NZTR, the threshold is an ISS >12 or cases where the trauma is fatal regardless of injury severity. In this audit, the ISS values were abstracted from the NZTR dataset. The auditors were able to access and review all road-based EMS records. In a small number of instances, a combined road/aeromedical record was reviewed. This combined view was only available in limited instances in which the patient record had been transferred to an air provider (to create a merged record), and that air provider used the same electronic record as Hato Hone St John. Around 20% of patients would have had a road-based EMS attendance and aeromedical transport to the hospital. The mode of transport to the hospital was not part of the dataset collected in this audit.

A retrospective evaluation of adherence to the New Zealand MTDP for a random sample of 100 cases (ISS >12) injured between 31 November 2017–30 November 2018, and who survived to hospital, was drawn from the linked dataset.

The study methods mirrored those used in a 2018 MTDP audit conducted by the National Trauma Network (in an email from B. Dicker in January 2022). Cases where the closest hospital to the incident was an advanced-level trauma centre were excluded, on the assumption that EMS personnel by default would go to that hospital. Cases without sufficient information to classify nature or mechanism of injury were also excluded. Any cases excluded from the 100 were replaced by a randomly selected replacement case from the NZTR. The EMS electronic patient record (ePRF) was extracted from the NZTR for each case and reviewed.

Audit process

An audit team was established that included six senior paramedics and one of the study investigators (BD). The audit team received a copy of the ambulance ePRF records for all cases, and based on the information contained, addressed the following questions in relation to the MTDP:

1. According to the MTDP, which hospital did the patient's injuries indicate that they should go directly to?
2. Which hospital did the patient go to?
3. Did the patient have unstable/life-threatening injuries that indicated that they needed to go to the closest hospital?

4. Did the patient have an injury that required a specialist hospital destination, for example spinal cord injury?

The primary outcome of interest in this study was adherence by EMS personnel to the 2019 MTDP. The 2019 protocol was used as it was the current protocol at the time the audit was conducted, and as such was familiar to the paramedics (clinical experts) reviewing the case files. In order to meet the criteria for direct transport to an advanced-level trauma centre or mid-level trauma hospital, a patient must meet the criteria detailed in the Appendices. For the purposes of the audit, adherence was indicated by the transport of injured patients from the scene to the appropriate initial destination based on meeting the respective regional MTDPs (see Appendices).

Adherence to the 2019 MTDP for all cases was determined by the outcomes of the audit team's analysis of each ePRF. The initial review of the cases was conducted by two auditors; if there was no consensus, a third auditor blinded to the initial outcomes reviewed the case, and if the outcome aligned with two of the three auditors, this was utilised. If the first arrival facility was the same as the recommended hospital as indicated by the nature of the patient's injuries, then the case was considered compliant. All cases that were not determined as meeting the criteria for major trauma by the auditors (i.e., no destination policy was required), or cases where patients were sufficiently unstable to need immediate medical attention were classified as adherent if they were taken to the closest hospital. Cases requiring direct transport to a specialist facility were classified as adherent if this occurred.

Other documented variables of interest included: gender, age group, date of injury, district health board (DHB) location of injury catchment, hospitals (initial hospital and on-transfers), definitive care hospital, ISS, patient status at scene and patient status at destination. In cases with multiple injuries, the primary diagnosis and most severe injuries were listed as the primary effect of the incident.

Statistical analysis

Descriptive statistics were used to describe the sample. The proportion of major trauma cases in the sample meeting the 2019 policy criteria for direct transport to one of the 22 major trauma hospitals were noted and the outcome of adherence to the MTDP was then reported.

Ethics

Ethics approval for the parent study was obtained from the Health and Disability Ethics Committee (Ref: 18NTB142).

Results

There were 1,754 cases captured by the NZTR between 31 November 2017 and 30 November

Figure 1: Study population.

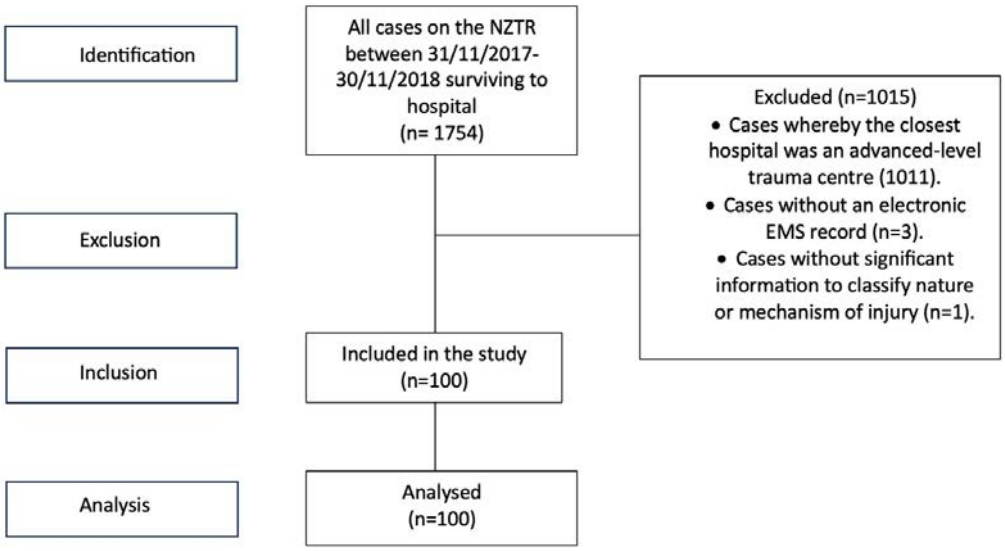

Table 1: Overall adherence to the Major Trauma Destination Policy (n=100).

Appropriate trauma facility	Total	Adherence to MTDP n (%)
Nearest hospital—low severity injury	34	34 (100)
Mid-level trauma hospital	43	42 (97.7)
Advanced-level trauma centre	13	8 (61.5)
Nearest hospital—unstable	10	10 (100)
Total	100	94 (94)

Table 2: Characteristics of audit cases and adherence rates by criteria (n=100).

Variable	n	n (%)
Age (years)		
0–14	3	2 (66.7)
15–64	70	65 (92.9)
65+	27	27 (100)
Sex		
Male	68	62 (91.2)
Female	32	32 (100)
Ethnicity		
Māori	32	28 (87.5)
Non-Māori	68	66 (97.1)

2018 (see Figure 1). Of these, 1,015 were excluded. The majority of those excluded (99.6%) were cases where the closest hospital was an advanced-level trauma centre. A random sample of 100 cases was selected from the 739 cases who met the study eligibility criteria.

Of the initial 100 randomly selected cases, four did not meet the eligibility criteria (three did not have electronic EMS records, and the remaining case had insufficient information regarding the nature of injury and of the incident itself) and were subsequently replaced.

Thirteen of the random sample of patients met the criteria for direct transport to an advanced-level trauma centre (Table 1). Of these, eight were taken to the appropriate destination. Of the 43 cases requiring transport directly to a mid-level trauma hospital, 42 patients were taken to the correct facility. All low-severity and unstable cases (all of which the MTDP requires to be taken to the local hospital) were transported to the correct destination. Overall, there was a 94% adherence rate to the MTDP.

Adherence to the MTDP is increased with age, as compliance improved with every increase in age bracket (Table 2).

Compliance increased with injury severity (Table 3), in contrast to the adherence of "threat to life" status, whereby this audit shows highest adherence in cases with "no" or "unlikely" threat to life both at the scene and in hospital. Adherence to the MTDP varied with different levels of respon-

siveness, with no clear trend evident. In terms of nature of injury, in particular the injury of different organ systems, intra-abdominal injuries had the lowest level of compliance.

Discussion

The aim of this study was to evaluate adherence to New Zealand's MTDP. The 94% adherence rate is high when compared with similar international audits.[5,7] A major contrast can be seen when comparing this study to Newgard et al.'s audit of the triage and destination of low-risk cases in the USA, as 34% of low-risk cases were still transported to advanced-level trauma centres against major trauma protocol recommendations.[15]

Interestingly, although all patients fitted the criteria for major trauma with an ISS >12, over

Table 3: Characteristics of audit cases—percent adherence by criteria (n=100).

Variable	n	Adherence to MTDP n (%)
Injury Severity Score		
<25	70	65 (92.9)
25–49	27	26 (96.3)
>49	3	3 (100)
Clinical status at scene*		
No threat to life	1	1 (100)
Unlikely threat to life	36	36 (100)
Potential threat to life	49	46 (93.9)
Immediate threat to life	14	11 (78.6)
Clinical status final*		
No threat to life	2	2 (100)
Unlikely threat to life	37	37 (100)
Potential threat to life	43	39 (90.7)
Immediate threat to life	18	16 (88.9)
Scene Glasgow Coma Score—Motor		
1–2	5	5 (100)
3–4	4	3 (75)
5–6	84	80 (95.2)
Missing	7	6 (85.7)
Scene Glasgow Coma Score—Total		
3–5	5	5 (100)
6–12	9	7 (77.8)
13–15	79	76 (96.2)
Missing	7	6 (85.7)

Table 3 (continued): Characteristics of audit cases—percent adherence by criteria (n=100).

Hospital Glasgow Coma Score—Motor 1		
1–2	6	6 (100)
3–4	3	3 (100)
5–6	81	75 (92.6)
Missing	10	10 (100)
Hospital Glasgow Coma Score—Total 1		
3–5	9	9 (100)
6–12	6	5 (83.3)
13–15	80	75 (93.8)
Missing	5	5 (100)
Responsiveness		
Alert	84	80 (95.2)
Voice	6	5 (83.3)
Pain	3	3 (100)
Unresponsive	5	4 (80)
Missing	2	2 (100)
Airway status		
Patent (clear)	95	89 (93.7)
Partially obstructed	3	3 (100)
Missing	2	2 (100)
Breathing status		
Effective	93	87 (93.5)
Ineffective	5	5 (100)
Missing	2	2 (100)
Mechanism of injury		
Motor vehicle incident**	57	53 (93.0)
Fall	29	28 (96.6)
Other***	14	13 (92.9)
Nature of injury		
Fractures (excluding skull)	45	44 (97.8)

Table 3 (continued): Characteristics of audit cases—percent adherence by criteria (n=100).

Skull fracture	2	2 (100)
Intracranial injury/TBI/concussion	30	28 (93.3)
Intra-abdominal injury	4	2 (50)
Intrathoracic injury	5	5 (100)
Multisystem injury	3	3 (100)
Spinal cord injury	4	3 (75)
Other****	7	7 (100)

*Clinical status at scene derived from the triage status at the scene, with triage status 1,2,3,4 correlating to immediate, potential, unlikely and no threat to life, respectively.
**Including road traffic incidents, off-road vehicle incidents, incidents involving a pedestrian.
***Includes animal attack/bite (n=2), assault (n=2), collapse (n=6), water sports (n=2), felling a tree, (n=1) unspecified (n=1).
****Includes contusion (n=1), nausea and vomiting (n=1), traumatic amputation (n=1), crush injury (n=2), traumatic pneumothorax (n=1), soft tissue injury to eye (n=1).

one-third of patients were determined by the paramedics as having a final status of being low acuity (clinical status) using the Emergency Ambulance Service Clinical Guidelines.[3] This finding suggests that there may be subsequent patient deterioration or differences in diagnostic capacity using the extensive in-hospital capabilities compared with those available in the pre-hospital environment, meaning that some injuries are occult/not able to be recognised pre-hospital. This finding may provide impetus for optimising EMS training or bringing further diagnostic techniques to the pre-hospital environment. Training of EMS personnel is variable internationally; in New Zealand, there are currently five levels of practice.[16] Of these practice levels, intensive care paramedics (ICP; postgraduate certificate qualified) and critical care paramedics (CCP; postgraduate diploma qualified) are the only qualified personnel that can perform endotracheal intubation, an advanced airway technique. In the rural setting, 74% of EMS attendance is by an ICP or CCP paramedic.[17] Increasing the proportion of CCP or ICP presence would increase the ability to provide critical advanced airway care at the injury site. CCPs or ICPs may also have a higher degree of clinical gestalt, which could enable a higher proportion of bypass of nearby hospitals to go directly to a major trauma centre. However, there would be challenges in resourcing such skills within the rural sector; in addition, the potential for skill attrition would be high due to low exposure to critical incidents. Other potential techniques for future investigation could be tools such as point-of-care ultrasound or lactate measurements, which could provide useful adjuncts to pre-hospital triage.[18,19] The introduction of other more physiological decision support tools, such as the pre-hospital National Early Warning Score, may also aid in supporting future bypass protocols.[20] Any changes in decision support tools and criteria would need to be carefully considered to ensure that such tools do not become overly cumbersome and complex.

This audit found that compliance was high in cases that were not classified as requiring transport to an advanced-level trauma centre at the scene. In comparison, cases needing to bypass the nearest hospital for advanced-level trauma facilities had a significantly lower compliance rate than cases that the protocol dictated should be taken to the nearest hospital—whether due to low severity or because they were unstable—were taken to the appropriate destination. Contrastingly, audits internationally demonstrate higher compliance when protocol requires bypass of nearest medical facilities compared to compliance to destination policy when injuries are less severe, which is the opposite trend to New Zealand.[6,21] MacKenzie et al.'s audit of compliance to major trauma destination protocols in the US found that there was higher compliance to protocols in cases of major trauma than cases that did not meet criteria for direct transport to an

advanced-level trauma centre.[6] An audit from the Netherlands conducted by Voskens et al. found that compliance increased with severity, with a 69% compliance rate in non-severe injury (not classified as major trauma) compared with a 78% compliance rate in more severe injuries that do classify as major trauma.[21] The reasons that a case may not have bypassed the closest centre despite the protocol may include: EMS providers not feeling confident to spend longer in transit with cases of major trauma, reduced awareness of the protocol and criteria for bypass of the nearest hospital or reduced capability to detect occult injury and therefore an under-estimation of severity. Reduced ability to pick up intra-abdominal injury at the scene, as evidenced by a lower compliance rate for major trauma characterised by intra-abdominal injury compared with other natures of injury, may have also contributed to cases of non-compliance to the MTDP.

The low level of compliance for intra-abdominal injuries found in this audit compared with other injury types may suggest that this injury type is less likely to be picked up correctly at the scene, and that recognition of intra-abdominal injuries is not as accurate using standard evaluation techniques at the scene. This suggests that increasing proficiency of detecting intra-abdominal injury at the scene may be a significant factor in increasing adherence rates to the major trauma destination policy. Practical applications of this finding could include training and resource allocation adjustments for FAST scanning/bedside ultrasound at the scene of trauma, or more education around the signs and symptoms of intra-abdominal injury that can be used effectively in the field. The numbers in each nature of injury category were relatively low, and therefore the findings need to be interpreted with caution. No previous published literature was located that had investigated the relationship between nature of injury and adherence to MTDPs.

A strength of this study is its alignment with methodology used in a 2018 New Zealand audit of the MTDP (in an email from B. Dicker in January 2022). The 2018 audit covered the period between 1 July 2017 and 30 June 2018, the present audit covering 31 November 2017 to 30 November 2018, so there is a minor difference in time period, but they are very similar in terms of trauma policy, both just over 1 year following the implementation of the MTDP. Our current methodology, however, has key differences. Firstly, the 2018 National Trauma Network audit over-reported compliance by auditing cases occurring in areas where the closest hospital was, by default, a major trauma hospital. The current methodology excluded cases that occurred in proximity to an advanced-level trauma centre, thereby reducing the possibility of over-reporting compliance. Interestingly, despite the 2018 study finding a 91% compliance rate to the MTDP with the reported limitation of over-estimating adherence, this study's adherence rate was 94%.

A New Zealand study looking at theoretical access to timely advanced-level trauma care identified lower access for Māori (New Zealand's Indigenous population) and older people.[22] These groups also have high rates of injury incidence[14,23] and a disproportionate burden of morbidity post-injury.[24,25] This audit found a difference in adherence for Māori compared with non-Māori patients, with 87.5% and 97.1% adherence rates respectively. This is a notable finding, as effective and adhered-to MTDPs can therefore potentially reduce the health burden on these already vulnerable communities. Due to the sample size of only 100 patients and use of a predominantly rural cohort, we were unable to report on Pacific peoples due to very small numbers. This is a key consideration for future analysis with a larger sample size. Given the exclusion of cases whereby the closest hospital was an advanced-level trauma centre, there were no cases from major centres included. Therefore, while this audit has a large representation of rural communities in the population, there is no way to compare those outcomes with the outcomes of urban communities.

The generalisability of the findings of this audit is limited by the random sample of 100 cases. Additionally, the low numbers of children in the present sample and cases with a high scene ISS (>49) reflect the New Zealand major trauma population but limit the generalisability of these findings to these groups. The experience of the EMS providers who attended the incident was not available in the data reviewed for this study. This information would have been helpful to provide insight into factors that may have impacted adherence. In addition, not all types of major trauma are represented, for example burns or penetrating injuries, limiting the audits' ability to assess MTDP adherence for these injury types. This audit used the 2019 MTDP to determine outcomes of adherence for cases occurring in 2017 for reasons outlined above. Therefore, this audit may have been limited by some minor changes between the 2017 and 2019 destination policies.

Although the cohort is 6 years old, there have been no significant shifts in practice since this time; therefore, the results are likely to still be relevant. In addition, the use of a cohort derived during the COVID-19 epidemic may have resulted in some unknown effects on destination adherence. However, it should be noted that due to New Zealand's strict border closure restrictions during COVID-19, the country did not experience the extent of the overwhelming impact on health services (including EMS) that other countries experienced. A future audit comparing a post-COVID period would be of interest.

Conclusion

The present study found high adherence to the New Zealand MTDP, with the majority (94%) of cases being taken to the appropriate destination directly from the incident scene. Contrastingly to the overall outcome, of those cases classified as meeting the criteria for direct transport to an advanced-level trauma centre, in just over 60% of cases the MTDP was adhered to.

In cases where the appropriate action was to bypass the nearest medical facility, this audit reveals potential scope for improvement, particularly when the injury severity is high. In order to make improvements, it is key that emergency services understand the reasons for the instances when there is non-adherence. Future investigations could seek to inform paramedics of patient final outcomes and whether knowledge of this would lead them to make different decisions in future. Moreover, are there changes that could be made to the pre-hospital destination guidelines to reduce the subjectivity; for instance, perhaps incorporation of physiological measures and/or additional decision support via telehealth or similar need to be made available to paramedics on scene.

COMPETING INTERESTS
HRC project grant 18/465: Auckland and Otago universities received funding to conduct the parent study that this paper forms a part of. One of the authors (Bridget Kool) was PI on that study and part of her salary covered. Data management costs were covered by the study.
Bridget Dicker is an employee of Hato Hone St John and this work was undertaken in "time only" as part of her employment.

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Appendices

Appendix 1: New Zealand out-of-hospital major trauma triage policy

New Zealand Out-of-Hospital Major Trauma Triage Policy

This document is for the use of clinical personnel when triaging patients with trauma in the out-of-hospital setting in New Zealand. It has been developed by the National Major Trauma Clinical Network in conjunction with the Ambulance Sector.

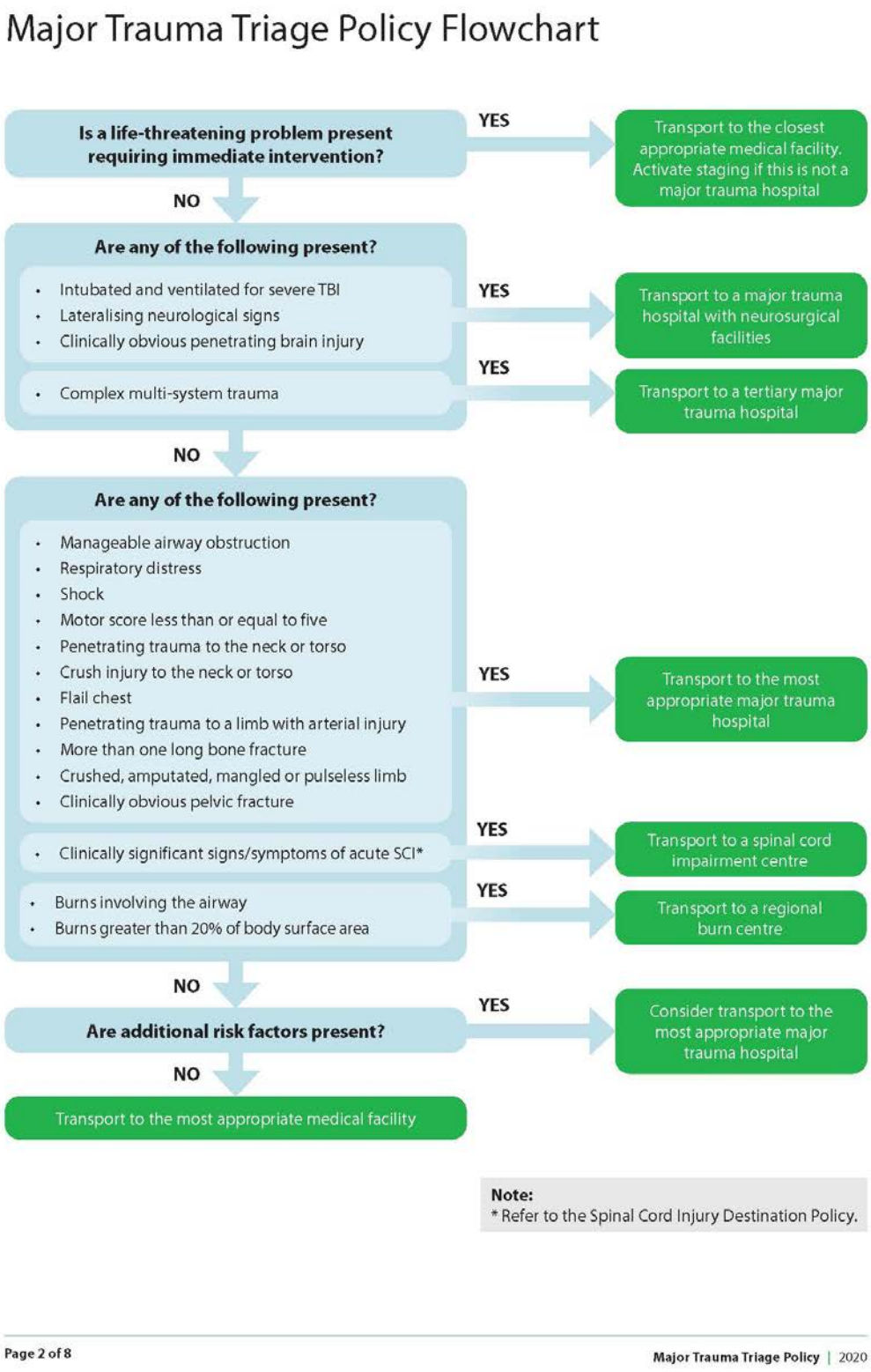
Publication date October 2020

Major Trauma National Clinical Network

St John

WELLINGTON FREE AMBULANCE

Appendix 1 (continued): New Zealand out-of-hospital major trauma triage policy



Appendix 1 (continued): New Zealand out-of-hospital major trauma triage policy

Major Trauma Triage Policy: Additional Information

Introduction

The information within this policy complements the major trauma triage flowchart for clinical personnel and should be read in conjunction with it. The major trauma triage flowchart is to be used by clinical personnel (for example ambulance and PRIME personnel) to identify which patients meet criteria for major trauma in the out-of-hospital setting. Patients who have been identified as having major trauma should be transported directly to a major trauma hospital whenever it is feasible and safe to do so.

Major trauma hospitals are those hospitals designated by the Regional Major Trauma Networks to receive patients who have major trauma. Further details are described in Regional Major Trauma Destination Policies.

Determining the most appropriate major trauma hospital

- Few hospitals in New Zealand have the facilities required to treat all the injuries a patient with major trauma may have and this includes many of the hospitals designated as a major trauma hospital. Clinical judgement must be used when determining which major trauma hospital the patient is transported to, taking into account:
  - The information within the Regional Major Trauma Destination Policies.
  - The patient's expected treatment requirements.
  - The transport time to the relevant hospitals.
- In most cases, the most appropriate major trauma hospital will be the closest major trauma hospital. However, in some cases there will be a choice of major trauma hospitals that the patient could be transported to within similar times. In this setting the patient should be transported to the major trauma hospital with the most appropriate facilities to meet the expected treatment needs of the patient.
- Personnel should seek clinical advice if they are uncertain.

Life threatening problems requiring immediate intervention

- It should be rare for a patient with a life-threatening problem to be transported to a medical facility that is not a major trauma hospital, because delays to definitive care worsen outcome. A patient with major trauma should be transported directly to a major trauma hospital unless the patient has an immediately life-threatening problem and there is a clear benefit from transporting the patient to a closer medical facility.
- However, some patients have a life-threatening problem requiring immediate intervention that cannot be provided by personnel at the scene, such that there is a high risk of death before reaching a major trauma hospital and the problem may be able to be rectified at a closer medical facility. Examples include:
  - Severe airway obstruction despite manual techniques and airway adjuncts.
  - Inadequate breathing.
  - Severe external bleeding that is not controlled.
- The closest appropriate medical facility will usually be a hospital, but sometimes it will be a medical centre, particularly in remote areas of New Zealand.
- The decision to transport a patient with a life-threatening problem to a medical facility that is not a major trauma hospital requires clinical judgement and must have a low threshold for seeking clinical advice. The decision should take into account the nature of the patient's injuries, the rate of deterioration, the relative proximity of the medical facilities and the personnel available at the medical facility.
- Personnel in the receiving medical facility must be notified as soon as possible, preferably before leaving the scene.
- Staging must be activated via Comms, preferably before leaving the scene, if the medical facility is not a major trauma hospital.

Appendix 1 (continued): New Zealand out-of-hospital major trauma triage policy

Severe traumatic brain injury (TBI)

- Most patients with severe TBI do not require urgent neurosurgery. However, patients with any of the following clinical features have a high probability of requiring urgent neurosurgery and/or neuro-intensive care and should be transported to a major trauma hospital with neurosurgical facilities, whenever this is feasible and safe:
  - Intubated and ventilated. These patients usually require neuro-intensive care and may require urgent neurosurgery.
  - Lateralising neurological signs, for example unilateral pupil dilatation or unilateral weakness. These patients usually require neurosurgery for extradural or subdural bleeding.
  - Clinically obvious penetrating brain injury. These patients usually require neurosurgery.
- Personnel should have a low threshold for seeking clinical advice if transport to a major trauma hospital with neurosurgical facilities will involve a prolonged flight, particularly if the patient is not intubated and ventilated.

Complex multi-system trauma

- Complex multi-system trauma cannot be tightly defined, and clinical judgement is required, but includes patients with major trauma involving very severe injuries to more than one body region.
- Patients with complex multi-system trauma will usually benefit from transport to a tertiary major trauma hospital that is also a tertiary hospital, provided this is feasible and safe. This is because tertiary major trauma hospitals have additional personnel and facilities to manage patients with complex multi-system trauma.
- Personnel should seek clinical advice prior to commencing transport, if transport to a major trauma hospital that is also a tertiary hospital will involve a prolonged flight.

Abnormal Primary Survey

Airway obstruction

- Clinical judgement is required when determining that the patient has manageable airway obstruction (as per step three in the flowchart), rather than life-threatening airway obstruction requiring immediate intervention (as per step one in the flowchart).
- For the majority of patients their airway obstruction is manageable and they can be adequately oxygenated using airway adjuncts and supplemental oxygen. If this is the case the patient should be transported to a major trauma hospital.

Respiratory distress

- A patient with chest wall bruising or a few isolated rib fractures will often have pain when taking a deep breath, but in order to have respiratory distress the patient must have clinical signs of difficulty breathing or severe pain with normal breathing.

Shock

- Shock is a clinical diagnosis and cannot be tightly defined using specified vital signs.
- Clinical signs of shock include tachycardia (unless the patient is beta-blocked or has 'end stage' shock when the heart rate is falling), a narrowed pulse pressure, vasoconstriction and an altered level of consciousness (usually occurs late in shock particularly in children and young adults and usually manifests as agitation with preservation of the ability to obey commands).
- Blood pressure is a poor guide to the severity of shock and must be considered as part of the overall clinical picture. Blood pressure may only begin to fall when shock is severe and blood pressure varies with age, sex, degree of fitness and medications.
- If an IV fluid bolus is clinically indicated the patient has shock.

Appendix 1 (continued): New Zealand out-of-hospital major trauma triage policy

Motor score of less than or equal to five

- A motor score of less than or equal to five is a more useful predictor of clinically important TBI than the GCS.
- Consider transporting to a major trauma hospital if they have a falling GCS or severe agitation, even if they are obeying commands.
- A patient with alcohol or drug intoxication who has a motor score of less than or equal to five following a mechanism of injury consistent with TBI, should be presumed to have severe TBI until proven otherwise, even if it is suspected that alcohol or drug intoxication is contributing to the altered level of consciousness.

Injury patterns

Penetrating injury to the neck or torso

- To meet the definition of penetrating injury to the neck or torso, there must be a strong clinical impression that the injury has penetrated:
  - The deep tissues when the injured region is the neck.
  - The thoracic cavity when the injured region is the chest.
  - The abdominal cavity when the injured region is the abdomen or pelvis.
- If the patient has a penetrating injury that appears to only involve skin or subcutaneous tissue and the patient's vital signs are normal, clinical judgement should be used and transport may occur to a hospital that is not a major trauma hospital.
- Arterial bleeding from penetrating injuries to the limbs is usually clear, particularly if it involves the brachial, femoral or popliteal artery. However, it is common for there to be some uncertainty as to whether or not bleeding from a limb is arterial. Provided the bleeding has been adequately controlled without a tourniquet and the limb has normal perfusion, clinical judgement should be used and transport may occur to a hospital that is not a major trauma hospital provided the hospital has the facilities to meet the patient's needs.

Crush injury to the neck or torso

- Most patients with a clinically significant crush injury will have an abnormal primary survey and this will trigger the need for transport to a major trauma hospital.
- If the crush injury is not clinically significant and the patient has normal vital signs, clinical judgement should be used and transport may occur to a hospital that is not a major trauma hospital provided the hospital has the facilities to meet the patient's needs.

Flail chest

- Flail chest is a clinical diagnosis. There must be clinical signs of paradoxical chest wall movement with breathing.
- The patient usually has very severe pain, but pain alone is not a diagnostic sign of flail chest.

More than one long bone fracture

- For the purposes of meeting criteria for major trauma, a fractured long bone requires the patient to have a clinically obvious fracture of the shaft of the femur, tibia or humerus.
- A fracture that is clinically isolated to the neck of femur or to the ankle is not considered a long bone fracture.
- No distinction is made between closed and compound fractures for the purpose of meeting criteria for major trauma.

Appendix 1 (continued): New Zealand out-of-hospital major trauma triage policy

Clinically obvious pelvic fracture

- It is rare to make an out-of-hospital diagnosis of a clinically obvious pelvic fracture because this requires an obvious major deformity or clear evidence of a pelvic fracture visible through a wound.
- The most common symptom of a pelvic fracture is the presence of pelvic pain, but the presence of pain alone is not sufficient to diagnose a clinically obvious pelvic fracture.
- There is no role for examining the pelvis for signs of instability or crepitus because the pelvis may be severely unstable without these signs being present and the force required to elicit signs may cause harm.

Spinal cord injury

- Refer to the Spinal Cord Injury Destination Policy.
- If the patient has clinically significant signs and/or symptoms of acute spinal cord injury, the patient should be transported directly to a spinal cord impairment (SCI) centre whenever this is feasible and safe. The patient should be transported to a SCI centre if there are other signs of major trauma in addition to that of spinal cord injury, provided this is feasible and safe, as the SCI centres are also major trauma hospitals.
- If it is not feasible or safe to transport to a SCI centre, for example the patient has other major injuries and is deteriorating, the patient should be transported to the most appropriate major trauma hospital.
- Have a low threshold for seeking clinical advice prior to commencing transport if this will involve a prolonged flight.

Burns greater than 20% of body surface area and burns involving the airway

- Transport the patient to a regional burn centre (Middlemore Hospital, Waikato Hospital, Hutt Hospital or Christchurch Hospital) if the patient has burns of greater than 20% of body surface area or burns involving the airway, provided this is feasible and safe.
- Hutt Hospital is not a major trauma hospital and if there are signs or symptoms of major trauma in addition to the burn injury, the patient must be transported to a major trauma hospital.
- The patient must be transported to a major trauma hospital if they are not transported to a regional burn centre.
- Burns involving the face, hands or genitals may require treatment in a regional burn centre. However, provided the burn injury is less than 10% of TBSA in an adult or less than 5% of TBSA in a child, treatment is not usually time sensitive and the patient should usually be transported to the most appropriate hospital, and subsequently transferred if required.

Additional risk factors

- Consider transporting the patient to a major trauma hospital if the patient has additional risk factors, but does not meet the criteria for having major trauma.
- Signs or symptoms include, but are not limited to:
  - Severe soft tissue injury, particularly if it involves the face.
  - Severe abdominal pain.
- High risk mechanisms of injury include, but are not limited to:
  - Ejection from a vehicle.
  - Fall greater than twice the patient's height.
- Patient risk factors include, but are not limited to:
  - Elderly.
  - Pregnancy.
  - Taking an oral anticoagulant.
  - Known bleeding disorder.

Appendix 1 (continued): New Zealand out-of-hospital major trauma triage policy

- Even in the presence of additional risk factors, if the patient has apparently minor injuries and normal vital signs, clinical judgement should be used and transport should usually occur to the most appropriate hospital, rather than to a major trauma hospital. This is particularly the case if a major trauma hospital is significantly further away than the alternative hospital.

Staging

- The majority of patients with major trauma should be transported directly to a major trauma hospital. However, it is occasionally appropriate for the patient to be transported to another medical facility (one that is not designated as a major trauma hospital) while a helicopter is dispatched to transport the patient to a major trauma hospital. This is termed staging and should only occur when all of the following apply:
  - The patient meets criteria to be transported by helicopter to a major trauma hospital.
  - Transport by road to the major trauma hospital is not appropriate because of distance.
  - The patient has a life-threatening problem requiring immediate intervention that cannot be provided by personnel at the scene.
  - The staging medical facility has personnel and facilities to meet the patient's immediate treatment needs.
  - The patient can be transported to the staging medical facility significantly faster than the helicopter can locate at the scene. 'Significantly faster' cannot be tightly defined and requires clinical judgement.
- When a medical facility is being used as a staging point:
  - The aim of treatment at the staging medical facility is to provide immediate resuscitation/treatment and prepare the patient for helicopter transport.
  - Personnel must notify Comms that the medical facility is being used as a staging point, prior to arrival at the staging centre and preferably before leaving the scene.
  - Personnel in the staging medical facility must be notified as soon as possible that the medical facility is being used as a staging point.
  - An appropriate helicopter and crew will be dispatched as soon as possible and preferably before the patient arrives at the staging medical facility.
  - Air Desk personnel are responsible for immediately arranging transport from the staging facility to a major trauma hospital.
- When a helicopter is being dispatched to a medical facility (including hospitals) that is being used as a staging point:
  - The helicopter mission will be dispatched as an out-of-hospital job and not as an inter-hospital transfer.
  - The clinical care of the patient during transfer will be provided by the helicopter crew.
  - If a doctor is available to be part of the usual helicopter crew they will be dispatched whenever this is feasible.
- If the patient is transported to a hospital and personnel are not using the hospital as a staging point and a decision is made by hospital staff to request a helicopter after the patient has arrived at that hospital, this mission/job will be dispatched as an inter-hospital transfer.

Additional information

Determining the most appropriate medical facility

- If the patient does not meet criteria to be transported directly to a major trauma hospital, they should be transported to the most appropriate medical facility, taking into account:
  - The location of the scene.
  - The anticipated healthcare needs of the patient.
  - Where the patient lives.
- The patient should be transported to a medical facility capable of meeting their anticipated healthcare needs whenever this is feasible. For example, a patient with a compound fracture should be transported to a hospital with orthopaedic surgical facilities and a patient with minor injuries should be transported to an appropriate medical centre.

Appendix 1 (continued): New Zealand out-of-hospital major trauma triage policy

Patients that rapidly improve without treatment

- A patient may initially meet criteria for major trauma but then rapidly improve without specific treatment.
- For example, a patient may have lost consciousness and then rapidly recovered, or had respiratory distress from an emotional cause that has rapidly improved.
- Provided the patient is very clearly improving and meets no other criteria for major trauma, clinical judgement should be used and transport may occur to a hospital which is not a major trauma hospital.

Ambulance status codes

- Status codes cannot be used to define the presence or absence of major trauma, for example not all patients assigned a status code of two will have major trauma.
- The major trauma triage criteria must be used to determine whether or not the patient has major trauma.

Appendix 2: New Zealand out-of-hospital major trauma destination policy—Northland and Auckland areas

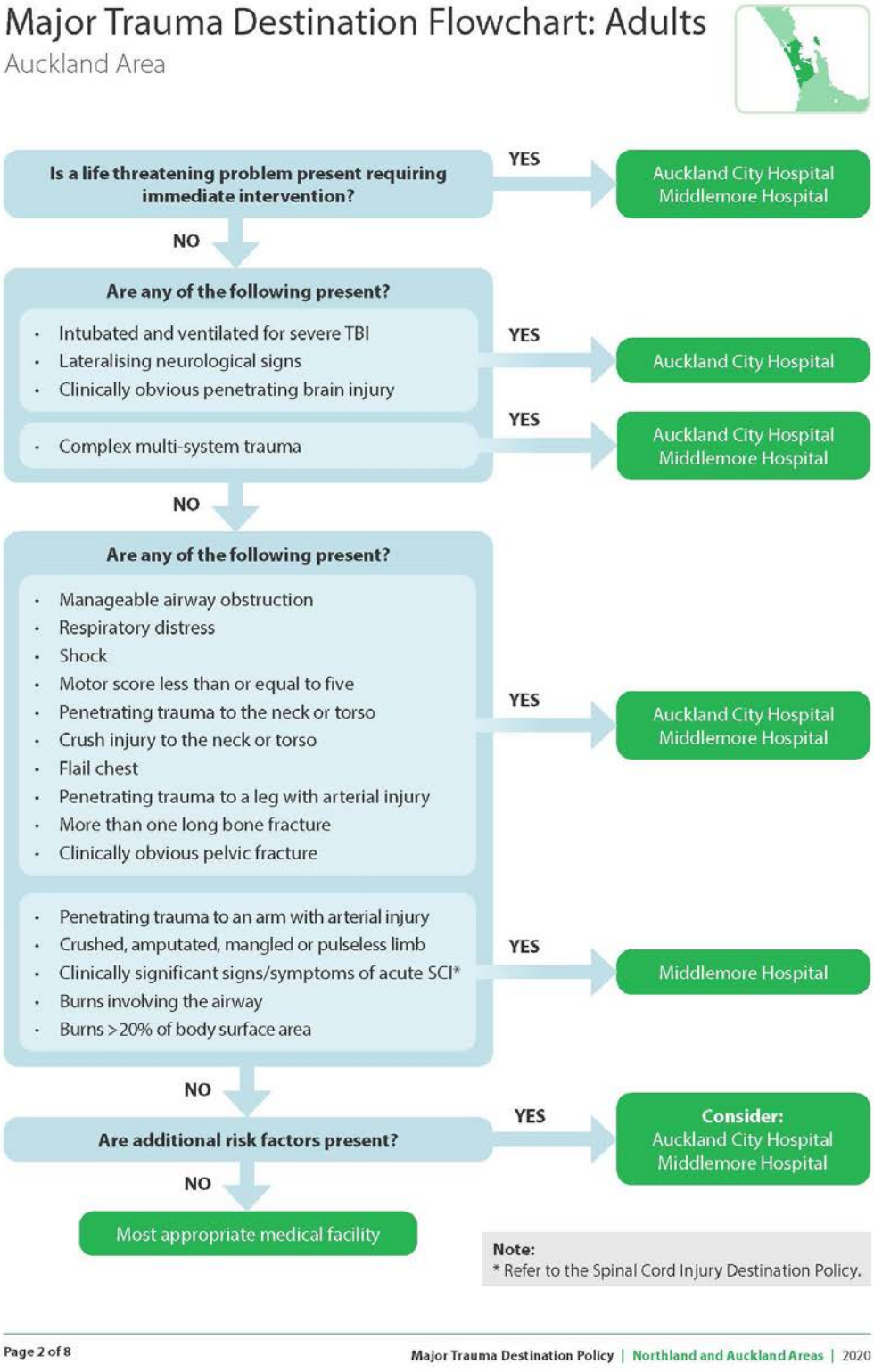
New Zealand Out-of-Hospital Major Trauma Destination Policy

Northland and Auckland Areas

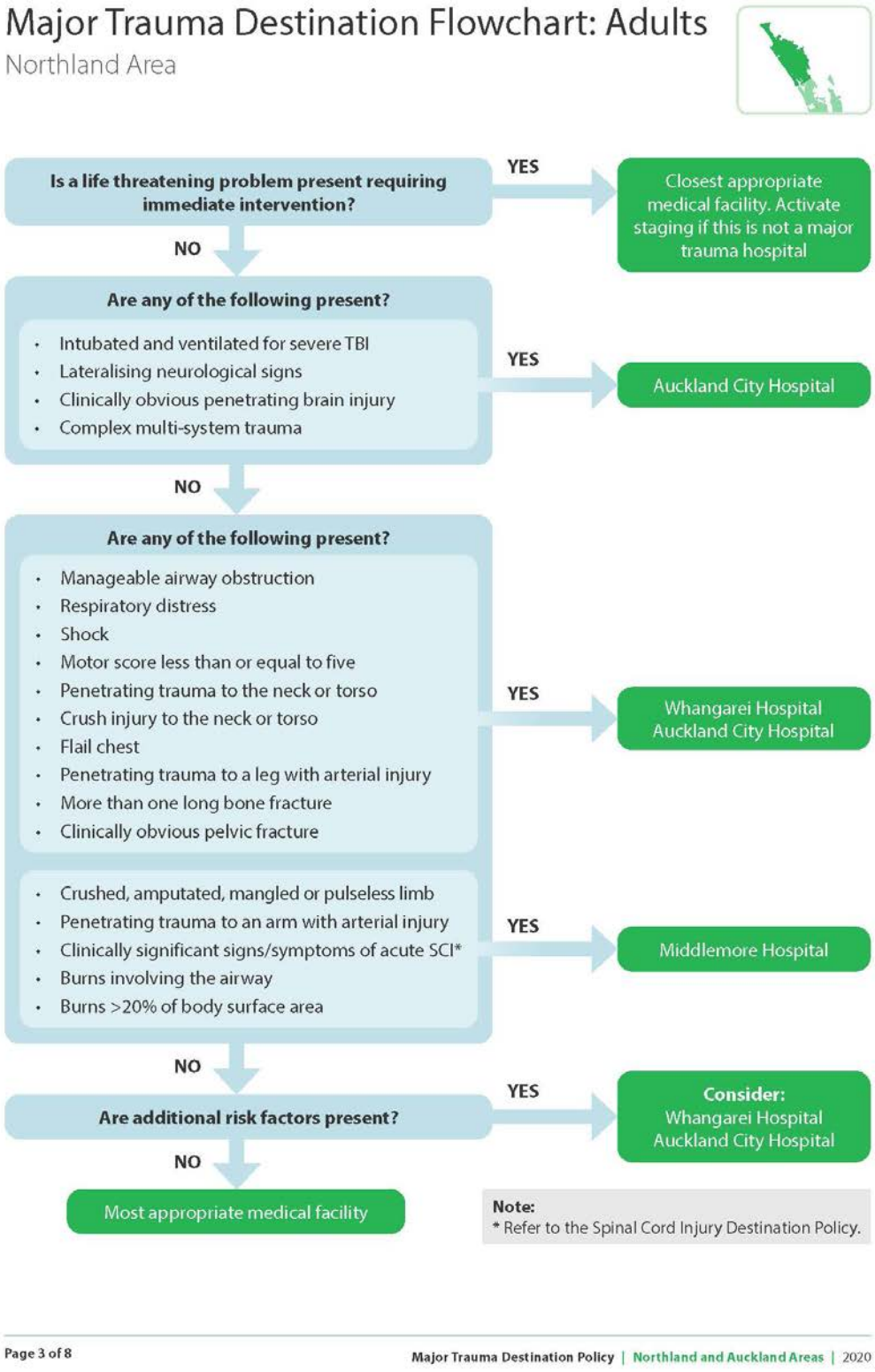
This document is for the use of clinical personnel when determining the destination hospital for patients with major trauma in the out-of-hospital setting in the Northland and Auckland Areas of New Zealand. It has been developed by the Northern Regional Major Trauma Network in conjunction with the National Major Trauma Clinical Network and the Ambulance Sector.

Publication date October 2020

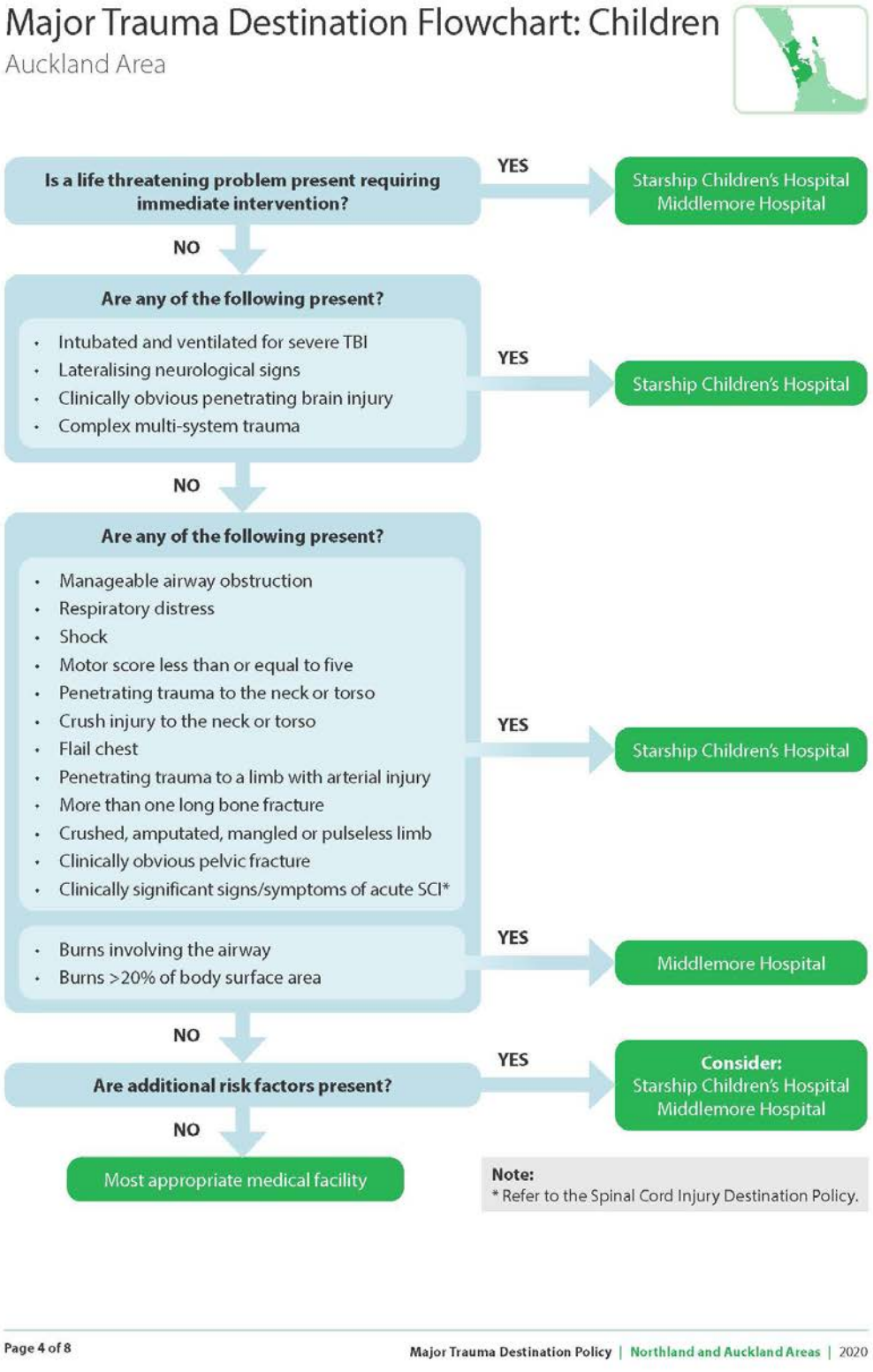
Appendix 2 (continued): New Zealand out-of-hospital major trauma destination policy—Northland and Auckland areas



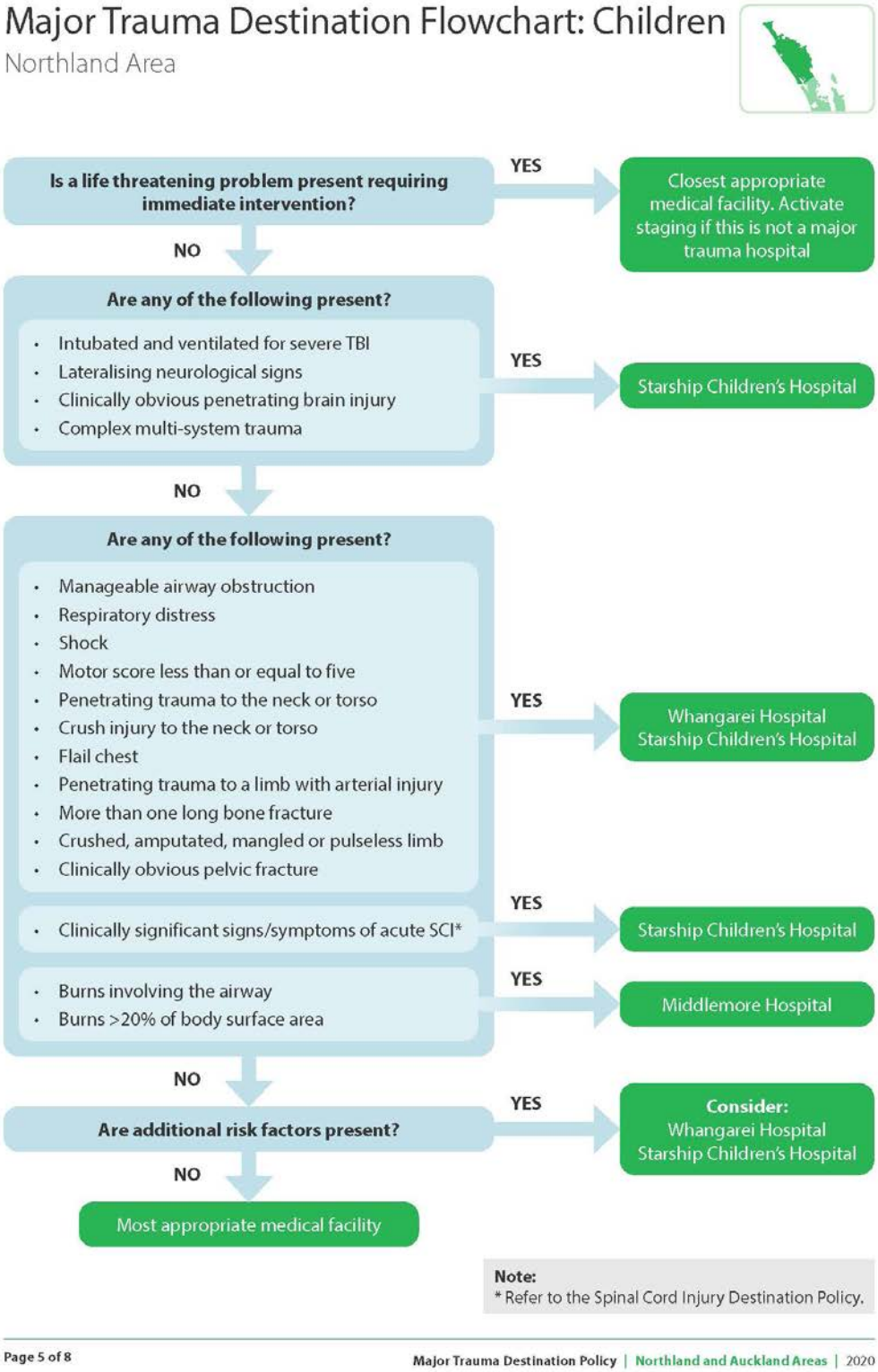
Appendix 2 (continued): New Zealand out-of-hospital major trauma destination policy—Northland and Auckland areas



Appendix 2 (continued): New Zealand out-of-hospital major trauma destination policy—Northland and Auckland areas



Appendix 2 (continued): New Zealand out-of-hospital major trauma destination policy—Northland and Auckland areas



Appendix 2 (continued): New Zealand out-of-hospital major trauma destination policy—Northland and Auckland areas

Major Trauma Destination Policy: Northland and Auckland Areas

Additional Information

Introduction

- This policy is for the use of personnel in the out-of-hospital setting, when determining the transport destination for patients with major trauma in the Northland and Auckland areas of New Zealand.
- It should be read in conjunction with the New Zealand Out-of-Hospital Major Trauma Triage Policy, the National Major Trauma Network Staging Guidelines, the New Zealand Spinal Cord Injury Destination Policy and the Ambulance Sector Clinical Procedures and Guidelines (CPGs).
- The goal of this policy is to ensure that patients with major trauma are transported directly to the most appropriate major trauma hospital, whenever it is feasible and safe to do so.

Major trauma hospitals

- The following hospitals are designated to receive patients with major trauma:
  - Whangarei Hospital (adults and children).
  - Auckland City Hospital (adults only).
  - Starship Children's Hospital (children only).
  - Middlemore Hospital (adults and children*).

  ***Note:** Middlemore Hospital is only designated to receive children with burns and children with a life-threatening problem requiring immediate intervention.
- The following hospitals are tertiary major trauma hospitals:
  - Auckland City Hospital (adults only).
  - Starship Children's Hospital (children only).
  - Middlemore Hospital (adults only).

Determining the most appropriate major trauma hospital

- The flowcharts describe the preferred major trauma hospital/s, based on the best descriptor of the patient's clinical condition.
- The patient should be transported to the preferred major trauma hospital as described in the flowchart, whenever it is feasible and safe to do so.
- If it is not feasible or safe to transport the patient to the preferred major trauma hospital or more than one major trauma hospital is listed as an option, the patient should be transported to the most appropriate major trauma hospital. This will usually be the nearest major trauma hospital, but it may be appropriate to transport the patient to another major trauma hospital if that hospital has the most appropriate facilities to meet the patient's needs.
- Personnel will determine the most appropriate major trauma hospital taking into account all of the following:
  - The information within this policy.
  - The patient's expected treatment requirements.
  - The transport time to the relevant hospitals.
- Personnel should have a low threshold for seeking clinical advice if the transport time to the chosen major trauma hospital is significantly longer (this is not defined and requires clinical judgement) than the transport time to the nearest major trauma hospital.

Appendix 2 (continued): New Zealand out-of-hospital major trauma destination policy—Northland and Auckland areas

Life threatening problems requiring immediate intervention

- Auckland Area: the size and geography of the Auckland Area is such that the patient should be transported to a major trauma hospital, even in the presence of a life-threatening problem requiring immediate intervention.
- Northland Area: the size and geography of the Northland Area is such that the patient should be transported to the closest appropriate medical facility if they have a life-threatening problem requiring immediate intervention that cannot be provided by personnel at the scene:
  - The decision to transport a patient with a life-threatening problem to a medical facility that is not a major trauma hospital requires clinical judgement and personnel must have a low threshold for seeking clinical advice. The decision should take into account the nature of the patient's injuries, the rate of deterioration, the relative proximity of the medical facilities and the personnel available at the medical facility.
  - Staging must be activated via Comms, preferably before leaving the scene, if the medical facility is not a major trauma hospital.
  - Personnel in the receiving medical facility must be notified as soon as possible, preferably before leaving the scene.

Severe traumatic brain injury (TBI)

- Most patients with severe TBI do not require urgent neurosurgery. However, patients with any of the following clinical features have a high probability of requiring urgent neurosurgery and/or neuro-intensive care and should be transported to Auckland Hospital (adults) or Starship Children's Hospital (children) whenever it is feasible and safe to do so:
  - Intubated and ventilated **or**
  - Lateralising neurological signs, for example unilateral pupil dilatation or unilateral weakness **or**
  - Clinically obvious penetrating brain injury.
- Auckland Area: patients with the above clinical features should be transported to Auckland City Hospital (adults) or Starship Children's Hospital (children), even if the scene is south of Middlemore Hospital, unless there is a compelling reason to transport to Middlemore Hospital.
- Northland Area: patients with the above clinical features should be transported to Auckland City Hospital (adults) or Starship Children's Hospital (children) if a helicopter is immediately available, unless there is a compelling reason to transport to Whangarei Hospital.

Complex multi-system trauma

- Complex multi-system trauma cannot be tightly defined and clinical judgement is required, but includes patients with major trauma involving very severe injuries to more than one body region.
- Auckland Area: patients with complex multi-system trauma should be transported to Auckland City Hospital (adults), Middlemore Hospital (adults) or Starship Children's Hospital (children).
- Northland Area: patients with complex multi-system trauma should be transported to Auckland City Hospital (adults) or Starship Children's Hospital (children) if a helicopter is immediately available, unless there is a compelling reason to transport to Whangarei Hospital.

Appendix 2 (continued): New Zealand out-of-hospital major trauma destination policy—Northland and Auckland areas

Limb injuries

- A differentiation has been made within the flowcharts between adults with an upper limb injury involving arterial injury and adults with a lower limb injury involving arterial injury.
- Adults with an upper limb injury involving arterial injury should be transported to Middlemore Hospital. This is because a combined approach involving plastic surgery and vascular surgery is almost always required and these services are only both available at Middlemore Hospital.
  - Auckland area: adults should be transported to Middlemore Hospital unless there is a compelling reason to transport to Auckland City Hospital.
  - Northland area: adults should be transported to Middlemore Hospital if a helicopter is immediately available, unless there is a compelling reason to transport to Whangarei Hospital.
- Adults with limb injury involving crush, amputation or mangling should be transported to Middlemore Hospital. This is because a combined approach involving plastic surgery and orthopaedic surgery is almost always required and these services are only both available at Middlemore Hospital.
  - Auckland area: adults should be transported to Middlemore Hospital unless there is a compelling reason to transport to Auckland City Hospital.
  - Northland area: adults should be transported to Middlemore Hospital if a helicopter is immediately available, unless there is a compelling reason to transport to Whangarei Hospital.
- Children with limb injuries involving arterial injury, crush, amputation or mangling:
  - Auckland area: children should be transported to Starship Children's Hospital unless there is a compelling reason to transport to Middlemore Hospital.
  - Northland area: children should be transported to Starship Children's Hospital if a helicopter is immediately available, unless there is a compelling reason to transport to Whangarei Hospital.

Burns

- Patients with a burn injury of greater than 20% of TBSA or burns involving the airway should be transported to Middlemore Hospital (if feasible and safe), including patients in the Northland area.
- Patients with a burn injury greater than 10% of TBSA in an adult or greater than 5% of TBSA in a child should be transported to Middlemore Hospital (including patients in the Northland Area) or to a hospital with surgical facilities.
- Burns involving the face, hands or genitals may require treatment in a regional burn centre. However, provided the burn injury is less than 10% of TBSA in an adult or less than 5% of TBSA in a child, treatment is not usually time sensitive and the patient should usually be transported to the most appropriate hospital, and subsequently transferred if required.

Appendix 3: New Zealand out-of-hospital major trauma destination policy—Midland area

New Zealand Out-of-Hospital Major Trauma Destination Policy

Midland Area

This document is for the use of clinical personnel when determining the destination hospital for patients with major trauma in the out-of-hospital setting in the Midland Area of New Zealand. It has been developed by the Midland Trauma System in conjunction with the National Major Trauma Clinical Network and the Ambulance Sector.

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Appendix 3 (continued): New Zealand out-of-hospital major trauma destination policy—Midland area

Major Trauma Destination Matrix

Midland Area

Area	Waikato					Bay of Plenty		Lakes		Taranaki		Tairawhiti
Incident Locality	WKO	THA	TOK	TAU	TEK	TGA	WHK	ROT	TPO	TBH	HAW	GIS
Condition	**Destination hospital**											
Life threatening problem requiring immediate medical intervention	Closest appropriate medical facility. Activate staging if this is not a major trauma hospital											
Severe TBI likely to require urgent neurosurgery[1] (aged ≥2 years)	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO
Severe TBI likely to require urgent neurosurgery[1] (aged <2 years)	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH
Complex multi-system trauma	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	GIS[2]
Manageable airway obstruction	WKO	WKO	WKO	WKO	WKO	TGA	TGA	ROT	ROT	TBH	TBH	GIS
Respiratory distress	WKO	WKO	WKO	WKO	WKO	TGA	TGA	ROT	ROT	TBH	TBH	GIS
Shock	WKO	WKO	WKO	WKO	WKO	TGA	TGA	ROT	ROT	TBH	TBH	GIS
Motor score less than or equal to five	WKO	WKO	WKO	WKO	WKO	TGA	TGA	ROT	WKO	TBH	TBH	GIS
Penetrating injury to the neck or torso	WKO	WKO	WKO	WKO	WKO	TGA	TGA	ROT	ROT	TBH	TBH	GIS
Crush injury to the neck or torso	WKO	WKO	WKO	WKO	WKO	TGA	TGA	ROT	ROT	TBH	TBH	GIS
Flail chest	WKO	WKO	WKO	WKO	WKO	TGA	TGA	ROT	ROT	TBH	TBH	GIS
Penetrating trauma to a limb with arterial injury	WKO	WKO	WKO	WKO	WKO	TGA	TGA	ROT	ROT	TBH	TBH	GIS
More than one long bone fracture	WKO	WKO	WKO	WKO	WKO	TGA	TGA	ROT	ROT	TBH	TBH	GIS
Crushed, amputated, mangled or pulseless limb	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	TBH	TBH	GIS
Clinically obvious pelvic fracture	WKO	WKO	WKO	WKO	WKO	TGA	TGA	WKO	WKO	TBH	TBH	GIS
Clinically significant signs/symptoms of isolated spinal cord injury[3] (≥15 years)	MMH	MMH	MMH	MMH	MMH	MMH	MMH	MMH	MMH	CCH	CCH	MMH
Clinically significant signs/symptoms of isolated spinal cord injury[3] (<15 years)	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH	SSH
Burns involving the airway	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO
Burns >10% of body surface area (≥15 years)	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO
Burns >5% of body surface area (<15 years)	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO
Major facial injuries with obvious deformity	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO	WKO

Transport direct to the destination listed provided it is feasible and safe to do so

CCH	Christchurch Hospital	**TEK**	Te Kuiti Hospital
GIS	Gisborne Hospital	**TGA**	Tauranga Hospital
HAW	Hawera Hospital	**THA**	Thames Hospital
MMH	Middlemore Hospital	**TOK**	Tokoroa Hospital
ROT	Rotorua Hospital	**TPO**	Taupo Hospital
SSH	Starship Hospital	**WHK**	Whakatane Hospital
TAU	Taumarunui Hospital	**WKO**	Waikato Hospital
TBH	Taranaki Base Hospital		

Notes:

- [1]Criteria for severe TBI likely to require urgent neurosurgery: Patient has been intubated and ventilated or has lateralising neurological signs (for example unilateral pupil dilatation or unilateral weakness) or has a clinically obvious penetrating brain injury.
- [2]Patients with complex multi-system trauma will only be transported to Gisborne Hospital by road. All patients with complex multi-system trauma in the Tairawhiti Area being transported by helicopter will be transported to Waikato Hospital provided it is feasible and safe to do so.
- [3]Criteria for clinically significant signs/symptoms of isolated spinal cord injury include: Paraplegia, quadriplegia, clinically significant limb weakness or clinically significant loss of sensation.

Appendix 3 (continued): New Zealand out-of-hospital major trauma destination policy—Midland area

Major Trauma Destination Policy: Midland Area

Additional Information

Introduction

- This policy is for the use of personnel in the out-of-hospital setting, when determining the transport destination for patients with major trauma in the Midland Area of New Zealand.
- It should be read in conjunction with the New Zealand Out-of-Hospital Major Trauma Triage Policy, the National Major Trauma Network Staging Guidelines, the New Zealand Spinal Cord Injury Destination Policy and the Ambulance Sector Clinical Procedures and Guidelines (CPGs).
- The goal of this policy is to ensure that patients with major trauma are transported directly to the most appropriate major trauma hospital, whenever it is feasible and safe to do so.

Major trauma hospitals

- The following hospitals are designated to receive patients with major trauma:
  - Waikato Hospital.
  - Tauranga Hospital.
  - Rotorua Hospital.
  - Gisborne Hospital.
  - Taranaki Base Hospital.
  - Starship Children's Hospital.
- Waikato Hospital is the tertiary major trauma hospital.

Determining the most appropriate major trauma hospital

- The destination matrix describes the preferred major trauma hospital, based on the best descriptor of the patient's clinical condition.
- The patient should be transported to the preferred major trauma hospital as described in the matrix, whenever it is feasible and safe to do so.
- To use the matrix:
  - Begin at the top and choose the locality that best matches the location of the incident.
  - Go down the matrix to the condition that best describes the patient's known injuries.
  - The hospital listed is the preferred major trauma hospital.
- If it is not feasible or safe to transport the patient to the preferred major trauma hospital, the patient should be transported to the most appropriate major trauma hospital. This will usually be the nearest major trauma hospital, but it may be appropriate to transport the patient to another major trauma hospital if that hospital has the appropriate facilities to meet the patient's needs.
- Personnel will determine the most appropriate major trauma hospital taking into account all of the following:
  - The information within this policy.
  - The patient's expected treatment requirements.
  - The transport time to the relevant hospitals
- Personnel should seek clinical advice if there is deviation from the matrix

Appendix 3 (continued): New Zealand out-of-hospital major trauma destination policy—Midland area

Life threatening problems requiring immediate intervention

- Transport the patient to the closest appropriate medical facility if the patient has a life-threatening problem requiring immediate intervention that cannot be provided by personnel at the scene.
- The decision to transport a patient with a life-threatening problem to a medical facility that is not a major trauma hospital requires clinical judgement and must have a low threshold for seeking clinical advice. The decision should take into account the nature of the patient's injuries, the rate of deterioration, the relative proximity of the medical facilities and the personnel available at the medical facility.
- Staging must be activated via Comms, preferably before leaving the scene, if the medical facility is not a major trauma hospital.
- Personnel in the receiving medical facility must be notified as soon as possible, preferably before leaving the scene.

Severe traumatic brain injury (TBI)

- Most patients with severe TBI do not require urgent neurosurgery. However, patients with any of the following clinical features have a high probability of requiring urgent neurosurgery and/or neuro-intensive care and should be transported to Waikato Hospital (if 2 years of age or older), or Starship Children's Hospital (less than under 2 years of age) whenever it is feasible and safe to do so:
  - Intubated and ventilated **or**
  - Lateralising neurological signs, for example unilateral pupil dilatation or unilateral weakness **or**
  - Clinically obvious penetrating brain injury.
- Personnel should seek clinical advice if transport to Waikato Hospital or Starship Children's Hospital will involve a prolonged flight, particularly if the patient is not intubated and ventilated.

Complex multi-system trauma

- Complex multi-system trauma cannot be tightly defined, and clinical judgement is required, but includes patients with major trauma involving very severe injuries to more than one body region.
- Patients with complex multi-system trauma should be transported to Waikato Hospital, provided this is feasible and safe.
- Patients with complex multi-system trauma in the Tairawhiti Area will only be transported to Gisborne Hospital by road. All patients with complex multi-system trauma in the Tairawhiti Area being transported by helicopter will be transported to Waikato Hospital provided it is feasible and safe to do so.
- Personnel should have a low threshold for seeking clinical advice if transport to Waikato Hospital will involve a prolonged flight.

Burns

- Patients with burn injury should be transported to Waikato Hospital in the following circumstances whenever it is feasible and safe to do so:
  - Burns of greater than 10% TBSA in an adult or 5% in a child.
  - Burns involving the airway.
- Burns involving the face, hands or genitals may require treatment at Waikato Hospital, however, treatment is not usually time sensitive and the patient should usually be transported to the most appropriate secondary hospital and be subsequently transferred if required.

Appendix 4: New Zealand out-of-hospital major trauma destination policy—Lower North Island area

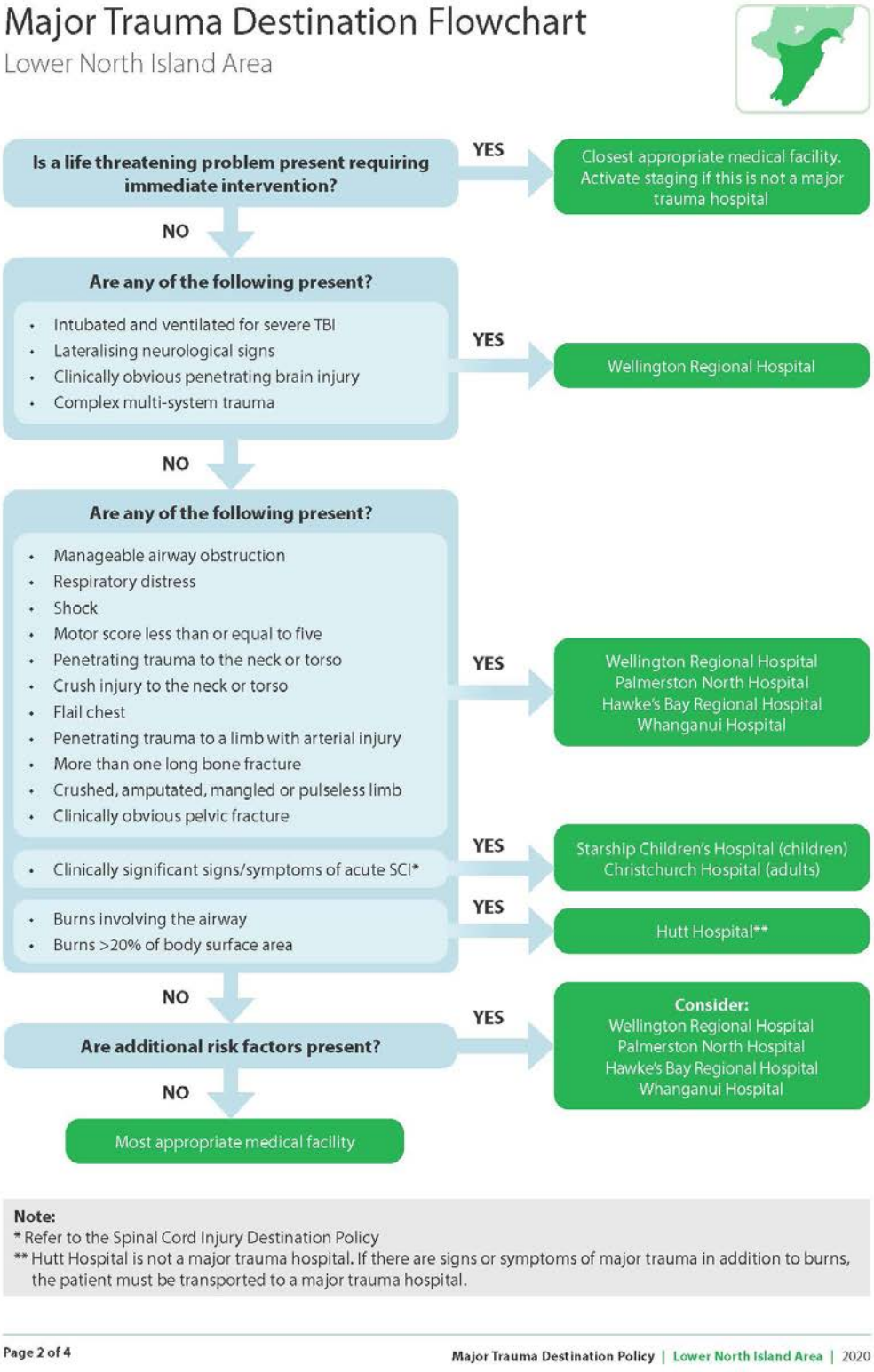
New Zealand Out-of-Hospital Major Trauma Destination Policy

Lower North Island Area

This document is for the use of clinical personnel when determining the destination hospital for patients with major trauma in the out-of-hospital setting in the Lower North Island Area of New Zealand. It has been developed by the Central Regional Major Trauma Network in conjunction with the National Major Trauma Clinical Network and the Ambulance Sector.

Publication date October 2020

Appendix 4 (continued): New Zealand out-of-hospital major trauma destination policy—Lower North Island area



Appendix 4 (continued): New Zealand out-of-hospital major trauma destination policy—Lower North Island area

Major Trauma Destination Policy: Lower North Island Area

Additional Information

Introduction

- This policy is for the use of personnel in the out-of-hospital setting, when determining the transport destination for patients with major trauma in the Lower North Island Area of New Zealand.
- It should be read in conjunction with the New Zealand Out-of-Hospital Major Trauma Triage Policy, the National Major Trauma Network Staging Guidelines, the New Zealand Spinal Cord Injury Destination Policy and the Ambulance Sector Clinical Procedures and Guidelines (CPGs).
- The goal of this policy is to ensure that patients with major trauma are transported directly to the most appropriate major trauma hospital, whenever it is feasible and safe to do so.

Major trauma hospitals

- The following hospitals are designated to receive patients with major trauma:
  - Hawke's Bay Regional Hospital.
  - Whanganui Hospital.
  - Palmerston North Hospital.
  - Wellington Regional Hospital.
- Wellington Regional Hospital is the tertiary major trauma hospital.

Determining the most appropriate major trauma hospital

- The flowchart describes the preferred major trauma hospital/s, based on the best descriptor of the patient's clinical condition.
- The patient should be transported to the preferred major trauma hospital as described in the flowchart, whenever it is feasible and safe to do so.
- If it is not feasible or safe to transport the patient to the preferred major trauma hospital or more than one major trauma hospital is listed as an option, the patient should be transported to the most appropriate major trauma hospital. This will usually be the nearest major trauma hospital, but it may be appropriate to transport the patient to another major trauma hospital if that hospital has the most appropriate facilities to meet the patient's needs.
- Personnel will determine the most appropriate major trauma hospital taking into account all of the following:
  - The information within this policy.
  - The patient's expected treatment requirements.
  - The transport time to the relevant hospitals.
- Personnel should have a low threshold for seeking clinical advice if the transport time to the chosen major trauma hospital is significantly longer (this is not defined and requires clinical judgement) than the transport time to the nearest major trauma hospital.

Appendix 4 (continued): New Zealand out-of-hospital major trauma destination policy—Lower North Island area

Life threatening problems requiring immediate intervention

- Transport the patient to the closest appropriate medical facility if the patient has a life-threatening problem requiring immediate intervention that cannot be provided by personnel at the scene.
- The decision to transport a patient with a life-threatening problem to a medical facility that is not a major trauma hospital requires clinical judgement and personnel must have a low threshold for seeking clinical advice. The decision should take into account the nature of the patient's injuries, the rate of deterioration, the relative proximity of the medical facilities and the personnel available at the medical facility.
- Staging must be activated via Comms, preferably before leaving the scene, if the medical facility is not a major trauma hospital.
- Personnel in the receiving medical facility must be notified as soon as possible, preferably before leaving the scene.

Severe traumatic brain injury (TBI)

- Most patients with severe TBI do not require urgent neurosurgery. However, patients with any of the following clinical features have a high probability of requiring urgent neurosurgery and/or neuro-intensive care and should be transported to Wellington Regional Hospital whenever it is feasible and safe to do so:
  - Intubated and ventilated **or**
  - Lateralising neurological signs, for example unilateral pupil dilatation or unilateral weakness **or**
  - Clinically obvious penetrating brain injury.
- Personnel should have a low threshold for seeking clinical advice if transport to Wellington Regional Hospital will involve a long flight, particularly if the patient is not intubated and ventilated.

Complex multi-system trauma

- Complex multi-system trauma cannot be tightly defined and clinical judgement is required, but includes patients with major trauma involving very severe injuries to more than one body region.
- Patients with complex multi-system trauma will usually benefit from transport to Wellington Regional Hospital, provided this is feasible and safe.
- Personnel should have a low threshold for seeking clinical advice if transport to Wellington Regional Hospital will involve a prolonged flight.

Burns

- Patients with a burn injury of greater than 20% of TBSA or burns involving the airway should be transported to Hutt Hospital, if feasible and safe. Hutt Hospital is not a major trauma hospital and if there are signs or symptoms of major trauma in addition to the burn injury, the patient must be transported to a major trauma hospital.
- Patients with a burn injury greater than 10% of TBSA in an adult or greater than 5% of TBSA in a child should be transported to Hutt Hospital or to a hospital with surgical facilities.
- Burns involving the face, hands or genitals may require treatment in a regional burn centre. However, provided the burn injury is less than 10% of TBSA in an adult or less than 5% of TBSA in a child, treatment is not usually time sensitive and the patient should usually be transported to the most appropriate hospital, and subsequently transferred if required.

Appendix 5: New Zealand out-of-hospital major trauma destination policy—South Island

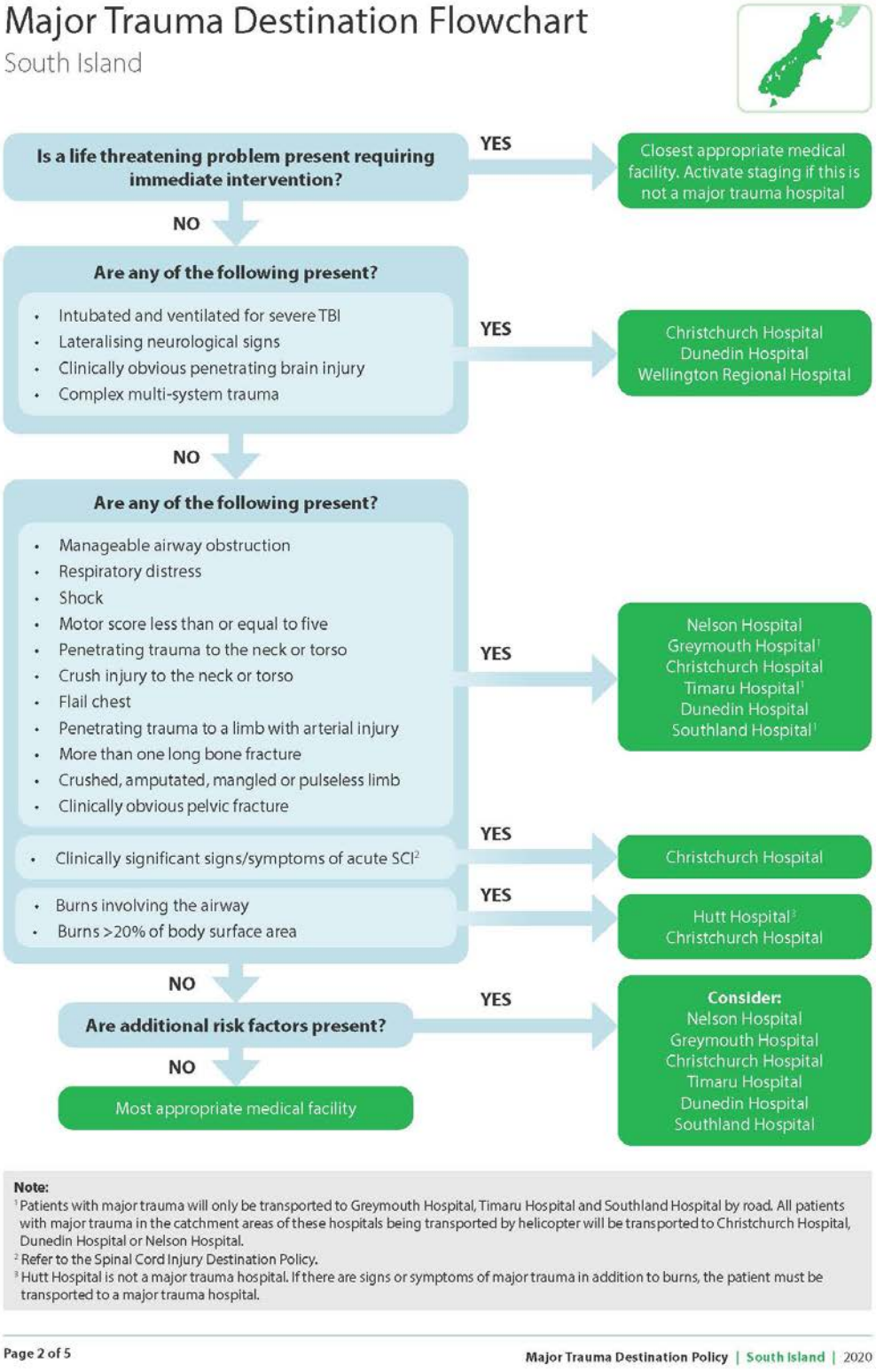
New Zealand Out-of-Hospital Major Trauma Destination Policy

South Island

This document is for the use of clinical personnel when determining the destination hospital for patients with major trauma in the out-of-hospital setting in the South Island of New Zealand. It has been developed by the South Island Trauma Workstream in conjunction with the National Major Trauma Clinical Network and the Ambulance Sector.

Publication date October 2020

Appendix 5 (continued): New Zealand out-of-hospital major trauma destination policy—South Island



Appendix 5 (continued): New Zealand out-of-hospital major trauma destination policy—South Island

Major Trauma Destination Policy: South Island

Additional Information

Introduction

- This policy is for the use of personnel in the out-of-hospital setting, when determining the transport destination for patients with major trauma in the South Island of New Zealand.
- It should be read in conjunction with the New Zealand Out-of-Hospital Major Trauma Triage Policy, the National Major Trauma Network Staging Guidelines, the New Zealand Spinal Cord Injury Destination Policy and the Ambulance Sector Clinical Procedures and Guidelines (CPGs).
- The goal of this policy is to ensure that patients with major trauma are transported directly to the most appropriate major trauma hospital, whenever it is feasible and safe to do so.

Major trauma hospitals

- The following hospitals are designated to receive patients with major trauma:
  - Nelson Hospital.
  - Greymouth Hospital[1].
  - Christchurch Hospital.
  - Timaru Hospital[1].
  - Dunedin Hospital.
  - Southland Hospital[1].
  - Wellington Regional Hospital.

  [1]**Note:** patients with major trauma will only be transported to Greymouth Hospital, Timaru Hospital and Southland Hospital by road. All patients with major trauma in the catchment areas of these hospitals being transported by helicopter will be transported to Christchurch Hospital, Dunedin Hospital or Nelson Hospital, provided it is feasible and safe to do so.
- The following hospitals are tertiary major trauma hospitals:
  - Christchurch Hospital.
  - Dunedin Hospital.
  - Wellington Regional Hospital.

Determining the most appropriate major trauma hospital

- The flowchart describes the preferred major trauma hospital/s, based on the best descriptor of the patient's clinical condition.
- The patient should be transported to the preferred major trauma hospital as described in the flowchart, whenever it is feasible and safe to do so.
- If it is not feasible or safe to transport the patient to the preferred major trauma hospital or more than one major trauma hospital is listed as an option, the patient should be transported to the most appropriate major trauma hospital. This will usually be the nearest major trauma hospital, but it may be appropriate to transport the patient to another major trauma hospital if that hospital has the most appropriate facilities to meet the patient's needs.

Appendix 5 (continued): New Zealand out-of-hospital major trauma destination policy—South Island

- Personnel will determine the most appropriate major trauma hospital taking into account all of the following:
  - The information within this policy.
  - The patient's expected treatment requirements.
  - The transport time to the relevant hospitals.
- Personnel should have a low threshold for seeking clinical advice if the transport time to the chosen major trauma hospital is significantly longer (this is not defined and requires clinical judgement) than the transport time to the nearest major trauma hospital.

Life threatening problems requiring immediate medical intervention

- Transport the patient to the closest appropriate medical facility if the patient has a life-threatening problem requiring immediate intervention that cannot be provided by personnel at the scene.
- The decision to transport a patient with a life-threatening problem to a medical facility that is not a major trauma hospital requires clinical judgement and must have a low threshold for seeking clinical advice. The decision should take into account the nature of the patient's injuries, the rate of deterioration, the relative proximity of the medical facilities and the personnel available at the medical facility.
- Staging must be activated via Comms, preferably before leaving the scene, if the medical facility is not a major trauma hospital.
- Personnel in the receiving medical facility must be notified as soon as possible, preferably before leaving the scene.

Severe traumatic brain injury (TBI)

- Most patients with severe TBI do not require urgent neurosurgery. However, patients with any of the following clinical features have a high probability of requiring urgent neurosurgery and/or neuro-intensive care and should be transported to Christchurch Hospital, Dunedin Hospital or Wellington Regional Hospital whenever it is feasible and safe to do so:
  - Intubated and ventilated **or**
  - Lateralising neurological signs, for example unilateral pupil dilatation or unilateral weakness **or**
  - Clinically obvious penetrating brain injury.
- Personnel should have a low threshold for seeking clinical advice if transport to Christchurch Hospital, Dunedin Hospital or Wellington Regional Hospital will involve a long flight, particularly if the patient is not intubated and ventilated.

Complex multi-system trauma

- Complex multi-system trauma cannot be tightly defined and clinical judgement is required, but includes patients with major trauma involving very severe injuries to more than one body region.
- Patients with complex multi-system trauma will usually benefit from transport to Christchurch Hospital, Dunedin Hospital or Wellington Regional Hospital, provided this is feasible and safe.
- Personnel should seek clinical advice prior to commencing transport, if transport to Christchurch Hospital, Dunedin Hospital or Wellington Regional Hospital will involve a prolonged flight.

Appendix 5 (continued): New Zealand out-of-hospital major trauma destination policy—South Island

Burns

- Patients with a burn injury of greater than 20% of TBSA or burns involving the airway should be transported to Christchurch Hospital or Hutt Hospital, if feasible and safe. Hutt Hospital is not a major trauma hospital and if there are signs or symptoms of major trauma in addition to the burn injury, the patient must be transported to a major trauma hospital.
- Patients with a burn injury greater than 10% of TBSA in an adult or greater than 5% of TBSA in a child should be transported to Christchurch Hospital or Hutt Hospital, or to a hospital with surgical facilities.
- Burns involving the face, hands or genitals may require treatment in a regional burn centre. However, provided the burn injury is less than 10% of TBSA in an adult or less than 5% of TBSA in a child, treatment is not usually time sensitive and the patient should usually be transported to the most appropriate hospital, and subsequently transferred if required.

Major trauma hospitals outside the South Island

- It may be occasionally appropriate for the patient to be flown to a hospital outside the South Island. For example, in the northern aspect of the South Island it may be appropriate for the patient to be flown to:
  - Wellington Regional Hospital if the patient has severe TBI or complex multi-system trauma or
  - Hutt Hospital if the patient has burn injury greater than 20% of TBSA or burns involving the airway.
- Personnel should have a low threshold for seeking clinical advice if a patient is being flown outside the South Island.

Intravitreal therapy in neovascular age-related macular degeneration—adapting to increasing demand and changing times

Brandon Nunns, Vidit Singh, John Ah-Chan

ABSTRACT

AIMS: To report the outcomes of patients with neovascular age-related macular degeneration (nAMD) at Palmerston North Eye Clinic (PNEC) during 2020 and 2021, comparing time to treatment initiation based on nurse-injector availability and during COVID-19 restrictions.

METHODS: Data were recorded from a prospective database for patients with nAMD at PNEC. Each patient's electronic health record was reviewed to ensure the accuracy of the database and to fill in missing data points. Statistics were done using Microsoft Excel and R.

RESULTS: One hundred and fifty-six eyes were diagnosed with nAMD during the study. Mean time from referral triage to first injection was 13.08 days across the study period. Time to treatment initiation was not statistically different by level of COVID-19 restriction but there was a significant difference in first specialist appointment to injection interval when three nurse-injectors were available compared to four. The effect seemed most evident in subsequent months after reduced nurse-injector availability began.

CONCLUSIONS: Despite an increase in nAMD diagnoses each year, PNEC continues to meet national guidelines for interval from referral to treatment initiation through innovations in practice. As demand for intravitreal injections continues to increase, further resourcing and research into newer agents will be required to keep wait times compliant with guidelines.

Age-related macular degeneration (AMD) is the leading cause of visual impairment in older adults in developed countries, including New Zealand.[1,2] Neovascular AMD (nAMD) represents a subset of AMD that can cause rapid and irreversible vision loss if untreated due to macular neovascularisation and subsequent macular scarring.[1] Since their approval in the early 2000s, intravitreal injections of anti-vascular endothelial growth factor (VEGF) have become the mainstay of therapy for patients with nAMD.[3] These agents oppose the effects of VEGF and have been found to improve and stabilise vision in nAMD.[3] Patients typically complete an induction sequence of three injections spaced 4 weeks apart, followed by repeat injections at fixed intervals or by a "*pro re nata*" (PRN) or "treat and extend" protocol to sustain the benefits achieved during induction.[1] Commonly used anti-VEGF agents in Palmerston North Eye Clinic (PNEC) include bevacizumab (Avastin®) and aflibercept (Eylea®).

The ongoing need for anti-VEGF therapy following induction has caused a substantial increase in workload for ophthalmology services world-wide.[4] PNEC is no exception to this, with a previous audit demonstrating a 32.6% increase in injections for those diagnosed with nAMD between 2018 and 2019.[5] Despite this, PNEC has not had any increase in medical staff. The demand for intravitreal injections is expected to continue rising with the increasing prevalence of AMD due to the ageing population.[2] The MidCentral Region will likely be disproportionately affected as existing population data show that 18.9% of people are aged over 65 years in MidCentral compared to the national average of 16.5%.[6]

To cope with increasing demand for intravitreal injections, ophthalmology services began training senior nurses to deliver injections as this has been shown to be an effective and safe practice.[7] At PNEC, this role has been expanded to include nurse-led "hybrid clinics", where patients with stable nAMD receive an intravitreal injection from a nurse-injector and have optical coherence tomography (OCT) and fundus photographs taken on the same day. These are reviewed by extended-practice registered nurses to determine appropriate timing of the next injection according to a standard treat and extend protocol. By reducing the number of patients with stable nAMD requiring consultant ophthalmologist review, clinic time can be reallocated to first specialist appointments

(FSA), reducing waiting times for new referrals. A 2019 study at PNEC showed an average time of 14.3 days from referral triage to first injection.[5] This almost achieves the Royal Australian and New Zealand College of Ophthalmologists (RANZCO) recommendation that patients with suspected nAMD are assessed within 1 week of referral and initiate treatment within 1 week following initial assessment.[8]

In recent years, the COVID-19 pandemic has posed major barriers to the delivery of healthcare services due to institutional policies to reduce the number of patients attending hospital, and self-imposed behaviours of the public to limit their exposure to the virus.[9] Many ophthalmology clinics reported fewer referrals and a rise in missed appointments during the pandemic.[9] This was expected to result in delayed treatment initiation and worse visual outcomes.[9]

The aim of this paper is to report the outcome of patients with nAMD at PNEC over the preceding 2 years. The primary outcome is the time from referral triage to first injection, to determine if PNEC is meeting the RANZCO guidelines. The time from triage referral to first injection will be compared by level of COVID-19 restriction and number of available nurse-injectors. Secondary outcomes include the change in visual acuity (VA), total number of intravitreal injections received and the final injection interval at 18 months from diagnosis.

Methods

In 2017, a prospective database of patients with nAMD was developed by PNEC. Details of each patient's treatment and visual outcomes are recorded in the database, either by a nurse or ophthalmologist, following each appointment. This study used the database to identify patients with a new diagnosis of nAMD in 2020 and 2021. Data on the number and type of intravitreal injections received, as well as VA at 6, 12 and 18 months after diagnosis, were collected. Ophthalmology clinic notes from each patient's electronic health record were reviewed to validate the accuracy of the data and identify the interval between referral triage, FSA and first intravitreal injection.

The study period of 2020 and 2021 was chosen as it reflects the period of peak disruption to healthcare services by COVID-19. The Mid-Central District Health Board (DHB) was under COVID-19 Level 3 and 4 restrictions between 23 March 2020–11 May 2020 and 17 August 2021–6 September 2021. Nurse-injector availability was as follows: Four injectors were available from January 2020 to September 2020 and from October 2021 until the end of the study period. There were three injectors between April 2021 and September 2021, two injectors between September 2020 and March 2021 and one injector in the month of March 2021.

Data are presented as proportions and summary counts. Statistical analysis utilised Microsoft Excel and R.[10,11] Comparison between groups utilised Mann–Whitney and Kruskal–Wallis tests. Confidence intervals (CI) were constructed using the Hodges–Lehmann estimator (HLE). P-values <0.05 were considered significant. Eyes from the same patient were treated independently during analysis. The triage to injection interval could not be determined in eight eyes due to an unknown referral triage date. Two eyes were referred for cataracts and one patient initially declined treatment, and so were not included in the analysis of triage to injection time. The FSA to injection interval was determined and is reported in all cases except for the patient who initially declined treatment. This study is a continuation of previously published work by Yap et al. and received locality approval from MidCentral DHB.[5]

Results

Patient characteristics

A total of 156 eyes from 135 unique patients were diagnosed with nAMD during the study period. Sixty-five eyes were diagnosed in 2020, compared with 91 eyes in 2021. The mean age in years at diagnosis in males was 80.3 (SD 8.2), in females was 80.6 (SD 7.9) and overall was 80.5 (SD 8.0). Other patient characteristics are reported in Table 1.

Injections and intervals

The mean time in days from referral triage to FSA (N=146) was 10.76 (SD 12.68) and from FSA to first injection (N=155) was 2.48 (SD 5.93), with 116 (74%) eyes receiving their first injection on the same day as FSA. The mean time in days from triage to first injection was 11.67 (SD 12.30) in 2020 (N=60) and 14.07 (SD 15.66) in 2021 (N=85), with an overall (N=145) mean of 13.08 (SD 14.37) across the study. Forty-eight (31%) eyes had an interval greater than 14 days between triage and first injection. The mean and median time from referral triage to first injection, and FSA to first injection by month of diagnosis, are displayed in

Table 1: Characteristics of patients diagnosed with nAMD at PNEC in 2020 and 2021 (N=135).

Characteristic	Number of patients, N/135 (%)
Sex	
Males	66 (49)
Females	69 (51)
Ethnicity	
NZ European	128 (95)
NZ Māori	2 (1)
Pacific	2 (1)
Other	3 (2)

Figure 1: Jitter plot with mean (blue) and median (yellow) time between referral triage and first intravitreal injection (N=145). The dashed line is at 14 days. The blue rectangles represent the timing of COVID-19 Level 3 and 4 restrictions affecting MidCentral DHB. The coloured bars indicate the number of nurse-injectors available at each time period.

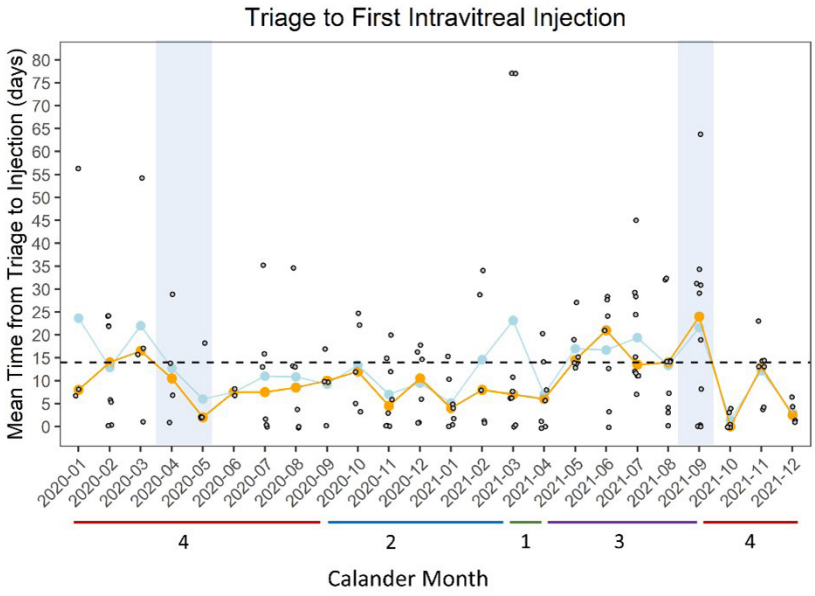


Figure 1 and 2 respectively.

The intervals from referral triage to first injection and FSA to first injection during and outside of COVID-19 restrictions are displayed in Table 2. There was no statistically significant difference in triage to first injection or FSA to first injection by level of COVID-19 restriction ($p>0.05$).

Table 3 displays the mean and median time from referral triage to first injection compared to the number of nurse-injectors. A statistically significant difference in FSA to injection interval by nurse-injector availability was noted ($p=0.005$). Further analysis with pairwise Mann–Whitney tests demonstrated this was due to a difference in FSA to injection time when three nurse-injectors were available compared to four ($p=0.0003$, HLE=$4.21e^{-5}$, 95% CI $6.69e^{-5}$–$2.57e^{-5}$).

Figure 2: Jitter plot with mean (blue) and median (yellow) time between FSA and first intravitreal injection (N=155). The blue rectangles represent the timing of COVID-19 Level 3 and 4 restrictions affecting MidCentral DHB. The coloured bars indicate the number of nurse-injectors available at each time period.

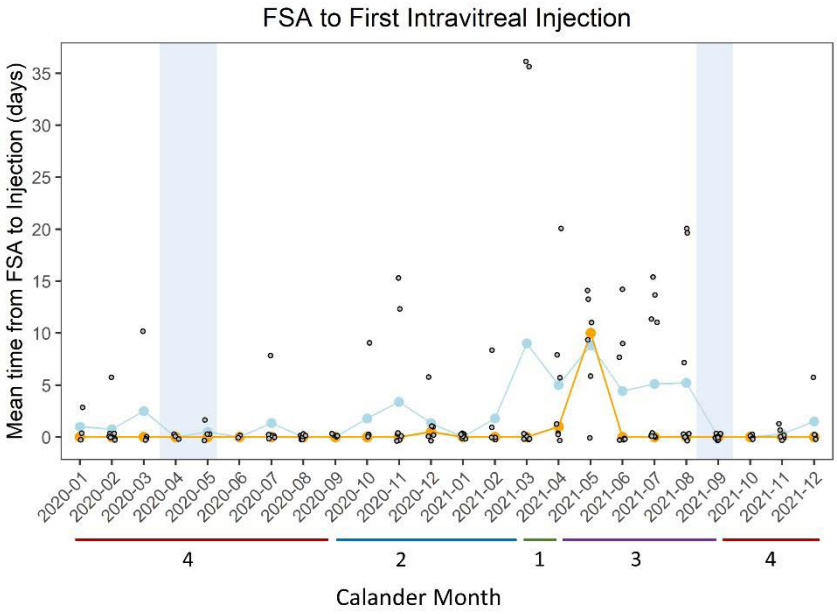


Table 2: Mean and median time in days from referral triage and FSA to first intravitreal injection during and outside of COVID-19 Level 3 and 4 restrictions.

Time period	N	Mean (SD)	Median	HLE	95% CI	P-value*
Referral triage to first injection						
During COVID-19 restrictions	6	13.33 (13.13)	10.5	4.84e-5	-9.0–13.0	0.86
Outside COVID-19 restrictions	139	13.06 (14.46)	10.0			
FSA to first injection						
During COVID-19 restrictions	6	0 (0)	0	0	-7.12e-5–0	0.15
Outside COVID-19 restrictions	149	2.58 (6.03)	0			

*P-value calculated by Mann–Whitney test.
FSA = first specialist appointment; HLE = Hoges-Lehmann estimate; CI = confidence interval, calculated by the Hodges-Lehmann estimator.

In 2020, 65 eyes were diagnosed with nAMD compared to 91 eyes in 2021. In the first 6 months of treatment, eyes diagnosed with nAMD in 2020 (N=65) received a total of 315 injections while those diagnosed in 2021 (N=91) received 419 injections. After 18 months, eyes diagnosed with nAMD in 2020 had received a total of 627 injections while those diagnosed in 2021 had received 876 injections. The mean final injection interval for eyes still receiving treatment after 18 months (N=111) was 8.8 (SD 4.1) weeks.

Following the 18-month treatment period, 111 eyes were still receiving injections. Of the 45 eyes not receiving treatment, 26 had end-stage disease, nine were in patients that declined ongoing treatment, six were in patients that had died, three were in patients lost to follow-up and one was treated with a PRN protocol and had a dry macula not requiring treatment.

Table 3: Mean and median time in days from referral triage and FSA to first injection based on the number of available nurse-injectors.

Number of available nurse-injectors	N	Mean (SD)	Median	P-value*
Referral triage to first injection				
1 Nurse-injector	8	23.13 (33.46)	7	0.06
2 Nurse-injectors	35	9.31 (9.12)	6	
3 Nurse-injectors	49	16.29 (13.32)	14	
4 Nurse-injectors	53	11.08 (12.81)	7	
FSA to first injection				
1 Nurse-injector	8	9.00 (16.66)	0	0.005
2 Nurse-injector	37	1.54 (3.66)	0	
3 Nurse-injector	50	4.36 (6.40)	0	
4 Nurse-injector	60	0.62 (1.97)	0	

*P-values calculated by the Kruskal–Wallis test.
FSA = first specialist appointment.

Table 4: Median VA in LogMAR across the study period based on triage to first injection interval.

Triage to injection	N	Initial VA median (IQR)	Final VA median (IQR)
Fewer than 14 days	88	0.61 (0.36)	0.54 (0.54)
14–28 days	39	0.60 (0.45)	0.60 (0.57)
More than 28 days	18	0.65 (0.47)	0.60 (0.65)

VA = visual acuity; IQR = interquartile range.

Table 5: Visual outcomes of patients diagnosed with nAMD in 2020 and 2021.

Outcome measure	2020, N/65 (%)	2021, N/91 (%)
Eyes with stabilisation or improvement in visual acuity	55 (85)	72 (79)
Eyes with improvement in visual acuity	8 (12)	22 (24)

During the study, 50 eyes switched from Avastin® to Eylea®. The mean number of injections before switching to Eylea® was 6.75 (SD 3.08). The mean final injection interval in weeks was 10.45 (SD 4.12) for those treated with Avastin® (N=66) and 6.26 (SD 2.57) for those treated with Eylea® (N=45).

Visual acuity

The median (IQR) initial and final VA based on triage to injection time is summarised in Table 4.

The number and percentage of eyes achieving stabilisation and improvement in VA is displayed in Table 5. At 18 months, 37 (24%) eyes met the monocular driving standard (N=156), with 66

(49%) patients meeting the binocular driving standard (N=135).

Discussion

Across the study period, we observed an increase in the number of eyes diagnosed with nAMD by 40% from 65 eyes in 2020 to 91 eyes in 2021, which is a continued increase compared to a previous PNEC study with 57 and 44 diagnoses of nAMD in 2018 and 2019 respectively.[5] The 50% increase in incidence between studies is consistent with the expected rise in cases with the ageing population.[2] Similarly, the number of administered injections increased by 39.7% from 627 in 2020 to 876 in 2021, which represents a substantial increase in the workload of PNEC. Despite the increased workload, PNEC achieved a mean time between triage and first injection of 13.08 days, which meets the RANZCO guideline of treatment initiation within 14 days.[8] This result compares favourably to findings in other healthcare systems, including the large National Ophthalmology Database (NOD) audit conducted in the United Kingdom in which only one-quarter of patients received treatment within 14 days of referral.[12]

Most patients were of NZ European ethnicity, with only two patients of NZ Māori ethnicity. This is lower than expected based on the Māori population size in Palmerston North but is consistent with the reported low prevalence of AMD in Māori and high prevalence in Europeans.[2,13] Barriers to accessing healthcare for Māori may also be implicated, though further studies would be required to assess this.

The increasing incidence of AMD has made it necessary to develop new strategies to keep wait times compliant with the RANZCO guidelines. This has been aided by the widespread adoption of the treat and extend protocol over the PRN protocol for intravitreal injections. The treat and extend protocol involves an injection at every visit, meaning the number of injections for each clinic is predictable and clinic resources can be prepared in a way the PRN protocol does not allow. PNEC's nurse-led hybrid clinics represent a unique integration of systems to streamline patient workflow by having imaging and injections on the same day, which extended-practice registered nurses review to determine subsequent treatment intervals by a treat and extend algorithm, with remote support available if needed. This allows more time for ophthalmologists to see new patients, reducing the time between referral triage and injection.

The majority of time between referral triage and first injection consisted of wait time for the FSA, as increasing numbers of patients received their first injection on the same day as their FSA by available nurse-injectors. Although there was no statistically significant relationship between triage to first injection and fewer nurse-injectors, there appeared to be a delayed effect in subsequent months that likely corresponded to the accumulation of patients created by the lack of same-day nurse-injector availability. The time from triage to injection returned within RANZCO guidelines once available nurse-injectors were sustained at an adequate level and the backlog was cleared. The increase in wait times appeared to disproportionately affect the time from FSA to first injection, with a statistically significant difference noted when three nurse-injectors were available compared to four, although the effect size appears to be small. This observation is likely because, in the absence of nurse-injectors, medical staff were unable to perform same-day injections during busy clinics. In addition to reducing wait times, nurse-injectors helped achieve other goals including fewer clinic visits for patients as injections are received during follow-up clinics, and less time for the administration components of organising clinics. This had the added environmental benefit of reducing patient travel-related carbon emissions, which is the largest contributor to emissions associated with intravitreal injections.[14] As the demand for intravitreal injections continues to increase, more resourcing will be important, particularly for injections and patient reviews at satellite clinics, helping to maintain acceptable wait times while also reducing inequity and travel-related emissions.

This study also assessed the impact of COVID-19 on triage to injection times. While there was no statistically significant difference, we observed a modest decrease in wait times during COVID-19 Level 3 and 4 restrictions compared to outside of these restrictions. This likely reflects PNEC's practice during COVID-19 Level 3 and 4 restrictions of deferring non-urgent and semi-urgent appointments to accommodate FSA for those with urgent or sight-threatening conditions, including suspected nAMD, to facilitate prompt treatment, which is important considering the morbidity associated with undiagnosed and untreated nAMD.[1] However, there were only six diagnoses of nAMD during COVID-19 restrictions, which may reflect a reduction in referrals from optometrists and general practitioners from the effect of COVID-19 on their practice, which would

be consistent with other ophthalmology services that reported a reduction in the number of referrals for nAMD.[9]

The median initial VA in LogMAR was similar regardless of triage to injection interval, although eyes with a shorter interval had the most improvement and best VA at the end of the study period. The percentage of eyes achieving an improvement in VA increased from 12% in 2020 to 24% in 2021. These are comparable figures to a previous PNEC study that demonstrated an improved VA in 10.5% and 31.8% of patients in 2018 and 2019 respectively.[5] The treatment of nAMD has not significantly changed during these periods, therefore we would not expect significant variability in outcomes—but, considering the increased demand for treatment, it is promising to see comparable outcomes to previous studies. We also observed stability of VA in 85% of eyes in 2020 and 79% of eyes in 2021 compared to the previous PNEC study that reported stability in 82.5% and 93.2% in 2018 and 2019 respectively.[5] These results are also comparable to the aforementioned NOD audit, suggesting PNEC is achieving similar visual outcomes to other developed countries.[12]

About half of patients maintained binocular VA meeting the NZ driving standard, which is slightly lower than the previous PNEC study that reported 58.3% and 62.5% of patients meeting the driving standard in 2018 and 2019 respectively.[5] This compares to the NOD audit that reported 40% of patients meeting the driving standard after 1 year.[12] Maintenance of driving standard vision is particularly important for the quality of life and independence of older adults, making it an important measure of vision to report.[15]

Eyes treated with Eylea® had a shorter interval between injections compared to those treated with Avastin®, despite the results of previous literature including the VIEW trial, which demonstrated non-inferior outcomes with Eylea® at larger intervals compared to the anti-VEGF agent ranibizumab—an agent demonstrated to be similar to Avastin®.[16,17] Our finding likely reflects more severe nAMD in those treated with Eylea® since eligibility criteria restrict its use to eyes with resistance to Avastin® following the induction series, and those that also have no structural damage to the fovea, among other criteria.[18] If access criteria to Eylea® were less restrictive, longer treatment intervals would likely be achieved. A newer intravitreal agent, faricimab, inhibits VEGF in addition to angiopoietin-2, another important molecule in angiogenesis and the pathogenesis of nAMD.[19] Faricimab has been shown to yield comparable outcomes at 12- and 16-week injection intervals compared to 4-weekly injections of ranibizumab.[20] Faricimab is not yet available in New Zealand, but, if introduced, may enable longer treatment intervals to be achieved. This could help alleviate the burden of frequent injections on patients and ophthalmology clinics and in turn improve wait times between referrals and treatment initiation.

The PNEC prospective database of individuals with nAMD is a useful tool to audit clinical practice and patient outcomes, but there is variability in the completeness of data since it relies on manual input. The lack of automation in data entry and the busy clinical environment meant it was necessary for each patient's electronic health record to be reviewed to fill in missing data points and ensure the quality of the data already within the database.

Another limitation of this study is the sample size in each of the groups being compared. Only six eyes were diagnosed with nAMD during COVID-19 restrictions, limiting the ability of our study to detect a statistically significant difference if one exists. This limitation also occurred when comparing intervals by nurse-injector availability as each subgroup has a reduced number of eyes.

This study is also limited by the definition of improvement and stability in VA. An improvement in VA is defined as an increase of 15 letters, while stability is defined as a loss of fewer than 15 letters.[21] This becomes a limitation at the extremes of VA, since those with good VA do not have a significant scope to improve their VA further, while those with poor VA are unable to lose 15 letters simply because of their starting acuity. These phenomena are termed the ceiling and floor effect respectively and are observed in other studies using these definitions.[21] We have reported the median for VA data to give a fairer representation of VA since it is less affected by eyes with extremes of VA.

The increasing demand for intravitreal injections to treat nAMD represents a significant increase in workload for ophthalmology services. The introduction of nurse-led injections and extended-practice nurse hybrid clinics has been instrumental in managing this demand at PNEC, especially considering the absence of increased funding for recruitment of ophthalmologists. As research into anti-VEGF and other agents increases, longer injection intervals may be achievable, which will help keep services compliant with RANZCO guidelines while reducing the treatment burden for patients and ophthalmology clinics.

COMPETING INTERESTS
Nil.

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Dying with and of dementia

Sandy Macleod

ABSTRACT

AIM: With an ageing population the prevalence of dementia increases. A healthcare crisis is looming.

METHOD: Dementia is a terminal condition. The latter, end-of-life phase of this disorder can be very challenging to manage. Patients, whānau and staff may struggle.

RESULTS: Clinical recognition of this phase may be difficult. Determining the appropriateness of medical interventions or palliation, likewise. The clinical load on the acute public hospital services is unbearable. The resources in the aged residential care services are limited.

CONCLUSIONS: A pragmatic and reasoned palliative approach by all professionals in the area is advocated.

Dementia is a progressive, life-limiting syndrome. The quality of life appears to slowly erode over time. Present figures reveal that 70,000 New Zealanders experience dementia/mate wareware.[1] The commendable public health endeavours to support and encourage an active and healthy older age lifestyle for those in the early and middle stages of a dementing condition, the expertise of older persons nursing and medical care and modern pharmacology may all improve the quality of remaining life, and even impede disease progression. Yet dying comfortably, peacefully and with dignity in advanced dementia is often not the eventual outcome of this, as yet, incurable disease.

Age is the major risk factor for dementia. With extra years come a deterioration of general health and an increase of disability, including neurodegenerative disorders such as dementia.[2] The influence of emerging parkinsonian Lewy Body-type dementias, the aged community's epidemic consumption of alcohol, and diabetic and cerebrovascular cerebral damage consequent to improved longevity because of modern management will further tax clinicians of the elderly with troublesome new challenges. If disease-modifying treatments are developed, their actions will likely be to delay neurodegenerative progression, and thereby improve the quality of life during the early and middle stages, though they will risk protracting and complicating the latter phases. The median survival time from symptom onset of dementia to death may be as little as 4–5 years, depending upon sub-type, stage of diagnosis and standard of care.[3] The median survival time in the advanced stages is 1.3 years, similar to that of, for example, metastatic breast cancer.[4] As to when the last year of life begins is difficult, indeed impossible, to determine accurately.[5] It is predicted that one in three people aged greater than 65 years will die with, or from, dementia.[3] About half of these people will die with moderate-stage dementia from comorbid cardiovascular, oncological and other systemic diseases; a quarter will die of severe dementia.[6] Around 70% of people with dementia have at least two comorbid chronic diseases, and the management and course of these conditions is often compromised by deteriorating cognition.[6] Most persons with dementia will die in hospital or residential care.[7] The usual drivers of dementia requiring institutional care are those of older age, medical frailty, severe behavioural symptoms and carer burden.[7] The tight health budgets of the currently stretched public health system will soon become inadequate to provide an acceptable standard of care for those with advanced dementia. In addition, there is limited availability of skilled carers to provide care for the cognitively infirm. A crisis is looming.

The Myth of Tithonus

Eos lamented that she would outlive her Trojan lover, Tithonus, so she asked Zeus to make him immortal, but she forgot to ask for him to be eternally youthful. Tithonus became daily older, greyer and more shrunken, his voice grew shrill and, when Eos tired of nursing him, she locked him in her bedroom, where he turned into a cicada.[8]

The Greek myth of Tithonus advertises the suffering of persons with dementia and the burden of their care.[8] According to various

interpreters of the myth, Eos did not abandon Tithonus despite her poor standard of care. She turned him into a cicada so no one would fault his mindless chirping and fragile body. After 3,000 years we should be doing better than Eos, but we are not.

The trajectory of dementia is unpredictable. The severity of dementia increases with age, but it can surprise. The journey may involve weeks, months, even years of humiliating revelations of cognitive disability, fading fine motor competency, loss of social skills, uncharacteristic behaviours, social "death" and an increasing dependency upon others. The psychological worries of the early stages of dementia become superseded by behavioural responses if or when confronted by overwhelming cognitive tasks. These include catastrophic reactions, cerebral panic attacks, which may result in physical reactivity—helpless paralytic immobilisation or, at other times, purposeless action including violence towards self and others. There comes a time on this journey when the damage done requires the practical help of others, as Hughlings Jackson's *Doctrine of Dissolution* in 1873 had conceptualised.[9] Difficult-to-manage neuropsychiatric symptoms can be eventually overwhelmed by symptoms of loss, somnolence, physical and mental inactivity (torpor) and apathy, which may paradoxically relieve some carer burden. As brain failure invariably advances the deliriant threshold falls, with recurrent deliria resulting in further brain injury. Personality change, psychoses, anxiety, depression, agitation and aggression can uncharacteristically emerge or be unmasked by the brain injury. Home care can become intolerable and dangerous. Yet glimpses of former self may still occur, such as flashes of humour and moments of reflection of past personal achievements. Tender, loving family reunions can still happen. Family and carers know this, though by the middle stages of this disease they may have had to surrender ongoing care to aged residential care facilities.

Suffering is reasonably assumed, though may be unable to be reported or objectively determined as capacity becomes compromised, then extinguished. The limited literature suggests many, if not most, suffer. One estimate is that nearly two-thirds of hospitalised end-stage dementia patients die with a "high" level of suffering.[10] Yet rarely, if ever, do persons experiencing the apparent indignities of a neurodegenerative disorder comment upon the quality of their existence—it is as if survival instincts and denial behaviours just take over as free will is lost. Witnesses also suffer: only 56% believe their relatives died peacefully of dementia.[11] "Dying of dementia with dignity" may be an aspiration. "*How people die remains in the memory of those who live on*" was reputedly said by Cicely Saunders, the pioneering palliative care exponent. Caring for the sick can be a positive experience but can also lead to high levels of carer burden, anxiety and depression.[12] Partners of people dying with dementia experience poorer health than those facing bereavement from other causes.[13]

Clinically determining when advanced-stage dementia becomes end-stage dementia is uncertain. Objective clinical signs are not well established. The bedside signs of those dying with dementia are conflated by comorbid disorders. If allowed, a typical dementia death involves precipitous loss of mobility, limitation of speech, physical discomfort and musculoskeletal pains, incontinence, debilitating fatigue and somnolence (Table 1). The accumulating effects of anorexia, anosmia, ageusia of ageing, loss of the fine motor skills necessary for independent feeding, dysphagia, unfitness to engage in the social aspects of dining, sarcopenia and, for some, hypermetabolic cachexia may result in irreversible inanition and malnutrition.[14] Minimal energy expenditure, weakness, forgetfulness and diminished hypothalamic perception of thirst and hunger result in decreased renal function and a frail state. Attentive mouth care relieves thirst, if present, but rarely does artificial hydration improve it. Death that typically occurs on average of 10 days after the cessation of nutrition and hydration is not due to starvation or dehydration.[5,15] There is a lack of evidence to support active interventions such as artificial hydration, enteral tube feeding and nutritional supports.[16,17] A loss of the emotion "disgust" leads to rejection of assistance with personal cares, despite overt need. Chemical or infective aspiration pneumonia may require anticholinergic medications or even a brief trial of antibiotics to ease respiratory congestion. An intractable physiological and behavioural determination to self-destruct eventuates and a deteriorating level of consciousness progresses to respiratory and cardiovascular shut-down, likely consequent to brain stem neural death. Usually this is a peaceful process though, if compounded by agitation or delirium, tranquilising medications may be indicated. The cause of death is frequently attributed to cardiac failure and/or pneumonia rather than the primary cause of illness,

Table 1: Indicators of impending end-of-life in neurodegenerative conditions.

• Rapid deterioration of independent and safe ambulatory ability (falls, inability to sit up or hold head up unsupported, ataxia, physical rigidity, immobilisation, primitive reflexes)
• Increasing dependence for personal care (dressing, feeding, bathing, shaving)
• Loss of urinary and faecal continence
• Loss of speech (linguistic regression, limited single intelligible words only, loss of speech)
• Difficulties swallowing (choking, recurrent aspiration pneumoniae)
• Increasing fatigue and drowsiness, torpor (diurnal and nocturnal)
• Loss of appetite and weight >10% (anosmia, inability to feed self, inanition, cachexia)
• Pain (agitation, generalised musculoskeletal pains, contractures)

dementia. Acknowledging diagnostic descriptors such as vital exhaustion, inanition and *genug* (Yiddish/German for "enough")[17] as mortal signs of dementia may more accurately reflect the final stage of dementia.

What could, or should, be the management of terminal dementia? Supportive nursing care is fundamental. Modern medicine can, and often does, offer antibiotics, fluid replacement, tube feeding, resuscitation and clumsy medicinal tranquilisation. But are these interventions instituted with palliative intent or because of clinician ease and procrastination? Procedures risk adverse effects and the inability to reverse aetiology indicates a high likelihood of recurrence. Such treatments may be medically futile. To "cloak" or palliate the associated emotional and physiological distress rather than to medically battle hopelessly and ineffectively is the more appropriate management of advanced dementia states.

Specialist palliative medicine is not a viable solution to the crisis. The specialties of geriatrics, neurology and psychiatry of old age, likewise. The disease time course is long, and the disorder a complex mix of neurological, psychiatric, psychological and physical symptoms. The impending tsunami of cases and resource limitations preclude these options. The role of these specialists will be to attend to the complex cases, usually cases with comorbidities of these respective specialties, to support community practitioners and to contribute to the literature to guide clinical practice. Managing advanced illness is a core component of all medical practice. Yet it features little in training. Most attendees of doctors, particularly the elderly, have chronic and incurable ills requiring supportive care. The fear instilled by modern medical practice is not that of death but of dying tortured by aggressive clinical interventions. Allowing a natural death requires skill and humanity. Managing pain, delirium, dyspnoea, distressed whānau, psychoses, frailties and aggressive outbursts can be challenging for all concerned but is possible and easier in the familiar environment of the person with dementia. Hospital admission for a person with dementia is often harmful, for in addition to it being confusing and disrupting, they have a higher risk of developing iatrogenic complications from polypharmacy, falls and hospital-acquired infections, these halving their survival time compared with those without dementia on admission.[18,19] Admission to acute general hospitals, knowing full well that the best outcome may be an extra few weeks of poor quality life in a psychogeriatric aged care facility, may be a costly exercise in medical futility. Protecting acute public hospitals, allowing them to do what they best do—which is not dementia care—is vital. Aged care facilities need to function as designated and funded, where residents who take ill are treated and taken care of.

Adapting the end-of-life choices legislation is not an option. No just society can contemplate euthanasia for ill persons who are cognitively incompetent. Additionally, because of the possibility of the "disability paradox"—a change of mind when actually experiencing a previously feared condition —acting on advance care directives in neurodegenerative conditions is fraught with

practical and legal uncertainties. It is medico-legally acceptable practice for doctors not to offer active interventions in conditions considered futile to treat. But it is a professional obligation to provide palliation in life-limiting disorders. A major tenet of palliative care is the involvement of the patient (and whānau) in decision-making. But this is not possible with those lacking capacity. Formal welfare guardians, if already appointed, can guide sensible management and need to be involved in determining management plans, though proxy decision makers are often inclined to support ongoing reasonably active treatment regimes. Family carer proxies show only mild to low agreement with stated end-of-life treatment preferences of people with dementia.[13]

Families invariably have hope and hopes may mute fear, though unrealistic hope can be psychologically damaging. Determining not-for-resuscitation status of the terminally ill should be a formality, but surrogate minders may opt for intervention if the attending doctors timidly decline to advise regarding potential harm and the extremely poor outcome of cardiopulmonary resuscitation (CPR) in this population.[20] Assuming some medical management assertiveness over the terminal phase of advanced dementia is necessary. A tailored palliative approach to advanced dementia is a major component of addressing the crisis in late-phase dementia care. Often the most difficult decisions of bedside doctors and proxy decision makers are to "do nothing" and not to embark upon futile treatments. Palliation is not doing nothing or clinical neglect.

The most feasible option in addressing the crisis presented by ageing and fading "baby boomers" is that of altering the culture and tasks expected of medical practice. This would need to be married to a better understanding of the natural prognosis of neurodegeneration. All doctors, nurses and aged care workers need appropriate expertise and confidence to manage all the stages of neurodegenerative disorders. Appropriate attention is being instilled into improving the quality of life in mild to moderately severe Alzheimer's dementia, though not to the late stages. Dementia is a catastrophic brain failure and is no different to heart, renal or respiratory failure, disorders in which sensible withdrawal of active interventions are frequently made. Yet advanced brain failure is considered differently when shifting the goal of care from prolonging life and maintaining function to maximising comfort.[21] Dedicated nursing and palliative care are indicated, appreciated and effective in comforting those dying with or of dementia. Prescribing effective and tolerable comfort medications for pain, anxiety, deliria, emotional distress, depression and psychosis requires a practice demanding considerable skill and a considered approach. Aged residential facilities must function as advertised and relieve emergency departments and acute medical services of their current burden. "Good" bedside decision making can avoid weeks to months of prolonged and poor-quality remaining life of the remnant cognitive shell of the unrecognisable loved one. Withdrawal of ineffective or harmful treatments is not therapeutic neglect; rather, it is core medical practice consistent with current medical knowledge. There are few more difficult tasks in the practice of medicine, and many other attractive and appealing professional roles, though few others requiring such a momentous attitude change to avert a mushrooming healthcare crisis. The public deserve end-of-life information about neurodegenerative conditions, healthcare trainees and practitioners likewise, and humane palliation and assertive clinical decision making is required, for the crisis is upon us. Sensible palliative care can improve symptom burden, prevent under-treatment and over-treatment of symptoms with unnecessary and burdensome interventions, reduce caregiver burden and enhance caregiver quality of life.[7]

COMPETING INTERESTS
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End-stage achalasia leading to acute upper airway obstruction and respiratory arrest with successful resuscitation, a case report

Jacob Arahill-Whitham, Ben Thomson, Vishak Surendra, Thomas Haig, Subhaschandra Shetty

ABSTRACT

Respiratory arrest secondary to megaoesophagus is a rare complication of achalasia. We treated an 85-year-old female with a history of achalasia who presented with sudden respiratory arrest and cardiopulmonary resuscitation in the community. In the emergency department, she was intubated for respiratory distress secondary to upper airway obstruction and reduced consciousness. Flexible nasal endoscopy revealed a retropharyngeal bulge, and computed tomography (CT) demonstrated megaoesophagus with distal tapering. She was managed with gastric decompression and percutaneous endoscopic gastrostomy (PEG) feeding with an uncomplicated hospital course. This case provides a rare differential for a patient with acute upper airway obstruction and cardiopulmonary arrest and is the first such case described in the literature in Aotearoa New Zealand.

Achalasia is a rare pathology of the oesophagus thought to result from degeneration of ganglion cells in the myenteric plexus. Subsequently, there is an impairment of relaxation of the lower oesophageal sphincter (LES) and lower oesophagus peristalsis.[1] Untreated, gradual dilation of the lower oesophagus can lead to end-stage achalasia/megaoesophagus. Achalasia has a bimodal presentation, typically diagnosed between ages 20 to 40 and 60 to 70.[1] Diagnosis typically involves high-resolution manometry (HRM), endoscopy and barium meal examination.[1] End-stage achalasia occurs with progressive loss of oesophageal ability to contract, decompensation and oesophageal dilation with tortuous angulation.[2] Histologically, the oesophageal paralysis corresponds with absent ganglion cells and severe neural fibrosis.[3]

Case

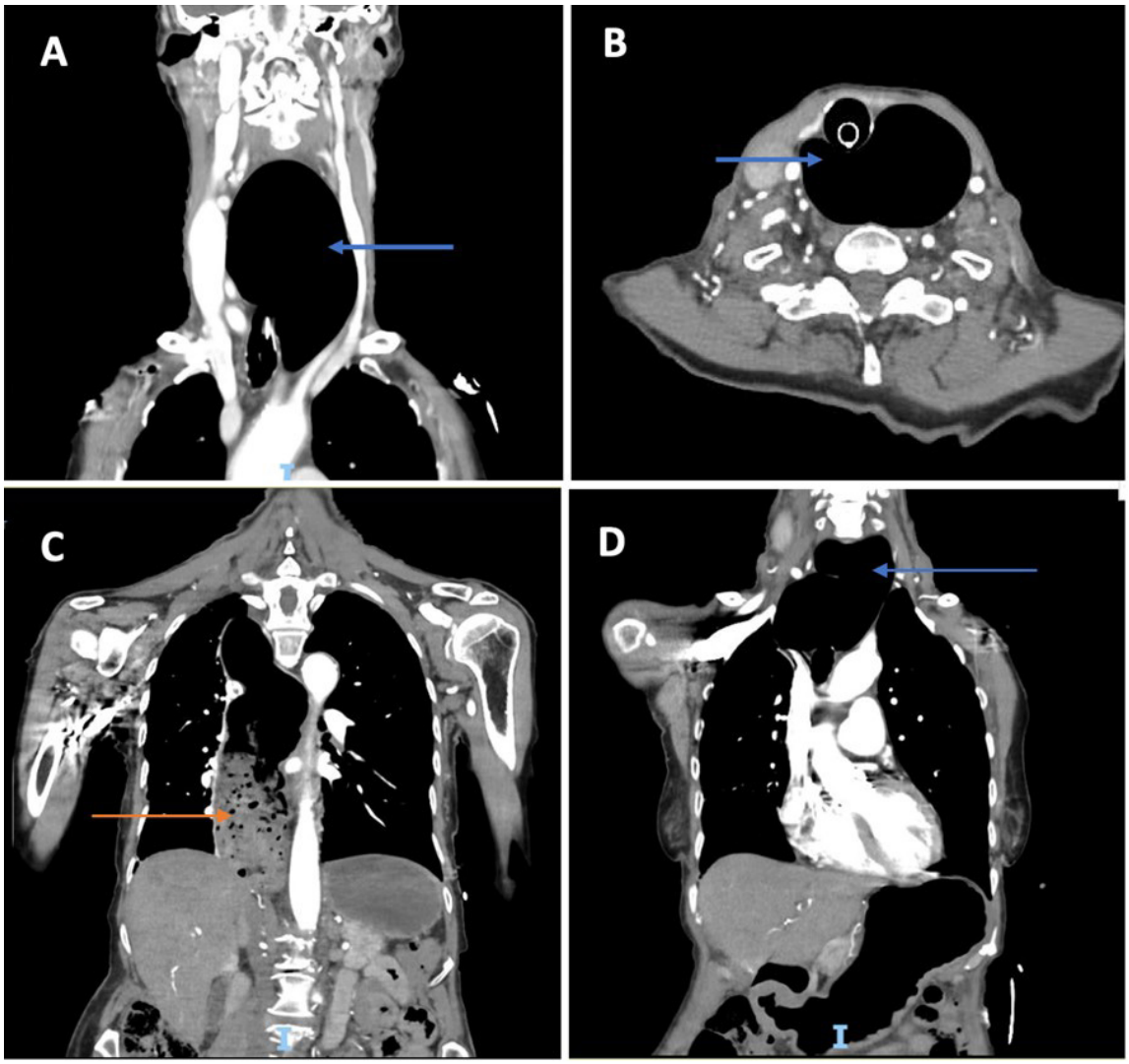
An 85-year-old female presented following sudden collapse and loss of consciousness while eating. Bystanders commenced CPR due to absent respiration before the arrival of emergency responders. Following ambulance transfer to the emergency department, she deteriorated again with increasing respiratory distress and reduced level of consciousness. Fibreoptic airway assessment before intubation revealed a mucosal bulging from the hypopharynx causing mechanical obstruction of the glottic opening. She was emergently intubated in the emergency department.

A venous blood gas revealed a respiratory acidosis consistent with hypoventilation, and a subsequent computed tomography (CT) identified that the abnormality was secondary to a grossly dilated oesophagus obstructing the upper airway (Figure 1A–B), which tapered down to the gastro-oesophageal junction as demonstrated in Figure 1C–D. There was no other sign of underlying pulmonary abnormality.

The patient's prior history was relevant for a clinical diagnosis of achalasia diagnosed in 1981 and undergoing a balloon dilatation that year. She had undergone an unremarkable gastroscopy in 2006 and another gastroscopy in 2013 that revealed a dilated and tortuous oesophagus, but the endoscopist believed the findings were not consistent with achalasia and no dilation was performed. She was never investigated with manometry. Other comorbidities included chronic obstructive airway disease.

Following partial decompression with a nasogastric tube, the patient was admitted to the intensive care unit and mechanically ventilated to correct the acid-base abnormalities. She was later extubated and stepped down to the ward.

Figure 1: Coronal (**A, D**) and axial (**B**) CT slices demonstrating gross distension of the upper oesophagus leading to clinical bulging of the neck, blue arrows. In the image (**C**), the orange arrow indicates food content within the distal oesophagus, which can be seen tapering to the gastro-oesophageal junction.



Unfortunately, the nasogastric tube became dislodged. She developed progressive upper airway obstruction and respiratory compromise, requiring re-intubation and re-insertion of a nasogastric tube with endoscopic guidance in the operating theatre. Following successful extubation, it was agreed between the patient, family and clinicians that she was not a suitable candidate for surgical correction of megaoesophagus given her age and comorbidities. The patient did not wish to be transferred to a tertiary centre where less invasive endoscopic procedures such as botox injection and balloon dilatation could occur. A percutaneous gastrostomy tube was placed for feeding. She was discharged home with multidisciplinary follow-up from dieticians and speech-language therapists and has subsequently established a near-normal oral dietary pattern.

Discussion

Bello et al.[7] first reported acute upper airway obstruction caused by achalasia in 1950. Since then, a relatively small number of presentations of acute airway obstruction secondary to achalasia and megaoesophagus have been reported, including four instances of sudden death.[8–10] There have been four published cases of cardiopulmonary arrest secondary to megaoesophagus with full recovery.[10–14]

This case presents a rare differential diagnosis for acute upper airway obstruction and respiratory arrest. The cause of airway obstruction could be temporised with the minimally invasive intervention of nasogastric decompression, and the patient recovered fully following resuscitation.

Achalasia can be radiologically graded based on the oesophageal diameter (I–IV).[4,5] Endoscopic botox injections and pneumatic balloon dilatation of the lower oesophageal sphincter can be offered to assist with voiding of the oesophagus, but do not address the impaired oesophageal peristalsis.[6] A number of surgical techniques exist to manage end-stage achalasia, such as Heller myotomy with Dor fundoplication, per-oral endoscopic myomectomy and oesophagectomy; however, these are associated with high risk of morbidity in high-risk patients.[6]

On endoscopic assessment, the patient had a widely patent lower oesophageal sphincter despite the grossly dilated oesophagus. The above endoscopic interventions were of unclear benefit for the patient and would have required transfer to a tertiary centre. Due to the non-functional oesophagus, a decision was made to manage the diagnosis conservatively due to frailty, comorbidities and the patient's wishes not to have further endoscopic or surgical procedures following discussion with the general surgical team, patient and their family.

Conclusion

This case highlights a rare complication of end-stage achalasia causing airway obstruction and respiratory arrest with successful resuscitation, and highlights some of the difficulties in the management of such conditions, particularly in rural settings.

COMPETING INTERESTS
The authors declare no conflict of interest in preparing this article.

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The need for transparent reporting of ethnicity in health research

Alana B McCambridge

Dear Editor,

I read with interest a recent *New Zealand Medical Journal* issue (Vol. 137 No. 1598) and noted four articles reported health-related data characterised by ethnicity.[1–4] Ethnicity is a measure of cultural affiliation and is self-perceived, and people can identify with or feel they belong to more than one ethnic group.[5,6] In New Zealand, ethnicity is of particular importance when considering the ethnic disparities in healthcare and health outcomes that persist. It is important that ethnicity is measured, analysed and reported as accurately and transparently as possible.

In two of the four articles that characterised their data by ethnicity in this issue, the authors described their ethnicity protocol. For example, Weatherall and colleagues' study on urinary incontinence used "total response ethnicity", which allows a person to identify with more than one ethnic group.[4] Ethnicity data were grouped into Māori, Pacific, Asian, and European/Other. This means that an individual who identifies as Māori/Pākehā would be counted in both the Māori and the European/Other groupings, or an individual that identifies as Sāmoan/German/Pākehā would be counted once in the Pacific and once in the European/other groupings. Because this study has opted to combine European and "Other", an individual who identified as African would be grouped together with people who identified as European. Grouping of the "Other" category can sometimes be done to avoid small sample sizes; however, it can also make invisible some ethnicities. Total response ethnicity (also termed total response overlapping) allows for a more complete understanding of ethnicity, as individuals can self-identify with as many (or up to six) ethnicities they feel they belong to.[5] However, as individuals can be counted more than once, the total denominator can be greater than 100% of the population, and overlapping data may obscure health disparities.

In contrast, Stedman and colleagues' study on paediatric type 1 diabetes used "prioritised ethnicity", which allocates people to a single ethnic group based on a priority order, even if they identify with more than one ethnicity.[3] The priority order, from highest to lowest, has been determined as: Māori, Pacific, Asian, Middle Eastern/Latin American/African (MELAA), Other, and European.[5] Stedman and colleagues then grouped their data into four groups: Māori, Pacific peoples, Asian, and European/Other, omitting MELAA as its own grouping and combining European and Other together.[3] The prioritised ethnicity protocol means that an individual who identifies as Tongan/Māori/Pākehā would be counted only as Māori, or someone who identifies as Sāmoan/Chinese would be counted only as Pacific. This can be problematic, as the prioritised order may not be representative of the ethnicity that an individual most strongly identifies with.[5] The order biases the statistics to over-represent some groups and under-represent others, and the forced categorisation of a given ethnicity is incongruent with ethnicity being self-identifiable.[5] As such, Stats NZ recognised the need to discontinue using prioritised ethnicity data protocols for official statistics.[7] However, for certain analyses there may be a need to reduce people to a single ethnic group and the prioritisation protocol aims to give greater visibility to ethnic groups of particular importance to policy.[5]

Unfortunately, the articles by Garrett and Gray[1] on diabetes-related lower extremity amputations and Richly and Romero Ferrando[2] on anti-NMDAR encephalitis did not report their ethnicity data protocols. A lack of reporting about how ethnicity is measured and analysed in research limits the generalisability of findings.

Researchers who use data from New Zealand health databases need to be aware of potential issues with ethnicity data quality. There is substantial evidence indicating a lack of compliance with ethnicity protocols throughout the New Zealand health and disability system.[8–10] Several barriers to compliance have been mentioned, such as IT systems and the range of systems in use, the cost of changing non-compliant systems, inadequate training and support in proper data collection and use and poor understanding of the rationale for

high-quality ethnicity data.[9,11] Researchers who use ethnicity data from health databases or who collect ethnicity for original research must ensure they understand the ethnicity protocols and treat ethnicity with the same rigour as any other variable. Consistency in the analysis of ethnicity would also allow for better synthesis of the literature, as well as comparisons between studies and over time. Better coordination is needed across the entire health and disability sector, including health research, to drive the changes needed to improve the quality of ethnicity data.[11,12]

The *New Zealand Medical Journal* should adopt a policy that requires all publications to clearly state their ethnicity protocol. Journal policies play a significant role in shaping research practices and ultimately influencing the evidence base that informs healthcare practice and policies. Better transparency and guidance in the reporting of ethnicity data would help to more accurately represent issues and inform potential strategies to address ethnic disparities in health outcomes in New Zealand.

Sincerely,

Alana B McCambridge

COMPETING INTERESTS
Nil.

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Editor's response to: The need for transparent reporting of ethnicity in health research

Frank Frizelle

Dear Alana B McCambridge,

Thank you for your letter to the editor on the need for transparent reporting of ethnicity in health research. I agree with your statement that in New Zealand (and elsewhere) "*Ethnicity is of particular importance when considering the ethnic disparities in healthcare and health outcomes*."[1,2] As a consequence, how we report ethnicity is important. Your point about the different forms of reporting ethnicity, i.e., "total response ethnicity" versus "prioritised ethnicity", is well made. I agree that we (the *NZMJ*) should consider adopting a policy that requires authors to state their ethnicity protocol. I will discuss this with the other *NZMJ* editors and will try and develop a policy by the end of the year. Thank you for bringing this to our attention.

With regard to your comment "*Researchers who use data from New Zealand health databases need to be aware of potential issues with ethnicity data quality*,"[1] I also agree. The *Journal* has reported repeatedly on the inaccuracy of ethnicity based on the National Health Index over the last 22 years (while I have been editor).[3,4] It is, however, slowly improving with the attention being drawn to it from many sources. It is also outside the *Journal's* scope to alter this, other than making people aware of this and reporting the issue when people study it.

Frank Frizelle
Editor NZMJ

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Physician associates: New Zealand should learn from the United Kingdom's mistakes

Martin McKee, Trish Greenhalgh, Barry Monk, Henry McKee

DeWolfe and Collins' editorial advocating the expansion of physician associates (PAs) in Aotearoa New Zealand[1] makes unsubstantiated claims and appears to be based on a highly selective reading of the literature. They state that there are 170,000 physician assistants/associates globally, but they do not discuss prevailing controversies in the United Kingdom (UK) about what exactly these individuals are trained to do (and to what standard), or issues of supervision, accountability and patient safety.

In the UK, PAs have been (controversially) employed in a wide range of duties from administrative and practical assistance to doctors to laparoscopic surgery, child protection and management of undifferentiated patients in primary care. The UK's General Medical Council and the Royal College of Physicians of London, which were at the forefront of promoting PAs, have been heavily criticised for declining to define any scope of practice for them.[2] While there are many international agreements on mutual recognition of qualifications for doctors (e.g., within the European Union), none exist for PAs. The mantra that PAs are "*trained in the medical model*" is oft repeated (including in this editorial), without ever clarifying what this actually means.[3]

The authors' claim that there is an "*impressive catalogue of … studies*" that identifies "*the PA as a highly trained, cost-effective and patient-satisfying addition to the workforce*" is unreferenced and reads as magical thinking. Readers will make up their own minds as to whether someone with a 2-year training course, following a degree that could be in English literature or homoeopathy,[4] can be described as "highly trained" when compared with a doctor. One ex-PA who is now a medical student wrote disparagingly about the lack of coherence or depth in their previous PA training.[5] Many UK PA courses are assessed predominantly by multiple choice examinations, have a pass mark below 50% and achieve at or close to 100% pass rates.

deWolfe and Collins' claim that the skill set of PAs aligns closely with that of the supervising doctor is also unreferenced, as is the claim that PAs, with only 2 years of training, can move easily between general practice, paediatrics and women's health. A UK study of anaesthesia associates (AAs, who undertake a PA role in anaesthetics) struggled to find any way their employment could be made economically viable given the ongoing requirement for supervision.[6] We know of no published research study showing that PAs are cost effective; such studies are ongoing in the UK.

Patient safety should be paramount in healthcare. The growing list of tragic errors involving PAs in the UK is leading some health organisations to reconsider their use. Research on patient safety involving PAs is sparse. There is, however, considerable evidence on the analogous role of nursing associates/assistants, which consistently shows that when these roles are introduced, even when numbers of registered nurses remain the same (and especially when they are reduced), patient outcomes suffer.[7]

deWolfe and Collins do not consider the adverse consequences of expansion of PA roles on the speciality training of doctors, which is now becoming a major problem in the UK. Nor do they discuss supervision and accountability. It is widely assumed that this occupational group will work under the supervision of a doctor, who will be held accountable if anything that goes wrong. There are major unanswered questions about how lines of responsibility and accountability will play out in practice, and how these formal arrangements may be misaligned with practice on the ground (in which, for example, a PA may put pressure on a very junior doctor to "sign off" prescriptions for drugs or requests for ionising radiation). Already, Freedom of Information requests in UK have uncovered numerous cases of PAs being used as direct substitutes for junior doctors (e.g., in on-call rotas), and legal cases have

held doctors accountable for the acts and omissions of PAs.

The editorial concludes by dismissing a few "*influential individuals*" in the Medical Council of New Zealand and the medical colleges. This is exactly the same language that was used to describe those of us who first expressed concerns in the UK. Yet, as experience has accumulated, one royal college after another,[8–10] along with the British Medical Association, have called for pauses, at a minimum, to the expansion of the PA occupation, with overwhelming votes in favour of this course of action where members were consulted.

In seizing on PAs as a near-universal and problem-free solution to the growing shortage of doctors, New Zealand is presented as joining a successful international movement. Yet where it has been tried, as in the UK, numerous problems are emerging and initial supporters are having second thoughts. We strongly advise you to learn from the UK's mistakes before choosing this path.

COMPETING INTERESTS
MMcK, TG and BM were signatories to a letter to the Royal College of Physicians of London calling for an extraordinary general meeting that changed the College's policy on physician associates. MM is a past president of the British Medical Association.

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Response: New Zealand physician associates and colleagues support regulation to provide safety first and foremost

Lisa Fitzgerald deWolfe

We wish to thank the authors (McKee, Greenhalgh, Monk and McKee) for their interest and for taking the time to write a letter to the editor. We reject their claim that our opinion is based on a highly selective reading of the literature. It has been important to develop a contemporary strategy for leveraging physician services that is reflected across the globe as we work with limited and expensive healthcare resources. The inclusion of physician associates (PAs) in national health workforce development is reflected in Europe (NL, UK, IE, DE, PL, BG, CH), North America, India and South Africa.[1] The issues raised about what "*exactly these individuals are trained to do (and to what standard), or issues of supervision, accountability and patient safety*"[2] are covered by scope of practice, and though this may vary from country to country, many have considerable similarity where resources are similar, e.g., comparable PA scopes of practice are an integral part of healthcare throughout Africa.[3]

Within the UK, "prevailing controversies" about PAs have arisen after 10 years of utilisation marred by a tragic incident about overlooking a deep vein thrombosis in a young woman.[4] But it is a tragedy not uncommon to all health systems and all who deal with an overworked and stressed urgent care situation. Improvements in health service delivery that are effective and comparable to that of doctors by using PAs are well established in the literature.[5] Physician acceptance of PAs and patient acceptance of PAs have been well examined.[6,7]

The General Medical Council (GMC) regulations and safety measures will soon be in place.[8] This strategy will address residual controversies common to a new profession, including professional identity, pay disparity, training positions and supervision. Overworked doctors compound this omission. Work stress causes misunderstandings, suboptimal scope and increases risk. It is important to note that the UK PA profession and most colleagues have been calling for regulation. There is a volunteer registry (Physician Associate Managed Voluntary Register [PAMVR]) and requirements that were carefully implemented to hold standards for the unregulated profession. One result is that UK PAs will finally have GMC accreditation, scope, standards and the mutual recognition of qualifications like doctors, conserving the profession's risks. With this improved public safety and transparency of the professional role, public safety and concerns can be alleviated. Statements and false accusations like "controversial employment" and "2-year training" are inaccurate. UK PAs are employed in hospitals, outpatient clinics, emergency departments and GP practices.[9]

International training programmes for the profession need to be recognised for their robust curriculum, intense clinical training and academic foundation. When new countries develop programmes, the accreditation standards can and should be utilised. In the UK, physician associate applicants must have high Bachelor's degree grades to be competitive, and most take CASPER and have additional science courses to be accepted. Biological, biomedical, life sciences and other healthcare-related degrees are familiar to those applying. Many hold professional degrees or have experience as paramedics, surgical assistants, lab/radiology techs, medical scribes or nurses, or sometimes a combination of these work experiences. They must take biology, chemistry, physiology and anatomy to be accepted. Experience working in healthcare is usually necessary to be competitive. PA programmes are designed to provide comprehensive medical education, with accreditation standards ensuring the quality of training. The competency of PAs is regularly assessed through national certification exams, and their performance in clinical settings is monitored

through ongoing supervision and professional development.

The heft of literature on the PA profession is extensive and published in upper-quartile peer-reviewed journals with high impact factors. In this decade alone, there have been more than 100 published analyses on PA activity, behaviour and utilisation. The burnout rate of PAs is less than that of physicians. Where PAs are employed in family practices, the physician burnout rate is lower than without PAs.[10]

The PA profession has provided high-quality, highly skilled, safe patient care for over 50 years. There are research, data banks and statistical analysis that outweigh the few critics that have surfaced to try to further delay a regulated UK PA profession to serve themselves and deny public protection.[11–13] New Zealand's workforce will benefit from expanding team-based care using PAs and not a physician imperative.

COMPETING INTERESTS
Nil.

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Chronic Arthritis: Classification and Principles of Treatment

NZMJ, 1924

Remarks to Open a Discussion at the British Medical Association Congress, New Zealand Branch at Auckland, 1924, *by* D. W. CARMALT JONES, M.D., F.R.C.P., *Professor of Systematic Medicine, University of Otago.*

I am reminded that this is not the first time that this subject has been discussed at Medical Congresses. I believe that archæological research in Egypt and elsewhere has discovered specimens of osteo-arthritis in human subjects which are at least 5000 years old, and in this year of grace we are met to find the place of that condition among the various forms of joint disease—for the point is not yet settled.

The inference, I think, is fairly obvious. There is no natural and indisputable classification of arthritis, and the reason for this is equally obvious. Joints are passive structures, they consist of articular surfaces, synovial membranes, ligaments and bones, and these are liable to damage or destruction from a variety of causes. Whatever the cause, and whatever the structure injured, the net result to the patient is much the same. The function of a joint is to permit movement of levers through a certain limited range, and when the joint is injured either too much movement is permitted, or not enough, generally the latter, and with the disturbance in function there is usually considerable subjective disability manifested by pain. Thus there is little difference to the patient whether his trouble is due to tubercular infection, hæmophilia or fibrositis, and the physical signs present in each of these forms of arthritis might present little difference from one another.

However, the prognosis and treatment of cases of arthritis of varying origin differ profoundly from each other, and some classification is required, but it should, I think, be remembered that any classification is arbitrary, and only to be adopted for convenience.

At the best of times many cases must be dubious, anomalous specimens are frequent, watertight compartments are not to be looked for, and the best classification we can arrive at will only be applicable to the common run of cases.

The classification which I am in the habit of adopting in teaching is etiological, and it can be applied to arthritis as to the diseases of any other organ or system.

The most easily recognisable causes of disease are, I think, the following:—1, Senility; 2, overwork; 3, malnutrition; 4, extraneous poisons; 5, metabolic poisons; 6, bacterial toxins; 7, trauma; 8, new growths. Each of these, of course, makes a heading with many subdivisions.

Of these, the first three, senility, overwork and malnutrition are probably contributory causes of osteo-arthritis, though I think infection is more important. Gout is recognised as due to metabolic poisoning, and bacterial toxins, in one way or another, are the causes of the recognised infective arthritides, tubercular, gonococcal, streptococcal and so forth, and I shall attempt to give my reasons for thinking them at least important contributory causes of muscular rheumatism, fibrositis, whether affecting joints or not, osteo-arthritis and rheumatoid arthritis. Trauma, used in a wide sense, includes direct inquiry to joints, and also hæmophilic and allied lesions, and other conditions, comparatively unimportant, such as pulmonary hypertrophic osteo-arthropathy, which one believes to be due to a physical cause, chronic venous congestion.

I suggest, then, that the chronic forms of arthritis which we may profitably discuss are gout, a metabolic toxæmia, direct infections of joints with recognisable organisms, traumatic lesions, including those due to hæmorrhage; about these there is not much dispute, the difficulty in classification lies among those which I have somewhat vaguely classed as infective, fibrositis, rheumatoid arthritis and osteo-arthritis.

Gout is perhaps a disease of decreasing importance at the present time. I, at any rate, have rarely, if ever, made the diagnosis in this country. Modern work on blood chemistry, which has illuminated so many problems in medicine, has so far taught us little with regard to gout. One view is that in gout there is a deficiency in the body of a ferment called "oxidace," in consequence of which the "purin" bodies which have

the formula C5 H4 N4 are imperfectly oxidised, uric acid being formed instead of urea. This is not the whole story, because in pneumonia and other diseases, uric acid is present in the blood in excess without producing the symptoms of gout. In gout, however, sodium bi-urate is formed in the blood and deposited in the tissues, and an attack of acute gout is associated with a sudden deposit of the kind. We need not, I think, now discuss the subject at length. Gout is generally considered a metabolic toxæmia, it is recognised clinically by its hereditary character, its usual incidence in middle-aged males, its peculiar onset, at night in the metatarso-phalangeal joint of the great toe, by the presence of tophi in the ears and other sites, and by its response to colchicum.